

# Cancer Publics

## The Private/Public Split in Breast Cancer Memoirs

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*L'auteure a choisi quelques exemples de travaux de mémoires sur le cancer du sein, à la fois textuels et visuels, publiés au Canada dans la dernière décennie, tel le livre de Libby Znaimer "In Cancerland: Living Well in the Best Revenge," celui de Laurie Kingston "I'm Not Done Yet: Living Through Breast Cancer" ainsi qu'un documentaire par Gerry Rogers "My Left Breast." Utilisant la théorie sur les sphères intime et publique développées par Lauren Berlant et Michael Warner, le texte analyse les écrits des survivantes comme des exemples de performances publiques sur l'intimité de la maladie. Ces histoires construisent et régulent le corps qui vit avec le cancer montrant comment l'expérience individuelle de la maladie est basée sur des structures systémiques, institutionnelles qui légitiment le discours spécifique médical, culturel, social, politique et environnemental sur le diagnostic, les traitements et la santé.*

As we are beginning to grasp the epidemic proportions of cancer, especially in the developed world, it also becomes apparent that in response to the growing demands of the market, cancer-related life writing, including personal memoirs, practical guides and manuals, and inspirational materials, is expanding into a multi-million dollar industry. An emerging constituency of survivors, victims, and their families is a mass consumer target for these publica-

tions which often capitalize on intimate hopes and fears and exploit the vulnerabilities of people touched by this dreaded disease. Using Lauren Berlant's concept of "intimate publics," I want to explore breast cancer memoirs, both visual and textual, as the space of exposure and public outing of intimate encounters with illness. Symptomatic of the shifting of private/public boundaries, such cancer publics construct the stage where private intensities of a personal illness appear as publicly performed narratives or images, and vice versa, where dominant representations and institutions of healthcare, medical research, and public fundraising are seen as resonating with intimate force. I refer for illustration to three Canadian examples of this genre, including two recent books: Libby Znaimer's *In Cancerland: Living Well Is the Best Revenge* (2007) and Laurie Kingston's *Not Done Yet: Living Through Breast Cancer* (2009), as well as an earlier film documentary by Gerry Rogers, *My Left Breast* (2000).

Their uses of such media as a newspaper column (Znaimer) and a blog (Kingston), both of which later become published texts, and a video documentary, literally turn cancer life writing into a mass-mediated, technologically multiplied representation of personal crises. This is a mass-produced intimacy in a double

sense, as on the one hand, it seeks and produces its own publics, and on the other, it is organized through various, often competing, public discourses around diagnosis, treatment, and well-being. Such medical, therapeutic, environmental, spiritual, feminist, or popular culture discourses recast interpretations of the subjective experience of breast cancer, reminding us of the systemic, institutional forces that embody public norms and structure the intimate field, including the affective dimensions of one's encounter with illness and mortality. Following Berlant, it might be interesting to "track the processes by which intimate lives absorb and repel the rhetorics, laws, ethics, and ideologies of the hegemonic public sphere" (2) in breast cancer narratives.

I also draw here on Michael Warner's reflections on publics and counterpublics, which he describes as "public-sphere theory," and which can provide new insights into what feminists have famously theorized as the personal is political. If, as he says, every text is in search of its public, in examining cancer memoirs we must consider what it means to address oneself to a public or to imagine oneself as belonging to a public. As cancer patients, to many in the mass audience the authors of these memoirs would personify "dreaded embodiment." Indeed, they report catching glances of people who are repulsed or

uncomfortable with visible marks of cancer, perhaps because “they don’t want to believe it could happen to them” (Kingston 67). Insofar as the self and identity are experienced as both private and public, these cancer narratives can be instructive in trying to understand how selfhood is a function of having constantly to negotiate the territory stretching between the extremes of “abjection and degradation” and “cleanliness and self-mastery” (Warner 24). Putting themselves out there and addressing strangers, these authors are engaging both public idioms and intimate feelings, tying together discourses and affects. They model a difficult embodiment, a different sociability and solidarity, setting up hope for the possibility of further change through an intervention into what it means to be public as a cancer patient.

Looking at Libby Znaimer and her *National Post* columns, Laurie Kingston and her blogger friends, and Gerry Rogers and her partner Peggy Norman filming each other, we can begin by asking simply: Why do they decide to go public with their stories? It seems that the experience of the trauma of cancer diagnosis mobilizes the need for witnessing, as if one can only truly live it if it is lived out intimately and intensely in front of public witnesses. But there is another possibility, too, that this trauma brings about such awakening, such heightening of the senses, the feeling of aliveness that is both intense and vulnerable, that it spurs a desire to access the everyday more fully, and, in fact, invites what Svetlana Boym calls graphomania (168). At the same time, we need to understand how a desire to make an impact circulates in such texts and encourages the possibility of writing as activism, of articulating dissenting identities, and trying to unblock what is perceived as unsayable. By studying these processes we can make sense of different perspectives on the social world we inhabit because publics have “fateful consequences” on what social roles and subjects—victims? activists? consumers?—can be envisioned as

possible (Warner 12). What would be the most compelling challenges of cancer counterpublics? What questions would they encourage us to ask? What actions to take? Would they lead to the possibility of a new rise of organized movements against the abuses of our bodies and our environments by the cancer industry, the medical establishment, Big Pharma, and our governments?

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The phenomenon of “intimate publics” visible in the popularity of confessional narratives and TV reality shows corresponds paradoxically with the neoliberal embracing of an increasingly privatized notion of identity, constituting a marked departure from the feminist insistence on seeing the political in the personal. We need to ask how writers or performers of intimate publics deal with this potential privatizing of a cancer patient’s identity and its consequences? How do they reinscribe and/or challenge this tendency? What normative horizons or ideologies frame their productions? What motivations? Are they still steeped in the dualisms of active/passive, normal/abnormal, healthy and diseased bodies, similar to binary constructions of ability and disability that deny the fluidity of their continuum? As Michael Warner shows, despite the distinction, “different senses of public or private typically

intermingle” (as in the very phrase “intimate publics”) and “most things are private in one sense and public in another” (30). This is acutely felt in the context of cancer stories, where the intimate and intuitive knowledge of one’s own body competes with the positivistic paradigm of medical science and where the rights to privacy, bodily autonomy, self-determination, and individualism are often applied in contradictory ways. Quite often patients’ public right of participation in decision making clashes with denials of autonomy through impositions of treatment protocols on private bodies, or alternately, discourses of private blame or individual heroism overshadow the social, public dimensions of the experience of cancer. I argue that if we examine the public/private split through the politics of health, gender, sexuality, class, and race in cancer narratives, we can see what possibilities of agency and mobilization they offer.

Concerning issues of health and constructions of breast cancer as illness in all three memoirs, pitting a sick body against a healthy body is consistent with ambivalent perception of the public and the private that determines which bodies can be put on display and made visible. One of the motivating factors in producing those accounts may have to do with a sense of self as fractured by cancer and longing for a restoration of narrative coherence. All three women talk about a radical split and banishment from the public sphere into the private world of dreaded embodiment. There is evidence of the stigma attached to illness. They experience derealization and resistance to depersonalization: on the one hand, “It is not me,” while on the other “I am not just a cancer patient.” Thus they engage in public reconstructions of personal identity, since “an assertive and affirmative concept of identity seems to achieve a correspondence between public existence and private self” (Warner 26). In this sense, cancer writing responds to the need for overcoming that form of social domination

which imposes invisibility and denies public existence to the marginalized subject.

All three authors embody different constructions of a cancer patient. They are not statistically typical: Libby has a BRCA-2 gene mutation while Laurie is young and HER-2 positive.<sup>1</sup> Gerry is also less than 40 when she receives her diagnosis. Libby is deferential toward her medical team, putting on an infantilized, self-styled persona of “Cancergirl”—a self-presentation that underscores her initial neediness, dependence, and ignorance. However, this performance of a docile female cancer patient who needs “care, kindness, and knowledge from others” (Znaimer 47) is soon replaced by a professional persona, a journalist interviewing her own doctors for her public newspaper column. This causes a substantial shift in the power dynamics between Libby and her medical team. Operating like a reporter “on a breaking story” gives her a sense of mastery in managing “the sheer volume of information” (Znaimer 37). At the same time, she injects hedonism and lifestyle orientation into her project of becoming a cancer patient as “a tennis-playing, gym-going alpha female who doesn’t miss a beat!” (Znaimer 42), and who sculpts her body with a personal trainer. She sees her treatment “as a temporary annoyance” (Znaimer 180) that can be mitigated with application of cheerfulness. At first she keeps her diagnosis secret, showing evidence of internalized bias against “The C-word”—something whispered, something to be dealt with in private. Yet, she eventually makes a leap from self-abjection to self-empowerment, assuming a public voice—professional, confident, articulate—and using it to speak matter-of-factly of her “private” experience. The celebrity status that she enjoys among her readers helps to lift the veil of secrecy and shame from breast and gynecological cancers.

Unlike Libby, who resists this identity, Laurie acknowledges that she “will always be a cancer patient”

(Kingston 12). After her metastasis is found, she is dealing with a prospect of terminal illness and palliative care, but luckily, she responds exceptionally well to treatment. She points out some absurdities of the system and worries about the cumulative build-up of her treatments with herceptin. Both Laurie and Gerry are aware of the toxicity of their chemo drugs and the carcinogenic potential of radiation,

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which they find scary. Gerry registers her concerns about side effects and expresses strong ambivalence about chemotherapy. We see her in the intimate moments when she is at her lowest—in bed, in a bathtub, or in the bathroom in front of the mirror—chronicling the terrible toll the excruciating cancer regimen takes on her body. They both struggle to foreground their agency and control. While Laurie uses her blog to express irritation at the paternalism of medical practitioners, Gerry brings her camera to medical appointments, in the process “transforming objective “looking” into subjective “seeing” (Hartman 160) as she deflects the medical gaze and recasts herself from the position of being looked at to that of active looking.

It is important to note that their identity as cancer patients is articulated together with, or more accurately, through gender constructions,

and that different discourses around femininity are used strategically to shape the public/private sense of self. What publicly sanctioned aspects of femininity do they flaunt? To a varying degree, each encodes traditional femininity associated with obsessive body image, especially around the concealment of hair loss, weight, fashion, shopping, maternal and wifely roles, and emotionalism. Gerry is the only one who openly challenges the oppressive politics of hair by engaging her entire community in a gigantic wig-making project, an equivalent of queer quilt activism, for which she solicits hair from all sources, including pet animals. The other two women record certain normative expectations of sunny disposition, of women being “nice” and easy-going, not cranky or angry. Laurie, for example, adopts a non-threatening persona inscribing conventional norms of selfless femininity defined through domesticity and motherhood. Even the “self-help” aspect of her multiple lists intended for other women is consistent with the female norms of providing care and nurturing. This strategy gains her the establishment’s endorsement in the form of Dr. Robert Buckman’s cover blurb and allows her to include mild critiques of public constraints on women’s subjectivity that prohibit expression of negative emotions to mothers and female cancer patients and recommend strength, self-control, and positive thinking. However, such critical interventions are couched in discourses of gratitude, modesty, ordinariness, and maternal sentiment, much the same as dark emotions are always cushioned with hope and programmatic optimism. Yet, while Laurie occasionally indulges in the comforts of traditional middle-class femininity and consumerism, her inscriptions of joys of ordinary life can be seen as subversive because the right to normalcy is supposedly incompatible with her situation as a cancer patient.

As Laurie uses her blog writing so as to distance herself from mixed emotions of doubt, fear, anger, and shame,



Irene Gust, "With Cancer Alone at Home," 2008, photo montage, 60 cm x 84 cm.

we recognize a socially sanctioned focus on attitude as a way of coping. Hence, rather than conducting sustained institutional critiques, cancer patients cultivate discourses around a personal attitude such as Libby's "Living well is the best revenge" or Laurie's "Badass Superhero" (Kingstone 221), wearing T-shirts imprinted with such messages as "Cancer can kiss my ass" (Kingston 91), or "Cancer is bad, but we will be badder" (Kingston 92). But unlike Libby, who completely trusts her doctors, women in Laurie's circle resign themselves to a kind of common knowledge that the medical system is of no use in many situations and rely on each other's accumulated experience in dealing with side effects. The phrase "Don't ask your doctor. Ask other women" (Kingston 99) reflects this pragmatic distrust of medical authority.

Consequently, there are significant differences in how each text constructs counterpublics to hegemonic perspectives on cancer. Libby refuses to recognize a public, political significance of her personal experience and its connections to a systemic problem.

A misread mammogram is an individual error; she doesn't challenge the diagnostic and treatment protocols. She extols pharmaceuticals as the highest achievement of science. The "why" of cancer is to her an "irrational question" (Znaimer 110), possibly because her case is linked to genetics. But not asking investigative questions about the etiology of cancer and the industry behind it and repeating the medical mantra of early detection (Znaimer 167), she contributes to naturalizing cancer as inevitable. She rejects the whole dimension of cancer linked to oppression, scoffing "the culture of victimhood" (Znaimer 203) and political correctness in such labels as "survivors" and "battle" with cancer (Znaimer 204). Her suggestion that we abandon this imagery and find another, to convey "the random ordinariness of a cancer diagnosis" (Znaimer 205), confirms her tendency towards normalizing this disease.

In contrast to Libby's individualism, Laurie becomes more and more radicalized, getting involved in collective action, from blogging to

conferences, and gradually incorporates political themes into her entries, passionately addressing the politics of pink and commercialization of breast cancer, as well as holding individual experts and health care providers to a higher standard. Similarly, Gerry is committed to documenting the ravages of brutal treatment regimens on her body and emphasizes the healing role of the community. They both offer an implicit polemic with Libby's "party girl" persona (Znaimer 107), by categorically refusing to see anything "sexy" in breast cancer (Kingston 115). In the section "Why I Write," Laurie reflects upon the public/private conflicts and contradictions of online journaling as a form of public exposure and self-censorship (Kingston 52). She politicizes her decision to go public in response to silence and denials of the severity of the cancer epidemic in the media.

Cancer memoirs confirm what we already know, that "not all sexualities are public or private in the same way" (Warner 24). Libby and Laurie reproduce heteronormative assumptions that the spouse or a partner is always

male, which clearly constructs a heterosexual public. They both impose heteronormative rules by silencing references to lesbianism (in Laurie's elision of her favourite singer Melissa Etheridge's sexuality) or flaunting sexist stereotypes (in Libby's fear of looking butch with her new growth of hair). The chapter in Znaimer's book called "Cancer and the Spouse" is a striking example of such oppressive exclusionary strategies mirroring the dominant public attitudes in enforcing the invisibility of lesbian couples. She not only reproduces the clichés of a heterosexual couple "doing it together," but also uses stereotypes of "tough" men "finding their own way of being useful" as a foil for her femininity (Znaimer 53). In this context, Gerry's filmic narrative has an important role to play, providing identification for a counterpublic by chronicling the lesbian couple's experiences with cancer that depict their intimate partnership and affection. She records her desire for love and tenderness amidst her suffering from the ravages of treatment and articulates her longing for pleasure, peace, and touch that will make her feel alive again. Framing the lesbian body through the caressing embrace of the lover's camera lens challenges the heteronormative gaze and celebrates the beauty of their relationship.

Similarly, these cancer narratives complicate the notions of class, white privilege, and the possibility of agency. We must ask: What admissions of economic privilege do they make publicly allowable? Is class privilege politicized or seen merely as a private matter of being "lucky"? How does it impact issues of social networks of support, institutional options, and access to experts and specialists? The three situations described in these memoirs span the range of possibilities from corporate entitlement to self-advocacy and rural neglect. Libby's privileged way of occupying social spaces translates into easy navigating of the health care system, giving her private access

to the medical establishment (she has her surgeon's pager number), CEOs, and people from the hospital foundation. She has benefited from counseling provided by CAREpath, a private company that runs assistance programs for well-insured corporate clients, whose services are out of reach for an average cancer patient. She focuses mostly on how cancer affects professionals, or people "in the public eye" (Znaimer 195), whose list includes Elizabeth Edwards, Marla Shapiro, Pamela Wallin, Beverly Thomson, or Wendy Mesley. Libby's class privilege is revealed even in her playful public wig poll: the idea that the *Post* readers should vote for the best wig for her, each of those natural hair wigs costing over a thousand dollars. Consequently, what she advocates is charity rather than activism, starting a hospital initiative to raise funds for needy "women who can't afford wigs" (Znaimer 86). Her shopping mall attitude to cosmetic surgeries and treatment options serves further to normalize and privatize cancer and ignore its political dimensions.

While Libby's privilege is extreme, the other two women also enjoy the benefits of their economic position even though as "ordinary" patients they have to be their own advocates. Hospitals make mistakes; Laurie's mammograms showing that she had cancer were initially shelved in the film library for several weeks. What stands out is Gerry's rural isolation and lack of direct access to such services as support groups. We see her talking over the radio with other women survivors or walking to the post office to collect packages for her wig-making bee. Yet, they all experience the impact of cancer on their work and are compelled to renegotiate their status. Significantly, they use this traumatic moment to find new professional roles for themselves. Libby, who initially fears that going public about her cancer will make her unemployable, and who actually suspects some existing gender bias, uses journalism to gain a sense of

mastery over her illness. Similarly, Gerry frames the experience of cancer through her filmmaking skills and literally and symbolically makes her living through it. And although Laurie loses her job with the union due to her chronic condition, she embraces new dimensions of herself as writer and activist, developing a sense of herself as "a creative person" (Kingston 251).

Whether it is an online journal, a newspaper column, or a film documentary, the cancer memoir constructs intimate publics in a paradoxical way creating a distance from self for the subject and a sense of proximity for strangers. For all three authors it has led to the creation of "virtual" friends, supporters, and sympathizers—people who care enough to send "nearly five hundred emails in a week" (Znaimer 83) to a newspaper columnist. Through blogging, Laurie has found "the community of strong, smart women who write openly and with great humour about breast cancer"—many of them activists who take on the cancer industry or look for a creative outlet to take a rebellious or celebratory stance (Kingston 12). The entry "Hi, Honey, I'm Home" is her love letter to her fellow bloggers, showing to what degree this public also mutually constructs her:

While it would be untrue to say that I cease to exist without you.... I do know that you help me to understand my thoughts and provide a venue for me to say the things I dare not speak aloud, even to myself. You are a reflection of me, a place for me to process my thoughts and figure out how life's events have made me feel. (Kingston 138)

One might ask, looking at Libby's, Laurie's, and Gerry's constructions of publics, When does a public become a community? Perhaps one difference might be located in the imaginary and spectatorial character of the public as opposed to the active involvement and presence of community mem-

bers for each other. However, these boundaries are fluid as participation in a public does create strong affective bonds between strangers (such as readers of a newspaper column or viewers of a reality show). Still, I believe that there remains a distinction to be made between community building and participation in this kind of “intimate public” which creates an illusion of proximity while maintaining separations among individual consumers-subjects.

Women’s cancer narratives are of particular interest to feminists because this type of life writing gives public, political relevance to personal accounts, in the consciousness-raising tradition of social movements, and enables an intersectional development of personal self-understanding, in the tradition of standpoint epistemologies. As the private experience of cancer is open to institutional intervention and interference on many levels, these stories reveal the public nature of the private, the internal connections that exist between being a cancer patient and the political, economic, environmental, social, and medical contexts. Moreover, the slogan “the personal is political” suggests that not only personal life can be transformed by political action, but also that politics is a function of personal location, that any views expressed by the writing subject must be seen in the context of her unique positioning, her experiences, and her subjective interests related to intersectionality.

In the final analysis, cancer narratives demonstrate the intermingling or fusion of the distinction between public and private. They indirectly compel us to ask repeatedly: Should nothing be private? Or should everything be privatized? The answers to these questions have consequences for women’s rights and for state actions. Sometimes “going public” is needed to entrench the right to private life, as in Gerry Rogers’ open depiction normalizing a lesbian relationship; at other times, cancer narratives enable us to see the dangers of privatizing

the public responsibility for care by not asking the right questions about cancer politics (as Libby does). The concept of “intimate publics” can be turned into a neoconservative strategy of containment and depoliticization, a far cry from the feminist slogan “the personal is political.” In the time of mass-mediated intimacy, the personal that is put on public display is not always political. It is not necessarily aimed at exposing the abuses of power but rather inviting acquiescence to the status quo. Yet even if it is not displayed for political reasons, it yields itself to being politicized through critical reading. In fact, the pink ribbon campaign represents a good example of such depoliticized “intimate publics,” attesting to how attempts to divest the stigma of shame and secrecy that had kept the experience of breast cancer locked up in the private sphere, away from the public, have been co-opted by the market to boost its profits and to raise funds for cancer research which, in turn, is becoming increasingly privatized.

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<sup>1</sup>BRCA1 and BRCA2 are breast cancer genes whose mutation increases susceptibility to breast cancer. Genetic abnormalities in BRCA1 and BRCA2 are more common in Ashkenazi Jewish women than in other women. Women with inherited breast cancer gene mutation are also at increased risk of developing ovarian cancer. On the other hand, her2 is a protein whose presence increases aggressiveness of breast cancer and its recurrence risk. Age is also a factor in breast cancer since younger

women tend to have more aggressive tumors than older women.

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