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13. ABSTRACT (Maximum 200 Words) The purpose of this study is to assess the ways in which mass media play a significant role in constructing the public's understanding of breast cancer as a social problem, a disease, and personal illness experience. This third annual report contains results of three main parts of the investigation. First is a survey of print media depictions of breast cancer from 1986-1994. This period was marked by controversy about the efficacy of lumpectomy compared with mastectomy, the increasing visibility of well-known women with the disease, and shift of attention to topics in mainstream publications, such as environmental and genetic factors, as well as an increased critique of medical practices. Second is an examination of the decision whether to use the drug tamoxifen as prevention with healthy women, albeit at high risk for breast cancer, as depicted in popular print media from 1993-1999. This saga features the hope of scientific progress pitted against a critique of "disease substitution" and pharmaceutical profiteering. Third is an analysis of the quandary of decision making around the topic of genetic testing for BRCA1 & BRCA2. Additionally, an "unplanned" research trajectory has been the connection between publicly communicated breast cancer narratives and the formation of health care policy.				
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Introduction

October, National Breast Cancer Awareness Month, is a particularly appropriate time to reflect upon the impact of mass media communications on public perceptions of this disease. During this time, newspapers, magazines, radio and television programs, and other forms of media report in abundance about treatments, prevention, early detection, and stories of survivors. The themes implicit in arguments, language, and strategies of these mass media accounts are the subject matter of this study. Its purpose is to assess the ways in which popular mass media play a significant role in constructing the sociocultural meanings embedded in the public's understanding of breast cancer as a societal problem, a disease, and a personal illness experience. The scope of the work includes four major phases: 1) an historical investigation of how breast cancer has been publicly depicted in popular print media over three decades, 1965-1995; 2) an analysis of how four current controversies regarding diagnosis, risk assessment, and prevention have been presented in popular print media over the five years between 1993-1998, 3) an examination of the implications of entertainment television having appropriated breast cancer as subject matter; and 4) a meta-analysis of the sociocultural impact of popular depictions in terms of citizen decision-making.

Body

Scope of Work for Year 3

Work completed during Year 3 includes the third portion of the first phase, i.e., the years 1986-1992 (and a selected portion of 1994) of the historical overview, and the second pair of controversies that comprise the second phase, analysis of print representations of four decision-making controversies related to breast cancer. Although not included in the original statement of work, an examination of the relationship between personal illness narratives and health policy formation was undertaken, as well. Each of these separate components will be described in this section, including findings.

Assumptions and Methods

The underlying premise of this research is that how mass media construct breast cancer for the public—its most prominent themes, controversial issues, memorable dramas and stories, and possible courses of action—affects how individual citizens become aware of, comprehend, and make decisions about breast cancer-related matters. As has been described in the previous annual reports, the study relies on qualitative, interpretive methods, an approach that has been well documented in communication research (Lindlof, 1995, Pauly, 1991), and in the social sciences generally (Denzin & Lincoln, 1998). Additionally, this type of analysis employed can also be understood as an application of cultural studies, discourse-based inquiry and criticism positioned within a historical and sociocultural frame of reference (Fiske, 1998).

Phase 1, Part C. For the historical overview segment of the project, the critical-interpretive process employed includes five elements: a) identification of thematic

categories, comparing how topic emphases change over time; b) identification of major public narratives, images, and metaphors that help to translate abstract and difficult biomedical matters in personal terms that draw the public's attention, provide motives, and coalesce attitudes; c) identification of underlying value-based ideologies in order to explicate the moral premises and arguments implicit in these media accounts; d) placement of issues specific to breast cancer within broader social/political/cultural contexts of the time; and e) assessment of how media constructions of breast cancer may influence individual citizens' choices and decision-making.

In the original statement of work, I anticipated that I would be examining breast cancer as depicted in popular print media, both magazines and selected newspapers, during the decade spanning 1986-1995. As the entire study has progressed, it became clear that I would have to find ways of compressing this segment due to a variety of factors—the huge volume of material, time constraints, and overlap with Phase 2, the inquiry into recent controversies, starting in 1993. Therefore, I made the decision to only look at popular periodicals between 1986-1992; however, even this became a monumental task. In order to decide when I had sufficient discursive data to examine for this part of the study, I followed the precepts of grounded theory (Strauss & Corbin, 1998), the influential qualitative method of analysis in which theory is generated directly from the data being examined instead of imposing a pre-formulated theory onto the data. According to this framework, data-gathering can draw to a close when there is conceptual saturation, defined as no new thematic categories being generated, which was the case at a point in which we had examined 146 magazine articles from this time period from a variety of publications, identified under the heading “breast cancer” in *The Reader's Guide to Periodical Literature* (see references for 1986-1992). Still that number was enough to indicate thematic trends for this time period. However, in 1994, an unusual event occurred that put breast cancer research on the front page of the *New York Times* and other major periodicals. This was the uncovering of fraudulent data entered in an already published major clinical trial, comparing the efficacy of lumpectomy with that of mastectomy. I judged this highly publicized drama to be worthy of special consideration within this study, so that an additional 23 sources (see References) were examined.¹

As we did in years 1 and 2 of the grant, the principal investigator and the research assistant read through each article, taking notes and coding the article for content. In addition to investigators' notes, several articles were copied because it was not possible to summarize all the content, or to adequately capture the style of writing or visual components (see Appendix A for coding categories and periodicals by typology). When review of identified articles was completed, the two investigators exchanged notes and copied articles to gain familiarity with the materials they had not yet read and to double-check coding. In the few cases in which there were differences about how to code a particular piece, the differences were discussed until a mutually satisfactory conclusion was reasoned through, a process integral to the interpretive approach. Unlike the

¹ Of course, the other extraordinary story about breast cancer that was publicized during the end of the decade between 1986-1995 was the discovery of the breast cancer gene. However, I chose not to include the articles about this event per se because its importance and implications are subsumed within our examination of genetic testing as a controversy.

previous years, the content category definitions seemed to hold up well to scrutiny and application, not needing to be modified. After all articles had been reviewed and content-coded, I conducted a rhetorical analysis, describing and evaluating the media themes of this time period, as reported in the Results section to follow.

Phase 2. The remaining two current controversies, the use of tamoxifen as a preventive with healthy (non-symptomatic), highly at-risk women and the quandary about getting tested for the breast cancer gene, were reviewed and analyzed during Year 3. Primary source materials for the past five years (1993-1999) were procured via on-line indexes: the Ibis/Ovid version of the *Wilson's Select Reader's Guide to Abstracts On-line* for popular magazines and the OCLC *First Search Newspaper Abstracts* for the *New York Times*. Altogether, 80 primary sources were examined (tamoxifen: 28 magazine articles, 11 newspaper articles; genetics: 27 magazine articles, 23 newspaper articles). The unifying theme of Task 2 is to investigate how the popular print media depict dilemmas in citizen decision-making in regard to breast cancer-related issues. In the case of tamoxifen, the controversy has been centered on whether the potential benefit of the drug in preventing breast cancer outweighs the dangers of exposing healthy women to known and unknown, endangering side effects. For genetic testing, public discussion has been concentrated on the balance between the questionable benefit of knowing that one is genetically predisposed to the disease, without benefit of a cure, and the risks of mental anguish, as well as endangerment to insurance, jobs, etc. Because this task differs in nature from Task 1, the coding categories used in the historical overview are not pertinent to the Task 2 examination. In order to focus these analyses on decision-making dilemmas, the principal investigator and research assistant took notes on each article, with the following issues in mind:

- What are the available choices?
- How does information supporting each alternative complicate or confuse decision-making?
- What are key words and/or images used to present the dilemma and possible solutions? Do such elements tend to predispose readers to a particular point of view?
- Does the author/article make an explicit recommendation on how readers should resolve the decision-making dilemma? If not explicit, is there an implicit course of action emphasized?
- Is this particular article reflective or constituent of a larger story, drama, repeated set of themes or argument that communicates a specific perspective on the topic?

Although there was no need to double-check coding, as in Task 1, the principal investigator and research assistant have continued the practice of exchanging notes and articles, and discussing questions and interpretations of the data.

Results & Discussion

Phase 1, Part C. Historical Overview: The Rise of Medical Fallability, 1986-1994

In a number of ways, many articles that appeared in this third decade echoed what had been written in the previous ten, or even twenty year period, particularly labeling treatment options as hopeful, framing medical treatment as military metaphors, repetitive

personal sagas of diagnosis and coping. Yet a closer examination reveals several deep, if not yet monumental, transitions were occurring, as reflected in the following themes.

Increasing visibility. In less than a decade after Audre Lorde vividly articulated the experience of having breast cancer in terms of loneliness, isolation, silence, and powerlessness, prominent women increasingly came forward, many to speak candidly of their illness experiences: actresses like Jill Ireland, Ann Jillian, Marcia Wallace, and Jill Eickenberry, journalist Linda Ellerbee, writers Erma Bombeck and Danielle Steele, PGA golfers, and, most famously, First Lady Nancy Reagan, who turned out to be a less willing role model. Such disclosures helped to de-stigmatize the condition, while at the same time emphasizing the frequency of its occurrence. Betty Ford and Ann Jillian, appearing together in a smiling pose on the cover of *Ladies Home Journal* with the caption, "We are survivors!" helped to propel that term into the common vocabulary. And most visible of all, bare-chested model Matushka, displayed her mastectomy scar, with a headline proclaiming, "You can't look away anymore," on the cover of a 1993 *New York Times Sunday Magazine*, unforgettably brought breast cancer to a new stage of candor and public attention.

Shifting Attention. Looking at Table 1, which summarizes the topical contents of magazine articles from 1986-1992, (and comparing it to similar tables for the previous two decades), some trends in new emphases can be discerned. From 1976-1985, articles about basic research, diagnosis, and treatment comprised 75% of the total themes that appeared in popular magazines. While these themes still predominate in the subsequent six years surveyed in this report, they now comprise only 55% of the total. In the earlier decade, articles concerned with epidemiology and genetics only comprised 7%; a few years later, these themes had increased to 21%, demonstrating increasing attention to such issues as environmental influences, a possible link between breast cancer and women who had taken the birth control pill, dietary correlates, and advances in genetic research. Even more striking is the change in another cluster of themes. In the earlier decade, articles related to activism, criticism, public awareness, politics, and social issues comprised only 6% of the total. By 1992, this same cluster of topics had increased to 29%. Furthermore, such articles were not just found in such likely publications as *Ms*, *Mother Jones*, or *New Republic*, which specialize in critical commentary, but also more mainstream sources like *Time* and even *Good Housekeeping*. For example, an argument holding doctors' neglect as largely culpable for women not having mammograms was prominently repeated. Concerns about home diagnostic devices, women's health centers being used to increase health care profits, and job discrimination, as well as the activist efforts of the Komen Foundation and Marilyn Quayle, wife of the vice president also garnered attention. A focus on the dilemma about whether insurers should cover the experimental treatment of bone marrow transplant (see Appendix B) was newly emerging. On the other hand, the incipient organization and efforts of the National Breast Cancer Coalition apparently had not yet captured the interest of the press.

Growing Burdens of Consumerism. A continuation of the major theme of the previous decade is the degree of responsibility for one's own health that had now been seemingly shifted to the consumer. One of the most excessive examples of this trend that was

repeated in many articles is the advice that when going for their routine annual mammograms, women should be checking for (and evaluating) such factors as number of rads exposure, calibration of equipment, frequency of maintenance and training of technicians! Given that there is an ongoing campaign simply to encourage women to get annual mammograms, the expectation that they will, on a large scale, acquire the expertise and assertiveness needed to ask such questions appears unrealistic, and arguably inappropriate for many consumers. In one article, a physician-author proclaimed that the more informed a woman is, the more confused and troubled she will be. The tone of this remark was not a put-down of women's intelligence, but rather a reflection of the increasing difficulties in trying to self-assess one's own risk for such weighty decisions as taking hormones, or drastic preventive measures, such as tamoxifen or prophylactic mastectomy. However, other trends in consumerism reflected in this literature were not centered on women's responsibilities so much as those of the health care establishment, such as concerns about the exclusion of women from medical research and the insufficient allocation of funding specifically for breast cancer research.

The New Medical Controversies and the Rhetoric of Medical Fallability. Of the ever-increasing list of dilemmas related to breast cancer that surfaced in popular periodicals, two major issues were taking center-stage at this time. One was the safety of silicone breast implants, which in its broadest sense was a matter of breast health for all women. However, to the degree that it was being widely used as a reconstructive option for women with breast cancer who had had mastectomies, it was tightly woven within discourses related to breast cancer: Had patients who had had these prosthetics implanted been put at increased risk for cancer recurrence, as well as other serious ailments? Even if the implants don't cause cancer themselves, did they make the task of diagnosing recurrences much more difficult? This problem, of course, would be argued for several years to come before a federal regulation and lawsuit brought some form of closure, though not entirely.

The second question of whether to have a lumpectomy or a mastectomy had been initiated in the mid-eighties with the publication of a major finding from the premiere clinical research program in the country, showing that both types of breast surgery were equal in efficacy, with the lumpectomy having the additional advantage of conserving much of the breast tissue in most cases. This is a debate that continues to occur today (see Mitchell, 2000 in the References). Fuel was added to this fiery controversy in 1988 when First Lady Nancy Reagan (followed a short time afterward by Supreme Court Justice Sandra Day O'Connor) chose the mastectomy option, both because (according to magazine reports) she felt more comfortable with the knowledge that the affected tissue was gone and because the necessary radiation that follows lumpectomy would have been a burden in light of her complicated schedule. Reagan's decision became a mini-controversy in itself—viewed by some as the wrong decision and a poor role model for American women, while others championed her right to choose. Given, then, that this had already been a hotly contested issue for several years, the 1994 discovery that fraudulent data had been used in the clinical trial referred to above, was front page news and continued to be discussed in the press for the following month. Thousands of women who had decided to have lumpectomies on the basis of this information reacted fearfully,

anxious that they had made the wrong choice on the basis of bad information, though re-analysis confirmed the validity of the first conclusions. The principal investigator, venerable breast researcher Bernard Fisher, was ousted from his position (though he was later vindicated). More importantly, the NIH cancer research program and the medical-scientific enterprise generally was called into question. Thus, as this third decade drew to a close, a rapidly growing critique of medicine and bio-science dominated public discourse, not only challenging, but overshadowing the ever-present rhetoric of scientific progress. Even the triumphal 1995 announcement of the discovery of the breast cancer gene evoked greater fears about how this new knowledge would be applied, even as it heralded a new age of promise and possibility.

Phase 2. Current Controversies related to Citizen Decision-Making and Breast Cancer. The discursive controversies involving the testing of tamoxifen as a prevention drug and the development of genetic testing for breast cancer share an important attribute in common, namely the conflict between the rhetoric of scientific progress and a heightening rhetoric of medical fallability, in which women's lives and the credibility of biomedical research hang in the balance. In either case, to make an informed decision about whether to get involved in either form of testing, women who considered themselves to be at high risk have to become immersed in sophisticated arguments and technical evidence in order to make decisions that could affect both the quality and longevity of their lives.

Part A: The Testing of the Drug Tamoxifen in Healthy, At-Risk Women

The hope of designer estrogens vs. evidence of "disease substitution." Tamoxifen, a form of synthetic estrogen, had a very credible history of helping to stave off recurrence in women with a previously diagnosed breast cancer by 45%. Thus, the leap to a trial to test the efficacy of preventing first cancers in highly at-risk, asymptomatic women seemed to be a natural progression for scientific research. Many articles portrayed the tamoxifen trial begun in April, 1992 with a very positive spin as a pioneering effort to develop "chemoprevention," particularly for women whose families have been devastated by breast cancer. In this 1990's version of the rhetoric of scientific progress, not only the clinical scientists in charge of the study, but the women who volunteered to participate were portrayed as "pioneers," willing to take on personal risks for the future of their daughters. There is much excitement at the apparent success of the trial, which was stopped after four years, a year short of its targeted conclusion because the results were so positive, it was felt unethical to keep the control group on placebos.

This success story is countered by a more ominous version that questions the credibility of the scientific community. The National Women's Health Network opposed this study from its inception, i.e. putting apparently healthy women in harm's way, and continues to question the reasoning and the credibility of the scientific community. News of a tamoxifen-related endometrial cancer death predated the study begun in 1992, but was not reported to the NCI until over a year after the tamoxifen trial was occurring. Thus, initial consent for participation in the trial was not informed by knowledge of this potential risk, an issue that became even more problematic as more endometrial deaths occurred with women in the study. Again, principal investigator Bernard Fisher is held

accountable for proceeding in the face of such a danger. Spokeswoman Cindy Pearson is featured in several sources, pointing out that this application of tamoxifen is not prevention, but merely substituting the risks of one kind of threatening disease for another.

Uncertainty and risk analysis. In addition to the increased risk of endometrial cancer, trial participants also faced four times the likelihood of having blood clots, another life-threatening condition. Thus, arises the issue of healthy (asymptomatic) women trying to assess whether their natural risk for breast cancer is high enough to gamble on exposing themselves to chemical-induced dangers. Complex computer software is developed to help women and their physicians calculate the statistical probabilities for breast cancer risk. The media accounts feature the role of uncertainty in such decisions, where consistent guidelines can be applied.

Profiteering. Also noted in popular periodicals is the profit motive for the large pharmaceuticals, Zeneca, which manufactures tamoxifen, and Eli Lilly, which makes raloxifene, the next generation designer estrogen which is now being tested against tamoxifen in healthy women (albeit, without benefit of a control group, as noted by Cindy Pearson). At stake is an "emerging market" of tens of millions of women, who consider themselves at high risk, for the synthetic estrogens to come. The message is that biomedical science is entwined with a business sensibility.

Part B: The Dilemma of Genetic Testing

The final controversy to be discussed is the least developed in popular discourse though its dramatic elements have been featured in several sources, namely the drama of coming to know one's destiny, in the face of very limited options. One of the featured benefits of knowing one has a form of the BRCA gene is being able to warn members of the family of the threat. But warn them for what purpose? This is the question that is pondered repeatedly. Interestingly, we found no articles that elaborated on the possibility of using the designer estrogens described above as a possible antidote to a genetic susceptibility. Instead, the specter of double prophylactic mastectomies is portrayed as the major option, albeit not entirely effective, for trying to maintain some control over a future destiny with this disease. Decision-making must take into account that limited and frightening preventive attempt countered against the social threat of confidential test data being used for purposes of job discrimination and insurance abandonment. In short, this is, at present, a no-win dilemma with few means for improving one's life if a positive result is discovered. An added feature, similar to the tamoxifen story, is the ever-present suspicion of profiteering at the expense of women's lives.

An Unanticipated Result: The Relation between Personal Narrative and Health Policy

In October, 1999, I was asked to develop a presentation and paper on breast cancer for a special conference entitled *Narrative Matters*, sponsored by the journal *Health Affairs* and its institutional partner Project Hope. The purpose of the conference was to explore the connections between personal illness or health-related narratives and how health policy is formulated and implemented. This was not a topic I had really thought about

before, but given the assignment, I was able to find several instances in the recent history of breast cancer in which those connections clearly existed. My work on this project provided me with a number of background materials, especially concerning the contested issue of the efficacy of autologous bone marrow transplantation as a treatment option. This work has resulted in two presentations and is currently in press at *Health Affairs* with an anticipated publication date of January. A longer, more detailed version of this paper will also be used as a chapter in the book planned as a final outcome to this study.

Commentary and Revisions in Statement of Work

In last year's annual report, I was quite candid in assessing delays in progress on this project. According to the original statement of work, the project should be completed by now in the form of a book manuscript. However at the end of year 3, I am where I intended to be at the end of year 2. There are many reasons for the delay, as previously explained, including personal life changes and the data-gathering and analysis taking much longer than originally conceived. As anticipated last year, I have not been able to do the television portion of the study as of yet. I have therefore requested, and am grateful to be granted a one year, no cost extension. With unexpended funds from the original budget, I will be able to hire a part-time research assistant here at Texas A & M during the spring and summer semesters, who will help me to complete Phase 3, the segment of the study in which we look at the appropriation of breast cancer as content for entertainment television, and the social, political, and cultural functions this serves. My plan—again a change from the original proposal—is to focus on the last viewing season (1997-1998) of *Murphy Brown*, in which breast cancer was featured as a sub-plot throughout the series. The integration of the experience of illness into a popular situation comedy makes for a rich, coherent, and appropriate vehicle for examining the research issues I have posed. During this final grant year, I will also endeavor to prepare as many book chapters based on the completed analyses described in the first three annual reports as I can get done.

Key Research Accomplishments

- Reviewed 169 original popular press source materials in order to analyze the media's depiction of breast cancer during 1985-1992, as it evolved from the previous decade.
- Reviewed 39 original popular press source materials from 1993-1998 in order to analyze and evaluate how depictions of tamoxifen prevention could influence the public's understanding of related issues and personal decision-making.
- Reviewed 50 original popular press source materials from 1993-1998 in order to analyze and evaluate how portrayal of genetic testing could influence the public's understanding and personal decision-making.
- Completed analysis of the relationship between popularization of personal breast cancer narratives and health policy decision-making.

Reportable Outcomes

- Presentation entitled "Out of the Closet and Into the Legislature: The Impact of Communicating Breast Cancer Narratives on Health Policy" at conference entitled Narrative Matters: Personal Stories and the Making of Health Policy, Airlie House, VA, March, 2000.
- B.F. Sharf & G. Gwertz. Informed Decisions or Mass Confusion? How Breast Cancer Controversies are depicted in Popular Media. Poster session, Era of Hope Department of Defense Breast Cancer Research Program Meeting, Atlanta, June 2000.
- B.F. Sharf (in press). Out of the Closet and into the Legislature: Breast Cancer Stories. *Health Affairs* 20 (1).

Conclusions

Themes from the previous decade—the shifting of difficult decision-making responsibilities to the consumer in the context of conflicting, inconclusive data—provide the background for the most recent section of the historical analysis. The next evolution is that a concerned, aware, and increasingly sophisticated and politicized citizenry question in earnest the integrity of biomedical science. The critique of the medical establishment's approach to breast cancer treatment and research has become highly visible and vocal at this point. It is very clear that the fruits of scientific progress, while laudable and desired, are a double-edged sword that consistently bring along unintended side-effects, profit motives, and difficult risk assessments. The disclosure of scientific fraud and cover-up both chasten the scientific community and sharpen the vigilance of

consumers and activists. Women's partnerships with medicine from here on in has far exceeded actualizing patient choice; it is now a matter of safeguarding lives from those in whom we have entrusted responsibility for research and healing.

A number of "so what" issues are implied in this work. Some possibilities I am in the process of developing are:

- Improving the physician-patient relationship, through more mass media examples of professional-lay partnerships engaged in conjoint decision-making, and sensitizing physicians and other health care personnel to the needs of addressing media information during clinical encounters;
- Changing the ways in which results of scientific studies are presented to the public, e.g. as work-in-progress rather than authoritative conclusions
- Re-thinking and clarifying the boundaries between citizen participation and responsibility in health care decision-making
- Examining the successes and limitations of breast cancer activism and its impact on other health-related special interests; and
- Appreciating how breast cancer as a social issue has changed and improved effectiveness of women's coalition-building and political influence.

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APPENDIX A

Content Categories

A Activism: Reports on the activities of organizations of survivors and others, trying to raise awareness and money, as well as influencing policies and practices related to breast cancer.

AT Alternative Treatment: Therapeutic modalities practiced outside of mainstream, allopathic medicine (e.g., laetrile, variety of pain control techniques).

BSR Basic Science Research: reports on laboratory-based research, including cellular activity, viruses, and animal experiments.

BH Breast Health: References to breasts in the context of non-cancer discussion. May include such frames of reference as sexuality, aesthetics, nurturance, and benign lumps.

C Coping: Descriptions of how individuals have dealt with the problems associated with being diagnosed and ill with bc, and its treatments. Includes most personal narratives (not only people with cancer, but also partners & additional significant others).

CR Criticism: Overt or implied disapproval of medical practices, scientific investigation or health policy related to breast cancer.

D Detection: Relates to the identification of breast cancer cells in living humans. Includes writing on the importance of early detection (sometimes referred to as "prevention"), as well as explanations, descriptions of diagnostic technologies, e.g., xerography, mammography, thermography, blood tests, BSE. [reasoning here. "Detection" is a more inclusive word than "diagnosis." For example, a recurrence may be detected.]

E Epidemiology: Prevalence or impact of bc on particular sectors of the population, e.g., racial, geographic. Includes environmental factors. Includes non-clinical human subjects research unless the research is specifically concerned with psychosocial issues.

G Genetics: Research, therapy, testing & counseling related to genes & BC [reasoning used here. This begins as BSR, but becomes much more inclusive. Identification of BC gene a major scientific discovery in itself.]

P Politics: Association of bc with political candidates, leaders and party platforms. How decisions made on funding bc research and deciding on funding priorities.

PC Patient Choice: Discussions related to shifting power relations between the medical community and patients regarding treatment decisions. Includes capabilities of patients to exercise autonomous decisions and partnerships with doctors.

Sharf: Annual Report, 2000

PA Public Awareness: Public registering its views about major news events, public figures, media representations related to bc. Issues may include tastefulness regarding privacy/publicity, how public reacts to controversies (eg, surgeries, when to get mammographies).

PS Psychosocial Factors: Reports of research and psychological treatments that assumes a connection of personality and mood with breast cancer. Explanations of impact of breast cancer on individual and family dynamics.

Note: Items coded in this category tend to focus on research findings and forms of therapy, rather than individual narratives of coping (C), e.g., a survey of the prevalence of marital problems for women with breast cancer vs. how an individual with a mastectomy dealt with her husband's aloofness after her surgery.

PV Prevention: Eliminating conditions that put people at higher risk for cancer including specific recommendations for diet and exercise

SI Social Issues: References to breast cancer-related social trends or policy applicable to broad segments of society. May include (but not limited to) precedent-setting legal decisions, social protests, public alerts and warnings, changes in health policy, etc

T Treatment: "Objective" (non-narrative) descriptions of mainstream, biomedical therapeutic procedures, e.g., mastectomy and other surgeries, chemotherapy, radiation. Also includes experimental treatments, clinical trials involving human subjects/patients (comparison among treatments, under scientific scrutiny).

Table 1
Magazines by Category, 1986-1992

N= 136	A	A T	BH	BS R	C	CR	D	E	G	P	PA	PC	PS	PV	SI	T
Miscella- neous	2	1	1	1	5	5	10	4		2	2	3	4	3	1	11
Women's	5		3	5	15	9	23	18	4	4	3	8	5	12	6	27
News	2	1	1	1	1	1	1	3	2			2	1	3	1	1
Total	9	2	5	7	21	15	34	25	6	6	5	13	10	18	8	39

Key to magazines:

Women's: Essence, Good Housekeeping, Ladies Home Journal, Lears, Ms, Vogue, Working Woman

News: Time

Miscellaneous: Consumer reports, Ebony, FDA Consumer, Mother Jones, New Choices for the Best Years, New Republic, Parents, Psychology Today, Saturday Evening Post, Science, Science Newsletter, Utne Reader

Key to categories:

- A Activism
- AT Alternative Treatment
- BH Breast Health
- BSR Basic Science Research
- C Coping
- CR Criticism
- D Detection
- E Epidemiology
- G Genetics
- P Politics
- PA Public Awareness
- PC Patient Choice
- PS Psychosocial Factors
- PV Prevention
- SI Social Impact
- T Treatment

APPENDIX B

**Out of the Closet and Into the Legislature:
The Impact of Communicating Breast Cancer Narratives on Health Policy**

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If we are to translate the silence surrounding breast cancer into language and action, then the first step is that women with mastectomies must become visible to each other, for silence and invisibility go hand in hand with powerlessness.²

Only twenty years ago when poet Audre Lorde published those words, they were considered revolutionary because--with a few notable exceptions--women did not disclose their personal stories of breast cancer to one another in private, let alone publicly. However, within the following decade, the walls of silence had fallen in, and now personal narratives of living with breast cancer have become nearly ubiquitous—through conversations, popular books, newspapers and magazines, televised depictions, and Internet chat. One of the latest evolutions is a book that appears in both print and on-line formats called *Show Me*, in which 23 women appear in color photographs before and after having breast cancer surgery. In frank detail, they display lumpectomies, mastectomies, and reconstructions, along with individual reactions, both positive and negative.³ Personal stories have raised social awareness, de-stigmatized the disease, celebrated survivors, and commemorated the dead. Beyond these achievements, breast cancer narratives have been influential in the establishment of significant health policies.

This essay spotlights several cases that illustrate ways in which personal breast cancer stories have affected or inspired policy decisions. Despite the specific reference to “the legislature” in the title, policy is conceived of here in a broad sense, including legislative decisions such as monetary allocations, societal mores, medical standards of care, and scientific research priorities. Many of these outcomes have been undeniably positive, but a situation will be examined in which the focus on personal narrative appears to have had a dysfunctional impact. And to the extent that bringing breast cancer out of the closet has been an effective role model for people suffering from other serious diseases, the publicizing of health narratives as a rhetorical strategy for influencing policy-making needs careful assessment. Thus, I conclude my analysis with several lessons learned, as well caveats, questions, and problems to overcome in the policy process.

Breast Cancer Narrative as Visionary

I began with Audre Lorde’s *The Cancer Journals*⁴, one of the earlier personal essays about living with breast cancer, not because it has a direct connection to health policy, rather because it sets the stage for what would follow. Lorde’s ongoing reflections during her diagnosis and treatment was published by a small, unknown press, yet it’s proven to be one of the most influential, enduring works of this genre. In some ways this is odd, since much of the journal addresses the issue of Lorde’s position as a black, lesbian poet dealing with the predicaments of this disease. Yet the loneliness she expresses is a feeling with which many women have been able to identify from whatever their specific social, cultural, or professional perspective. She comments upon the implicit social policies that had encased this disease, especially the impetus toward silence and invisibility. In one memorable anecdote she politely rejects the offer of a prosthesis from a well-meaning American Cancer Society volunteer in favor of acceptance of the scarred chest that marks her encounter with cancer. Further, she presciently wonders, “What would happen if an army of one-breasted women descended

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upon Congress?"⁵ With those words, she prefigures the notion that women with breast cancer have the capacity to join together in order to influence the policy-making process. Lorde alerted us to the idea that shared biographies are integral with advocacy, and advocacy, of course, aims at altering policy.

Breast Cancer Narrative as Catalyst to Reform

*My story is not a model, but an example of what can be done.
It helps to be stubborn and have a loud voice.*⁶

Even before the vision of women with breast cancer descending upon Washington, another woman's foresight had already brought change to medical practice. In 1975, Rose Kushner, a journalist and survivor, put her investigative skills to use in understanding the life-threatening disease that afflicted her. The resulting book⁷ was a brief account of her own illness, with a lengthy analysis and critique of the then-current epidemiological and clinical approaches to breast cancer. With an emphasis on participating in one's own health care decision-making in an informed manner, Kushner's book was excerpted in a number of newspapers and women's magazines, and remained in circulation until the early 1990's. With instincts far ahead of the time, she brought to the surface a number of issues still currently discussed, including environmental toxins, limitations of mammography, dangers of irradiation, and unnecessarily mutilating surgery, all of which have policy implications.

However, the most direct connection to a policy change was her concentration on the issue of why it was standard medical procedure for physicians to perform a one-step biopsy and mastectomy. Patients were routinely expected to give consent to this procedure before anesthesia, thus facing the terrifying prospect of waking up to find a confirmed diagnosis of cancer and their breast gone in one fell swoop. In her own case, Kushner searched until she identified a well qualified physician who would agree to a two-step process that separated biopsy results from the surgical treatment to follow, giving her a chance to rebound from the diagnostic bad news and consider options for surgery. Her subsequent research supported her argument that this procedure would not adversely affect prognosis, and would benefit women psychologically. Based on this information and her own tenacity, Kushner single-handedly lobbied the cancer establishment to change the customary treatment, based on tradition and paternalism, rather than evidence. Her efforts resulted in a change of standard clinical procedure to the two-step biopsy and treatment decision—an amazing feat for a lone citizen-activist.

Breast Cancer Narrative as Political Motivation

*We start today's program with a moment of silence for [Marian Cortez] who died April 3 of this year, two months from her 50th birthday. . . . Her passion for finding a cure for this disease to save her daughter from its ravages was as great as her compassion for those afflicted with it. . . . [Marian] will be missed but her spirit will continue to lead the fight.*⁸

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The National Breast Cancer Coalition (NBCC) is an advocacy organization formed in 1991, comprised of more than 500 groups and 60,000 individuals. With a motto of "grassroots advocacy in action," NBCC's goals include promoting research; improving access to screening and treatment, especially for the underserved and uninsured; and increasing the influence of survivors in legislation, regulation, and clinical trials.

For the past eight years, NBCC has sponsored an annual advocacy training conference, attended by hundreds.⁹ Participants are provided information on issues like new medications, research initiatives, and legislative process, to enable them to speak with credibility about the legislative priorities identified by NBCC.¹⁰ The beginning of each half-day conference session is marked by a tribute to a deceased person, a "non-survivor," who is remembered for her efforts in breast cancer advocacy during her lifetime. The format of these remembrances is a mini-narrative of that person's life and contributions, while her image is shown on wide-screen monitors throughout the room. Such memorials are extremely poignant, reminding each participant of her own mortality, underscoring the importance of the day's activities, and providing a vivid illustration of the direct link between influencing legislative health policy and the life-or-death situation of an individual. The conference culmination is Lobby Day, during which participants noisily demonstrate outside Congress, followed by state delegations talking with their elected representatives about the prioritized issues.

On the other side of the equation, several legislators have been affected profoundly by cancer narratives—their own stories, those of loved ones, and those of their constituents—that have inspired them to develop particular professional priorities. Two examples spanning both sides of the political aisle in Congress provide evidence of the power of meaningful health narratives on political agenda-setting.

Throughout his lengthy career, Senator Tom Harkin (D-IA), a senior member of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, has championed funding of various medical research projects,¹¹ with breast cancer in the forefront over the past decade. In addition to characterizing cancer as "a leading killer," an official response from his office states Harkin's interest is also influenced by the fact that "his only two sisters died at a young age from breast cancer. Neither of them had ever had a mammogram, and if they had, he strongly believes they would be alive today."¹² His legislative achievements include dramatic increases for funding of breast cancer research, such as the Department of Defense research program, as well as treatment, prevention, and screening programs for lower income women.

The other example indicates that the influence of cancer narratives upon Congressmen does not have to stem from direct personal involvement. Former Senator Alfonse D'Amato (R-NY) had also been a member of the Senate Appropriations Committee.¹³ To my knowledge, D'Amato did not face a personal or close familial encounter with cancer as did Harkin, but he was very affected by the life stories of a large number of Long Island constituent-survivors who suspect an environmental cancer cluster in their community. While his motivation may have originated as a political move to procure women's votes, D'Amato became "an invaluable ally" to several local advocacy groups

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and the NBCC.¹⁴ Breast cancer narratives, whether from the standpoint of ordinary citizen or lawmaker, are inspirational. They motivate individuals to take certain life turning points and actions in hopes of memorializing some, while improving the future for others.

Stories Can Make Bad Policy

Much of the public's exposure to breast cancer information is communicated through the mass media, which often employ narratives to focus attention. In 1993, the story of Nelene Fox, a 38 year old California mother of three, received a good deal of media attention. After being diagnosed with advanced breast cancer and exhausting all conventional therapies, she was advised by her doctors that her only remaining chance for survival was autologous bone marrow transplant (ABMT), a risky process involving extremely high dose chemotherapy. Her HMO refused to pay for the \$140,000 procedure because the treatment was classified as "experimental," meaning that insufficient scientific evidence existed to prove that it extends a patient's life. Though Mrs. Fox's local community eventually raised the money for treatment, she died soon after undergoing ABMT, with many speculating that she was unable to begin in time to get the beneficial effect. Her brother, a lawyer, sued the HMO, convincing the jury to award \$89,000 in damages to her family. Similar law suits with similar results soon followed.¹⁵ The dilemma of ABMT was compounded by prolonged difficulty in recruiting sufficient numbers of subjects for clinical trials, since patients with advanced disease were repeatedly told at cancer centers that this treatment had shown promising results. Furthermore, media publicity about the Fox case eventually succeeded in forcing widespread insurance reimbursement, thus discouraging patients from enrolling in clinical trials while making ABMT "the cash cow for the cancer service."¹⁶ This problem of inadequate volunteers for investigations, in turn, delayed a conclusion about the efficacy of the treatment. Despite the optimism conveyed by some physicians and the popular media in the 1980's and '90's, in April, 1999, the National Cancer Institute issued an announcement concluding from accumulated available studies that ABMT does not benefit individuals with breast cancer.¹⁷

The power of the story of Nelene Fox and others like her persisted for years. The public narrative of bone marrow transplant portrayed managed care protecting its profits by barring women from the treatment some doctors told them would be their only chance for survival. Women, in turn, for years fought to have ABMT, even though there was little or no data to support this choice. By going this route, the confirmatory information that can only come from clinical trials was delayed for years, and in the end, we have come to discover that the insurers had valid grounds for their decision to withhold payment and that we held on to a story of false hope for much too long.

Assessing Impact

The preceding analysis reveals several lessons about the consequences of publicizing personal stories of breast cancer on health policy formation. The public airing of personal breast cancer stories has resulted in de-stigmatization; improved awareness and community involvement, and the opportunity for individuals to assume greater decision-

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making and provision of input to the scientific and legislative processes. Positive outcomes also include that stories can:

- envision alternative and more empowering alternatives, as Audre Lorde demonstrated;
- identify key issues of concern to people with the disease, such as Rose Kushner did with inappropriate surgical procedures.
- inspire efforts to provide better care, more resources, and deeper involvement for critical priorities, both for citizen advocates and elected legislators.

The influence that communication of breast cancer stories has had on policy formulation also imparts a more negative lesson, as the ABMT experience makes painfully clear: individual stories should not be taken as scientific proof, either by policymakers or survivors themselves. It also raises difficult questions about how the national health care budget should be determined. Successful advocacy strategies modeled by AIDS activists in the 1980s set an example for breast cancer activists in the '90s; breast cancer advocacy, in turn, is influencing efforts on behalf of ovarian and prostate cancers. But as each "disease specific" group becomes organized to ask for more attention and increased funding, what will happen? The leaders of the NBCC reply that the answer lies in increasing the total budgetary pot for health care, so that all problems are adequately attended to.¹⁸ While appealing, this solution seems hopelessly unrealistic to me. National health care expenditures are already at an all-time high, preventive care is continuously shortchanged, and the list of disease advocacy groups continues to grow. It seems inevitable that the "squeaky wheel gets the grease" approach to health appropriations is either on a collision course that pits one worthy group against another, or that attention will pivot from one priority to another before long-term outcomes can occur. Furthermore, for each story told, what has been omitted? For instance, what about heart disease, the biggest killer throughout the population (in the U.S., 503,000 women die annually from cardiovascular disease versus 43,000 from breast cancer¹⁹)?²⁰ Should disease incidence be emphasized as a more important criterion for policy decisions or do more affecting personal illness stories of heart disease need to be created?

Clearly, personal narratives are powerful, rhetorical strategies, as well as humane, existential expressions of suffering and memorials to loved ones. Only through the riveting communication of such narratives have we arrested alienation from the ill and constructed understanding of what it means to live with breast cancer (or Alzheimer's or Parkinson's or spinal chord injury). However, as a society, we have reached a point of necessity to develop more conscious, sophisticated criteria for evaluating illness narratives. This is, naturally, a knotty task since individual stories of suffering have authenticity and validity for the teller and for others similarly afflicted. In Aristotelian terms, the force of illness narratives is derived from *pathos* (emotional proofs) and *ethos* (character-related proofs).²¹ In order to use personal narratives as a means of affecting health policy, there remains the challenge to effectively combine stories with the other form of rhetorical proof, *logos* (logic, the rational). For the recipients of illness stories--lawmakers, policy wonks, the public--several difficult questions must be investigated. What are the criteria for making judgments about better and worse stories as a basis for generalizing public policy? How do we distinguish among competing *and* compelling

narratives? Is it possible to move to a different level of story-telling, one that can transcend competitive narratives? These are complex problems, yet the value of grappling with such dilemmas is quickly recognized when compared with the memories of an era when the telling of such stories was repressed.

NOTES

- ¹ A. Lorde, *The Cancer Journals*. (Argyle, NY: Spinsters Ink, 1980), 61.
- ² See: N. Willdorf, "Women Share Their Personal Encounters with Breast Cancer," *The Chronicle of Higher Education* (March 8, 2000): <http://chronicle.com/free/2000/03/2000030801t.htm>; and *Show Me: A Photo Collection of Breast Cancer Survivors' Lumpectomies, Mastectomies, Breast Reconstructions and Thoughts on Body Image*: http://www.suslovedmd.com/community/library/cancer_survivors/cancer_survivors.htm.
- ³ Lorde, *The Cancer Journals*.
- ⁴ *Ibid.*
- ⁵ R. Kushner, *Breast Cancer: A Personal History and an Investigative Report* (New York: Harcourt Brace Jovanovich, 1975), 11.
- ⁶ *Ibid.* Later revised and re-published as: R. Kushner, *Why Me?: What Every Woman Should Know about Breast Cancer to Save Her Life* (New York: New American Library).
- ⁷ This quotation is part of a memorial given at the National Breast Cancer Coalition Advocacy Training Conference, May 24, 1999. A pseudonym has been used in place of the original name invoked in this quoted material for reasons of confidentiality.
- ⁸ The description that follows is based on my first-hand, ethnographic participant-observation at the 1999 NBCC Advocacy Training Conference in Washington, D.C.
- ⁹ In 1999, the NBCC legislative priorities included increased funding for peer-reviewed research; follow-up treatment for women found to have cancer through federal screening programs; insurance coverage for treatment for people participating in clinical trials; endorsement of a meaningful patients' bill of rights; and prohibition of insurance and employment discrimination based on genetic information.
- ¹⁰ Harkin's staff states that he "has never advocated 'earmarking' of NIH funds for

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one disease or condition over another." S. Corlette, Personal Correspondence, Office of Senator Tom Harkin, U.S. Senate, Washington, D.C. (January 30, 2000).

11 Ibid.

12 Like Senator Harkin, former Senator D'Amato, through his office staff, denied my request for a telephone interview.

13 M. Goldstein, "Come and Be Counted: The Story Behind the Long Island Breast Cancer Study," *Mamm: Women, Cancer, and Community* 2 (July/August, 1999): 41-49, 72-73.

14 M. Meyer and A. Murr, "Not My Health Care," *Newsweek* (January 10, 1994): 36-38.

15 G. Kolata and Kurt Eichenwald, "Hope for Sale," *The New York Times* (October 3, 1999): 1, 40, 41. Interestingly, major advocacy groups like the NBCC have not recommended women choose on their own to have ABMT; instead, they provided significant assistance in recruiting participants for clinical trials, so that appropriate evidence upon which to make an informed choice could be gathered.

16 National Breast Cancer Coalition Statement on Bone Marrow and Stem-Cell Transplants (April 15, 1999): <http://www.natlbcc.org/press/stemcell.asp>

17 B.F. Sharf, Interview with Fran Visco, President, National Breast Cancer Coalition, (Philadelphia, PA., February 7, 1994).

18 <http://www.americanheart.org/statistics/biostats/biowo.htm>;
<http://www.cancer.org/statistics/99bcff/who.html>

19 For example, breast cancer is "only" the eighth highest disease in the U.S. regarding mortality, while AIDS ranks 17th. However, AIDS receives the most money for research, \$1.8 billion in the NIH budget. Heart disease has the largest mortality rate, but its NIH budget is half a billion dollars less than that for AIDS (Statistics cited from: J. Stossel, "Lobbying for Lives," *20/20* (ABC News, October 11, 1999). Transcript available at http://www.abcnews.go.com/onair/2020/transcripts/2020_991011_disease_trans.html.

20 L. Cooper, *The Rhetoric of Aristotle*, (New York: Appleton-Century-Crofts, Inc., 1960).