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## **Gender, Power, and Feminisms in Breast Cancer Advocacy: Lessons from the United States and Poland**

**ABSTRACT.** The United States breast cancer movement helped to transform breast cancer's social and medical landscape domestically and, in some ways, internationally. However, differences in gender identities, power relations, and the role of feminism(s) cross-culturally also shaped breast cancer advocacy itself. After giving a brief introduction to the socio-historical context of the U.S. and Polish breast cancer movements, this article illuminates some of the linkages and divergences between the United States and Poland to demonstrate the role of gender and power in social movements that concentrate exclusively on women's (health) issues, namely breast cancer. This comparison of social phenomena from two countries illuminates the impact of cultural patterns on models of activism as they relate to feminism and traditional gender roles.

**KEYWORDS:** breast cancer, epistemology, feminism, gender, health social movements, cross-national comparison

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## Introduction

The status of women vis-à-vis the medical system in the United States changed profoundly in the last century. Katherine Lee Bates's account of the illness and death of historian and social reformer Katharine Coman (1857-1915), which was distributed to family and friends, and eventually published nine decades later, appears to have been the earliest example of an "illness narrative," revealing the importance of social contexts on the individual experience of illness (Leopold, 2014). The letters (from 1917 to 1922) from pseudonymous Barbara Mueller to her surgeon William Stewart Halsted – the medical pioneer who developed the invasive and debilitating radical mastectomy that removed the breast, axillary lymph nodes, and chest muscles – likewise highlight what it was like for a woman to experience breast cancer amid gendered, paternalistic doctor-patient interactions and the rising eminence of modern surgery (Leopold, 1999). Three decades later, mastectomy patient Terese Lasser founded the first formalized, all-volunteer, peer-to-peer program to provide practical and emotional support to breast cancer patients treated with the Halsted mastectomy (Reach to Recovery, 1952). Read against the abundance of contemporary breast cancer narratives that focus on personal empowerment and informed decision-making illuminate profound changes in what is now known about breast cancer and in women's roles as patients/consumers of health care and biomedicine.

Breast cancer illness narratives and social activism over time reveal women's responses (some explicitly feminist and others not) to the social stigma of cancer, fear of death, inaccessible medical language, invasive treatments, authoritative doctor-patient relationships, and limited social and practical support for the diagnosed. One of the earliest non-religious organizations focused on cancer, the American Society for the Control of Cancer (now the American Cancer Society) established a Women's Field Army in the 1930s to wage a domestic war on the disease (Davis, 2007). The 2-million-woman-volunteer-network buoyed, rather than resisted, traditional gender expectations as it focused on breast cancer's devastation to women's roles in, and obligations to, the American family. Women canvassed friends and neighbors to raise money, gain supporters, influence public perceptions, and encourage women to adhere to conventional medicine. Though disbanded in the early 1950s, the Field Army left a legacy that continued to shape American

attitudes about breast cancer and women's role in the fight (Lerner, 2001).

With powerful allies in private and public sectors, the American Cancer Society continued to be a primary source of information to the public about breast cancer and to promote women's conciliatory behavior in relation to the medical establishment (Sulik, 2014, p. 37). Concerned that women feared breast cancer treatment more than the disease (i.e., the debilitating Halsted mastectomy remained standard treatment for breast cancer well into the 1970s despite evidence that the procedure did not reduce breast cancer mortality), the Society adopted Terese Lasser's Reach to Recovery program in 1969. The program provided temporary breast prostheses to enable women to conform to their wardrobes and normalize their appearance. Program volunteers were breast cancer survivors who would enter medical settings to share information about the program. What's more, they would serve as walking evidence of medicine's ability to "cure" breast cancer. Solidifying the authority of expert medical knowledge, Reach to Recovery even forbade volunteers from discussing medical information to avoid contradicting doctors (Batt, 1994). It was the American Cancer Society's Reach to Recovery mode of breast cancer advocacy that quickly made its way to Poland and many other countries (Mazurkiewicz, 2012, p. 103).

After the Second World War, the context for Polish women differed dramatically from their Western European and American counterparts as the communist state (est. 1945) promoted women's emancipation strictly in terms of family and work. Thus, Poland's political system itself was a likely barrier to the development of a politicized breast cancer movement (cf. Mazurkiewicz, 2012). Medical authority and professionalization further thwarted health-centered grass roots organizing. For the most part, only professionals had the social capital to organize laypersons into formalized patient-centered groups. As the breast cancer movement developed, it was primarily oncologists or oncological nurses who led the patients' groups.

The first breast cancer support group (1983) was led by rehabilitant Krystyna Mika and, in a sense, by oncologist Andrzej Kułakowski, who had recently completed his medical internships in the United States. Another important figure to offer strong support was president of the Polish Anti-Cancer Committee, oncologist Zbigniew Wronkowski. Unlike many U.S. groups that facilitated emotional support through the development of peer networks, the support group provided only rehabilita-

tion exercises as forms of medical aftercare. Rehabilitant Krystyna Mika opposed adding an emotional support component because she believed such friendship networks were nonessential to aftercare and may be potentially harmful to members who would inevitably grieve the deaths of support group friends who had negative prognoses. As a result of the exclusivity and hierarchical structure of the program, Mika remained a key figure in Poland's movement for at least a decade. In fact, she was the primary driver in the formation of a Polish breast cancer movement.

Some members of the Polish movement now view Mika's resistance to the establishment of peer-to-peer networks as a personal desire for power. Krystyna Wechmann, now president of the federation of Amazons' associations, explained that Mika preferred to maintain professional control of the patient groups and viewed one of the first patient-run clubs (in 1991) as a "coven of witches" because it did not have "trained" volunteers (Zierkiewicz, Wechmann, 2013, p. 54-5). Although the Amazons continued to cooperate closely with medical professionals and rehabilitants, they eventually resisted such opposition to patient self-organization and chose to operate independently. Unfortunately, the groups did not realize that beyond meeting friends and gaining access to professional physical therapy, an organized, patient-centered network could itself have advocacy potential.

Contrary to the norm, some patients' groups (similar to many breast cancer advocates in the United States) did believe that women needed emotional support to adjust to social life after a breast cancer diagnosis, not only physical rehabilitation. Several of the existing clubs (e.g. in Kielce, Poznań, and Wrocław) established a federation in 1993 based on the U.S. Reach to Recovery model that was led by patients themselves. Some groups developed cooperative relationships with local hospitals that enabled volunteers who completed a course in psychology to visit patients. Of the registered Amazonian associations, hundreds of members have since completed a course that enables them to provide volunteer patient support in Poland's hospitals.

There are several obvious American influences in Poland. Building from the Reach to Recovery model described above, voluntarism is a central feature of women's organizing. Breast cancer survivors (referred to as *Amazons*) started new support groups, and the first annual awareness march (reminiscent of the physical-based awareness events in the U.S.) was organized in 1996. Like October's Breast Cancer Awareness Month in the United States, October 17<sup>th</sup> was declared Poland's

“Day of the Breast Cancer Fight” in 1998. By 2010, there were over 200 Amazonian groups in Poland, with over 15 thousand members some of whom volunteer in hospital settings (Sulik & Zierkiewicz, 2014).

Poland has strong traditions of political demonstrations, but after the fall of communism in 1989 and the introduction of a capitalistic/neo-liberal system women’s rights from a feminist perspective were not on the forefront of an activist agenda. Although some young women organized with feminist intent, their efforts fell largely outside of breast cancer advocacy, which was the domain of diagnosed, older women (cf. Malinowska, 1999). Thus, the Amazons did not develop a capacity to participate in public debate or take an activist orientation with regard to research or medical practice as their American counterparts did. The marches, organized in many cities and towns, are the primary means of public engagement. Even these are aimed at transferring a value system rather than engaging in social change. Additionally, the Polish movement is not religious in origin, but the bulk of its membership is Catholic. On the first Saturday in October, the official Amazon march (i.e. a pilgrimage) takes place in Jasna Góra, known as the holiest place in Poland (Sulik & Zierkiewicz, 2014). Given women’s secondary roles in the Catholic Church, it is not surprising that Catholic Amazons may also view women’s civic roles as subsidiary.

To understand breast cancer advocacy in light of the similarities and differences in the American and Polish context, we first outline the feminist roots of the United States movement, the cultural shift toward the feminization of the disease (via the social cause), the role of survivorship within a broader (gendered) cancer ethos, and the ongoing resistance that stems from a continuing feminist bent within the movement itself. We then explain the evolution of Polish movement from a single group to nationwide network of organizations that was from the onset more conciliatory to medical authority than its American counterparts. Loosely adopting a community-oriented model of advocacy based on female essentialism and traditional women’s roles, the Polish movement never really found its own identity.

### **Feminist influences in the U.S. breast cancer movement**

Arising from the women’s, Patients’, and consumer movements of the 1970s, breast cancer advocates helped to de-stigmatize the disease, promote solidarity among some groups of women, provide emotional

and practical support to the diagnosed, expose medical practices to public scrutiny, increase federal funding and consumer input for breast cancer research, and elevate the social status of the survivor. What transpired was a vibrant and successful health social movement made up of diverse constituencies and motivations. Yet the breast cancer movement is not, nor has it ever been, a consensual force represented by a single organization. There are indeed thousands of community-based organizations across the nation fueled by membership, volunteerism, grant funding, local fundraisers, and increasingly corporate sponsorship. For more than 30 years these advocates have focused on women's experiences as survivors, educators, and informed decision-makers to influence collective action, public policy, and awareness of breast cancer as a critical women's health issue (Sulik, 2012).

The *feminist* roots of the breast cancer movement in particular organized to push the medical profession, government regulators, and researchers to address shortfalls in progress against breast cancer (Casamayou, 2001; Lerner, 2001b; Ruzek, 1978; Stabiner, 1997). Drawing attention to rising incidence, high mortality, the limited efficacy and deleterious effects of cancer drugs and conventional treatments, controversies surrounding screening mammography, and other ineffective aspects of the cancer industry, feminist activists led the charge to question medical authority, demand treatment alternatives and second opinions, and insist that empowered patients who had accurate and accessible information could (and should) play a central role in their medical decisions (Spanier, 2010).

Despite the centrality of feminist perspectives within the burgeoning breast cancer movement and its role in changing women's status vis-à-vis the biomedical system, feminisms did not reflect the perspectives or activities of the entire movement. By the 1990s changes in public policy, heightened media exposure, and the increased visibility of breast cancer resources and support groups elevated the social status of breast cancer and "the survivor" in ways that gave the movement more clout even as it quelled feminist initiatives aimed at evidence-based medicine and health social justice. An overarching "culture of survivorship" oriented to optimism, personal empowerment, and the "survivor" as an identity category helped to dilute and homogenize breast cancer activism as the wealthiest and most visible advocacy groups institutionalized within a professionalized cancer establishment that largely rebuked feminist perspectives. The resultant pink ribbon culture, repackaged for mass

distribution, came to rely on publicity, fundraising, and corporate and political influence to maintain breast cancer's status as the most popular social cause in American culture.

The 'pink ribbon culture' that supplanted grass roots activism in the American mainstream was far afield from both the disease experience and the critical feminist stance that sought to change the course of the epidemic, promote equity, and fix flaws in the existing cancer system (see Baralt & Weitz, 2012; King, 2006; Klawiter, 2004; Leopold, 2014; Ley, 2009; McCormick, 2010; Sulik, 2012). In 2001, Barbara Ehrenreich critically argued in *Harper's Magazine* that breast cancer had become a "Cancerland" characterized by a cancer-industrial complex and breast cancer marketplace that was full of ultra-feminine, infantilizing pink kitsch and a battle cry of survivorship that denigrated death and dying while it demanded cheerfulness, sentimentality, and self-transformation in the face of the disease and its treatment. This clear and scathing commentary, still accurate today, raises a critical question: **How did the politicized feminist stance that galvanized much of the early breast cancer movement transform into a feminized consumption-based aesthetic?**

### The feminization of breast cancer

The culture of breast cancer draws upon the institutional strength of the existing gender system for its symbols, messages, and stories. The use of the color pink easily conjures the imagery and discourse of traditional femininity – innocence, morality, nurturance, emotional sensitivity, selflessness, and the feminine half of heterosexuality. Inscribing breast cancer awareness with the color pink (i.e., the breast cancer ribbon and the entire landscape of 'pink ribbon culture') activates normative gender expectations. Images abound of a sisterhood of women draped in pink, enthusiastically supporting one another, selflessly organized, and optimistically calling attention to the need for awareness, research, and funding in the battle against breast cancer – a socially constructed, epic war that venerates the fight while neglecting the lived experience of the disease.

Pink also references a society that celebrates women's breasts as the principal symbol of womanhood, motherhood, and female sexuality. Since breast cancer places the integrity of a woman's body in jeopardy, restoring the feminine body or at least normalizing its appearance is



a sign of victory. Wigs, makeup, fashion, prosthetic breasts, and reconstruction help women to maintain a socially acceptable feminine appearance that urges women to choose between devaluing their bodies (I don't need my breasts anymore anyway), hyper-valuing their bodies (Without breasts I don't feel like a whole woman), or viewing their scars as a badge of honor. Such messages interlock gender expectations that value younger women's healthy bodies for their sexual primacy and devalue the perceived disorder of older, dis/abled, or diseased bodies.

The breast cancer marketplace thereby offers medicine, technology, "awareness," and other products and services to encourage women diagnosed with breast cancer to keep their femininity and sexual appeal intact, or at least as normalized as possible (Sulik, 2012, p. 35-49). The political economy of breast cancer likewise promotes a highly individualized approach to managing breast cancer both as a personal problem and as a public issue. In this way, contemporary pink ribbon culture colonizes both the "personal is political" sentiment of second-wave feminism (replacing it with the story of the triumphant survivor, as an ideal type) and also the potential of cultural resistance and conscientious consumption central to feminism's third wave (neutralizing critical analysis of systemic social and cultural factors with entertainment-based fundraising and symbolic action). Unlike early feminist breast cancer activism that pressed for informed decision-making and social justice, the multi-billion dollar breast cancer industry unites women's and patients' empowerment with a compatible consumption-based logic.

### **She-roic survivorship and the masculine/feminine ethoi of U.S. cancer culture**

Breast cancer in the United States is embedded within the dramatic scientific and rhetorical struggle that is the national, 40-year war on cancer. Gender is at work here too as competing agents and social forces shape the language, beliefs, and experiences of cancer both as a disease (biological underpinnings) and as an illness (socially constructed). Rhetoric imbued with traditionally masculine or feminine characteristics encourages specific modes of cancer survivorship that reinforce and obscure the gender system. Specifically, the gendered illness identities of celebrity cancer survivors help to socially construct masculine/feminine ethoi in American cancer culture (Sulik, 2012, p. 78-100).



The masculine ethos represented by men such as champion cyclist Lance Armstrong (and now disseminated wholly through the **LIVESTRONG** charity he founded) aligns with imagery of victorious heroism, sporting competition, and war metaphor (Sontag, 2001; Seale, 2001). In sharing his cancer biography publicly, Armstrong painted a portrait of himself that acknowledged his cancer diagnosis and treatment while obscuring its reality beneath heroism and an almost inhuman capacity that resonated with socially dominant masculine ideals that encourage men to render their illnesses invisible, or heroically transform them into social capital (Lorber & Moore, 2002). Because masculinity is socially valued in a binary system (Douglas, 1984),<sup>1</sup> a man who follows the **LIVESTRONG** example will fight cancer heroically and admirably, with strength, perseverance, and victory, without compromising his masculinity; in fact, choosing the masculine ethos will increase his social capital. A woman who chooses the **LIVESTRONG** masculine ethos must transgress gender boundaries to do so successfully, as the masculine ethos demands individualism and emotional suppression while taking a competitive and aggressive stance. Because the masculine ethos is highly valued in American culture, even women cancer survivors will garner social capital in the attempt.

When Lance Armstrong – the man – fell from grace after a doping scandal in 2012, he was stripped of the seven Tour de France titles he won from 1999 to 2005. By October of that year, he resigned as chairperson of the Lance Armstrong Foundation and from the board of directors a month later. Attempting to separate the **LIVESTRONG** brand from the person who later admitted to doping in an interview with Oprah Winfrey, the foundation officially changed its name to the Livestrong Foundation in November 2012. Aside from the “Our Founder” section, Armstrong has been almost completely erased from the **LIVESTRONG** website. Yet the perseverance, strength, and courage that form the organization’s culture remains: “We are charting a *strong, independent* course *forward* that is focused on helping people *overcome* financial,

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<sup>1</sup> Mary Douglas argues that ambiguity is a source of powerful symbolism within cultures because societies tend to view ambiguous phenomena as dangerous. To deal with ambiguity, first the phenomenon is socially assigned to one of two possible categories (i.e., normal/abnormal, good/bad, health/illness, masculine/feminine, pure/polluted, and so on). Then, it is avoided whenever possible. If an anomalous situation materializes that cannot be categorized or avoided, it is destroyed. In the gender order, the feminine side of the binary classification parallels the abnormal, bad, ill, polluted.

emotional and physical challenges related to cancer [Emphasis added]" (Maclaggan, 2013). Since the gender system also functions as a symbolic system, dichotomous pairs of characteristics (e.g., strong/weak, independent/dependent, forward/backward, overcome/submit) are quite obvious and correspond with the gender binary masculine/feminine. Whereas the term "helping" could be cast as a feminine attribute typical of women's normative nurturance, the sentence is weighted toward the masculine characteristics that permeate the masculine ethos.

A feminine ethos represented by women such as comedian Gilda Radner, best known for her work on NBC's *Saturday Night Live*, favors nurturance, empathy, and a relational orientation that resists war metaphor and conventional models of survivorship. After Radner died from ovarian cancer at age 42, a network of affiliate clubhouses for people of all ages living with any type of cancer was started in her name (i.e., Gilda's Club). Understanding that cancer does not occur in isolation but within families and social networks, the clubs were designed to promote emotional and social support through community-building, shared experience, and respect for the many personal approaches to living with cancer. The informality of the organizational setting (as suggested by the use of Gilda's first name in the title) lends itself to a feminized private sphere. When coupled with her career in comedy, the feminine illness identity Radner represents is trivialized even though she represents a class of superwomen who successfully manage roles such as marriage, motherhood, and career. Because femininity is socially devalued in the binary gender system, men who prefer the feminine survivorship ethos risk demasculinization whereas women who do so are able to adhere to traditionally feminine expectations.

In pink ribbon culture, the she-ro (an amalgamation of the masculine/feminine ethoi) is the protagonist of the epic breast cancer story (Sulik, 2012, p. 101-10). This *ideal type* – ubiquitous in magazines, memoirs, advertisements, news stories, and breast cancer awareness events – is a breast cancer superwoman who courageously, passionately, and aggressively "battles" disease. Although the she-ro faces tremendous emotional and physical challenges, she triumphantly fights breast cancer with style, optimism, and feminine accessories. What's more, the she-ro is transformed by her breast cancer experience and shares lessons learned. Instead of being presented as one possible way to deal with breast cancer, as the feminine ethos would suggest, the she-ro is cast as the universal breast cancer survivor.

Despite the feminist underpinnings of the breast cancer movement, these survivorship models clearly rely on a binary gender system while simultaneously neutralizing feminist strategies to promote women's agency. The "she-roism" of pink ribbon culture claims women's empowerment through a homogenized version of advocacy that fosters, and depends upon, highly personalized, mass-mediated consumption. The she-ro helps to construct a cancer-fighting aesthetic that diverts attention from feminist critiques within breast cancer and other women's health social movements that focus on the limits of biomedicine and the health care system and the lack of attention to cancer causation, primary prevention (avoiding cancer in the first place), recurrence (when cancer returns), and metastasis (when cancer spreads to distant organs). The she-ro encourages other survivors and their supporters to sanction a multi-billion dollar breast cancer industry that relies on mass media, professional advocacy, commercialization, and political networks for profit and self-perpetuation. The cultural representations of breast cancer advocacy overwhelmingly present an image of solidarity that grew out of different "cultures of action" within the movement itself (Klawiter, 2004), whereas the individual breast cancer survivor who does not fit the pink mold must seek out her own support systems outside of the mainstream.

### **Resisting the de-politicization of mainstream breast cancer campaigns**

In early 2012 a scandal involving one of the "most trusted" breast cancer charities in the United States and the nation's leading provider of reproductive health care unleashed an international debate about breast cancer advocacy and industry. A decision by Susan G. Komen for the Cure ("Komen") to cut future funding for one of its grantees, the health network Planned Parenthood, set off a firestorm of intense backlash from journalists, social media sites, more than two dozen senators (Democrats), and other public figures. Komen reversed its stance in three days, yielding to the pressure. Against the background of commercialization and the professionalization of advocacy, what most shocked women's health advocates and the general public was the suggestion that this controversy seemed to represent a unique moment in breast cancer's history, as the first time politics had ever exerted influence. But as stated previously, breast cancer advocacy emerged from deeply politicized social movements that worked to uncover beliefs, values, and politics already embed-

ded in existing knowledge and practices, and to challenge medical authority and 'expert' control over scientific and medical information.

Such feminist perspectives on the sciences also aligned in part with the medical profession's movement toward evidence-based medicine (EBM) – a practice that involves integrating individual clinical expertise with patient choice and the best available external clinical evidence from systematic research (Spanier, 2010). From this perspective, empowered decision-making requires critical thinking to understand the strengths, limits, and uncertainties of biomedicine, and how these issues impact individual and collective approaches to breast cancer individually and as a social problem in need of complex, multi-faceted solutions. Along these lines, critical health literacy involves extracting information, comprehending its relevance, and analyzing it effectively so that it may be used for one's own benefit and for the benefit of one's community, or society more broadly (Netbeam, 2000; Sulik, Cameron & Chamberlain, 2012).

There remain groups in the contemporary breast cancer movement that maintain a critical stance (see Boehmer, 2000) and focus on empowerment at personal and community levels to improve the social, economic, and environmental determinants of health (e.g., National Breast Cancer Coalition, Breast Cancer Action, Breast Cancer Fund, and others). However, mainstream breast cancer campaigns have constructed a portrait of breast cancer as the apolitical "sweetheart of health-related causes" such that the depoliticization of mainstream breast cancer advocacy masks the already embedded political underpinnings and ideologies (Baralt & Weitz, 2012). An examination of the conflicts of interest within and between advocacy groups reveals how political (and corporate) interests influence the public policies, research trajectories, health communication strategies, and fundraising activities promoted. Consequently, mainstream public discourse about breast cancer (including risk, causation, screening, prevention, treatment, health disparities, and the epidemic at large) lacks the critical (and feminist) edge that was so vital to early breast cancer activism. Despite this, feminist and evidence-based analyses within the U.S. breast cancer movement are still growing from these early roots.

### **The Polish breast cancer movement**

In a practical sense, it is men (in their prestigious roles in a 1980s socialist medical system) who set the tone for women's social engagement in Poland's breast cancer advocacy. A handful of male physicians

who returned from internships in American hospitals were the first to encourage women treated for breast cancer to provide emotional support for women awaiting mastectomy. The arrangement was beneficial to the medical system since the diagnosed were more likely to accept treatment if they could talk with other women who had already faced similar situations. At this point in Poland's history most women lived in traditional social settings and, in accord with socialist ideology, viewed critiques of gender relations and the production of knowledge inherent to feminisms to be "an invention of the rotten West."<sup>2</sup> Many of the contemporary Amazons<sup>3</sup> were raised during this period and continue to hold conservative beliefs about the nature of social relations. Thus, there is an absence of feminism in the public discourse of Polish Amazons.

In addition, some Polish activists hold the conviction that it is not worthwhile to put effort into social movements because they are united under the banner of mutilated femininity (i.e., a colloquial phrase that equates the bodily harm stemming from cancer and its treatment with a distorted sense of self, social position, and moral value). Likewise, studies show that patients after breast cancer treatment join Amazon clubs not to advocate for a particular agenda but to obtain free rehabilitation. They openly admit that the history of the Amazons movement, its ideological underpinnings, and its dissemination of political or cultural views are not within their scope of interests.<sup>4</sup> In fact, those who engage most in the Amazons clubs are retired elderly, Catholic women who are trying to stay socially active. They meet with friends, take excursions to rehabilitation centres, and participate in the annual pilgrimage to the Black Madonna sanctuary in Częstochowa (Jasna Góra), one of the most important events for the Amazons (cf. Samson, Jansen, Notermans, 2014). Few of the Amazons volunteer at oncology wards, which had been one of the primary goals of the clubs when they first began.

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<sup>2</sup> The Polish anti-feminist sentiment is well developed by Ewa Malinowska (2001).

<sup>3</sup> Unlike the term "survivor" taken by the U.S. breast cancer movement to abolish the victimization stigma associated with breast cancer, Polish breast cancer patients rejected the term due to its association with the Holocaust. As Zygmunt Bauman (2007) explains, the term survivor is too ambiguous in this region of the world. Polish women diagnosed with breast cancer euphemistically call themselves Amazons (a term also used by people without cancer), suggesting an affinity with ancient, legendary warriors.

<sup>4</sup> See research report, *Kluby Amazonki - Twoją Szansą* (Fundacja Ekspert-Kujawy, kwiecień-maj 2012).

The Federation of Amazon clubs has been ongoing for over 20 years now, and the *status quo* of the movement seems to be secure largely due to the belief that traditional feminine unity is necessary for women's community-building and that the Polish feminist movement in general has been inadequate in gaining broad-based support.<sup>5</sup>

### **Lack of feminist discourse in Polish breast cancer culture**

The lack of feminist reflection among Poland's breast cancer advocates as described above has had two notable positive consequences. First, the traditional understanding of femininity as an identity category that binds together women of different social backgrounds obscures social divisions, such as age, social class, educational background, etc. Femininity – regarded as a meta-level existential experience *sui generis* – makes it possible to establish a sense of equality and shared experience among the women in the patient groups. Unlike the formality in most social situations in Poland in which salutations and surnames are used, Amazons level the playing field, so to speak, by calling one another by their first names.

Second, dismissing considerations of gender as both socially constructed and rooted in equalities enables the formal consolidation of the Amazons movement and buttresses the sense of community within its ranks. Seemingly, Polish Amazons form a homogenous social grouping of shared beliefs, associations, and assumptions upon which they may implement corresponding programs. Differences that may arise between clubs (such as access to scientific professionals to provide public education or advice, businesses to give financial backing, or media attention) stem from zoning, the overall number of members, or the shifting age composition of the groups as greater numbers of younger women are diagnosed with breast cancer.

Despite the benefits of solidarity based on traditional femininity, the lack of feminism in Poland has had negative consequences. Most women are unaware of the medicalization of health and disease (including

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<sup>5</sup> In 2014, gender became the subject of many Polish scientific and journalistic debates - but not by feminists who educate the public on socio-cultural identity, but by right-wing circles diverting public attention from other matters. In a sense, gender became a media artifact before any cultural change could occur.

breast cancer) or the construction of patient's role<sup>6</sup> as central processes within the socio-medical setting. In addition, the male dominated political system makes it difficult for women's health issues to gain ground. Whereas in the United State, key organizations in the breast cancer movement have had clear legislative agendas with regard to women's health issues such as federal allocations for breast cancer research, access to screening and treatment through federal programs, ensuring the participation of educated patient advocates in all levels of health care decision making, to name a few, norms of feminine politeness and moderation have limited the capacity of Polish Amazons to bring important women's health issues to the fore. The notion that women's roles are of lesser value than those of men remains strong in contemporary Polish society, and among most Amazons.

The role of medical authority especially among Polish doctors remains strong in Poland. Though the Amazons may complain about the quality and efficacy of their medical care privately to friends and family, some practice what might be dubbed a "surgeon cult" in which they place complete trust in their surgeons not only to carry out surgical procedures but also to make other/non-surgical medical decisions for them (Zierkiewicz, 2010). Women's gratitude to surgeons for having "saved their lives" paired with a lack of understanding about the social determinants of modern biomedicine facilitate an attitude among the Amazons which can be characterized as both passive/trustful and "wishful" (i.e., having an optimistic belief about the future that is not based in evidence or realities) (cf. Mazurek, 2013).

In 2006 – inspired by western activists – members of all the clubs, at the same time, sent protest letters to the Speaker of Parliament office to draw political attention to discrimination against women who lived too far from oncology centers. Local hospitals did not have oncology units and travel to oncology centers was too difficult for many women to obtain routine care, including diagnosis and treatment from oncology professionals. They argued that place of residence should not determine one's medical options. The action elicited no response from the politicians, and nothing was done to lessen the hardship of those who lived in remote areas, far from specialized clinics. Viewed as a devastating defeat, club members never took this sort of public action again. The veritable disre-

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<sup>6</sup> Such issues are taken more broadly only recently (cf. Domaradzki, 2010; Gromkowska-Melosik, 2013; Leźnicki, 2013).



gard of their efforts to impact public policy solidified a peculiar dissonance; that public action was at odds with the concept of natural, modest and conciliatory femininity. As mentioned previously, such sentiment is common among Polish women on the margins of political engagement.<sup>7</sup> The absence of feminist reflection in the Polish discourse on breast cancer further precludes Amazons from acknowledging that, in reality, no one represents their interests or is concerned with satisfying their needs.

Without critical feminist reflection, the essentialist approach to sex that prevails within the Amazon movement ostensibly erases differences in age, class, wealth, education, sexual orientation, ethnicity, religion, and other social categories. Addressing such issues in public debates and discussion groups are considered either irrelevant or potentially hazardous. Thus, Amazons downplay inner tensions by supporting an interpretation that frames these as a direct result of “woman’s nature.” Compulsive adherence to the claim that “the ultimate thing uniting all women is being a women” (an expression authored by Betty Davies, often cited in one of the Polish commercial magazines) suggests that the contemporary woman should accept her womanly lot, thereby rendering women’s socio-political action improbable. There is no place in political life for emotionality, proneness to injury, and a tendency to exaggerate difficulties, the qualities cast as exclusive to woman’s domain. That said, there are other barriers to political activism among those experiencing health and age inequalities as well as the (self)isolation and physical difficulties that stem from cancer treatment. Many of the women of the Amazon community are marginalized elderly, barely able to manage their conditions. For them, politics seems low on the hierarchy of basic needs.

By organizing and financing breast cancer awareness campaigns and activities, the medical establishment, along with mass media, political agents involved in public health, and cosmetics/fashion/beauty companies – also foster the Amazon’s apolitical, non-feminist stance as well as individuality and obedience to the biomedical paradigm. Some examples include: the annual Marches of Life and Hope (coined the pink ribbon parades); health promotion campaigns that encourage women to partic-

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<sup>7</sup> The history of social movements, analyses of the dominant patterns of women’s roles, as well as statistics on the gender of persons occupying high public positions show the existence of several barriers to organizational, legislative and mental hamper or even discourage women to political activity (cf. Walczewska, 1999; Graff, 2001, 2008; Penn, 2003; Lisowska, 2008; Fuszara, 2011; Siemieńska, 2011; Zielińska, 2011; Krzyżanowska, 2012; Hryciuk & Korolczuk, 2012).

ipate in scientifically controversial mammography screening programs or the scientifically unsubstantiated practice of breast self-examination; calendars of nude, post-mastectomy women to encourage surgery<sup>8</sup>; and illness narratives that allow readers to learn something about what it means to experience cancer personally. The absence of a feminist bioethics debate to problematize such processes of secondary socialization contribute to the construction of a women-friendly acquiescence to (bio)medicalization. Without consciousness that a woman's body (and especially her breast) is a battlefield between political, cultural, medical factions (cf. Yalom, 2012), such social relations help to distract the Amazons from their needs and from ways to formulate viable options for change. This is why, paradoxically, many Polish women view institutional agents as advocates for women's health.

It is difficult to assess the cost/benefit balance of Polish Amazons' partially self-imposed entrenchment in traditional social roles and processes. However, unequal social arrangements tend to diminish the possibility that the Amazons will find their place among organized groups of patients that hold a non-normative stance (cf. Łysak, 2007), as such participants would lack the all-encompassing and accepted message that the essentialists claim. Likewise, supporting representatives of biomedicine and politicians responsible for public health have become the *raison d'être* of Amazonian organizations, thereby thwarting critical thinking about the strength, limits, and uncertainties of biomedicine and health care delivery systems. With the rise of Internet portals and social media, more patients have started to make demands of medical professionals. However, cancer patients still tend to be the most obedient to medical authority.

**The trouble with gender: half-woman, holy mary,  
and the performance of womanhood as a group strategy  
for inspiring solidarity and benevolence**

For Polish women diagnosed with breast cancer, sex is typically framed along in accord with essentialist narratives revealed in personal

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<sup>8</sup> None of the eleven calendars previously issued contest the biomedical paradigm or what Susan Love has described as „slash, burn, poison” approaches to treatment. Some of them essentially advertise for the medical system by including a „guide to diagnostic procedures and treatments” and addresses for oncology centers.

stories featured in mass media, in-depth interviews, illness narratives (e.g. journals, diaries, memories), and the way in which their naked breasts are portrayed in artistic photographs.<sup>9</sup> Both the Amazons and the health and other professionals helping them to treat and manage their breast cancer emphasize the problem of losing one's womanhood through breast and hair loss (cf. Marcinkowska *et al.*, 2012). Even confronting the possibility of death may be less important to some diagnosed women than is the fear of hurtful reactions from others about their non-normalized appearance. A pseudo-clinical phrase that encapsulates this phenomenon is "the half woman complex" (cf. Mika, 2005). Women who are deprived of the "feminine attribute" (e.g. Chwałczyńska *et al.*, 2004) are perceived as inadequate, incomplete, or abnormal. Whereas Audre Lorde (1980) fiercely criticized camouflaging the "deficiency" with prosthetic breasts and/or wigs as a way of dealing with this stigma and concomitant social rejections, such insinuations fortify the mutilated femininity espoused by some Amazons.

Today the opposite strategy is in operation, a socially sanctioned, public de-stigmatization of breast cancer to encourage not only public acceptance of the diagnosed but also public admiration. Such de-shaming is carried out in multiple ways: a seemingly candid discussion about the disease and treatment; an overt display of scars in breast cancer photographs; the public sharing of private information, especially when it involves the blessings of medicalized recovery, such as breast reconstruction after mastectomy; the enthusiastic involvement in awareness campaigns and events (such as walking in the October marches, being a member of Amazon clubs, or wearing cancer emblems such as the Amazon Federation's badge, the pink ribbon). The de-stigmatization of breast cancer in these ways occurs seamlessly through mass media, proclamations from officials dealing with public health, doctors who assure their patients that medicine is capable of not only curing cancer but restoring Amazons femininity, and cosmetologists who offer a portfolio of services that promise to "look good" so they will then "feel better."<sup>10</sup> Such destigmatization could be viewed as a progres-

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<sup>9</sup> The only article in which the identity of women with breast cancer is described from the perspective of constructivist is „Written from the body...” (Wiatr, 2006). Its author is a sociologist who uses queer theory to show how women after mastectomy make use of cultural meanings to cope with the stigma of proteus and reconstituted femininity.

<sup>10</sup> There is considerable interest in workshops like „Look good, feel better” among Polish women – described by Ellyn Kaschak (1996, p. 194; see too Sharma & Black, 2001;

sive turn, but since the bulk of the messaging furthers adherence to biomedical authority and protocols may have the effect of decreasing women's choices and empowerment with regard to their own health.

Typically, Amazons affiliated with the clubs do undergo an image transformation following treatment for breast cancer.<sup>11</sup> They strive to look better (i.e., more womanly) by putting on make-up, dressing in frocks, fixing their hair. These actions ostensibly are to reduce the possibility that others might claim that the disease (or its treatment) may have left an indelible, corrupt mark on the body or gender identity. Moreover, this womanly appearance should also evoke strong associations with health and vitality to signify unalloyed optimism.<sup>12</sup> By conveying "healthy femininity" Amazons become "eligible" for public admiration. That said, the heightened attention that breast cancer has received in mass media during recent years has also elicited a sense of fatigue on the part of the public.

Likewise, even though members of the Amazon clubs try to duplicate the western "Amazonian optimism" that mass media and corporations find easier to advertise, they also recognize the role of the "everlasting sufferer." In Polish society, ideal womanhood is represented by Pieta, the Mother of God, viewed as courageous through experiencing excruciating pain after the death of her only son (albeit not the Virgin Mary;

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Ucok, 2007). And not only among new patients, but also long-term Amazons who are offered leadership training and "classes in make-up."

<sup>11</sup> As a result of treatment and an almost immediate awareness of the pressures surrounding diagnosed women to uphold the norms of femininity, some Amazons develop a new sense of gender – as if, once "disembodied" (denatured), they bear the sole responsibility of (re)constructing gender and so begin to engage actively in gender performance. For some women, this may evoke strategies utilised by drag queens who enact or parody femininity (cf. Malinowska, 2012, p. 110-13). Clubs that encourage women to "look good" through these workshops may be viewed as forms of secondary socialization (i.e., retraining women into femininity). Like a person in drag, volunteers enact a somewhat exaggerated femininity so that soon after treatment they will be seen by others as healthy, beautiful and not having cancer. At some point during the „performance" women might „expose themselves" to talk about their experiences with cancer, perhaps even baring a mastectomy scar but the point is not to raise consciousness of gender constructions (Joan Riviere, via Szczuka, 2001, p. 187). The purpose of the performance is to have shock value in which the patient may yet believe that her altered state can still be feminine.

<sup>12</sup> This image is in contradiction with the „sick role" and the popular expectations aimed at patients (see Parsons, 2010) and with former the representations of other diseases, which until recently dominated Western culture - especially tuberculosis (Sontag, 1999; see too Schubert, 2011).

Kościańska, 2012). Pieta's sorrow is framed in a way that corresponds to their experience of a mortal disease, and fear for their children and their future life (the bulk of Amazons are also mothers). The clubs do not arrange sessions of collective self-pity, but they also do not question the validity of expressing frailty, helplessness, or confusion (as Barbara Ehrenreich experienced when she tried to express such feelings in open forums; 2007). Amazons implicitly consent to the sharing of pain (physical, psychological, or existential) with other Amazons. In this way, the Amazons' Annual pilgrimage to the Black Madonna sanctuary to pray during a mass organized especially for them reinforces the predominant, deep-rooted belief that spiritual reconciliation is the right, and perhaps only choice they have as women to deal with their plight (Samson, 2010). Importantly, Amazons are expected to wear their own emblem during this ritualized practice (showing an archer); the pink ribbon is not appreciated.

Similar to their American counterparts, Polish Amazons do receive the social recognition that comes with an optimistic, feminine front. However, such recognition does not transform into political action, advocacy, or even comprehensive support. Social solidarity with the Amazon movement, wholly tied to traditional femininity and idealized womanhood, is fragile when it engages beyond these structures. Solidarity is no longer present for Amazons who decide to engage with what is still a masculine sphere of politics. Unfortunately, it is within the political sphere that citizens have the greatest chance of bringing about changes to the social system. It would be fruitful for Amazons to create political alliances that have the capacity to influence pharmaceutical and other companies, and to rethink their goals, strategies, and the barriers that prevent them from achieving them. To do so, they would need to access feminist and critical bioethics research, become involved in participatory research, establish patients' boards to evaluate government positions on public health, engage in grass roots political organizing and social media, and develop a broad based agenda that includes public policy recommendations.

### **Women's health, feminism, and epistemologies of ignorance**

The American turn toward a feminized consumption-based aesthetic undermines the feminist ideals that led to considerable changes in breast cancer policy and practice as well as the status of women as agents in their

own right in relation to biomedicine. However, the feminist legacy within the breast cancer movement remains and is visible within an array of breast cancer (and other women's health focused) advocacy groups. There is a common saying in Poland – "The American says, "I'm a feminist, but..." whereas the Polish woman says, 'I'm not a feminist, but...' – that speaks to the feminist underpinnings yet slippage of the United States breast cancer movement compared to the traditional gender binary that firmly grounds the Polish movement. Both scenarios view women's empowerment as central. However, there is still considerable silence, denial, and contradiction within both patient/ /advocacy contexts.

In our concluding analysis we discuss areas of epistemological influence (internal and external to the breast cancer movements themselves) in terms of Nancy Tuana's taxonomy of "epistemologies of ignorance," which highlights the ways resistance movements identify, critique, and transform ignorance to achieve their goals (Tuana, 2006). Tuana identifies these epistemologies as follows:

1. Knowing That We Do Not Know, But Not Caring To Know
2. We Do Not Even Know That We Do Not Know
3. They Do Not Want Us To Know
4. Willful Ignorance
5. Ignorance Produced By The Construction Of Epistemologically Disadvantaged Identities
6. Loving Ignorance

We discuss the role of such epistemologies within the American and Polish breast cancer movements.

### ***1. Knowing That We Do Not Know, But Not Caring To Know***

Breast cancer is fully institutionalized within both the U.S. and Polish medical systems, yet scientific information about prevention, causation, risk, detection, treatment, and aftercare remains in many ways controversial, abstract, and incomplete. Breast cancer has many misunderstood causes, and known risk factors (such as age, reproductive factors, inherited genetic mutations, postmenopausal obesity, hormone replacement therapy, alcohol consumption, and previous history of cancer of the endometrium, ovary, or colon) account for less than 30 percent of breast cancer cases (Hulka & Stark, 1995; Love, 2005). Few interventions reduce risk, and none of them prevent breast cancer.

In the U.S. context, the proliferation of medical information and personal illness narratives through the Internet, advice books, and self-help groups have advanced lay knowledge about preventive medicine and

medical treatment while simultaneously introducing new fears and anxiety about the multitude of options and outcomes. The origins of consumerism in the U.S. breast cancer movement, and health care more generally, are closely tied to the social movements of the 1960s and 1970s in which individuals and lay interest groups began to challenge the authority of experts and the dominance of the medical system. As consumers, individuals who used health services would be empowered to play an active role in making informed choices about their health. The social transformation from patient to medical consumer occurred both as trust in the American medical system eroded (Mechanic, 1996) and as the term “consumer” became the label of choice within health and social services and the medical system became increasingly more complex (Kapp, 1999; Hardey, 2001). The medical consumer is characterized as optimistic, proactive, rational, responsible, and informed.

Thus, there is pressure to “want to know” and the U.S. breast cancer survivor is socially and culturally predisposed to be an informed and self-determined woman capable of making empowered decisions. In many cases, breast cancer survivors/medical consumers do seek and critically evaluate information and then uses it to influence their medical experience. *Being an informed medical consumer is not always something people want to do or feel capable of doing. But the social obligation to be informed pressures even these people to find a way to get enough information to feel that they have made the best choices for themselves.*

In the Polish context, medical consumerism and the development of more cooperative doctor-patient relationships has not taken hold in the same way. Women patients have little to no knowledge about the biology of breast cancer and believe this knowledge lies (appropriately) with the doctor rather than the patient. Likewise, physicians evaluate patients and dictate which medical issues to take seriously and discuss with them. Perceptions and treatment of lymphedema provides a case in point. Lymphedema is an abnormal accumulation of lymph (fluid) in the arm, hand, fingers, wrist, elbow, shoulder, neck, breast, chest, or any combination of these areas, on the same side of the body that was treated with surgery or radiation. The excess fluid leads to persistent swelling and other symptoms, including pain, heaviness, firmness, tightness, and numbness. Although the condition is now taken more seriously in the United States (largely as the result of breast cancer advocates pushing doctors to address it) the condition still is frequently misdiagnosed, ignored, and routinely goes untreated. In Poland, the situation is even



worse and those who develop lymphedema after treatment often do not get help. Doctors assume that women brought the condition on themselves (i.e., carrying heavy bags or doing chores without resting) and do not feel obligated to treat it. Instead, it is assumed that post-treatment rehabilitation will remedy the problem. Unequal power relations between women and their doctors serves as a mechanism of preserving a medical hierarchy in which doctors' interests take priority over those of patients (Zierkiewicz, 2010).

### ***2. We Do Not Even Know That We Do Not Know***

There is growing evidence that people want to play a more active role in medical decision making, and that they experience better health outcomes when they do (Veroff, Marr & Vennberg, 2013). In this regard, patients may seek professional/expert knowledge to better understand their diagnoses, treatment options, and susceptibility to diseases and medical conditions. However, there are major gaps and limitations in a person's capacity to understand abstract scientific and medical information or know what applies to a particular diagnosis. A wider conception of health and illness in relation to society (i.e., lay knowledge) comes into play when patients/medical consumers engage with the medical system and interpret lay and professional information in the evaluation of their medical options.

In the United States medical consumers tend to want to be informed *enough* to believe they are responsibly and proactively making the right choices, but amid complicated or inconclusive information, this still requires people to place confidence in professional knowledge (Sulik & Eich-Kroh, 2008). As informed patients, political activists, and active participants in their health and medical care, the women's health movement and the feminist ilk of the breast cancer movement succeeded in expanding women's support networks and access to biomedical information in order to enhance their ability to engage with professional knowledge and increase their control in medical decision-making. The National Breast Cancer Coalition's Project LEAD, for example, teaches laypersons to understand technoscience in order to increase their understanding of the complexities of breast cancer and to use that information to influence public policy and research agendas. Likewise, the environmental breast cancer movement has used scientific research and biomedical knowledge to understand the relationship between breast cancer and the environment and work toward alleviation (Ley, 2009). By

encouraging women to be proactive, informed, and rational, the goal is to help women to judge the quality of their health care, understand medical evidence, and get the highest quality of care possible.

Despite this, new treatments are continually being developed, studied, and marketed as the ever-increasing abundance of specialized medical information enables the medical system to retain a level of authority such that they patients may not even know that there is information outside of their purview (Sulik & Eich-Kroh, 2008; Moynihan & Casels, 2005). This situation is especially applicable in Poland, where women patients are only beginning in recent years to establish peer-to-peer networks through social media and message boards that enable them to share information and experiences that might impact their decision-making. At the same time, traditional gender norms remain strong thereby limiting women's critical questioning of existing social institutions, including medicine. Polish psychologists further essentialist ideology by exerting the "half woman complex" on women treated for breast cancer, suggesting that they ought only be concerned with femininity and appearances. Since Polish women tend to view themselves as strong, brave, reasonable and innately powerful (especially vis-à-vis their feminine identity) they tend to see feminism as marginal, dangerous, or unnecessary.

### ***3. They Do Not Want Us To Know***

The systematic cultivation of ignorance is an ongoing issue in biomedicine. The information provided by pharmaceutical companies and medical technology manufacturers, professional associations, governmental organizations, advocacy groups, and others may omit negative research findings or unanticipated side effects, or they may otherwise misinform the public or demonstrate bias in favor of their preferred interventions and treatment modalities (Dwan *et al.*, 2008; Krzyzanowska, Pintilie & Tannock, 2003; Lewin, 2013). Mammography, either conventional film or newer digitalized versions, is the best known and most widely promoted imaging technology for breast cancer detection today. Between 1987 and 2000, the percentage of women in the United States over age 40 who reported that they had a mammogram in the previous 2 years increased from 39 to 70 percent. However, mammography emerged as the predominant technology to screen for breast cancer (taking top billing over Clinical Breast Exams) not because evidence showed it to be the best at the time, but because corporations and influ-

ential professional groups invested in the technology (Spanier, 2010; Sulik, 2012). In recent years, the minimal-to-no benefit of screening programs when it comes to reducing breast cancer deaths has become more obvious to some, as have the harms of overdiagnosis (i.e., finding breast cancers or conditions that are not life threatening and would not produce symptoms in a person's lifetime) and overtreatment (i.e., treating those conditions unnecessarily) (Bleyer & Welch 2005).

Physicians too may feel uncomfortable discussing the risks, harms, or potentially limited effectiveness of a particular medical intervention or treatment with patients and may err on presenting the "bright side" of an intervention (e.g., prettier breasts, after reconstruction; a slimmer body and nicer hair, after chemotherapy; or even a healthier social and personal life, after psychotherapy) (Ehrenreich, 2007; Carter, 2003; Kaschak, 1996). In handling the medical side of the doctor-patient equation, some physicians may even withhold information from patients in the belief that disclosure is "medically contraindicated" (i.e., therapeutic privilege) (Ellingson, Buzzanell, 1999). The American Medical Association advises physicians to assess a patient's capacity to receive information at any given time and tailor disclosure accordingly (Bostick *et al.*, 2006). In Poland, Amazons who try to discuss their health problems with oncologists are treated as "difficult cases" or persons who don't want to be healed. Knowing that asking questions or revealing lay expertise in medical environment is not well tolerated, women with breast cancer tend to hide their opinions (Mazurek, 2013).

#### **4. Willful Ignorance**

People also make medical decisions based on fear, convenience, or the desire to be given a limited set of choices rather than learning about the complexities and ambiguities inherent to biomedicine or the health care system in general. A patient may prefer not to be given the results of a test or the details about a diagnosis or treatment, learn whether a family member has a genetic abnormality, or obtain any medical information that lacks the certainty of a specific treatment protocol. Such knowledge can be distressing, futile, or even harmful. Likewise, physicians have major gaps in their understanding of biomedical uncertainties. Therefore, they may not know how to talk to patients about them, or they may follow off-the-shelf protocols rather than investigating evidence-based alternatives (Zwolsman *et al.*, 2013).

One of the leading public and international health institutes in Europe, the Swiss Medical Board, is a nongovernmental, independent health technology assessment initiative in Switzerland that functions under the auspices of the Swiss Medical Association, the Swiss Academy of Medical Sciences, and the Conference of Health Ministers of the Swiss Cantons. The Board is mandated “to contribute to the improvement of the health of populations internationally, nationally and locally through excellence in research, services and teaching and training.” After the board was called to prepare a review of mammography screening (Jan. 2013), it released a report of its findings, which were made public on February 2, 2014. Based on the board’s review of available evidence, it concluded that (1) no new systematic screening mammography programs should be introduced, (2) all forms of mammography screening must be evaluated for quality, (3) women must be given clear and balanced information on the benefits and harms of screening, and (4) systematic mammography screening programs in Switzerland—due to the tool’s limited utility for reducing mortality and the increased likelihood of harm from overdiagnosis and overtreatment – should be phased out (Biller-Andorno & Jüni, 2014).

The board’s strong recommendation differs dramatically from the “early detection is the best protection” slogans that pervade many breast cancer awareness campaigns and public health promotion programs internationally. Weighed against the slight benefit of repeated screening were the harms of increased biopsies and the overdiagnosis of breast cancers that would never have produced symptoms in a person’s lifetime or become clinically relevant. Overdiagnosis can increase the impact of cancer on quality of life and longevity because it leads to overtreatment, exposing patients to potential harms without offering any benefits. The Swiss Medical Board argued that beliefs in screening, rather than evidence, were at issue.

It is easy to promote mammography screening if the majority of women believe that it prevents or reduces the risk of getting breast cancer and saves many lives through early detection of aggressive tumors. We would be in favor of mammography screening if these beliefs were valid. Unfortunately, they are not, and we believe that women need to be told so.

The question is do the women want to know? In the United States, the answer is mixed.

### ***5. Ignorance Produced By The Construction Of Epistemically Disadvantaged Identities***

If cognitive authority is determined by the character of the speaker and perceptions of her or her reasonableness and intellectual capacity then the credibility of entire groups of people to engage with expert/professional knowledge may be called into question. The Women's Health Movement played a vital role in transforming how women would interact with the traditional medical system, influencing how they would understand medical care for themselves, their families, and their communities (Ehrenreich & English, 1989; Zimmerman & Hill, 2000; Morgen, 2002). As informed patients, political activists, and active participants in their health and medical care, the movement sought to expand women's support networks and increase women's sense of control. Envisioning women as informed and self-determined, capable of making empowered decisions, the notable *Our Bodies, Our Selves* (1973), placed women's health in a new socio-political context, helping to launch the national and international Women's Health Movement. Identifying and collaborating with individuals and organizations that provide services, generate research and policy analysis, and organize for social change, the book urged women to inform themselves about health issues (Sulik & Eich-Krohm, 2008).

Feminist efforts to expand women's roles as experts of their own bodies and medical decisions was been the center of social organizing as the U.S. breast cancer movement grew in the 1980s (Sulik, 2012). The term *survivor* was used strategically to de-stigmatize breast cancer and empower diagnosed women to take personal and collective action. Just as the survivors' movements against sexual violence used the survivor role to replace the role of victim, the breast cancer movement used survivor discourse to promote women's empowerment and personal transformation, and to give voice to previously hidden personal experiences. The words and perspectives of breast cancer survivors emerged in support settings, public demonstrations, and personal accounts.

In Poland, no such transformation occurred. The privatization and depoliticization of women's illness experiences of breast cancer occurred almost from the start of educational campaigns as they started to integrate into popular culture around 1995, especially in women's magazines. The magazine *Twój Styl* now devotes nearly an entire issue to breast cancer education every October, and this particular magazine played important role in establishing of Poland's "Day of the Breast Cancer

Fight” on October 17<sup>th</sup>. Whereas the magazine’s first issue re-published the compelling self-portrait photograph of artist Matuschka baring her mastectomy scar to reveal the devastation of breast cancer treatment on women’s bodies, subsequent issues changed in orientation. Breast cancer was not a feminist issue, but a medical and personal one. This is classic binary privileged professional medical authority and downplayed women’s experiences as emotionally laden. When other media and public institutions (e.g., the NHI) followed the magazine’s approach to reporting on the topic – namely the intimate personal story coupled with women’s innate vulnerability plus the added strength, courage and determination to face the breast cancer threat – paralleled the commercialized version of the breast cancer survivor in the United States (i.e., the she-ro). Since there was no critical activism to counter such portrayals, this transformation of the public sphere and health discourse surrounding breast cancer consistently avoided or omitted issue of gender and women’s self-determined empowerment. Ironically, recent years have witnessed a backlash to the public focus on breast cancer in Poland.

### ***6. Loving Ignorance***

While Tuana’s taxonomy of willful ignorance focused on difference, it opens a discussion of engaging with what escapes representations. Similarly, conflicting medical claims about risk, prevention, detection, diagnosis, treatment, follow-up – even the definition of what counts as life-threatening – appear almost weekly in news headlines. In sharing scientific controversies with the public, the stories often promote anxiety and confusion rather than confidence and clarity about how to make sense of the current state of knowledge. Ironically, a common “the more we learn the less we know” sentiment rivals competing headlines about “great new treatments” and “cures close at hand.” Are these headlines selling news by instilling fear, hope, and ultimately, confusion? Sometimes. Yet debates, doubt, and uncertainty are also essential to scientific processes. Biomedicine progresses through trial and error, hypothesis testing, and the systematic collection of evidence that both confirms and disconfirms developing theories. Over time, if it works as it should, this iterative process develops into a *body of evidence* to inform both clinical practice and the future of research. As researchers chip away at medical problems and develop more nuanced understanding of the conditions that affect them, they publish articles in medical journals to share legitimate uncertainty about what works, to which degree, what doesn’t, and why.

Proponents of feminist science add significant value to evidence based medicine in that it appreciates scientific knowledge as incomplete, uncertain, and relative. Feminist science views science as an intellectual activity conditioned by historical circumstances, societal beliefs, and accepted norms (Spanier, 2010). Feminist science scholars question how scientists set priorities, determine research questions and theoretical frameworks, engage in particular types of research methods, interpret data and validate knowledge, draw conclusions and make recommendations (Longino, 1990). Many of the key figures in the U.S. breast cancer movement used these kinds of questions to develop new support systems for the diagnosed and advance breast cancer research. Bonnie Spanier argues that the more radical (and feminist) elements of the breast cancer advocacy movement joined with the medical profession's evidence-based medicine efforts to make western and complementary medical systems more reliable and more consumer-based as well (Spanier, 2010, p. 99). In accepting what we cannot know and challenging what we do know, health social movements have the potential to improve the accuracy and reliability of science and medicine while promoting individual empowerment and health social justice.

## Conclusion

This comparison of the breast cancer movement in the U.S. and Poland, a first of its kind, opens discussion of the role of gender, feminism, and social context in creating health social movements, particularly when they involve a health issue that primarily affects women. By viewing these social movements in light of their feminist (or nonfeminist) underpinnings we see how women's status in the broader culture impacts collective action in addition to women's individual roles in relation to the medical system. Interestingly, the lack of feminist progress in Poland parallels the diminished role of feminism in the U.S. breast cancer movement as the illness/cause gained increased social status, visibility, and resources. The commercialization of breast cancer coupled with its embeddedness in an increasingly corporatized biomedical system is at odds with the empowerment potential of informed patients/medical consumers who are able to integrate lay and professional knowledge and thereby improve aspects of not only their individual health outcomes but of women more generally. It remains to be seen how either of



these nations will respond to increased medicalization and the technological imperatives that are now driving health and illness. Certainly, the women on the front lines of advocacy now face crucial decisions about which road(s) they will take to ensure adequate support for those diagnosed with breast cancer while attending to the epidemic at large.

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