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Résumé de l'article

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GOING FLAT: BREAST CANCER, MASTECTOMY AND THE POLITICS OF CHOICE

ABIGAIL B. BAKAN

Abstract: Breast cancer, if it advances, is life threatening. It is also widespread. My life was changed when I was diagnosed with breast cancer. There was much that I did not expect, including a hegemonic culture of "breast conservation." I opted to "go flat" after bilateral mastectomy, resisting reconstruction plastic surgery. A politics of choice-like that demanded for reproductive rights—has yet to find similar resonance in the world of breast cancer treatment. This article considers reconstruction hegemony and the emerging movement to advance the choice to be, in words coined by a pioneering Facebook group, Flat and Fabulous.

Resume : Le cancer du sein, s'il se développe, est une menace de mort. Il est aussi très répandu. Ma vie a été transformée lorsque j'ai été diagnostiquée avec un cancer du sein. Il y avait beaucoup de choses auxquelles je ne m'attendais pas, en particulier l'hégémonie d'une culture de la préservation du sein. J'ai choisi d'adopter l'"option platte" après une double mastectomie et de résister à la tentation de la chirurgie plastique de reconstruction mammaire. Une politique du choix-comparable à celle qui s'applique aux droits de reproduction-n'a pas encore trouvé d'écho dans le domaine du traitement du cancer du sein. Cet article considère l'hégémonie de la reconstruction mammaire ainsi que l'émergence d'un mouvement promouvant le choix comme étant-selon les termes inventés par un groupe de pointe sur Facebook—"plat et parfait"!

INTRODUCTION: BREAST CANCER, MASTECTOMY, AND THE POLITICS OF CHOICE

reast cancer is scary. If it is left untreated, the cancer will advance and become a life threatening disease. According to data collected in 2017, breast cancer will take the lives of an estimated 5,000 women in Canada per year ("Breast Cancer Statistics"). Breast cancer is also a gendered disease. While men are susceptible to breast cancer, the rate of diagnosis is much less than for women, with estimated deaths at 60 per year according to the same data. These scary statistics, however, are not isolated abstract figures. They are also associated with politically and socially constructed barriers that limit access to information, quality public health care, and other forms of economic, gendered, racialized and health-related support (see Lorde; Sontag; King; Hendler; Turner; Brenner). All diseases demand attention from multiple disciplinary lenses (consider, for example, the social and political factors that enter into experiences of HIV-AIDS, cholera, malnutrition, or the recent COVID-19 pandemic). Cancer, however, requires an especially interdisciplinary analysis; it has proven to be particularly entwined with and shaped by the stigma of death (Mukherjee).

For those who are able to access effective medical treatment, particularly in the early stages of the disease, the risk of death from breast cancer however drops steeply. Significantly, 87 percent of those diagnosed with breast cancer will survive at least five years ("Breast Cancer Statistics"). Many will live long, healthy lives, and moreover, survival rates are increasing. Between 2003 and 2012, the death rate declined by an average of 2.6 percent per year, and the death rate today is the lowest recorded in Canada since 1950. The Canadian Cancer Society estimates that between 1987 and 2012, over 32,000 cancer deaths were avoided ("Breast Cancer Statistics"). The reason for this decline is widely considered to be based on the expansion of cases that are detected at an early stage, in the case of breast cancer through mammographic screening and improvements in treatment options. Most of us are touched by cancer, either in our own health conditions or through the experiences of friends or loved ones. As life expectancy increases, one in two will face a cancer diagnosis according to projected averages. And most will live for some time even if diagnosed with cancer—overcoming, coping, or adapting as treatments continue to be researched and made available to designated populations. Importantly, even many who have been given terminal cancer diagnoses live long and healthy lives (Turner). We need to dissociate cancer from presuming an outcome of death, and begin conceptualizing a rich and meaningful life *after a diagnosis* of cancer.

In 2016, my life was changed when I was diagnosed with breast cancer. This occurred from a routine mammographic examination, unaccompanied by any palpable symptoms. Suddenly I became one of those statistics. There was much that I did not expect, one aspect of which was a hegemonic-or dominant-culture of what is referred to in the medical profession as "breast conservation" (or "breast-conserving" surgery and treatment). The challenges and problematic nature of the hegemonic culture of breast conservation is the subject of this article. I was privileged to be able to access the most advanced medical treatments available; I was and remain surrounded by multiple communities of outstanding support; and I have now been given the "all clear" following the original diagnosis. However, following a bilateral (double) mastectomy, I was also met with a barrage of highly sophisticated and unexpected information, and considerable formal and informal pressures, regarding how to cope with my treatment. Specifically, I was repeatedly invited to "replace," "rebuild," and "reconstruct" the absented breasts. I found that my decision to adapt to my new, disease-free body by "going flat" brought me into an emergent, new political moment.

Surgery is the first line of treatment for breast cancer. However, as my experience demonstrates, treatment often comes along with much more than medical attention. The Canadian and US medical community overwhelmingly advocate for breast conservation. But how does one respond to such a standardized norm? It seemed to me that there should be some choice here.

My research and experience have indicated that life after breast cancer is currently framed according to a presumption of breast deficit—in other words, that mastectomy only means loss, lack, and absence. In my experience, however, there is also much that is gained from the experience of "going flat", and this needs to be understood for its positive elements as well as the negative ones. Breast reconstruction has been and will be a positive and healthy option for some women. But, a politics of choice—such as the politics that came to mark the movement for reproductive choice in Canada—has yet to become the norm in breast cancer treatment. Choice is conceived here as enabling those diagnosed with breast cancer to consider available treatment and post-treatment options without pressure based on gendered and patriarchal norms that idealize female breast conservation as the optimal outcome.

Advancing genuine choice regarding life after breast cancer is timely. Given that more women are living after treatment of breast cancer, the political and social contexts that shape treatment and post-treatment options—*choices*—are starting to be revealed, bringing the hegemonic attitude towards breast reconstruction into sharp relief and contest. The remainder of this article is divided into two parts: the first critically examines the hegemonic promotion of breast conservation and reconstruction; the second turns to Flat and Fabulous—a name drawn from a Facebook support group for women who choose not to have reconstruction after breast cancer surgery—and the politics of choice. The article concludes with some considerations for future advocacy and research.

BREAST CONSERVATION AND RECONSTRUCTION HEGEMONY

moment of reflection and personal ethnography might assist in contextualizing this argument. Once I made it clear that I was not interested in reconstruction, I was informed by a caring practitioner associated with the hospital where I was treated that there was an offer to "change your mind at any point." There is apparently no statute of limitations in Ontario for publicly insured reconstruction following breast cancer. I found myself sur-

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rounded by experienced and expert breast cancer professionals who confirmed this-doctors, interns, nurses, social workers, receptionists, and volunteers. At almost every turn, I was asked if I wanted to have reconstruction during or after surgery, even though I had made it abundantly clear that I did not. There was obviously an institutionalized directive to "inform" patients about reconstruction, repeatedly, and even after it was recorded that such information had been duly delivered. I felt that there was a sort of collective, unspoken professional anxiety about my decision to live as an adult flat-chested woman. I was informed, again repeatedly, that I would likely regret my decision. This is part of a general culture of paternalism that is normalized in the breast cancer medical world (see Lagnado). I was surprised, however, to learn how deeply this paternalism has affected treatment options for breast cancer. My choice to "go flat" was, apparently, at best unusual and unfamiliar, at worst considered selfdestructive. While this was not easily traceable to any single source, the general culture of "offering reconstruction" was clearly the norm among practitioners. The aim was to ensure that I was really, fully, truly informed of the option to have new breasts "reconstructed" either from transplanted tissue (autologous reconstruction) or using breast implants.

I was invited shortly after diagnosis to attend an annual event that takes place in over 30 cities across Canada and the US: National Breast Reconstruction Awareness (BRA) Day ("BRA Day"). I attended the Toronto event in October 2016, and learned a great deal, not least about hegemonic breast conservation. The event featured practicing plastic surgeons who specialized in the procedure, and women who had reconstructed chests, in well-planned public presentations. BRA Day also featured numerous information booths as well as a "show and tell lounge," where women with reconstructed breasts shared shirtless stories. Significantly, National Breast Reconstruction Awareness Day traces its origins to an initiative by a Canadian plastic surgeon, Dr. Mitchell Brown, in 2011. Brown is credited with coining the expression "close the loop on breast cancer," now a brand slogan for BRA Day ("Breast Reconstruction Awareness Day" 1).

The event, *inter alia*, is presented with a tone of joy and celebration. It forwards the potential for newly built "breast mounds" to redress the sense of loss that comes from breast deficit. For those who have already concluded they are seeking reconstruction, it is likely very useful. However, it is also seemingly untroubled by decades of feminist and intersectional analyses of the patriarchal gaze and objectification of the female body. In fact, impressionistically, diversity does not even figure into the projections and images associated with the extensive material promoted by BRA day in Toronto, a city known as one of the most ethnically diverse in North America. Indeed, even the history and context of the idea of breast augmentation in the medical field seemed oddly absent (see Peters and Fornasier). Instead, the event praises the plastic surgeons, mostly but not exclusively male, and their skill in rebuilding absented female breasts ("All About BRA Day"; see also Hill et al.).

Certainly, the event is not intended to be anything more than a day of information to enable options and support for those who are on a path towards reconstruction after breast cancer surgery. Perhaps criticism due to omission could be read as unfair. However, based on my own experience at the October 2016 Toronto event (the first to be organized after my diagnosis and treatment), as well as the October 2018 Toronto event (which I attended with the eye of a researcher), and related research, the messaging is dangerously one-sided. Indeed, breast reconstruction is presented as a necessity to "close the loop on breast cancer," turning the iconic pink ribbon, which is open at the bottom, into a closed, and complete, figure eight. Women are invited to be and feel "whole" again when they sport reconstructed breasts. Then they will be, apparently, fully healed after the physical and emotional hardships of a breast cancer diagnosis and treatment.

With many years of my own and others' feminist scholarship and activism upon which to stand (see Bakan and Stasiulis; Bakan and Kobayashi; Abu-Laban), it soon became obvious that there was a need for greater attention to a politics of choice in the world of life after breast cancer. There have been, arguably, several waves in breast cancer treatment, as there have been in feminist theory and activism generally, even if the framework remains contested (Orr

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et al.). Historically, breast cancer was commonly treated with "radical" mastectomies, a major surgical intervention which removed the entire breast as well as lymph nodes and portions of muscle tissue along the chest wall, and sometimes additional bone mass. This method was advanced by Dr. William Stewart Halsted (1852-1922), who established a school of breast cancer treatment grounded on the principle of ever-widening surgical excision particularly associated with the Johns Hopkins Hospital (Halsted). Another US surgeon, Willy Meyer, independently advanced the same surgery as a way to treat breast cancer (Mukherjee 60-72). The results, in terms of treating cancer as a life-threatening disease, were significant; women who were diagnosed with breast cancer and treated with radical mastectomies lived longer. However, the impact on their quality of life following the surgery was harsh: "With the pectoralis major cut off, the shoulders caved inward as if in a perpetual shrug, making it impossible to move the arm forward or sideways" (Mukherjee 65).

Fortunately, over time this standard treatment has come to be seen as unnecessary (Veronesi et al.). The transformation in standard treatment is itself a product of advocacy for women's health as well as advances in medical research regarding cancer generally. Currently, mastectomy is commonly seen as a last resort following other treatment options, and when conducted is normally a "simple" mastectomy surgery that preserves the musculature in the chest wall. Advocacy for "breast conservation" therefore follows a wave of advance in the treatment of breast cancer that is related explicitly to wider advances in women's rights and women's health.

Enter the issue of breast reconstruction. This can be seen as consistent with attention to breast conservation as a challenge to the predominant reliance on radical mastectomies. However, breast reconstruction is not a treatment for cancer, but addresses the results of surgery that are part of cancer treatment. For some women, reconstruction has led to a sense of restored health, agency, and wellbeing following the devastating realities of breast cancer diagnosis and treatment (Anstett). But this major and complex surgery has also become identified as an inevitable, or necessary, part of the breast cancer "journey." Here, the gaze on the objectified female breast and

the related patriarchal and racialized history of medicalization and healthcare in capitalist societies such as Canada and the US are consistent with the perspectives that inform the advancement of breast conservation hegemony (Stasiulis and Bakan 107-139; Calliste). The major "choices" presented at BRA day revolve around options about the type of reconstruction: immediate or delayed reconstruction; transplanted tissue or implants; transplants from the stomach, back, or buttocks. Information about the risks and side effects of reconstruction are generally minimized. Also minimized or absented are other options that avoid reconstruction altogether-going flat on one or both sides, or the addition of creative tattoos. The options promoted on BRA Day are not unique, but typical of the breast cancer industry. One study published in 2016, designed to assess how patients in the US are informed about breast reconstruction (conducted over 20 months at a single site, among 126 patients planning mastectomy) concluded that knowledge of the risk of complications was particularly low, with only 15 percent of respondents indicating they were accurately informed; the majority lacked information or were misinformed (Lee et al., "How Informed" 1105). Further, there is a racialized, classed, and potentially heteronormative dimension to this knowledge: "Lower knowledge was associated with non-white race, less education, lower income, and single relationship status" (Lee et al., "How Informed" 1105-06).

The rise of the breast conservation wave is also located geopolitically. It is traceable largely, though not exclusively, to the US medical establishment. In a context of widely privatized medical insurance, the costs of breast reconstruction in the US were prohibitive up until recently. Accessing the procedure was particularly discriminatory for breast cancer patients from rural areas, low-income economic status, and those who were racialized minorities (Lee et al., "Quality of Patient Decisions"). However, following considerable advocacy, the Women's Health and Cancer Rights Act was passed in the US in 1998, a law that requires group health plans to cover reconstructive procedures (Anstett 3). In Canada, where there is generally more widely accessible public health, "breast reconstruction after cancer surgery is covered by most provincial and territorial health insurance plans" ("Breast Reconstruction"). However, the educational context and promotion of the breast conservation industry has closely followed the US pattern. Notably, while breast reconstruction surgery is automatically covered by the Ontario Health Insurance Program (OHIP), for example, revision of scars to achieve a fully flat appearance after mastectomy is not ("Frequently Asked Questions").

FLAT AND FABULOUS AND THE POLITICS OF CHOICE

he pivotal alternative to breast reconstruction following mastectomy, the choice to "go flat" either asymmetrically or symmetrically, has received far less attention. Still emergent, and only through advocacy among those who have elected this path, this option is currently gaining legitimacy and recognition. Information regarding the limitations of and alternatives to reconstruction has been generated by women's choices and reflected in a current of social awareness. However, data on trends according to available statistics regarding reconstruction after mastectomy is a contested field (Joyce). According to one 2015 study in the US, only 25 percent of women in that year who underwent mastectomies had immediate reconstruction following breast cancer treatment, yet "[m]edical literature largely starts from the assumption that [women who have mastectomy] want to have reconstruction and emulate their missing breast(s)" (Joyce 4). The number of women opting for breast reconstruction after mastectomy increased in the US by 35 percent between 2000 and 2015 (Rabin, "After Mastectomies"), but it is not clear if this rate is continuing (see Anstett 4; Yang et al.). It is estimated that overall, in the US, "roughly 25 percent of double-mastectomy patients and 40 percent of single-mastectomy patients opt out of reconstruction" (Guthrie, "Why More Breast Cancer"). There is no doubt, however, that reconstruction is the medically advocated norm, where it is assumed that "[b]reast reconstruction can help restore body image and alleviate distress associated with mastectomy," even though this assumption is not based on substantive research on actually "evaluated patient perceptions and outcomes" (Pusic et al. 2500).

GOING FLAT

Certainly, for some, reconstruction is an affirming and healthy option. The goal of surgical reconstruction following mastectomy is to produce "breast mounds," either from tissue transplanted from the woman's body or through implants. Surgically constructed or tattooed nipples complete the procedure. To the external observer these often "look and feel" like natural breasts. But to the woman herself, the breast mound is often numb and lacks feeling. Despite the promotional climate in the medical industry, a systematic review of US studies (up to 2009) on reported outcomes comparing those who had and had not undergone reconstruction following mastectomies indicated that there were no notable differences between the groups in terms of "quality of life, body image and sexuality" (Lee et al., "Patient-Reported Outcomes" 129). For those who have had reconstruction, complications can be extensive. These can include failure of the surgery resulting in a need for deconstruction, hardening of the tissue surrounding a breast implant (capsular contracture), implant rupture, and various serious illnesses. The latter include breast implant-associated anaplastic large cell lymphoma (BIA-ALCL), a form of cancer (Grady). In 2019, the US Food and Drug Association (FDA) Commissioner issued a statement indicating new information suggesting potentially higher risks of BIA-ALCL, and warned two breast implant manufacturers (Mentor and Sientra) with letters for failing to comply with FDA requirements ("Statement from FDA Commissioner"; "FDA Issues Warning Letters"; see also Grady and Rabin). Also in 2019, Health Canada issued a statement indicating a higher rate of confirmed and suspected BIA-ALCL than previously reported, and alerting health care professionals to attend to signs and symptoms of the disease ("Health Canada Will Be Updating Its Safety Review"; see also Cribb and McLean; Adhopia and Ouellet). Notably, one of the major identified sponsors of BRA Day in Toronto, 2018, was Mentor, one of the implant corporations that received a warning letter from the FDA. This is suggestive of motivations for the celebratory breast reconstruction awareness event based more on generating sales and reproducing patriarchy than on expanding health and wellness following breast cancer treatment.

The hegemony of reconstruction discourse presumes a singularity to the "woman" who has had breast cancer surgery that is starkly unaffected by decades of feminist debates, not only in scholarship, but also in policy and daily life in contemporary civil society (see "BRA Day: Breast Reconstruction Awareness"). My own observation of the Toronto, 2016, National BRA Day event saw a large audience of several hundred women, featuring two women speakers and a panel of plastic surgeons. Anecdotally, the examples and stories forwarded at BRA Day appear to be demonstrably profiling white women, and the assumption of heteronormativity was widespread. These are characteristics identified to be consistent with cancer treatment generally in Canada and the US (see Taylor and Bryson). I returned to observe the Toronto BRA Day in 2018, and the largely white demographic had not changed, even in a city which is noted for being among the most racially diverse in North America (see "BRA Day: Breast Reconstruction Awareness").

Those seeking other options have, however, been asserting the legitimacy of their choices. A growing body of scholarly research, investigative reporting, social media, films, and blogs are challenging the predominant assumptions that go with the widespread "image of a smiling, pink clad woman with round breasts" so ubiquitous in "breast cancer awareness marketing" (Joyce 3). This current is indicated qualitatively and anecdotally by a social media Facebook group, Flat and Fabulous, founded by two women who met through The Scar Project, a 2011 documentary about young breast cancer survivors (Jay). The Flat and Fabulous Facebook group received wider public attention when an article was written in The New York Times, calling attention to the reconstruction industry and the experiences of those who came to the decision to go flat (Rabin, "'Going Flat' After Breast Cancer"). The article was based on extensive research with medical practitioners and women who had had breast cancer. It stated the case clearly about the pressure for reconstructive surgery following breast cancer treatment, placing this in a wider context. The *Times* article deserves quotation at some length:

In promoting the surgery, doctors cite studies that suggest breast reconstruction improves a woman's quality of life after

cancer. But some women say that doctors focus too much on physical appearance, and not enough on the toll prolonged reconstructive procedures take on their bodies and their psyches. Up to one-third of women who undergo reconstruction experience complications. A systematic review of 28 studies found that women who went without reconstruction fared no worse, and sometimes did better, in terms of body image, quality of life and sexual outcomes. "That's the dirty little secret of breast reconstruction: The risk of a major complication is higher than for the average elective surgery," said Dr. Clara Lee, an associate professor of plastic surgery at Ohio State University who performs the procedure. Ms. Cuozzo, who appeared in the Facebook video ... spent a year having her breasts rebuilt after a double mastectomy, but after four infections in five months, she had the implants removed. The reconstruction, she said, "was getting worse than the cancer." (Rabin, "'Going Flat' After Breast Cancer")

More voices were and are coming forward from multiple sources, including film and blog posts, as well as multidisciplinary scholarly research (see, for example, Guthrie, *Flat*, "How Sexism," and "Why More Breast Cancer"; Skene; Joyce; Gao; "A Matter of Choice"; Brown and McElroy; Newman). These are signals of a rising new, vibrant social movement, one that is already indicating and affecting change. For example, the Canadian Cancer Society now lists "Choosing to Stay Flat" on its website ("Choosing to Stay Flat"). In April 2018, a collective of "flatties" in the United States came together to launch the website Flatclosurenow.org, which is "dedicated to ensuring breast cancer patients and providers understand that 'going flat' is a valid, beautiful, and healthy surgical option after mastectomy" (*Flat Closure Now*).

Returning to my personal experience, I have been heartened to have the opportunity to join a number of closed Facebook groups, specifically dedicated to advocacy and support for those of us who have chosen to go flat after breast cancer diagnosis and mastectomy. These Facebook groups are a central support for those who need a community, and also serve as centres for movement building to ad-

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vocate for change. These Facebook groups include: Flatties Unite; I Wanted to Be Flat; Flat in Canada; Flat in Toronto and GTA; and Fabulously Flat. The numbers reported are in the hundreds for some sites, others are in the thousands. Another group supports women who have had breast implants and have experienced serious and often unrecognized or minimized health challenges as a result: Breast Implant Illness and Healing by Nicole. The group has over 113, 000 members (Nicole).

As the community of those who resist the hegemony of breast conservation and reconstruction grows, new language has evolved to express the experiences and range of emotions. One important term that is gaining traction is "flat denial," defined as "when a surgeon's actions deny their patient a flat mastectomy result, whether through misalignment of expectations, lack of training or intentional disregard" (Bowles). Kimberly Bowles, who identifies as a "Pittsburgh scientist, artist, wife, mother, cancer survivor and flat advocate," started Not Putting on a Shirt. This site offers extensive resources "for optimal surgical outcomes for women who choose to go flat after mastectomy" (Not Putting on a Shirt). It is inspired by Kim's story, when she arranged a plastic surgeon at the time of her double mastectomy, and explicitly requested a flat result. As she was going into surgery on the operating table, the surgeon informed her that he would leave excess skin, in case she might "change her mind" and opt for reconstruction (Not Putting on a Shirt). This action was taken without consent, but has been defended in the months following as consistent with established medical practice.

Again returning to my personal situation, my choice to go flat was also resisted, but ultimately the surgeon agreed and the procedure followed smoothly. However, this agreement was not without challenge, as it was outside the normal hierarchy of medical authority. As my treatment plan was being finalized following final tests and diagnosis, an attending nurse waited until the surgeon had left the hospital room following final sign-off. At this moment, she informed me, "With any other surgeon, we would be sending you for a psyche assessment now." The implication was that my decision to opt for a double mastectomy to address early stage breast cancer was the

product of mental instability. Indeed, some medical professionals have asserted such choices constitute a disease separate from cancer, apparently "an epidemic" (Lagnado). The questioning of a patient's psychological stability in order to refuse or redirect treatment is of course not uncommon in the medical profession, targeting, for example, women, Black communities, trans people, the LGBTQ community, people with disabilities, and immigrants (see Roberts 90-91; Garner; Sontag; Lorde). My experience, however, is perhaps notable because I had advocated for a kind of surgery identified in current medical guidebooks for practicing breast surgeons to generate "highly curable" results, a phrase rarely associated with cancer treatment ("Princess Margaret" 107). For Kimberly Bowles and many others, experiences are far more serious: "They go into mastectomy expecting a flat result, and wake up to something completely different" (*Not Putting on a Shirt*; see also Guthrie, "How Sexism").

Finding community in the face of such experiences is crucial to healing. Community support also inspires advocacy to expand choice, and in turn serves to break barriers regarding ascribed norms regarding gender and ability. This movement is consistent with the goals of disability studies and activism that have challenged the dominance of the idea of the "normal" healthy body. This is the "normal body" that is assumed to be the same as the "healthy body." When the normal becomes ill or impaired, it is expected to demand repair with prosthetics and other material and social devices (see Betcher; Erevelles).

One indication of the success of the going flat movement is change in fashion options, including forwarding new clothing designs for women with one breast ("uniboobers") or no breasts ("flatties"), and web-based initiatives such as Empowerhaus.co and Idontneedtwo.com. One particularly important fashion intervention has been sponsored by Ana Ono, which features designer lingerie for women who have been treated for breast cancer (Dale; Isis). In 2019, New York fashion week included the Ana Ono runway show (now an annual event) notably featuring a diverse group of models all of whom were living with stage 4, metastatic breast cancer. This form of breast cancer is a progression of the disease that affects 30 percent in the



US of those who are diagnosed, but is the subject of only 3-7 percent of research dollars (Isis).

Ana Ono New York Fashion Week, credit Charise Isis 2019

This movement is only recently coming into wider public view. However, attention to the politics of choice and women's rights following mastectomy is not new. For example, in 1980, Black feminist author Audre Lorde shared her story of dealing with breast cancer and finding herself scolded by a nurse for declining to wear a prosthetic to a follow up appointment (Lorde 60). As she boldly stated:

a woman who has one breast and refuses to hide that fact behind a pathetic puff of lambswool which has no relationship nor likeness to her own breasts, a woman who is attempting to come to terms with her changed landscape and changed timetable of life and with her own body and pain and beauty and strength, that woman is seen as a threat to the "morale" of a breast surgeon's office! ... I refuse to have my scars hidden or trivialized behind lambswool or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim.... (Lorde 61-62)

In sum, there is an apparent need for a shift in the paradigm, from a standardized assumption of "closing the loop" on breast cancer through a hegemonic focus on breast conservation and reconstruction to a politics of informed choice. The latter has been advanced in another context, women's reproductive health.

The Canadian pro-choice movement advocated for a woman's right to choose over decades of activism and advocacy. It can serve as an important model regarding the social, political, and economic context of women's health more generally, and is suggestive of a way to reimagine options following surgical treatment for breast cancer. The pro-choice movement advocated for the rights of women to control their bodies, but also to demonstrate capacity to make life and death decisions. These were specifically associated with reproductive freedom, considering options to terminate safely an unwanted pregnancy, or to make an informed choice to carry a pregnancy to term (Pelrine; Brodie et al.). Framing abortion in this way, by associating it with women's right to choose, was ultimately successful in challenging abortion laws in Canada. Certainly, major gains have been achieved regarding issues associated with women's choices to have or not to have children, and relatedly, to choose if or when to terminate an unwanted pregnancy. Considering choice in this manner is distinct from a focus on the neoliberal market model of "choice," which idealizes the abstract individual as if devoid of material and political difference (for a critique, see Abu-Laban and Gabriel).

Instead, the lessons of the pro-choice movement link medical issues with those of social, economic, and political rights, and can be suggestive of an intersectional approach (see Crenshaw; Bakan and Abu-Laban). The gains are signified by the 1988 *R. v. Morgentaler* decision, when the Supreme Court of Canada invalidated previous federal legislation that criminalized access to abortion services on grounds of violation of the Canadian Charter of Rights and Freedoms. However, this is not only an historical example. Advocacy continues to be needed to ensure women's right to choose regarding access to publicly funded abortion across the provinces of Canada (see Johnstone; Johnstone and Mcfarlane). An important proviso regarding the relationship of these issues is in order. In forwarding a politics of choice, it is not suggested that pregnancy is comparable to cancer; simply put, pregnancy, unlike cancer, is not a disease. Rather, the suggestion is that there are grounds to extend a conversation in terms of a critique of patriarchal norms, women's agency, gendered issues of bodily integrity, intersections of gender, race, ability and class, and life or death decisions. These involve a relationship between people who are diagnosed with breast cancer, including women and men, and a medical system that includes trained, professional practitioners, and extensive informational and technical resources. From this perspective, the issues of choice drawn from decades of public policy and social movement advocacy associated with reproductive rights can be brought into dialogue with the politics of women's altered bodies after mastectomy, and related matters of quality of life after breast cancer.

CONCLUSION: TOWARDS FUTURE RESEARCH

The preceding discussion has attempted to name and question the hegemonic paradigm of breast conservation, and relatedly, assumptions of breast deficit as the main effect of mastectomy. Alternatively, other options, including the option to go flat, deserve greater attention. A politics of choice, inspired by, but not identical to, the politics advanced in Canada regarding abortion rights, can be helpful in such a conversation. Considering a politics of choice regarding life after breast cancer treatment has the potential, arguably, to expand our understanding as well as to open space for wider social and medical communities. Rather than assuming that there is a single "normal" and universalized healthy outcome to breast cancer treatment, we would be well served to imagine multiple open-ended outcomes where agency and choice are centred among multiple potential, and potentially positive, options.

This remains, however, challenging territory. For example, intersectional approaches to choice at the interface of agency and the medical establishment are relevant, including experiences of transgendered/transsexual men and women. The ready access to breast recon-

structive surgery for women diagnosed with breast cancer is notably in contrast to requests from trans communities seeking similar plastic surgery. Men who have been diagnosed with gynecomastia, the medical term for excessive breast tissue, are also generally supported in obtaining desired surgery (Garner). Yet there are demonstrable barriers faced by male-to-female trans people seeking medical support for breast construction, a surgical procedure very similar to post mastectomy breast reconstruction (Garner). These, and other related examples, could potentially be brought into a wider public conversation under the umbrella of a politics of choice.

And, to conclude, a final note on my personal experience. Fourteen months after mastectomy surgery, I returned to another hospital for a second surgery, this time a day clinic procedure with two plastic surgeons for scar revision, to produce a flatter outcome following the mastectomy. An attending nurse was on intake, one I had not met previously. When she looked at my chart and saw my flat chest, she burst out in laughter—as in deep hold-your-belly guffaw laughter. Spittingly, she stated, "Flatter than flat? That's a new one!" However, the surgery, again, went well. After the procedure, following the careful and professional attitude of the surgeons, who were of course her superiors in the medical hierarchy, the attitude of the attending nurse changed. As I changed clothes and received post-op instructions, she was now demure. "You could wear a T-shirt, I see," she stated. "And maybe you'll start a trend." I replied, "Already have. Read the *New York Times.*" I exited with a bit of bounce in my step.

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WORKS CITED

- "A Matter of Choice: Mastectomies Without Reconstruction." CBS New, 12 Mar. 2017, https://www.cbsnews.com/news/a-matterof-choice-mastectomies-without-reconstruction-2/
- Abu-Laban, Yasmeen, editor. *Gendering the Nation-State: Canadian* and Comparative Perspectives. UBC P, 2008.
- Abu-Laban, Yasmeen and Christina Gabriel. *Selling Diversity: Immigration, Multiculturalism, Employment Equity and Globalization.* U of Toronto P, 2008.
- Adhopia, Vik and Valérie Ouellet. "Safety Review of Breast Implants Reopened After Implant Files Stories." *CBC News*, 12 Feb. 2019, https://www.cbc.ca/news/health/breast-implants-safety-review-1.5016697?fbclid=IwARoFyFtlp84FJHqrlJ9WQtl-GU53Yy1ZIR-yLzV31KlPGaweYnYT6dn1V2wM.
- "All About BRA Day in Toronto with Dr. Brown and Dr. Somogyi." *Toronto Plastic Surgery*, 4 Oct. 2018, https://www.torontoplasticsurgery.com/all-about-bra-day-toronto/.
- Anstett, Patricia. Breast Cancer Surgery and Reconstruction: What's Right for You. Rowman and Littlefield, 2016.
- Bakan, Abigail B. and Audrey Kobayashi. *Employment Equity Policy in Canada: An Interprovincial Comparison.* Status of Women Canada, 2000.
- Bakan, Abigail B. and Yasmeen Abu-Laban. "Intersectionality and the United Nations World Conference Against Racism." *Atlantis: Critical Studies in Gender, Culture and Social Justice*, vol. 38, no. 1, 2017, pp. 220-35.
- Betcher, Sharon. "Putting My Foot (Prosthesis, Crutches, Phantom) Down: Considering Technology as Transcendence in the Writings of Donna Haraway." *Women's Studies Quarterly*, vol. 29, nos. 3-4, 2001, pp. 35-53.

- Bowles, Kim. "Going Flat: Your Body, Your Choice." Young Survival Coalition, 3 Jan. 2019, https://blog.youngsurvival.org/going-flat-your-body-your-choice/.
- "BRA Day." Canadian Cancer Society, http://www.bra-day.com/.
- "BRA Day: Breast Reconstruction Awareness." *BRA Day Toronto*, program brochure, 17 Oct. 2018.
- "Breast Cancer Statistics." *Canadian Cancer Society*, http://www.cancer.ca/en/cancer-information/cancer-type/breast/statistics/?region=on.
- "Breast Reconstruction." *Canadian Cancer Society*, http://www.cancer.ca/en/cancer-information/cancer-type/breast/reconstruction-and-prostheses/breast-reconstruction-surgery/?region=on.
- "Breast Reconstruction Awareness Day: A Program of Canadian Breast Cancer Foundation. Toronto's Flagship BRA Day Event." *BRA Day Toronto*, program brochure, 19 Oct. 2016.
- Brenner, Barbara. *So Much to Be Done: The Writings of a Breast Cancer Activist.* U of Minnesota P, 2016.
- Brodie, Janine et al. The Politics of Abortion. Oxford UP, 1992.
- Brown, Maria Teresa, and Jane A. McElroy "Sexual and Gender Minority Breast Cancer Patients Choosing Bilateral Mastectomy without Reconstruction: 'I Now Have a Body That Fits Me.'" Women and Health, vol. 58, no. 4, 2018, pp. 403-18.
- Calliste, Agnes. "Women of 'Exceptional Merit': Immigration of Caribbean Nurses to Canada (1960-1962)." *Canadian Journal of Women and the Law*, vol. 6, no. 1, 1993, pp. 85-102.
- "Choosing to Stay Flat." *Canadian Cancer Society*, http://www.cancer.ca/en/cancer-information/cancer-type/breast/reconstruction-and-prostheses/choosing-to-stay-flat/?region=on.
- Crenshaw, Kimberlé. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine,

Feminist Theory and Antiracist Politics." University of Chicago Legal Forum, vol. 1989, no. 1, 1989, pp. 138-67.

- Cribb, Robert and Jesse McLean. "'My Entire Body Was Shutting Down.' Breast Implant Recipients Say Doctors Gloss Over Risks." *The Star*, 30 Nov. 2018, https://www.thestar.com/news/ investigations/2018/11/30/my-entire-body-was-shutting-downbreast-implant-recipients-say-doctors-gloss-over-risks.html.
- Dale, Elizabeth. "Redefining Mastectomy Bras to Meet Breast Cancer Patient Needs." *HuffPost*, 24 Jun. 2015, https://www.huffpost.com/entry/redefining-mastectomy-bras-to-meet-breastcancer-needs_n_7571896.
- Erevelles, Nirmala. Disability and Difference in Global Contexts: Enabling a Transformative Body Politic. Palgrave Macmillan, 2011.
- "FDA Issues Warning Letters to Two Breast Implant Manufacturers for Failure to Comply with Post-approval Study Requirements." US Food and Drug Association, 19 Mar. 2019, https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/UCM633890.htm
- "Frequently Asked Questions." *My Reconstruction*, http://myreconstruction.ca/faq/.
- Flat Closure Now, 2019, https://www.flatclosurenow.org/
- Gao, Shan. "Apparel Design Process: Shifting the Basic Pattern Block into a New Framework to Fit the Demands of Post Double Mastectomy Women." MSc thesis, Department of Human Environmental Sciences, U of Arkansas, 2014.
- Garner, T. "Chest Surgeries of a Different 'Nature." *Annual Review of Critical Psychology*, vol. 11, pp. 337-56.
- Grady, Denise. "A Shocking Diagnosis: Breast Implants 'Gave Me Cancer." *The New York Times*, 14 May 2017, https://www.nytimes.com/2017/05/14/health/breast-implants-cancer.html.
- Grady, Denise and Roni Caryn Rabin. "Reports of Breast Implant Illnesses Prompt Federal Review." *The New York Times*, 19

Mar. 2019, https://www.nytimes.com/2019/03/19/health/breastimplants-fda-illness.html.

- Guthrie, Catherine. *Flat: Reclaiming My Body From Breast Cancer*. Skyhorse, 2018.
- -. "How Sexism in Medicine is Hurting Breast Cancer Survivors." *Cosmopolitan*, 6 Sep. 2018, https://www.cosmopolitan.com/ health-fitness/a22984204/breast-cancer-survivors-mastectomy-sexism/
- -. "Why More Breast Cancer Survivors Are Going Flat." Oprah, 20 Sep. 2017, http://www.oprah.com/inspiration/going-flat-whysome-women-reject-breast-reconstruction-surgery.
- Halsted, William S. "The Results of Operations for the Cure of Cancer of the Breast Performed at the Johns Hopkins Hospital from June, 1889, to January, 1894." Annals of Surgery: A Monthly Review of Surgical Science Since 1885, vol. 20, no. 5, 1894, pp. 495-555. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1493925/.
- "Health Canada Will Be Updating Its Safety Review of Breast Implants." *Health Canada*, 12 Feb. 2019, http://healthycanadians.gc.ca/recall-alert-rappel-avis/hc-sc/2019/69052a-eng.php.
- Hendler, Sue. *Dying in Public: Living with Metastatic Breast Cancer.* Edited by Christine Overall, Michael Grass House, 2012.
- Hill, Elspeth J. R. et al. "Can I Cut It? Medical Students' Perceptions of Surgeons and Surgical Careers." *The American Journal of Surgery*, vol. 208, no. 5, 2014, pp. 860-67.
- Isis, Charise. "#NotJustOne." *The Grace Project*, 13 Feb. 2019, http://the-grace-project.org/2019/02/notjustone/?fbclid=IwAR2Ylte5wvo6Ekg8JJkmPbBXq2D57T6r4t62wiMBtjM-LlFA63cwxlZDdJio.
- Jay, David. *Baring It All. The Scar Project*, 2011, http://www.thescarproject.org/documentary/.

- Johnstone, Rachael. *After Morgentaler: The Politics of Abortion in Canada*. UBC Press, 2017.
- Joyce, Marianne A. "Rejecting Reconstruction After Breast Cancer: Managing Stigmatized Selves." MA Thesis, Department of Sociology, U of Massachusetts, 2015.
- King, Samantha. *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy.* U of Minnesota P, 2006.
- Lagnado, Lucette. "Defying Doctors, More Women with Breast Cancer Choose Double Mastectomies." *The Wall Street Journal*, 10 Jul. 2015.
- Lee, Clara et al. "Patient-Reported Outcomes of Breast Reconstruction After Mastectomy: A Systematic Review." *Journal of the American College of Surgeons*, vol. 209, no. 1, 2009, pp. 123-33.
- Lee, Clara Nan-hi et al. "How Informed Is the Decision About Breast Reconstruction After Mastectomy: A Prospective, Cross-sectional Study." *Annals of Surgery*, vol. 264, no. 6, 2016, pp. 1103-09.
- Lee, Clara Nan-hi et al. "Quality of Patient Decisions About Breast Reconstruction After Mastectomy." *JAMA Surgery*, vol. 152, no. 8, 2017, pp. 741-48.
- Lorde, Audre. The Cancer Journals. Aunt Lute Books, 1995.
- Mukherjee, Siddhartha. *The Emperor of All Maladies: A Biography of Cancer*. Scribner, 2010.
- Nicole. "Welcome to Healing Breast Implant Illness." *Healing Breast Implant Illness*, https://healingbreastimplantillness.com/healing-breast-implant-illness/
- Not Putting on a Shirt, https://imean.home.blog/.
- Newman, Amie. "To Have or Have Not: Breast Reconstruction and 'Going Flat." *Our Bodies Our Selves*, 3 Nov. 2016, https://www.ourbodiesourselves.org/2016/11/to-have-or-havenot-breast-reconstruction-and-going-flat/.

- Orr, Catherine M. et al., editors. *Rethinking Women's and Gender Studies*. Routledge, 2012.
- Pelrine, Eleanor Wright. *Morgentaler: The Doctor Who Couldn't Turn Away.* Gage Publishing, 1975.
- Peters, Walter and Victor Fornasier. "Complications from Injectable Materials Used for Breast Augmentation." *Canadian Journal of Plastic Surgery*, vol. 17, no. 3 2009, pp. 89-96.
- "Princess Margaret Cancer Centre Clinical Practice Guidelines." Breast Site Group. University Health Network, May 2017, https://www.uhn.ca/PrincessMargaret/Health_Professionals/ Programs_Departments/Documents/CPG_Breast_Breast-Cancer.pdf.
- Pusic, Andrea L. et al. "Patient-reported Outcomes 1 Year After Immediate Reconstruction: Results of the Mastectomy Reconstruction Outcomes Consortium Study." *Journal of Clinical Oncology*, vol. 35, no. 22, 2017, pp. 2499-06.
- Rabin, Roni Caryn. "After Mastectomies, an Unexpected Blow: Numb New Breasts." *The New York Times*, 29 Jan. 2017, https://www.nytimes.com/2017/01/29/well/live/after-mastectomies-an-unexpected-blow-numb-new-breasts.html.
- -. "'Going Flat' After Breast Cancer." The New York Times, 31 Oct. 2016, http://nyti.ms/2dWDoSx.
- Roberts, Dorothy. Fatal Invention. New Press, 2011.
- Skene, Pat. "Surviving Breast Cancer and Learning to Be Flat and Fabulous." *Sixty and Me*, https://sixtyandme.com/survivingbreast-cancer-learning-to-be-flat-and-fabulous/.
- Sontag, Susan. *Illness as Metaphor and AIDS and Its Metaphors*. Picador, 1998.
- Stasiulis, Daiva K. and Abigail B. Bakan. *Negotiating Citizenship: Migrant Women in Canada and the Global System*. U of Toronto P, 2005.

- "Statement from FDA Commissioner Scott Gottlieb, M.D. and Jeff Shuren, M.D., Director of the Center for Devices and Radiological Health, on Efforts to Evaluate Materials in Medical Devices to Address Potential Safety Questions." US Food and Drug Association, 15 Mar. 2019. https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm633602.htm.
- Taylor, Evan T. and Mary K. Bryson. "Cancer's Margins: Trans and Gender Nonconforming People's Access to Knowledge, Experiences of Cancer Health, and Decision-Making." *LGBT Health*, vol. 3, no. 1, 2016, pp. 1-11.
- Turner, Kelly A. *Radical Remission: Surviving Cancer Against All Odds.* Harper Collins Publishers, 2014.
- Veronesi, Umberto et al. "Twenty-Year Follow-up of a Randomized Study Comparing Breast-Conserving Surgery with Radical Mastectomy for Early Breast Cancer." New England Journal of Medicine, vol. 347, no. 16, 2002, pp. 1227-32.
- Yang, Rachel L. et al. "Trends in Immediate Breast Reconstruction across Insurance Groups after Enactment of Breast Cancer Legislation", *Cancer*, vol. 119, no. 13, 2013, pp. 2462-68.