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Dead by 50: Lay expertise and breast cancer screening

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ABSTRACT

This paper examines the reactions of women with breast cancer to the 2009 U.S. Preventive Services Task Force recommendations for mammography screening. Specifically, it analyzes electronic postings about the Task Force's recommendations from five breast cancer discussion boards between November 17, 2009 and December 17, 2009. Women's opposition to the recommendations is best understood as a clash between scientific and lay expertise concerning the priorities of medicine and notions of evidentiary significance. We highlight the *connective logic* – or *connectivity* – that underlies lay expertise in the electronic era. Connectivity is a unique way of knowing that emerges from an experiential connection to illness and a virtual connection to others with the same illness. Connectivity is based on forms of evidence that enhance the moral authority of lay claims for medical succor. Connectivity is a potent element in contemporary lay challenges to scientific expertise and will become increasingly influential as online illness affiliation becomes ever more commonplace.

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Introduction

In November 2009, the U.S. Preventive Services Task Force published new guidelines for breast cancer screening (U.S. Preventive Services Task Force, 2009). Departing from established recommendations (U.S. Preventive Services Task Force, 2002), the new guidelines recommend against *routine* screening mammography (i.e., in the absence of breast cancer symptoms or risk factors) for women in their forties and stipulate that women between the ages of 50 and 74 be screened every two years rather than every one to two years.

This paper examines the opposition the guidelines engendered among laywomen who had (or have) breast cancer as expressed on popular breast cancer discussion boards. The Task Force guidelines and women's reaction to them serves as a paradigmatic illustration of a contemporary clash between scientific and lay ways of knowing. For example, this case captures a conflict that Collins and Pinch (2005) call the two faces of medicine. Whereas medical science takes a long-term perspective and focuses on health outcomes at the population level, individuals prioritize medicine's commitment to provide urgent "succor" (i.e., help in the face of a difficult situation) (Collins & Pinch, 2005). Likewise, having a particular illness provides the lay person with experiential

evidence about her illness, which can be at odds with scientific expertise. Both of these aspects of lay knowledge are altered and enhanced in the context of the online illness affiliation. Our analysis draws and builds on a body of scholarship concerning disputes between medical and lay expertise (Brown, 1992; Collins & Pinch, 2005; Kroll-Smith & Floyd, 1997; Zavestoski et al., 2004) by highlighting the explicitly *connective* logic that underlies lay expertise in the electronic era. That is, we use this particular conflict between scientific and lay expertise to demonstrate the conceptual dimensions of *connectivity*.

Connectivity is a way of knowing about illness that is generated in online illness forums. It emerges from the interaction between an experiential connection to illness and a virtual connection to others who share the same illness. Through online illness affiliation, new evidence and notions of evidentiary significance are generated that enhance the moral authority of lay claims for medical succor. We maintain that connectivity is a potent element in contemporary lay challenges to scientific expertise and will become increasingly influential as online illness affiliation becomes ever more commonplace.

It is important to note that we do not take a position on whether the Task Force recommendations are based on good or bad medical science, or, whether women's opposition to them is scientifically sound. Rather, we are interested in understanding laywomen's assessments of the recommendations, the connective logic that underlies their assessments, and the outcomes and consequences of their assessments as they develop in online forums.

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Background and conceptual framework

The U.S. Preventive Services Task Force provides evidence-based recommendations concerning preventive health care services for the general U.S. population (Agency for Healthcare Research and Quality, 2010). Courtesy of sensationalist print and electronic media, the findings of this previously obscure panel, housed in the U.S. Department of Health and Human Services, became a public and political issue overnight. A good deal of the public controversy is attributable to timing and political haymaking. The recommendations were released when the Obama administration's health care bill was under debate in the U.S. Congress. As such, they intersected with real and politically-manufactured public anxiety about the prospects of rationing under a system of government-sponsored health care. The Task Force is technically an independent, non-governmental panel of experts. Nevertheless, the Obama administration's response in the wake of the recommendations (e.g., the announcement from the Secretary of Health and Human Services distancing the agency from the recommendations), as well as a rushed Congressional approval of an amendment forbidding insurance providers from using the guidelines to deny routine mammography, illustrate a clear recognition of the political stakes. But what made the political stakes so high in this particular instance is a public faith in the efficacy of mammography.

Sacred technology: the rise of breast cancer screening

In her account of the dramatic rise and centrality of Magnetic Resonance Imaging (MRI) in medical practice and as a cultural icon, Kelly Joyce (2008) evokes Émile Durkheim's *Elementary Forms of Religious Life* by referring to MRI as "a sacred technology." According to Joyce (2008: 149) the machines and the images they produce "serve as totems, or sacred objects." For physicians and laypeople alike, these totems represent a profound hope in the ability of technology to cure disease and extend life. Joyce's insight extends to the case at hand: over the course of the last several decades screening mammography has become "a sacred technology" in the war against breast cancer.

Maren Klawiter (2008) describes the emergence, in the 1970s and 1980s, of a new "breast cancer regime," with mammography as its primary focus. Before the 1970s, early detection meant that women with breast cancer symptoms should see their doctor immediately so that timely treatment could be initiated. Under the new regime, discourses and practices of early detection reframed healthy, asymptomatic women as at-risk and moved them "en masse into the medical machinery of breast cancer" (Klawiter, 2008: 86). By the end of the 1980s the annual mammogram for healthy women, touted as the most important weapon in the war against breast cancer, was solidly institutionalized in U.S. health care practice and policy (Lerner, 2001; Olson, 2002).

Laywomen embraced this norm. As increased media coverage and public service campaigns served to push breast cancer into the national spotlight and escalate the fear of contracting the disease, women "hoped that screening would help them be" "survivors" rather than "victims" (Klawiter, 2008; Lantz & Booth, 1998). Whereas less than 300,000 women in the U.S. had received a mammogram in the mid-1970s (Olson, 2002), by the late 1980s 39 percent of women over the age of 40 had received a routine mammogram; and, that percentage grew to 50 percent by 1990 and to over 70 percent by 2000 (Breen et al., 2007). Having a mammogram is now an annual ritual for many American women. Participating in the ritual affirms the narrative promoted by the breast cancer establishment: "a story of individual control and survivor pride, a narrative of hope, and a declaration of faith in the steady progress of science and medicine" (Klawiter, 2008: 145). In short,

mammography symbolizes empowerment and optimism in the face of uncertainty and fear about breast cancer.

Despite its status as a "sacred technology," it is fair to say that there has never been scientific consensus concerning the efficacy of screening mammography. From the onset there have been concerns about its value in general and its suitability for women under the age of 50 in particular (Bailar, 1976; Lerner, 2001; National Institutes of Health, 1997). Many of the long-standing concerns about mammography, including a link between the radiation exposure of screening and breast cancer, the risks of false positives and follow-up interventions (e.g., biopsies), the possibility of over diagnosis (i.e., treating cancers that would never become clinically significant), and the troubling lack of an association between increased screening and declining mortality rates, inform the recent Task Force recommendations. In other words, the rise and continued reign of mass mammography screening is linked to effective actions and claims on the part of key stakeholders (e.g., the American Cancer Society, American College of Radiology, General Electric, Susan G. Komen for the Cure, etc.) rather than the demonstrated efficacy of the practice per se (King, 2006; Lerner, 2001).

By calling into question the established discourses and practices of the breast cancer regime, the new guidelines challenge these key stakeholders and represent a threat to a number of organizational, professional, and economic interests. That these stakeholders would strongly oppose the guidelines is unsurprising. With a unique position in the unfolding conflict, women who have been diagnosed with and treated for breast cancer under the established regime also strongly oppose the new guidelines.

Scientific vs. lay expertise in the electronic era

There is a body of research that highlights the increasing number of cases where expertise based on medical science and lay experience are at variance. Examples include disputes about the role the environment plays in many illnesses (Couch & Kroll-Smith, 1997; Zavestoski et al., 2004), contestation about whether or not conditions like fibromyalgia and chronic fatigue syndrome are "real" at all (Barker, 2005; Kroll-Smith & Floyd, 1997), disagreements about the link between autism and childhood vaccinations (Casiday, 2007), and controversies about what types of research and treatment protocols are most efficacious for certain illnesses (Epstein, 1996). In each of these cases the dispute pits the claims of scientific experts against the claims of individuals suffering with illness or those who care for them.

When medical science provides accounts of laypeople's health problems that are profoundly incommensurate with their experiences, laypeople set out to create their own coherent accounts and solutions. For example, neighbors amass data to confirm a disputed link between negative health outcomes and exposure to toxic hazards; parents of children with autism pool their experiences to demonstrate the disorder's causal relationship to vaccinations that medical science denies; and individuals with fibromyalgia collude to affirm the reality of their condition despite medical skepticism (Barker, 2005; Brown, 1992; Casiday, 2007). In some cases lay opposition crystallizes into embodied health movements that use "the body as a counter-authority to challenge science in its epistemological processes and its institutional power" (Zavestoski et al., 2004: 254). Since the early 1990s, for instance, activists in the environmental breast cancer movement have drawn on their collective experiences to critique the breast cancer regime for its narrow focus on "genetics, lifestyles, and personal responsibility" and its concomitant failure to study and address the link between environmental toxins and breast cancer (McCormick, Brown, & Zavestoski, 2003: 545). Whether at the level of the individual, a group, or a social movement, lay expertise emerges from personal experience and as such represents an

eschewal of the notion that value-neutrality is a privileged way of knowing. Above all, laypeople want their first hand knowledge to be brought to bear in the search for rational remedies to their problems (Brown, 1992; Kroll-Smith & Floyd, 1997).

Although it has not been a central empirical focus of the above body of research, it would be difficult to overstate the influence of the Internet in facilitating lay expertise (Conrad & Stults, 2010). In the process of navigating the vast sea of online information, patients frequently become experts about their own health problems, thereby weakening the division between professional and lay expertise (Clarke, Mamo, Fishman, Shim, & Fosket, 2003; Kroll-Smith & Floyd, 1997; Nettleton, Burrows, & O'Malley, 2005). It would also be difficult to overstate the influence of the Internet in making lay expertise a *collective* phenomenon. Whereas the experience of illness has often been characterized by isolation, the Internet now provides laypeople with unprecedented opportunities to affiliate with individuals who share their illness (Conrad & Stults, 2010; Fox & Fallows, 2003). There are electronic support groups for nearly every illness. In countless online forums, laypeople give and receive emotional support, as well as share information about the health conditions from which they suffer (Barker, 2008; Hardey, 1999; Henwood, Wyatt, Hart, & Smith, 2003). These groups distribute available scientific medical knowledge, but they also gather and synthesize their collective illness experiences to produce interpretations of and remedies for their conditions. It follows that sometimes lay derived claims will contradict those offered by medical experts and that this will happen with greater regularity as online illness affiliation becomes increasingly widespread.

Connectivity conceptualized

We arrive at the case at hand. The Task Force recommendations and the response to them by laywomen on popular breast cancer discussion boards expose incommensurate ways of ordering the world. Through a close examination of women's reactions to the recommendations, we demonstrate that this discrepancy is best understood as a clash between scientific and lay expertise concerning the priorities of medicine and notions of evidentiary significance. Of particular interest to us is the connective logic – or connectivity – that is generated in illness-based electronic forums as a counter to scientific expertise.

Connectivity is a unique way of knowing about illness. The origins of connectivity are found in the interaction between an experiential connection to illness and a virtual connection to others who share that illness. The veracity of this type of expertise significantly emboldens lay interpretations about the appropriate role or priority of medical science. Often in a state of intense emotional distress, individuals look to medicine to address their pressing and concrete suffering. The tangibility, urgency, and emotionality of lay suffering are intensified via virtual connections with others who share a similar urgency and emotionality, thereby enhancing the moral authority of laypeople's claim on medicine as succor. Connectivity is also founded on new types of data and standards of evidence. By itself, an experiential connection to illness enables laypeople to become what Collins and Evans (2002) call "experience-based experts," but, where illness is concerned, expertise of this type ordinarily builds upon experience that is distinctly personal in nature. Because the Internet puts hundreds (sometimes thousands) of people who have an illness in connection with one another, the foundation of their expertise is altered and enhanced. Online illness forums are ready-made laboratories for making observations and drawing conclusions about experiential patterns or trends based on a large collection of personal narratives. These observations and conclusions are endowed with significance

and legitimacy precisely because they emerge from a shared experiential connection to illness. In these regards, connectivity gives laypeople newfound authority to challenge science and its privileged ways of knowing.

Data & methods

Discussion boards exist as a collection of electronic postings that individuals write, send, and read in real or delayed time. The discussion boards used in this study were selected using a Google search for "breast cancer support" conducted on 1/9/2010. We selected five open discussion boards (i.e., those that do not require membership to access) from among the top websites listed in this Google search.

The data include all posts related to the Task Force recommendations posted between November 17, 2009 and December 17, 2009 (the month immediately following the announcement of the recommendations) for four of the sites. For the largest site in our study, which had more than 70 threads and 3000 posts related to the Task Force recommendations during the month studied, we took a random (20 percent) sample of threads ($n = 15$ threads; 147 postings). Even using this technique, there were more postings from more participants on this site than any of the others. In total there were 483 posts from 202 women, two of whom posted to two of the five discussion boards during the period studied. The mean number of posts per person was 2.62, the mode and median were 1, and the most active poster (excluding forum administrators) contributed 18 posts.

There are many complex and unresolved issues when it comes to observing and reporting online communications (Walther, 2002). In order to reap the benefits of naturalistic data and minimize ethical concerns, we limit this study to open discussion boards (Hewson, Yule, Laurent, & Vogel, 2003). Because none of these discussion boards require registration or membership, the conversations on them are decidedly on the public end of the "public" vs. "perceived private" continuum of cyberspace (King, 1997). This renders the unauthorized analysis of their communication relatively unproblematic (Seale, Charteris-Black, MacFarlane, & McPherson, 2010). Nevertheless, and in line with a long-standing ethical tradition in social science research, we anonymize the participants and the discussion boards throughout the paper. Although there are benefits associated with using this type of unobtrusive research method, we also recognize the limitations of merely observing online communications. We must, for example, take participants at their word, so to speak. In addition, we are unable to confirm the implied meaning of an author's posting or say with certainty how it is interpreted by others. These are particularly thorny problems given that electronic postings are frequently haphazardly written (Mann and Stewart 2003).

The method of analysis used in this study can be described as narrative or discourse analysis. There are no clear boundaries between these related types of qualitative analysis. Narrative analysis "identifies the basic story which is being told, focusing on the way an account or narrative is constructed, the institution of the teller and the nature of the audience as well as the meaning of the story or 'plot'" (Spencer, Ritchie, & O'Connor, 2003: 200). Discourse analysis, commonly associated with the Foucauldian tradition, examines texts or communication with an eye toward assessing how social meaning and experience are shaped or mediated by that knowledge (Snape & Spencer, 2003). Whatever name one might give to the following process, its goal is to ascertain, present, and analyze the key thematic or discursive elements in these postings.

We coded the postings as follows. Together we read through all of the postings for one site and identified a number of prominent themes. Using these themes as codes, we each independently coded the posts from this site. Next, we met, compared coding, and

resolved any discrepancies. In the process, we identified several additional thematic codes. Using the now expanded coding schemata, we each independently coded the postings from two additional sites, met and compared coding, and resolved any discrepancies. Lastly, we each independently coded one of the final two sites. We coded and analyzed the postings using NVivo, a computer-assisted qualitative data analysis software program. The most commonly identified codes are captured under the first four subheadings in the following analysis.

Analysis

Experts without expertise

The women on the discussion boards collectively discredit the Task Force on grounds that its members have no connection to breast cancer. Indeed the general tenor of the posts on all five discussion boards can be described as total outrage at how incongruent the recommendations are with what everyone who knows anything about breast cancer knows to be true. For example, there was widespread disbelief and anger at the reversal of what is understood as the central rallying cry in the war against breast cancer – early detection saves lives. The following post is typical in this regard:

- There is not NEARLY enough explanation being given for this abrupt about-face. Ever since I was a little kid, I've known about the importance of women [...] having mammograms. This is a HUGE, 180 degree shift coming after decades of them telling us the opposite and so far I have yet to hear any good explanation for it.

In addition to revealing the institutionalization of a set of beliefs and practices established under the existing breast cancer regime, the above post, like many others, conveys a sense of utter betrayal. Seemingly from nowhere, the recommendations contradict what millions of American women have been told to do (and have done) for decades. In the wake of twenty years of progress in the campaign for breast cancer awareness, the women describe the recommendations as “a slap in the face,” “a set back” and a return to “the Dark Ages.” One woman described the recommendations as having effectively “turned the pink world upside down.”

The fact that the guidelines were so uninformed and “out of sync with reality” led the women to question the panel’s expertise. The question was frequently raised: “Just who are these so called experts?” In response, the names and titles of the panel members were circulated on three of the five sites. What struck the women about the group they dubbed the “Hall of Shame” is that none of them had any connection to breast cancer detection or treatment. There were, it was noted, no oncologists, no radiologists, or no breast surgeons on the Task Force. When one woman reported: “Just heard on CNN—not a single oncologist was on the task force!” another quickly responded “It figures!!” In addition to questioning the Task Force’s professional expertise, the women also suspect that none of its members had any personal connection to breast cancer. A number of women concluded that the results surely would have been different if the Task Force members had mothers or sisters or wives with breast cancer, or if the women on the panel had faced a breast cancer diagnosis themselves.

The women also challenged the credibility of Task Force by calling attention to its potential economic and political agendas.

Dozens of posts asserted that the recommendations were designed to increase insurance companies’ profits. One post briefly summed up the general sentiment: “This sucks! It’s about money! And it’s not about women’s health.” A flurry of posts accused Dr. Susan Love, a well-known figure in the fight against breast cancer who came out publicly in support of the guidelines in a number of TV interviews, of having become a pawn of the insurance industry. The women were understandably concerned that insurance companies would use the recommendations to deny mammography to women under 40. In fact, many suspected that the insurance industry was responsible for the recommendations. As seen in the following post, the rhetorical pitch was high.

- Hate to say it but it sounds like insurance companies are behind this more than anything else. Here is our New Health Reform.... kill off as many as possible. Right now, insurance companies do not charge us for yearly mammograms but this could and will change if these guidelines are allowed to stand.

The federal government in general, and President Obama’s health care reform in particular, were also blamed for the Task Force recommendations. That a government panel with no breast cancer experts could make decisions about women’s breast health was broadly attacked: “Just one more reason i don’t want the f...ing government making choices about my healthcare...let’s not take it personally...it’s only dollars and cents ladies. Oh God give me a podium....i am PISSED!!!” Similarly, some of the women claimed that the recommendations smacked of President Obama’s plan to create a “socialist” health care system. The partisanism was overt. One woman suggested that not only was President Obama (who she referred to as “BO”) out to kill seniors through the well publicized death panels, but the new recommendations made clear that he was also out to kill *women*. No doubt, this woman continued, Michelle Obama had her annual mammogram and it was paid for by taxpayers.

The women were quick to point out that the experts who really knew and cared about breast cancer strongly opposed the guidelines. They eagerly shared electronic links to public statements made by central players in the breast cancer establishment on television and radio, and in the print media. The organizations affiliated with all five discussion boards also issued statements in opposition to the new recommendations. “Did you all read the statement on the HOME PAGE [...] It sounds like they aren’t happy either.” Through their exchanges the women confirmed who really “knows what they are talking about” (Collins & Evans, 2007) and why; namely, those with a proximate professional or personal connection to breast cancer. The reaction to the recommendations among trusted individuals and groups corroborated the women’s fears. Nevertheless, they were reassured to be amidst an orchestrated effort on the part of bona fide experts – those with breast cancer expertise – to help the pink world right itself.

Witness the evidence

Whereas the Task Force’s lack of expertise about breast cancer was blamed for yielding misguided recommendations, the discussion boards quickly elicited one real story after another, woven together into an authoritative and unified testimonial, as evidence of the ability of mammography to save lives. In series of long threads, giving a powerful sense of just how many lives would be affected, the women explained that, if they had followed these guidelines, they would have been dead by 50.

- A mammogram also saved my life. If I had waited till I was 50 I would probably be dead, since at 48, my cancer was already invasive. This is very disturbing as you said!

¹ The posts on the messages boards frequently include ellipses. We use [...] to denote places where we have omitted a section of text from the original posting. Ellipses not in brackets appeared as such in the original post.

➤ I would be dead...not a big issue for everyone but clearly a reason for me to get emotional about it.

As these posts reveal, not taking these recommendations personally proved to be an understandably difficult task. Reconstructing their own experiences under the rubric of the new guidelines, the women imagined tragic scenarios in which their cancer would have grown undetected for years and eventually taken their lives. The inability to know how any of these particular cases would have played out had another course of action been taken is an unanswerable question. At issue, however, is the very real and deeply felt sense on the part of these women that their fate would have been tragically altered by the new recommendations.

Curiously, most of the stories posted as evidence of the guidelines' foolhardiness unintentionally corroborate the thrust of those guidelines, namely, that the benefits of *targeted* diagnostic mammography exceed those of mass screening. Paraphrasing the most common diagnostic story told on the discussion boards: I discovered a lump in my breast and then my doctor ordered a mammogram that confirmed the presence of cancer. The following post is paradigmatic in this regard:

➤ I was really casual about the lump I found, because I've always had fibrocystic lumps in my breasts. I figured it was just another lump. My family doc INSISTED I get a mammogram. I was 37 and between Stage II and Stage III. I'll say it again...if I had waited until I was 50 to get my first mammo I would not have been alive. Sorry, it's difficult for me to be objective about this issue!

Another women "shuddered to think" what might have happened had she waited until 50 to have her first mammogram, given that her grandmother and mother died of breast cancer, and both she and her sister were diagnosed in their 40s.

A small handful of women described being diagnosed by way of routine screening mammography, but, even some who fell into this camp bolstered the claims of the Task Force. One 49-year old complained: "What a crock. It was the yearly mammo that picked up the DCIS." The dramatic rise in the incidence of DCIS (ductal carcinoma in situ) is among the rationales given by the Task Force for changing the screening guidelines. DCIS is readily picked up in mammograms done on younger women but there is insufficient evidence that the outcome of these cancers benefit from early treatment (or from treatment at all, since not all cases become invasive).

The women's personal stories, accumulating in long threads of unfortunate scenarios averted only due to early detection via mammography, serve as stark and compelling evidence that the guidelines are reckless. Despite the fact that most of the women described a diagnostic sequence that would not in theory have been influenced by the new guidelines (i.e., they clinically presented symptoms, had known risks factors, or were diagnosed after age 50), the recommendations strongly contradict the narrative synthesis that emerges from within these online forums that point to the unquestionable ability of mammography to save many lives. Connectivity produces an interpretation of the evidence that is distinct from the sum of its parts.

The experiential significance of mammography

A theme present in the postings on all five sites was that the recommendations demonstrated a significant lack of concern on the part of the Task Force for the value of human life. There was wide agreement, confirmed by the media, that if the recommendations were enacted fewer cancers would be detected and more women would die. One woman noted, "What I heard on the news

last night is that these recommendations would result in more deaths from breast cancer.... My question is 'What is the value of a human life?' I would hope that the value is priceless."

The matter of assessing the value of a single life is a particularly personal issue for the women posting on the message boards. Many feel that they nearly lost (or may still lose) their lives to breast cancer; as such, they have first hand knowledge about just how precious a single life is. In their minds, the Task Force clearly lacked this knowledge. As seen in these posts, emotions ran high as the women could not help but conclude that the Task Force did not consider their lives or the lives of other women worth saving:

- What about people like me? Are we expendable?????
- No mammos for women under 50 is horrible – what are we, worth nothing to anyone?

On the dramatic side, some postings accused the Task Force of being "criminal," "murderous," and "having blood on their hands." Summing up the matter, another woman suggested that the Task Force be renamed "Every Woman Doesn't Count." For these women, breast cancer is concrete and personal, not abstract and statistical. To their dismay, the Task Force had not equated the increased number of deaths that might be associated with reduced screening with real people. Many of the women were deeply disturbed by the "1 in 1904" finding presented in the Task Force recommendations as evidence of mammography's inefficacy. According to this finding, 1904 women aged 40–49 must undergo routine screening to find 1 woman with breast cancer that will benefit from treatment. The women were enraged at the heartless and insensitive implication that it is not worth all that screening just to save one life. This launched a thread of posts from women declaring themselves to be *the* "1." Although they were upset that the Task Force reduced lives to statistical abstractions, many of the women also felt a profound identification with the "1" person in the statistical report. Most of all they wanted their experience to bear witness that cold facts alone lose sight of real people.

A number of women interpreted the various claims in the Task Force report concerning the alleged harms associated with routine testing of women age 40–49 (e.g., psychological trauma, unnecessary testing and biopsies, and inconvenience due to false positives) as further evidence of the panel's disregard for human life. "False-positives? So what? Better to be safe than sorry, in my opinion. I'd rather have an unnecessary biopsy than die of undetected cancer." The posters felt that the Task Force had significantly over-emphasized the risks of false positives, but had woefully underestimated the risks of missing true positives. How absurd, one woman reflected, that the panel worried more about causing anxiety in women without breast cancer than it worried about not finding and treating women who do have breast cancer. This was all the more troubling, several women pointed out, since no one dies from anxiety. Likewise, the women who described their own experiences of having mammograms that resulted in false negatives or false positives did not consider this sufficient reason to cease routine mammography for women under 50 altogether.

- I agree that they need to find better ways of screening younger women with denser breasts, but that doesn't mean that some women should die, or have more advanced cancer while we are waiting for those things to happen. Why are they gambling with our lives?

For the women on these discussion boards, there is no question that less than perfect technology saves lives, and that a little "inconvenience" or over-testing is a small price to pay. Their shared stories

emphasize the potential risks of not screening and treating cancers over and above the potential risks of screening or treating non-evasive cancers. The evidence for the significance of mammography is found in the *personal* significance of mammography in *all* of their lives. Unlike the abstract and statistical conclusions of a panel of heartless scientific experts, the women judge their collective flesh and blood experiences to expose the real costs of the recommendations.

Patient empowerment in an electronic era

As pre-existing communities created on the basis of the shared experience of breast cancer, the discussion boards provided a ready-made forum for the women to express their collective outrage at the new guidelines and the organizational means to act upon it. At first, some of the women described how the guidelines threaten the very foundation of activism that many survivors recognize as a way to feel proactive in the face of a frightening and seemingly uncontrollable disease (King, 2006). The following post powerfully conveys this reaction:

➤ [P]art of the reason that it's so upsetting to me is that so many of us participate in the Komen walk/run or other efforts that stress AWARENESS and EDUCATION as well as fundraising. The only tangible thing we can do to prevent our sisters, friends and daughters from going through this terrible experience is to serve as a reminder to the women in our lives to "get your mammo-grams", "do your self-exams", "be proactive", blah blah blah. Now they're telling us that all of that is useless. ... It just brings back the same old feelings of helplessness I had when I was diagnosed...

This expression of wavering and disempowerment, posted the very morning the new guidelines were made public, was short lived. The guidelines represented a new and urgent call to action. The women quickly and forcefully made themselves heard. They coordinated letter and email campaigns directed at their local political representatives and members of the Task Force, contacted local print and TV media outlets, signed and distributed petitions, and encouraged each other to write, blog, and shout about their opposition in every way possible. On one site there was a call for a "Million Boob March" on Washington, accompanied by jokes about whether or not "falsies" could count in the attendance tally.

Sharing their personal stories was at the heart of the protest campaign. One of the sites coordinated a protest petition that was signed by over 1500 women. In addition to lending their signature, women were asked to state their age at time of diagnosis and describe how their experience would have been negatively impacted by the new guidelines. One woman, encouraging others to sign the petition, explained, "All we can do is speak up and let everyone know what our own experiences are..." Another declared, "We all need to speak out about this injustice! It is up to the survivors to make sure that as few as possible women walk in our shoes!!" The women were emboldened to use their shared experiences to defeat the guidelines and be a voice for women who would otherwise not have the benefits of early screening technology.

The women's personal experiences left them with an informed position concerning what an ideal screening protocol for all women ought to be. To paraphrase a widespread opinion, "The women on this site could develop far better guidelines." For starters they would recommend lowering (not raising) the age at which screening should begin and screen more (not less) frequently. "My personal opinion on this is instead of starting mammograms at 50 they should [...] start them at 30. There are so many young gals posting on this site who were diagnosed before 30 and definitely

before 40." Others concurred and shared their observation that the women on their discussion boards keep getting younger and younger every day. Several posts explained that the Task Force should visit their discussion boards and gather data about the ages of the women if it needed proof about the importance of screening young women. Some suggested that screening every six months would be more appropriate because certain breast cancers, especially those in younger women, can be particularly aggressive. Similarly, and as captured in the following post, the ideal guidelines should be more, not less, ambitious: "We shouldn't worrying [sic] about getting the guidelines back to what they were, they should be even more strict. I like the idea of a mammo one year and an MRI the following." The women had a number of detailed plans for improving screening guidelines and they all pointed in the opposite direction of those advanced by the Task Force.

If, however, the Task Force guidelines should somehow prevail, the women insisted they would have to be subverted. To that end, they shared tips on how to circumvent the guidelines. Several posts recommended that young women tell their physicians that they have an extensive family history of breast cancer in order to ensure they receive a potentially life-saving mammogram. Using her wit to make the point, one woman suggested that individuals tell their doctors that their mothers, fathers, sisters and grandmothers had or have breast cancer, that their breasts are radiating in pain, and that their husbands had noticed changes in the appearance of their breasts. One woman warned, "We are all going to have to be more aggressive than ever about getting tested, scanned, mammo'd whatever it takes to stay ahead of the beast!"

With their shared knowledge under attack, the women's anger was matched only by their determination to bring their personal and collective expertise to bear. Their experiential and virtual connection to one another authorized and mobilized them to have a say in the scientific guidelines about which they are the objects.

The sacred and the heretical

As seen, the dominant stance vis-à-vis the recommendations expressed on the discussion boards was unambiguously oppositional. Although this stance primarily emerged organically as a representation of the women's collectively distilled experiences, at times it was more overtly enforced. Amidst the oppositional milieu described thus far, a lone voice challenged the forecasted horror stories by noting that the guidelines applied only to routine screening and not diagnostic mammograms.

➤ These guidelines, had they been in place, would not have killed you, me, or any other young woman with an aggressive cancer! If you have a doctor who is going to IGNORE A LUMP or other symptom because you are not yet 50, then you need to get another doctor! These guidelines are not telling doctors to ignore the obvious! ... They are telling them to stop giving cancer-causing, highly ineffective screenings to healthy women with no risk factors and no family history!

This woman was by far the most outspoken supporter of the guidelines on any of the sites and she posted to two of the discussion boards during the period studied. In both forums her posts were either ignored or challenged. In a very emotional response to the above post, one woman disputed each claim, point by point, before stating that she was taking a break from the conversation because the conflict was too upsetting. In another instance, the heretic quoted above asked a newly diagnosed woman if the mammography that had just detected her cancer was a screening or diagnostic mammography. A third woman quickly

chimed in noting that this question, directed at someone who just learned she had breast cancer, was deeply insensitive. The harsh reprimand silenced this line of questioning.

Although only this one woman actively defended the new guidelines, a few others did wonder about the possible merits of some aspects of the recommendations. One woman wondered if it was possible that her cancer was actually caused by radiation exposure. She described having six mammograms on one of her breasts in a short period of time, ordered by her health care provider who saw something suspicious but could not confirm a cancer diagnosis. “Sure enough,” she was finally diagnosed with cancer in the very breast that had been radiated over and over again. A woman who had been diagnosed in her early 40s entertained another troubling premise. Maybe the mammogram and the subsequent treatment saved her life; but maybe it didn’t. Maybe she could have lived for 40 years without the cancer causing her any harm. After all, she asked, why has the widespread use of mammography not led to a reduction in breast cancer mortality?

A few women raised difficult and unsettling questions, but none of them successfully dampened the collective opposition to the guidelines. Likewise, the sole voice of dissent was unable to derail the collective stance. As noted, the organizations overseeing each of the discussion boards made formal statements in opposition to the guidelines. With this as a backdrop and, in combination with the fear and anger expressed by the overwhelming majority of the posters, the social dynamic effectively discouraged friendly debate concerning the merits of screening mammography. As also seen in the robust attack on Dr. Love on all five discussion boards, the heretic plays an important role in reproducing the sacred.

Conclusion

The Task Force recommendations and women’s reaction to them on these discussion boards expose a conflict between the two faces of medicine (Collins & Pinch, 2005). The Task Force recommendations represent medicine as science. This face of medicine answers the big questions. It takes a long-term approach in its search for the best solutions for the largest number of people. The “1 in 1904” finding presented in the Task Force report, seen by the women as utterly callous, is an illustration of the “well-meaning clumsiness” of medicine as science as it attempts to do the greatest good and avoid the greatest harm (Collins & Pinch, 2005: vii). Medicine as science will oppose the interest of the “1” in exchange for improving the long-term outcome of a population. The women on these discussion boards prioritize the face of medicine as succor. That is, they emphasize medicine’s obligation to prevent or alleviate *individual* suffering in the here and now. They are the “1.” The clash is between big- and small-scale questions, long- and short-term solutions, and population and personal outcomes. The conclusion drawn by each side makes “sense within its own context” (Collins & Pinch, 2005: 2).

The disparate conclusions drawn by these two constituencies also capture the divergent evidentiary foundations of scientific and lay ways of knowing. The Task Force recommendations are based on epidemiological modeling techniques designed to assess the efficacy of screening mammography in reducing breast cancer mortality using statistical measures of significance and certainty. Thus, as Phil Brown (1992: 274) explains, epidemiological studies favor false negatives over false positives: “they would prefer to claim falsely that an association between variables does not exist when it does than to claim an association when there is none.” This preference is realized in the Task Force recommendations: “For biennial screening mammography in women aged 40 to 49, there is moderate certainty that the net benefit is small” (U.S. Preventive Services Task Force, 2009: 717). Grounding its claims in scientific

protocol, the Task Force is cautious to not overstate an association and prefers to err on the side of under screening.

The women discredit the Task Force and its conclusions because of its distance from the particulars of breast cancer. None of the panel members has any expertise in breast cancer. In contrast, the women see their immersion in the experience of breast cancer as the basis for their expertise. It is precisely their personal connection to the subject at hand that endows them with authoritative knowledge and valuable insights. In the process of bringing the particular and concrete aspects of their illness experience to challenge scientific expertise, the women disavow the notion that value-neutrality and objectivity are privileged ways of knowing. The women’s conclusions are based on the personal significance of screening. With few exceptions, the women on these discussion boards attribute their survivorship directly or indirectly to mammography. They are living proof that mammography saves lives and there is little a scientific report can do to alter this belief. Thus, when it comes to assessing the association between screening and outcome, the women favor false positives. They would prefer to claim falsely that the benefits of screening exist when they do not, than to claim the benefits of screening do not exist when they do. The women are inclined to overstate the association and prefer to err on the side of over screening.

The women’s opposition to the guidelines is substantially bolstered by their involvement on the discussion boards. The act of coming together yields intensely emotionally-charged evidence of how many lives have been saved by mammography and how many will be lost if the new screening recommendations are followed. Condemning dissent and evading uncertainties, the women’s individual stories are synthesized into an interpretation that is different from and more potent than the sum of its parts. This is not to suggest that the women on these sites are wrongheaded or that they have been swept away by collective hysteria. Rather it is to acknowledge the important social aspects of illness affiliation that are facilitated by the Internet, and to recognize their influence. Specifically, online illness affiliation generates collective experiential evidence, influences the interpretation of that evidence, and intensifies the resulting lay appeal for succor. We suggest the term *connectivity* to capture these elements of lay expertise.

Not only does connectivity give laypeople the moral authority to challenge scientific expertise, it also provides them with the means to do so. Already organized into online groups, the women reacted quickly in an effort to bring their expertise to this crucial policy debate. What we have described, therefore, is more informal than “popular epidemiology” or an “embodied health movement” (Brown, 1992; Zavestoski et al., 2004) in that it bubbles up from routine online interactions. But for this reason it is also more readily available and easily mobilized. The Internet politicizes and democratizes medicine in a way that is categorically new from what was possible before the existence of very large virtual communities. Whether or not the connective logic of lay expertise in this or other cases results in accurate or erroneous conclusions, it will likely be a potent element in future challenges to medical expertise in tandem with the increase in online illness affiliation (Conrad & Stults, 2010).

A number of caveats are in order. First, women who do not have breast cancer undoubtedly have different reactions to the new guidelines than women who do. This study is unable to address this likelihood. Second, we are not suggesting an artificial divide. Although we have described how laywomen’s expertise is connective (i.e., experientially and socially derived), there are social aspects to science as well. Building on the insights of Bruno Latour, for example, others have ably shown aspects of medical “*science in action*” – namely, that social dynamics and processes often underlie what is judged to be biologically factual (Epstein, 1996; Joyce, 2008). Our claim is more a matter of emphasis. Specifically, in this paper we

have emphasized the connective logic of lay expertise in the electronic era. Third, what we have described is informed by its American context. All the discussion boards used in this study are U.S. websites, dominated by American participants. Embedded within the story line one sees a reflection of core American cultural norms, including individualism, the authenticity of personal testimony, and anti-government sensibilities (Ehrenreich, 2009; Kaminer, 1999). As such, the extent to which the dimensions of connectivity described herein transcend national boundaries is a topic for future investigations. This point suggests a more general set of future research questions concerning connectivity. For example, does connectivity exist in some or all other online illness forums (i.e., are there specific conditions under which connectivity emerges or fails to emerge?). Comparative case studies are needed to answer such questions.

For good or ill, it seems unlikely that evidence-based medical recommendations, like those provided by the Task Force, can peacefully resolve policy decisions concerning access to health care services. Undoubtedly aware of the controversial charter of its recommendations, the Task Force report opens with a statement to that effect: "The USPSTF recognizes that clinical and policy decisions involve more considerations than this body of evidence alone" (U.S. Preventive Services Task Force, 2009: 716). In theory, a major benefit of evidence-based medicine is that decisions about medical care and the related use of scarce resources are based on demonstrated efficacy rather than consumer demand, physician anecdote, or market incentives. Insofar as this case is demonstrative of disputes between scientific expertise and lay experience concerning the merits of health care services, the public seems unlikely to believe in the value-neutrality of evidence-based medicine. In this regard lay experts have something in common with social scientists who point to the constrained character of what counts as "evidence" within evidence-based medicine (Timmermans, 2010). Moreover, as seen in this case, laypeople will also discount scientific expertise on grounds that it lacks experiential insight. In pursuit of medicine as succor, the connective logic of lay expertise will push for medical interventions even when they are (statistically speaking) of marginal net benefit. The connective character of lay expertise promises to further complicate meaningful health care reform and runs the risk of pushing us in the unsettling direction of greater medicalization.

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