Tracing the Role of Gender in the History of Breast Cancer Social Movements

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Breast cancer is a health issue of central importance as the most common cancer affecting Canadian women. One in nine women are diagnosed with breast cancer during their lifetimes; an estimated 23,400 women in Canada will be diagnosed this year and 5,100 will die as a result (BCSC, 2011). While sex is the single risk factor for breast cancer that all women share, considerations of gender shift and change throughout time reflect gender as a social construct that “extends beyond the boundaries of biologically defined categories of sex” (Benoit & Shumka, 2009, p. 7). Gender includes the social, cultural and economic factors that influence the socially constructed roles and relationships, personality traits, attitudes, behaviours, values, and influence assigned to women, men and other gender groups in a particular society (Clow et al., 2009, p. 11; Greaves, 2009, p. 3).

There are multiple symbolic meanings associated with women’s breasts in Western society, including representations of sexual pleasure

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and desire, nurturing and motherhood. Many people and groups seem to place a claim on the breast.

Men and women are aroused by it, artists represent it, poets apostrophize it, babies are nourished by it, fashion and commerce fetishize it—and disease afflicts it. All of these responses to the breast, including the last one, are conditioned, if not wholly determined, by the culture in which they operate. The breast attracts so much attention and is a site of conflict for so many of society’s values and beliefs that it often seems not to belong to a woman at all (Leopold, 1999, p. 1).

Women’s breasts are also now associated with ideas about danger and risk: the “risk of disease, risk of defeminisation, risk of deformity, [and] risk of death (Klawiter, 2008, p. xx). The public awareness of breast cancer and a perception of susceptibility and risk act to mobilize support for collective action (Brown et al., 2002). Health social movements have become central to research conducted by medical sociologists and anthropologists in order to understand the ongoing transformation of bodies, biomedicine and health care, and subsequently our experiences of health, risk, disability, illness, and disease (Klawiter, 2008, p. 289).

The breast cancer social movement is a single-issue movement as it is organized around one specific disease; however it is also one of the broadest of health social movements as it draws from multiple influences and crosses institutional domains, disease regimes, fields of contention, and cultures of action (Klawiter, 2008, p. 248). The groundwork for the breast cancer social movement began in the 1970s with public education work and the women’s health movement, followed by HIV/AIDS activism in the 1980s which provided a new model for public impact on health policy, and significant lobbying efforts for increased research in the 1990s. Based on findings from a critical literature review, this article will consider these factors and the continually evolving role of gender in breast cancer social movements and the illness experience. It will begin with an overview of the history of breast cancer and disease regimes to provide historical context before examining the emergence of breast cancer as a site for collective action in health social movements. Feminist, postcolonial and queer theories have pushed the boundaries of concepts such as woman, sex, and gender and highlight the importance of analyses in health that “contextualize women in their diverse social and economic circumstances and understand gender as inseparable from other forms of social difference such as race, ethnicity, culture, class, sexual orientation, gender identity and ability” (Morrow et al., 2007, p. 9).
The History of Breast Cancer & Disease Regimes

Historically, ideas about women’s risk for developing cancer were entangled with ideas about a woman’s “essential nature” (Jasen, 2002, p. 20). During the Enlightenment period (1750s-early 1800s), the association between menopause and cancer was supported by humoral theory which promoted the idea that the breasts become engorged and developed tumours after menstruation ceased and the body became ‘uncleansed.’ Disease theory during this time period was founded on the belief that health status was negotiated by the body and mind, with a level of responsibility placed on the individual themselves. The belief in psychosomatic causes of disease was especially strong, as “[w]omen made of frail fibers, were seen to have easily impressionable souls and unquiet hearts readily carried away by lively imagination” (Bronfen quoted in Jasen, 2002, p. 25).

There was a shift towards research at the cellular level during the Victorian era (mid 1800s-1900), although the association between breast cancer and hysteria was still common in medical literature in the late 19th century. Interestingly, it was during this era that public silence surrounding breast cancer became deeply entrenched. This silence was perpetuated by the notion that deaths caused by cancer were a social taboo in middle- and upper-class society, as well as being compounded by the breast’s association with sexuality and a violation of the mother’s nourishing breast (Jasen, 2002, p. 28-9; Schulzke, 2011).

Klawiter (2008) provides an important contribution to the literature surrounding a historical analysis of breast cancer social movements with an alternative approach focusing on the disease regimes in which breast cancer was medically managed in individuals and publicly administered in populations. Disease regimes are defined as consisting of the “institutionalized practices, authoritative discourses, emotional vocabularies, visual images, and social scripts through which diseases are socially constructed, medically managed, publicly administered, and subjectively experienced” (Klawiter, 2008, p. 33). The concepts of disease regimes are utilized to discuss the regime of medicalization and biomedicalization related to breast cancer.

The first regime of breast cancer, the regime of medicalization, originated during the early 1900s after a shift in impressions of the human body occurred. Humoral medicine was gradually replaced by scientific medicine which was founded upon new “technologies of seeing,” including the microscope and medical dissection (Klawiter, 2008). The research on breast cancer during the first half of the 20th century placed a significant emphasis on the natural pathology of the breast and away from causal factors outside the body, including dangers of “civilization” or trauma to the breast (Jasen, 2002). Though this process was initially resisted by both women and their physicians, it was
during this time period that breast cancer became distinguished from other cancers, with its own origins which could be treated through surgery. By framing breast cancer as a curable disease, this regime re-framed breast cancer patients as potentially curable (Klawiter, 2008, p. 75).

As scientific medicine was institutionalized, it became an elite profession with largely white, upper-class, Christian men acting as its practitioners. The regime of medicalization transformed the clinical relationship in terms of the power dynamic between physicians and patients, creating a new social script of the “sick role” which located the power and authority with male physicians and placed female patients in a position of compliance. The patient’s narrative about their illness experience no longer held significant value, but rather the diagnosis came from the physician who now focused on the body’s interior while subsequently creating new meanings of illness and reinforcing and reproducing the dominant gender order (Klawiter, 2008, p. 62-3; Schulzke, 2011).

During the regime of medicalization breast cancer was diagnosed through surgical biopsy and the Halsted radical mastectomy became the dominant treatment among North American surgeons. However, rather than performing two separate procedures, a radical mastectomy was performed if the biopsy results were malignant, while the patient remained unconscious. When the breast cancer patient awoke from the biopsy and radical mastectomy, she awoke “not as a cancer patient but as a mastectomee who had been successfully treated for a condition that was not called by name, at least not in front of the patient” (Klawiter, 2008, p. 77). The sick role which emerged in this regime segregated and isolated those who were ill from those who were not and did not allow for the forming of a collectivity. For instance, in the case of new mastectomees, patients were required to leave the temporary sick role and return to their regular lives and responsibilities immediately (Klawiter, 2008, p. 37).

It was during this period that a war on cancer was declared by government and the medical profession in which “only neglected cancer is incurable” (Jasen, 2002, p. 36; Boehmer, 2000; King, 2008; Potts, 2004a). Breast cancer patients who were subjects of the medicalization regime were shaped and influenced in particular ways: i) by experiences within their diagnoses and treatments; ii) by the norms of non-disclosure rooted within interactions between physicians, surgeons and patients; and iii) by the normalization processes which encouraged “cured” women to return to their daily activities and pass as “normal” women (Klawiter, 2008, p. 75). The regime of medicalization was deeply entrenched in traditional gender roles of this time period in which male surgeons and occasionally the patient’s husbands made the decisions regarding
women’s treatments without consulting the patient and requiring compliance and obedience on the part of the patient. Women were also blamed for failing to be vigilant in detecting breast lumps and engaging with the medical system which is reflective of traditional gender norms (Boehmer, 2000; Jasen, 2002; King, 2008; Klawiter, 2008; Schulzke, 2011).

A second regime of breast cancer, the regime of biomedicalization emerged during the 1970s and 1980s with new developments in biomedical research and cancer epidemiology. This regime moved discourses and practices of risk to the forefront and included changes in the practices of education and measures and promotion of early detection, diagnosis, disclosure, treatment, and rehabilitation. This included the development of new screening practices and the construction of all women, regardless of whether they are symptomatic, into risky subjects who are responsible for the status of their own health and must participate in the screening practices (Klawiter, 2008, p. 86).

During the late 1970s, feminist health activists argued against the one-step biopsy and Halsted radical mastectomy as paternalistic and patriarchal which denied women their rights to be informed of their diagnoses and participate in the decision making process, rather than the physicians, surgeons and/or their husbands making these decisions on their behalf (Boehmer, 2000; Klawiter, 2008). The processes involved in the medical management of disease include the emergence of informed consent, the refinement of surgical procedures, increased use of adjuvant therapies, redefining the roles and responsibilities of the roles of patients and physicians, and the development of rehabilitation programs which addressed the experiences of isolation among breast cancer patients (Klawiter, 2008).

Historically breast cancer was a private, even secretive disease associated with feelings of shame. Breast cancer emerged into the public domain in the 1970s through the influence of feminism and the women’s movement, as well as the role of the media and the public breast cancer cases of prominent American women such as Shirley Temple Black, Betty Ford and Happy Rockefeller who encouraged early detection and intervention (King, 2008, Sherwin, 2006). While these prominent women were willing to speak publicly about their experiences with breast cancer, it is important to note that their positions of privilege and status influenced their ability to do so.

Breast cancer was now framed as a disease at which every woman is at risk and that required continual vigilance by individual women. During this time measures of surveillance and detection were heavily promoted as the “moral duty” of women, including engaging in breast self-exams, clinical examinations and mammographic screening. The temporary sick role for symptomatic women from the regime of
medicalization was replaced by a permanent risk role for all women. While the processes involved in the regime of biomedicalization did not improve breast cancer incidence or mortality rates during the 1970s or 1980s, the subjects and social relations of the disease regime were transformed and created the conditions for collective action among the “risky subjects” including asymptomatic women, women in treatment for breast cancer, women at risk of recurrence, and women in remission (Klawiter, 2008, p. 38-40).

**Health Social Movements**

Women are often key actors in the mobilization around public health issues, including breast cancer (Williams et al., 1995). The tradition of hiddenness and invisibility associated with breast cancer led women to seek support from each other and to “form associations that could serve as the basis for organizing and taking action to improve treatment and to increase public awareness” (Schulzke, 2011, p. 43). Health social movements are formally defined as “collective challenges to medical policy, public health policy, belief systems, research and practice which include an array of formal and informal organizations, supporters, networks of cooperation and media” (Brown & Zavestoski, 2005, p. 1). Brown & Zavestoski (2005, p. 9) note three ways in particular in which health social movements are able to affect contemporary society. First, health social movements have the potential ability to produce changes in the public health care system in terms of health care delivery, social policy and regulation. Secondly, health social movements can affect contemporary society through changes produced in the field of medical science, including promoting new and innovative hypotheses and methodological approaches to research, as well as advocating for changes in funding priorities. Finally, health social movements can influence society by calling for processes of democracy within institutions that influence medical research and policy-making. Health social movements act as a “critical counter-authority aimed at democratizing and reshaping social policy and regulation in a way that transforms the socioeconomic and political conditions that underlie distributions of health and disease among populations” (Brown & Zavestoski, 2005, p. 14).

Brown et al., (2004, p. 60) contend that the traditional approaches to social movements do not account for the importance of the illness experience or the role of class in terms of access to health care or positive health outcomes. Until recently, the majority of health social movements focused more on expanding access to and improving the quality of health care as seen in health access and constituency-based movements. The third category of health social movements, embodied health movements, addresses some issues of health care access but focuses
more on the personal understanding and experience of illness (Brown & Zavestoski, 2005). Embodied health movements address the experience of disease, disability or illness by challenging science on etiology, diagnosis, treatment, and prevention. Interestingly, members of embodied health movements may also include people who are not ill themselves but see themselves at risk for the disease, as well as those who experience the disease through family connections. Examples of embodied health movements include the breast cancer movement, as well as the tobacco control movement and the HIV/AIDS movement (Brown, 2007; Brown & Zavestoski, 2005; Brown et al., 2004). While other types of social movements may possess one or two particular characteristics, Brown et al (2004, p. 54-5) contend that embodied health movements are unique in possessing three specific characteristics including introducing the biological body to social movements; challenging existing medical and/or scientific knowledge and practice; and activists' involvement and collaboration with scientists and health professionals in pursuing treatment, prevention, research and expanded funding.

The experience of the disease within the body produces a particular disease identity which represents the intersection of the social construction of illness with the personal experience of a biological disease process. It is important to note that those with the disease experience are in a unique position of living with the disease process, and the personal experiences, interpersonal effects and the social ramifications of the illness. This experience may also be shared with family and friends who engage in collective action related to the illness (Brown et al., 2004). Brown et al (2004) argue that the significance of the experience in the embodiment of a disease is reflected in the options available to an embodied health movement when it is mobilized. The personal experiences possessed by those with a disease identity within an embodied health movement prove valuable in terms of a lived experience and perspective that is not available to others, as well as a moral credibility to the social movement within both the public and scientific realms. A collective illness identity emerges when individuals develop a “cognitive, moral, and emotional connection” with other illness sufferers (Brown et al., 2004, p. 60).

The concepts of collective identity and disease identity are combined to create a politicized collective illness identity which is “linked to a broader social critique that views structural inequalities and the uneven distribution of social power as responsible for the causes and/or triggers of the disease” (Brown et al., 2004, p. 60). One of the factors involved in the development of a politicized collective illness identity is a common experience with the government, medical and scientific institutions involved in the creation of a dominant
epidemiological paradigm. Most illnesses in western society are viewed through a unique dominant epidemiological paradigm which involves a set of beliefs and practices about a disease, its causation and treatment that are embedded in science, government and public life (Brown et al., 2006; Brown, 2007; Potts, 2004b; Zavestoski et al., 2004). The dominant epidemiological paradigm is influenced by the biomedical model of disease which focuses on anatomy and physiology, and causes of disease at the cellular, hormonal and genetic levels (Rosser, 2000). This paradigm is characterized by a “hegemonic outlook on disease that emphasizes individual behavioural factors rather than environmental and social factors as keys to disease prevention” (Brown, 2007, p. 21).

The dominant discourse in both breast cancer research and educational campaigns is directly influenced by the dominant epidemiological paradigm which emphasizes individual-level approaches to prevention, detection and treatment, including changes in lifestyle, utilization of mammographic technology to detect tumours, and treatment options which include surgery, radiation and chemotherapy. This approach frames breast cancer as a preventable disease by placing the onus of responsibility on the individual in terms of managing personal risk factors and behaviours, including diet, age at first birth, alcohol consumption, smoking, and exercise. However, this diverts attention from risk factors which may exist outside of the individual’s control such as surrounding social, economic, political, and environmental factors that may contribute to the disease and its progress (Brown et al., 2006; Potts, 2004a; Zavestoski et al., 2004).

Activists criticize the biomedical model which they argue treats disease as a discrete entity occupying the body and in turn, the body as a discrete entity which is separate from the person occupying it (Brown et al., 2004, p. 61, 67). The critique situated within the politicized collective illness identity removes the onus of responsibility for both the treatment and prevention of disease from the individual and places it on social institutions. Brown et al., (2006) argue that challenges to the breast cancer dominant epidemiological paradigm are located primarily within the United States as a result of the strength of the breast cancer movement and particularly the environmental breast cancer movement; however I would suggest that the challenges to the dominant epidemiological paradigm are also occurring in other western countries, including Canada. Breast cancer social movements in both Canada and the United States have been directly influenced by the women’s movement and the HIV/AIDS movement.
The Influence of the Women’s & HIV/AIDS Movements on Breast Cancer Activism

The feminist movement in Canada shares many features with the larger movement which began in the United States during the 1970s, including providing resource and support services, and campaigning for increased research funding and access to health care facilities (Wilkinson, 2007). The most well-known message associated with the second wave of feminism during the 1960s and 1970s is the slogan “the personal is political.” The idea that the personal is political demonstrates that what appears on the surface to be a personal and private issue is often influenced by systemic power relations. This slogan “illuminates patterns of domination that had long been ignored and it provides the grounds for challenging apparently ‘natural’ gendered behaviours” (Sherwin, 2006, p. 6). This message has provided the foundation for many activist initiatives and transforming women’s experiences from personal issues into considerations for a public agenda through politicization (McCormick et al., 2003). Proponents of the personal is political message aim to both empower women and respond to these issues in a collective, political way (Sherwin, 2006).

The cancer movement has clearly been influenced by the women’s movement and women’s health movement in Canada and the United States as it has been organized around a feminist analysis which argues that cancer is a political issue (Boehmer, 2000). In a discussion about gender and determinants of health, Benoit and Shumka (2009, p. 5-6) note a systemic bias as a result of the historical health research that was based solely on the experiences of men and an inability to disentangle biological and social conditions which influence health outcomes. In terms of the cancer movement specifically, challenges include obtaining equal funding for women’s and men’s diseases and guaranteeing women’s inclusion in clinical trials where women were historically underrepresented. While this type of liberal feminism attempts to address gender inequality, it does not necessarily address issues of race, class and sexual orientation (Boehmer, 2000).

In addition to the women’s movement, the breast cancer social movement has been significantly influenced by the HIV/AIDS movement. The World Health Organization has divided the HIV/AIDS epidemic into three distinct time periods, including the silent period from 1970-1981, the initial period of discovery from 1981-1985, and period of worldwide mobilization from 1985-1988 (Boehmer, 2000). When considering the historical response by the gay community to the HIV/AIDS epidemic, Boehmer (2000, p. 13) notes that community-based HIV/AIDS organizations began with an uncritical view of biomedicine and with an expectation of a cure for the disease. However, because of what was perceived as an unsatisfactory response from the biomedical
community, this approach was quickly replaced by lay participation coupled with a critical political analysis of biomedicine and healthcare (Boehmer, 2000; Epstein, 1998). The social movement activism surrounding HIV/AIDS demonstrates the process of lay engagement with science and also how this engagement can shape the movement itself (Epstein, 1998). This was the first health social movement to change participants from being labelled as disease victims into activist experts (Epstein, 1998; King, 2008). The rejection of the label of ‘victim’ by HIV/AIDS activists led to the recognition that identity categories, the means through which people with disease are labelled and categorized, could significantly shape the course of a disease and society’s response to it has had profound implications for the formation and strategies of health activists movements in the wake of the AIDS epidemic (King, 2008, p. 106).

Despite significant differences in the history, biological and social epidemiology of breast cancer and HIV/AIDS, and despite the influence of the women’s health movement and feminism, it was the politicization of HIV/AIDS that paved the way for the politicization of breast cancer and the participation of women who had not previously been active in social movements (Boehmer, 2000; Klawiter, 2008). The dominant discourse on both breast cancer and HIV/AIDS often blames the individual, with individual behaviours and lifestyle choices including diet, exercise, age at childbirth, and utilization of mammographic technology in relation to breast cancer and choices surrounding safer sex and injection drug use related to the transmission of HIV. The attribution of blame shifts attention away from structural and external variables related to the incidence rates for both breast cancer and HIV/AIDS (King, 2008).

Breast Cancer & Cultures of Action

Since the early 1990s there has been an ongoing cultural transformation in which breast cancer has shifted from a historically stigmatizing disease of individuals suffering in isolation, to a neglected epidemic filled with public debate and political organizing, as well as an experience in which many women with breast cancer dismiss the label of “patient” and embrace an identity associated with being a “survivor” (King, 2008, p. x). The promotion of lay involvement and the validation of experiential knowledge aligns itself with the well-established concept in medical sociology and anthropology that people have an illness experience when suffering from a disease, condition or syndrome. Popular participation of the lay public related to breast cancer in both
science and politics has created a shift, moving the experience of breast cancer from a personal and private illness to a collective and politicized experience.

Klawiter (2008, p. 44) uses cultures of action as a “heuristic device for conceptualizing and mapping patterns of similarity and difference within social movements.” Cultures of action are produced by individuals, groups, agencies, organizations, councils, corporations, and coalitions and involve shared goals, assumptions and discourses among interactions involving allies and opponents. They change over time as a result of influence from the actions of members and relationships with other cultures of action, as well as the shifting dynamics in the discourses and practices the culture of action is attempting to influence (Klawiter, 2008; Zavetoski et al., 2004). Interestingly during the same time period in the 1990s and in the same area, three different cultures of action emerged within the Bay Area of San Francisco field of contention.

Moffett (2003, p. 290) contends that breast cancer advocacy groups have three goals in particular including i) raising awareness about breast cancer and promoting the use of biomedical processes, such as mammographic technologies; ii) providing emotional support for women in varying stages of breast cancer; and iii) raising funds or promoting that funds be allocated towards scientific research for breast cancer. This is reflected in the first culture of action; however it is not the case in the second or third as each specific culture of action had unique priorities and employed different discourses related to breast cancer, promoted different understandings about gender, race, class, and sexuality, as well as different identities and body politics (Klawiter, 2008).

1) Culture of Early Detection & Screening Activism

The discourse surrounding breast health began to emerge in the early 1990s; however these discussions about breast health were linked exclusively to breast cancer screening as part of breast cancer awareness and early detection campaigns. This is evidenced by the focus of the *culture of early detection and screening activism* which emerged in the San Francisco Bay Area and drew upon the strong evidence and science related to the detection and treatment of breast cancer (Brown et al., 2002; Klawiter, 2008). Similar to the breast cancer awareness campaigns of the 1970s and 1980s, this culture of action involves the promotion of breast self-examination, clinical breast exams and mammographic screening as life-saving technologies while simultaneously placing the onus of responsibility to comply with screening for early detection on individual women. Rather than engaging in contentious forms of protest such as the other cultures of action in this area, a culture of consensus emerged which “privileged the identity of ‘breast cancer survivor’ and
tied this identity to the physical display of heteronormative femininity” (Klawiter, 2008, p. 134). The discourse focused exclusively on a lack of awareness about breast cancer and financial, cultural and physical barriers to screening. The promotion of mammography within this culture of action framed every woman as a “risky subject” while increasing women’s concern about their individual risk of developing breast cancer. Concerns about access to mammographic screening for medically marginalized women, particularly low-income, uninsured women of colour became a priority at this time (Klawiter, 2008). It is important to note that this was not unique to the San Francisco Bay Area, but was also occurring nationally and internationally. One may draw parallels between these issues in the United States and similar concerns about access to mammographic screening in rural and isolated areas of Canada.

The representative symbol associated with the culture of early detection and screen activism is the now well-known pink ribbon. Based on focus group research, cosmetics company Estée Lauder created, produced and marketed the ribbon with the colour pink meant to represent heterosexual femininity and hope (Estée Lauder, 2010; Jain, 2007). The utilization of the pink ribbon in marketing campaigns which began in the 1990s has inextricably linked corporations and cause-related marketing with messages of breast cancer awareness that are grounded in a discourse that privileges the identity associated with survival combined with images of positivity, femininity, beauty and hope (Batt, 1994).

This culture of action blurs the boundaries between social movement activists, the state and private industry, while benefiting from the pink ribbon marketing campaigns and philanthropic activities related to breast cancer. The tangible successes of this movement lie in addressing the unequal access to mammographic screening in marginalized communities. This culture of action operates on a discourse of hope which advertises a sense of control for women through participation in early detection and screening activism, despite being risky subjects (Klawiter, 2008).

2) Culture of Patient Empowerment & Feminist Treatment Activism

The second culture of action that emerged in the Bay Area, patient empowerment and feminist treatment activism, occurred during a time when cancer was viewed as an “acceptable epidemic” (Klawiter, 2008, p. 164). Participants in this movement were influenced by the women’s health movement, feminism, and the lesbian community and worked towards creating a discourse that was feminist, anti-racist, not exclusively heterosexual, accommodating towards people with (dis)abilities, and also recognizes non-Western alternative therapies.
(Klawiter, 2008, p. 170). Addressing concerns of racism, classism and sexism allows for the framing of breast cancer as a disease which is influenced as much by factors of economic, social and cultural factors as genetics. Issues of breast health were addressed as situated in these plural environments and positioned in conflict with the culture of early detection and screening activism (Davis & Webster, 2002; Eisenstein, 2001; Klawiter, 2008; Potts, 2004a).

This culture of action constructed a feminist discourse to emphasize the importance of empowerment for breast cancer patients, as well as challenging the positive discourse of survival and the unscarred heteronormative feminine bodies that were utilized and promoted within the culture of screening and activism and in the mainstream media (Klawiter, 2008). Feminist activists challenge the positive discourse promoted by pink ribbon activists with narratives that drew attention to the false promises and misrepresentation of the cancer establishment, to the ineffectiveness of mammographic screening, the unreliability and toxicity of treatments, the chronic nature of the disease for many women, the inadequacy of research, the lack of scientific understanding and medical progress on the disease, the emphasis on individual risk factors, and the low priority given to cancer prevention (Klawiter, 2008, p. 175).

This positive discourse was challenged by creating social spaces which promoted alternative images, discourses and ways of embodying breast cancer (Klawiter, 2008).

The culture of patient empowerment and feminist breast cancer activism was founded upon a culture of caring and compassion for women diagnosed with breast cancer and advocating for direct services and support for women with cancer. While the feminist cancer activist supported the promotion of universal access to mammographic screening for all women, this culture of action also challenged the idea that unpleasant emotions such as sorrow, grief and aggression should be suppressed. Rather than using the symbolic pink ribbon, feminist cancer activists utilized “Cancer Sucks” buttons and photographs of bald, one-breasted women while arguing that the survival discourse and “pretty pink ribbons distorted the ugly realities of the disease” (Klawiter, 2008, p. 169).

3) Culture of Cancer Prevention & Environmental Risk

The third culture of action that emerged in the Bay Area in the 1990s, the culture of cancer prevention and environmental risk, frames breast cancer as a 21st century phenomenon by engaging with issues of
environmental health (Klawiter, 2008). It recognizes that the lifestyle choices and behaviours women are encouraged to engage with in order to prevent breast cancer, such as diet, exercise and age at which she has her first child, are significantly influenced by her socioeconomic status and her cultural environment and do not account for factors that are beyond her personal control (Leopold, 1999). Eisenstein (2001, p. 84) contends that the idea of bodies existing separately from their environments distorts the complexity involved and calls for a recognition of “the interpenetration of bodies and their overlapping environments.” In this perspective, “the gendered experience of breast cancer leads... [activists] to experience their disease not as a personal trouble to be dealt with through lifestyle changes, but as a condition caused by social and environmental factors that are shaped by powerful social institutions” (Zavestoski et al., 2004, p. 569). Similar to the feminist breast cancer activists, the environmental breast cancer movement problematizes the heterosexual norms of femininity that are utilized in the media’s portrayal of breast cancer through the involvement of the beauty and fashion industries in the events and campaigns associated with National Breast Cancer Awareness Month, and the mainstream breast cancer movement’s promotion of heteronormative femininities (Brown, 2007; Jain, 2007; Klawiter, 2008; Zavestoski et al., 2004).

Zavestoski et al (2004, p. 565) note three specific considerations related to gender which create difficulties in the attempts by activists’ to transform popular and medical notions of breast cancer and situate them into a broader social and environmental context. The constraints include depictions of activists as “hysterical women” which has its roots in the 19th century medical literature linking breast cancer and hysteria (Jasen, 2002). The second element includes a marginalized illness experience of breast cancer where women are socialized and encouraged to present themselves as having “normal” bodies. The “struggle for normalcy often begins as soon as the disease is detected, intensifies as treatment becomes more aggressive, and continues long after the disease is cured” (Schulzke, 2011, p. 37; Klawiter, 2008). Finally, the third element involves the sexualization of breast cancer through the media. While this sexualization results in greater media coverage, it also parallels the experience of breast cancer with the loss of one’s sexual identity which shifts attention away from important structural critiques (Zavestoski et al., 2004, p. 576).

This culture of action utilizes confrontational politics and public protests in its attempts to challenge private industry, local and state government, the other cultures of action, and public attitudes and perceptions. While the culture of early detection and screening activism uses the pink ribbon as its representative symbol and the culture of patient empowerment and feminist treatment activism uses the “Cancer
“Sucks” buttons, the culture of cancer prevention and environmental risk utilizes a poison skull to demonstrate the health hazards of environmental contaminants. Couch and Kroll-Smith (2000, p. 388) find that in this movement, there are “people who find the authoritative voices of science and medicine unable to make sense of their bodies and environments. Importantly, they are doing more than questioning the use of expert knowledge. Indeed, they often become experts themselves.” It is in this case that despite constraints, gender can also enable the efforts of activists. Perhaps most importantly, activists utilize their embodied knowledge and lay expertise which creates a unique perspective while they work to “transform personal experience into scientific knowledge and then into political action” (Zavestoski et al., 2004, p. 572; Potts, 2004b).

Each of the three cultures of action, the culture of early detection and screening activism, the culture of patient empowerment and feminist treatment activism, and the culture of cancer prevention and environmental risk provided important contributions to the breast cancer social movement which can be seen throughout the United States and Canada. The breast cancer movement provides a unique example of activists’ efforts that utilize ideologies from health, environment and women’s movements (McCormick et al., 2003). The cultures of action which emerged in the 1990s helped shape the breast cancer social movement into one of the popular and influential movements of the last twenty-five years (Klawiter, 2008, p. 277).

**CONCLUSIONS**

Breast cancer is an important area of research for developing critical theory, policy and practice (Wilkinson, 2007). Breast cancer in contemporary society has distinct similarities to the disease a hundred years ago. In both time periods, the medically accepted forms of treatment carry significant risks, cannot offer a guaranteed cure for the disease, and there are concerns surrounding the effectiveness of disease prevention (Leopold, 1999). Considering the history of breast cancer clearly demonstrates how something that appears to be an objective concept is influenced by cultural factors and the influence of contemporary beliefs about gender, the mind, bodies, and personal responsibility has implications for discussions of illness (Jasen, 2002, p. 42).

It is clear from examining the historical context of breast cancer that the role of gender evolves throughout time. This article demonstrates significant advances as a result of women’s health and HIV/AIDS activism more broadly and the breast cancer health social movement specifically, including women’s bodies being included in
clinical trials and research, as well as gaining the autonomy to make healthcare and treatment decisions. However, it is clear that gender still plays a role in the marginalized illness experience, the heteronormative images associated with pink ribbon campaigns, and the sexualization of breast cancer in the media.

Breast cancer is influenced by sociocultural, political, economic, and environmental factors, although these considerations should not dismiss the importance of the role of participants themselves in breast cancer social movements. An ethical and political shift in the conceptualization of risk would challenge the traditional expertise in biomedicine and acknowledge the legitimacy of lay knowledge claims and a citizen expertise in discussions of breast cancer risk (Potts, 2004a, p. 134). The “[l]ived risk is much more ambiguous and subjective than scientific risk, but it is no less real” (Jasen, 2002, p. 18). The value of experiential knowledge is demonstrated perhaps most clearly when considering that women with breast cancer and participants in breast cancer social movements have an embodied experience in relation to this risk; as it is described “[w]e are the body of evidence” (Potts, 2004a, p. 141).

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