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## Rejecting Reconstruction after Breast Cancer: Managing Stigmatized Selves

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REJECTING RECONSTRUCTION AFTER BREAST CANCER:  
MANAGING STIGMATIZED SELVES

A Thesis Presented

by

MARIANNE A. JOYCE

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
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MANAGING STIGMATIZED SELVES

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## ABSTRACT

### REJECTING RECONSTRUCTION AFTER BREAST CANCER: MANAGING STIGMATIZED SELVES

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After a mastectomy due to breast cancer, a woman faces a choice about whether to undergo cosmetic reconstruction of her breast(s). In choosing reconstruction, women restore not only their bodies but their socially acceptable selves. In spite of this, most choose not to have reconstructive surgery. Though they are in the majority, not much is known about these women, and about what they do to navigate through life with a body that does not meet expectations of femininity. In this project, I use the case of women who choose not to have reconstruction and not to simulate their missing breast(s) to explore the boundaries of the socially acceptable body.

Drawing on interviews with women who did not have reconstruction, examination of depictions of bodies on breast cancer organization web sites, and content analysis of their discussion board postings, I analyze women's choices not to reconstruct their breasts and place those choices in the context of modern breast cancer culture, which promotes an ideal 'survivor' body. I find that these women emphasize concerns about stigma and authenticity and that these concerns are expressed through appearance changes that vary across public and private settings. This research extends our understanding of deviant bodies to understanding the stigma of socially incomprehensible bodies. Further, it makes explicit the assumptions about selfhood that are implied by both current popular perception and sociological work on stigmatization.

## TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS .....	iii
ABSTRACT .....	iv
CHAPTER	
1. INTRODUCTION AND BACKGROUND.....	1
Modern Breast Cancer Culture .....	2
Medical Context .....	4
2. LITERATURE REVIEW .....	7
Breast Cancer Narratives.....	7
Stigmatized Bodies .....	8
The (Authentic) Self.....	12
3. METHODS.....	15
Interviews .....	16
Content Analysis.....	17
Breast Cancer Organization Web Sites.....	17
4. ANALYSIS .....	21
Depictions of cancer online.....	21
Stigma .....	23
Isolation and Invisibility .....	24
Interaction.....	25
New Identities .....	28
Maintaining Coherent Selfhood.....	29
5. CONCLUSION .....	33
APPENDIX: INFORMED CONSENT MATERIALS.....	36
REFERENCES .....	34

## CHAPTER 1

### INTRODUCTION AND BACKGROUND

Nonmeaning in something that for others is pregnant with meaning is itself a kind of meaning in absentia.

–Fred Davis, *Fashion Culture and Identity*, 1994

[P]rotheses are often chosen, not from desire, but in default. Some women complain it is too much effort to fight the concerted pressure exerted by the fashion industry. Being one-breasted does not mean being unfashionable. . . In some cases, it means making or remaking clothing or jewelry. The fact that the fashion needs of one-breasted women are not currently being met doesn't mean that the concerted pressure of our demands cannot change that...The design and marketing of items of wear for one-breasted women is only a question of time, and we who are now designing and wearing our own asymmetrical patterns and New Landscape jewelry are certainly in the vanguard of a new fashion!

-Audre Lorde, *The Cancer Journals*, 1980

After a mastectomy due to breast cancer, a woman faces a choice about whether to undergo cosmetic reconstruction of her breast(s). In choosing reconstruction, women restore not only their bodies but their socially acceptable selves. In spite of this, most choose not to have reconstructive surgery. Though they are in the majority, not much is known about these women, and about what they do to navigate through life with a body that does not meet expectations of femininity.

In this project, I use the case of women who choose not to have reconstruction and then not to simulate their missing breast(s) to explore the boundaries of the socially acceptable body. Through interviews and content analysis of discussion board postings, I analyze women's choices not to reconstruct their breasts and place those choices in the context of modern breast cancer culture. I find that these women emphasize concerns about

stigma and authenticity and these concerns are expressed through appearance changes.

Stigma is managed but in turn affects sense of self.

### **Modern Breast Cancer Culture**

In recent years, there has been a growing body of work critiquing the mainstream breast cancer movement (known as “Pink Inc.”), especially as it relates to ‘pinkwashing’<sup>1</sup> – the selling of pink beribboned products that promise a donation to breast cancer foundations<sup>2</sup> (Sulik 2010). The growing response to Pink Inc. has been largely framed around a critique of this commodification and on the lack of attention to environmental issues. Women with cancer express concerns about the promotion of products made by companies that may be contributing to the environmental causes of breast cancer, as well as the tendency to donate a very small proportion of profits to cancer research.

Critics have taken Pink Inc. to task for its relentless positivity and the framing of all women who have had cancer as ‘survivors.’<sup>3,4</sup> Breast cancer is now often depicted as a foe to be vanquished through bravery and force of will. One can even be labeled a “previvor” by

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<sup>1</sup> This term was coined by Breast Cancer Action as part of their “Think Before You Pink” campaign.

<sup>2</sup> The Komen foundation has been the main target for this backlash, as they have been heavily involved in pink product marketing. In 2012, the foundation also came under fire after it pulled funding from Planned Parenthood. This increased the backlash and renewed focus on critiques of Pink Inc. overall.

<sup>3</sup> The notion of a person with cancer being a ‘survivor’ did not exist until the 1980s and has been controversial from the beginning (Kolata 2004).

<sup>4</sup> The positivity emphasis is hardly new (Polishuk and Winnow 1991) and not aimed just at breast cancer patients (Ehrenreich 2009)

staying cancer-free despite having a gene mutation or other heightened risk factors for the disease (FORCE N.d.).

Comparatively little attention has been paid to how Pink Inc. affects women's lives in other ways. The image of a smiling, pink clad woman with round breasts is everywhere in breast cancer awareness marketing, but this image has gone largely unexamined. Though there is not overt condemnation of women who do not reconstruct, there is, following Saguy and Ward (2011), a lack of *counter-ideology* about these women's bodies. Breast cancer culture celebrates a return to health and breastedness through reconstruction, but has no positive narrative about alternatives.

Whereas Pink Inc. serves to include women who have had breast cancer within already existing normative ideas about the body, in this project I instead focus on women who are challenging those ideas. This challenge occurs through the rejection of prostheses, a socially unrecognizable action (Sandell 2008).

How women negotiate these choices can only be understood in the context of expectations about the 'normal' woman's body as well as the 'survivor' body. Writing about women without reconstruction or prostheses participating in a breast cancer charity walk, Klawiter describes their presence as "a doubly loaded act of defiance. Not only are they rejecting the *code of invisibility*, but the way in which they are doing so directly challenges dominant norms of beauty, sexuality, and femininity" [emphasis added] (2000:78). Yet, the women she describes are participating in a walk for people with a disease that has breastlessness as a likely outcome, and are literally embodying that. Of anywhere one might expect single or no-breasted women to be prevalent, it is at a breast cancer walk.

This woman is not often depicted in the breast cancer movement or popular culture. Though some (e.g. Thorne and Murray 2000) have rightly taken coverage of breast cancer to task for tending to focus on women's bodies rather than their health, thinking about which bodies are present within that coverage can similarly serve as a critique of current breast cancer culture. Women represented in Pink Inc. marketing conform to normative ideas about bodies and health. In this context, how do women make sense of their bodily choices after breast cancer? What can their experiences tell us about bodily transgression? In exploring these questions, we can also gain insight into why Lorde's prediction did not come to be.

### **Medical Context**

About 40% of the over 230,000 women diagnosed with breast cancer this year will undergo mastectomy (National Cancer Institute N.d.; Klem 2013). Medical literature largely starts from the assumption that these women want to have reconstruction and emulate their missing breast(s), but most women *do not* get immediate<sup>5</sup> breast reconstruction. Current national data from SEER indicates a reconstruction rate of about 25% per year. This rate has increased since the 1990s (Morrow et al. 2001)<sup>6</sup>, though changing medical knowledge and evolving perceptions of reconstruction complicate identifying a clear trend<sup>7</sup>

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<sup>5</sup> Immediate is defined as within four months. This 'catches' some women who can not have truly immediate surgery, who delay their decision, or who later choose to reconstruct. Data on how many women are in this latter group is limited to small-scale studies so it is difficult to generalize about rates of delayed reconstruction.

<sup>6</sup> The reasons for this change in rates include medical developments, changing ideas about reconstructive safety, and shifting notions of appropriate psychological adjustment (Jacobson 1998; Schain and American Cancer Society 1998).

<sup>7</sup> However, prophylactic mastectomies are on the rise (Habermann et al. 2010). The discovery of the BRCA1/2 gene mutation, narratives of decision making around this (e.g.

and rates do vary geographically (Agarwal et al. 2011; Nelson et al. 2012). Data most supports three factors influencing rates: medical context, racial and ethnic background, and age (Morrow et al. 2001; Reuben, Manwaring, and Neumayer 2009; Sisco et al. 2012).

Regardless of all these complicating factors, in almost every existing study, the *most common outcome* for a woman after mastectomy is not to have reconstructive surgery of her breast(s). Nationally approximately 70,000 women per year are choosing not to have breast reconstruction after mastectomy.

Researchers assume that women who do not have surgery will instead wear prosthetic breast(s). No large-scale studies have been done about prosthesis usage, but Glaus and Carlson (2009) found that around 30% of women who have prostheses don't wear them all the time. More research needs to be done in this area. Messages from both health professionals and prosthesis providers communicate that prostheses are needed in order to stave off health effects such as loss of balance and spinal issues<sup>8</sup> and there is a long tradition of offering prosthesis information and temporary supplies at the hospital bedside (Lorde 1980; Queller 2011). This tendency to present only certain options is reflected not just in medical literature, but in women's personal narratives. Breasts that are no longer diseased have thus become medicalized (Ferguson 2000; Leopold 2000).

I give this overview of factors influencing reconstruction decisions for context – this paper does not delve into how women come to their decision not to reconstruct, but rather **departs from a point at which they have already made that choice**. Existing research also does not shed much light on variations within the non-reconstructors. I argue that we

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Queller 2011) and high-profile women such as Angelina Jolie (Jolie 2013) having prophylactic surgery may be influencing this change.

<sup>8</sup> Medical evidence for this is weak. See Hojan et al (2014).

should think about women with breast cancer as inhabiting three categories rather than two – reconstructors, non-reconstructors mimicking breasts, and non-reconstructors not mimicking breasts – with women being able to easily travel between the latter two groups due to the use of removable prostheses. In this project, I show how women's choices matter *after* surgical decision-making.

## CHAPTER 2

### LITERATURE REVIEW

#### Breast Cancer Narratives

Much of the work to date that does address the choices of women around reconstruction is not found in the academic literature, but arises out of the tradition of the personal narrative, which began almost 40 years ago with books such as *First, You Cry* (Rollin 1976) and *The Cancer Journals* (Lorde 1980), along with Kushner's more technical but still autobiographical *Breast Cancer: A Personal History and Investigative Report* (1975). In turn, some academic texts have drawn on these narratives, as they often provide a rare source of material on experiences from that era (Leopold 2000).

Lorde's work is the source for the most well-known depiction of resistance to reconstruction<sup>9</sup>. She rejected the temporary cotton prosthesis given to her post-surgery by Reach to Recovery (a program of the American Cancer Society still running today) and upset her doctor's office by showing up to appointments without it. She later imagined clothing designed for women like her and wondered why it did not exist. Reading *The Cancer Journals* 35 years later, I wondered why no one seemed to answer her call.

Lorde's and others have become classic works that ushered in a wave of women being critical of their treatment and of the medical establishment that is still present in

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<sup>9</sup> As recently as the 1970s, reconstruction was novel and women had to advocate for themselves to have any part in the decision-making process of whether to get *mastectomy*, much less reconstruction (Crile 1973; Kushner 1975) .

today's memoirs, and more recently, blogs and art projects. Though situated as autobiographies or self-help works, they are often distinctly sociological in their attempts to link personal experiences of cancer with broader social forces influencing treatment recommendations, funding, and expectations of feminine survivorship (Pirok 2014). This may be in part due to their increased diversity, both in authorship and form (DeShazer 2013).

However, the only two (relatively) well-known depictions of women with unreconstructed bodies are photographic projects, one by and of the artist and model Matuschka that famously graced the cover of the *New York Times Magazine* (Farraro 1993; Matuschka N.d.) and the other a poster of Deena Metzger, showing her with arms outstretched, a tattoo over her mastectomized left side (Hammid, Metzger, and Levrant de Bretteville N.d.). Other art projects, though not as prominent, also confront this subject (DeShazer 2013).

### **Stigmatized Bodies**

If the individual is to be unconcerned about the others present . . . then it will be useful if they have the same feeling about him . . . For the individual, then, what is perceived as a normal situation is likely to be one in which he is unconcerned about the others' concerns, including the concern about him (Goffman 1972:282).

The first breast cancer walks and awareness months took place in the mid-80s and the first pink ribbons appeared in 1991, building awareness and visibility of the disease (Sulik 2010). Having breast cancer in and of itself has lost most of its stigma, in contrast to

the shame that surrounded it in the 1970s and 80s (King 2012), though some does remain (Else-Quest and Jackson 2013).

The cultural context dominated by the Pink movement has moved cancer from a hidden secret shame to a valiant struggle, one that produces not patients but survivors (King 2012). The cancer *itself* is no longer the stigmatizing object it once was, but the enduring bodily signs of the cancer are, calling into question the ‘survivor’ who does not strive to correct, erase, and cover them. The very concept of the survivor implies an element of choice and will (DeShazer 2013:91). The implication, then, is that those who died failed, did not try hard enough, did not fight this metaphoric battle. To fit the ideal, the woman must not just survive medically, but conform to a version of triumph and health that includes expectations of breastedness. Returning to a ‘normal’ appearance is viewed as a return to the self and to happiness (Ucok 2002).

Aligned with these expectations, normative expectations of the cancer survivor’s body persist. To escape stigma, the survivor needs to participate in the emulation of health and reconstruction: not just literal reconstructive surgery, but a rebuilding of the pre-cancerous body in form and meaning. Rabinovitch, in her memoir, realizes that breast cancer “is an illness that has not quite shaken off its taboos. Death is not the secret any more, but what the treatment does to women — attacking the hair, the breasts . . .” (2007 :115). Psychological research has found that illnesses that are more visible tend to attract more stigma (Knapp-Oliver and Moyer 2009; Else-Quest and Jackson 2013), and although breast cancer is not always visible, reconstruction choices often are. Failing to reconstruct disrupts the dominant narrative of rebuilding and reclamation that is all over Pink Inc.’s triumphant walks and tales of survivorship. In Frank’s (1995) terms, women who reject

reconstruction deviate from the normative restitution illness narrative, in which a return to the prior state of health is the desired and expected outcome.

The mastectomized body then has a stigma in the historical sense– it is marked, and that mark is a bodily signifier of difference (Goffman 1963). Though the mark is not always easily visible, it is always in danger of being revealed – in Goffman’s terms, women with non-reconstructed breasts are always discreditable and in danger of becoming discredited. This conceptual divide parallels what psychologists have called ‘felt’ versus ‘enacted’ stigma, used to distinguish fear of stigmatization by others from its occurrence (Taylor-Gooby 1976; Scambler 1998). Though most sociological approaches do not distinguish as sharply between interior experience and action, the assertion that felt stigma can be in effect more powerful than enacted stigma plays out below in the discussion of women’s appearance choices.

A woman with unreconstructed breasts suffers a clear abomination of the body, whether or not she chooses to use a prosthesis. A missing breast has particular social meaning beyond just empty space: it is a lack, a shortcoming (Stirling, Manderson, and MacFarlane 2010). Without a prosthesis to emulate wholeness, she is not always discredited, but always discreditable (Goffman 1963:41-48). This categorization depends on not just her appearance choices, but the physical and social context she is within at the moment. The woman may not know at any given time where she falls on this divide, leaving her in a liminal space. Women who embrace a choice that requires stigma management (no reconstruction and limited prosthesis use) are constrained within that choice by their perceptions of others. Since they may be read differently across context, they may also perform appearance differently. They may be discredited, become discredited, or may stay unstigmatized due to incomprehensibility. To be discreditable, there has to be a socially

recognizable stigma in danger of being exposed. Breastlessness is not recognized as a choice women make, and may be difficult for people to 'see' because they have no frame of reference for it.

In broader context, women who resist reconstruction are also often unrecognizable. In research studies that do address reconstruction, it is generally taken as a good (Handel et al. 1990), or the purpose of the research is to promote it as a valid choice (e.g. Reaby and Hort 1995). Several researchers divide their samples into two distinct groups -- reconstruction and prosthesis (e.g. Reaby and Hort 1995). Because of the nature of prostheses, studies can not cleanly divide women into the "prosthesis group," though they may try to do so anyway. One can always, sometimes, or never wear a prosthetic, since they are easily removed<sup>10</sup>. Cromptvoets (2005) does attend to the fact that the distinction is one that is socially created, discussing the reconstruction/prosthesis split as one that is within the two choices women are normally offered, but most research does not recognize this. The overall lack of attention to this issue is typical of an Irish study of prosthesis use: after acknowledging that "not all women who have had a total or partial mastectomy will want or require an external breast prosthesis," they claim that "there is a growing demand for breast reconstruction after breast surgery" (Gallagher et al. 2009:4). The framing of this information elides the fact that prosthesis use is not universal and is echoed in study after study. There is an erasure of other options, a lack of space for them.

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<sup>10</sup> Prostheses are offered in many materials (most commonly silicone), shapes, and sizes, and some are marketed for specific uses (swimming, working out). They are generally placed into a special bra, or against the skin with adhesive. They are meant to be easily taken on and off.

The erasure of women's choices about reconstruction takes place alongside the presumption that breasts are central to women's sense of self. The breast has been a key part of historical conceptions of women's femininity, power, and sexuality (Yalom 1997), yet this is often accompanied by heterosexist assumptions about how women wish to present themselves (Sedgwick 1999). In this context, not emulating the missing breast(s) becomes almost unthinkable, impossible. Women who choose this are "unintelligible" (Sandell 2008) and so invisible. Their choice is so infrequently depicted, even within breast cancer awareness materials, as to largely erase it. Widespread knowledge of reconstruction and perceptions about its popularity may in itself alter what women think of as their ideal post-surgical body (Cromptvoets 2005:77). We are only able to choose options that we recognize as existing.

### **The (Authentic) Self**

Women with breast cancer primarily deal with stigma related to bodily changes and interacting with others using their 'new' bodies. These stigmatizing processes take place in specific cultural contexts and rely on shared understandings of personhood. In the context of modern U.S. breast cancer culture, the survivor narrative rests on a particular conception of the self.

The dominant, modern notion of the self in the United States is individualistic and interior. This self is stable, stigma is enacted upon the body, and the self responds to it. This conception of the self is roughly Cartesian in nature; the mind and body are separate entities.

Similarly, the idea of the self implied by the modern breast cancer movement is that the body represents the self but does not determine it. In this sense, the body is taken as the outer expression of an inner self. However, Pink Inc. also situates the body as having a more important role in shaping the self. Normative breast cancer culture reads survivorship through words and actions, but also through a return to health and physical reconstruction (Ucok 2002). Women who do not chose reconstruction are excluded from participating in the individualistic narrative of the survivor who has beaten cancer; instead their bodies are constant sites of negotiation and self-formation because they defy the expected progression from patient to 'survivor'.

These notions of selfhood are in contrast to the self that is described by a symbolic interactive perspective, in which the body is co-constituted with the self: the self not just encompasses the body but simultaneously is the body (as in Sartre [1956] 2013). Body and self have a dialectical relationship, neither independent of nor completely defined by the other (Thomas-MacLean 2004:630). Therefore, bodily stigmas (either felt or enacted), and specifically abominations of the body, act upon the self and influence its perpetual remaking.

In the context of personhood, authenticity cannot be understood without locating it in a particular notion of the self. The very basis of Mead's ([1934] 2009) classic description of the development of the self is a process of interaction, and as Blumer conceptualized it, selfhood is simply the ability to be an object to your own action ([1969] 1986:12). Being authentic, 'true' to oneself, or feeling 'like' oneself is incompatible with an interactionist understanding of how we exist in the world (cf Vannini and Franzese 2008) because the self is continually undergoing processes of change. Yet, the concept of authenticity is deployed by the women I studied. The common concept of self discussed above is one that has some

core and stable essence that serves as a point of comparison, and deviation from that core can be interpreted as inauthentic.

## CHAPTER 3

### METHODS

There is a lack of research on women who do not choose to have breast reconstruction. Because this group is so under-studied, variation within it is mostly unknown and unattended to. This project begins to address that by studying one group of women— those who choose to seldom or never wear prostheses— and looking at their experiences, focusing on clothing as a site of decision-making tension about bodily presentation.

In order to gather data on women who choose not to reconstruct *and* not to emulate the look of ‘healthy’ breasts, I took a two-pronged approach. First, I identified companies making clothing designed for women who choose not to have reconstruction after mastectomy. This clothing caters to those who need to dress a single- or no-breasted body. However, there are only three of these companies, all very small and one now defunct. Not only has no one has done research on these companies, very little attention has been paid to clothing and breast cancer at all, and that work has not been built upon (e.g. Feather, Rucker, and Kaiser 2009).

Because women buying from these companies are a small and difficult to access group, I also broadened the reach of the study through data from three popular breast cancer web sites, using both the visual depictions on them and the content of their discussion boards. In the latter, I focus on information about women’s experiences looking for clothing options and support related to not reconstructing.

## **Interviews**

I conducted four qualitative phone interviews with women in the U.S. and Canada who purchased clothing from a company (here called Defy) that makes garments aimed at women who have had mastectomy without reconstruction, and also conducted two in-depth interviews with the company's founder.

Defy's garments are largely designed for women who choose not to wear prosthesis to emulate their missing breast(s). They often emphasize asymmetry or flatness, and are made differently for women with right or left mastectomies. Though mostly embracing changed bodies, some garments have camouflaging volume.

Participants were recruited through contacts from the owner of Defy and the owner of another company, Smooch. Only customers of Defy responded to the call<sup>11</sup>. They are all self-identified Caucasian women in opposite-sex relationships.

I used the interviews to develop sensitizing concepts (Blumer 1954) that I then explored in the content analysis of online discussion boards. The initial concepts found in the interviews that I later built on when conducting content analysis were a.) a sense of invisibility in the breast cancer community and b.) conflicted feelings and choices about bodily presentation.

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<sup>11</sup> The owner of the third company I identified refused to participate. The owner of Smooch agreed to participate but did not follow through despite multiple rescheduling attempts. The owner did put out a call for interviews to customers on my behalf.

## **Content Analysis**

### **Breast Cancer Organization Web Sites**

The initial research discussed above (Klawiter 2000; Thorne and Murray 2000) that indicates current breast cancer culture privileges depictions of the normative survivor is quite limited. I chose to build on it through analyzing how women are pictured on the web sites of major breast cancer organizations.

Then, in order to capture more information about a group that is difficult to identify and study, I also turned to three sources for publicly posted internet content about having a non-reconstructed body and choosing not to wear prosthetics: Breastless (BL), dedicated to information and resources for women who do not have reconstruction; the Cancer Connections (CC) public discussion boards; and the Young Cancer Page (YC) discussion boards<sup>12</sup>. All organization names have been changed. Taking the concepts developed from the interviews I analyzed the text of the web posts and, using a quasi-grounded theory approach, built upon them.

Breastless is a general information site that also archives women's individual essays on living without reconstruction. At the time of my data collection, there were 7 essays submitted from readers, mostly in their 40s and 50s, who did not have breast reconstruction and never or rarely use prostheses. The Cancer Connections boards (CC) are hosted on the site of the same name, a very large nonprofit organizational site with articles

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<sup>12</sup> Another board was originally included from 'Big Org', but during my data collection, they posted a large notice on their forum homepage stating that the forums were not to be used by researchers or journalists (though they are in fact accessible and public). In light of this, I removed the Big Org data from the analysis.

on all aspects of cancer. The Young Cancer Page (YC) is targeted at the experiences of younger women, but there are no age limits on participation. They also provide information and host in-person events.

None of the boards allow calls for research, so analysis was limited to existing information<sup>13</sup>. All data from the boards is public, that is, accessible to anyone online without a password or other barrier. However, I assigned pseudonyms to (already largely pseudonymous) usernames and changed minor details in order to lend an extra layer of privacy (following Wilkinson and Thelwall 2011), since participants may have varying levels of awareness about the accessibility of their posts.<sup>14</sup> I also altered the exact wording of lengthy quotations in order to prevent easy identification of phrases from this project by search engines.

Due to the large volume of content on both discussion boards (tens of thousands of posts), I restricted my use in two ways: through searches of relevant sub boards and

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<sup>13</sup> YC denied my application to put a call through their boards because it did not fit with their current prioritized areas of research.

<sup>14</sup> The Code of Ethics of the American Sociological Association does not specifically address matters of online research, but it does state that use of public information does not require informed consent (American Sociological Association [1999] 2008). The Association of Internet Researcher guidelines, as cited in Lomborg (2012), advocates use of the distance principal (how removed the person is from the text) and perceived privacy (how private the person interprets their behavior to be) to guide the need for informed consent. I came to my determination because the data is, *in fact*, publically accessible, and because although the analysis here is about individual statements and motivations, it is not a study of any individual and does not attempt or desire to identify posters. The use of pseudonyms for what are already pseudonymous poster names and the alteration of details adds another layer of privacy in that it prevents passages from this paper being searched directly online. Finally, I believe that general knowledge of internet privacy is quickly evolving and that perceived privacy has rapidly diminished across all areas of the internet.

through keyword searches. I limited analysis to discussions of and by women<sup>15</sup> who did not have reconstruction and who discussed prosthesis use, focusing on those who sometimes or always went without prosthetics.

Data from both the interviews and text used for the content analysis were input into NVivo qualitative analysis software and analyzed for emergent themes using a broadly grounded theory approach, returning to the data as new themes emerged.

In analyzing the online data, I was attentive to discussions of factors known to affect prosthesis use: age, race, and insurance/medical context<sup>16</sup>. Of these, only age emerged as a topic of conversation. Though insurance status did not, related medical concerns did. Race did not emerge as a discussion theme in the context of living without reconstruction. While likely an important component of women's experiences, it did not arise as a topic of discussion, and I did not feel there was sufficient context to determine whether this was due to whiteness being perceived as the default category online, discomfort discussing race, or other unknown factors. This is an area ripe for future research.

In general, posters do not identify their demographic attributes, though they do list age with some frequency. Rather, signatures typically contain a list of diagnoses, treatments, and dates, sometimes along with an inspirational quote. On some sites the norm is to have short summary while others list each event, so that every post ends with several lines of

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<sup>15</sup> Less than 1% of breast cancer cases occur in men (American Cancer Society 2014a). The majority of male mastectomies are actually performed to correct Gynecomastia (enlarged breasts) (American Cancer Society 2014b; Huber 2012). No one I interviewed or selected for the content analysis identifies as non-female but had they I would have excluded them from analysis due to the different bodily norms, issues, and expectations for them.

<sup>16</sup> Insurers in the U.S. have been mandated to cover breast reconstruction since 1998 (United States Department of Labor N.d.).

data. The listing of these events adds useful context in a forum for patients so that one can see what the poster has experienced and use that to contextualize their postings, but it is not axiomatic that they would identify this way. Some users have a photo avatar, but not all do, and they rarely show more than the head and shoulders. Posters may mention more traditional markers of identity and group membership in passing, but it is the specific bits of diagnosis and treatment data that situate them within the group of cancer survivors. In this context women use medical information rather than 'typical' categories such as race or age to signal group membership. They are participating in a community that creates new categories of group affiliation and identity that are not present in broader society.

Neither my interviewees nor the population of the discussion boards are representative of the population in a statistical sense. However, they are the most meaningful population for this analysis because they represent the women most committed to rejecting the normative expectations of post-mastectomy choices. Any difficulties or limitations they experience may thus be experienced by others.

The sense of invisibility and conflict about presentation I found in my interviews was also prevalent in the discussion board postings. A deeper look at the message boards led me to organize these and other issues as fundamentally concerns about stigma and selfhood that ran through women's discussions of living without reconstruction.

## CHAPTER 4

### ANALYSIS

#### **Depictions of cancer online**

To further establish other's initial findings about bodily expectations within the modern breast cancer context, I examined three major cancer organizations' web sites and how they depict the bodies of women with cancer. Because this project focuses on appearance, I analyzed images only, not text<sup>17</sup>. I culled all of the images from the sites' main pages, the landing page for all major subpages, and online store pages when applicable. Across the three sites, 48 images depicted either clothing or women.

Thirty five images depicted women: 22 at Big Org, six at Cancer Connections, and seven at Young Cancer Page. On Big Org's page, of the six images where a woman's chest was visible, all six depicted what appeared to be 'normal' breasts. Whether the breasts were naturally that way, reconstructed, or with prosthesis, it was not possible to discern in any of the six photos. Three of the women have short stories attached to their images, but in none of them do we find out what they did concerning reconstruction.

Comparable images were found at CC and YC. The CC page is very text-heavy, and so its lack of depiction should be noted in that context, because it does not frequently show *any* type of body. Of the bodies shown, only one was of a woman that may have unreconstructed breasts. There is no text describing her so this is my own interpretation of the photo. In many of the pictures the chest was not clearly visible. Similarly, at YC, most of the photos

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<sup>17</sup> Two of the three sites do have text acknowledging that not having reconstruction is a valid option. In both cases, this information is located three layers into the page structure (as a sub-sub-section), and notably one site does not discuss this option at all in main pages or subsections.

were head and shoulders shots, so that the breasts were not visible. In wider shots, the photos were either too small to see the chest area or it was obscured by an object. There are some vignettes about women on YC like there are on BO, but they either tell a story that includes reconstruction or avoid the topic altogether. Notably, none of 35 images of people depicted scars, bruises, ports, drains, or other indicators of ill health from breast cancer treatments.

Thirteen images showed clothing for sale. On the site that had the most clothing, I went further into the section, where there were 27 women's tops for sale, 16 of which were pink, and 23 of which either had a pink ribbon on them or displayed words that fit the 'survivor' narrative (such as hope). For all sites, the clothing fit guide is like the one you would find in an average catalogue. No special attention is given to the chest area, and there is no mention on the page of how the clothing would work for women with mastectomies, in surgical recovery, or without reconstruction. Though this section is explicitly marketed to women who are likely to have had breast cancer, it addresses cancer only in the way that Pink Inc. generally does, with feminine symbolic products. Lorde's prediction of a new movement in fashion has not come true, even within the breast cancer organizations. Decades later, Rabinovitch questions how she is supposed to wear "skinny breast-cancer awareness t-shirts with round targets on them" (2007:126), and only discovers fashionable options for herself upon being styled by *Vogue* for an article.

Depictions of women on these sites is only one way to examine how choices around reconstruction are addressed, but the erasure of breasts from the breast cancer movement's images is indicative of an erasure of illness overall. This focus on health and 'wholeness' privileges survivors (DeShazer 2013), and further those survivors that depict a narrow type of survival, a literal reconstruction of the pre-illness body. Even within the breast cancer

community, a narrow conception of survivorship and what women look like persists, bearing out the claims of prior research.

### **Stigma**

Online, women's narratives display concerns about bodily stigma and its management. Discussions that center on isolation and invisibility, interaction, and the creation of new identities show some of the ways that these concerns about stigma are expressed.

Single- or no-breasted bodies are not present in society at large nor in depictions of the breast cancer movement. Women who choose not to reconstruct feel isolated and invisible. They demonstrate that they perceive their bodies to be non-normative or even nonsensical, again echoing Sandell's (2008) insights.

Women in this study are overtly concerned about how their changed bodies might make others overly attentive to them and thus uncomfortable because of what they see. The tension from being simultaneously comfortable and uncomfortable parallels the key differences between being discredited and discreditable. A woman with a reconstruction or even with a prosthetic is largely able to stay on the discreditable side of that divide. A woman with a completely flat or an uneven chest, however, is in a more liminal space. Further, tensions around bodily presentation in public versus private spaces reflect the importance of context in shaping women's bodily decision-making. Finally, some women choose to embrace a new identity around mastectomy in order to present a consistent bodily appearance and make sense of what are otherwise socially unreadable bodies.

## **Isolation and Invisibility**

In hundreds of pages of texts from message boards, I only found one mention of reconstruction as the most common outcome of mastectomy. Rather, many women either guessed that they were in the minority or used the boards to ask questions about how many people reconstruct and to express happiness at finding others with whom to discuss and validate their choices.

Both interviewees and discussion board members emphasize how they have felt alone, unusual, and invisible. One woman also describes how, even in the context of a breast cancer support group, they had frequent guest speakers (doctors) who came to discuss reconstruction, but never a speaker who discussed alternatives. Even on websites designed to meet the needs of others dealing with the same issues, they feel isolated, and in fact discussions of life without reconstruction or prostheses compose a tiny segment of these boards. Some of these issues are summed up by interviewee Elizabeth:

I always feel that my decision to not have the reconstructive surgery and to not wear a prosthetic is odd. I, I don't feel like that's the accepted way. The accepted way is either to get the reconstructive surgery or to always wear a prosthetic. So yeah, I feel like, gosh I'm not doing it right. And I have no idea how many other people out there are like me, you know. I, I don't know if that decision really is that odd, I mean, I think it's a minority decision, but I don't know how much of a minority am I. You know, is it one out of five people that make this decision or one out of two hundred?

Because most women only have a vague idea of the possibilities open to them to reject reconstruction and emulation of breasts, their choices are made in a context of constraint and uncertainty. Elizabeth's worry about "doing it right" is situated in a social isolation that inhibits her ability to be aware of ways in which other women face these same issues.

Lorde (1980) identified this isolation as arising out of the pressure to get reconstruction

and use prostheses, in that it prevents women from literally being able to see and identify each other as survivors of breast cancer.

The isolation of these women amplifies their stigmatization. They are unable to fully access a sense of group belonging that might change their performance of deviant appearance. They form some nascent community online, but due to its virtual nature, they can not perform appearance with these women in their everyday lives. Because of the geographic spread of the members, regular in-person contact is not possible, although sometimes members meet up at events. In many ways we have now recognized that the online world is part of the 'real' world, but in this case it provides a barrier to group action because that action (performing breastlessness) is so grounded in the physical world.

Occasionally, women do acknowledge that their isolation is informed by representations in that larger world and directly engage in discussions of representation in breast cancer movements, discussing how pink marketing tries to "prettify" a painful illness experience (Amy, CC). As Tonya (CC) says, "it seems to me that now that breast cancer is not a hush hush disease that covering up that we have had mastectomies should be a thing of the past." Here she affirms the finding that, while breast cancer is now a disease with a large public presence, within that visibility there is still stigma about the physical effects of the disease on women's bodies.

### **Interaction**

Women repeatedly discuss their bodily choices in the context of interacting with others and anticipating their responses. They explicitly talk about the stress of being discreditable (though not in those terms) and wondering what and if people know. Their experiences are reminiscent of someone hiding a shameful secret. Some do take a more

forward approach, like Carol below, yet within this rebellious narrative she still acknowledges others' discomfort and even evaluates its severity.

I've been stared at in that OMG kind of way and it REALLY bothers me . . . Sometimes I'm fed up with feeling I have to wear [a prosthesis] just so other people don't get uncomfortable. I was hiking last weekend and walked past a group of young women who were probably horrified (I'm a [unilateral mastectomy], so that might have been even worse for them). Well, too bad.

Beyond just thinking about possible responses, several women are clearly concerned with managing the emotions of others. As Rita (CC) says, "I always felt apologetic when I hugged a person who knew, and they had that startled look for a second." One interviewee who said she does not care about what others think and is not even uncomfortable changing at the gym then also said that she often wears large sweatshirts to "hide", and another talks about not wanting to upset or embarrass others through her clothing choices. The women recognize their existence as a potential "aesthetic challenge" (Ucok 2002) to others. The idea of being comfortable in their own bodies, but not wanting to make others uncomfortable is a theme—and this is key— even among women who claim not to worry about others' opinions, echoing Lorde's realization:

The real truth is that certain other people feel better with that lump stuck into my bra, because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference (1980: 65).

At least one woman does challenge this idea, explicitly saying that she does not want to wear prosthesis to make others feel better. However, hers is not the dominant feeling among this community.

The main way this tension over appearance plays out is among different spaces. I find that these women's statements reflect a division between home and not-home, roughly equating to private and public. This was overwhelmingly the biggest factor that arose in the discussion boards when women talked about their appearance choices.

Women talk about either taking prosthetics off or wearing more revealing clothes when at home alone or around family. They share stories of unexpected and unplanned forays into the public sphere, whether from an unexpected guest or an urgent trip to the pharmacy made without changing first. Jill (CC) has taught her teenage children to call her with a warning if they are having friends over so that she can put on her prosthesis. Charlene (YC), in a thread about missing one's breasts, says "I miss it when the doorbell rings . . . I always have a dilemma when the bell rings...Do I have time to put the [prosthesis] on?" The scenario of an unexpected guest was a common theme. While Charlene allows for the possibility of not having time to change, others simply state that they *have to* do something, whether that is having another person answer the door, hurrying to change, or not answering at all.

These actions are underlain by concerns about the potential stigmatizing judgments of others. Women have to balance their own physical comfort with social comfort and visibility, where visibility is largely expressed in terms of public/private distinctions. Charlene's story is not unique in its description of switching prosthetic use within the home context. She does not miss the breast in the sense of longing for it and being psychologically affected, but misses the convenience of not worrying about that aspect of her self-presentation.

In contrast, women largely employ strategies when outside the home to obscure their bodily reality. Some use prosthesis, while others use clothing and accessories to distract or obscure, with many women engaging with a variety of methods to hide their bodies. Common clothing options include layered tops, jackets, scarves, and voluminous fabric to obscure the breasts.

Even within a group of women who choose to reject what they perceive as the popular choice to reconstruct, distinctions are still made about audience and propriety. While a few women discuss *never* wearing prosthesis, many more create a boundary between home and not-home, in which the home is where they can reject reconstruction, but outside that context they are careful about presentation and manage stigma through camouflage.

### **New Identities**

Lastly, a sub-set of women online have self-identified with being flat-chested (because they had double mastectomies without reconstruction) and have created a sense of group belonging over their lack of breasts in a discussion thread. These women exhibit a kind of defiance, with the poster who started the thread explicitly saying that she does not want it to be a space for apologizing about their choices. Alicia (CC) even situates her posting in a broader context, wondering if women sometimes get reconstruction due to pressures to appear normal and not “shocking”. In most posts, they realize that they are potentially confronting stigma, but use this identity to push against it.

However, it is important here to attend to the distinctions between post-mastectomy flat-chestedness and ‘natural’ flat-chestedness. These women are completely lacking breasts but have changed bodies from surgical procedures, so they can not pass as

'naturally' flat chested in many situations. They have scars, but also lumps and bumps, and may even have concavity on over their sternum and ribs. Amanda (CC) expresses surprise over this exposed anatomy, joking "who knew my ribs were so bumpy?" However, women with bilateral surgery can more easily be read as normal than can women with unilateral mastectomies.

To counter stigma they may also align with other ways of being in a flat-chested body that are socially recognized, such as very slim, athletic, or youthful. This allows them to claim some identity in a way that other isolated women cannot. Their bodies permit some cover under different categories. Women talk about welcoming the removal of their breast since they were just going to get more "saggy" and "baggy" as they moved into their 80s and beyond. As Julie (CC) says, "Having the body of an 11-year-old when you're 65 is NOT a bad thing in my opinion!" The mastectomied body is socially unreadable, but these women find a way to inhabit their bodies more comfortably by thinking of themselves as being read into other categories, such as 'young' or 'athletic'.

### **Maintaining Coherent Selfhood**

As one of my interviewees put it, she became "a one-breasted woman in a world where you're supposed to have two breasts." Given this, how do women view themselves and their changed bodies? The choices that women make about managing potential stigma are made in the context of their understanding of the body-self relationship. I find that these women reveal tensions between dominant notions of the self and their experiences of bodily presentation. This is mainly apparent through discussions of authenticity.

In the broadest sense, breast implants and prostheses are fake in that they are not living tissue, but foreign objects put into or onto the body. Some comments reflect this, such as Susan's (CC) indecision about reconstruction due to not wanting something fake "hanging" off of her body, or Julie's (CC) description of implants as "lumps." No matter how realistic looking, implants are not flesh. Some reconstructions use tissues from elsewhere on the body, but they still look and feel different than breasts. Women do vary on whether they feel that they are more authentic for not having reconstruction, beyond just the fact of having fake body parts.

More interesting, though, is the frequency with which *language about authenticity* is found. Women talk about their bodies almost as billboards, and about not presenting an appearance that conflicts with reality, about not appearing fraudulent. This is found in Rita's (CC) reflection that "the best thing about going flat is that I feel like myself, instead of knowing the boobs are fake." Rita's body is part of her construction of selfhood. Her self is intact with the removal of body parts, but adding replacements disrupts her sense of authenticity. She implies that getting breast reconstruction would create a false pretense. Christina (CC) takes this further, when she writes about her dilemma of interviewing for jobs and the choice of whether to be "honest" as opposed to wearing her prostheses. Others respond in understanding of her position, one going so far as to talk about whether she would be being misleading people if she were to be inconsistent in wearing them. The prostheses are viewed as fundamentally different from other ways one could vary appearance from day-to-day.

These notions of falsification or trickery are in contrast to some of my interview data, where women discuss interactions in terms of comfort rather than 'truth.' We may be

able to understand both of these positions through Lorde's (1980) account of rejecting prostheses because they made her feel alien to *herself*.

The use of terms like 'real', 'fake', and 'fraud' demonstrate the belief that there is some real, internal self against which we can measure our bodies and experiences, whether that self is physical or not. Many women discuss breasts as being both a physical and symbolic part of themselves, and often use the language of 'natural' or 'whole' to express this. This language implies that we cannot make certain choices about our bodies and retain authenticity. If the fakeness were just a literal statement about silicone and stuffing, it would not also imply fraudulence and misrepresentation. We put many things in and on our bodies, from nail polish to tattoos, to pins, staples, and plates, but they do not all carry the significance with which these women are imbuing their prostheses. The possibility of alternative bodies for these women is limited once that body is conceptualized not as a self-expression but as a social being.

Some women, most notably on Breastless, deploy language about the self in a different way. They reject reconstruction and embrace their new bodies, identifying with the change to the point that they submit essays to this site; however they also claim that the body is not the self. Amber makes the strongest statement, that her body is not part of the "real" her, which can be located in things like her hobbies and beliefs. Her self is internal and her body a vessel. More common is Jamie's claim that her body does not *determine* her self, that she is more than her body.

Conflict arises when women try to enact 'truthful' bodily representations while also handling potential stigma. How do these tensions get resolved? Above, I showed how women maintain distinctions between public and private as a way to handle their decisions

about presentation. However, this conflicts with their stated goals of being true or real. Above we see how sometimes this leads to a choice to be 'natural' and not use prostheses. One other way this is resolved that is popular among those discussing non-reconstruction is through the use of camouflaging clothing. They discuss the best styles, necklines, and fabric to cover themselves and how to "pull the eyes up" (Carrie, CC) to other areas or distract using jewelry and accessories. Through wearing loose, layered, or otherwise obscuring clothes, the women can maintain that they are not being 'fake' while also protecting themselves from the judgmental gaze of others.

I set out to study companies providing clothing to women who choose not to reconstruct in order to understand more about the experiences of women with stigmatized bodies. I found that there were so few companies and customers that I turned to broader discussions of reconstruction online to find out how these women handled breastlessness. In the end, I return to clothing, but instead of it being embraced for an alternative form of bodily presentation, I find it deployed as a stigma management device.

## CHAPTER 5

### CONCLUSION

This paper highlights the tension I find in our understanding of the experience of breast cancer, where the breast is definitionally central to these issues, but is often simultaneously absent. The lived realities of women and the actual bodily effect of the cancer are not given attention within the breast cancer awareness movement. Lorde (1980) believed that the promotion of prostheses served to keep women's suffering and the real effects of breast cancer literally, and thus socially, hidden. I find evidence for her claims even after decades have passed.

The messages of the mainstream breast cancer movement exacerbate and recreate the tension about the place of the breast. Women feel that their choices are erased, and though those who opt out of reconstruction are the clear majority, they end up feeling like a small, isolated group. Indeed, Information about the experiences of women *within* the non-reconstruction group is lacking. Specifically, we do not have much good data on prosthesis use, from basic frequency to factors affecting use and satisfaction.

Within this isolation, women navigate what they perceive as an unpopular choice (not to reconstruct or wear prostheses) and face difficulties enacting this choice across different social contexts. They draw boundaries between public and private and alter their appearances depending on setting.

In rejecting reconstruction, these women embrace the idea that the self is not determined by the body, and that they can retain their identity despite major physical changes. Though in general these women ascribe to the idea that their bodies do not

determine their identities, and that their selfhood is therefore intact, they modify their bodily presentations in order to accommodate potentially stigmatizing others and manage the perceived emotions of others.

Cromptvoets describes prostheses users as doing “daily body work” (2005: 89), but we all do daily, hourly, continual body work of some sort. Women with reconstruction or those who opt out of emulating breasts altogether can not exempt themselves from this labor. Their labor just takes on another form.

Exploring parallels between the women in this study and women who have breast surgery for other reasons may be instructive. Recent work by Gimlin (2013) suggests that we may be in the midst of a shift of attitudes about so-called cosmetic breast reconstruction, with less emphasis on ‘natural’ looks. If what women with breast cancer want to emulate (their own breasts) starts to diverge from what those who get elective surgery are envisioning, will that change decision-making or their understanding of the body-self relationship?

Finally, an issue many women brought up that I have not explored in depth here is the sense that their isolation partly arises from an inadequate marketplace to respond to their clothing needs. They talked about their desire to find clothes that fit their altered bodies. The three companies I first identified for this research are all very small operations, largely run by a single person and with limited products that are mostly quite expensive. Even setting aside the idea that a woman might want clothing tailored to her asymmetrical or flat chest, undergarments are not available that take her into account, and many of the products promoting the breast cancer movement are tight or revealing. Culturally, these women have found each other in small corners of large message boards, but the mainstream

breast cancer movement all but ignores them. An analysis of existing breast cancer 'survivor' products and their limitations might be a fruitful extension of this research.

**APPENDIX**  
**INFORMED CONSENT MATERIALS**

**Consent Form for Participation in a Research Study**  
**University of Massachusetts Amherst**

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**Researcher(s):** Marianne Joyce

Faculty Sponsor: Robert Zussman

**Study Title:** The Pink Look: Breast Cancer and Non-Conforming Bodies

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**1. WHAT IS THIS FORM?**

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research.

**2. WHO IS ELIGIBLE TO PARTICIPATE?**

Anyone who is an owner or customer of selected companies that make clothing for women with mastectomies can participate. You must be at least 18 years old to participate.

**3. WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this research study is to understand more about women who choose not to have breast reconstruction after surgery. Most women choose this option after having a lumpectomy or mastectomy, but not much is known about their choices and experiences.

**4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

The study will take place in one face-to-face interview or phone interview. It will last approximately 60 minutes.

**5. WHAT WILL I BE ASKED TO DO?**

If you agree to take part in this study, you will be asked to talk to the researcher about your experiences. Questions will cover your history of cancer (if you have one), your decision-making about breast reconstruction, your choices about clothing and appearance, and your thoughts about the breast cancer awareness movement. You may skip any question you feel uncomfortable answering.

You will also be asked to submit a photograph of yourself wearing the clothing. Many people do not know what this type of clothing looks like and seeing it may help them understand

what the research is talking about. **Providing a photo is optional.** You can do the interview and not submit a photograph.

#### **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may not directly benefit from this research; however, we hope that your participation in the study may add to our understanding of women's choices about their bodies and health.

#### **7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?**

The study will ask you to discuss personal subjects that may be stressful or uncomfortable. You may skip any question at any time.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

The following procedures will be used to protect the confidentiality of your study records:

- The researchers will keep all study records in a secure location. Paper files will be kept in a locked filing cabinet.
- Research records will be labeled with a code. A master key that links names and codes will be maintained in a separate and secure location. The master key will be destroyed three (3) years after the close of the study.
- All interview materials (electronic files with audio tapes of interviews) will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.
- All photographs (electronic files of photographs you provide) will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.
- All photographs will have faces obscured.
- At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format. You will be given a pseudonym and minor details will be changed to protect your identity.

#### **9. WHAT IF I HAVE QUESTIONS?**

You can take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Marianne Joyce, at 413-367-6526 or [majoyce@soc.umass.edu](mailto:majoyce@soc.umass.edu). If you have any questions concerning your rights as a

research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at 413-545-3428 or humansubjects@ora.umass.edu.

#### **10. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

#### **11. WHAT IF I AM INJURED?**

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting treatment.

#### **12. SUBJECT STATEMENT OF VOLUNTARY CONSENT**

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

#### **Interview consent:**

\_\_\_\_\_  
Participant Signature                      Print Name                      Date

#### **Photograph consent. Check one and sign:**

☐ I did not provide a photo.

☐ I agree that the photograph(s) I provided may be used for conference and other research presentations

☐ I do NOT agree that the photograph(s) I provided may be used for conference and other research presentations

\_\_\_\_\_  
Participant Signature                      Print Name                      Date

**Researcher signature:** By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of person obtaining consent    Print Name    Date

## B. Recruitment Materials

### **For owners:**

Dear [Name]:

I am a sociologist who is doing a research project about women's experiences with their bodies after breast cancer. Discovering [Company] has been helpful to me in thinking through these issues, and I am hoping to make a discussion of the work you do part of a project I am doing on women's experiences with choosing not to have reconstructive surgery. I was wondering if you would be willing to speak to me about the company and about your own experiences. Ideally I would like to interview you in person, but a phone interview is also possible. Please let me know if you would be open to speaking about your work. You can reach me at [majoyce@soc.umass.edu](mailto:majoyce@soc.umass.edu) or 413-367-6526.

### **For customers:**

(Through the owners so that I do not have access to customer info. before consent)

Hello,

My name is Marianne Joyce and I am a sociologist who is doing a research project about women's experiences with their bodies after breast cancer. [Owner] is contacting you on my behalf to ask if you would be willing to speak to me about your experiences as a customer of [Company]. Although many women do not have breast reconstruction after their surgeries, not much has been written about their thoughts and experiences. I hope that by learning more about your decision to shop with [Company] we can increase our knowledge of the different ways women choose to present themselves through their appearance and decisions that they make about their bodies.

I will be conducting informal interviews that last about one hour. These can be done in person or over the phone. If you are interested, please reply to me at [majoyce@soc.umass.edu](mailto:majoyce@soc.umass.edu) or call 413-367-6526. Contacting me does not obligate you to do the interview and I would be happy to answer any questions you may have.

Sincerely,

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