"It's Just about being Fair": Activism and the Politics of Volunteering in the Breast Cancer Movement

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Activism and the Politics of Volunteering in the Breast Cancer Movement

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Constructions of women’s activism as social service, volunteer, or charity work contribute to the relative invisibility of these forms of activism. The author conducted field research at an affiliate office of the Susan G. Komen Breast Cancer Foundation. She analyzes how these women volunteers resist the label “activist” at the same time that they engage in activities that resemble activism. The author also examines the reasons for their resistance to the term. Her analysis shows that implicit connections between constructions of activism and gender shape the extent to which volunteers think of their work either as political or as activism. In light of Komen’s heteronormative gender ideology, the author concludes by raising questions about the relationships among gender, activism, and civic participation.

Keywords: activism; volunteer; breast cancer; politics

Obviously I care about this stuff but I’m just not that political.

—Cathy, breast cancer movement participant

The way that we think about activism and social change is socially constructed, and these constructions are linked to gender. As the breast cancer movement participant expresses in the introductory quote, caring and “being political” can be conceived of as distinct, and sometimes opposing, ways of being. In this article, I argue that one consequence of this distinction is that much of women’s activist work goes unnoticed. In what follows, I analyze the connections between activists’ gender ideologies, the way that they do their activism, and the way that they and others

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conceive of their activism. Specifically, I analyze data from my ethnographic research at an affiliate office of the Susan G. Komen Breast Cancer Foundation. Komen is an organization dedicated to raising funds for breast cancer research, promoting awareness about breast cancer, and overcoming specific inequalities within the health care system. Komen’s primary interests are increasing the availability of mammograms to all women and promoting better relationships between doctors and their breast cancer patients. The organization’s particular constructions of activism and gender, as well as those of its participants, make it an especially good site for analyzing the connections that I explore in this article.

An examination of constructions of activism as linked to this breast cancer movement organization challenges us to clarify and reconsider existing conceptions of activism. It also demonstrates the ways that some political actors work to avoid having their actions be conceived of as political. This point is especially salient in light of research such as that by Eliasoph (1998) on the efforts made by many Americans to avoid politics. Eliasoph argued that civic etiquette, which discourages imaginative and open-minded conversation in public, has caused politics to evaporate from the public realm. In an effort to appear unpretentious and inclusive, said Eliasoph, Americans have in fact stifled open, public discourse about social problems and other matters about which members of communities share concern. Her arguments are based on more than two years of participation in several organizations, which Eliasoph presented as falling within one of three categories: Volunteers, recreation groups, and activists. Although she demonstrated that members of all of these groups avoid politics, she distinguished between them in terms of the way that each avoids politics and the potential of each to open up public conversation and promote social change.

In particular, Eliasoph’s (1998) differentiation between activist and volunteer groups is striking. Activists are presented as more cynical than volunteers but also more accepting of the belief that conversation about important matters is an important aspect of what they do and of social change. Volunteers, on the other hand, are said to be more focused on action and emphasize doing over talking. Another difference cited by Eliasoph concerns the production of knowledge: Activists are more likely to understand themselves as knowledge producers, volunteers as knowledge consumers. Yet in spite of these differences, Eliasoph pointed out, both activists and volunteers generally share with other members of the American public a desire to avoid public, political talk.

My analysis of the Komen participants supports Eliasoph’s (1998) argument that many Americans work diligently to avoid politics and construct themselves as nonpolitical at the same time that they participate in politics through conversation, activism, and volunteer work. But I also suggest an important extension to these arguments: That gender is central to conceptual distinctions between activist and volunteer and, more generally, that gender plays a key role in how politics is understood and enacted. The efforts of participants at Komen show that some women avoid politics for reasons that have to do with gender. Mainstream conceptions of being political are oftentimes incongruent with mainstream ideals of women as
compassionate yet nonconfrontational. Avoiding politics is about gender because women in particular have historically been relegated to the realm of the private and the nonpolitical. Perhaps, as Eliasoph argued, almost all Americans produce apathy. But women’s apathy seems incongruent with stereotypical images of them as caretakers and nurturers. Thus, mainstream ideals seem to purport that it is all right for women to care. These same ideals, however, also make clear that it is not all right for women to care in a way that might disrupt existing social institutions and social organization.

The mainstream ideals to which I refer above could be described as heteronormative ideals. Heteronormativity refers to an ideology of sex and gender that emphasizes differences between men and women, establishes heterosexuality as the norm at the same time that it favors homosocial connections between women, and generally reifies notions of women as dependent on men for economic support and survival. In what follows, I demonstrate that Komen’s heteronormative stance toward gender and its relationship to mainstream institutions and ideologies shape the work that it does and how it conceives of that work. In addition to the point about heteronormativity, I problematize notions that social movement activists must embody outsider status to be perceived as such. This last point links to the distinctions Eliasoph (1998) made between activists, volunteers, and social groups. Komen blurs the lines between these three, and I demonstrate how in the following discussion.

While much of what the Komen women do resembles activism, they do not understand themselves as activists. Their rejection of the term exemplifies their own statuses and life circumstances at the same time that it imposes certain limits on their effectiveness. Avoiding politics has the consequence of suppressing activists’ and volunteers’ “public-spiritedness instead of letting it circulate” (Eliasoph 1998, 245). Without a conception of what they do as political, activists and volunteers think about their efforts as purely self-interested rather than as contributing to the public good. Furthermore, overlooking the connections between gender and avoiding politics leave an important aspect of activism and politics unexamined.

The question of whether we can or should ascribe the label “activist” to those who choose not to identify themselves that way is reminiscent of feminist debates about whether we can ascribe the label “feminist” to those who do not identify as such. Through their research on working-class women’s activism, Bookman and Morgen (1988), Naples (1992, 1998), and Pardo (1995) demonstrated that much of the activism conducted by self-proclaimed nonfeminists in fact resembles feminist activism. Pardo suggested that those who do not define themselves as feminists but who employ “implicitly feminist practices” (1995, 357) might best be described as “border feminists.” Likewise, I argue that those engaged in activities that are implicitly activist but who do not define themselves as activists, such as the women at Komen, could be conceived of as border activists. As I demonstrate in this article, the belief that actions are either entirely activist or entirely nonactivist is a dichotomy that is not strictly experienced in many women’s everyday lives. The context,
intent, and result of actions must be considered to fully understand and evaluate them.

My initial impressions of the Komen Foundation were influenced by an understanding of activism and feminism as strictly distinct from mainstream institutions and ideologies. I entered the project not with the intent to study activists but rather with a general interest in charity workers and in women of the upper class—an interest that had been inspired by the work of Kaplan Daniels (1985, 1988) and Ostrander (1984, 1993). I took Ostrander’s assertion that sociologists too rarely “study up” as an interesting challenge and decided that Komen would be a good site for doing just that. What I found was a kind of activism that had not been very seriously examined by scholars of social movements and politics. Although I entered the project with a well-ingrained sense that activists do not make their beds with economic powerhouses like car manufacturers or pharmaceutical companies and that feminists do not wear pink, I began to wonder whether there might be exceptions to my narrow conceptions. In the end, I came to the conclusion that to view the Komen women’s work in any way other than as a form of activism is to reproduce problematic assumptions that marginalize and exclude women from public life.

Since I argue that constructions of women’s volunteer work should be reconceived, it would be imprudent to ignore the question of how such constructions compare to those of men’s volunteer work. Participants at the Elks Club, for example, probably would not think of themselves as activists, just as many of those at the Komen Foundation do not. But such social and/or professional clubs are generally not organized around a particular social issue or cause. They differ, therefore, from the kinds of volunteers that I analyze. The kinds of women’s volunteer work that I analyze are centered on one cause, or set of causes, rather than around sociability. That the distinctions between women’s activist and volunteer work are not as well conceived as they could be means that many different types of women volunteers tend to get lumped into the same category. In reality, women’s activism and volunteer work challenge boundaries between activist and volunteer. These conceptual challenges are the focus of this article.

DATA AND METHOD

At the first Komen fundraiser that I attended, a 5K run/walk, I came early to the suburban shopping mall that hosted the event to pick up my race number. I found myself surrounded by, instead of the SUVs and minivans that normally occupied the parking lot, a sea of pink: Pink ribbons, pink tents, women clad in pink T-shirts and pink hats. When I looked closer at the T-shirts, I noticed signs attached to them that said things such as, “For my mom—I love you!” and “We will get through this together!” I also noticed the booths of race sponsors and supporters. Some of the booths were draped in BMW logos, others covered with hospital names and pharmaceutical lingo. Then I saw another T-shirt sign. This one said, “In the fight of my life.” I wondered what exactly these women were fighting for, who they were
fighting, and what that fight had to do with the BMW and other logos displayed. I decided to find out the answers to these questions by joining the organization as a researcher and fellow volunteer.

The Susan G. Komen Breast Cancer Foundation was founded in 1982, just when the breast cancer movement began to take shape and within the context of an increasingly powerful antifeminist backlash. During this same period, women’s self-help movements began to gain momentum (Taylor 1996; Taylor and VanWilligen 1996), further shaping the context within which women’s social movement activity in the United States took place. The antifeminist backlash and the self-help movements created an environment conducive to individual-oriented change (as opposed to structural or institutional change). As others have pointed out, breast cancer activism was introduced in the United States within a “context of increasing conservatism and medicalization, coupled with the continuing influence and transformation of American feminism” (Taylor and VanWilligen 1996, 124). In many cases, women drawn to the breast cancer movement included those who had not previously participated in social movement activities or activism.

Nancy Brinker founded the Komen Foundation in honor of her sister Susan who died from breast cancer (Brinker and McEvily Harris 1995). The Komen Foundation’s mission is “to eradicate breast cancer as a life-threatening disease by advancing research, education, screening, and treatment” (Brinker and McEvily Harris 1995, 205). Using social and political connections, including a relationship with Barbara and George Bush (Klawiter 1999), Brinker succeeded in amassing vast support for the cause, specifically for her foundation. The Race for the Cure, a 5K and one-mile run/walk event, is Komen’s largest and most well-known fundraiser. Since the foundation’s inception, the Race for the Cure has grown so much that it is now held at varying times throughout the year in more than 100 cities across the country.

I conducted approximately 125 hours of ethnographic field research at a state affiliate office of the Komen Foundation from January 1999 to June 2000. Although the project eventually became central to my dissertation, my participation was initially part of a project for a field methods practicum. I was allowed access to Komen after a phone call to the director of the state affiliate in which I described my interest in studying “how women volunteers get things done.” My description to the director was vague only because that was as much as I knew at the time about what I wanted to study. The director told me she would be glad to have me participate in the organization while studying it. From that point on, although I occasionally provided updates about my research and analysis, the director and other participants (all of whom also knew I was a researcher) expressed very little interest in my research. Understandably, my primary identity from other participants’ perspectives seemed to be simply that of fellow volunteer. As per my agreement with the Komen women, I use pseudonyms instead of their real names in all reports and have altered other potentially identifying information.

During the first six months of the research, I participated in monthly steering committee and race-planning meetings, conducted weekly volunteer hours in the
Race office (out of which the Race for the Cure is organized and coordinated), and volunteered at a variety of fundraising events. I continued my participation in the organization until the summer of 2000, but my participation became more event-oriented after June of 1999. My analysis is based on data from these months of participation and drawn from field notes that I maintained while engaged in the project. I maintained these notes by keeping handwritten notes as appropriate during meetings and events. Immediately following these contacts, I would transcribe my written notes into a word processing program and also include additional information about my observations that I recalled but was unable to write out in my handwritten notes. In addition, the typed notes include reflections on and analyses of the observations that I recorded.

It is important to note that my participation with Komen was more complex than can be conveyed by simply stating the number of days or hours that I spent there. The following excerpt from my field notes, in which I describe my arrival at a fundraising event, demonstrates this point:

When I arrived, Carla greeted me with a hug and when Nina saw me she greeted me with an even bigger hug. As she hugged me, Nina said, “Welcome to the family,” and went on to say she is glad I’m going to be a part of the organization.

Beyond the indicators of my participation such as number of hours and months volunteered, I formed relationships with the women at Komen that cannot easily be quantified. In particular, I found myself spending the greatest amount of time with three women, Carla, Jane, and Polly. All three women work or have worked as full-time volunteers for the organization. They do not hold paid positions elsewhere. While research that necessitates forming relationships with participants poses certain challenges for both social scientific inquiry and for the relationships themselves (such as the possibility of silencing participants or of allowing analysis to be silenced because of relationships with participants), my methodological strategy also enables me to make important contributions to organization participants, the causes for which they work, and the social scientific study of activism and feminism. As a participant, I offered my research site the obvious benefit of needed volunteer “man” power. As a social scientist engaged in the field that I study, I offer the possibility of greater understanding of women’s activism and of the links between activist and volunteer, feminist and nonfeminist.

To support its massive fundraising efforts through events such as the Race for the Cure, Komen relies heavily on the volunteers at its affiliate sites, many of whom use their own social and political connections to drum up local support, just as Brinker did in founding the organization. The affiliate office where I participated is staffed predominantly with white, middle- and upper-class women volunteers in their late 30s to 60s, many of whom are married and have children. Possibly due in part to their demographic characteristics, women such as those at Komen have more typically been studied as charity workers (Kaplan Daniels 1985) or as members of elite society (Ostrander 1984, 1993) rather than as activists.
Although the exclusion of such women from consideration as activists may be warranted to a certain extent due to their privileged class positions and mainstream connections, I suggest that despite its embeddedness within the mainstream, in fact through that embeddedness, Komen works to bring about social change in areas related to breast cancer. Indeed, Komen’s role in the breast cancer movement has been almost paradoxical, “acting as both a ground-breaking pioneer and a force of conservatism” (Klawiter 1999, 190) as the movement has come into being within the context of an increasingly conservative political culture (Taylor and VanWilligen 1996). In the following sections of the article, I discuss how the Komen women’s activism takes place within a frame of heteronormativity, how their work is political, and how they challenge gender without explicitly identifying as feminist.

CHARITY WORK, ACTIVISM, AND HETERONORMATIVITY

In her history of women in America, Evans stated that nearly every group of women, in their own way, has “used voluntary associations to express their interests and to organize for public activity” (1997, 4). Indeed, women have a long history of voluntary activity and, as Kaminer stated, from the beginning, it “has both liberated women and kept them in their place” (1984, 11). Women have used social reform organizations and charities “to expand the parameters of their influence and reshape public discourse on the content and meaning of their lives” (McCarthy 1990, 11). Through clubs, charities, and associations, women formed interpersonal ties to each other while at the same time creating a space for themselves within which the possibility of public involvement and institutional reform existed (Evans 1997). Yet in spite of the historical legacy provided by woman volunteers before them, Kaplan Daniels (1985) claimed that even decades later, volunteer and charity work remain largely invisible. Kaplan Daniels argued that because it is most typically women’s work and because women are presumed to have a natural affinity for it, volunteer and charity work often get overlooked.

Perceptions of volunteer work as something other than activism take away from the fact that many women volunteer as a way to become involved in public life and to effect change in their communities. This is certainly the case at Komen. Many Komen volunteers use their volunteer work as a way of connecting with other women who share the common experience of a breast cancer diagnosis. At some affiliates, Komen is particularly important in the social lives of its volunteers because many do not hold paid employment outside the home. Yet volunteers tend to downplay the important role of charity work for their own lives and for the larger society (Kaplan Daniels 1985). This is the case even at Komen, where the results of their efforts include things such as mammography equipment for clinics, funding for breast cancer research, and treatment for women with cancer. Each of these results clearly has value for constituents of the breast cancer movement, but
movement participants seem to forget that such equipment and health service availability are the direct result of the work that they do.

Kaplan Daniels pointed out that volunteers often downplay the significance of the work that they do. One woman charity worker that Kaplan Daniels interviewed described her volunteer work as just doing something with a “fun group of girls” (1985, 371). Similarly, Komen volunteer Nina described her volunteerism to me as “just a bunch of us girls out there having a good time.” When I asked Darcy why she volunteered at Komen, she said, “You meet so many neat women here. They all care, they’re all nice, and they’re just a great group of gals.” Another volunteer, whom I met briefly at a fundraising event, told me she was there “to get out and have a good time.” When I asked if she was there as an activist, she laughed and said, “No, I’m not like that.” Even Komen’s awareness-raising events are framed as harmless, nonpolitical activities. One year during my participation, I received a monthly calendar of Komen events that indicated that our task for August was to “Have fun. Play golf, drive BMW’s, and other fun things.” Although the reference to playing golf and driving BMWs is relevant to Komen’s mission (both refer to specific fundraising events held every summer), outsiders who saw the calendar might misconstrue Komen as merely a privileged women’s social club.

Based on Nina’s, Darcy’s, and other participants’ assessments, one might think Komen participants spend time at the organization simply for lack of anything else more interesting or fun to do. In fact, this is not the case. Nearly every participant I met during my 18 months of research cited, in one form or another, a desire to change the breast cancer climate for women in the United States as a central motivation for participating. Yet like the women whom Kaplan Daniels (1985) interviewed, by emphasizing the sociable aspect of what they do, the Komen women imply that their efforts are unimportant and do not qualify as activism.

Talking about what they do as fun depoliticizes participants’ actions. But some participants seem to describe their work as fun as a way to legitimate it to themselves. If it were more than fun, that might mean that it is political, and doing political work seems to be viewed as too contentious by many women at Komen. Thus, rather than framing what they do as political, they use the rhetoric of “fairness.” During a conversation with Carla about feminism, activism, and the breast cancer movement, she told me that she prefers “not to affiliate with one movement or another—it’s just about being fair.” Polly and Jane express similar sentiments. It was also common for discussions in steering committee meetings to focus on the need for women to receive “fair medical treatment.” Furthermore, in one steering committee meeting, a participant was actually chastised for suggesting that signing petitions and sending form letters to politicians might make a difference. Instead, other committee members argued that any letters to representatives should be original because, in the words of one participant, “mass letters and petitions don’t do anything.” Eventually, the conversation was dropped without resolution in favor of focusing the rest of the meeting on planning an upcoming fundraising event. The strong reaction against mass letters and petitions seemed in part to do with a desire on the part of most participants to distinguish Komen from those organizations that
engage in more blatantly political actions. For Komen participants, viewing what they do as simply fair, not political, is an essential aspect of their volunteer identities. This is linked to a traditional vision of gender in which politics is thought of as best left to men.

One might view this perspective as simply rational—not constructing their work as political allows the Komen women to maintain strong partnerships with corporations that might frown on political activism. But the avoidance of politics is more than rational choice—it is enmeshed in participants’ identities as women, even as ladies, who do volunteer work because it is good and right and because that is what women with means such as theirs do. Constructing their actions as nonpolitical fits within the broader frame of many Komen women’s lives, lives that are organized around a heteronormative construction of gender in which women’s primary identities center on their roles as wives and mothers.

It is important to note that historically, women volunteers entered the world of politics and civic affairs at the same time that they remained the primary caretakers of their homes. In other words, while the first women volunteers may have been pioneers in a certain sense, they were not in others, for they did not challenge gender-based divisions of labor. Likewise, heteronormative constructions of gender play out in the lives of individual Komen volunteers. For example, Polly’s daughter volunteers at the office during school breaks because her mom has had breast cancer and she wants to support her. Although Polly’s husband also wishes to show his support for Polly, he does so by providing financial resources both directly to Komen and also to Polly so that she may work for Komen as a full-time volunteer. The same is true for Jane, whose husband works in a prestigious job for pay while she volunteers at Komen. Polly’s and Jane’s stories are not unlike that of other Komen women; many are wives and mothers who work full-time or nearly full-time as volunteers for the foundation. These women’s families help out in the way that they do because they are defined in terms of their status as wife and mother. It may not be a surprise, then, that these women gain sponsors, donors, and event participants by appealing to those who care about their mothers and wives.

As an organization, Komen also uses heteronormative notions of gender to further its mission. At the affiliate office where I participated, Komen holds an annual fashion show. The fashion show serves a dual purpose: First, to raise funds by charging admittance and obtaining sponsorship from local companies but also to “show off” breast cancer survivors by displaying them as the fashion show models. All of the models are treated to complimentary makeovers before the fashion show, and wigs are provided, with a complimentary fitting and consultation, to women who are undergoing cancer treatment and have lost their hair. Survivors are also “displayed” at many affiliates’ annual Race for the Cure events. The display of survivors is meant to celebrate and honor them—and it also serves the purpose of promoting the idea that breast cancer survivors are indeed suitable for display.

Komen’s presentation of the organization is heteronormative in other ways, too. For example, Komen makes appeals by using the image of mothers, sisters, and wives to gain support. In a recent organization newsletter containing an article
about the National Football League’s sponsorship of Komen, we learn that “NFL players always pay tribute to their biggest fans—their moms.” One local sponsor placed an ad in a regional magazine that said, “For Our Mothers, Daughters, Sisters—We Support Race For The Cure.” As readers, we are told that if we really love our mothers, daughters, and sisters, we will support Race for the Cure, too. Of course, everyone, whether heteronormative or not, has a mother, and many also have daughters and sisters. It is important to note, however, that the ad is draped in drawings of pink ribbons and is in a flowery font, indicating its authors’ intent for readers to have a very particular, and heteronormative, vision of gender and sexual relations in mind when viewing it.

For the women at Komen, thinking of their work as political is complicated even more because of their perception of politics and activism as conflictual and as the opposite of fairness (recall the volunteer who told me she is “not like that” when asked if she is an activist). One participant described Komen to me as “not political but positive and proactive.” The Komen women’s moralist vision of order and consensus, while key to motivating themselves and others to believe that they can make a difference, impedes their ability to see their work as political in any way. Yet similarities do exist between the type of volunteer work that is often characterized as nonpolitical and the sort of activism that tends to get classified as political. Komen’s work is not just about a bunch of girls having fun. Komen’s work is also about empowering women to believe in themselves, and their rights, so that they will take the initiative to advocate for their own health and ensure that their doctors assist them in this endeavor.

There were times, of course, when the task of taking on the breast cancer epidemic seemed to dampen the outlooks of even the most positive of volunteers at Komen. During a conversation with Pamela, she told me about an experience that led her to question the priorities of the medical community and its respect for issues, such as breast cancer, that primarily affect women. Pamela, in a manner not unlike other women at Komen, commented to me that she tells her doctor at every appointment that she is convinced there is something about the environment or women’s lifestyles or “something” that is causing increasing numbers of them to become inflicted with breast cancer. Her doctor, she says, tells her the women she knows have simply had bad luck. In reference to her doctor, Pamela told me, “He just brushes me aside. It’s like he thinks I’m paranoid or something.” Pamela seems sure, however, that her sense about breast cancer is more than simple paranoia and that if doctors took her and other women’s concerns seriously, we might be better able to reduce the number of women who are diagnosed each year.

A similar theme emerged one night during a steering committee meeting at which a woman came to speak about her personal experience with breast cancer and read poetry that she had written about the experience. Throughout the guest speaker’s presentation, many heads nodded in what seemed to be a knowing agreement when criticisms were raised about interactions with medical professionals. In portions of her presentation, the guest speaker expressed her own belief in a link between “environmental pollutants and breast cancer.” Although Komen as an
organization has been noticeably silent about the possibility of such a connection (presumably because of its strong corporate sponsorships), that night, individual Komen participants were not silent. Instead, participants generally agreed with what their guest speaker had to say, expressing support through verbal and nonverbal cues. This, along with stories like Pamela’s, provides evidence that the women at Komen do recognize that personal troubles are often politically constituted. Although they did not express this directly or in the language of social science, these stories indicate some recognition that breast cancer and its cure are linked to forces larger than the individual women who are inflicted with the disease.

**BORDER ACTIVISTS?**

Despite evidence that some women at Komen sense a connection between their individual life circumstances and larger-scale forces, a certain degree of disconnection still exists between participants’ abilities to recognize larger social forces that help perpetuate social problems such as breast cancer and understanding how the work that participants do to change those problems qualifies as activism. It is important to note Komen’s emphasis on empowering the individual. Thinking about social change in terms of the individual is arguably the most pervasive, most readily available, way in America of conceiving the possibilities for social change. Komen is concerned with empowering women to believe in themselves as individuals with certain rights and responsibilities, and it spends a significant portion of its resources on educating and providing advocacy for individuals. A nontrivial segment of resources goes toward promoting self breast exam and increasing individual awareness and familiarity with one’s unique body and health needs. Serving the immediate needs of individuals detracts organization resources away from serving the larger community. Whether out of necessity or out of preference, focusing so heavily on the individual can sometimes work to the detriment of Komen’s larger goals dealing with equality for women in health care. Furthermore, focusing on individuals takes away from participants’ efforts to construct breast cancer as a social problem.

Although much of their focus is at the individual level, Komen does not entirely neglect larger-level concerns. Some participants do demonstrate an understanding that gender relations are organized in such a way that even empowered women are often disempowered simply as a result of their gender—even empowered women face an unfriendly health care system when they are diagnosed with breast cancer. This is evident in, for example, the story Lora told me about her own experience. Lora said she had always thought of herself as “having lots of confidence” but that after having made numerous trips to her doctors and still not having convinced them that the lump she had discovered should be “checked out,” she began to think of herself as “crazy and maybe overreacting or paranoid.” Komen’s answer to this problem is to try to increase general awareness about breast cancer so that women will feel more educated and better prepared to advocate for themselves.
Aside from the overemphasis on individual forces and individual-level change, other distinctions between politics and “their work” are present in the way that Komen participants pursue their goal of eradicating breast cancer. Carla says she is not an activist or a feminist because, “I don’t burn the flag or my bra or anything.” And as one non-Komen breast cancer activist said of Komen, “They’re not political. They raise awareness and are about empowering individual women. They don’t do any lobbying” (participant at 2001 breast cancer conference). Many Komen participants are likely to agree with this representation. They tend to articulate conventional symbols of politics as innately connected to activism. Carla and other women at Komen are reluctant to adopt identities that might make them appear to be too contentious, instead choosing to use relationship-building strategies that enable them to persuade local companies to host and support fundraising events and recruit mainstream media to publicize the events. The Komen women are extremely committed to changing the breast cancer climate for women (this is the case, at least, if the number of hours they put into volunteering is any indication of their commitment). In Carla’s case, her sister’s diagnosis with breast cancer led Carla to quit a paid professional position to dedicate herself full-time to the breast cancer cause. Thus, while these women remain highly dedicated to the cause for which they work, they tend not to describe themselves as activists. Yet what these women do is political and could reasonably be conceived of as activism.

One distinction between activists and volunteers that Eliasoph (1998) raised is that activists more often think of themselves as knowledge producers while volunteers are more likely to consider themselves knowledge consumers. If we use this distinction as a defining feature of the difference between activists and volunteers, then perhaps Komen belongs in the volunteer category. During my participation, the Komen women occasionally hosted expert guest speakers at their committee meetings. Although the steering committee members knew plenty about breast cancer both through their own personal experiences with the disease and through their participation at Komen, and although many of them could easily converse with guest speakers about breast cancer research and treatment, steering committee members rarely demonstrated their own knowledge about breast cancer. Instead, the following interaction between a man guest speaker and committee members was more typical:

The doctor showed some fairly graphic slides with pictures of lymph nodes and breast tissue being cut into and removed. Each time one of these slides appeared, at least a couple of the women would groan or squeal. . . . At one point the doctor asked, “Am I grossing people out?” A couple of the women said yes and one woman said, “I bet you’re a fun guy at parties!” Everyone laughed at this. Later there were slides showing the equipment that doctors use for removing tissue and one woman shouted out, “It looks like the X-Files!”

What is striking about this interaction is its gendered character. When guest speakers were women, the Komen women more often engaged the speaker in serious conversation. Furthermore, and even though at least one woman doctor sat on the
committee regularly, the four doctors who were invited to speak to the committee during my participation were all men. Women guest speakers included a nurse and a breast cancer survivor. I therefore interpret these interactions as more indicative of the Komen women’s stance toward gender and gender relations than as evidence that they should be viewed as volunteers. The degree to which the Komen women exposed their own expert knowledge shifted depending on the gender identity of their guest. The extent to which they projected a carefree, positive, and faint-of-heart image also seemed to shift with guest speakers’ gender identities.

The Komen women’s insistence on being perceived as positive is directly linked to the idea that women, especially feminine women, are not supposed to be political or divisive. Underneath their ideas about the distinctions between positive action and political activism are very particular, and somewhat problematic, conceptions of feminism. Without a shared conception of alternative, and less stereotypical, ideas about gender and feminism, the Komen women may be unable to think of themselves as activists for a positive vision of women’s activism is difficult to construct alongside stereotypical notions of gender and feminism. Of course, the Komen women do not want to be constructed as activists. But the point is that they resist being understood as activists and as feminist for the same basic reason—they do not question normative notions of gender—and this construction of gender prevents them from establishing connections across a broader spectrum of breast cancer or women’s issue groups. By adopting a different view of their activity, the Komen women might in fact strengthen feminism by making it more ideologically inclusive and strengthen the breast cancer movement by bringing together currently competing/opposing strands within the movement. In the meantime, the results of the Komen women’s efforts indeed remain: Funding for clinics, education of medical professionals, and increased awareness of potential breast cancer patients.

So is what the Komen women do activism? In the traditional sense, possibly not. As their annual fashion show indicates, Komen does not challenge normative ideologies of gender (which some breast cancer activists posit contribute to breast cancer patients’ poor treatment). But if we look beyond some of the tactics that Komen uses, aspects of activism are revealed in their work. Of course, in the same moment that elements of activism are revealed in Komen’s efforts, so too is the somewhat paradoxical role that Klawiter (1999) has suggested Komen plays in the breast cancer movement. That role is revealed in the moment that Komen encourages women to not feel ashamed about their breast cancer at the same time that it offers wigs to fashion show participants. The Komen women’s efforts might therefore be best described as border activism—while what they do implicitly resembles key aspects of activism, they do not define themselves as activists.

Earlier in the article, I suggested some parallels between the “sociability workers” that Kaplan Daniels (1985, 1988) studied and the Komen women. These women, like the charity workers in Kaplan Daniels’s study, do not call themselves activists. This might be explained by the strong sociability element in both groups’ efforts. But a key difference exists between these two groups—one that I suggest
separates volunteers from activists. The Komen women’s efforts center on a single social problem rather than, or in addition to, a more diffuse desire to contribute to the good of the community within which they live. Although their backgrounds and expressed motivations for their work are similar (as is the relative invisibility of what they do), what brings the Komen women closer to the borders of activism is their focus on the single cause of breast cancer and concurrent construction of breast cancer as a social problem. To overlook this point is to relegate women like those at Komen to the margins of public life.

NONFEMINISTS CHALLENGING GENDER

I have suggested that the extent to which women activists and volunteers think of themselves as activists is connected to their own constructions of gender and feminism. Indeed, activism and feminism are linked, and the question of what constitutes feminist activism is complex for feminism has a long and diverse history (Marx Ferree and Hess 1985). Feminists have long debated the question of whether we can ascribe the label “feminist” to activists who may not define themselves as such. Yet what the Komen women describe as simply “being fair” could just as easily be called “being feminist.” For example, educating women about their bodies and their health for the purpose of balancing power differentials between women patients and their doctors is a strategy that was also used by participants in the feminist women’s health movement of the 1960s and 1970s. Likewise, what many of the Komen women describe as nonpolitical and nonactivist in many ways borders on what might be conceived as activism. Thus, in some ways, the Komen women challenge gender even though they do not view themselves as feminist.

Of course, Komen’s emphasis on heteronormativity complicates the suggestion that they might be feminist activists dedicated to social change. Although Komen’s stated aim is to eradicate breast cancer as a life-threatening disease, implicit in the way that they go about meeting this aim is another goal—to show that women with breast cancer are, or can transform themselves into, feminine beings. At the same time that Komen targets the medical community to try to improve the way that doctors treat women with breast cancer, they also target what they perceive to be a generally accepted view that women with breast cancer have lost their femininity. Within a social movements frame, one might understand these actions as a form of meaning work, a “struggle over the production of ideas and meanings” (Snow and Benford 1992, 136). The Komen women are engaged in a kind of meaning work not in the sense that they wish to change our ideas about medical science or about femininity but rather in the sense that they wish to change our ideas about the women who get breast cancer and how we should perceive them.

Social movements scholars have sometimes distinguished between what groups like Komen do and what activist groups do as a difference between self-help and activism (Taylor 1996; Taylor and VanWilligen 1996). Key to self-help rhetoric is the concept of empowerment, and this concept is linked to participants’ tendency to
avoid politics and to construct their work as simply fair. Some non-Komen breast cancer activists, including a group of participants I met at the 2002 World Conference on Breast Cancer, express that “empowerment” is too vague a term and that it does not fully embody the political struggle in which breast cancer activists “should be” involved. But empowerment is central for Komen. The Komen women’s work is driven in large part by a desire to empower women. Nancy Brinker, who started the Komen Foundation, believes that her sister Susan may not have died from breast cancer had her doctors taken her concerns more seriously and thus detected the breast cancer earlier on (Brinker and McEvily Harris 1995). Brinker founded Komen in part to empower women in a way that she believes Susan had not been.

Brinker’s vision of women effecting change by empowering themselves has attracted so many that Komen now maintains affiliate offices in states throughout the country. Komen’s emphasis on empowering individual women challenges gender by promoting a vision of gender in which women have the right to care for their own needs. Of course, as I discussed in earlier sections of the article, Komen also projects and supports a heteronormative ideology in which women are presumed to be particularly apt at caring for others. But in spite of the potential tensions between challenging gender and asserting a heteronormative ideology, the fact remains that Komen has managed to effect change by not rocking the boat. This change is evidenced by the many accomplishments of the organization. In the state where I participated, Komen provides funding to about 300 clinics that offer mammograms and diagnostic services to uninsured/underinsured women, and in less than a two-year period, the affiliate office funded five local research grants. Komen does not fit neatly into existing conceptions of activism or feminism—it does promote change to a certain extent but it does so by working from within mainstream institutions and ideologies.

**CONCLUSION**

When I first attended the Race for the Cure, I was left with questions about whom the Komen women are fighting and what that fight has to do with company logos displayed at the event. If we ask the Komen women themselves, they are likely to say they are not fighting anyone. Indeed, that may very well be the case. Instead, Komen and its participants use their connections with mainstream institutions and organizations (e.g., the BMW corporation) and their heteronormative construction of gender to guide their fundraising efforts. As I was told, the Komen volunteers prefer to think of their work as “positive and proactive” rather than political. Being positive and proactive should not negate the possibility that these volunteers are activists or that they are engaged in feminist work, but the Komen women perceive their work as transcending the dirty work of politics. Without an understanding of gender that allows them to reconcile their image of the good woman with that of the political actor, these women are left with no choice but to conceive of their work as nonpolitical.
These contradictions, between the Komen women’s political/activist voluntary activity that challenges the consequences of traditional visions of gender and their promotion of a heteronormative gender ideology, contribute to continuing contradictions present in women’s voluntary activity and to setting the context within which women’s activism and charitable work exists. Indeed, the legacy of women’s volunteer work laid the groundwork for such contradictions. Lebsock has said that one of the most intriguing qualities of early women reformers was “their capacity to combine and contain many seeming opposites” (1990, 47). Nonetheless, voluntary organizations have provided an outlet for women to exercise some degree of power and control over their own destiny (McCarthy 1990). Today, as in the past, women have used connections with one another through clubs and voluntary associations to resist knowledge that does not represent their experience, to construct new knowledge about women and their needs, and as locations from which to gain empowerment.

So what does this mean for how we study activism and social change? In the case of Komen, emphasizing femininity, and thus differentiating themselves from men, fosters a sense of camaraderie among women. Viewing their experiences as shared, rather than private, is an important first step in consciousness raising. Komen’s heteronormative construction of gender enables participants to conceive of their shared experiences with breast cancer as problematic and thus challenge the conditions that they face as a result of those experiences. At the same time, it prevents them from taking an approach that might more fully re-envision traditional gender ideologies and political action. The case of Komen demonstrates the complex relationships among gender, activism, and civic participation.

As Eliasoph (1998) argued is the case with many Americans, the Komen women try to avoid politics or at least avoid the appearance of being political. But analyzing the case of the Komen women furthers Eliasoph’s work by revealing gender as a key feature in the creation of Americans’ political apathy. Moreover, Komen blends previous distinctions made by Eliasoph and others (e.g., Oliver and Marwell 1992) between activist, volunteer, and recreational group member. The Komen women’s status as women who exist within a particular gender system provides the context for these blurred distinctions. Their status as women, for example, means that they will be more likely to be viewed as volunteers than activists. Their status as women also supports their social ties to one another. In a heteronormatively oriented society, the very common Komen scene of a group of women sitting around a table discussing details of their personal lives while stuffing Komen brochures into envelopes is not surprising. Women are expected to maintain homosocial connections with one another. The discussion around the table, although personal, is also political. In the course of conversation about a recent trip to the doctor, for example, these women may discover a shared discontent about their treatment by a male-focused medical establishment. Thus, their homosocial connections facilitate their political awareness and activism.

An advantage of ethnographic methodology is that it enables us to view these complexities as parts of a whole. The Komen women help us appreciate that
feminism and activism are complex concepts, as are the lives of those who engage in practices related to these concepts. Komen has empowered women to see that they are not alone—that others have had less than ideal experiences with medical professionals—and that others too have experienced the feelings of disempowerment that come with losing one’s sense of femininity, beauty, and womanhood. By talking to each other and to women outside the organization, Komen volunteers promote the notions that women are not to blame for unsatisfactory communication with their doctors, although they can do something about it, and that breast cancer survivors have not lost their femininity, and that indeed they can do something to regain it. As Eliasoph (1998) pointed out, activism is not just about winning battles over specific issues, even though that is how politics is often conceptualized. Rather, some activism has more to do with inspiring public discussion about issues that are of concern to the members of a community. This too is political. Political action occurs when an individual or a group engages what is often referred to as the public sphere. Indeed, much of Komen’s work is geared toward bringing discussions about women’s health and bodies out into the public. Of course, politics is not only what occurs in the public sphere (McAdam 1988)—politics can also be about setting the agenda, reframing the issue, and even personal empowerment—and Komen is engaged in each of these activities.

As the preceding discussion demonstrates, women’s charity work is in fact more than just fun and games. Historically, women have used voluntarism as a means for becoming engaged in public life and for working to shape, change, and resist social norms and institutions (Kaminer 1984; McCarthy 1990). Women’s voluntarism should thus be analyzed from the perspective that it may indeed qualify as a form of activism. Furthermore, as researchers, we should be open to the notion that the organizations within which this activism occurs may be feminist organizations. By accepting the complexities that are inherent within organizations like Komen, we are left with a richer understanding of “activism” and “feminism.” By expanding our conceptions of these terms, we are provided the opportunity to analyze the contributions made by organizations that we might otherwise ignore. Those who accept this challenge not only offer the possibility to “break new ground and increase [our] understanding of feminism, organizations, and social movements” (Yancey Martin 1990, 202) but can also open up the possibilities for a broader spectrum of individuals and groups who share a concern for women’s rights to establish connections with new allies.

NOTES

1. Indeed, just as individuals “do gender” (West and Zimmerman 1987), so too do activists do activism in a way that is gendered.

2. See Gagné (1996) for an informative analysis of how this perspective is especially problematic for understanding women’s social movements.
REFERENCES


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