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Women's Activism for Breast Cancer Informed Consent Laws

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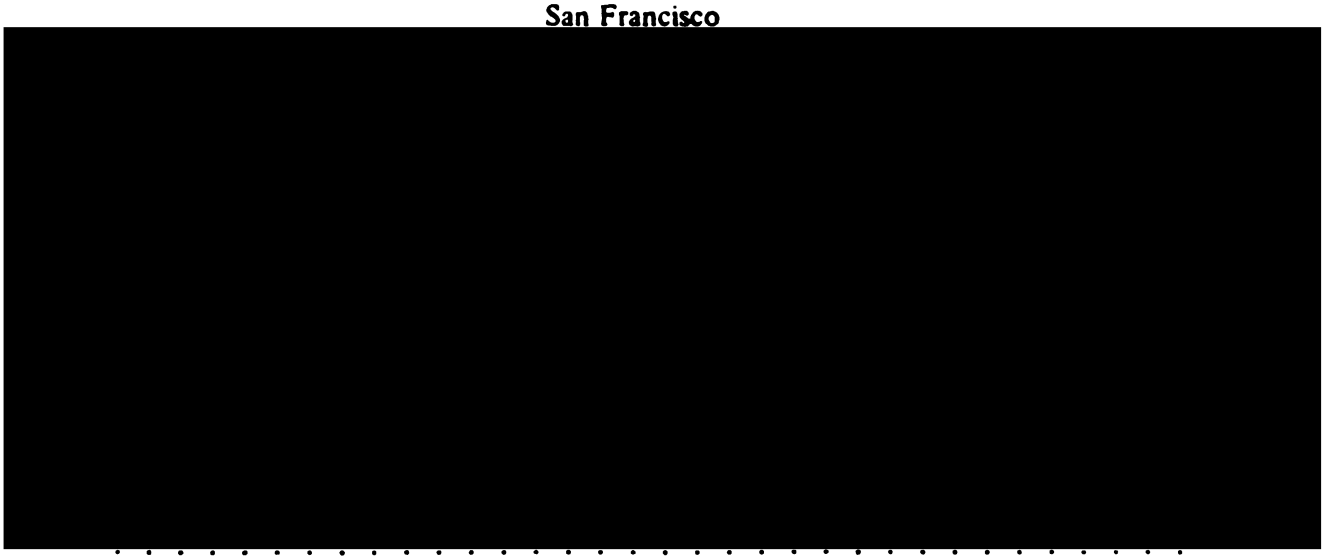

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This dissertation is dedicated to the memory of Barbara Rosenblum and Rose Kushner. I was honored to know these two women, and learned from them. Their political work made the world a better place for me.

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Sheryl Ruzek was the first to introduce me to Breast Cancer Informed Consent Laws, women's health care politics, and the Women, Health and Healing Program at UCSF. As a social work intern in a community hospital I was appalled at the way women were being railroaded into treatments that they probably would not have chosen were they active participants in these decisions. At the time I made the wise decision to complain to Sheryl. She told me about a law that had just passed in California, got me to join the Coalition for the Medical Rights of Women in San Francisco, and told me that I probably would do

better as an academic than a social worker, handing me a flyer announcing the Women, Health and Healing program of study at UCSF. The rest is history.

I also received intellectual support from the members of my writers' group, especially Petra Liljestrand, Cheryl Hall, Sherrie Fox, Patricia Flynn and Lora Lempert. Members of the Bay Area Chapter of Sociologists for Women in Society also listened to presentations of various preliminary versions of my dissertation, and I thank them for their feedback, especially the late Barbara Rosenblum, Anna Hazan, Elinore Lurie, Rachel Kahn-Hut, Marilyn Little and Joyce Bird. And finally, Robert Alford reviewed my work and advised me when I was a student in his research seminars at UC Santa Cruz. In addition I thank the student members of the research seminar at UC Santa Cruz.

I am very grateful to all the people who agreed to be interviewed for this study, and for a pilot study I did in 1984 and 1985 of women who had had breast cancer. I remember each of them vividly, their stories are seared into my mind, I felt honored to work with them. I owe them, for without their cooperation I would not have been able to do this study.

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Virginia Olesen, Adele Clarke, Alice Philipson, Cheryl Hall and Sheryl Ruzek offered me work paid from their grants. Alice Philipson and Petra Liljestrand lent me their car so that I could commute to UC Santa Cruz to attend a research seminar, and let me stay in their home when mine was damaged by fire. Vincent Montini, my brother, contributed a case of audiotapes, which I used for my interviews.

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# Women's Activism for Breast Cancer Informed Consent Laws

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## ABSTRACT

This study examines a group of ex-breast cancer patients who worked for the passage of Breast Cancer Informed Consent Laws in their state legislatures during the decade of the 1980s. It reviews the political process of these women, with special attention to the resistance their efforts met, especially from physician groups. The findings fall into two categories: those referring to the activists and those of the political process. In terms of the activists, it was found that their identities as women and American Individualists were central in their conceptualizations of the issue and the political strategies which they used to address it. It was found that the ideologies of social movements, as filtered through popular culture, especially that of the women's, women's health and consumer movements framed the way the activists conceptualized their issues and were incorporated in the activists' rhetoric, even though these women did not participate in these movements per se. In fact, despite the activists identifying as

women and borrowing select feminist ideologies, they distanced themselves from the identity of feminist, thereby segregating their effort from a larger program of feminist reform. Emotion played a key role in the activists' efforts: anger catalyzed them into action, yet adhering to cultural beliefs regarding women, they did not express anger in public. They did, however, express grief at public hearings for the law, garnering sympathy which they were able to direct to support of their Law.

In the second category of analysis, that of the political process, it was found that activists were generally pleased with the outcome of their efforts, especially the media coverage they received. Even though Breast Cancer Informed Consent Laws were passed in 16 of the 22 states in which they were introduced, often the activists efforts were coopted, so that the passage of the Law actually advanced and protected the professional autonomy of physicians at the expense of patient rights. This finding is examined in relation to the works of Gamson, Gusfield and Edelman on symbolic politics.

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# Chapter 1

## Introduction

Since 1979, former breast cancer patients have joined with legislators in 22 states to advocate for the introduction and passage of informed consent laws that pertain specifically to a patient's choice of breast cancer treatment (see Appendix A for a list of states in which a law was introduced). These Breast Cancer Informed Consents Laws, and the ways in which women advanced their consideration, are the subjects of this dissertation.

### Prior Sociological Studies of Women and Breast Cancer

During the past two decades, there has been an array of studies of women and breast cancer. These studies can be categorized into four groups: 1) studies on Breast Self Examination; 2) studies of the disclosure of a breast cancer diagnosis; 3) studies on the social support that women with breast cancer receive; and 4) studies on the politics of women and breast cancer.

An early social psychological study of breast self examination (BSE) was published by Manfredi, Warnecke and Graham in 1977. It was an examination of the relationship between fear, perceived susceptibility, and belief in the efficacy of early detection of breast cancer and BSE. Their major finding was that belief in the efficacy of early detection was the strongest correlate of the women's performance of BSE. In 1979, Patricia Kelly published an investigation of the

characteristics of women who practice BSE. She found that the women who did do BSE stated two major reasons for doing so: 1) increased awareness of the importance of early detection; and 2) increased concern about personal vulnerability to breast cancer. Recently, Finley, Francis and Lefevre (1989) examined factors associated with BSE via a literature review and analysis of data from interviews. They found that those most likely to practice BSE regularly were younger, college-educated, of medium to high income levels, married and employed.

In the second category, that of studies on the diagnosis and disclosure of breast cancer, there are two major articles. In the first, Polissar and Finley (1985) studied the key factors in the choice of one-step or two-step biopsy and surgery for breast cancer. They found that the use of the two-step procedure was associated with younger age of the patient, less suspicious symptoms or mammogram results, younger physician cohorts, and hospitals with government and health maintenance organization proprietorship. A second study by Kathryn M. Taylor (1988) addressed the issue of what physicians tell patients about serious illness, and how they arrive at that decision. Taylor was a participant observer in 188 events when the physician told a woman her diagnosis of breast cancer. Taylor described how the 17 surgeons at a Canadian breast cancer clinic developed, organized and implemented their disclosure policies, and the strategies they utilized to routinize a task they defined as difficult and unpleasant.

During the 1980s there were several articles published on social support of women with breast cancer. Holly Peters-Golden (1982) interviewed 100 women with breast cancer on their expected and actual social support regarding their illness experience. Funch and Marshall (1983) examined the role of stress, social support and age in survival from breast cancer. The next year, Funch and Marshall (1984) continued their study of women with breast cancer, this time attending to self-reliance as a modifier of the effects of life stress and social support. Also in 1984, Bloom and Spiegel published a study on the relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Next, Neuling and Winefield (1988) reported their study of social support from family, friends and surgeon, and its relation to recovery after surgery for Breast Cancer. The most recent articles in this category are studies of the social support within the marital dyad. Lewis and Woods (1989) analyzed the questionnaire responses of fathers of young children whose wives had breast cancer. Finally, Vinokur and Vinokur-Kaplan (1990) studied patterns of social support in older married couples in which the women had breast cancer.

The last category of articles, those which considered the political issues associated with breast cancer, covered a wide array of topics. First was a study of personnel directors by McCharen and Earp (1981) of the factors that influenced their decisions to hire (or not hire) women who had a history of breast cancer. They found that five factors could explain 69% of the variance in hiring practices:

size of company, level of sick leave benefits, company involvement in employees' medical insurance, employers' education, and their personal experience with breast cancer. Next there was a study by Sue Cannon (1989) of the difficulties a sociologist encounters when studying women and breast cancer treatment. Cannon found that sociologists working in medical settings often encountered questions of involvement, detachment, and personal responsibility, and that these issues had even greater significance when studying breast cancer. The final article in this category was an examination by Montini and Ruzek (1989) of history of the radical mastectomy as a the treatment of choice for breast cancer patients, and the difficulty proponents of alternative treatments had in getting clinicians to offer less intrusive treatments.

## The Present Study

This dissertation is classified in the last category, studies of the politics of women and breast cancer. It is a study of women's efforts to get Breast Cancer Informed Consent Laws introduced and passed in their state legislatures. My aim is to explore the conditions under which small, single-issue movements of women activists are and are not successful in attaining their goals.

I begin by laying out the context in which this effort arose. In Chapter Three I address the issue of why this effort for a law particular to breast cancer arose. In it, I discuss the development of the controversy over the alternative treatments for breast cancer, and how that controversy became public knowledge.

In the next chapter, I explain the legal doctrine of informed consent, and how it had been used prior to its application to breast cancer treatment. Then I go on to a set of chapters in which I present my empirical findings. In Chapter Five, I introduce the women who advocated such laws, their identities and their ideologies. In the next chapter, I consider the strategies and tactics these women used to get such laws introduced and passed, with a special focus on the role of emotion. In Chapter Seven I describe the reactions to the women's efforts from the those in the media, legislators, physicians, and those in the American Cancer Society. In the following chapter I discuss the consequences of the introduction of the Law in the various states, especially the attempts to coopt the effort and the personal consequences for the women involved. I end this dissertation with a consideration of the theoretical implications of my research for future study of symbolic health care politics.

# Chapter 2

## Methodology

In this study, I mainly used qualitative methodology, and employed a quantitative method to do a small portion of the background research. I chose qualitative methods because I knew that they would be the best means of obtaining the type of data that would shed light on my research questions. I also knew, from preliminary participant observation in the field, that the phenomenon under study was not a mass phenomenon, consequently, I would not be able to collect enough quantitative data to do a meaningful quantitative analysis. The method of qualitative analysis I used was grounded theory (Glaser and Strauss, 1967).

### Background Quantitative Data Collection and Analysis

When I started this study, I knew that the Breast Cancer Informed Consent Law had been introduced in about 20 states, but I did not know if some states would be more relevant for my analysis, and why that would be. I planned to start my data collection by selective sampling (Schatzman, 1973:38). I use the term selective sampling as

> ...the calculated decision to sample a specific locale or type of interviewee according to a preconceived but reasonable initial set of dimensions (such as time,

> space, identity) which are worked out in advance for a study (Glaser, 1978:37).

In order to sample selectively, I wanted to be able to locate each state in some sort of political context. Since a Breast Cancer Informed Consent Law could be labeled a liberal reform measure, I thought it important to be able to forge some contextual understanding of claims of a "liberal" or a "conservative" state.

My primary objective was to determine if the states in which a Breast Cancer Informed Consent Law was introduced varied in terms of political climate from the states in which the law was not introduced. To make this determination, I collected two sets of data for each state:

1) policy legacy - whether or not the state had a history of enacting legislation similar to Breast Cancer Informed Consent Laws, i.e. patient/consumer protection legislation; and

2) potential mobilization - whether or not there existed in any given state potential support for this law from potentially sympathetic organizations.

In terms of the history of legislation, for each state I collected data as to whether or not the state had the following laws:

Patient Access to Medical Records

Mental Health Bill of Rights

Subsidy of Abortion through Medicaid reimbursement

Minors' Access to Abortion Services

Statutory Provisions regarding Informed Consent

Ratio of Democrats to Republicans in State Legislatures

Standards of Disclosure as determined by State Courts

Number of Leading Court Cases on Informed Consent

In terms of potential political support for a Breast Cancer Informed Consent Law, for each state I gathered data on the number of organized groups active in each of the following categories:

Number of women's organizations in the state

Number of local chapters of NOW in the state

Number of DES Action groups in the state

Number of state and local government consumer agencies

I gave each indicator a value. For dichotomous indicators, I gave the value of +1 to the component of the indicator that was in the direction I hypothesized would correlate with a Breast Cancer Informed Consent Law introduction. I gave the value of -1 to the component of the indicator that was in the direction opposite to the one which I expected to be correlated with Breast Cancer

Informed Consent Law introduction. For the continuous variable indicators, I assigned a -1 to relatively low scores, a 0 to relatively medium scores, and a +1 to relatively high values. See Appendix B for a set of Tables that list all the indicators and their corresponding values.

Then, for each state I formulated a composite measure for policy legacy and potential political mobilization by adding all the scores together (see Appendix B, Summary Table 13). I found that of the 22 states in which a Breast Cancer Informed Consent law was introduced, 15 of them had high positive scores in terms of political climate and potential mobilization. Of these 15 states, the law actually passed in 12. Of the seven states in which a law was introduced even though by my computations one would not expect that given the history and political climate of the state, in 4 states the law passed.

I did this work for two reasons: 1) I expected to have to select a few states as case examples; and 2) I expected that when I interviewed informants they would refer to the political history and context of their states. Neither of these two expectations materialized. When I started collecting data I realized that there were so few activists in each state, that this was such a small phenomenon, that I would be able to collect all the data in all the states. Second, the activists I interviewed very rarely referred to the political history and context of their state, and rarely were involved with any political organizations. Therefore, my expectations led me to a set of negative findings--that the activists worked alone, for the most part without others and without organizational support. Secondly, they conceptualized their efforts as taking place in a political, historical and

organizational vacuum, most lacking experience in the political scene in which they operated.

Sources of Qualitative Data

My four sources of qualitative data were: 1) archival; 2) media; 3) reports of professional organizations; and 4) interviews. Because I discovered, in my preliminary participant observation, that this was an especially small-scale phenomenon, I decided that my general strategy would be to be exhaustive in my data collection efforts. Therefore, in each of these four categories, I attempted to collect all the available data.

In collecting archival materials I searched state statute books to get copies of the Breast Cancer Informed Consent Laws that passed. I also contacted state law librarians to obtain records of any hearings on the Breast Cancer Informed Consent Laws that were introduced. Because the name of the legislative sponsor of the law was attached to any law that passed or any record of the hearings on this law, from this process I was able to generate a list of the state legislators who introduced these bills.

Next I searched for media accounts of the introduction of Breast Cancer Informed Consent Laws. I used the *Nexus* service to access United Press International and Associated Press releases, and I used *Newsbank* microfiche to locate stories published in local newspapers. From the newspaper accounts I was

able to generate a list of names of people, predominantly women, who were active in the effort for a Breast Cancer Informed Consent Law in their state.

Next I wrote to the legislators who introduced the Breast Cancer Informed Consent Law in their respective states and the lay activists in each state asking if they would be willing to be interviewed regarding their involvement with this law. I interviewed every person who agreed to participate in this study (one legislator refused because of lack of time). My interview schedule is included in Appendix C. Transcripts of these interviews were my primary source of data.

Often those I interviewed offered to send me additional materials, such as personal written correspondence between themselves and others involved in the effort, videotapes of their appearances on local television, clippings of relevant articles, and copies of their testimonies at legislative hearings. At times they referred me to others involved in the effort, and I interviewed them as well.

My final source of data were special interest reports on Breast Cancer Informed Consent Laws issued by the American Cancer Society and the American Medical Association.

## Method of Qualitative Analysis

The social situation which I was studying was quite complex, and therefore I chose the grounded theory method of analysis. I sought a method that would enable me to capture a great deal of the variation that characterized women's advocacy for Breast Cancer Informed Consent Laws. I used this method to code

my data, develop concepts, and link the concepts in an effort to produce a theoretical basis for my understanding of the action in this arena.

## Coding

As I was collecting data, I began coding, a process of examining the data to raise questions and to generate hypotheses about conceptual categories and their relationships. I did this close examination of the data with attention to the actors' own viewpoints, to glean their understandings of interaction, process and change. Generative questions that guided my investigation were:

--Who were all the actors involved in this process?

--Who were these women activists for this law (identity)?

--What were their ideologies? To what degree were these shared and by whom?

--What strategies and tactics were used to promote or block the passage of Breast Cancer Informed Consent Laws?

--What conditions advanced or hindered the goals of the various groups in this arena with respect to the Breast Cancer Informed Consent Laws?

--What were the consequences of this process of getting or blocking the Breast Cancer Informed Consent Laws?

In coding I sought "leads, ideas and issues *in* the data themselves" (Charmaz, 1983:113). My coding process resulted in a set of concepts, which I then clustered into categories. Examples of these include:

Category: Ideologies of American Political Participation

Codes: I act alone

I am not associated with organizations

There ought to be a law

Category: Past Social Movement Influence

Codes: Consumerism

Women's Movement

Women's Health

Category: Feminism

Codes: Feminist Rhetoric

Anti-Feminist Rhetoric

Non-Feminist Rhetoric

Disclaimers regarding feminist identity and association with feminist organizations

Category: The use of Emotion

Codes: Women's grief

Women's fear

Women's rage

Physicians' anger

Gendered expression of emotion

Category: Media

Codes: Drama/action

Heroines, Individual focus, leaders

Congruence with cultural mythology

Category: Physicians' Responses

Codes: Activists are uniformed

Activists are irrational

There is no controversy regarding Breast Cancer Treatment

There is no inequality in the physician-patient relationship

BCIC Laws are not the solution to the problem

BCIC Laws would do more harm than good

BCIC Laws are unworkable

Category: Outcome of the effort

Codes: Success

Failure

Pre-emption

Cooptation

As can be seen my codes were of two types: in vivo codes, that is phrases "taken from or derived directly from the language of the substantive field, essentially the terms used by the actors...themselves" (Strauss, 1987:33); and sociological constructs, that is "codes formulated by the sociologist...based on a combination of the researcher's scholarly knowledge and knowledge of the substantive field under study" (Strauss, 1987:34).

Moving Toward Conceptual Relationships

After forging codes and categorizing them, in subsequent coding I constantly returned to the data to verify the codes. As I attempted to uncover the main issues in this arena (from the point of view of the actors in it), I generated provisional hypotheses about conceptual relationships. I continued to code additional data, with an eye toward the "goodness of fit" between my theoretical constructs (e.g. cooptation) and the data. I continued to revise and amend my concepts and categories, and evaluated their relative salience. At this point I was doing what we call focused coding, that is, when the researcher "takes a limited

set of codes that were developed in the initial phase and applies them to large amounts of data" (Charmaz, 1983:116).

I worked toward confirmation of the relationships between categories by sampling theoretically. "Theoretical sampling is a means for checking out hunches and raising specific questions. It provides a way to check the scope as well as the depth of the category....Theoretical sampling refines, elaborates, and exhausts conceptual categories" (Charmaz, 1983:125). For example, when I discovered there was a relationship between the identity of the activists and their distancing themselves from feminism, I went through the data set again, this time sampling and intensively coding any mention of feminism and identity.

As a result of these comparisons I was able to capture the range of variation present in this arena of action. By 'staying close to the data,' I was able to ensure that my conceptualizations and hypotheses directly addressed the full range of variation within this social setting. I also strove to ensure that there was "goodness of fit" between the data and the emerging theory. Throughout the process of analysis I reworked, reorganized and re-articulated the components of my theory to ensure validity. One strategy I used to move toward validity was triangulation (see Denzin, 1978:291-307), that is, using multiple data sources to assure that all were leading to similar conclusions. Another strategy was attempting to refute my own ideas by searching for negative cases. For example, early in the coding and data collection process I found that the American Cancer Society was usually against Breast Cancer Informed Consent Laws. I developed a

hypothesis that the American Cancer Society generally opposed the Law because it was a physician-dominated group and, as such, allied with physicians who resisted the Law given that they perceived this Law as a threat to their professional autonomy. From that point on I was very attentive to any cases where the American Cancer Society was supportive of the law, and studied the conditions under which they were supportive in an effort to expand or contradict my hypothesis.

In sum, utilizing intensive, systematic coding and the strategy of the search for the negative case, I have attempted to realize adequacy, plausibility and consistency in this research.

# Chapter 3

## Why Breast Cancer? Why Now?[1]

In order to understand why there was an effort for Breast Cancer Informed Consent Laws, we need to locate this effort in its historical context. In this chapter I demonstrate that women's activism for Breast Cancer Informed Consent Laws took place under two conditions: 1) the public attention focused on a controversy within the profession of medicine regarding the efficacy of various traditional and new approaches to treating breast cancer; and 2) popular awareness of gender relations between the predominantly male surgeons and predominantly female patients.

### Surgeons' Resistance to Change regarding the Adoption of Less Mutilating Treatment Approaches to Breast Cancer

Surgeons have dominated the diagnosis and treatment of breast cancer in the United States since the turn of this century (Montini and Ruzek, 1989). By the mid-1970s (if not many years earlier), radical mastectomy was not simply an accepted medical treatment, it had become an orthodoxy within surgery. In the view of Dr. Oliver Cope (1965:121), a noted breast cancer specialist critical of the field, the situation was, " 'Radical mastectomy and that's it,' rather than 'Where is the disease, what are its habits, and how can I best treat it?'"

Yet, beginning in the 1940s and 1950s, a few researchers were investigating the relative survival advantage of radical mastectomy compared to less intrusive procedures--modified radical mastectomy (amputation of the breast and lymph nodes in the armpit, and removal of the pectoralis minor adjacent lymph nodes), and lumpectomy or local excision (removal of the tumor plus a wedge of surrounding tissue) followed by radiation therapy (e.g., McWhirter, 1948; Baclesse, 1949; Mustakallio, 1954; McWhirter, 1955). The contested scientific question was not which technique was most effective. Rather it was a theoretical issue that nineteenth century physicians had "settled"--the question of breast cancer being a local as opposed to a systemic disease. Basic scientists had evidence that cancers sometimes spread to the lymph nodes deep within the chest wall, which could not be removed even by radical mastectomy. In addition, immunologists had accumulated evidence that in many cases malignant cancer cells were liberated into the blood stream and their destruction or survival was determined by an immune mechanism. Given this evidence, some scientists asked "whether more is gained by removing the cancer tissue than is lost by a major operation which might disturb both the humoral and the cellular immune processes designed to suppress them" (Atkins et al., 1972).

The growing number of reports of good survival rates for women treated with minimal surgery (McWhirter, 1948; McWhirter, 1955; Crile, 1961), combined with the findings of immunologists, attracted considerable interest in Europe and Canada. Between 1955 and 1961, British investigators came to believe that the

evidence was strong enough to warrant a formal clinical trial designed to test the hypothesis that in cases of early breast cancer radical mastectomy was no more effective in preserving life than simple wide excision of the tumor. In their view, it seemed "not only ethical to conduct such a trial but imperative that this should be done in view of the mutilating character of one of the alternatives" (Atkins et al., 1972, pp. 423-424). In the United States there was little receptivity by the medical community to asking such a question (Cope, 1977; Crile, 1973; Schachter and Neuhauser, 1981), nor was there interest in conducting a clinical trial--something which is done at that rare point in the history of a medical technology when many agree that it is unclear which treatment is most effective.

By the early 1970s, reports of the first British clinical trial and others had been published in the medical literature (Crile, 1961; Cole, 1964; Fisher et al., 1970; Bruce, 1971; Burn, 1974; Hamilton et al., 1974). None of these studies provided evidence that minimal surgery resulted in either better or poorer outcomes in terms of survival than the standard Halsted radical mastectomy. That is, modern scientific research methods did not produce evidence that the Halsted radical mastectomy, a procedure established in the 1890s on the basis of case reports of a small number of women with advanced cases of breast cancer, was indeed superior in comparison to the lesser procedures. Despite these data, surgeons in the United States retained their conceptual model of breast cancer and defended their position on the superiority of radical mastectomy relative to the lesser procedures. As Baum (1981:1105-1106) pointed out,

> This rejection of data in favor of the hypothesis is known as conceptual rationalism and has nothing to do with science. The more scientific response to data that fail to corroborate a theory is to construct a better-fitting alternative.

Most physicians are not scientists, despite medicine's public image to the contrary. Prescriptive statements to patients about safety, efficacy, and prognosis are based in large part on the clinician's own training and practice values, beliefs, customs and habits, rather than on "scientific certainty." Clinicians are trained to manage uncertainty in clinical practice, training that tenuously bridges scientific theory and clinical experience (Fox, 1957). To "manage" this uncertainty, medical education teaches physicians in training to adopt a pose of certainty even in the face of uncertain clinical situations (Atkinson, 1984).

Breast cancer treatment is especially uncertain because there are competing theories of cancer at the root of the breast cancer treatment controversy. The theory that breast cancer is a systemic rather than a local disease had critical implications for treatment. Surgeons need the local disease model to justify certain breast cancer treatment policies. For example, in order for surgeons to maintain their claim for the treatment of cancer, that cure can be effected by excising the diseased organ, cancer must be seen primarily as a local disease. In contrast to surgeons, oncologists, radiologists and proponents of

chemotherapy need a systemic theory to pursue their clinical specializations. Biomedical scientists and epidemiologists who have less direct investment in any specific theory or treatment procedure also align themselves with one or the other theory at particular points in time, but can shift their views without consequence. Thus the conflicts over breast cancer treatments between scientists, who wish to rationalize the practice of medicine by disseminating only technologies validated by research, are somewhat different in nature from conflicts between and among clinicians, which are grounded in the emotional, political and economic interests they have in maintaining extant treatment approaches (Montini and Slobin, 1990).

In 1970 at the urging of his patients, Dr. Oliver Cope, Emeritus Clinical Professor of Surgery at Harvard Medical School, published a ground-breaking article presenting the need for nonmutilating breast cancer treatment of women in *The Radcliffe Quarterly*, a lay publication. He also appeared in a documentary film, "Taking Our Bodies Back" (Lazarus, 1974), produced by the Boston Women's Health Book Collective. Here Cope argued forthrightly that local excision, radiation, and chemotherapy were preferable for many women. His statement, published in Belita Cowan's (1977) influential book, *Women's Health Care: Resources, Writings, Bibliographies*, further publicized these views and established him in feminist circles as the leading proponent of humane, nonmutilating breast cancer treatment. In 1973, Dr. George Crile Jr., Emeritus Consultant in Surgery at the Cleveland Clinic, published his book, *What Women Should Know About the Breast Cancer Controversy*, drawing much public attention

to the emerging policy debate. Both men were widely quoted in women's magazines, feminist publications, and the news media. This appeal to an interested outside audience took the controversy out of the limited professional circles in which these minority critics had been ignored or outvoted. At the very least the appeals sounded by these eminent physicians provided alternative ideas to those in the dominant surgical circles of the time. Moreover, they reverberated strongly in a climate wherein critical views of the medical establishment were becoming more common.

Several other factors moved the breast cancer controversy out of medical journals read only by scientists and clinicians into a national debate. Within the women's movement, health activists criticized the entire health care system for providing what they deemed inappropriate and inhumane treatment of women (Ruzek, 1978). Radical mastectomy was singled out as a treatment which could not be justified scientifically, and which violated women's body-self callously and cruelly disregarding women's fears, feelings, or other psychological and social needs (Barry, 1972; Frankfort, 1972; Seaman, 1972; Shinder, 1972; Bart, 1973; Frankfort, 1973). Both feminists and consumer health activists espoused the view that no woman entering a hospital for a breast biopsy should be required to sign a form consenting to radical surgical procedures during the same anaesthetic episode (then common practice). Instead, these groups insisted on a woman's right to a two-step procedure--first the biopsy and later, fully informed about the options, a woman should be able to elect which treatment (radical or minimal

surgery and/or radiation) was best for her. The controversy over treatment options was heightened by women's own substantial fear of breast cancer--often referred to in the press as "the disease women fear most" (Ruzek, 1978).

Both the quantity and tone of articles on breast cancer indexed in *Reader's Guide to Periodical Literature*[2] (1949-1984) and published in popular magazines changed dramatically during the early 1970s. From 1964 to 1973 there was an average of four magazine articles per year on breast cancer in lay literature. In 1974 the average jumped to 20 articles per year and remained at that level through 1984. Before 1970 almost all the breast cancer articles concerned biomedical topics such as inheritance, detection, and post-mastectomy survival. From 1970 on, for every three articles published regarding biomedical topics, there was one article dealing with patients' rights (women's choices, alternative treatments) or about the breast cancer treatment "controversy" (Montini and Ruzek, 1989:13-14). (See Figure 1).

Many books about breast cancer were published by women such as Rose Kushner (1975, 1984), Betty Rollin (1976) and Mary Spletter (1982). These lay authors appeared on radio and television advocating women's right to receive care which they chose, given that there was no compelling scientific evidence that radical mastectomy provided any survival advantage over lesser, nonmutilating treatments. Organizations such as the National Women's Health Network, the Breast Cancer Advisory Center, and feminist health clinics supported this effort by publicizing referral lists and advice "hot lines."

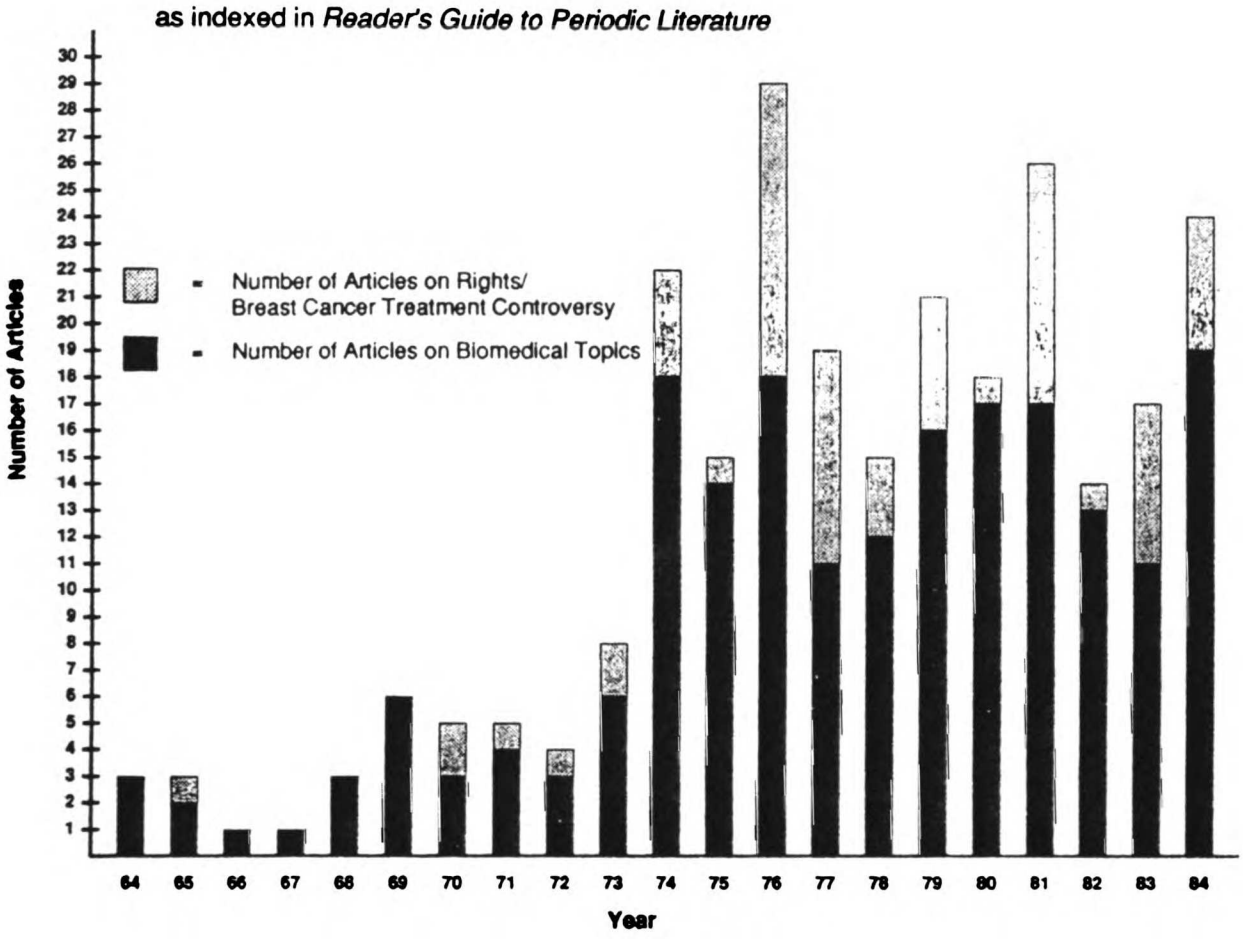



*Figure 1.* Popular articles on breast cancer published during 1964–1984

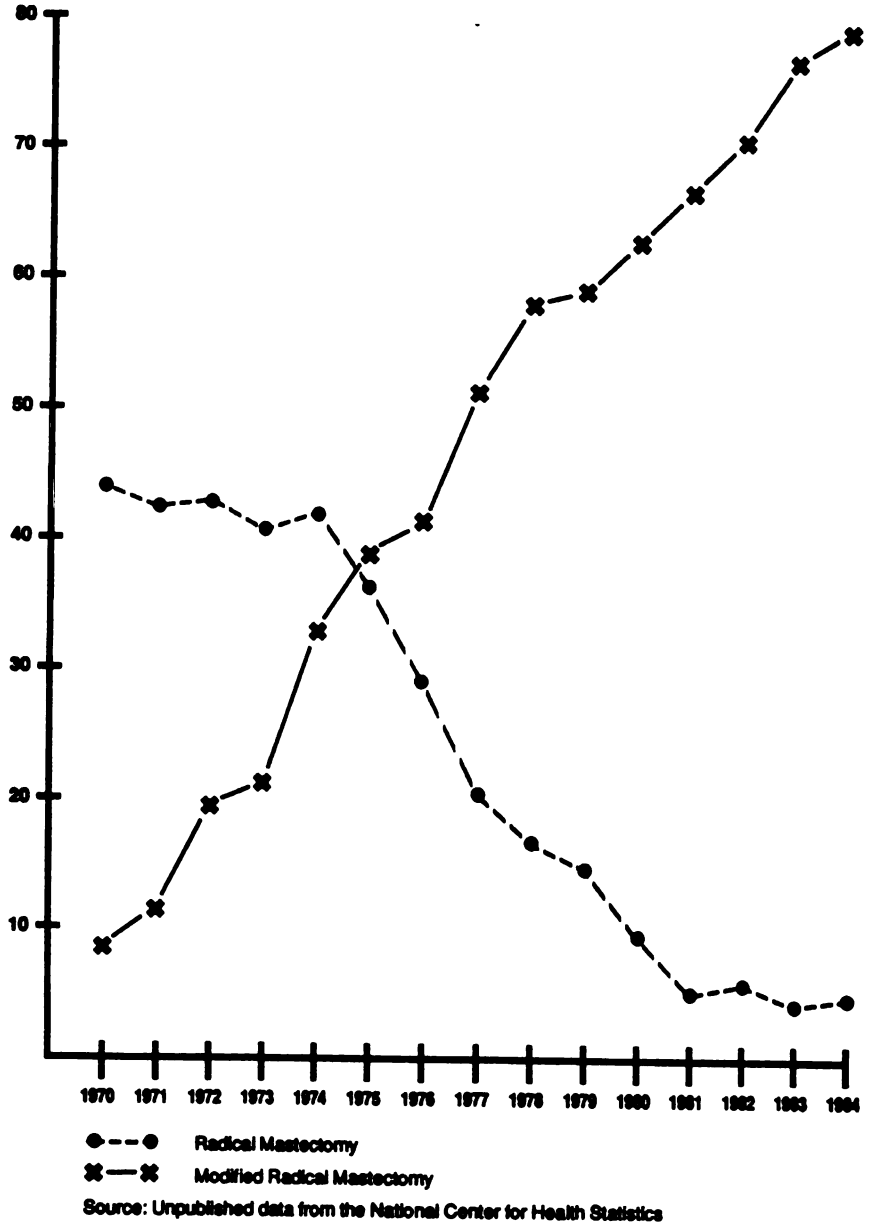
From: Montini, Theresa and Sheryl Ruzek. 1989. "Overturning Orthodoxy: The Emergence of Breast Cancer Treatment Policy." Research in the Sociology of Health Care Vol. 8:p. 14.

The number and rate of women receiving radical mastectomies began to fall from 46,000 per 100,000 operations in 1974 to 6,000 per 100,000 operations in 1981 (see Montini and Ruzek, 1989:13-15). (See Figure 2.) Some breast cancer surgeons did acknowledge that the impetus for a change in the treatment they offered came from their patients. In his 1970 article, Cope recounts the story of how the refusal of radical mastectomy by two of his patients in the 1950s led him to experiment with the combination of lumpectomy and radiotherapy. In a 1985 television interview, surgeon Susan Love declared in support of lumpectomy, "This treatment option was not developed by doctors and surgeons looking for a better way. It was women who said, 'I refuse mastectomy. You better find another way to treat me'" (ABC News, 1985). However, some surgeons publicly declared that they weren't going to do lumpectomies "despite what the *Ladies Home Journal* says" (Ruzek, 1978:114).

Gender Relations between Male Surgeons and Female Patients

A second important consideration when trying to understand why there was activism specific to breast cancer, is that at this point in time many women had been sensitized by the women's movement generally and the women's health movement in particular to a gender analysis of the doctor-patient relationship. There were very few structural situations in medicine in which the practitioners were predominantly male, and the patients were predominantly female (e.g., gynecology, obstetrics, uterine cancer).

*Figure 2.* Rate per 100,000 of operations on the breast for all U.S. females by year




From: Montini, Theresa and Sheryl Ruzek. 1989. "Overturning Orthodoxy: The Emergence of Breast Cancer Treatment Policy." Research in the Sociology of Health Care Vol. 8:p. 16.

Within Blumer's theoretical framework (1969:100), the women's movement can be characterized as a general social movement. As such it is

> ...constituted by gradual and pervasive changes in the values of people--changes which can be called cultural drifts. Such cultural drifts stand for a general shifting in the ideas of people, particularly along the line of the conceptions which people have of themselves, and of their rights and privileges. Over a period of time many people may develop a new view of what they believe they are entitled to--a view largely made up of desires and hopes. It signifies the emergence of a new set of values, which influence people in the way in which they look upon their own lives (Blumer, 1969:100).

Given that the ideologies of the women's movement had seeped into popular culture, some of the women who were proponents of Breast Cancer Informed Consent Laws were absorbing such new views of the roles of women. They reinterpreted their breast cancer treatment experience from a gender-conscious perspective. For example, this quote is from the testimony of a representative of the National Organization of Women at a state legislative hearing on the Breast Cancer Informed Consent Law:

> Today's woman wants to be able to participate in deciding her destiny, including deciding on the therapy procedure to be used in breast cancer, and women are tired of being ordered what to do by male surgeons (as reported by Barton, 1982:747).

Yet another example is this newspaper description of a legislator who introduced the Breast Cancer Informed Consent Law in her state:

> She became interested in breast cancer treatment after watching a television interview on the cancer and various treatments. It appeared to her that male surgeons were very quick to suggest a radical mastectomy as the only method. "We all know if the situation was a man faced with such surgery, the man wouldn't be so anxious to run and have that type of surgery," she said (as reported by Norvelle, 1982).

Blumer (1969:100) contended that:

> The development of the new values which such cultural drifts bring forth involve some interesting psychological changes which provide the motivation for general social movements. They mean, in a general

> sense, that people have come to form new conceptions of themselves which do not conform to the actual positions which they occupy in their life. They acquire new dispositions and interests and, accordingly, become sensitized in new directions; and, conversely, they come to experience dissatisfaction where before they had none.

I contend that breast cancer was "singled out" for attention by women who were sensitized by the popularized ideologies of the women's movement. These ex-breast cancer patients attended to the gender asymmetry between the breast cancer practitioners and the breast cancer patients. As women, they "developed a new view," and they "experienced dissatisfaction where before they had none" as Blumer framed these processes (1969:100).

## Notes

[1]Portions of this chapter have been taken from an article I wrote earlier with Sheryl Ruzek. See in Bibliography, Montini and Ruzek, 1989.

[2]There are problems with using *Readers' Guide to Periodical Literature* as a source of primary data. It is unclear what the criteria are for including certain publications and excluding others. Another potential problem is the system of indexing. It is often not clear from the title of the article what the article is about, or why it is or is not indexed under a certain subject heading.

## Chapter 4

## The Legal Doctrine of Informed Consent

Women activists applied the legal doctrine of informed consent in an effort to advance their interests and protect their rights with regard to breast cancer treatment. The legal doctrine of informed consent was developed in the courts and pertains to the patient-physician relationship. Legal and medical historians generally agree that the doctrine of informed consent began to develop at the beginning of the 20th Century in an effort to protect the patient within the patient-physician relationship, given the inherent imbalance of power, which at this time was beginning to favor the physician. Physician groups were generally able to counter what they perceived as a violation of the privacy of the patient-physician relationship, by lobbying state legislatures to pass laws that reversed or limited the progressive informed consent doctrine as advanced by the courts.

The law of informed consent developed within the context of malpractice court actions filed by patients against physicians. The few early Informed Consent cases in this century focused on procedures performed by physicians on patients who had not given consent. The best known case from the early 20th Century was *Schloendorff V. Society of New York Hospital* in 1914. In this case the judge clearly set forth the patient's right to self determination:

> Every human being of adult years and sound mind has
> a right to determine what shall be done with his own

> body; and a surgeon who performs an operation without his patient's consent commits an assault . . . (211 NY 125, at 127).

Historians of medicine contend that it is reasonable to regard *Schloendorff* and similar decisions as at least in part motivated by the attempt to preserve some balance of power between the patient and the physician in the face of the rapidly expanding professional monopoly of "regular" physicians (Starr, 1982; Pernick, 1982).

It was "not until the latter half of this century that the courts began to combine the provider's traditional duty to secure consent with the new affirmative obligation of disclosure--a duty to warn--resulting in a new doctrine of informed consent" (President's Commission, 1982:20). Essentially, the informed consent doctrine states that before a physician may administer any treatment, the patient must be adequately informed about the proposed therapy and its effects, and must freely consent to being treated.

Standards of Disclosure

The informed consent doctrine requires the physician to disclose information to patients that will enable them to make their own intelligent choices about treatment. If a patient challenges a physician in court regarding informed consent compliance, the court reviews the claim in terms of the "standards of

disclosure" adhered to in the state at that time. These standards were usually developed in the courts through case law, but more recently they have been legislated as well.

There are two major variations of this standard. In some states judgment with respect to whether (or not) a physician has provided the necessary information to the patient is determined by reference to the custom among physicians in general. Specifically, whether a particular physician's disclosure is legally adequate depends on whether it is what a reasonably prudent physician would have disclosed to a patient in the same or similar circumstances. This is referred to as a professional standard of disclosure.

In other states the adequacy of disclosure is judged by reference to what a reasonable person in the patient's situation would have found material to making a decision about the treatment in question. Under this rule, the formulation of the standard of disclosure is taken away from expert medical witnesses and given to the jury. This is referred to as a patient standard.

The patient standard of disclosure was made explicit in a 1972 case, *Canterbury V. Spence*. In this decision the court stated that

> . . . Respect for the patient's right of self determination on a particular therapy demands a standard set by law for a physician rather than one which physicians may or may not impose upon themselves (409 U.S. 1064 (1972)).

"According to the *Canterbury* decision, the viability of the informed consent doctrine was the ability of the court to impose a standard for information disclosure as determined by law, rather than one developed by physicians" (Kaufmann, 1983:1661).

Despite the potential significance of the *Canterbury* ruling concerning informed consent, the patient standard for the adequacy of information disclosure did not displace the professional standard in most states. According to Caroline Kaufmann, a sociologist who studied informed consent:

> By the end of the '70s it became clear that the informed consent requirements drafted by the *Canterbury* decision in 1972 and adopted by those courts following *Canterbury* were being reversed by state laws. The medical profession was for the most part successful in attempts to gain legislative relief from those aspects of mandatory disclosure which it found most burdensome (Kaufmann, 1983:1661).

For example, according to Burton A. Johnson (1980), the patient standard of disclosure was established in the state of New York in 1975. During that same year, there was a "malpractice insurance crisis" in response to which New York physicians threatened to strike unless legislative relief was granted on a number of malpractice issues. The New York legislature responded by passing a series of

laws that re-established the professional standard of disclosure, and suspended the patient standard of disclosure (Johnson, 1980:287-288). The patient standard of disclosure as advanced in the *Canterbury* case has generally been upheld in court cases. The major impediment to the spread of the patient standard has been pressure from hospital and physician groups upon state legislatures to pass laws which stemmed the advancing tide of malpractice litigation[1] (Rosoff, 1981:41).

Breast Cancer Informed Consent Laws

From my interviews of the activists, I was able to develop a composite of components of a model Breast Cancer Informed Consent Law. This constructed ideal law would have three components:

1) specification of the kind of information about breast cancer that is to be given to the patient, especially information regarding alternative treatments to radical mastectomy.
2) some provision regarding consent, especially the timing of consent (before treatment), and by whom consent is given (given by the woman herself), and for what (biopsy only vs. biopsy and mastectomy).
3) penalties for physician noncompliance.

None of the Breast Cancer Informed Consent Laws that passed had all three of these components (See Table 1 for the components of each law that

passed). But the Breast Cancer Informed Consent Law that passed in California in 1980 had the informed component and the penalty component:

> The failure of a physician and surgeon to inform a patient by means of a standardized written summary.... in layman's language and in a language understood by the patient of alternative efficacious methods of treatment which may be medically viable, including surgical, radiological, or chemotherapeutic treatments or combinations thereof, when the patient is being treated for any form of breast cancer constitutes unprofessional conduct (Cal. Health & Safety Code Section 1704.5 1980).

In subsequent years the Breast Cancer Informed Consent Laws that were introduced in the states varied as to the presence or absence of these three components, as well as the strength of each component. (See Appendix D for the text of the Laws that passed.) In general, the laws that were introduced later were weighted toward the "informed" component, that is they required physicians to inform a patient about medically viable alternatives to radical mastectomy. Physicians would be in compliance if they gave the patient a copy of a brochure written by a group of physicians charged to do so. Usually these patient

Table 1: Breast Cancer Informed Consent Laws

| State | Year Passed | Information Provisions | Consent Provisions | Penalties |
|---|---|---|---|---|
| Massachusetts | 1979 | X | | |
| California | 1980 | X | | Unprofessional Conduct |
| Hawaii | 1983 | X | X | |
| Louisiana | 1983 | X | X | |
| Kansas | 1984 | X | | Revoke License |
| Pennsylvania | 1984 | | X | Civil Liability |
| New Jersey | 1984 | | X | Review by State Board of Medical Examiners |
| Minnesota | 1984 | X | | |
| Florida | 1984 | X | | |
| Georgia | 1984 | X | | |
| Kentucky | 1984 | X | | |
| Virginia | 1984 | | X | |
| New York | 1985 | X | | *** |
| Maryland | 1986 | X | | Revoke License |
| Michigan | 1986 | X | | *** |
| Maine | 1989 | X | | *** |

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*** In these states specific provisions were attached to the law to assure that physicians would suffer no penalties if they did not comply with the Breast Cancer Informed Consent Law.

education laws had no penalties for non-compliance. An example of such a law was the one passed in Minnesota:

> . . . every patient or resident suffering from any form of breast cancer must be fully informed, prior to or at the time of admission and during her stay, of all alternative effective methods of treatment of which the treating physician is knowledgeable, including surgical, radiological, or chemotherapeutic treatments or combinations of treatments and the risks associated with each of those methods (Minnesota, Vol. 11, Section 144.651, 1984).

In states such as Virginia, New Jersey and Pennsylvania, what was heralded as a Breast Cancer Informed Consent Law was actually a law that encoded a hospital surgical consent form specific to Breast Cancer treatment. These laws made no provision for relaying to the patient information regarding treatment, much less giving the patient alternatives. In fact they restored the doctor-patient relationship to its previous position before the evolution of standards of disclosure: that is, in order to avoid battery charges the physician must get consent from a patient. This type of Breast Cancer Informed Consent Law does address the issue of one-step vs. two-step procedures (see Chapter 3). For example, the law that passed in Virginia stated:

> If it is determined that I have a malignant tumor in my breast or other breast abnormality requiring surgery, then I authorize Dr. _____ to perform such operations or procedures, including breast removal, which are deemed necessary (Virginia, Professions and Occupations, Section 54-325.2:2, 1984).

One recent Breast Cancer Informed Consent Law that passed in Michigan in 1986 moved away from the reasonable patient standard of disclosure and reestablished the professional standard of disclosure:

> A physician's duty to inform a patient under this section does not require disclosure of information beyond what a reasonably well-qualified physician licensed under this article would know (Michigan, M.C.L.A. Section 333.17013, 1986).

Notice that this does not require a physician to provide the information that a reasonable patient would want to know.

This Michigan law also had a provision protecting physicians from malpractice litigation:

> A patient who signs a form pursuant to subsection 5, shall be barred from subsequently bringing a civil

> action against the physician providing the summary or brochure described in subsection 2 (Michigan, M.C.L.A. Section 333.17013, 1986).

This law is different from the first Breast Cancer Informed Consent Law that was passed in California in 1980, in that the Michigan law does not have the three ideal components of a Breast Cancer Informed Consent Law: 1) specification of alternative treatments; 2) a provision regarding consent; and 3) penalties for non-compliance. As stated above, the law is favorable to physicians in that the professional standard of disclosure is employed, and the law protects the physician from possible subsequent malpractice litigation. I will offer an analysis of this change in the quality of Breast Cancer Informed Consent Laws over time in Chapter 8. Until then, Chapters 5, 6, and 7 will describe the process of getting Breast Cancer Informed Consent Laws introduced and passed.

## Note

[1]To date, state governments have taken various steps to limit the extent of provider liability, including: limiting specific types of damages; placing caps on total recoveries; changing the collateral source rule; allowing periodic payment of damages; and establishing patient compensation funds (Pierce, 1985:20-22). Other considerations have included: statues of limitations; establishing legal standards of care; establishing qualifications of expert witnesses; and clarifying and limiting informed consent (Pierce, 1985:22-24).

# Chapter 5

## The Women Activists: Identities and Ideologies

My initial research questions were: Who are these women and why did they get involved? Despite the fact that I did not ask for specific demographic information from my respondents, from my observations I would characterize the activists as women who had had breast cancer, were over 40 years of age, lived at the level of middle class, were white and, to a lesser degree, rarely had more than a high school education and did unwaged or pink collar work.

Politically, these women breast cancer advocates were American populists and individualists (Bellah, 1985) who accepted the basic tenets of the social order. First, they shared American values regarding government and public policy in that they believed in the efficacy and responsiveness of the political system. In numerous interviews women told me that their initial reaction upon knowing that there was controversy regarding the choice of breast cancer treatment was, "There ought to be a law." Second, they believed in personal rights, especially the idea that women and patients should have choice and control in their treatment. And third, they believed that one person could change the system, that one woman could stand up and effect changes in government that would pressure clinicians to change medical practice. Along this line, they believed that women as consumers were powerful, that the medical market would respond to patients' protests.

These beliefs guided many of their choices of political strategies, and many of their interpretations of the outcomes of their activism.

In a sense, these activists can be viewed as agitators. Blumer (1969) considered the subject of agitation in an essay on social movements:

> Agitation operates in two kinds of situations. One is a situation marked by abuse, unfair discrimination, and injustice, but a situation wherein people take this mode of life for granted and do not raise questions about it. Thus, while the situation is potentially fraught with suffering and protest, the people are marked by inertia. Their views of their situation incline them to accept it; hence the function of the agitation is to lead them to challenge and question their own modes of living. It is in such a situation that agitation may create social unrest where none existed previously. The other situation is one wherein people are already aroused, restless, and discontented, but where they either are too timid to act or else do not know what to do. In this situation the function of agitation is not so much to implant the seeds of unrest, as to intensify, release, and direct the tensions which people already have (Blumer, 1969:104).

Instead of finding a dichotomy as Blumer predicted, I found a more complex situation. For years patients took for granted "abuse, unfair discrimination, and injustice" within the medical system. The other situation Blumer outlined, where people are already aroused, restless and discontented, but do not know what to do, was also evident. These women were upset by the treatment they were receiving in the medical system, but felt powerless to do anything. In this empirical work I found that both situations often existed simultaneously. Hence at this point I developed central research questions: What led these women to challenge and question their modes of living? What catalyzed their release of the tensions they harbored?

I contend that this shift in thinking was a reflection of the ideologies of the social movements which preceded the period in which these laws were introduced. These women were agitating for Breast Cancer Informed Consent Laws during the late '70s and early '80s. Some of the social movements of the late '60s and early '70s immediately preceded this time period.[1] Specifically the consumer movement, the women's movement, and the women's health movement, each and all provided an ideological framework within which these activists could define their situation as problematic and conceptualize a better situation.

For example, one respondent gave a reflection of consumer ideology when she told me about her interactions with practitioners:

> I hold up a little white glove and say, 'Wait a minute, we're going to talk about this.' And I do it to garage

> mechanics, TV mechanics, the men who painted my roof, doctors, dentists, lawyers and preachers, and everybody else. I'll be 65 in July and I've lived long enough to understand this is a cold, cruel world unless we know our rights.

An activist member of the Public Citizen Health Research Group reflected an ideology of the women's health movement when she commented:

> I think it's absurd to say giving people options of treatment interferes with the practice of medicine. It's the woman's health and it's her choice (as quoted in *American Medical News*, 1983:1).

At this point I would like to clarify that the ideologies of these movements seeped into popular culture where they were accessible to these women, but that does not necessarily mean that these women adopted them knowingly or proudly. As discussed herein, as well as in Chapter 3, my study evidenced that these movements had indirect effects on the ideologies of the women, who themselves had little or no direct movement involvement (see also Mueller, 1984). In fact, most of the women I studied went so far as to distance themselves from feminism, as well as from mass movements. For example, one activist told this story to a journalist who relayed it this way:

> ...She then channeled her anger into lobbying to revive the dead legislation, working with feminists, but insisting she was not one herself.
>
> "When I started I thought ERA was a detergent," she joked (Daniel, 1984:4).

When a physician wrote an article expressing the view that it was unfortunate that the debate over Breast Cancer Informed Consent Laws had taken on the "emotional overtones of women's rights and freedom of choice" (Carter, 1982a:338), another activist distanced herself from social movement organizations when she responded:

> ....I would like to inform the doctor that the only organizations I belong to are the Republican Party, The National Automobile Club and Mastectomy Recovery Plus. I've been a fighter all my life and don't need organizations to do my fighting for me.

Even though these women did not accept the identity of activist or feminist, they did invoke the ideologies of these movements to give meaning to what happened to them during their process of breast cancer treatment. As such, my findings are similar to other feminist scholars who study women involved in

political activism to advance the rights and status of women, yet do not adopt a feminist identity.

Ruth Milkman (1985) studied women's union activism in the 1970s. She found that "women union activists.....typically rejected any direct identification with the women's movement" (Milkman, 1985:307). Yet, she also found that union women

> readily endorse the movement's basic goals, a phenomenon perhaps best captured in the familiar 'I'm not a women's libber, *but*...' In particular, and more than any other feminist principle, the ideal of gender equality in the labor market has won enormous popular support. To be sure, structural change in the labor market has lagged far behind the attitudinal shifts (Milkman, 1985:309).

Beth Schneider (1987) made a similar observation, and offered a preliminary analysis of the phenomenon. Schneider had her students interview women, and a subset of them claimed that they were not feminists, but that they supported women's rights. Schneider found that these women wanted to distance themselves from popular conceptualizations of feminists as bra burners, hippies, lesbians and radicals who spend their time at public marches and rallies.

The most recent analysis of women activists distancing themselves from a feminist identity is Gorham and Andrews' (1990) study of Canadians in the La Leche League. They found that:

> The resistance to feminism displayed by many middle-class women can partly be explained by the fact that in recent years the message of feminism has been distorted by those who control opinions in our culture. Non-feminist women see the image represented by the beautiful, young superwoman of television commercials and mass entertainment, who both manages a successful, lucrative career and serves the needs of a husband and children. It is clear to them that this image does not reflect their own situation, nor does it represent a solution to their deep concerns about the needs of their children, and their own needs as mothers. Many non-feminist women mistake this 'lifestyle feminism' for genuine feminism and fail to see that the television image represents the co-optation of feminist goals by consumer capitalism. They remain unaware of debates within feminism, and do not know that there is an important body of feminist analysis that has been concerned with the

> devaluation of mothering and with our society's lack of concern with children (Gorham and Andrews, 1990:240).

Gorham and Andrews (1990:250) found that the women in La Leche League had to adopt their ideology in relation to "the increasing sophistication of the feminist message and its partial acceptance into mainstream culture." They found that even though the women they interviewed attacked "the feminist movement," their discourse was influenced by and reflected current feminist thinking (pp. 254,255). The movement-specific content of the ideology of the women in La Leche assimilated "information whose significance has been emphasized by the feminist movement itself" (p. 255). Gorham and Andrews attributed this to feminist ideology and imagery being absorbed into mainstream culture (p. 258).

In sum, the women who advocated for Breast Cancer Informed Consent Laws gave evidence that they were aware of their identity as women, but adopted a non-feminist perspective (Overall, 1987:4-5). The activists had a clear sense of themselves as women, a female identity culturally relevant to the dominant social norms. This identity, so far as my evidence shows, did not include a departure from those norms, either with regard to role equity or role change. Thus, the identity was not influenced by feminist ideology, though their actions partook of feminist activism. They were affected by the ideologies of social movements,

especially the consumer, women's and women's health movements. The women's political ideologies generally reflected beliefs of populism and individualism. In the next chapter I attempt to demonstrate how these identities and ideologies influenced the women's choice of strategies and tactics.

## Note

[1]It is important to note that the Black Civil Rights movement was the "mother" movement of most of the social movements prevalent in the 1960s and early 1970s. See especially Freeman, 1973 and Ferree and Hess, 1985 for a specification of the connections between the second wave of feminism and the ideologies, symbols, strategies and organizations of the civil rights movement.

# Chapter 6

## The Use of Emotion

In their efforts for Breast Cancer Informed Consent Laws, women activists sought to change a highly delimited area of the existing social order. These women were reformers in the Blumerian sense (1969:112) in that they accepted the basic tenets of the social order and worked within the established social institutions of government to achieve their narrow aim. In their efforts at reform, they affirmed values prevalent in American society, especially those of equality and self-determination, and worked to extend these rights to women as patients.

As mentioned in the previous chapter, these women can be viewed as agitators in that they attempted to "gain the attention of people; ....excite them, and arouse feelings and impulses; ....and give some direction to these impulses and feelings through ideas, suggestions, criticisms, and promises" (Blumer, 1969:104). But, they were also conformers, in that they were not willing to challenge gendered stereotypes regarding women. They attempted to advance the rights of women through working within the confines of popular stereotypes regarding women. In this chapter I will attempt to demonstrate that the activists used two stereotypes of women--as the social group culturally associated with emotion, and as the "weaker sex" in need of protection--to sensitize legislators and the public to their plight. They used emotion to get the attention of the public, arouse sympathy, and direct this feeling toward support of a Breast Cancer

Informed Consent Law. This law would then "protect" women through the patriarchal arm of the state.

In general, most women got the idea for a Breast Cancer Informed Consent Law from hearing about an effort for such a law reported in the media. Usually these women approached legislators they knew through personal contacts, or presented the idea at a community forum meeting hosted by a legislator. In a few states, the legislator was an initiator of the effort for the law and was later joined by aggrieved women. After the law was introduced, often a public hearing before the legislature was held. Women activists testified at these hearings. This was usually the point at which the media began reporting the story.

It has been noted by social scientists such as Hilgartner and Bosk (1988) and Gusfield (1989) that social issues presented in a dramatic way have a higher probability of successfully getting and keeping public attention than do other issues. These analysts have also noted that arguments for or against a social issue that are rooted in deep mythic themes or broad cultural preoccupations have a high probability of gaining public awareness and understanding. I contend that the drama used in this arena was consistent with widely shared cultural myths regarding women. Underlying the debates regarding Breast Cancer Informed Consent Laws were claims that women were emotional rather than rational (see Heller, 1980) and needed protection.

When former breast cancer patients and women legislators brought their concerns regarding patients' choice of breast cancer treatment before state

legislatures, they did so in the context of trying to gain support for a law. Given the limited "air time" in any public arena, activists' concerns were often distilled to that of conflict between male surgeons and female patients. In terms of emotion and the presentation of an emotional self, a distinction emerged between rationality and emotion. The male professionals were portrayed as rational, while the female activists were portrayed as emotional. The opposing camps were painted as physician-scientists who were above emotion, versus women moved by emotion to do something about this terrible situation.

From my perspective as researcher, there was little difference between the two groups in the type or magnitude of their emotions, but there were notable differences in whether and how emotions were expressed. Women were fearful of breast cancer and the treatment, were angry about the way they had been treated by practitioners, and grieved over the ways they were hurt during their illness experiences. Physicians feared the change this law entailed, especially with regard to erosion of their authority and the threat of malpractice, and were angry that their judgement, motivations and humanity were being publicly questioned. (The physicians' responses will be considered in the next two chapters.)

## Fearful of Breast Cancer

It was argued by those in favor of the law that the law was needed because women feared not only breast cancer, but the treatment. They argued that a Breast Cancer Informed Consent Law would demystify the treatment and make

women feel as if they had some measure of self determination regarding the choice of treatment. Both camps seemed to subscribe to shared cultural beliefs about the nature of women. Those who argued for and against Breast Cancer Informed Consent Laws both agreed that women were more "emotional." The women activists used this difference to advance the argument that because women were more emotional, they needed special treatment and protection provided by law. For example, one legislator who introduced the Breast Cancer Informed Consent Law in her state wrote:

> The patient in whom a breast cancer diagnosis has been made is a terribly frightened woman, frantic with anxiety, feeling alone, forlorn and forsaken. Can a woman in such an emotional state be adequately advised and informed of what is to happen if the biopsy is unfavorable? She may appear to understand, as she sits in her doctor's consultation room, but as the fateful proceedings unfold, her outlook, like that of the frightened child she had become, is subject to vast change (Harrison and Stovall-Hurdle, 1982:748).

Angry about the way they were treated

Regarding shared cultural beliefs about gender and the expression of emotion, my observation was that the activists subscribed to notions of the relative

propriety of women expressing grief versus the relative impropriety of women expressing anger. One of the things that angered women patients was physicians' lack of feelings and lack of compassion for their feelings. For instance, in her testimony before a state legislature, a Breast Cancer Informed Consent Law activist recounted the effect on her of her practitioner's lack of emotional expression:

> . . . Totally devastated by his cool, indifferent diagnosis, I managed to assert myself by saying that I did not wish to have a mastectomy, to which this elderly surgeon replied, "How many children do you have? How old are they? Don't you think they need you? Think about it and see me in two weeks." DEATH was the only alternative this man had given me if I did not subject myself to his horrible mutilative surgery (Roach, 1979).

The former breast cancer patients involved in the effort for Breast Cancer Informed Consent Laws were often motivated to advocate for this law as a result of the anger that was engendered from their treatment experience. In each of the first two states where the Breast Cancer Informed Consent Law was introduced during 1979 and 1980, there was a single woman activist on whom the media focused. In news feature articles on each of these women, it was mentioned

numerous times that they were angered by their treatment experience. For example:

> . . . The woman, Marjorie Roach of Burlington, subsequently found a surgeon who would remove only the breast tumor -- the so-called "lumpectomy" operation --and a radiotherapist who would treat the disease with radiation. She is reportedly doing well today, but her anger did not go away (Knox, 1980).
>
> . . . During her treatment, she met a number of other breast cancer patients who had experienced similar difficulties in obtaining information on treatment alternatives. Angry and indignant at this widespread failure to counsel adequately breast cancer patients, Mrs. Roach contacted her state senator, Carol Amick. Senator Amick agreed to co-sponsor a bill requiring that breast cancer patients receive full information on treatment options (AICR, 1984:8).
>
> . . . Thus, as a result of that first surgeon's intransigence and that patient's anger and determination, Massachusetts last summer became the first state to require doctors by law to tell breast

> cancer patients about "all alternative treatments which are medically viable" (Knox, 1980).

And the story of the activist in another state:

> This week, California's 1981 law requiring that breast cancer alternative treatments be provided in printed form becomes viable -- and Ristom's anger was a major force behind that law.
>
> . . . Ristom was angry when she began her campaign that culminated in the law -- after recovery from breast cancer diagnosed in 1979 which was treated with radiation implants instead of the mastectomy her surgeon had scheduled without even consulting her -- and she is still angry today.
>
> "I'm enraged that many women still aren't being told of alternatives. They have a right to individualized treatment," Ristom said, "to make an informed choice before they have a breast amputated" (Sinrud Shade, 1983:C7).

Yet, in a personal interview of an activist in another state, the activist told me repeatedly that she had no anger. There was a fair amount of consistency in

the activists' public presentations of an emotional self, especially at legislative hearings regarding this law, in that the women almost never publicly expressed personal anger, and almost always expressed grief. I hypothesize that this was due to two conditions: 1) the nature of politics at the state level; and 2) beliefs regarding appropriate gender-specific emotional expression in public.

In two studies of the debate over abortion at the state level (Steinhoff and Diamond, 1977; Ginsburg, 1989), researchers have made similar observations -- that in state settings, where actors are known to each other, moderation is rewarded over radical action. It was found by Steinhoff and Diamond (1977), who studied conflict over abortion legislation in Hawaii, and Ginsburg (1989), who studied the same in North Dakota, that both sides tended to lobby and debate in an ordered, pluralistic fashion because these tactics were legitimate, tasteful, and effective, especially in small states. I contend that the Breast Cancer Informed Consent Law activists understood that in the small, personal setting of state legislative hearings, their efforts would be better served by garnering sympathy for their grief than by angrily demanding rights.

Second, I believe the activists did not express anger directly or publicly because of their adherence to cultural beliefs regarding women, especially that anger is an inappropriate feminine expression, and that grief is an acceptable feminine expression. Even though these women were angry, and were reported as such in news accounts, they did not express that feeling in public, for to do so

would be a violation of gender norms. Instead they appealed to legislators on the basis of their grief.

Grief regarding the illness experience

After a Breast Cancer Informed Consent Law was introduced, most often a public legislative committee hearing was scheduled. In a pragmatic culture such as the United States, first-hand experience is effective testimony. First-hand experience is narrative, hence these special narratives, the "atrocity stories" became very important. The narration of the experiences of these women provided a context in which legislators could "take the role of the other" and sympathize with the plight of these women, and thereby be moved to act in support of their Law.

The concept of atrocity story was developed in medical sociology by Stimpson and Webb (1975) and was later used by Marcia Millman (1977). In the findings of these medical sociologists the experience was conceptualized as a private event, and as a malpractice. In contrast, the women activists I studied differed in that they conceptualized their illness experience not as a personal misfortune or professional error, but as willful misconduct and ignorance on the part of their surgeon toward patients. For example, this story is typical:

> . . . On Thanksgiving weekend, while bathing, I found a lump. . . The following Monday I had my regular prenatal checkup with my gynecologist, who said it was most likely due to a milk gland.

But he would like for me to have it checked by a surgeon as soon as I delivered the baby.

My fourth child was born in January. Within an hour after his birth, a surgeon examined my breast and said it was just a harmless little lump. But he would like to see me in 6 weeks. At this visit he assured me that it was nothing to worry about. He even commented that it was getting smaller. He asked that I come back in a month. The month passed and I returned. The surgeon, showing little concern, said it was unchanged and harmless. I then asked that he remove it, for my peace of mind. He called the hospital and arrangements were made.

The morning of surgery I felt like I needed to know a few answers. So I asked if he thought everything would go O.K. in surgery. He replied, "Why, you'll be talking to your husband by 10 or even 10:30." That was as close to a mastectomy as the conversation ever went.

I woke up to a horrendous, burning pain from my armpit to my waist, caused by over 200 stitches. The clock said 4 o'clock. No one had to tell me, I knew the worst had happened. I not only lost my breast, both pectoral muscles, the chest wall, the lymph glands under my arm. . . I LOST CONTROL. Just because a person is put to sleep he should not lose control of their life. The surgeon paged

> my waiting husband, had him sign an additional consent form, and proceeded with this surgery. My tumor measured only 1.5 centimeters (the size of a BB) and the malignancy had not spread.
>
> . . . I had been home a week when a friend, who is a nurse, came to visit. And she asked if I had had a radical. I replied, "Helen Mae, I had a mastectomy." She then explained to me the various ways of removing a breast. When my husband came home I asked him if he knew there was more than one way to remove a breast and he said no. We both felt so ignorant. (Alford, 1984)

In response to stories such as these, legislators, media representatives, and the public audience were apt to feel shock and compassion. One legislator who introduced the bill in her state told me about the hearings:

> . . . I had women there telling their experiences, nurses and lawyers, women who really were from all walks of life that had suffered the same tragedy. It was just shocking, it was just shocking . . . Nobody could believe this. I had the press there, I mean it was awful, it was awful. And I didn't have to say anything expect introduce the people. I mean I didn't have to make an emotional plea after these women spoke. It was apparent that there was a major problem. . . .The

> people who voted against the bill had to do it with
> their eyes down because it was just incredible.

The activists told their stories to legislators not as people who experienced a personal misfortune, but as activists exposing a system of widespread moral transgression in need of remedial action. Similar to disability rights advocates (see Scotch, 1984:162), Breast Cancer Informed Consent Law activists were able to engender public sympathy for their plight, and direct that sympathy to support of their law.

Emotional Catharsis

For the activists, there was a positive personal consequence of the process of getting their law passed. Many of the women experienced a personal catharsis (Scheff, 1979) that allowed them some emotional resolution regarding their negative experience with the medical system. For some, participation in the hearings helped them break the secrecy and silence regarding the fact that they had had cancer, and moved them closer to emotional closure regarding their experience. Many of the women who testified felt some emotional resolution regarding their negative experience with the medical system. As one respondent told me in an interview:

> . . . On the way back *(from the hearing)* I said, 'Ann
> and Luther, I have something to tell you. I will never

ever complain about my Radical again, or breast cancer again. I have gone as far as I can go with this, and I'm O.K. about it, I'm accepting it, and I promise you from this day forward, it doesn't bother me.' Because I felt like some good had happened because of this. Does this make sense?

(TM: Yes.)

So I'm O.K., I'm O.K. about it. I never cry about it anymore, I never--even when I put on a bathing suit and some of my scar shows--I never cry about it. And I don't because I feel like I have accomplished something.

"Going public" with their atrocity stories had another consequence. Many women reported that it contradicted a sense of personal alienation and shame. In many social worlds, having cancer and not being able to manipulate the medical system to one's advantage are occasions for stigma. By going public, that is having positive media attention, many women were able to put to rest residual feelings from their negative medical experience.

Summary

In public forums regarding the law, the women activists presented themselves in a consistently engendered manner. One could argue that they were 'doing gender' (West and Zimmerman, 1987) in this context in that they intentionally and clearly remained within the boundaries of commonly held beliefs about femininity. They framed their appeal to a predominantly male legislature in terms of women needing the protection that the Breast Cancer Informed Consent Law would provide.

The activists were catalyzed by their anger, yet used their stories of grief to gain sympathy from legislators and the public as a way to garner support for their Breast Cancer Informed Consent Law. They did not challenge the commonly held beliefs that women are the more emotional gender, instead they used this stereotype as license to dramatically portray their plight. They worked within the confines of gender stereotypes by not expressing anger publicly and not making demands, instead expressing an aggrieved feminine self in need of protection. In the next chapter I review the responses of their audiences, the media, legislators, and physician groups.

# Chapter 7

## Reactions: Media, Legislators and Physicians

As the women activists' for Breast Cancer Informed Consent Laws publicly presented themselves and their plights, the media, legislators and physicians responded to them. A typical composite story of an effort for a Breast Cancer Informed Consent Law would start when a woman received a diagnosis of breast cancer, and then had an upsetting encounter with a breast cancer practitioner. Some women discovered during or after their breast cancer treatment that there were alternative treatments to breast cancer about which they had not been advised. This discovery usually resulted in anger. Whether or not the women knew of Breast Cancer Informed Consent Laws, they generally contacted a state legislator, told their story, and requested that there be a law to address their concern. The legislators typically introduced a Breast Cancer Informed Consent Law and scheduled a public hearing on the topic. It was usually at the public hearing that the media, other legislators and physician groups learned of the Law and developed their views. It was often at the point of the hearing and because of the ensuing publicity that Breast Cancer Informed Consent Laws became a focal point of action of other similarly aggrieved women, legislators and allied organizations.

The Media

There was a good fit between the media and the activists in terms of both goals and methods. Media coverage is expensive in time and staff. Therefore, for the sake of cost-cutting, convenience, simplicity and rapidity, a few individuals receive the lion's share of coverage (Oberschall, 1978). This worked well for the activists, for they thought of themselves as individuals who worked alone. This born-of-expediency media construction of "stars" has the potential to invest a few people with more influence and importance than they actually have. It gave the activists the respectability they needed to make their claims on the legislature and, in turn, on medical professionals.

The media were very useful to activists. When I asked the activists how they got the idea for a Breast Cancer Informed Consent Law, they most often told me they had read about it in a newspaper or magazine, or saw a national TV magazine show that featured an activist from another state. In this way, the media served as an effortless, costless communication system for women to spread the idea that women were being wronged by medical professionals, and that this situation could be remedied by a specific state law.

The media were one of the vehicles the activists used to develop public opinion favorable to the passage of Breast Cancer Informed Consent Laws. Through the media the women were able to present themselves to an indifferent or disinterested public in hopes of gaining their support. The activists were in a difficult position, given that they were acting as advocates, and not as

representatives, of women who would someday be diagnosed with breast cancer and face treatment decisions regarding their disease. It is understandably difficult to rally a constituency in support of this issue. This would potentially mean that an individual woman would have to envision herself as a future victim of breast cancer, and then act on that possibility. The women activists for the Breast Cancer Informed Consent Laws contended that they acted in behalf of this group that would potentially be exploited by surgeons in the future, but did little to establish ties of any strength among them. Instead, these women put forth their atrocity stories, trying to awaken the sympathy of a middle class public (Blumer, 1969:113).

Whether or not they had a real or assumed conscience constituency is somewhat irrelevant, because in most states legislators responded to the activists as if they did. In this sense, the media functioned as an effective substitute for movement organization and structure. Activists were able to convey a mass message without mass events. The media presented the potential of reaching isolated, individual media consumers to whom they could convey their ideas. In effect, for a variety of reasons, but especially because their "bluff" was never called, they were able to substitute mass media for mass mobilization.

Media attention affected the activists personally. Through media attention they imagined they had a public, that they could reach their constituency. In a sense the media provided them with an opportunity for a "symbolic interaction,"

engendering feelings of solidarity with women with whom they were not in personal contact.

The Legislators

In my study state legislators responded to the publicity these activists were able to generate, as well as used their involvement with the effort for Breast Cancer Informed Consent Laws to generate media attention for themselves. The activists may have dissociated themselves from various women's and consumer groups, but legislators did not necessarily perceive their efforts for Breast Cancer Informed Consent Laws as being separate from the pressures of women and consumer groups' lobbying. During the decade of activism for this law, the 1980s, there was much talk of a "gender gap" in voting patterns. Also during this decade there were a series of court cases involving women as health care consumers, notably the Dalkon Shield case and the Ortho Pharmaceutical suit linking spermicide use and birth defects. In this regard, support for this law could be conceptualized by legislators as a way of appearing to be responsive to their women constituents as well as fulfilling their responsibility for the stewardship of public health.

To legislators, who had been previously sensitized by women's political organizations and feminist activism, these former breast cancer patients were symbols of vast multitudes of women voters, as in this anecdote told to me by one Senator about another:

> ....Well, the bill passed. The vote in the Senate was 37 to 1. The one opposing vote came from a guy....After the vote he realized that he was in a lot of trouble back home. You know, you can do just about any damn think you want [in the capitol], but you start going back [to your district] and telling the women .... I mean a vote like that shows that you really don't give a damn. His aide, who is a woman, sent down a memo telling him you better change your vote or you'll never make it off that floor alive. Well, he stood up and he said that he realized he made a terrible....He wanted to call the vote again so that he could vote **FOR** it. He said, 'This way I'll be able to go home.'
>
> We got a lot of bru-ha-ha going down here. There's a whole bunch of things that you can do and your constituents will be tolerant of, but I'm not looking to anger 51% of them in one fell swoop.

I argue that the legislators had nothing to lose, and could possibly acquire some good publicity if they supported this law. In each state, the consistent adversaries to a Breast Cancer Informed Consent Law were the American

Medical Association and the American Cancer Society. From the legislators' perspective, the politically savvy approach to this situation was to strike a balance between the desires of the activists and the potential reaction to the law by the American Medical Association and the American Cancer Society. Most legislators resolved their dilemma by introducing a law that was weakened enough so that it had no bite, thereby skirting the disdain of the American Medical Association and the American Cancer Society, but that retained some symbolic value, so as to please the activists.

Physicians' Response - Dedramatization

In response to the Breast Cancer Informed Consent Law activists' dramatic and effective portrayal of the need for these laws, representatives of physicians groups, such as the state medical association, or physician-dominated groups such as the American Cancer Society, as well as legislators controlled by physician interests, all used strategies to dedramatize (Moyer and Clignet, 1980) the need for Breast Cancer Informed Consent Laws. First and foremost of the strategies of dedramatization was dismissing the activists as uninformed and irrational. Other strategies included: denying the existence of controversy within the field of medicine regarding Breast Cancer Treatment; denying the existence of inequity within the male/surgeon--female/breast cancer patient relationship; and arguing that the Breast Cancer Informed Consent Laws were not the true solution to the problem, would cause more harm than good, and were unworkable. In addition,

physicians asserted that if an informed consent law were enacted specifically for breast cancer treatment, it would open the floodgates for a whole host of legislation particular to every known ailment. For example, this physician was quoted in a news article:

> If the legislature requires informed consent for this type of surgery, it will hear demands for the same sort of coverage for others "with emotional problems (arising from) another organ," Buchanan warned (Cox, 1982:A6).

The main strategy used by physicians to dedramatize the need for Breast Cancer Informed Consent Laws was to dismiss the activists as irrational. The belief that the women activists were more emotional was used by physician groups to discredit them and their efforts for this law. Physicians argued that women's claims for a Breast Cancer Informed Consent Law were illegitimate because they were based on feeling as opposed to rationality. One set of claims advanced was that the law was not valid because it was in response to women's hyper-emotionality, as this doctor contended in an article in a national medical journal:

> Unfortunately, the debate about the treatment of primary breast cancer has taken on the emotional overtones of women's rights and freedom of choice. This public debate ignores totally the heterogeneity of

> breast cancer and the available data. What is worse, the emotionalism impedes the clinical research that will have to be done if the questions are to be adequately answered. There is no clearly optimal therapy for primary breast cancer. It is still a halfway technology and we are still learning (Carter, 1982a:338).

Breast Cancer Informed Consent Law activists countered these charges by reaffirming the cultural beliefs regarding the naturalness and rightness of women to base their actions on feeling. In response to this physician's article, one activist sent the following letter to the editor (which was never published):

> . . . Yes, I do get "emotional" when I look in the mirror and see my body whole and unscarred. I was "emotional" when I refused a mastectomy and searched for alternative procedures. I get quite "emotional" when women I counsel -- and save from unnecessary mastectomies -- say to me, 'I feel that God sent me to you.'
>
> It is "emotional" women who are responsible for our effective rape laws, child molestation laws, and drunk

> driving laws, just to name a few. We "emotional" women are productive, constructive and creative. If women are to be criticized for not wanting their bodies mutilated, for insisting on being informed of alternatives (my surgeon preferred to keep these a secret from me), for feeling they have the right to decide what they want done to their own bodies -- yes, freedom of choice -- then I am certain I represent all women when I say we have every right to be "emotional" and we happily wear that label as a badge of honor (Ristom, 1982).

Others in opposition to the Breast Cancer Informed Consent Law argued that if the law were passed, women would be too emotional to be able to handle it, appreciate it, or make the right decision if given the choice of treatment. This was evidenced in this excerpt from a physician's article in a state medical journal:

> No matter how informed the patient is regarding treatment modalities for the various tissue diagnoses of "breast cancer" and its metastases, the choice of treatment can be colored by affect.

> If a woman's self-esteem is strongly tied to her body image, assimilation of volumes of scientific research will not alter this factor in her decision-making. If a woman's marriage partner or lover is strongly attached to the breast, research into medical literature will be focused on ways to preserve the breast, so as to save the relationship (Haun, 1982:753).

Physicians' Resistance

The professions of law and medicine have a long standing antipathy regarding patient consent to medical treatment (Kaufmann, 1983). In general, physicians in my study believed that there should be no laws that interfere with the practice of medicine. These sentiments were repeated throughout the American Cancer Society's report on Breast Cancer Informed Consent Laws:

> In some states organized medical groups, among others, have opposed this type of legislation....Others feel that the basic patient/physician relationship should not be mandated by governments and governmental agencies....It was felt that it was inappropriate for government to legislate "viable alternatives" for cancer patients....Although the division *{ACS}* supported the concept of "informed consent," it

> did not support government regulation of the patient/physician relationship....The Division *{ACS}* approved the intent of the bill, but expressed opposition to government legislating the patient/physician relationship (American Cancer Society, 1983).

Advocates for informed consent generally believe that laws would serve as a vehicle for establishing patients' rights to make knowledgeable and voluntary decisions to accept or refuse various forms of treatment (Kaufmann, 1983:1657). In her review of two decades of medical literature on Informed Consent, Kaufmann (1983) found that physician critics opposed informed consent for numerous reasons. In my study I found confirmation of Kaufmann's observations, in that the claims physicians made to counter Breast Cancer Informed Consent Laws can be similarly categorized. Below I list Kaufmann's categories followed by examples from my data:

1. Physicians challenged the necessity of the doctrine (Kaufmann, 1983:1657)

   Example: "It slipped by us the first time," said Willard Osburn, director of legislative activities for the medical society. "We've lobbied against it because we don't feel special legislation is needed. If you spelled informed consent out for breast

cancer, you'd have to do it for every surgical procedure" (*American Medical News*, 1983:1).

2. Physicians found the extended liability burdensome (Kaufmann, 1983:1657)

   Example: "At the time the law was proposed, there was some concern," Shea [assistant director for government relations at the Massachusetts Medical Society] said. "Some physicians were concerned that we could not cover all the alternatives and by trying to do so, we were opening ourselves to more liability" (*American Medical News*, 1983:1).

3. Physicians considered informed consent a challenge to their autonomy (Kaufmann, 1983:1658) and their right to establish norms of professional conduct and to police themselves (p. 1661)

   Example: In addition to opposing the legislative sanctions, the society argued that proper disciplinary measures already exist within the state's Commission on Medical Discipline. If a doctor failed to properly inform a patient about the possible types of surgery or outcome of treatment, a patient could file a complaint and the doctor's license could be revoked, according to Dr. Jose Martinez, chairman of the society's legislative committee (Walsh, 1982:3).

4. Physicians claimed that the realities of clinical practice make the involvement of patients in medical care difficult (Kaufmann, 1983:1659)

Example: McDonald said listing all alternatives and risks can hurt patients. "If these breast cancer girls prevailed, we'd have a lengthy, detailed permission, which would amount to non-informed consent because it would be 10 to 15 pages long. If you gave that form to me to give out, I promise half my patients would go cross-eyed before they finished reading it." The forms could frighten patients into refusing necessary treatment because of confusion over all the information presented, said McDonald, a Medical Association of Georgia member (Downey, 1984).

5. Physicians believed that informed consent undermines the fiduciary relationship between physician and patient (Kaufmann, 1983:1661)

Example: Robert J. McKenna, MD, Clinical Professor of Surgery at the University of Southern California School of Medicine agrees. "I am strongly opposed to legislating a mode of treatment and a legalistic approach to informing patients. The doctor-patient relationship is based on trust" (Stockwell, 1983).

6. Physicians believed that informed consent erodes their therapeutic privilege to withhold information if the physician feels it is not in the patient's best interests to disclose (Kaufmann, 1983:1662).

Example: There can be little doubt that special breast cancer legislation will put such pressure on a physician. Even though the

> physician may believe disclosure of an alternative is not in the best interest of the patient, the physician's risk of exposure to a law suit has to increase if there is a statutory mandate and he or she refuses to make the disclosure (Goolsby, 1982:759).

I also found a general unanimity in physicians' oppositional claims. I attribute this to three factors:

1. As Kaufmann (1983) has identified, there are clear professional ideologies regarding informed consent.
2. National physician organizations (or physician-dominated organizations such as the American Cancer Society) paid extensive attention to Breast Cancer Informed Consent Laws. For example, the American Medical Association assigned a staff attorney to periodically write legislative reports and distribute them to state medical associations. In 1983 the American Cancer Society published a report, *Division Involvement in State "Informed Consent-Breast Cancer Treatment" Laws/Legislation* which delineated many of the opposition rationales presented above. This national report was also distributed to state branches of the Cancer Society.
3. Similarly to the activists, many physicians learned of efforts for Breast Cancer Informed Consent Laws in other states through the media. When compared to the activists, physicians were advantaged in that they had

national professional organizations that published specialty newsletters and journals. Often these newsletters and journals featured articles on Breast Cancer Informed Consent Law efforts.

Summary

In general, efforts for Breast Cancer Informed Consent Laws were the result of the spontaneous impulses of individual women with little experience or knowledge of the political process. These activists were able to get attention for their issue given that their presentation was dramatic enough to warrant media coverage. Legislators who had experienced previous efforts of women's, consumers' and women's health groups were a receptive audience. Support for Breast Cancer Informed Consent Laws legislators with a way to appear to be responsive to women constituents. Physician groups generally opposed the women's efforts by emphasizing the dichotomy between rationality and emotion. Physicians claimed that they were operating from a rational basis to counter activists' "emotional," thereby illegitimate, presentations. Physicians also resisted the Law on the grounds that they believed there should be no "outside" interference with the practice of medicine.

## Chapter 8

## Outcome of the Effort: New Advantages for Women?

In evaluating the efforts for Breast Cancer Informed Consent Laws, one could argue that the activists were generally successful, given that a law was passed in 16 of the 22 states in which it was introduced. On closer examination, however, it was apparent that there were changes in the contents of the law over time. Breast Cancer Informed Consent Laws passed earlier in the 1980s were stronger than those that followed.

As I noted in Chapter 4, there are three components of an Informed Consent Law: 1) requirements to disclose information about treatment to patients; 2) duty to obtain patients' consent before proceeding with treatment; and 3) penalties for practitioners' non-compliance. Table 1 is a chronological listing of the Breast Cancer Informed Consent Laws that passed in terms of these three components.

As can be seen in Table 1, in thirteen of the sixteen states the Breast Cancer Informed Consent Law specifically indicated that women should be informed of the equally efficacious alternative treatments for breast cancer. This provision was in response to the concerns prevalent at this time, namely the controversy within the profession of medicine regarding treatment alternatives (as described in Chapter 3). In three of the states with informed provisions,

Table 1: Breast Cancer Informed Consent Laws

| State | Year Passed | Information Provisions | Consent Provisions | Penalties |
|---|---|---|---|---|
| Massachusetts | 1979 | X | | |
| California | 1980 | X | | Unprofessional Conduct |
| Hawaii | 1983 | X | X | |
| Louisiana | 1983 | X | X | |
| Kansas | 1984 | X | | Revoke License |
| Pennsylvania | 1984 | | X | Civil Liability |
| New Jersey | 1984 | | X | Review by State Board of Medical Examiners |
| Minnesota | 1984 | X | | |
| Florida | 1984 | X | | |
| Georgia | 1984 | X | | |
| Kentucky | 1984 | X | | |
| Virginia | 1984 | | X | |
| New York | 1985 | X | | *** |
| Maryland | 1986 | X | | Revoke License |
| Michigan | 1986 | X | | *** |
| Maine | 1989 | X | | *** |

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*** In these states specific provisions were attached to the law to assure that physicians would suffer **no** penalties if they did **not** comply with the Breast Cancer Informed Consent Law.

California, Kansas and Maryland, penalties were attached to physician non-compliance to the law.

In two states, Hawaii and Louisiana, the Breast Cancer Informed Consent Laws have both information and consent provisions. In neither of these states were penalties attached to the law for physician non-compliance.

In three states, Virginia, Pennsylvania and New Jersey, Breast Cancer Informed Consent Laws only had consent provisions. As can be seen in Appendix D, these laws were tailored in response to the one-step (biopsy plus mastectomy) versus two-step procedure (biopsy and mastectomy separated) controversy described in Chapter 3. In New Jersey and Pennsylvania penalties were attached to the law for physician non-compliance.

In three of the final four states in which a Breast Cancer Informed Consent Law was passed, the Law contained specific provisions that weakened it. For example, the New York Breast Cancer Informed Consent Law included a clause, "Nothing in this section shall be construed to create a cause of action for lack of Informed Consent..." (NY, 1985, Public Health Law, Article 24, Section 2404). The Michigan Breast Cancer Informed Consent Law contained a similar, if more explicit clause,

> A patient who signs a form pursuant to subsection 5 shall be barred from subsequently bringing a civil action against the physician providing the summary or brochure described in subsection 2 based on failure to

> obtain informed consent... (Michigan, 1986, M.C.L.A. Section 333.17013)

The Maine (1989) law is similar to the Michigan law. These provisions limit or prevent the patient from using the law in a suit against the practitioner. As Kaufmann (1983:1657) has noted, physicians have challenged the necessity of the doctrine of informed consent because it extended liability for physicians (p. 1657). These clauses go beyond limiting liability, and actually revoke the patient's right to sue his or her practitioner.

As evident in Table 1, Breast Cancer Informed Consent Laws were not uniform across states. In most states, there was provision for patient education about alternative treatments. In a few states, what were called Breast Cancer Informed Consent Laws were no more than consent bills that addressed the one-step versus two-step procedures. In general, there was a trend toward weaker laws by the end of the 1980s. This led to my examination of the process of getting the law passed, with special focus on the role of physician groups.

## Physician Groups' Cooptation Efforts

In his review of social movements since 1945, Gamson (1975:29) considered the outcomes of social movements. He conceptualized four outcomes of social challenges: success, failure, cooptation and pre-emption. Gamson described a social movement as coopted if the activists were accepted, but their

program of reform was not. Gamson described a social movement as pre-empted when the movement resulted in new advantages, but the activists were not accepted.

Gamson presented a more complex scenario than simple success or failure. My study adds further complexity by considering by whom were the activists accepted or not accepted, and by considering the degree to which the Breast Cancer Informed Consent Law that was passed actualized the activists' goals. For example, when examining these two issues from the perspective of physicians, one can see that they never fully embraced the concept of Informed Consent nor the spirit of the law. But they did come to acknowledge that some sort of action on this issue was probably inevitable.

In my study I identified four categories of physician groups' response to efforts for Breast Cancer Informed Consent Laws: 1) No response - physician groups were unaware of the effort; 2) Compromise offer - physician groups became aware of the effort early and offered a plan to avert passage; 3) Involvement - physician groups realized that they could not prevent passage and became involved in the process to shape the law; 4) Post-passage involvement - physicians learned of the effort late, or were unsuccessful in defeating the law, and became involved at the stage of preparation of the standardized written summary.

*No Response: Unaware*

Early efforts for Breast Cancer Informed Consent Laws received little attention from physician groups. For example, the first Breast Cancer Informed Consent Law was passed as an amendment to the Massachusetts Patients' Bill of Rights in 1979. This event was recounted in *Family Practice News* as such:

> Most Massachusetts physicians were unaware that such an amendment was even under consideration, and only learned of it in the newspapers the day following passage, several physicians told this newspaper....Dr. Levene told this newspaper that the breast cancer legislation "came as a great surprise to us. We knew nothing about it until we read that it had been passed. We did not attend any hearings, we didn't even know there were any" (International Medical News Service, 1979).

*Compromise Offer: Education not Legislation*

If physician groups learned of an effort for a Breast Cancer Informed Consent Law early in the process, they often made a plea for "education not legislation." They tried to strike a compromise--the physician group would educate its members about the various breast cancer treatments and the need for consent to procedures, thereby making legislation unnecessary. Given this

promise, legislators often withdrew or defeated the Breast Cancer Informed Consent Law. The following is an American Cancer Society account of the success of this strategy in Oklahoma:

> A Breast Cancer Patient's Consent Law was introduced and subsequently withdrawn during the 1982 session of the legislature. The sponsor of the bill agreed to withdraw the proposed legislation after the Oklahoma State Medical Association (OSMA) agreed to work out their own program to inform breast cancer patients of alternative treatments. To date (May, 1983) the OSMA has not followed through with its pledge. The Division *{ACS}* is now working closely with the state representative who sponsored the original bill (American Cancer Society, 1983).

While this strategy worked in several states, it "backfired" in Maryland. In an interview with the late Rose Kushner, she said that in Maryland a Breast Cancer Informed Consent Law was first introduced in 1982 at the urging of the Maryland Women's Health Coalition. It was opposed by the Maryland State Medical Society and died in Committee. In 1985 the law was reintroduced, and this time the legislative sponsor of the bill asked Rose Kushner to come and testify in behalf of the Law. A surgeon from the University of Maryland testified

against the Law, asking that the Medical Society be given a chance to comply with the spirit of the Law voluntarily. After Rose Kushner negotiated with the surgeon from the Medical Society, the legislative sponsor of the law agreed to withdraw it upon two conditions: 1) that the Medical Society develop and distribute an informational brochure describing the alternative forms of treatment for breast cancer for physicians to give to their patients; and 2) that the brochure have a postage paid receipt attached addressed to the Health Department that the patient would send to acknowledge that she was given the brochure. The Medical Society printed 100,000 copies and distributed 65,000 to all physicians in the state. At the end of one year the health department received 81 acknowledgements from patients. With this evidence the legislator introduced the law again. According to Rose Kushner,

> When we got up to testify we told the committee, they remembered everything that happened last year, we said 'Look, all we're asking for is that you mandate that the doctors have to give out this super-duper publication that they spent so much money to print and mail.' And the official lobbyist for the State Medical Society, her argument just fell....she left. And the Law just sailed right through.

*Involvement*

If physician groups learned about the effort for a Breast Cancer Informed Consent Law when it was underway, they got involved in the process and attempted to shape the outcome. The American Cancer Society's report on Breast Cancer Informed Consent Laws described the organization's involvement in one state as such:

> It is interesting to note that the Massachusetts Division *{of ACS}* was initially opposed to the proposed "patients' rights" law. Despite its opposition, it was decided to become involved in the process once the Division realized that some sort of law would be passed with or without Division support. The Division became involved and was successful in seeing that the law's language was written to insure that risky, unproven alternative methods of treatment would not be presented as viable medical alternatives (American Cancer Society, 1983).

*Post-Passage Involvement*

If physician groups learned of the effort for a Breast Cancer Informed Consent Law late in the process, or even after it passed, in some states they were able to get involved at the implementation stage. For example, many Breast

Cancer Informed Consent Laws stipulated that physicians would be in compliance with the law if they gave patients a standard written summary of breast cancer treatment alternatives. These brochures were to be written in "laymen's" (sic) language. The laws usually did not state who was to develop this brochure, but often the legislators contracted this work to an official government agency, such as the Board of Medical Quality Assurance, or a state cancer organization, such as the McDowell Cancer Network, or formed a committee.

Physicians were generally on record against a standardized written summary. One physician explained:

> Such a document, however carefully developed, will certainly raise more questions that it answers. Alternatives will be proposed that may seem attractive to patients but do not, in the judgement of their physicians, offer the best opportunity for survival. Furthermore, given the rapid advance of medical science, any treatment summary will soon be outdated, at least in part. In short, physicians are going to have to do a lot of explaining (Carter, 1982b:176).

In California, the second state in which a Breast Cancer Informed Consent Law was introduced and passed, physicians got involved late in the process. In this state the legislature delegated the development of the standard written

summary to the Cancer Advisory Council, a group of physicians appointed by the Governor. Many of my data sources (interview, media, organization's report) reported that the physicians undermined the brochure construction process. According to an American Cancer Society report:

> The California legislature, during 1979-80, was the scene of a protracted debate regarding the merits of a proposed Breast Cancer Patients Consent Law. After approval by the Assembly and Senate in 1980, it took three years and thirty rewrites to produce a brochure that was acceptable to physicians, patients' groups, state officials and legislators for distribution to cancer patients. The brochure finally became available in 1983.

This account was given by one of the activists who participated in the process:

> What they did was they made a draft on one sheet of paper, one eight and a half by eleven. And they said, 'This is the brochure.' So I could see....that they would do anything possible to gut the bill. This was to denigrate the law and to gut it, because all it did was list the procedures: Halsted Radical number one, Modified Radical, and described the one-step biopsy,

> and that was it. And I said to *{Senator}* Roberti, 'Look, any body could go to a book and get all of these procedures, they didn't even follow the law. The law says that each procedure must be described by the advantages, disadvantages and the risks. They did none of this.' Then I knew I had to get involved, and that really ruined my employment agency. Two years of drafts, it was just horrendous, because I could not give any time to my employment agency....The reason that the brochure took two years is because of the Cancer Advisory Council.

Outcomes from the Perspective of the Activists

Many weak, symbolic laws were able to slip passed the activists without protest because, in general, most of them lacked any political experience. Given their political naivete, they were happy that their law passed. But I found that they were not altogether oblivious to the fact that the laws they worked for were weak. As part of my interview schedule I asked if they had any evidence that the law was effective in their state. Most said that they didn't have any evidence that the law changed anything, but they were happy with the process of getting the law passed. They claimed that the process generated so much publicity about breast cancer treatment alternatives, the controversy over the relative advantages and

disadvantages of mastectomy, and a woman's right to participate in the decision-making process, that their goals were met by public education rather than by legislation. From their perspective, the media attention was so good, that even though they thought the law was ineffective, they believed they were a success because they were able to use the media to raise consciousness among patients, and most doctors became, and I quote, "damn scared of possible malpractice." So even though they lost the law, they figured they won the education.

The activists, in interaction with the media, and witnessed and aided by legislators, operated and measured their achievements in the realm of individual experience rather than by noticeable concerted mass actions. This effort for Breast Cancer Informed Consent Laws was "a crystallization of much of the motivation of dissatisfaction, hope and desire awakened by the" (Blumer, 1969:102) consumer, women's and women's health movements. This motivation was focused on a limited action to advance human rights in the way these women believed they could be effective.

# Chapter 9

## Summary and Implications

In this chapter I briefly summarize the major points of my study around two dimensions: 1) the activists and their efforts for a Breast Cancer Informed Consent Law; and 2) more general issues regarding the political process of getting a law passed in a state legislature.

### The Activists

With respect to activists, three major analytic concerns emerged: 1) their identities as women and as American individualists; 2) their ideologies, especially those that were filtered through popular culture from the women's, women's health and consumer movements; and 3) the activists' expression of emotion during the political process.

#### *Identity*

In this study of women's activism for Breast Cancer Informed Consent Laws, I found that the activists' identities were central to my analysis of their efforts. First and foremost, the activists were very conscious that they were women. They identified as women to the extent that they chose political strategies that were consistent with popular gender beliefs prevalent in the U.S. at the time. Consistent with gendered ideologies regarding women, the activists

publicly presented themselves as women with strong emotional responses to their (mal)treatment and in need of state protection. Their identity as women also guided their presentation of self at legislative hearings for Breast Cancer Informed Consent Laws in that they were careful not to express anger (socially taboo for women). Their main strategy was the public expression of grief in order to awaken public sympathy.

Given that the majority of the activists were women and that a Breast Cancer Informed Consent Law could be conceptualized as feminist in intent, there was a distinct possibility that the activists' publics may have assumed that they were feminists. Activists directly addressed this misconception by distancing themselves from not only the stigmatized identity of feminist, but also from feminist organizations. Members of these organizations could, of course, have aided and advised the activists so that they would not have to reinvent politics, and could have framed this effort in continuity and connection with other efforts to advance the rights and status of women.

Another important identity was the activists' political self constructions. These women were American individualists. I use Bellah's (1985:30) meaning of individualism, "a sense of respect for the integrity and dignity of the individual person and a belief in the efficacy of the individual's action." They conceptualized themselves as working alone, distanced themselves from movements and organizations, and worked without a sustaining institutional context.

When these women were aggrieved, they reacted as American populists in that they believed government could be used in the interests of common people. They believed that laws could solve social problems, so they worked for Breast Cancer Informed Consent Laws. This solution was also based, in part, on their ideology of American individualism, in that they believed that politicians and government are accessible and responsive to common persons working alone.

*Social Movement Ideologies*

In my study I found evidence that these women were influenced by the ideologies of social movements despite their lack of participation in them. The first was the women's movement, which had as a central ideology equality between men and women. Women activists interpreted their interactions with male practitioners as evidencing their practitioners' lack of respect for them as gender equals. The second was the women's health movement, espousing the ideology that women have the right to self-determination in matters regarding their bodies. Women activists interpreted their breast cancer experience and subsequent interactions with practitioners as evidence of practitioners' lack of concern for their rights of physical integrity and autonomy. And finally, the activists reflected ideologies of the consumer movement, especially the notion of the diminishing status differential between practitioners and consumers, and the belief in protective legislation.

*Emotion*

Most of the activists had the experience of breast cancer treatment in common. In many cases the experience resulted in personal feelings of rage. They were angry that they were not respected as women and as consumers; they were angry at physicians' inability to equalize relations between practitioner and patient; and they were angry at male practitioners' inability to act in an emotionally sensitive manner, given the seriousness of their diagnosis and treatment decisions.

While their rage may have been the catalyst for their activism, in public they expressed grief over the way they were treated. I found evidence of fear, rage and grief in the data I collected, but when trying to persuade others to support their efforts, the activists did so on the basis of gaining sympathy for their plight.

In the interplay of these three categories the complexity of political participation is revealed. More importantly, my study demonstrates certain subtleties in the interplay of these three themes, subtleties not clearly recognized in the literature on political participation. It is clear that the activists "borrowed" those portions of feminist ideology that were most congenial to their own views of themselves as women and of women's place. Thus, the ideologies of social movements are sometimes influential beyond the participants and historical era of the movement. But ideologies are not necessarily wholly accepted, they are often

selectively adopted and adapted for their utility. Indeed, it might even be said that the activists' espousal of the cultural values of individualism and populism overrode the feminist values of organization and collaboration, thus demonstrating the tensions between traditional American cultural values and the ideologies of more recent social movements.

Even the partial effect of the adoption of feminist thought, especially perceived inequities between women and men, female patients and male physicians, was integral to the use of emotion in this effort--it provided the source of anger which catalyzed many activists. These inequities, following Gusfield's (1963) formulations from his study of the American Temperance Movement, may be conceptualized as status inconsistencies. The central thesis of Gusfield's study was that the American Temperance Movement was a symbolic crusade by native Protestant rural middle class persons to assert and assure their social status, a position which they felt was threatened by changing social conditions. According to Gusfield (1963):

> Status discontents are likely to appear when the prestige accorded to persons and groups by prestige-givers is perceived as less than that which the person or group expects. The self-esteem of the group member is belied by the failure of others to grant him the respect, approval, admiration, and deference he feels that he justly deserves. This may occur when a

> segment of the society is losing status and finds that prestige-givers withhold expected deference. It may occur when a groups is making claims to greater prestige than it has made in the past and finds that prestige-givers do not comply with the new claims (Gusfield, 1963:17-18).

I compare my research to Gusfield's in that the women in my study were experiencing a change in status. Gusfield's subjects acted on their perception of diminishing status, my subjects were acting on their expectations of rising to equal status in their interactions with practitioners, the majority of whom were male.

In Gusfield's study, the native Protestant rural middle class group acted upon their fear of diminishing status by advocating the Prohibition laws at the state and federal level. According to Gusfield,

> Even if the law is not enforced or enforceable, the symbolic import of its passage is important to the reformer. It settles the controversies between those who represent clashing cultures. The public support of one conception of morality at the expense of another enhances the prestige and self-esteem of the victors and degrades the culture of the losers (Gusfield, 1963:4-5).

Parallel to Gusfield's findings, I found that the women I studied acted upon their rage and advocated for Breast Cancer Informed Consent Laws at the state level. These laws had the potential to symbolically ensure the rising status of women in the physician-patient encounter, and symbolically lower the physicians' power and authority. But, a central issue of any symbolic law is the question of implementation. I now turn to my second set of major points, those dealing with the issues of political process.

Political Process

In this study of women's activism for Breast Cancer Informed Consent Laws, may aim was to explore the conditions under which small, single-issue movements of women activists are and are not successful in attaining their goals. By the end of my study, I found that the concept of success was far more elusive than I had initially anticipated. Two problematic areas emerged: 1) From whose perspective should success be judged? and 2) What should the measurement of success be? Whether or not the law was actually passed was meaningless unless the content of the law was examined. In other words, what law was passed? In this section I frame my discussion of these two questions in juxtaposition to previous studies of outcomes of political efforts.

*Gamson: The Meaning of Success*

In his meta-analysis of the outcomes of modern social protest efforts, Gamson (1975) divided outcomes into two basic clusters, "one concerned with the fate of the challenging group as an organization and one with the distribution of new advantages to the group's beneficiary" (Gamson, 1975:28). Following this analysis I asked, did the media, legislators and physician groups accept the women activists as valid spokespersons for women patients, or did they deny such acceptance? I contend that all three audiences accepted the women as advocates, but that the physicians refuted the claims of the activists on the basis that they were being delivered by women, an illegitimate source.

The second question that follows from Gamson's analysis is whether the activists gained the advantages they sought. To this I also have a mixed response. The women got publicity which drew public attention to their issue and educated the public about the breast cancer treatment controversy. Their Law was also passed. But, upon closer examination of the legislation that passed, one finds that many of the laws were altered to the extent that they actually advanced physician interests at the expense of patients' rights. This anomaly led me to consider the various instrumental versus symbolic benefits of legislation, an area explored by Gusfield.

*Gusfield: Instrumental versus Symbolic Goals*

Gusfield (1963) contended that the instrumental goals and effects of legislation were "slight compared to the response which it entails as a symbol, irrespective of its utility as a means to a tangible end" (p. 169). He argued that the significant meanings of a law were not to be found "in the intrinsic properties of the action, but in what it has come to signify for the participants" (p. 21). My findings were similar, in that when I asked the activists about their satisfaction with the outcome of the effort, they acknowledged that there was no empirical evidence of change, but they felt satisfied with the process of getting the law passed. In passing their Law, an official body had conferred legitimacy on their claims and visions, and had concurred in the women's denunciation of certain medical practices and their practitioners (see Garfinkel, 1956:421).

The Breast Cancer Informed Consent Law was a legislative innovation and, similar to most innovations, it was only partially accepted. But, even though only partially accepted, it did result in the state getting involved in a dispute regarding professional control. In this conflict, the state did exercise its authority over the powerful institution of medicine, even if only in a symbolic gesture.

*Edelman: Symbolic Politics*

In my study I found concurring evidence to support Gusfield's (1963) emphasis on the importance of the symbolic aspects of popular efforts for specific legislation. But, even though symbolic legislation may not have instrumental

effects, it could still be opposed. In my study I found that those in opposition to Breast Cancer Informed Consent Laws, specifically physician groups, fought this symbolic law and in some cases were able to shape the Law to their advantage. This phenomenon has been studied extensively, especially by political sociologist Murray Edelman (1960, 1964, 1971). In his studies of anti-trust regulation, poverty, and urban movements, Edelman found that much symbolic legislation was ineffective and unenforced by design. He contended that groups continue to advocate for such legislation because the public act of the passage of the law reduces tensions between the groups in conflict:

> We have already noted that it is one of the demonstrable functions of symbolization that it induces a feeling of well-being: the resolution of tension. Not only is this a major function of widely publicized regulatory statutes, but it is also a major function of their administration. Some of the most widely publicized administrative activities can most confidently be expected to convey a misleading sense of well-being to the onlooker because they suggest vigorous activity while in fact signifying inactivity or protection of the "regulated" (Edelman, 1960:702).

In this study I found that the introduction of a Breast Cancer Informed Consent Law was a tremendous symbolic victory for the activists, in that they felt the government was intervening to protect women. I found that politicians were also able to benefit from a reassured constituency, given their symbolic gesture affirming their support of women. Physician groups, far more organized and politically knowledgeable at national as well as state levels, were able to take advantage of a quiescent public to work to advance their aims--a turn from the constraints of informed consent and malpractice toward professional standards and limited liability. This was not an anomalous situation. Edelman (1960, 1964, 1971) found that in many cases research has indicated that government exists to protect the interests of the organized:

> ....It is only as symbols of this sort that these statutes have utility to most of the voters. If they function as reassurances that threats in the economic environment are under control, their indirect effect is to permit greater exploitation of tangible resources by the organized groups concerned than would be possible if the legal symbols were absent. Those who are deprived become defenders of the very system of law which permits the exploiters of resources to act effectively (Edelman, 1960:702).

Similar to Edelman's (1960) findings regarding efforts for anti-trust legislation, in this study I found a situation wherein the activists turned to the state in advocating protective legislation. The state legislatures, long influenced by powerful interests, acknowledged the women's concerns and passed symbolic legislation. Physician groups were able to use the efforts for the law as an occasion to counter or reshape legislation they found burdensome. Women activists were satisfied by the passage of the Breast Cancer Informed Consent Law, even though in many states the lack of execution or the actual formulation of the law diluted or even contradicted their intentions.

A broader analytic point to be considered is that this conflict over Breast Cancer Informed Consent Laws may be representative of deeper cultural conflict, that is the tensions between those advocating for women's rights in the realm of body integrity, self determination, need for protection, and respect for expression of emotion versus the entrenched and powerful institution of medicine vested in the status quo. In this contest, the state symbolically backed the those advocating for change, even though the Law was used to fortress the power of the profession of medicine.

## Questions for Further Investigation

In my study I found numerous consequences of this small effort for social reform. I demonstrated that identity, ideology and emotion all need to be considered in an analysis of political activism. Also demonstrated was that

outcome is a complex construct: there was no unitary determination of success. Research questions for further investigation include:

--Identity: What is the relationship of identity(ies) of activists to the strategies and tactics they adopt in political arenas?

--Ideologies: In political efforts, what ideologies are borrowed from whom/where? How are the ideologies modified to fit the activists' needs and identities, and to fit the contingencies of the specific political context?

--Ideologies filtering through popular culture: What are the effects of ideologies of social movements as they become popularized beyond the movement participants and the historical period of the movement?

--Emotion: What is the role of emotion in social movements? What is the role of emotion in political activism? How is the expression of emotion linked to gender in political and other public arenas?

--Evaluation of Outcome: When evaluating the outcome of a political effort, how does it vary by perspective of the participants?

--Gender and Political Activism: How does political activism vary by gender? How do cultural beliefs regarding gender augment or hinder efforts by single-gender groups (such as a comparative study of Mothers Against Drunk Driving and Men Against Violence)?

--Professional Privilege: In what small, single issue, local conflicts are broader cultural clashes between the populace and the medical profession enacted? To

what degree are these small scale populist conflicts successful in the face of the organizational power of the professions?

--State versus federal levels of activism: What are the differences between organizing or acting for change on the state level versus the federal level?

--Social Movements: To what degree do social scientists need to revise their conceptualizations of social movements in the modern era? Is a movement possible without mass participants and organizations? To what extent can mass media be substituted for mass mobilization?

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## Appendix A

## States in which a Breast Cancer Informed Consent Law was Introduced

| Year | State | Outcome |
|---|---|---|
| 1979 | Massachusetts | Passed |
| 1980 | California | Passed |
| 1982 | Maryland | Defeated |
| | 1985 reintroduced | Defeated |
| | 1986 reintroduced | Passed |
| 1982 | Virginia | Defeated |
| | 1984 reintroduced | Passed |
| 1982 | Oklahoma | Defeated |
| 1982 | Pennsylvania | Defeated |
| | 1984 reintroduced | Passed |
| 1983 | Hawaii | Passed |
| 1983 | Louisiana | Passed |
| 1983 | Mississippi | Defeated |
| 1983 | New York | Defeated |
| | 1985 reintroduced | Passed |
| 1984 | Minnesota | Passed |
| 1984 | New Jersey | Passed |
| 1984 | Kansas | Passed |
| 1984 | Florida | Passed |
| 1984 | Georgia | Passed |
| 1984 | Kentucky | Passed |
| 1985 | Illinois | Defeated |
| 1985 | Ohio | Died |
| 1985 | Oregon | Died |
| 1986 | Michigan | Passed |
| 1986 | South Dakota | Defeated |
| 1989 | Maine | Passed |

## Appendix B

## Summary of Quantitative Pilot Study

Table 1: Patient Access to Medical Records

I gathered data on whether or not there was a state law ensuring patients' access to their medical records because I reasoned these laws paralleled the Breast Cancer Informed Consent Law in that they asserted the patient's prerogative and advanced patients' rights. I hypothesized that the Breast Cancer Informed Consent Law was more likely to be introduced in states that had laws ensuring patient access to medical records. I gave a +1 to states that had this law, and a -1 to states that did not.

| | |
|---|---|
| Alabama | -1 |
| Alaska | +1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | -1 |
| Colorado | +1 |
| Connecticut | +1 |
| Delaware | -1 |
| Florida | +1 |
| Georgia | -1 |
| Hawaii | -1 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | +1 |
| Iowa | -1 |
| Kansas | -1 |
| Kentucky | -1 |
| Louisiana | -1 |
| Maine | +1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | -1 |
| Minnesota | +1 |
| Mississippi | +1 |
| Missouri | -1 |

Table 1 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | -1 |
| Nevada | +1 |
| New Hampshire | -1 |
| New Jersey | -1 |
| New Mexico | -1 |
| New York | -1 |
| North Carolina | -1 |
| North Dakota | -1 |
| Ohio | -1 |
| Oklahoma | -1 |
| Oregon | -1 |
| Pennsylvania | -1 |
| Rhode Island | -1 |
| South Carolina | -1 |
| South Dakota | +1 |
| Tennessee | +1 |
| Texas | -1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | -1 |
| West Virginia | -1 |
| Wisconsin | -1 |
| Wyoming | -1 |

Source: Winslade, William J. 1982. "Confidentiality of Medical Records." *The Journal of Legal Medicine* 3(4):497-533.

Table 2: Mental Health Bill of Rights

This indicator measured the degree to which a state had complied with the federal Mental Health Systems Act (MHSA), which included a patients' bill of rights (section 501). State compliance was voluntary, given that Congress made the Act a recommendation. Twenty-two state substantially complied with at least one third of section 501 of MHSA. I included this indicator because I believed that a patients' bill of rights in a sister health care category, such as mental health, would be an indication that there was an ideology of patients' rights in the state. I hypothesized that the likelihood of a Breast Cancer Informed Consent Law being introduced would be higher in states that had adopted the MHSA patients' bill of rights. States which did adopt it were assigned a +1, states that did not were assigned a -1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | +1 |
| Arizona | +1 |
| Arkansas | +1 |
| California | +1 |
| Colorado | -1 |
| Connecticut | +1 |
| Delaware | +1 |
| Florida | +1 |
| Georgia | +1 |
| Hawaii | +1 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | -1 |
| Iowa | -1 |
| Kansas | +1 |
| Kentucky | -1 |
| Louisiana | -1 |
| Maine | +1 |
| Maryland | -1 |
| Massachusetts | -1 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | -1 |
| Missouri | +1 |

Table 2 continued

| | |
|---|---|
| Montana | +1 |
| Nebraska | -1 |
| Nevada | +1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | -1 |
| New York | +1 |
| North Carolina | -1 |
| North Dakota | -1 |
| Ohio | +1 |
| Oklahoma | -1 |
| Oregon | -1 |
| Pennsylvania | -1 |
| Rhode Island | -1 |
| South Carolina | -1 |
| South Dakota | -1 |
| Tennessee | -1 |
| Texas | -1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | -1 |
| West Virginia | -1 |
| Wisconsin | +1 |
| Wyoming | -1 |

Source: Lyon, Martha A. et al. 1982. "Patients' Bill of Rights: A Survey of State Statutes." *Mental Disabilities Law Reporter* 6(3):178-201.

Table 3: Subsidy of Abortion through Medicaid reimbursement

My rationale for including this indication was that abortion was an issue somewhat parallel to Breast Cancer Informed Consent in that it was a women's health concern laden with controversy. My hypothesis was that states which subsidize abortion services for Medicaid-eligible women would be more likely to introduce a Breast Cancer Informed Consent Law. States which did subsidize abortions with Medicaid funds were given a +1, states that did not were given -1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | +1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | -1 |
| Connecticut | +1 |
| Delaware | -1 |
| Florida | -1 |
| Georgia | -1 |
| Hawaii | +1 |
| Idaho | -1 |
| Illinois | -1 |
| Indiana | -1 |
| Iowa | -1 |
| Kansas | -1 |
| Kentucky | -1 |
| Louisiana | -1 |
| Maine | -1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | -1 |
| Mississippi | -1 |
| Missouri | -1 |

Table 3 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | -1 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | -1 |
| New York | +1 |
| North Carolina | +1 |
| North Dakota | -1 |
| Ohio | -1 |
| Oklahoma | -1 |
| Oregon | +1 |
| Pennsylvania | -1 |
| Rhode Island | -1 |
| South Carolina | -1 |
| South Dakota | -1 |
| Tennessee | -1 |
| Texas | -1 |
| Utah | -1 |
| Vermont | +1 |
| Virginia | -1 |
| Washington | +1 |
| West Virginia | +1 |
| Wisconsin | -1 |
| Wyoming | -1 |

Source: Torres, Aida et al. 1986. "Public Benefits and Costs of Government Funding for Abortion." *Family Planning Perspectives* 18(3):111-118.

Table 4: Minors' Access to Abortion Services

Similar to the previous indicator, I hypothesized that the Breast Cancer Informed Consent Law would be more likely to be introduced and passed in states in which minors have access to abortion services. I reasoned that the issue of minors' access to abortion was similar to Breast Cancer Informed Consent because it was an individual rights issued regarding the health interests of women. I assigned states that gave minors the right to abortion a +1, and states that denied this right a -1.

| | |
|---|---|
| Alabama | +1 |
| Alaska | +1 |
| Arizona | -1 |
| Arkansas | +1 |
| California | +1 |
| Colorado | +1 |
| Connecticut | -1 |
| Delaware | +1 |
| Florida | +1 |
| Georgia | +1 |
| Hawaii | +1 |
| Idaho | +1 |
| Illinois | +1 |
| Indiana | -1 |
| Iowa | -1 |
| Kansas | -1 |
| Kentucky | +1 |
| Louisiana | +1 |
| Maine | +1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | +1 |
| Missouri | -1 |

Table 4 continued

| | |
|---|---|
| Montana | +1 |
| Nebraska | -1 |
| Nevada | -1 |
| New Hampshire | +1 |
| New Jersey | -1 |
| New Mexico | -1 |
| New York | +1 |
| North Carolina | +1 |
| North Dakota | -1 |
| Ohio | +1 |
| Oklahoma | -1 |
| Oregon | +1 |
| Pennsylvania | -1 |
| Rhode Island | -1 |
| South Carolina | +1 |
| South Dakota | -1 |
| Tennessee | +1 |
| Texas | -1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | +1 |
| West Virginia | -1 |
| Wisconsin | -1 |
| Wyoming | -1 |

Source: Sollom, Terry and Patricia Donovan. 1985. "State Laws and the Provision of Family Planning and Abortion Services in 1985." *Family Planning Perspectives* 17(6):262-266.

Table 5: Statutory Provisions regarding Informed Consent

In most states the standards of disclosure regarding informed consent were set by the courts. The courts tended to be progressive, ruling toward the patient, or reasonable person standards of disclosure (see Chapter 4). In states which did have legislation regarding informed consent (e.g. New York), the law generally returned the standards of disclosure to the professional standards. I hypothesized that Breast Cancer Informed Consent Laws, which are close to the patient standard of disclosure, would be more likely to be introduced and passed in states that did not have statutory provisions regarding informed consent. Therefore, I gave states that did not have statutory provisions a +1, and states that did have statutory provisions a -1.

| | |
|---|---|
| Alabama | +1 |
| Alaska | -1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | -1 |
| Connecticut | +1 |
| Delaware | -1 |
| Florida | -1 |
| Georgia | -1 |
| Hawaii | -1 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | +1 |
| Iowa | -1 |
| Kansas | +1 |
| Kentucky | -1 |
| Louisiana | -1 |
| Maine | -1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | -1 |
| Mississippi | -1 |
| Missouri | -1 |

Table 5 continued

| | |
|---|---|
| Montana | +1 |
| Nebraska | -1 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | +1 |
| New York | -1 |
| North Carolina | -1 |
| North Dakota | -1 |
| Ohio | -1 |
| Oklahoma | +1 |
| Oregon | -1 |
| Pennsylvania | -1 |
| Rhode Island | -1 |
| South Carolina | +1 |
| South Dakota | +1 |
| Tennessee | -1 |
| Texas | -1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | -1 |
| West Virginia | +1 |
| Wisconsin | +1 |
| Wyoming | +1 |

Sources: Rosoff, Arnold J. 1981. *Informed Consent: A Guide for Health Care Providers*. Rockville, MD: An Aspen Publication.
*and*
President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1982. *Making Health Care Decisions* Vol.3. Washington, DC: U.S. Government Printing Office.

Table 6: Ratio of Democrats to Republicans in State Legislatures

I hypothesized that a Breast Cancer Informed Consent Law would be more likely to be introduced in a state legislatures with a Democratic majority. This was because the Democratic party had a tradition of championing liberal humanitarian reform legislation, as well as being permeable to grass roots organizations (Freeman, 1986). States which had legislature that was 68-95% Democratic were assigned a +1; states with 52-67% Democrats in the legislature were assigned 0: and states with 19-51% Democrats in the legislature were given a -1. Nebraska, a state without a party system, was left blank.

| | |
|---|---|
| Alabama | +1 |
| Alaska | -1 |
| Arizona | -1 |
| Arkansas | +1 |
| California | 0 |
| Colorado | -1 |
| Connecticut | -1 |
| Delaware | 0 |
| Florida | +1 |
| Georgia | +1 |
| Hawaii | +1 |
| Idaho | -1 |
| Illinois | 0 |
| Indiana | -1 |
| Iowa | 0 |
| Kansas | -1 |
| Kentucky | +1 |
| Louisiana | +1 |
| Maine | 0 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | -1 |
| Minnesota | 0 |
| Mississippi | +1 |
| Missouri | 0 |

Table 6 continued

| | |
|---|---|
| Montana | 0 |
| Nebraska | |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | 0 |
| New Mexico | 0 |
| New York | 0 |
| North Carolina | +1 |
| North Dakota | -1 |
| Ohio | 0 |
| Oklahoma | +1 |
| Oregon | 0 |
| Pennsylvania | -1 |
| Rhode Island | +1 |
| South Carolina | +1 |
| South Dakota | -1 |
| Tennessee | 0 |
| Texas | +1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | 0 |
| West Virginia | +1 |
| Wisconsin | 0 |
| Wyoming | -1 |

Source: *State Elective Officials and the Legislatures*. 1985. Lexington, Kentucky: The Council of State Governments.

Table 7: Standards of Disclosure as determined by State Courts

Given that Breast Cancer Informed Consent Laws are in intent similar to patient standards of disclosure (see Chapter 4), I reasoned that they would be more likely to be introduced and passed in states with such standards. Therefore, states which had a patient standard of disclosure as determined by the courts were assigned a +1, states with no standards of disclosure were assigned 0, and states with professional standards were assigned -1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | +1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | -1 |
| Connecticut | 0 |
| Delaware | -1 |
| Florida | -1 |
| Georgia | 0 |
| Hawaii | 0 |
| Idaho | -1 |
| Illinois | -1 |
| Indiana | -1 |
| Iowa | -1 |
| Kansas | -1 |
| Kentucky | -1 |
| Louisiana | +1 |
| Maine | 0 |
| Maryland | +1 |
| Massachusetts | -1 |
| Michigan | -1 |
| Minnesota | +1 |
| Mississippi | -1 |
| Missouri | +1 |

Table 7 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | -1 |
| Nevada | 0 |
| New Hampshire | -1 |
| New Jersey | -1 |
| New Mexico | +1 |
| New York | 0 |
| North Carolina | -1 |
| North Dakota | -1 |
| Ohio | +1 |
| Oklahoma | +1 |
| Oregon | +1 |
| Pennsylvania | +1 |
| Rhode Island | +1 |
| South Carolina | 0 |
| South Dakota | 0 |
| Tennessee | -1 |
| Texas | -1 |
| Utah | +1 |
| Vermont | 0 |
| Virginia | -1 |
| Washington | +1 |
| West Virginia | 0 |
| Wisconsin | +1 |
| Wyoming | -1 |

Sources: Rosoff, Arnold J. 1981. *Informed Consent: A Guide for Health Care Providers*. Rockville, MD: An Aspen Publication.
*and*
President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1982. *Making Health Care Decisions* Vol.3. Washington, DC: U.S. Government Printing Office.

Table 8: Number of Leading Court Cases on Informed Consent

I reasoned that in states with a relatively high number of court cases on Informed Consent, people in the legal arena would be more likely to be aware of the doctrine and its utility. Additionally, in states with a relatively high number of court cases on informed consent, physician groups would also have more awareness, and thereby attempt to push for legislation that would favor their interests. Therefore, for two contradictory reasons, I hypothesized that in states with a high number of court cases on informed consent, a Breast Cancer Informed Consent Law was likely to be introduced and passed. States in which there were 1 to 2 cases on informed consent were assigned a -1. States in which there were 3 to 7 cases on informed consent were assigned a 0. States which had 8 to 26 cases were assigned +1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | -1 |
| Arizona | +1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | 0 |
| Connecticut | -1 |
| Delaware | 0 |
| Florida | +1 |
| Georgia | +1 |
| Hawaii | -1 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | -1 |
| Iowa | 0 |
| Kansas | +1 |
| Kentucky | 0 |
| Louisiana | +1 |
| Maine | -1 |
| Maryland | -1 |
| Massachusetts | 0 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | -1 |
| Missouri | 0 |

Table 8 continued

| | |
|---|---|
| Montana | 0 |
| Nebraska | -1 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | 0 |
| New Mexico | +1 |
| New York | +1 |
| North Carolina | 0 |
| North Dakota | 0 |
| Ohio | 0 |
| Oklahoma | 0 |
| Oregon | 0 |
| Pennsylvania | +1 |
| Rhode Island | 0 |
| South Carolina | -1 |
| South Dakota | 0 |
| Tennessee | 0 |
| Texas | +1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | 0 |
| Washington | +1 |
| West Virginia | -1 |
| Wisconsin | 0 |
| Wyoming | -1 |

Source: Rosoff, Arnold J. 1981. *Informed Consent: A Guide for Health Care Providers*. Rockville, MD: An Aspen Publication.

Table 9: Number of Women's Organizations in the State

My rational for including an indicator on the relative number of women's organizations in each state was that I expected that the Breast Cancer Informed Consent Law would be introduced and passed in states with a high number of women's organizations. This was because I expected that legislators in states with a high number of women's organizations would have been sensitized to women's political issues, and would assume that the Breast Cancer Informed Consent Law had a constituency. States with no women's organizations were assigned a -1. States with 1 to 3 women's organizations were assigned a 0. States with 4 to 98 women's organizations were assigned +1.

| | |
|---|---|
| Alabama | 0 |
| Alaska | -1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | +1 |
| Connecticut | 0 |
| Delaware | 0 |
| Florida | 0 |
| Georgia | +1 |
| Hawaii | -1 |
| Idaho | 0 |
| Illinois | +1 |
| Indiana | 0 |
| Iowa | -1 |
| Kansas | 0 |
| Kentucky | -1 |
| Louisiana | 0 |
| Maine | -1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | 0 |
| Missouri | +1 |

Table 9 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | 0 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | 0 |
| New York | +1 |
| North Carolina | -1 |
| North Dakota | 0 |
| Ohio | +1 |
| Oklahoma | 0 |
| Oregon | -1 |
| Pennsylvania | +1 |
| Rhode Island | 0 |
| South Carolina | -1 |
| South Dakota | 0 |
| Tennessee | 0 |
| Texas | +1 |
| Utah | -1 |
| Vermont | 0 |
| Virginia | +1 |
| Washington | +1 |
| West Virginia | -1 |
| Wisconsin | +1 |
| Wyoming | 0 |

Source: *A Woman's Yellow Pages: 570+ Organizations Concerned with Women's Issues*. 1981. Washington, DC: Federation of Organizations for Professional Women.

Table 10: Number of local chapters of NOW in the state

My rationale for collecting data on the number of local chapters of the National Organization of Women (NOW) within each state was similar to the previous indicator. I predicted that a high number of chapters would be positively correlated with the Breast Cancer Informed Consent Law being introduced and passed in the state legislature. My reasoning was that state legislators in states with many chapters of NOW would probably have had some experience dealing with women's organizations, and some exposure to women's legislative concerns. States with 0 to 7 chapters I assigned a -1. States with 8 to 13 chapters I assigned a 0. States with 14 to 54 local chapters of NOW were assigned +1.

| | |
|---|---|
| Alabama | 0 |
| Alaska | -1 |
| Arizona | 0 |
| Arkansas | -1 |
| California | +1 |
| Colorado | +1 |
| Connecticut | 0 |
| Delaware | -1 |
| Florida | +1 |
| Georgia | 0 |
| Hawaii | -1 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | +1 |
| Iowa | 0 |
| Kansas | -1 |
| Kentucky | 0 |
| Louisiana | -1 |
| Maine | -1 |
| Maryland | 0 |
| Massachusetts | 0 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | 0 |
| Missouri | 0 |

Table 10 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | -1 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | -1 |
| New York | +1 |
| North Carolina | 0 |
| North Dakota | 0 |
| Ohio | +1 |
| Oklahoma | -1 |
| Oregon | 0 |
| Pennsylvania | +1 |
| Rhode Island | -1 |
| South Carolina | -1 |
| South Dakota | 0 |
| Tennessee | +1 |
| Texas | +1 |
| Utah | -1 |
| Vermont | 0 |
| Virginia | +1 |
| Washington | +1 |
| West Virginia | 0 |
| Wisconsin | +1 |
| Wyoming | -1 |

Source: *Local Chapter Directory*. 1979. New York: National Organizations for Women.

Table 11: Number of DES Action groups in the state

I included the number of DES Action groups in the state as an indicator because these groups were similar in organizational purpose and form to Breast Cancer Informed Consent groups. Their ideology was similar as well, given that both groups were composed of women who were aggrieved by the medical system and were seeking to protect and warn other women so that their experience would not be repeated. Both groups tended to be composed of a few active women with a larger potential membership and conscience constituency. If a state had no DES Action groups, I assigned it a -1. If it had 1 to 3 groups, I assigned it a +1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | -1 |
| Arizona | -1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | +1 |
| Connecticut | +1 |
| Delaware | -1 |
| Florida | +1 |
| Georgia | +1 |
| Hawaii | -1 |
| Idaho | -1 |
| Illinois | -1 |
| Indiana | -1 |
| Iowa | +1 |
| Kansas | +1 |
| Kentucky | -1 |
| Louisiana | +1 |
| Maine | -1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | +1 |
| Mississippi | -1 |
| Missouri | +1 |

Table 11 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | +1 |
| Nevada | -1 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | +1 |
| New York | +1 |
| North Carolina | -1 |
| North Dakota | -1 |
| Ohio | +1 |
| Oklahoma | -1 |
| Oregon | +1 |
| Pennsylvania | +1 |
| Rhode Island | -1 |
| South Carolina | -1 |
| South Dakota | -1 |
| Tennessee | -1 |
| Texas | +1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | +1 |
| West Virginia | +1 |
| Wisconsin | +1 |
| Wyoming | -1 |

Source: Patricia Cody, interviewed by Theresa Montini, January 29, 1987. San Francisco: DES Action National Headquarters.

Table 12: Number of state and local government consumer agencies

I have included an indicator of the number of consumer organizations in a state to gauge both the legislators' potential perception of anticipated organizational support of a Breast Cancer Informed Consent Law, as well as some indication of the popularity of consumer ideology in a state. I hypothesized that a high number of consumer organizations would be positively correlated with the introduction of a Breast Cancer Informed Consent Law in a state. States which had 1 or 2 consumer agencies were given a -1. States which had 3 to 7 consumer agencies were given a 0. States which had 8 to 64 consumer agencies were assigned a +1.

| | |
|---|---|
| Alabama | -1 |
| Alaska | 0 |
| Arizona | +1 |
| Arkansas | -1 |
| California | +1 |
| Colorado | +1 |
| Connecticut | 0 |
| Delaware | -1 |
| Florida | +1 |
| Georgia | -1 |
| Hawaii | 0 |
| Idaho | -1 |
| Illinois | +1 |
| Indiana | +1 |
| Iowa | -1 |
| Kansas | 0 |
| Kentucky | -1 |
| Louisiana | 0 |
| Maine | -1 |
| Maryland | +1 |
| Massachusetts | +1 |
| Michigan | +1 |
| Minnesota | 0 |
| Mississippi | -1 |
| Missouri | 0 |

Table 12 continued

| | |
|---|---|
| Montana | -1 |
| Nebraska | -1 |
| Nevada | 0 |
| New Hampshire | -1 |
| New Jersey | +1 |
| New Mexico | -1 |
| New York | +1 |
| North Carolina | -1 |
| North Dakota | 0 |
| Ohio | +1 |
| Oklahoma | 0 |
| Oregon | -1 |
| Pennsylvania | +1 |
| Rhode Island | -1 |
| South Carolina | 0 |
| South Dakota | -1 |
| Tennessee | -1 |
| Texas | +1 |
| Utah | -1 |
| Vermont | -1 |
| Virginia | +1 |
| Washington | +1 |
| West Virginia | 0 |
| Wisconsin | +1 |
| Wyoming | -1 |

Source: *Consumers' Resource Handbook*. 1984. Washington, DC: U.S. Office of Consumer Affairs.

Summary Table 13: Ranking of States by Summary of all the indicators.

This table gives the values of the summation of all the indicators. In states with a high positive summary score, I would expect a Breast Cancer Informed Consent Law to be introduced and passed. States with a high negative score are states in which I would not expect a Breast Cancer Informed Consent Law to be introduced and passed. In states in which a Breast Cancer Informed Consent Law was introduced and or passed, I indicated this to the right of the summary score.

| | | | |
|---|---|---|---|
| California | +9 | BCIC Law introduced | BCIC Law Passed |
| Maryland | +7 | BCIC Law introduced | BCIC Law Passed |
| Virginia | +7 | BCIC Law introduced | BCIC Law Passed |
| Massachusetts | +6 | BCIC Law introduced | BCIC Law Passed |
| Michigan | +6 | BCIC Law introduced | BCIC Law Passed |
| Minnesota | +6 | BCIC Law introduced | BCIC Law Passed |
| New York | +6 | BCIC Law introduced | BCIC Law Passed |
| Florida | +5 | BCIC Law introduced | BCIC Law Passed |
| Illinois | +5 | BCIC Law introduced | BCIC Law Defeated |
| Washington | +5 | | |
| New Jersey | +4 | BCIC Law introduced | BCIC Law Passed |
| Ohio | +4 | BCIC Law introduced | BCIC Law Died |
| Wisconsin | +4 | | |
| Connecticut | +2 | | |
| Georgia | +2 | BCIC Law introduced | BCIC Law Passed |
| Colorado | +1 | | |
| Louisiana | 0 | BCIC Resolution intro. | BCIC Resl. Passed |
| Missouri | 0 | | |
| Pennsylvania | 0 | BCIC Law introduced | BCIC Law Passed |
| Texas | 0 | | |
| Alaska | -1 | | |
| Oregon | -1 | BCIC Law introduced | BCIC Law Died |
| West Virginia | -1 | | |
| Hawaii | -2 | BCIC Law introduced | BCIC Law Passed |
| Kansas | -2 | BCIC Law introduced | BCIC Law Passed |
| New Mexico | -2 | | |

Summary Table 13 continued

| | | | |
|---|---|---|---|
| Arizona | -3 | | |
| Indiana | -3 | | |
| Oklahoma | -3 | BCIC Law introduced | BCIC Law Defeated |
| Tennessee | -3 | | |
| Maine | -4 | BCIC Law introduced | BCIC Law Passed |
| Mississippi | -4 | BCIC Law introduced | BCIC Law Defeated |
| Montana | -4 | | |
| North Carolina | -4 | | |
| South Carolina | -4 | | |
| South Dakota | -4 | BCIC Law introduced | BCIC Law Defeated |
| Arkansas | -5 | | |
| Delaware | -5 | | |
| Alabama | -6 | | |
| Kentucky | -6 | BCIC Law introduced | BCIC Law Passed |
| Nevada | -6 | | |
| Rhode Island | -6 | | |
| Iowa | -7 | | |
| Vermont | -7 | | |
| Nebraska | -8 | | |
| North Dakota | -8 | | |
| Idaho | -9 | | |
| Wyoming | -9 | | |
| New Hampshire | -10 | | |
| Utah | -10 | | |

## Appendix C

## Interview Schedule

*Individuals*

1. How did you get interested in Breast Cancer Informed Consent Laws?
2. About how many persons were involved in this effort in your state?
3. How did you connect with / find each other?
4. When did you begin organizing? How long did this effort last?
5. Did any individuals oppose you? What was the nature of that opposition?

*Organizations*

6. In what other organizations have your been active in the past?
7. What organizations did you form to augment your efforts?
8. What organizations, if any, did you draw upon for help, advice or assistance?
9. Were other organizations a help or a hindrance? How?
10. Of the organizations that were helpful, what kind of assistance did they give?
11. Of the organizations that opposed your effort, what types of resistance did they pose?
12. Did any organizations initiate action on the law? Which ones?
13. Who were the officers most active in pushing for this action?
14. What was the reaction of other organizations when the Law was introduced?

15. Was there any opposition when the Law was introduced?

16. Who opposed it?

17. What actions did they take?

18. Was the governor in favor of the Law?

19. When was all this happening?

*Laws*

20. How did you decide to work toward passing a law? Did you consider other options first?

21. How was the law drafted? Did you work from any model statutes? Who drafted it? Did you copy another state's Law?

22. When was the first draft completed? When was the last draft completed? What were some of the major differences between the first and the last drafts?

*Political Process*

23. What was it like trying to get this law passed? What was difficult or easy about the process?

24. Was the governor receptive or resistant to this type of legislation? Why?

25. Was the legislature receptive or resistant to this type of legislation? Why? Is there a history of this type of legislation in your state?

26. Does the legislator who introduced the Law have a history of sponsoring this type of legislation? Does he or she have a history of alliances with groups such as yours or any groups with which you were allied?

27. What type of political activities did you engage in in order to get this Law passed?

    a. Did you organize a letter writing campaign?

    b. Did you contact key legislators?

c. Did you organize a phone-in campaign?

d. Did you organize any demonstrations?

e. Did you send delegations to see key legislators?

f. How were they picked?

g. Did you appear at hearings?

h. Are there copies of the statements you made? Would you send me a copy?

i. Did any other organizations make statements? Do you remember which ones?

j. Any other political action?

28. When were all these political activities taking place?

*Outcome*

29. Does your state have a standardized written brochure on Breast Cancer treatment alternatives? If so, could you tell me about the process of drafting that brochure?

30. Do you feel that the Law is effective in your state?

31. What are you doing now that this effort is over? Have you continued in any sort of political work?

32. Would you be willing to be interviewed on this topic again?

33. Do you know of any other individuals in your state who were involved in this effort that you think would be good people for me to talk with?

34. Do you know of any other individuals or organizations in other states that were involved in efforts for Breast Cancer Informed Consent Laws?

## Appendix D

### Breast Cancer Informed Consent Laws

Massachusetts, 1979 (Public Health, Hospitals 111 Section 70E)

Patients' and Residents' Rights

Every patient or resident of a facility shall have the right (h) in the case of a patient suffering from any form of breast cancer, to complete information on all alternative treatments which are medically viable.

California, 1980 (Health and Safety Code, Section 1704.5)

Breast Cancer; failure of physician and surgeon to warn patient of alternative methods of treatment; unprofessional conduct; standardized written summary

The failure of a physician and surgeon to inform a patient by means of a standardized written summary, as developed by the department on the recommendation of the Cancer Advisory Council, in layman's language and in a language understood by the patient of alternative efficacious methods of treatment which may be medically viable, including surgical, radiological, or chemotherapeutic treatments or combinations thereof, when the patient is being treated for any form of breast cancer constitutes unprofessional conduct within the meaning of Chapter 5 (commencing with Section 2000) of Division 2 of the Business and Professions Code.

A standardized written summary in layman's language and in a language understood by the patient, to be developed by the department on the recommendation of the Cancer Advisory Council and printed and made available by the Board of Medical Quality Assurance to physicians and surgeons, informing the patient of the advantages, disadvantages, risks and descriptions of the procedures with regard to medically viable and efficacious alternative methods of treatment, which is given to the patient shall constitute compliance with the requirements of this section.

Maryland, 1986 (Health-General, Section 20-113)

Breast Cancer
Alternative methods of cancer treatment

(a) Duty of physician to educate patient. Before a physician treats any patient for any form of breast cancer, the physician shall educate the patient of alternative methods of treatment that may be medically practicable.

(b) Duties of Department. The Department of Health and Mental Hygiene shall:

(1) Provide a standardized written summary in layman's language that:

(i) Lists all effective methods of treatment for breast cancer that may be medically practicable including surgical, radiological, chemotherapeutic, and combinations of those treatments; and

(ii) Describes the advantages, disadvantages, risks, and procedures associated with each method of treatment listed;

(2) Update the standardized written summary annually;

(3) Distribute the standardized written summary to each hospital, clinic, and physician's office and other facility that performs treatments of breast cancer.

(c) Requirements of physician. A physician satisfies the requirements of subsection (a) of this section if:

(1) The physician provides a breast cancer patient with the standardized written summary described in subsection (b) of this section in language that the patient understands;

(2) The patient receives the standardized written summary within 5 days of the start of the treatment for breast cancer; and

(3) The patient signs a statement provided by the Department of Health and Mental Hygiene acknowledging the receipt of the standardized written summary.

(d) Exceptions. This section does not apply if the attending physician certifies that:

(1) Treatment for breast cancer occurred within 5 days of the physician informing the patient of the diagnosis; and

(2) Treatment within this period of time was necessary to save the life of the patient.

(e) Violations; penalties. A physician who violates any provision of subsection (a) of this section is subject to the provisions of Section 14-504 (27) of the Health Occupations Article. (1986, ch. 559)

Virginia, 1984 (Professions and Occupations, Medicine and Other Healing Arts, Section 54-325.2:2.)

Informed consent for treatment of breast tumor; paragraphs required in form.

Before a physician operates on a patient for a tumor of the breast, a consent form shall have been executed which includes the following:

"CONSENT FOR TREATMENT OF BREAST TUMOR"

Sign option (a) or option (b), or option (a) and option (b).

(a) I authorize Dr. _____ to perform a
Breast Biopsy _____
side (right and/or left)

_____
Patient's or other authorized person's Signature

(b) If it is determined that I have a malignant tumor in my breast or other breast abnormality requiring surgery, then I authorize Dr. _____ to perform.such operations or procedures, including breast removal, which are deemed necessary.
Procedure:

_____

_____
Patient's or other authorized person's Signature
(1984, c.88; 1985, c.328)

Pennsylvania, 1984 (Health and Safety, Chapter 27B, Sections 5641 and 5642)

Informed Consent for Treatment of Breast Cancer

Section 5641 Consent for treatment of breast cancer
Before a physician operates on a patient for a tumor of the breast, a consent form shall have been executed which includes the following:

"CONSENT FOR TREATMENT OF BREAST CANCER"
Sign option (a) or option (b), or option (a) and option (b).

(a) _____ Breast Biopsy
Side (right or left)

_____
Patient's Signature

(b) If it is determined that I have a malignant tumor in my breast or other breast abnormality requiring surgery, then I authorize Dr. _____ to perform such operations or procedures, including breast removal, which are deemed necessary. I have been informed of the current medically accepted alternatives to radical mastectomy.

Procedure: _____

_____
Patient's Signature

Section 5642. Civil liability; disciplinary action
In addition to civil proceedings, failure to comply with the provisions of this act shall subject the physician to disciplinary action under the act of July 20, 1974 (P.L. 551, No. 190), known as the Medical Practice Act of 1974, or under the act of October 5, 1978 (P.L. 1109, No. 261), known as the Osteopathic Medical Practice Act.

Hawaii, 1983 (Titles 34-38, Section 671-3)

Informed consent; board of medical examiners standards

(c) On or before January 1, 1984, the board of medical examiners shall establish standards for health care providers to follow in giving information to a patient or a patient's guardian, to ensure that the patient's consent to the performance of a mastectomy is an informed consent. The standards shall include the substantive content of the information to be given, the manner in which the information is to be given by the health care provider and the manner in which consent is to be given by the patient or the patient's guardian. The substantive content of the information to be given shall include information on the recognized alternative forms of treatment.

Louisiana, 1983 (House Concurrent Resolution No. 125)

A CONCURRENT RESOLUTION

To urge and request all physicians in Louisiana to advise their patients, orally and in writing, of the alternatives to a radical mastectomy prior to performing such a procedure.

WHEREAS, radical mastectomies are performed daily upon women in Louisiana and the United States as a whole; and

WHEREAS, this procedure is often traumatizing and demoralizing for the women who have undergone a radical mastectomy; and

WHEREAS, recent medical research and opinion indicate that in many cases there are alternatives available to women facing this procedure; and

WHEREAS, it is the responsibility of the attending physician to fully inform his patient of the alternatives to and implications of any surgical procedure; and

WHEREAS, true consent to what happens to one's self is the informed exercise of a choice which entails an opportunity to evaluate knowledgeably the options available and risks attendant upon each.

THEREFOR, BE IT RESOLVED by the House of Representatives of the Legislature of Louisiana, the Senate thereof concurring, that all physicians in Louisiana are hereby urged and requested to advise their patients, orally and in writing, of the alternatives to a radical mastectomy prior to performing such a procedure.

BE IT FURTHER RESOLVED that, prior to performing a radical mastectomy on any woman, each attending physician is also urged and requested to obtain the signature of the woman on a copy of the written advisement wherein she acknowledges that she has been informed of the alternatives to a radical mastectomy.

BE IT FURTHER RESOLVED that the legislature does also urge and request each attending physician performing a radical mastectomy to provide the woman with a copy of this written advisement signed by her and make a copy of this written advisement a part of the medical record of each woman upon whom he has performed a radical mastectomy.

BE IT FURTHER RESOLVED that as copy of this Resolution be transmitted to the Louisiana State Board of Medical Examiners, which board is requested to make known the contents of this Resolution to all physicians who may perform radical mastectomies or who may advise patients who may be subject to such procedures.

_____Speaker of the House of Representatives

_____President of the Senate

New York, 1985 (Public Health Law, Article 24, Section 2404)

Breast Cancer; duty to inform

1. The commissioner shall develop a standardized written summary, in plain non-technical language, which shall explain the alternative medically viable methods of treating breast cancer, including but not limited to hormonal, radiological, chemotherapeutic or surgical treatments, or combinations thereof.
2. The standardized written summary for alternative breast cancer treatments shall be provided by a physician to each person under his care who has been diagnosed to be afflicted with breast cancer upon said diagnosis, or as soon thereafter as practicable.
3. Nothing in this section shall be construed to create a cause of action for lack of informed consent in any instance in which such cause of action would be limited by section twenty-eight hundred five-d of this chapter.

[Note: Section 2805-d. is Limitation of medical malpractice action based on lack of informed consent.]

Minnesota, 1984 (Volume 11, Section 144.651)

Patients and residents of health care facilities; bill of rights

1983 Amendment

(22) Every patient or resident suffering from any form of breast cancer shall be fully informed, prior to or at the time of admission and during her stay, of all alternative effective methods of treatment of which the treating physician is knowledgeable, including surgical, radiological, or chemotherapeutic treatments or combinations of treatments and the risks associated with each of those methods.

New Jersey, 1984 (Chapter 9, Title 45)

1. Before a physician operates on a patient for a tumor of the breast, the physician shall obtain written consent from the patient or the patient's authorized representative on a form which allow the patient: a. to give consent only for a biopsy; b. to give consent to perform any necessary operation or procedure including breast removal if it is determined that the patient has a malignant tumor in his or her breast or other breast abnormality; or c. to give consent for both a biopsy and an additional operation or procedure if necessary.
2. A physician who fails to comply with this act is liable for action by the State Board of Medical Examiners pursuant to R.S. 45:9-1 et seq.

Kansas, 1984 (Healing Arts, 65-2836)

Revocation, suspension, or limitation of licenses; grounds; consent to submit to mental or physical examination implied.

(o) Failure by persons licensed to practice medicine and surgery to inform a patient suffering from any form of abnormality of the breast tissue for which surgery is a recommended form of treatment, of alternative methods of treatment specified in the standardized summary supplied by the board. The standardized summary shall be given to each patient specified herein as soon as practicable and medically indicated following diagnosis, and this shall constitute compliance with the requirements of this subsection (o). The board shall develop and distribute to persons licensed to practice medicine and surgery a standardized summary of the alternative methods of treatment known to the board at the time of distribution of the standardized summary, including surgical, radiological or chemotherapeutic treatments or combinations of treatments and the risks associated with each of these methods. Nothing in this subsection (o) shall be construed or operate to empower or authorize the board to restrict in any manner the right of a person licensed to practice medicine and surgery to recommend a method of treatment or to restrict in any manner a patient's right to select a method of treatment. The standardized summary shall not be construed as a recommendation by the board of any method of treatment. The preceding sentence or words having the same meaning shall be printed as a part of the standardized summary. The provisions of this subsection (o) shall not be effective until the standardized written summary provided for in this subsection (o) is developed and printed and made available by the board to persons licensed by the board to practice medicine and surgery.

Florida, 1984 (Professions and Occupations, Section 459.0125)

Breast Cancer; information on treatment alternatives

(1) Definition. As used in this section, the term "medically viable," as applied to treatment alternatives, means modes of treatment generally considered by the medical profession to be within the scope of current, acceptable standards, including treatment alternatives described in the written summary prepared by the Florida Cancer Control and Research Advisory Board in accordance with s. 381.3712(4)(m).

(2). Communication of treatment alternatives. It is the obligation of every physician treating a patient who is, or in the judgment of the physician is at high risk of being diagnosed as having breast cancer to inform such patient of the medically viable treatment alternatives available to such patient; to describe such treatment alternatives, and to explain the relative advantages, disadvantages, and risks associated with the treatment alternatives to the extent deemed necessary to allow the patient to make a prudent decision regarding such treatment options. In compliance with this subsection:

(a) The physician may, in his discretion:

(1) Orally communicate such information directly to the patient or the patient's legal representative;

(2) Provide the patient or the patient's legal representative with a copy of the written summary prepared in accordance with s.381.3712(4)(m) and express his willingness to discuss the summary with the patient or the patient's legal representative; or

(3) Both communicate such information directly and provide a copy of the written summary to the patient or the patient's legal representative for further consideration and possible later discussion.

(b) In providing such information, the physician shall take into consideration the emotional state of the patient, the physical state of the patient, and the patient's ability to understand the information.

(c) The physician may, in his discretion and without restriction, recommend any mode of treatment which is in his judgment the best treatment for the patient.

Nothing in this subsection shall reduce other provisions of law regarding informed consent.

(3) Records. Every physician treating a patient who is, or in the judgment of the physician is at high risk of being, diagnosed as having breast cancer shall indicate on such patient's medical records compliance or noncompliance with the provisions of subsection (2).

Florida continued

[Note: s. 381.3712(4)(m) is: By January 1, 1985, the board shall develop and prepare a standardized written summary, written in layman's terms and in language easily understood by the average adult patient, informing actual and high-risk breast cancer patients of the medically viable treatment alternatives available to them in the effective management of breast cancer; describing such treatment alternatives; and explaining the relative advantages, disadvantages, and risks associated therewith. Such summary, upon it completion, shall be printed in the form of a pamphlet or booklet and made available to physicians and surgeons in this state for their use in accordance with s. 458.324 and to osteopathic physicians in this state for their use in accordance with s. 459.0125. The board shall develop and implement an educations program, including distribution of the pamphlet or booklet developed under this paragraph, to inform citizen groups, associations, and voluntary organizations about early detection and treatment of breast cancer.]

Georgia, 1984 (Professions, Businesses & Trades, Section 84-902 [43-34-21])

Composite State Board of Medical Examiners; establishment; qualifications of members, duties and powers

(g) When funds are specifically appropriated for such purpose, the board shall publish an informational booklet on breast cancer and the treatment of breast cancer. The booklet shall contain a summary of the latest information on breast cancer and, in brief form, shall discuss the generally accepted and widely prevailing medical and surgical treatments for breast cancer. The booklet shall include a valid assessment of the relative risks and benefits of the accepted and widely prevailing methods of treatment. A copy of the booklet shall be made available by the board to every appropriate physician in the state. A letter by the board shall accompany this booklet stating that the board urges the physician to distribute a copy of the booklet to teach and every patient whose disease or course of treatment is covered by the material in the booklet. Copies shall also be available to any person upon request at a gee prescribed by the joint-secretary sufficient to cover the cost of printing and distribution. The booklet shall be updated and redistributed at such times as the board shall deem necessary.

Kentucky, 1984 (Occupations and Professions, Section 311.935)

Disseminating Information on Treatment of Breast Cancer
Preparation of standardized written summary of information on alternatives in treatment of breast cancer--Distribution to patients.
(1) No later than one (1) year after July 13, 1984, the McDowell Cancer Network, Inc. and the James Graham Brown Cancer Center shall jointly develop and submit to the cabinet for human resources and may periodically update a standardized written summary, in layman's language and in language understood by the patient, of the advantages, disadvantages, risks and descriptions of all medically efficacious and viable alternatives for the treatment of breast cancer.
(2) The cabinet for human resources, within ninety (90) days of receipt of the summary, shall print and make available to all licensed physicians in the Commonwealth sufficient copies of the standardized written summary for distribution by such physicians to their patients.
(3) Upon receipt of the summary, any physician licensed under the laws of the Commonwealth who treats a patient for any form of breast cancer shall provide the patient with a standardized written summary, as provided under this section, informing the patient of medically efficacious and viable alternative methods of treatment for breast cancer which may include surgical, radiological or chemotherapeutic treatment or combinations thereof.

Michigan, 1986 (M.C.L.A. Section 333.17013)

(1) Beginning 120 days after the effective date of this section, a physician who is administering the primary treatment for breast cancer to a patient who has been diagnosed as having breast cancer shall inform the patient, orally and in writing, about alternative methods of treatment of the cancer, including surgical, radiological, or chemotherapeutic treatments, or any other generally accepted medical treatment. The physician also shall inform the patient about the advantages, disadvantages, and risks of each method of treatment and about the procedures involved in each method of treatment.

(2) If a patient receives a standardized written summary or brochure, as described in this section or subsection (3), the physician shall be in full compliance with this section, including both the written and oral requirements. The standardized written summary:

(a) Shall be developed by the department of public health in cooperation with the chronic disease advisory committee.

(b) Shall be drafted in non-technical terms that the patient can understand.

(c) Shall inform the patient about alternative methods of treatment of breast cancer, including surgical, radiological, or chemotherapeutic treatments, or any other generally accepted medical treatment.

(d) Shall inform the patient about the advantages, disadvantages, and risks of each method of treatment and about the procedures involved in each method of treatment.

(e) The standardized written summary or the brochure described in subsection (3), or both, shall be made available to physicians through the Michigan board of medicine and the Michigan board of osteopathic medicine and surgery. The Michigan board of medicine and the Michigan board of osteopathic medicine and surgery shall notify in writing all physicians subject to this section of the requirements of this section and the availability of the standardized written summary within 100 days after the date this amendatory act is enacted into law.

(3) For purposes of subsection (2), a physician may use a brochure which contains information substantially similar to that contained in the standardized written summary developed by the department of public health and which is approved by the department of public health.

(4) The department of public health, after consultation with appropriate professional organizations, shall develop the standardized written summary required by subsection (2) within 90 days after the date this amendatory act is enacted into law.

Michigan continued

(5) A form, signed by the patient, indicating that the patient has been given a copy of the brochure or the standardized written summary shall be included in the patient's medical record.
(6) A physician's duty to inform a patient under this section does not require disclosure of information beyond what a reasonably well-qualified physician licensed under this article would know.
(7) A patient who signs a form pursuant to subsection (5), shall be barred from subsequently bringing a civil action against the physician providing the summary or brochure described in subsection (2), based on failure to obtain informed consent, but only in regard to information pertaining to alternative forms of treatment of breast cancer, and the advantages, disadvantages, and risks of each method.

Maine, 1989 (Sec. 1. 24 MRSA Section 2905-A)

Informed consent for breast cancer

1. Duty of physician. Notwithstanding section 2905, a physician who is administering the primary treatment for breast cancer shall inform the patient as provided in this section, orally and in writing, about alternative efficacious methods of treatment of breast cancer, including surgical, radiological or chemotherapeutic treatments or any other generally accepted medical treatment and the advantages, disadvantages and the usual and most frequent risks of each.
2. Written information. The duty to inform the patient in writing may be met by giving the patient a standardized written summary or brochure as described in subsections 3 and 4.
3. Standardized written summary. The standardized written summary may be developed by the Bureau of Health after consultation with the Cancer Advisory Committee.
4. Brochure. The brochure must be one which is approved or made available through the National Cancer Institute, the American Cancer Society, the American College of Surgeons or any other recognized professional organization approved by the Bureau of Health.
5. Signed form. A form, signed by the patient, indication that the patient has been given the oral information required by this section and a copy of the brochure or the standardized written summary shall be included in the patient's medical record.

Maine continued

6. Extent of duty. A physician's duty to inform a patient under this section does not require disclosure of information beyond what a reasonably well-qualified physician licensed under Title 32 would know.
7. Actions barred. A patient who signs a form described in subsection 5 is barred from bringing a civil action against the physician, based on failure to obtain informed consent, but only in regard to information pertaining to alternative forms of treatment of breast cancer and the advantages, disadvantages, and risks of each method.
8. Application of this section to common law rights. Nothing in this section restricts or limits the rights of a patient under common law.

FOR REFERENCE

NOT TO BE TAKEN FROM THE ROOM

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