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13. ABSTRACT (Maximum 200 Words) <p>The purpose of this study has been and continues to be an assessment of 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 fourth annual &amp; final report primarily summarizes work conducted as a result of a one-year extension of remaining grant funds. This portion of the study focuses on a case study of a viewing season of the situation comedy, <i>Murphy Brown</i>, during which the lead character was portrayed as being diagnosed and treated with breast cancer, while coping with demands of daily living including work, friendships, and parenting. This case is an exemplar of the simultaneous attempts to use entertainment television for the pro-social objective of raising awareness and extending understanding about this disease, as well as appropriating the dramatic aspects of this same life-threatening disease for entertainment purposes. Of special interest is the use of comedy to communicate serious information and, often poignant, issues.</p>
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## Introduction

As I've written my annual reports in the past three years, I've usually been thinking of the implications of public communication about breast cancer in the context of October, National Breast Cancer Awareness Month. This year, the national context is strikingly different. Of course, breast cancer remains a critical, persistent health care issue; the annual runs, media programming, pink ribbon display, publicized hospital mammography testing, etc. continue as they have over the previous decade. But this year, public communication on all issues has been over-shadowed by the terrorist attacks of September 11 and the aftermath, including a nation at war, anthrax outbreaks around the country, and profound anxiety about changes in the American way of life. One manifestation of these events, one month following the initial tragic events, was a self-conscious, national grappling with re-gaining a sense of humor, as reflected in the opening show of the fall television season of *Saturday Night Live*, when producer Lorne Michaels asked New York Mayor Guiliani if it was "okay to be funny." This theme of *using comedy to cope with tragedy*, explicitly the use of televised situation-comedy as an approach to the tragedy of breast cancer, is the focus of this year's annual report.

As has been explained in the previous annual reports, the overall purpose of this study has been 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 has included 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. Since this is also a final report, I will summarize the work that has been completed throughout the duration of this project, as well as the remaining work that will continue after the cessation of funding.

## Body

### Scope of Work for Year 4

Work completed during Year 4 has focused on the third objective, regarding the appropriation of breast cancer as subject matter on entertainment television. A general review of literature on the portrayal of serious health issues on entertainment television (i.e., in contrast to news reporting) was undertaken. My central effort has been devoted to an analysis of the 1997-98 viewing season of *Murphy Brown (MB)*. During its final year, this popular situation-comedy dedicated a prominent, ongoing storyline to the title character's diagnosis and experience of living with breast cancer. The strategies, themes, problematics, and responses to concerted efforts on the part of the show's producers and star at raising awareness about the disease have been the focal points of my analysis.

### 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).

As the most widely accessible and influential of popular media, television is a primary means of health education in the U.S. Analysis and evaluation of entertainment television programming in terms of pro-social objectives has become a genre of media scholarship known as *entertainment-education*. The majority of previous studies have been devoted to developmental and health promotional efforts (e.g., family planning) especially in international settings outside the U.S., using specially designed scenarios on *telenovelas* or soap opera formats (Singhal & Rogers, 1999) via television and, to a lesser degree, radio, as well as music videos. Less attention in this mode of scholarship has been given to regularly-scheduled U.S. prime-time programs that feature depictions of the experience of living with cancer or other serious diseases. Of these, the shows have been primarily dramatic in format (see, for example, Sharf & Freimuth, 1993; Sharf et al., 1996 on ovarian cancer; Arrington & Goodier, 2001 on prostate cancer). Breast cancer has been formerly featured in the context of situation-comedy, perhaps most memorably on a single episode of *All in the Family*. The present study centers on a comedy that made a major attempt to break previous molds in terms of 1) carrying the breast cancer motif throughout the entire viewing season, 2) carefully combining the sit-com episodes with targeted public service messages, and 3) attempting to deal with pointed messages related to the breast cancer experience in a variety of contexts. Like other entertainment programming that has attempted to create cancer plots, *Murphy Brown* did not sustain widespread viewership and received mixed critical reviews. Nonetheless its prominence as a long-standing, award-winning program and ambitiousness in purpose justify a careful examination of what happens when breast cancer is featured on the “small screen.”

Although I had videotaped eight episodes of *MB* in 1997-98 when the shows were originally aired, I was unable to capture all the pertinent episodes in which aspects of Murphy's illness was the major plotline. Thus, several weeks of this year were spent in efforts to obtain copies of the remaining episodes. Through Warner Brothers, the production company that now owns the rights to the program re-runs, I was able to obtain copies of three additional hours of pertinent episodes.

All episodes were reviewed at least twice by myself and my research assistant. In discussions that followed, we identified key themes, “take-home” messages for television audiences, and strategies for making difficult issues related to living with breast cancer palatable as entertainment. As a method of triangulation, we talked through individual

observations and responses. Our interpretations also were developed in light of critical commentary published when the show originally aired. Also incorporated in the analysis are frequencies of telephone contacts received by the Susan G. Komen Foundation for the three day period following the showing of a public service announcement for the Foundation during one of the *MB* episodes. In addition to investigating the problem of how and why to treat breast cancer as a comedic subject, I also explored the question of what it means to appropriate cancer, especially the experience of illness, as popular entertainment: How did the *MB* breast cancer plotline compare to other programming efforts to depict breast cancer as education-entertainment? How well does such fare sustain viewers' interest? What pro-social functions are served, and how effectively? And is there a "backlash" effect that trivializes a major health calamity?

### Results & Discussion

**Precursors to *MB*.** As part of the cultural studies approach used throughout this project (i.e., investigating the focal documents within a broad sociocultural framework), the *MB* episodes were examined in the context of previous mainstream television programming that had made use of breast cancer as a thematic motif. Before watching and analyzing the *MB* tapes, my research assistant and I watched and discussed previously-televized episodes from other shows preserved on video. Some of these are more dated programs, including a two-part episode of *Dallas* from the early 1980s in which a major character's diagnosis and mastectomy are portrayed with high melodrama, emphasizing loss of feelings of femininity and threats to marriage and sexuality, as well as a significant two-part episode of *Cagney & Lacey* from 1985 in which Lacey makes the decision to have a lumpectomy instead of a mastectomy, discovering that her chances for survival are comparable with either option. This program emphasized increased patient decision-making, related to newly released research findings of that period. Others programs viewed were more contemporary with *Murphy Brown* (mid-1990s). These included a few after-school specials with dramas targeted to the concerns of adolescent girls whose mothers had been stricken with the disease; an episode from *Dr. Quinn, Medicine Woman*, that provides a quasi-historical version of how a woman afflicted with breast cancer might have been treated in the 19<sup>th</sup> century American frontier; and an episode from *Chicago Hope*, in which a very young woman being cared for the show's cast of medical personnel is faced with the loss of her breast. One day-time soap opera, *General Hospital*, has incorporated a breast cancer subplot for several years, featuring such serious elements as participation in a support group, fear of recurrence, etc. Also reviewed were single episodes of two situation-comedies that focused on anxiety related to undergoing mammography after finding a lump (though not resulting in cancer); in one of these, the comedy is predicated on the plot twist of a male character discovering a breast lump. Other prime-time shows have used breast cancer as a foundation for eccentric plots (e.g., a fraudulent "quack" taking advantage of desperate patients on *Law & Order*, a dying patient giving birth on *ER*). The most exploitive example were several episodes from the prime-time series, *Sisters*, in which one of four adult sisters is depicted through a diagnosis and period of coping with the worry of having breast cancer, albeit in a rather light-hearted way (e.g., the afflicted sister is seen in front of a vanity mirror, fantasizing how she will look in a parade of exaggerated wigs).

In sum, breast cancer has had a sporadic history over the past two decades on American entertainment television, ranging from its use as an incidental device to further other plot development to positioning it as the main topic, most often with tragic overtones. There seems to be an unstated presumption that featuring breast cancer as a theme is a pro-social form of communication in itself, in terms of increasing public awareness about this disease (though it's not at all clear that what is being communicated is accurate or realistic information). Only in a few instances have issues that go beyond individual fear and coping been dealt with.

**Overview & Thematic Emphases on MB.** Beginning in 1987, the situation comedy series, *Murphy Brown*, had been an extremely popular, award-winning show. Portrayed by well-known actress Candice Bergen, Murphy Brown became such a part of the cultural landscape that Murphy was sometimes referred to as a role model for American women. The program had especially garnered public attention when its title character was singled out for criticism regarding violation of family values by then Vice President Dan Quayle. However, by the mid-1990s, the program had significantly declining viewership. Thus, it was announced in advance that the 1997-98 viewing season, its tenth, would also be its final one. The summer before this season began, it was also publicly announced that Murphy would find out she has breast cancer, a decision made by Ms. Bergen and the show's original producer as a socially significant way for this television character to make her exit. There was a fair amount of both critical and viewer anticipation about this plot development, though the season finished with disappointingly low viewer attention and much, though by no means universal, criticism that the insertion of breast cancer had been a ploy to regain viewership that had failed to achieve the goal.

Of the twenty-two episodes within this final season, the issue of Murphy's bout with breast cancer is mentioned on nearly every one, and more than a third feature her illness as a major focus. Consistent with the regular format of the program, Murphy's illness was depicted primarily in the context of her longtime work relationships at a network news show, highlighting matters of affection, dependency, awkwardness, and loyalty, and less so in personal relationships outside of work, including encounters with physicians. Disease-oriented topics that were touched on included mammography and biopsy diagnostic procedures, decision-making about confusing treatment options, lumpectomy, chemotherapy and its side effects, and concern about recurrence. Psycho-social-related topics included coming to grips with having cancer; talking with small children about the disease; re-negotiating relationships with friends after diagnosis and the need for social support; coping with aging, changes in body image and sexuality; and facing mortality. True to the show's character and history, a few issues of societal relevance were also embedded within the cancer plotlines including the ethics of fund-raising, and, especially, the controversy surrounding the use of medical marijuana.

In short, this was an ambitious undertaking that genuinely tried to bring several aspects of the experience of living with breast cancer front and center to the American viewing public in a highly entertaining and palatable manner.

**Interpretive Assessment.** Despite the fact that breast cancer has incorporated in other entertainment television programming, it remains difficult subject matter to use for the purpose of public health entertainment-education. Generally, cancer, and the fear and sadness it evokes, is a turnoff to audiences, wishing to relax at home during primetime television viewing; breast cancer, in particular, remains a threatening subject for women. Thus, it was no small decision for the popular situation comedy *Murphy Brown* to feature its major character as undergoing breast cancer throughout the 1997-1998 season. Critical commentary debated whether this was a courageous socially responsible move to raise public consciousness or a blatant bid to increase flagging viewership in the show's tenth and final run. Ironically, making cancer a central plot theme probably ensures that some regular viewers will drop out, rather than guaranteeing that new viewers will start watching. Moreover, the show took on the formidable task of integrating this sobering topic within a half-hour comedy format over a lengthy period of time with the challenge to presenting such issues with a balance of poignancy, credibility, and humor.

In a further effort to advance both the education and social action agendas of this project, three episodes incorporated collaborative public service announcements, first from the American Cancer Society, and then two others with the Susan G. Komen Breast Cancer Foundation, under the sponsorship of Ford Motor Company, which is the largest sponsor of the Komen Foundation's *Race for the Cure* fundraising initiative. Rather than appending these PSAs at the tail end of the episodes where they could easily be avoided, they were instead inserted at mid-way points, using Ms. Bergen as a "real-life" spokesperson, adjacent to her playing the character of Murphy undergoing the illness. Analysis of data from the phone bank of the Komen Foundation indicates more than a doubling of phone calls after the first PSA (I was unable to obtain comparable data from the ACS).

My assessment is that the program was indeed well written and acted, and that its creators accomplished many of the difficult objectives I have described in terms of disseminating a great deal of information, illuminating controversial social issues, and dealing with very serious matters in a comic format. To a much greater degree than the previously discussed shows, *MB* conveyed much more medical and personal information about breast cancer, showing its effects on an already well-established and widely known character (compared to the aforementioned longitudinal attempt on *Sisters*, *MB*'s achievements were truly considerable). While the character of Murphy Brown was an exaggerated personality, both in terms of her media persona and personality foibles, as a female role-model, she represented an independently-minded, self-supporting single working mother, hard-working woman, and vulnerable, aging individual. These qualities are ones with which many ordinary viewers can identify, and thus to see Murphy undergo the varied aspects of illness is an appropriation of breast cancer which seems to make sense and have a defensible purpose that extends beyond entertainment. Perhaps only the *Cagney & Lacey* episode rivals *MB* for potential social impact. Why then did it fail to capture the attention of most of the viewing public? While a prolonged dramatization of the cancer experience provides a venue for a detailed and realistic exploration of what it means to live with this disease, it appears to be an overexposure in terms of sustaining interest of television audiences, even if presented in a relatively unobtrusive way, i.e.

intertwined with other plots and incorporating humor. To see life with cancer played week after week, even in humorous situations, apparently is not entertaining enough. This is an important outcome to consider as increased efforts are being made to utilize health-based education-entertainment in our mass media.

### Key Research Accomplishments

- Reviewed more than 40 critical reviews and approximately 20 hours of videotaped material in order to analyze the *MB* series on breast cancer

### Reportable Outcomes

- B.F. Sharf (2001). Out of the closet and into the legislature: Breast cancer stories. *Health Affairs* 20, 213-218 (copy appended).
- **B.F. Sharf** & B. Creel (forthcoming 2003). Making Comedy of Cancer: *Murphy Brown's* Final Confrontation. *Qualitative Studies in Education*.
- Amayo, H., Petersen, J. & **Sharf, B.F.** (Eds., forthcoming 2003). Constructing an illness: Breast cancer & discourse. Special issue of *International Journal of Qualitative Studies in Education*.

### Conclusions and Self-Commentary

This year's final report has been based on work done during a no-cost extension year of the original grant. The television is well underway but is not yet completed. I expect the final analysis will contain a conceptual understanding of the strengths and shortcomings of using comedy to communicate about breast cancer in popular culture venues, as well as pragmatic recommendations in the development of entertainment-education on television.

In this final statement, I wish to comment on my own work during this grant period, I have examined a huge amount of popular media material that spans a 35 year period of time. This is what I had contracted to do in my grant proposal. What I have not yet accomplished is the reportable outcomes of these analyses in multiple publications and/or a book. Even though the grant period is ending, it remains my plan to produce the published work, which I anticipate will contribute to the rhetorical understanding of how breast cancer is socially constructed and shapes public understanding and decision-making.

I must be honest in saying what I am sure is obvious to reviewers reading this report. I am very disappointed not to have produced during the past four years what I had promised to produce. I realize I have been given significant resources and opportunities

for a purpose to which I remain very committed, and I am sorry to have gotten behind. What I am about to write is not an excuse, but an honest explanation of what has happened. To some degree I bit off more than I thought I could handle in the expected time period. However, more to the point, life got in the way of my original plans. A year into the work, I was offered a very good position that motivated my family and I to uproot ourselves after more than 20 years in Chicago. Following the move to Texas, I faced major adjustments in terms of new job responsibilities and a living situation. I also got caught in an awkward situation between two institutions as far as this grant is concerned (i.e., I remained on the University of Illinois at Chicago payroll for the grant work, even though I am now located at Texas A & M). This circumstance became a major obstacle this past year, because of lack of communication or miscommunication between the two universities. To be perfectly candid, I have spent much more energy and time this year in trying to negotiate a sub-contract than in actually focusing on the research. Finally and most significantly, I have become increasingly sicker myself from the effects of rheumatoid arthritis, which is causing me to be severely fatigued and in chronic pain frequently and for more prolonged periods of time than at the time I wrote the grant proposal. A severe bout over the past several months is largely responsible for the extreme tardiness of this report.

I am most appreciative of this funding and will continue to work and produce in ways that will justify the investment that has been made in me. I will forward any future publications to this agency.

**Personnel hired on the grant, 1997-2001**

PI, Barbara F. Sharf, University of Illinois and Texas A & M University

Research Assistants: 1997-2000, Gwynne Gertz, University of Illinois

2001, Rebecca Watts, Nicholas Rangel, and Bonnie Creel

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**APPENDIX**

A REPRINT FROM

# HEALTH AFFAIRS

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*Using And Misusing Anecdote  
In Policy Making*

BY JOHN E. McDONOUGH

*Out Of The Closet And Into The Legislature:  
Breast Cancer Stories*

BY BARBARA F. SHARF

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# Using And Misusing Anecdote In Policy Making

*A former state legislator explains the beauty and peril of allowing storytelling into the policy process.*

BY JOHN E. McDONOUGH

**PREFACE:** During the 2000 presidential campaign, Al Gore's questionably accurate tale of his dog paying less than his mother-in-law for the same drug, and years ago, President Ronald Reagan's similarly creative story about a nonexistent "welfare queen," share a common thread. They underscore the power of stories to dramatize political positions, despite the moral and informational hazards of personal narratives as policy currency. The policy anecdote is an omnipresent form of policy discourse that Health Affairs attempts to capture in a responsible and literary way in the Narrative Matters column. With support from the Kellogg Foundation, in March 2000 Health Affairs convened a group of writers, health policymakers, editors, and journalists to explore the role of the personal essay in the making of health policy. The following commentaries from that conference by John McDonough and Barbara Sharf address the power and the pitfalls of the personal story in the health policy process. McDonough, a former politician, and Sharf, a professor of communication and humanities, derive strikingly similar conclusions from quite different vantage points.

**I**N 1991 I WAS A LEGISLATOR in the Massachusetts House of Representatives arguing against deregulation and market-based health care as a means of controlling health costs. I carried a nine-inch pile of evidence everywhere—to hearings, press conferences, meetings, and floor debate. Half the pile was made up of empirical, peer-reviewed studies demonstrating the efficacy of state-run hospital rate-setting programs. The other half consisted of peer-reviewed studies failing to identify improvements in cost or access from managed care. By contrast, deregulation advocates—corporate benefit managers, insurance and hospital executives, and union welfare fund trustees—had no empirical evidence to support their case.

My opponents were unimpressed by my pile and, in the context of the times, were right. They

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knew what they saw on the ground—a bewildering regulatory behemoth, calcified by years of political deals between hospitals and the state, that prevented them from negotiating contracts that would give them more value and accountability. My studies were based on pre-1985 data; the research community pretty much gave up studying rate setting after that, satisfied with results showing that it worked. But the fast-changing health system bore little resemblance to that earlier period, and the research community had yet to grasp what was happening in the field. My adversaries spoke from the real world, telling anecdotes describing their actual experiences in controlling costs by becoming active, aggressive purchasers of health care. In the end, their perspective mattered more than the reams of scientific evidence I brought to the debate.

The lesson that personal observation can easily trump hard data revealed itself again to me the following year. I lacked firsthand knowledge of the 1993 bill mandating Massachusetts insurers to pay for bone marrow transplants for breast cancer patients, because I didn't sit on the relevant committees. But I had read accounts of the hearings and discerned a familiar dynamic. Breast cancer victims and their advocates argued that greedy insurance companies and HMOs refused to pay for these transplants because they were too costly, regardless of the benefits. Women who had undergone this treatment testified to its life-saving value. Insurers argued that the treatment's efficacy had not been scientifically demonstrated and that suffering from the treatment was as inordinate as its cost. They were then portrayed as callous, white, male-dominated parties who were insensitive to women's health needs.

### When A Story Is Off Base

I CONSIDERED TAKING ISSUE WITH THE BILL but had learned, as most legislators do, to pick my fights. Initiating opposition that would be futile and would be viewed as blind to women's health needs didn't make sense. The measure passed both houses easily and was signed into law by then Gov. William Weld, an otherwise vigorous critic of health insurance mandates. A similar pattern played out in many other states and the federal government, which approved their own mandates in the 1990s.

But the rush by providers, patients, and states to provide, obtain, and finance these services had an unfortunate effect. Researchers could find few volunteers for controlled studies to evaluate the treatment's effectiveness. Indeed, not until 1999 were studies com-

pleted demonstrating that bone marrow transplant, much more costly and painful than conventional treatments, was no more effective in extending the lives of breast cancer victims.

These two encounters illustrate both the value and harm of relying on storytelling in making public policy. Stories can enable lawmakers to understand a legitimate need for policy change but just as readily can lead them to make bad policy decisions. Stories can bring to life drab data analyses, helping us to visualize problems and opportunities for change. But stories also can lead us down wasteful and dangerous paths and blind us to uncomfortable truths we would prefer to ignore, like the fact that there yet is no easy cure for breast cancer.

It comes as no surprise, then, that almost as common as using narrative and anecdote in policy making is criticizing them. Former Minnesota state legislator Lee Greenfield often remarks that one compelling anecdote (true or false) at a crucial moment in a floor debate can vaporize a mountain of data and careful policy analysis.

**“Stories can enable lawmakers to understand a legitimate need for policy change but just as readily can lead them to make bad policy decisions.”**

### Anecdote's Inescapable Humanity

**W**HY IS NARRATIVE SO CENTRAL to policy making? Because it is central to life. We live our lives crafting, telling, and receiving stories. We tell our loved ones stories from our day. We catch up with old friends by sharing tales from our lives. We receive from all forms of the media stories to help make sense of our world. In constructing our stories, we are necessarily selective in choosing and editing details to drive home a lesson, to engage our audience, or to meet time, space, and other constraints.

This is true for the hardest of sciences. “So much of science proceeds by telling stories,” writes Harvard naturalist Stephen Jay Gould, in *Bully for Brontosaurus: Reflections in Natural History*. He sees us as “vulnerable to the constraints of this medium” because we are unaware of our tale telling in observing the natural world. “We think that we are reading nature by applying rules of logic and laws of matter to our observations,” he says, “but we are often telling stories.”

Policymakers, like scientists, are as human as the rest of us. Part of our uniquely human heritage involves telling stories to find meaning from the events, data, and stimuli in our lives. Most policymakers, and especially legislators, have not had training in research

methods and share the layperson's suspicion of statistical analysis. The adage "Lies, damn lies, and statistics" makes more sense to most of them than does the value of the r-square.

### Values Versus Data

PERHAPS THE REAL POWER OF STORIES lies in their reflection of ideas and values. As Deborah Stone argues in her book *Policy Paradox*, much of the policy process involves debates about values masquerading as debates about facts and data. "The essence of policymaking in political communities [is] the struggle over ideas," she writes, even though in legislatures and other deliberative bodies, participants engage in fierce debate about data and statistics as though the process were a straightforward search for truth. Her view, which I share, challenges the concept of policy making as simply a scientific exercise in data analysis.

I recall numerous debates in the Massachusetts legislature on whether to mandate use of seat belts and motorcycle helmets, provide clean needles to addicts, require insurance coverage for infertility treatments, dictate gun ownership restrictions, and obligate employers to provide health insurance to their workers. In each case, both sides argued about data as if identifying the right statistic

would compel the other side to surrender. But data were only rhetorical weapons used to bolster competing values.

When policy differences are grounded in divergent value structures, empirical research rarely helps much until participants allow for those value differences. Recognizing differing value frameworks marbled through a policy

dispute can enable participants to reach a resolution that acknowledges those differing concerns, or can make it clearer why agreement is not possible.

In 1995, while chairman of the legislature's insurance committee, I remember how community housing activists fought with insurance company executives over home insurance "redlining"—an unwillingness to write coverage of homes in marginal urban neighborhoods. A series of trust-building exercises brought both sides to a greater appreciation of each other's differences and led to passage of consensus anti-redlining legislation the following year.

That said, stories' power also can have an adverse effect. When false or out-of-context stories provide the basis for public policies

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**"In the Massachusetts legislature data often were only rhetorical weapons used to bolster competing values."**

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that impose requirements on unwilling citizens, those suffering the imposition may, with reason, feel indignant. An untrue or misused story in everyday life holds little impact beyond a few individuals, but in public policy it may result in adverse consequences for millions. Ronald Reagan's reference to a mythical Chicago welfare queen—happily collecting her monthly check while sitting pretty at home—tarnished the way Americans viewed recipients of government assistance in ways that set the tone for a public and congressional backlash against helping needy populations in the early 1980s.

### Using Stories Wisely

**T**HE QUESTION TO ASK IS, How do we craft a more appropriate role for narrative and anecdote in the policy process? Narrative should be to policy making what suitable case study is to empirical research. Case study alone can never establish scientifically based claims but does play a key role in the research enterprise. One valid, well-documented case study can effectively demolish a theory, demand rethinking of an approach, or set the stage for further empirically based investigations.

In a similar way, contextually appropriate stories used in the policy environment can identify important, neglected policy problems. For example, no policy analysis can illustrate the need for culturally competent health care as compellingly as Anne Fadiman's account of a Hmong child's experience with epilepsy in *The Spirit Catches You and You Fall Down*. Anecdotes help to signal problems with existing programs or policies that have been unrecognized or insufficiently understood. They can even provide evidence that a program or law is working as intended. Stories assist policymakers in thinking about the consequences of rival policy choices. Also, most policy decisions cannot wait for the gold-standard randomized clinical trial, while many others do not even lend themselves to scientific investigation. Valid stories and anecdotes are better than nothing to guide decisionmakers. Stories also help policymakers to think about the potential political impact of their policy decisions.

Stories even benefit lawmakers when the going gets tough. In my years in the Massachusetts legislature, I developed great affection and respect for the long-serving representatives who would regale newer members with tales from other eras. During the difficult fiscal crisis of 1989–1991, hearing their stories of what worked to control the impact of the previous fiscal meltdown (in the mid-1970s)—and understanding that “this, too, shall pass”—was enormously helpful

when the pressures seemed unending.

But using narrative to make policy requires the same standards of validity as those applied to case study. Lack of accountability is the bane of storytelling in the policy environment. A story needs to be true and presented in a context that does not distort its relevance to the policy choice at hand. Red herrings are unacceptable. For instance, I remember that to prove their harmlessness, an angry landlord once ate lead paint chips before a Massachusetts legislative health committee hearing. Policymakers must develop the necessary discipline to be intelligent consumers of anecdotes.

### How Do You Know That?

GIVEN THE PACE AND FRENZY of their world, policy veterans may find it unrealistic to consistently pay scrupulous attention to sources and truth. The most valuable approach may therefore be a defensive one. A research methods instructor taught me that one of the most powerful questions one can ask is, "How do you know that?" After receiving his advice, I began asking this question carefully and respectfully in public hearings and in corridor conversations. I was amazed by the results. The most brazen and self-confident witness could melt when pressed for the validity and appropriateness of a source. A few choice responses: "I

read it somewhere, but I can't remember where." "My brother told me." "Everyone knows that!" (my personal favorite).

Asking "How do you know that?" may not come naturally to policymakers. Many public officials develop (or possess *a priori*) a tendency to accept the individual stories of their constituents. Perhaps they do this in response

to routine accusations of losing contact with the "folks back home." Real folks don't discuss the latest issue of the *New England Journal of Medicine*; they tell stories about their lives. And when they meet a politician, they continue their storytelling to communicate what's important to them.

Some constituents' stories are off the wall, while others are pertinent and valuable. The challenge is not to get narrative and storytelling out of policy making. They are oxygen to the process and cannot be eliminated. We might as well try to ban conversation. The challenge is to raise everyone's skill level—officials and citizens alike—to be more intelligent consumers of stories.

**"Real folks don't discuss the latest issue of the *New England Journal of Medicine*; they tell stories about their lives."**

# Out Of The Closet And Into The Legislature: Breast Cancer Stories

*How narratives about one disease have shaped policy.*

BY BARBARA F. SHARF

**I**N LIVING COLOR twenty-three figures appear in photographs before and after breast cancer surgery in *Show Me*, a recent book in both print and online forms. The women display in stark detail lumpectomies, mastectomies, and reconstructions, along with their individual reactions to these treatments. Clearly, women have come a long way since the stigmatized silence of twenty years ago, when poet and cancer sufferer Audre Lorde urged them to “become visible to each other” in order to “translate the silence surrounding breast cancer into language and action.” Her statement was considered revolutionary because, with few exceptions, women then did not disclose their personal stories of breast cancer to one another privately, let alone publicly. Yet by the 1990s the walls of silence had crumbled, and personal narratives of living with breast cancer became nearly ubiquitous—through conversations, popular books, newspapers and magazines, television, and Internet chat rooms.

Personal stories of breast cancer have raised social awareness, destigmatized the disease, and been key in creating significant changes in health policies. Legislative allocations, medical standards of care, and scientific research priorities have all been altered by women’s storytelling about breast cancer. Shifts in policy influenced by powerful illness narratives have been mainly positive, but sometimes compelling stories can lead to undesirable outcomes as well.

## One-Breasted Women On The Steps Of Congress

**A**UDRE LORDE WONDERS in *The Cancer Journals*, “What would happen if an army of one-breasted women descended upon Congress?” Lorde presaged the notion that women with breast cancer can join together to influence the policy-making proc-

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ess. She alerted us to the idea that shared biographies are integral to advocacy, and advocacy, of course, can alter policy.

Indeed, in the words of Rose Kushner, "It helps to be stubborn

**"Kushner's 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."**

and have a loud voice." Even before Lorde's vision of women with breast cancer descending upon Washington, another woman's foresight had brought change to medical practice. In 1975 Kushner, a journalist and cancer survivor, put her investigative skills to use in understanding the life-threatening disease that afflicted her. *Breast Cancer: A Personal History and an Investigative Report* 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. Kushner called for women to participate in making their health care decisions in an informed manner. Her book was excerpted in newspapers and women's magazines, and remained in circulation until the early 1990s. With instincts far ahead of her time, Kushner brought to the surface a number of policy-related issues still debated today, including environmental toxins, the limits of mammography in detecting cancer, the dangers of irradiation, and the need (or not) to undergo mutilating surgery.

Kushner's most direct impact on policy involved the question 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—all in one fell swoop. Kushner found a well-qualified physician who agreed to a two-step process for her that separated biopsy results from surgical treatment. This gave her a chance to rebound from the bad news about her biopsy result and consider her options. Her subsequent research supported her argument that a two-step process would benefit women psychologically while not harming their prognosis. Based on this information and her own tenacity, Kushner single-handedly lobbied the cancer establishment to change the customary treatment, which had been 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. Fortunately, today's Rose Kushners needn't act alone.

## The Multiplying Effect Of Numbers

**W**E START TODAY'S PROGRAM with a moment of silence for Marian Cortez [not her real name] who died April 3 of this year, two months from her fiftieth 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." Thus opened a plenary session at a National Breast Cancer Coalition (NBCC) advocacy training conference in 1999.

The NBCC, formed in 1991, now comprises more than 500 groups and 60,000 individuals. Its mission is to promote research; improve access to screening and treatment, especially for the underserved and uninsured; and increase survivors' influence in creating and implementing legislation, regulation, and clinical trials. For the past nine years the group has sponsored an annual advocacy training conference, attended by hundreds. Participants are provided information on new medications, research initiatives, and legislative process, to enable them to speak with credibility about the legislative priorities identified by NBCC. (In 1999 priorities included increased funding for peer-reviewed research, follow-up treatment for women found to have cancer through federal screening programs, and insurance coverage of treatment for people participating in clinical trials.) The beginning of each half-day session is marked by a tribute to a deceased person, remembered for her efforts in breast cancer advocacy. These remembrances take the form of a mini-narrative of the person's life and contributions, while her image is shown on wide-screen monitors. The memorials are poignant, reminding each participant of her own mortality, underscoring the importance of the day's activities, and vividly illustrating the direct link between health legislation and individual lives. The conference culminates in Lobby Day, when participants noisily demonstrate outside Congress, then organize by state to talk with their elected representatives about the NBCC's prioritized issues.

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## When Cancer Hits Home

**O**N THE OTHER SIDE OF THE EQUATION legislators can be especially receptive to cancer narratives when they or someone they love has had cancer, or when constituents convey cancer stories. Two examples spanning both sides of the political aisle in Congress underscore the power of health narratives to affect political agenda setting.

Sen. Tom Harkin (D-IA) has championed funding of various medical research projects throughout his lengthy career. Breast cancer has been his central focus over the past decade. Harkin—a senior member of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education—characterizes cancer

**“Personal accounts of illness can create a huge stir but may not always result in positive consequences.”**

as “a leading killer.” His interest in the disease is also influenced by the fact that according to his office, “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.” His legislative achievements include dramati-

cally increasing funding of breast cancer research and creating treatment, prevention, and screening programs for lower-income women.

Members of Congress don’t have to be personally involved with the disease to be moved by cancer stories. Former Sen. Alfonse D’Amato (R-NY) had also been a member of the Senate Appropriations Committee. To my knowledge, D’Amato did not face a personal or close familial encounter with cancer, as did Harkin, but was swayed by the stories of a large number of Long Island constituent-survivors who suspect an environmental link to the cancer cluster in their community. The senator’s motivation may have begun as a political move to procure women’s votes, but D’Amato became a valuable ally to several local advocacy groups and the NBCC.

### Making Bad Policy

**P**ERSONAL ACCOUNTS OF ILLNESS can create a huge stir but may not always result in positive consequences. One case in point is the story of Nelene Fox, a thirty-eight-year-old California mother of three. In 1993, 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 an autologous bone marrow transplant (ABMT), a risky process involving extremely high doses of 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 extended a patient’s life. Fox’s local community raised the money for treatment, but she died soon after it.

Sympathizers speculated that she was unable to begin treatment in time to get the beneficial effect. Her brother, a lawyer, sued the

HMO and convinced the jury to award \$89,000 in damages to her family. Similar lawsuits with similar results soon followed. Questions that many physicians had about the efficacy of ABMT were compounded by prolonged difficulty in recruiting enough subjects for controlled clinical trials, since patients with advanced disease were repeatedly told at cancer centers that this treatment had shown promise. Media publicity about the Fox case succeeded in forcing widespread insurance reimbursement, further discouraging patients from enrolling in clinical trials. Thus, conclusions about the efficacy of the treatment were tragically delayed until 1999, when the National Cancer Institute announced that, based on available studies, ABMT does not benefit persons with breast cancer.

The Nelene Fox story and others like it persisted for nearly a decade. For years women fought to have ABMT, even though there was little or no data to support this choice. As John McDonough notes in the previous essay, going this route meant that the evidence that can only come from clinical trials was tragically delayed. 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.

Personal breast cancer stories have inspired efforts by citizen-advocates and legislators to provide better care and more resources for the disease. But as the ABMT experience makes painfully clear, individual stories should not be taken as scientific proof.

### Moving Beyond The Disease-Of-The-Week

BREAST CANCER STORIES' INFLUENCE ON POLICY also raises larger, more difficult questions about how the national health care budget should be determined, as each disease-specific group organizes to ask for more attention and increased funding. Breast cancer advocates in the 1990s adopted the successful strategies of AIDS activists in the previous decade. Breast cancer advocacy, in turn, is informing efforts to focus on ovarian and prostate cancers, and the list of disease advocacy groups continues to grow. NBCC leaders argue that we should increase the total budgetary pot for health care so that all problems are adequately addressed, but this solution seems hopelessly unrealistic. Prevention, for example, continues to be shortchanged, despite the fact that national health care spending is already at an all-time high.

Narratives about disease invariably lead to the question of how we decide which disease deserves the most notice. Should disease

## NARRATIVE MATTERS

### THE PERSONAL ESSAY AND HEALTH POLICY

incidence rather than visibility be emphasized as a more important criterion for policy concern? If so, then heart disease, which hasn't generated as many moving stories as have AIDS and breast cancer, should be our nation's central focus. The public and Congress have heard most about AIDS and cancer because of the vocal strength of

**“Should disease incidence rather than visibility be emphasized as a more important criterion for policy concern?”**

those constituents. But heart disease, the biggest killer in this country, affects far greater numbers: More than 500,000 women die from cardiovascular disease each year, compared with 43,000 from breast cancer. Yet the National Institutes of Health budget to research heart disease is half a billion dollars less than that for AIDS, which ranks seventeenth

among diseases causing mortality in the United States. Do heart disease advocates need to create more affecting personal illness stories? It seems inevitable that the squeaky-wheel-gets-the-grease approach to appropriations will pit one worthy group against another, or that attention will pivot from one priority to the next before long-term outcomes can occur.

Personal narratives are powerful, rhetorical strategies, as well as humane expressions of suffering and memorials to loved ones. The riveting communication of such narratives enlightens our understanding of what it means to live with breast cancer (or Alzheimer's or Parkinson's or spinal cord injury). As a society, however, we need to develop more sophisticated criteria for evaluating illness narratives. This is a knotty task because stories of suffering have authenticity and validity for the teller and for fellow sufferers. In using personal narratives to affect health policy, the challenge is to effectively combine the emotional *pathos* and character-related *ethos* of stories with the other form of rhetorical proof, *logos* (the rational). Recipients of illness stories—be they lawmakers, policy wonks, or the public—face difficult questions. What are the criteria for making judgments about stories as a basis for generalizing public policy? How do we distinguish among competing narratives when all are compelling? Is it possible to move to a different level of storytelling, one that transcends competing narratives? The value of grappling with such complex questions is self-evident to those of us who remember an era when women didn't tell breast cancer stories.

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