

STRANGE AND FAMILIAR: NARRATIVES OF EMBODIMENT AND  
OBJECTS AFTER BREAST CANCER

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## CHAPTER 1: INTRODUCTION

On October 1, 2014, the *Today Show* featured Joan Lunden, a journalist and recent cover model for *People Magazine*. The reason Lunden's cover was notable is two-fold: she was undergoing treatment for breast cancer and she chose to do the cover without hair. That is, she made the difficult decision not to wear her wig. For Lunden the cover was empowering, and while she did wear a wig for the *Today Show* segment, the magazine cover remains noteworthy. Altogether, Lunden's magazine cover, her appearance on the *Today Show*, and the various other media forms she engaged are significant. Through these discursive practices Lunden, like other famous women before her, comes to embody breast cancer survivorship (Dubriwny 2007). In this case, Lunden's positive attitude in the face of a harrowing experience and wig use negotiations are not only idealized by her celebrity, but also normalized through neoliberal imperatives that equate the appearance of health with empowerment. Her stories and experiences, while unique and particular, come to represent *the* breast cancer experience. Moreover, Lunden symbolizes neoliberal citizenship, in the context of pink ribbon culture, through the equation of positivity with health and thus, individual worth (Guthman 2011). This representation, and others, play upon but don't speak the largely undocumented dual nature of survivorship as both strange—a foray into unknown territory so to speak—and familiar—it is, in many ways, an exacerbation of feminized disciplinary practices.

At the end of the segment Lunden, Hoda Kotb, several other NBC anchors, and audience members formed a line and exited the set while dancing to “Happy” by Pharrel.

In its entirety, this news segment turned celebration is indicative of American pink ribbon culture and all its neoliberal characteristics. It is a mixture of fear, struggle, celebration, and femininity packaged into a knowable, understandable experience: the embodiment of seemingly contradictory characteristics. The end result is a somewhat puzzling display that amplifies the individual spirit and desire for survival while rendering invisible many breast cancer patients, stories about their bodies, and the objects that accompany life after breast cancer. Breast cancer survivorship, as it is lived, however, is much less jovial than it is unpleasant. It is an intensive embodiment of struggles to maintain normalcy in light of profound changes to the body and self.

Through the process of making breast cancer an appealing cause a gulf was created between that which is exemplified through pink ribbon culture and women's lived experiences with, and stories about, breast cancer (Sulik 2012). These discrepancies have been well documented by feminist scholars. Foremost among them, is Audre Lorde's (1980) intimate revelation of her experience facing a burgeoning breast cancer industry that, under the guise of recovery, encouraged women to wear prosthetic breasts after mastectomies. For Lorde, however, recovery meant coming to terms with her one-breasted body. Samantha Crompton (2006) documented discrepancies between women's experiences with their post-mastectomy bodies and the promises made by prosthetic manufacturers. Promises hinged on reductive ideas about gender, bodily wholeness, and normalcy. More recently, Gayle Sulik (2011) named the phenomenon which has "...transformed breast cancer from an important social problem that requires complicated social and medical solutions to a popular item for public consumption" —*pink ribbon culture* (2011: 4,9). The gulf between experience and expectations set up by pink ribbon

culture contributes to a number of confusions. Ultimately, misunderstandings regarding science, medicine, and the environment displace women's embodied experiences to produce a cohesive, consumable, and knowable experience symbolized by a pink ribbon and thus rendered familiar. This is all done under the guise of promoting women's wellbeing while increasing profits for corporations involved in pink ribbon marketing (King 2006).

The aforementioned works are fundamental in breast cancer scholarship, which has tried to make sense of women's experiences with breast cancer and the larger social and cultural processes that inform individual illness. Nonetheless, while these influential and important works detail the discrepancies between experience and pink ribbon culture, most do not go far enough to explore the strange and familiar aspects of breast cancer evidenced in the intricacies of erasure that result from the promotion of a dominant narrative, the nuances of the survivor hierarchy that is constructed in pink ribbon culture, and the competing qualities of cancer artifacts and pink ribbon commodities. My project fills this gap with emphasis on the role of objects in pink ribbon culture and survivorship through analysis of data from interviews and participant observation.

First, I asked which breast cancer narratives are missing or minimized by the dominant narratives in pink ribbon culture in order to demonstrate how experiences rendered strange are couched within a larger context that makes them familiar to survivors overall. Then I asked how breast cancer survivors made sense of embodiment in light of an emergent survivor hierarchy constructed through pink ribbon culture in order to establish the strange ways survivor's experiences are ranked in order to produce some experiences that are more familiar than others. Finally, I inquired about the material

components of survivorship in order to explain how pink ribbon commodities and cancer artifacts embody the strange and familiar ambivalence associated with breast cancer.

Through this project, I sought to attend to the discrepancy between experiences constructed by pink ribbon culture and women's lived experiences. Analysis of the data revealed that the strange and familiar interactions between bodies and objects were responsible for much of the discrepancy due in part to the absence of the corporeal, the messy, and the unsightly from pink ribbon culture. Objects are prominent in the narratives featured throughout this dissertation because they were a noteworthy feature of the data from interviews and participant observation. My focus is rooted in the issues and concerns expressed by breast cancer survivors and illustrates the variety of experiences encompassed within pink ribbon culture.

The variation between the depiction of breast cancer survivors' experiences exemplified by Lunden's story and the lived realities of other women's experiences, exemplified by Rita's story reveal a discrepancy in pink ribbon culture. Rita, a 68-year-old African American woman, shared with me some of the unexpected difficulties she faced after chemotherapy.

I think everybody kinda [sic] had the expectation that after the chemo was over I wouldn't need help to get anywhere, I'd be better... well it was just the opposite because of all these other problems. I still all of a sudden had to go to an eye doctor, all of a sudden had to go to an ear doctor all of a sudden had to go to a foot doctor... and now I'm looking at surgeries for those two things... (Rita)

Rita, along with her friends and family, was surprised at the struggles she faced even after ending chemotherapy. Alongside a lumpectomy, chemotherapy, and double mastectomy with immediate reconstruction Rita experienced a myriad of negative health effects, which complicated her life in unexpected ways. Since Rita had been healthy, or

in control of her body, prior to her breast cancer diagnosis she, and others, equated control over the body and its processes as empowerment. This demonstrates the extent that neoliberalism has been thoroughly incorporated into not only social programs but also mental schemas (Dubriwny 2013). Finding little information or support from her doctors and insurance company Rita devised her own methods for lessening discomfort and regaining control over her body. She wore white cotton gloves and socks to lessen friction against neuropathic fingers and toes and she placed tissues between her glasses and cheeks to soak up tears before the salt could dry out her skin. Rita's experience of the discrepancy between what is expected, and produced by pink ribbon culture, and her lived experience, is marked by the objects she used to manage her survivorship. These, and other discrepancies are not accounted for amid the joyousness of American pink ribbon culture nor in breast cancer scholarship.

### ***Literature Review***

This project uses three themes to explore the nuances of breast cancer survivorship in light of discrepancies between lived experience and representations in pink ribbon culture: narrative, embodiment, and objects. These themes have been addressed in scholarship from multiple fields including sociology, cultural studies, media studies, medical anthropology, critical theory, women's and gender studies, and nursing. A broad central goal in the work across these disciplines is to lessen suffering from isolation and uncertainty for patients and survivors and produce knowledge that is rooted in the body and also attends to cultural processes. In sociology, especially, analysis of illness narratives provides a mechanism by which experiences are understood amid larger social context such as the development of neoliberalism. Literature from women's and

gender studies is similar and it often seeks to highlight the voices of groups marginalized because of sex or gender with special emphasis on subjectivity. Additionally, work from nursing provides practical clinical solutions to issues related to the struggle associated with illness and care-providing. Altogether, work in these disciplines which employ narratives, embodiment, and objects as themes, point to the ways that sharing narratives about illness, particularly the material components of survivorship, helps to recuperate voices muted by the constraints imposed by cultural phenomenon.

### *Narratives*

Drawing from a variety of disciplines I use *narratives* to make sense of breast cancer survivors' mode of storytelling within the context of pink ribbon culture.

Narratives play an important role in shaping how illness is understood and the purposes it can serve. Sharing a personal or illness narrative is a way to help others through detailing a shared embodiment and allows the storyteller to reflect back on a difficult or trying experience as positive (Potts 2000). Sharing a story in order to help others and viewing one's experience as positive are two ways narratives are used to make sense of breast cancer and transform the experience from personal tragedy to a way to help others and better one's self. Yet, narratives and the ways women tell stories are deeply influenced by widely shared cultural narratives (Manderson 2011).

For breast cancer survivors, pink ribbon culture has a profound influence on the ways stories are told, what parts are left out, and how the experience is framed overall. As a result, breast cancer scholars criticize pink ribbon culture for producing narratives that encourage ignorance, focus on the individual, and create an environment where only certain types of stories are acceptable (Segal 2007). Focus on the individual, especially,

reflects the application of neoliberal ideology to health and women's bodies (Gill and Schraff 2011, Dubrinwy 2013).

Illness experiences detailed through narratives demonstrate the interconnectedness of bodies, health and illness, and the larger social world (Kleinman and Seeman 2007). The act of storytelling is “deeply social” and “the outcome of an extended process of interpreting ordinary experiences” (DeVault 2014: 23). As such, sharing a story of illness is profoundly personal, exceptionally social, and provides opportunity for commonality in the experiences of individual bodies (DeVault 2014). Moreover, within each individual illness experience narrative is evidence of the permeation of cultural beliefs, ideologies, and dominant narratives (Kleinman and Seeman 2007). Within pink ribbon culture having a story to share is, in many ways, a requirement of those who participate. As a result, survivors' narratives often reflect the dominant themes in pink ribbon culture. This does not mean, however, that breast cancer narratives are not also a way to reclaim one's body and share personal truths.

Storytelling, or sharing illness experience narratives, is important because it provides the storyteller with a mechanism to excavate a voice lost to illness (Frank 2013). Coming to voice through narrative is, for feminist scholars, a rejection of socially imposed silence and a call to action (Lorde 1980, McKenzie-Mohr and LaFrance 2014). As DeVault (1999) suggested, and Sulik (2011) reiterated, dominant cultural narratives and the accompanying language are ineffective for women to voice their experiences. Through narratives survivors assert their subjectivity and express criticism of pink ribbon culture, although the critique might be veiled by the limitations of language. Master narratives and through those, dominant discourse, maintain the status quo which leads to

a lack of representation of certain experiences and stories (McKenzie-Mohr and LaFrance 2014). Recovering survivor's voices amidst the dominant pink ribbon narrative, then, is an effort to transcend the limitations imposed by language and pink ribbon culture. Since personal narratives are not written or told outside of culture and society feminist scholars are sensitive to critique women's lived experiences as depicted through their narratives (Potts 2000). Nonetheless, survivors' narratives offer evidence of co-option.

The dominant narrative seeps into women's personal stories through the use of various narrative forms. For example, Dubriwny (2007) argues that the media's representation of Betty Ford's personal experience with breast cancer was told using two, at times contradictory, narratives: the medical success narrative and the medical research narrative. Through these narratives Betty Ford came to embody, and symbolize for subsequent generations, the ideal breast cancer patient (Dubriwny 2007). Her story and recovery have come to stand in for the entirety of women's experiences with breast cancer to the detriment of other stories—in essence, Betty Ford was Sulik's "she-ro" before the development of pink ribbon culture. Nevertheless, Betty Ford's story points to the ways public personal narratives become incorporated into the dominant narrative, but also the role public narratives play in reducing the stigma associated with breast cancer.

Alongside the development of pink ribbon culture, biomedicine has been criticized by various scholars for producing certain types of narratives to the exclusion of others (Thomas-MacLean 2004, Charon 2006). Narrative tropes offered by biomedicine depict experiences that end neatly; which conflicts with women's experiences with breast cancer (Thomas-MacLean 2004). To complicate this, Thomas-MacLean (2004) argues for reconstruction narratives, which incorporate reconstruction and prosthetics into breast

cancer narratives. These components were prominent features in the narratives women shared with me. This suggests that reconstruction narratives, to an extent, have entered the realm of pink ribbon culture, a phenomenon that was underway but had not yet reached its current level of saturation when MacLean conceived of the idea. Many stories in my study were dominated by the struggles of life after breast cancer, especially the every day tasks of managing bodies with objects. These kinds of narratives demonstrate the liminality of illness by making it difficult to locate a clear end to the illness experience.

Nevertheless, bracketed understandings of illness are reflected in dominant pink ribbon narratives. Dominant narratives, which coalesce through various media representations, create a salient image of breast cancer that privileges the individual, encourages consumerism, and focuses on recovery (Segal 2007). These components of the dominant narrative were articulated in the news stories about Betty Ford's experience with breast cancer and reappeared within my interviews with breast cancer survivors. Moved by feminist breast cancer scholars who lamented the constraints of the dominant narrative and its focus on positivity, personal enrichment, and optimism (Ehrenreich 2009, Segal 2008), I geared my project towards uncovering the discrepancy between the dominant narratives and women's lived experiences. Since the limited scope of appropriate responses to breast cancer has the effect of silencing alternative stories (Ehrenreich 2009, Crompton 2006), it is important to highlight those experiences.

The same limitations imposed through exclusions in pink ribbon culture are also imposed during support groups, which are often intended to be places to share stories and heal from traumatic experiences. In their analysis of support groups Coreil, Wilke, and

Pintado (2004) found that members employed a cultural model of illness characterized by recovery that emphasized optimism and personal growth. These sentiments were echoed even when telling stories of trauma and grief and were evoked in criticisms of other's emotional stories (Coreil, Wilke, Pintado 2004). These patterns also emerged in the support group I attended which created tension among the members. The cultural model of illness Coreil, Wilke, and Pintado (2004) described is complemented by the survivor hierarchy, the hierarchical ranking of survivor's experiences based on the extent they parallel the dominant narrative, which is informed by the same influences.

The emphasis on positivity in women's breast cancer narratives within Coreil, Wilke and Pintado's (2004) support group is reflective of the power of dominant narratives, which seep into the everyday lives of breast cancer survivors. Other characteristics of dominant narratives include use of militaristic and masculinist language (Sulik 2012, Cromptoets 2006, Lerner 2003, Eisenstein 2001), emphasis on "traditional" womanhood (Dubriwny 2013), and focus on personal responsibility to manage risk (Dubriwny 2013, Davis 2008). These characteristics appear in survivors' narratives both simultaneously and independently and may also be accompanied by recognition of the limitations posed by this language.

The sum of these features produces a particular narrative about a specific type of person with breast cancer who detects it early, receives treatment, and successfully recovers (Davis 2008). More than that, the particular person evoked is white, middle-class, heterosexual and identifies as a wife and mother (Davis 2008). And while many women with breast cancer fit the normative construction, there are countless others who do not.

Narratives that run counter to the dominant are necessary to shed light on the multitude of breast cancer experiences. Counter-narratives exist in multiple forms and can be evident even within dominant narratives. Strategies include use of metaphor, humor, and the presence of narrative debris (McKenzie-Mohr and LaFrance 2014:193). Through attentive listening, breast cancer researchers can ascertain these strategies and find space for counter-narratives even within stories that appear to reflect the dominant narratives. These techniques allowed me to locate a survivor hierarchy within breast cancer survivor's narratives, which is a means of asserting, and downplaying, one's survivorship in order to adhere to the dominant narrative. Yet, even within stories that reproduce the survivor hierarchy, women articulate nuances that complicate the classifications associated with survivorship.

### *Embodiment*

The importance of attending to processes of embodiment has been amplified through recent feminist sociological scholarship on the body. My project continues the trajectory through emphasis on narratives that revolve around experiences with embodiment and objects. This project and my focus on embodiment reflect the cultural turn in feminist sociology, which contributed to a lively scholarship on the body and embodiment. In light of this, there are several points of agreement among feminist scholars in regard to the body and embodiment.

First, embodiment is a social and historical process through which the self comes into being and the body materializes (Cregan 2006, Grosz 1994, Williams and Bendelow 1998, Noland 2009, Burkitt 1999, Weiss 1998). I use this component of embodiment to make sense of how survivors' narratives reflect understandings of the body and medicine

at a particular point in time. This is to say that in the midst of pink ribbon culture women's embodiment, or the ways bodies come to reflect the intersection of biology and society (Krieger 2005), differ from women's embodiment during eras when breast cancer was an unrecognized, unspoken experience. Similarly, embodiment scholars agree that embodiment is an entanglement of mind and body and, importantly, body and society (Blackman 2012, Shilling 2007, Kruks 2001, Williams and Bendelow 1998). The notion of an entanglement, when used to understand the body, is important to my project because it allows for multiple, overlapping, spheres of influence to impact the shape of survivors' bodies and their respective narratives.

Since there is room for multiplicity, or an understanding that bodies and experiences are never singular, embodiment scholars find that individuals can embody many things (Cregan 2006, Burkitt 1999). This means that one can embody feelings, emotions, and statuses related to a variety of experiences and body forms. Informed by the understanding of embodiment as reflective of experience, my project uses the complexities of women's experiences with breast cancer to make sense of the body/object relationship in addition to giving insight into the shape their narratives take. Crucially, with the body conceived of as the locus of regulatory norms, which materialize as race, class, gender and sexuality, embodiment reflects not only personal experience, but also large-scale mechanisms for organizing society (Butler 1993, Cregan 2006, Frost 2001).

Although embodiment can and does reflect regulatory norms, it is also the means through which difference is articulated (Butler 1993, Grosz 1994). This idea is noteworthy for my understanding of the survivor body as a potential, particularly in my analysis of experiences that have been erased from pink ribbon culture. Bodies that

materialize outside of the two-breasted norm tell different stories than those that adhere to normative post-cancer embodiments. Nonetheless, these understandings of embodiment are a means to disrupt and reject mind body dualisms and press for an open, layered, and complex understanding of the body as being in the world (Thapan 2009). Finally, I add to Krieger's (2005) definition of embodiment as the physical expression of the intersection of biology and society by demonstrating how pink ribbon culture informs the ways women embody survivorship and how survivors' understand that process.

Body experiences are informed by innumerable factors with embodiment playing a role in work (Kang 2010, Mears 2011), beauty and body image (Gimlin 2002, Jeffreys 2005, Grogan 2007, Edmonds 2010), identity (Thapan 2009, Crossley 2001, Poovey 1995, Sharp 2006), movement (Young 2005, Noland 2009), technology (Toffoletti 2007, Shilling 2005), and health and medicine (Turner 1984, Hogle 1999, Pitts-Taylor 2007, Mol 2002) to name a few.

Much of the work on the body and embodiment regards health, illness, and medicine. As arguably embodied conditions, health and illness provide an ideal medium in which to study embodiment because of the fluidity of these conditions. Specifically, embodiment in breast cancer research focuses on understanding women's decisions regarding treatment and testing (Lende and Lachiondo 2008, Hesse-Biber 2014), confronting altered bodies (Manderson 2011, Thomas-MacLean 2004), normalization (Lorde 1980, Sulik 2012, Cromptvoets 2010), and the commodification of experience through goods and services (King 2006, Dubriwny 2012). My project speaks to many of these areas as well as the meanings of interactions between bodies and objects.

Analysis of decision-making processes reveal that women's embodied

experiences and subjective assessments of risk are more powerful and meaningful determinants of how women make decisions than knowledge produced in biomedicine (Lende and Lachiondo 2008, Hesse-Biber 2014). Decisions about the body are embedded in what Hesse-Biber (2014) terms the “nexus of decision making” and have much less to do with statistics than embodied knowledge and women’s everyday lives. My research echoes this in that many women made decisions about reconstruction or prosthetic use based on their knowledge of other survivors’ experiences, their perception of others, and their own past experiences with illness and treatment.

After a breast cancer diagnosis and treatment women are confronted with profoundly altered bodies (Manderson 2011). As such, another decision involves which, if any, reconstructive surgeries women want to undergo. This decision, like all treatment related decisions, is informed by pink ribbon culture. However, pink ribbon culture has been critiqued for transforming breast cancer into a crisis of femininity, with greater emphasis on restoring beauty, than challenging the politics of breast cancer (Lorde 1980, Sulik 2012). Consequently, how women decide to proceed reflects the interaction of biology and culture and desires to embody a particular mode of survivorship.

The struggles, tensions, and suffering that result from breast cancer reflect larger cultural anxieties about the body, in general, and women’s bodies in particular. Depictions of women’s bodies as untrustworthy or villainous, as seen on a t-shirt that reads, “Yes, they’re fake! The real ones tried to kill me!” pervade not only women’s narratives about breast cancer, but throughout American pink ribbon culture. Analysis of the ways Swedish women manage body experiences after breast cancer found women responding to altered bodies as “strangers” (Lindwall and Bergbom 2009). Through this,

women are constructed in opposition to their bodies, which have been fundamentally altered as the result of a betrayal—the body allowing a tumor to grow. Lindwall and Bergbom (2009) found within the overarching theme of *body as a stranger* emerged the body as a failure, the body as a prison, and the body as a home where struggle is taking place. Notions of bodily betrayal emerged in regard to the development of lymphedema after breast cancer. For many survivors in my study, like Lindwall and Bergbom’s participants, the body itself, rather than surgical error or a common side effect, was seen as the source of trouble.

There are alternate understandings of the body after breast cancer, however. When women play a more active role in making healthcare decisions, through alternative health practices, bodies are understood differently (Salamonsen, Kruse, and Eriksen 2012). Within the context of making decisions women conceived of their bodies as gauges, potential gauges, and as informing women of changes. With the body experienced as a guide, women reported feeling like active agents in their recovery process (Salamonsen, Kruse, and Eriksen 2012).

Breast cancer, its treatments, and the conditions it contributes to, is a life long process that complicates the divisions between sickness and health (Thomas-MacLean 2004). The long term effects include changes in breast sensation, appearance, and effects from treatment like early menopause, weight gain, and lymphedema (Thomas MacLean 2004). Navigating these changes requires women to confront breast cancer and its effects on a daily basis. My project speaks to this issue by introducing pink ribbon commodities and cancer artifacts as two means by which survivorship is embodied. I argue that the lymphedema sleeve is one of many strange and familiar objects that challenge

understandings of embodiment produced by American pink ribbon culture. However, the role objects play in embodiment and the complexity they lend to survivorship is an important, but understudied, part of understanding women's experiences with breast cancer.

### *Objects*

Even within critiques of pink ribbon culture there is a lack of discussion of objects that inform breast cancer survivorship. Objects, in general, are recognized as having multiple, context dependent meanings which take shape through interactions with human actors (Lynch 2009, Griswold, Mangione and McDonnell 2013). Objects inform human knowledge and experience and how the body materializes. One such object are prosthetic devices which are intended to “restore function or for physiological effect,” and have as many social uses as they do material purposes (Ott 2002:33).

Prosthetic materiality, however, is part of the meaning making process in that their shape, fit, and design impact not only the wearer's body, but also understandings of the human body. Prosthetics, as Jain (1999) notes, are not exclusively enabling to the wearer. She cautions scholars from using the “prosthetic trope” and dismissing the material life of prosthetics because it puts forth, and supports, a very limited understanding of the relationship between humans and prosthetic objects. That is, the corporeal relationship between bodies and prosthetics and the meanings those relationships convey are more complex than simply labeling prosthetics as enabling. Women wearing prosthetic breasts or wigs, with reconstructed breasts, or lymphedema sleeves experience tactile sensations from those objects. Jain (2013) describes these objects as “cusp objects”—either enabling someone to “pass” or not. Although Jain's

(2013) arguments about cusp objects are based on personal experience, the either/or analysis leaves out some of the complexities of the body/object relationship such as ensuring the object helps one pass requires significant effort. Objects, in whatever form, require vigilant self-monitoring to guarantee that one has the best chance to pass. Nonetheless, Jain's is one of the few social science works that explore this issue.

The material effects of prosthetics include more than producing the appearance of body wholeness; they also cause discomfort, limit mobility, and strain financial resources. Furthermore, the difference in the depiction of prosthetics in marketing strategies and every day use represents a slippage: the promise of a return to normalcy and a desire for normalcy never manifest through the use of prosthetic breasts (Cromptvoets 2012). Drawing from Cromptvoets (2013) I expand on the idea of the promise to explore the strange and familiar components of pink ribbon commodities and cancer artifacts, like breast prosthetics which were shown to be contentious devices in my interviews. They were materially uncomfortable for some women and problematic for their effectiveness, or lack thereof, for others. With a range of uses from fashion accessories to medical devices, breast prosthetics serve multiple functions, both of which work to create a two-breasted feminine form (Gardner 2002). The importance of embodying a two-breasted feminine form, even after cancer, is an issue for feminist breast cancer scholars (Lorde 1980, Cromptvoets 2012). The debate over whether prosthetics are an important part of women's recovery or symbolic of the objectification of women's bodies remains relevant (Lorde 1980, Cromptvoets 2012, Ehlers 2012). Critics argue that emphasis on reconstruction and prosthetic breasts turn breast cancer into a cosmetic issue and hide mastectomied-women from one another (Lorde 1980,

Crompvoets 2012). However, Ehlers (2012) argues that the debate itself sets up a false binary between having reconstructive surgery or wearing prosthetics and being one-breasted or flat after surgery. The former is understood to reproduce gender norms whereas the latter is understood as resistance to gender norms. This binary displaces the very real ways the body and internal and external prosthetics interact. Furthermore, the debate glosses over the ways women learn to incorporate and accommodate prosthetics and reconstruction into their daily lives; which further marginalizes women with breast cancer (Ehlers 2012). Drawing from Ehlers (2012) I dwell on the material effects of prosthetics, other cancer artifacts, as well as pink ribbon commodities to fill the gap in the literature and attend to the nuances left out of the aforementioned debate.

Recently, breast cancer related commodities, which are objects featuring a pink ribbon, have garnered more attention from activists, researchers, and lay people (King 2006, Sulik 2012). Breast cancer organizations like Breast Cancer Action have come out against “pink washing” through their *Think Before you Pink* campaign which asks consumers to be more critical of the pink ribbon commodities they purchase (Sulik 2012). In addition to symbolic association with breast cancer, pink ribbon goods highlight connections between women and consumption and equate purchasing with political participation, altruism, and good citizenship (King 2006). Through cause related marketing, objects with little to no connection to breast cancer bear the pink ribbon and cement breast cancer’s status as a concept brand (Sulik 2012). Beyond commodified reminders of breast cancer awareness, pink ribbon goods are manifestations of neoliberalism, capitalism, and post-feminism’s impact on understandings of health, problem solving, and the role of the market in every day life (Dubrwin 2013). Missing

from these conversations, however, are the strange and familiar ways both cancer artifacts and pink ribbon commodities influence embodiment and survivors' narratives. My project addresses these concerns and adds to work like Jain's (2013), King's (2006), and Sulik's (2011) by focusing on the dual nature of the objects that factor into survivors' experiences with breast cancer.

### ***Methods and Data***

This project, guided by feminist theories and methodologies, used participant observation and semi-structured, in-depth interviews to collect women's narratives about their experiences with breast cancer.

#### *Participant Observation*

Participant observation is an ethnographic, qualitative, research method that places the researcher in a social setting with their participants (Maddison 2007). It can, and does, take place in multiple settings within a single project. Various health and body scholars have used participant observation as a supplement to interviews because it allows for the emergence of multiple understandings of the phenomenon at hand (Martin 2007, Manderson 2011, Thomas-MacLean 2004a, 2004b, Lende and Lachiondo 2008). As cited in Maddison (2007), Licheterman (2002) argues that participant observation coupled with interviews provides a unique interpretation of lived experience. For example, Martin (2011) supplemented interviews with participation and observation at support group meetings, industry conventions, and various other arenas to gain a fuller perspective of constructions of personhood in cases of bi-polar diagnosis. The combination of both methods allows for richer understanding of the phenomenon under study and provides dual settings for its articulation. In many ways, participant

observation provides a base to the interview, allowing the researcher to establish rapport prior to scheduling an interview. The data gathered through participant observation is field notes on interactions, experiences, observations, surroundings and events (Cerwonka and Malikki 2007).

#### *Finding Locations for Participant Observation*

To begin, I searched for “support groups in Mid Missouri” on Google. I found a local support group that met monthly. For access I called the group organizer and asked permission to attend as a researcher. The organizer granted permission for the initial visit and I elicited a written permission form and verbal permission from support group members for subsequent visits, per IRB guidelines. The support group was unaffiliated with any larger organization although many members were active volunteers with Susan G. Komen for the Cure and at local cancer hospitals.

After attending several support group meetings I researched local mastectomy fitter training classes. I found and registered for a course put on by Anita International in June 2014. Anita International manufactures breast prosthesis and mastectomy bras, in addition to various other undergarments. The class consisted of 8 hours of training and provided a binder of information detailing the company’s history, products, and information on prosthetic breasts and breast cancer.

As I built rapport with support group members I was invited to various local breast cancer events including the Komen Race for the Cure, Komen Tea, and a research symposium and luncheon. At these events I sat with group members and engaged as a breast cancer supporter. I did not take notes during meetings or events to avoid being obtrusive and violate group member’s privacy (Martin 2007). Afterwards, I wrote field-

notes based on my experience noting the themes, standout quotes, and a general discussions.

### *Interviews*

Interviews were an important addition to participant observation. The intimate setting allowed me to discern individual perspectives that were not as apparent in the group settings.

I employed semi-structured interviews, which are organized according to an interview guide, but tended to follow the path set by the respondent (Hesse-Biber 2006). This allowed room for the respondent to take the interview in different directions, telling stories they determined to be important. This was an important part of conducting feminist oriented interviews because participants are considered active agents of knowledge such that interviews should be...“engaged, interactive, and open-ended” (Bloom 1998:17). Furthermore, the responsibility for meaning making is shared between feminist interviewers and their participants (Hesse-Biber 2006).

Through this joint venture the semi-structured in-depth interview reveals respondent’s lived experiences, thoughts, feelings, and reflections (DeVault 1999, Hesse-Biber 2006). However, it is not a uni-directional exchange of information. As an exercise in reflexivity and to build rapport I shared with the respondents the impetus for my study—my grandmother’s breast cancer in the 1970s and her silence about the experience. This is part of a participatory interview model, which is intended to decrease the power differential between researcher and participant (Hesse-Biber 2006).

### *Interview Structure*

Interviews were semi-structured, but tended to follow a progressive path

beginning with diagnosis and ending with recovery. They lasted between 1 and 2 hours, with some exceptions.

To organize and guide the interview process I created an interview schedule, which can be found in Appendix A. It is divided into four domains of inquiry (Hesse-Biber 2006): general questions, questions about decisions, questions about feelings about the body before and after breast cancer, and questions focusing on women's thoughts, sense of stigma and a prompt to provide any missing information. General questions focused on demographic information like education level, career, marital status, whether the participant has children or not, when and how they were diagnosed, the type of breast cancer and the type of treatment they received. The second set of questions revolved around decisions about reconstruction and prosthetic use, asked about influences, the decision making process, and how the decision informed recovery on a physical and emotional level. The third section focused on feelings about the body before and after breast cancer, how various normalization techniques influence one's feelings, and how breast cancer and normalization have changed their lives. A fourth section asked questions about thoughts on causation, whether they feel discriminated against, their take on the survivor subject position, and views on whether and how breast cancer was a personally transformative experience. These questions were informed by themes that emerged during three support group meetings prior to beginning the interview process.

#### *Recruitment and Sampling*

Interviewees were recruited at the support group and through snowball sampling, which allows researchers to “observe shared cultural codes in the community one is researching” (Pitts 2003:19). With the help of the support group organizer I solicited

interviews at the end of one meeting. The only requirements for participation were that each person self-identified as a woman over 18 and had undergone a lumpectomy, mastectomy, or double mastectomy due to a breast cancer diagnosis. At the end of each interview I asked the participant to pass on my information or provide contact information for another interested breast cancer survivor. Additionally, the support group organizer sent out an email, of her volition, soliciting interview participation on my behalf.

### *Data Processing*

The data for this project took two forms: interview transcripts and field-notes from participant observation. I recorded and took notes during each interview, unless the participant requested otherwise. I downloaded the interview recording onto my password-protected laptop after each interview. Then, I uploaded audio files to ExpressScribe, a data transcription program, and I transcribed interviews verbatim, taking notes during the process (Thomas-MacLean 2004). Professionals at rev.com also transcribed several interviews after I received a small grant from the Department of Sociology. After transcription I read each interview holistically and line-by-line and compiled a summary.

I kept track of common themes and exemplary quotes as I read interview transcripts (Hesse-Bieber 2006). The summaries and notes were used to aid in developing themes (Thomas-MacLean 2004). Finally, I grouped emergent themes from the interviews and field notes together to allow for patterns to transpire (Brunet et al 2013).

### *Chapter Overview*

The chapters that follow explore the strange and familiar components of breast cancer survivors' illness narratives as they encounter erasure, the survivor hierarchy, and

manage and maintain survivorship. In chapter two I use an intersectional analysis to explore the nuances of erasure in medical settings and pink ribbon events as it results in the dismissal of difference amongst breast cancer survivors. Chapter three follows up on the consequences of erasure by introducing the concept of the survivor hierarchy. In this chapter I expose the narrative mechanisms that contribute to and challenge the survivor hierarchy and the consequences of such a ranking system on breast cancer survivorship. Chapter four details the material components of survivorship and complicates the notion of survivorship as a state of achievement. I make the distinction between cancer artifacts and pink ribbon commodities in order to draw out and complicate the strangeness and familiarity of each. I argue that pink ribbon culture erases the body to the extent that objects oriented toward the body are “strange” yet the work of cancer artifacts, to mimic the body, renders them familiar to survivors. In the conclusion I argue that breast cancer survivors are asked to ease our collective conscious through their survivorship. I also discuss the importance of this project, offer ideas for future projects and recommendations for how this project can be used to benefit breast cancer survivors.

## CHAPTER 2: ENCOUNTERING ERASURE

*“Yes, crazy stuff goes on in the world of breast cancer!” –Anne*

During a mammogram in a crowded room one of several attendees accidentally stepped on the foot pedal that increased the pressure of the mammogram plates to the maximum. Anne cried out in pain and was told casually they could stop and re-start the process or continue despite her discomfort. She chose to continue rather than undergo the procedure a second time. When Anne shared her breast cancer story with me I was taken aback by some of her experiences. After more interviews, the strange things that happened to her while under treatment for breast cancer became more commonplace. Other women shared stories of lost files leading to delayed diagnosis, phlebotomists unaware that blood could not be drawn on the side of a mastectomy, and other blunders. What I first thought of as a rather strange, and uncommon, experience became part of a pattern of incidents where women’s care was compromised—that is to say it grew familiar.

The breast cancer narratives Anne and the others shared with me, while often reflective of dominant breast cancer narratives, also contained experiences that could not and would not be accounted for within pink ribbon culture. As Gayle Sulik (2011) demonstrated, pink ribbon culture produces particular kinds of stories about breast cancer to the extent that the imagery upheld has a limiting and stigmatizing effect on women whose stories differ. This erasure suggests that much of the silence and stigma that surrounded women suffering from breast cancer prior to the 1960s has simply changed forms, not gone away (Sulik 2012).

Informed by Sulik's analysis, my work adds to the critique of pink ribbon culture and dominant narratives by detailing survivors' experiences in medical and pink ribbon encounters. I argue that these encounters, seemingly strange at first, are revealed to be familiar to breast cancer survivors as they often reflect patterns of discrimination related to gender, race, class, sexuality, health, and age.

More specifically, medical encounters are instances where women interact with medical professionals within the context of their breast cancer diagnosis, treatment, and reconstruction. In this setting components of survivor's identities emerge and reflect absences in pink ribbon culture. That is to say, analysis of women's narratives about medical encounters demonstrate incidents related to regulatory norms that are unaccounted for amidst the joyousness of pink ribbon culture. Many of these encounters are characterized by medical consumerism, which makes breast cancer survivors responsible for making informed decisions about their care and treatment all the while tacitly discouraging women from questioning the care and treatment proscribed to them (Sulik 2012). For example, the way that medical consumerism encourages women to be informed, yet uncritical, produces two-breasted bodies by encouraging reconstruction. This, as demonstrated by several survivors featured here, is not always reflected on positively. Normative gendered embodiment demands two-breastedness, yet the lived experience of being two breasted after breast cancer can and does reflect unaccounted for complexities.

Similar to the way resistance is discouraged by medical consumerism, pink ribbon encounters thrive on the promise of "sisterhood" which has the effect of consolidating experiences to produce a knowable, relatable survivor experience. Sulik (2011) explains

that pink ribbon “sisterhood” is marketed as the best, often only, form of support available to women with breast cancer. Yet, sisterhood is a raced and classed relationship that tacitly excludes those who do not adhere to normative constructions of survivorship. As such, pink ribbon encounters are instances where survivors experience the discrepancy between their embodiment and the regulatory norms encouraged by sisterhood, which is produced in community events, support group meetings, and in interactions with others. Under the guise of sisterhood, being unwell after finishing treatment for breast cancer is in conflict with the transformation narrative produced and encouraged in pink ribbon culture. As such, women who continue to struggle with the negative effects of chemotherapy and radiation are silenced by the imperatives of sisterhood to be the *right kind of sick* (Sulik 2012).

Medical consumerism and sisterhood, within their respective encounters, have the effect of silencing women’s experiences. They are an impediment to sharing stories that are different from the dominant narrative and negate many of the purposes of sharing an illness narrative: to make sense of one’s experience and to help others (Potts 2000). This is done by unspoken encouragement to conform bodies and narratives to that which is recognized and valuable in pink ribbon culture. Consequently, it is crucial to highlight, and reveal, narratives that correspond with experiences absent from pink ribbon culture to make it more representative and more capable of creating the change early activists hoped for.

The stories of experiences told here reflect embodiments different from those imposed by pink ribbon culture. Embodiment, defined as the physical manifestation of social and biological processes (Krieger 2005), is reflected in the stories survivors tell

about their experiences at a particular junction between experience and the biological processes that accompany it. Embodiment is always social, historical, and contingent (Cregan 2006, Grosz 1994, Williams and Bendelow 1998, Noland 2009, Burkitt 1999, Weiss 1998). For example, to embody breast cancer survivorship means to physically articulate a body altered by cancer and the influence of pink ribbon culture—in this instance, particularly, the impacts of medical consumerism and sisterhood. That is, to incorporate the norms and values of pink ribbon culture into one’s being both consciously and unconsciously. The embodiments encouraged by pink ribbon culture reflect normatively feminine ideals such as two-breastedness and the espousal of a survivor identity that is reflected in decisions made about treatment and a positive personal transformation narrative.

The narratives breast cancer survivors shared with me represent experiences that have been erased by and through pink ribbon culture. Narratives, or more specifically illness narratives, are understood as “the story of an illness and its effects on a person’s life” (Sulik 2012:321). By highlighting these stories within the context they emerge my goal was to expose some of the experiences marginalized by pink ribbon culture. The narratives absent in pink ribbon culture paint a picture of breast cancer that is more complex, less individualistic, and reflective of longstanding patterns of inequality whereby women, people of color, and those with other marginalized identities are devalued. Thus, the strangeness of the experiences to follow are met with the familiarity of the patterns of inequality that have persisted over time.

### *Medical Encounters*

Breast cancer scholars argue that cultural shifts have changed the meaning of breast cancer, how the public understands it, and the prescribed treatments (Klawiter 2008, King 2009, Sulik 2012). The shift towards biomedicine beginning in the 1970s and 1980s, or the regime of biomedicalization as Klawiter refers to it, led to a general increase in awareness, medical interventions, and use of technology. As such, women's encounters with medicine within the regime of biomedicalization differ from encounters in the regime of medicalization. For example, the practice of informed consent has changed the doctor/patient relationship. Where doctors, surgeons in particular, once made decisions about how to proceed while patients were under anesthesia the process now requires a patient's consent. Consequently, medical consumerism has played upon the premises of informed consent to construct medical experiences as largely based in choice. Women are now expected to have the knowledge and ability to make informed decisions about their health (Sulik 2012). While informed consent is a powerful and important development giving women the ability to accept or decline various procedures making the right decision is informed by pink ribbon culture in addition to evidence based medicine.

Patient empowerment plays an important role in the regime of biomedicalization and when coupled with pink ribbon culture it takes various forms. The November 2014 meeting of the Support Group was held at an interactive theatre performance put on by the Theatre Department at a local university. The goal of the performance was to empower patients to speak up in meetings with medical professionals. The playwright was a friend of the group and breast cancer survivor. She, and several graduate student assistants, collected stories from breast cancer survivors on their experiences with

medical professionals while undergoing treatment for breast cancer. The resulting performance was comprised of three different real-life scenarios, which were based on compilations of the experiences of several women in the support group.

The first play “Diagnosis” revolved around the dialogue between Donna, a patient about to be diagnosed with breast cancer, and her physician Dr. Beckart, an older, white man with a rough demeanor and business-like approach to patient interactions. This scene demonstrated the often dehumanizing way physicians deliver a cancer diagnosis. In the performance Dr. Beckart curtly delivered Donna’s diagnosis:

**Dr. Beckart:** (*Reading it as he sits down on a stool. He looks up and addresses Donna.*) You have invasive breast cancer. The tumor is so large it has to come out so you are looking at surgery, chemotherapy and radiation.

The character playing Donna is in disbelief and asks Dr. Beckart if she will die.

After some conversation he responds:

**Dr. Beckart:** Well as I was saying, I’m confident in the treatment I will prescribe. Your chances of survival are much better than twenty years ago. Frankly, back then you would have been a “goner”.

Dr. Beckart’s behavior struck a cord with the audience members. During the interactive component of the presentation several women from the support group asked questions such as whether he knew someone with breast cancer and his thoughts on the importance of psychological care. It was evident that women who directed their questions towards the doctor had similar experiences with their doctor; it may have been one of their stories. Other audience members asked the patient character, Donna, how she felt about the doctor’s bedside manner, if she felt she spent enough time with the doctor, and if she understood her diagnosis. Finally, an audience member asked the nurse what she thought her role should be. I got the sense, having spent time with the women in the

support group and hearing their stories, that the question and answer session was an opportunity to interrogate representatives of their own doctors, nurses, and former selves. This was one of the goals of the interactive performance: to empower the audience to question medical professionals.

Yet, pink ribbon culture and the medical consumerism on which it rests, discourages critical engagement. This legacy, coupled with the gender dynamics of many women's experiences with male surgeons makes empowerment in this context difficult to realize. The medicalized regime where doctors and surgeons are the supreme authority (Klawiter 2008) is supposed to have given way to a new doctor patient relationship. However, the regimes overlap and the interactions between physicians and patients are often reminiscent of bygone eras. Dr. Beckart's approach to cancer care and treatment was described by an audience member and former nurse as typical of an earlier age in medicine where male physicians were thought to possess expert and authoritative knowledge far superior to their female patients and nurses. The power of the differential between male healthcare professionals and female cancer patients was and remains an issue that women confront in their experience with breast cancer.

This short interactive theatre performance is one example of a woman's encounter with medicine that is not accounted for within pink ribbon culture. The gruffness of the exchange, the allusion to death, and the hopelessness with which the character is left run counter to the emotions and feeling rules (Sulik 2012) set up by and through pink ribbon narratives. However, this performance also points to the ways breast cancer survivors themselves challenge pink ribbon culture. Despite the seemingly hegemonic nature of pink ribbon culture there are always stories that differ, like those presented here, and help

to make pink ribbon culture less oppressive. Nevertheless, problematic interactions between male physicians and female patients are not the only antiquated practices that remain in medical encounters in the context of pink ribbon culture. There are enduring erasures, which result in the dissolution of differences among and between women with breast cancer.

Pink ribbon culture as well as stereotypes about gender and ideas about the appropriate shapes and sizes of women's bodies influence medical encounters. The stories women shared with me, particularly about their surgeons, revealed a tacit preference for particular kinds of gendered bodies. Those bodies were fit, small, whole, and two-breasted. Not surprisingly, white, feminine bodies with two symmetrical breasts are normative prior to cancer and after cancer (Eisenstein 2001). Barb a 54 year-old hotel event planner shared her experience with a breast surgeon regarding reconstruction. She explained:

You don't want to doubt the doctors until you've had quite a bit of experience, do you know what I'm saying? At first when you really don't have much, if you haven't been around people that are sick or been through it yourself, you believe whatever the doctors say. You don't challenge them. He's a man, and he's like "I really think with your age, you really need a good body."

When Barb reflected on her experience with the surgeon she felt like she had been coerced into making a decision based on her age and perceptions of her heterosexuality. Moreover, the surgeon's assessment of Barb's "need" for a "good body" is rooted in oppressive ideas about gender, femininity, and beauty. Here, reconstructed breasts are what constitute a "good body". They're also determined to be vital to recovery, positive self-assessment, and body image. After surgery, Barb's survivorship is characterized by the embodiment of normative femininity signified by two breasts. Thus, to embody breast

cancer survivorship is to embody feminine gender ideals both before and after breast cancer.

Barb's narrative demonstrates that the embodiment of breast cancer survivorship is more complicated than what is suggested by pink ribbon culture and more complex than surgeons present to their patients. Feelings of regret, discomfort, and anger are left out. Since Barb's current body is different than the one she desired she struggled to maintain a semblance of normalcy with breast she felt were misshapen.

I think I got talked into it. They're like your age, you're not married, you feel good about your body. If I had to do them over again I wouldn't, because they're horrible. Can't find bras to fit. No one really knows how to fit you with a bra. They're not natural shapes. It's a weird feeling when you're laying down at night, you can feel them.

Finding bras, a familiar task for many women, becomes a strange undertaking when reconstructed breasts are shaped differently than the breasts bras are manufactured to fit. This seemingly mundane struggle, the result of surgical interventions and a surgeon's insistence, is part of Barb's lived experience and her survivorship. Barb's narrative suggests there is a market for bras made to fit reconstructed breasts since it is a common choice for breast cancer survivors but the lack of bras made specifically for reconstructed breasts reveals another problem with dominant pink ribbon cultural narratives: the promise of normalcy after breast cancer.

As Barb's example demonstrates, surgeons make decisions with their patients based on gender, age, and body type. But, Barb's gender, and lack of knowledge and experience with medical professionals rendered her unable to express her desires. The result is that Barb is unhappy with her body and plans to have her reconstructed breasts removed in the future. Anne, also 46 at the time of diagnosis, experienced a similar

scenario when her surgeon made a decision about the type of cut he did to remove her breast. She described when her surgeon informed her of the particular style of cut he made so that she could wear low-cut fashions without exposing a scar.

Dr. Smith tried to go down a little bit where he did his incision you know trying to make it ok for like low cut dresses or swimming suits. He didn't need to do that and had he asked me before I'd say don't worry about it, just get the cancer out that's all I want, you know.

Similar to Barb, Anne's experience with her surgeon was informed by preconceived ideas about white American femininity and proper embodied womanhood. Anne and Barb, both in their 40s at the time of diagnosis, embodied a particular type of white American womanhood. Prior to their surgeries both Barb and Anne were able bodied, thin, normatively attractive, and inexperienced in medicine. The intersections of these axes produced a body that could be molded into a particular feminine form. Their pre-surgery bodies, and the meanings those bodies evoked, informed how their bodies would come to look after surgery, and their perceptions of their surgeon's practices. The possibility of different bodies after breast cancer was made inconceivable by the surgeon's gendered notions of appropriate bodies. Pervasive in these ways of thinking are associations of women with body obsession, or of being pre-occupied with body aesthetics (Bordo 1995). This persists even when cancer is a reality and death a possibility. Thus, the concerns surgeons imagine women have are privileged over worries about living with an able body, feeling good about their bodies, and survival. Many of the ideas surgeons have about women's bodies, in general, are based on an assumption of whiteness. Women of color, African American women in particular, have unique experiences of oppression based on the intersection of race and gender within medical

encounters. These experiences, however, are rendered invisible by the work of pink ribbon culture.

Pink ribbon culture has been criticized for producing an image of breast cancer that is overwhelmingly white and middle class (King 2006, Sulik 2012). Images of breast cancer survivors are primarily white which helps to cement the association of breast cancer with white woman (Eisenstein 2001). Limited representations of breast cancer survivorship reflect the erasure of African American women's narratives in pink ribbon culture, a phenomenon noted by breast cancer scholars and many breast cancer survivors in my study.

African American women's unique experiences of oppression result from being both women and black (Collins 2002, hooks 1981). Racial inequality, environmental racism, and structural racism no doubt inform African American women's experiences with breast cancer; yet, there remains confusion as to the source of high breast cancer mortality rates for black women compared to white women. Discourse on individual responsibility, personal choice, and assumptions about gender and racial equality provide justifications and legitimations for disparities in health (Gill and Scharff 2011).

During our interview, Rita a 68 year-old, African American woman shared her experience with a delayed diagnosis. However, the reason for her delayed diagnosis was not that Rita did not seek out a mammogram; instead, her information was lost when the hospital changed computer systems.

Now I've lost 4 months of my early diagnosis and they tried to make me feel like oh it didn't matter because the mammography was the same as it was in the past. I said are you kidding me, are you really trying to convince me of that? When you know better and you know that I should know better? That if you hold a cancer in your body for 4 months without any intervention that cancer has the opportunity to spark off someplace else in your body and create something that is incubating

and so tiny that you can't see it on a mammography uh you cant see it in traditional testing at that infancy stage so you can't tell me that I don't have any other cancer in my body. I lost my early diagnosis opportunity, I lost 4 months of time and you all need to stop trying to BS me about that, you know? And they were pushing me to do mastectomy right away and so I just said you know what I think I need a second opinion. I think I need to go some place else.

As a nurse with a master's degree in Public Health Rita was vigilant about having annual mammograms and conducting self-breast exams. Consequently, her story contradicts the narrative that posits black women as either unwilling to have mammograms or unaware of the benefits of early detection. This is not to argue that a single example disproves knowledge about why black women disproportionately lack early detection. Rather, it is to show that these narratives are not all encompassing and there are myriad of cases that do not fit. It would be more beneficial to shift the focus to how race as a system of inequality makes it more difficult for African American women to seek out and find proper care.

The lengthy gap between hospital staff's knowledge that Rita had breast cancer and the time that she was informed of her diagnosis caused Rita a great deal of distress. One can argue that technical difficulties are responsible for the mix-up, but Rita's race and gender cannot be separated out from the experience. With breast cancer commonly understood to be something that impacts middle class white women, her status as a semi-retired working-class, 68 year old black woman contributed to her, and thus her file's, invisibility.

Rita's experience with delayed diagnosis is common among African American women who are also less likely to meet the 5 year survival mark than white women and Latinas and also face the highest increase in breast cancer rates among all those classified as women of color (Kaspar and Ferguson 1997:10). The primary explanations for the

difference in breast cancer rates between women of color and white women include: access to care, late diagnosis, poverty, discrimination, and language barriers (Kaspar and Ferguson 1997:10).

Rita, like other healthcare workers, was aware of the statistics on African American women with breast cancer. This knowledge circulates among health professionals and breast cancer survivors alike. Marilyn, a breast cancer survivor and former nursing administrator shared what she knew of African American women's experiences with breast cancer during our interview.

Before I worked at Ellis, I worked for the Breast and Cervical Cancer Control Project, which is free mammograms and breast exams. The inner cities are just terrible, because they don't trust anybody. First of all, they don't have any transportation. They don't have the money to pay for transportation to get to wherever you're doing your exams. They're just afraid of any entity; that they're going to come in and take over. I don't care if you give them a chariot and drive them to the door of the facility, many times they won't go. Fear, lack of education are two big deterrents. Then childcare. It's a whole 'nother world. Culture plays a big part....Try and do a lot of stuff in black churches, to provide education about breast cancer, or any kind of cancer, about hypertension, about high cholesterol. If you can get your foot in the door with one person in that church, then you can start maybe making some inroads because they'll believe their person before they'll believe you.

In this excerpt "inner city" is code for black or African American. This type of coded language is reflective of the colorblind turn, wherein white people maintain that they do not see race (Bonilla-Silva 2006). Here, those that live in the inner city are also poor, lack transportation and resources, and have a distrust for outsiders, especially white people in perceived positions of authority. This breast cancer survivor and former nurse explains that black churches are the key to getting to this underserved and seemingly undereducated demographic. Despite access difficulties it is clear that there is a set of knowledge about African American women that circulates through the healthcare

community and pink ribbon culture.

With the dominant narrative in pink ribbon culture putting forth an image of breast cancer survivors as primarily white and middle class the concerns of economically disadvantaged women are rendered invisible. The erasure of the economic toll of breast cancer on survivors and their families contributes to the stress and strain of a life threatening illness. One's material existence can be and is threatened as a result of the exacerbated costs of chemotherapy, not to mention purchasing the almost endless tool kit of supplies to help normalize the body after surgery. Moreover, erasure of the lived realities associated with economically disadvantaged breast cancer survivors renders the contingencies of survivorship invisible.

The inability to have one's material needs met has a well-documented negative influence on health (Wilkinson 2005, Ferguson and Kaspar 1997). In regard to breast cancer experiences, poverty has a lasting influence impacting one's access to treatments, ability to pay for treatments, and recovery time to name but a few. And, while there are programs to help pay for mammograms for low-income women, through Susan G. Komen for the Cure, the American Cancer Society or various other organizations, beyond screening the effects of poverty are largely invisible. As Ferguson and Kaspar (1997) demonstrated, poverty shapes women's experiences with breast cancer in terms of "late diagnosis...and...poor treatment...resulting in higher mortality rates" (183). These factors are separate, but not distinct, from a lack of insurance. At the core, a breast cancer diagnosis for a poor or otherwise economically disadvantaged woman risks her material existence, not only in terms of the toll the disease takes but also in affording care.

Women's concerns with their finances make focus on getting well a double

burden. Not only are their anxieties disregarded but many medical professionals fail to understand the inability to focus on treatments and healing when one's material existence is not guaranteed. Brianna shared:

The main thing I was worried about was work because I'm self-employed, and you know, they always tell you don't worry about it, well ok. Who's going to pay your bills and take care of all that type of stuff? That was the most nerve wracking part for me, luckily I was on my husbands insurance.

As the owner and sole employee of a small cleaning business Brianna is responsible for not only performing the necessary duties of her role as housekeeper, but all the paper work and administrative duties as well. Brianna's question about who will pay her bills reflects both medical bills and those associated with her business. To discount these very real concerns is to misunderstand breast cancer survivors as embodied individuals. Furthermore, it erases Brianna's existence as a working class woman and small business owner.

Kelly described her concerns in a similar manner. After joking that she first worried about not "looking good bald", she worried about how she would finance breast cancer treatment.

My first thought was "I'm not going to look very good bald." My second thought was, "if I have to take a lot of time off work for this, how am I going to pay my bills?" Cause I'm single...I live by myself. A single income person. So.... And but I just thought, well you know I'll just do what I need to do, if I have to borrow, I'll borrow. I'll do whatever is necessary. (Kelly)

Doing "whatever is necessary" is a common theme in situations where women lacked insurance or needed to continue working. It exists, however, within the realm of a system that assumes heterosexual coupling where a male breadwinner can sustain the family unit while a woman receives treatment and recovers from breast cancer. The innumerable women left out of this discourse suffer the uncertainty of how they will pay

for expensive cancer treatments intended to prolong life. This erasure contributes to the stress and strain that accompanies uncertain material existence. Those with little or no health insurance, with or without partners to help with the burden of cost, face unique circumstances as well.

As a graduate student and 37 at age of diagnosis Matilda was relieved when the Affordable Care Act made it so breast cancer would not be considered a pre-existing condition. However, the costs not covered by graduate student insurance were and continue to be a great financial burden. Matilda explained:

And with student health you know there's a lot of out of pocket you have to pay and as a student you don't get that much pay so I kinda had to figure that out and [the doctor is] like "oh don't worry about it, you'll deal with that later" and I'm like I don't think so... I don't think I'm going to deal with it later I need to deal with it while my brain is ok.

The timeliness of figuring out how she would pay for her treatments was especially pressing for Matilda because of her concerns with “chemo brain,” or the reported decrease in cognitive abilities after chemotherapy. Financial concerns are not limited to young breast cancer survivors. Those past retirement age also confront the fear and uncertainty associated with an unstable income and ever increasing medical bills. Financial problems are compounded by the intersections of one's race, class, marital status, and age. Rita, 68, explained:

Yah, I should have retired by now but I'm like many other baby boomer nurses who were born in that era that we were just juggling career and home and problems all at the same time and we moved around a lot and we found ourselves with problems in marriage and problems with kids and all kinds of things that caused us to change jobs frequently so I don't have a pension. I didn't stay on a job long enough to qualify for a pension so I need to work...So this is knocking me on my tail for finances. And so it's a good thing I did save when I was working because um, now my saving is just about cleaned out.

At the time of our interview Rita had just finished chemotherapy but had not had

reconstruction, another costly procedure. Nonetheless, her savings were nearly gone shortly after beginning treatment for breast cancer. Even with Medicare, as Rita explained, the portion of the bill she was responsible for well exceeded her ability to pay.

I couldn't even imagine it myself. \$14,000 for the first bag of IV. I said what the heck is in there, gold? You know they couldn't explain it. They had some, some added things that were uh supposedly just to get you started in chemo, uh. I don't know. I couldn't get a clear explanation anyway after that, every week after that was \$8,000. \$8,000 for the eleven weeks, \$14,000 for the first week and \$8,000 thereafter for 11 weeks. And Medicare paid 80% of that and I'm left with the 20.

The lack of transparency regarding the contents of chemo drugs is a frustrating factor for those who struggle to afford the treatments. There is little question as to the importance of receiving the treatments and even those who struggle to pay bills insist that it was “worth it.” There comes a point, as Rita describes, where there is no money left to give and nothing to be taken as payment. This situation is one informed by systems of inequalities that merge to make cancer simply unaffordable for many women in America.

Rita shared:

Yah, I said, well they can't get blood from a turnip. I don't have that kind of money. So they can keep billing me until, the only thing they could take, I don't have any property other than what I live in. I don't have any fancy car. My old car out there is a 2000 and it's paid for you know, so there's nothing for them to take from me. All they could do is put a lien on this house when I sell it and ask for the money.

The options Rita is left with, a lien on her house, is a threat ultimately caused by her breast cancer diagnosis, that is not accounted for within pink ribbon culture. This sort of financial turmoil exceeds living on a budget and going without small luxuries. Rita's, and many others, material existence is threatened by a cancer industry that produces costly treatments that damage women's overall health which impinges on their ability to work.

The medical encounters discussed here point to the failure of pink ribbon culture to account for the various ways breast cancer is dealt with across and between class lines reflecting the invisibility of working class and poor women within the dominant narrative. Moreover, the racialized and classed understandings of breast cancer assume a normative form that leaves little space for alternative embodiments. Specifically, bodies that do not adhere to the middle class, white, two-breasted, thin, aesthetic are erased. Lastly, the notion that breast cancer can be a middle class disease is premised on the idea that a woman with breast cancer has a husband, or at the very least some sort of male partner, that provides a substantial portion of the pair's income.

Assumptions about heterosexuality are inherent in pink ribbon culture. The heteronormativity associated with emphasis on survivors' roles as wives and mothers is met by a conspicuous absence of any discussion of women's' sexuality. Many women experience sexual side effects from being thrust into early menopause as a result of breast cancer treatments. This stems from chemical combinations in chemotherapy as well as the removal of estrogen producing organs in the body (Love 2010). Nonetheless, women who have not yet undergone menopause experience symptoms including hot flashes, vaginal dryness, weight gain, and osteoporosis among other indications. However, medical encounters often lack discussions of the sexual side effects that women experience as a result of breast cancer treatments. Whether this neglect is due to assumptions about the lack of women's interest in sex or presumptions about sexuality and age, many survivors are disadvantaged by the silence surrounding women's sexual needs. Kay explains that as part of a newly married couple sex was and remains an

important part of her relationship with her husband, but she experienced severe vaginal dryness.

I think the vaginal dryness, that bothered me a lot, and probably I think I just felt more bad for my husband. It's like, okay, this hurts. I'm bleeding. This isn't good. We haven't been married all that long. I wasn't that way when we were dating or first married because I wasn't on the Femara. I'm sure he was thinking, what happened to before?

The pain she experienced prevented Kay and her husband from carrying on a sexual relationship like they had prior to these developments. This made Kay feel inadequate and she worried, not about her own pleasure, but her husband's. The "before" experience is used as a bench mark for a good body, with good sexual abilities, compared to her current body, which makes her feel bad for her husband. These sort of feelings are not only reflective of the privileging of male sexuality, but also of the dictates of heteronormativity which maintain a singular form of penile-vaginal intercourse as *the* way of engaging in sex (Rich 1980). Kay went on to share a medical encounter she had with her doctor after bringing up this issue.

Yeah, it is very frustrating. Again, I think people this far out, the doctors really don't know. Dr. Joe just laughed at me when I said I am so dry and it hurts. I actually bleed afterwards. How did he put it? Comparing me to like a 95-year-old woman and he just laughed about it. It's like, oh, no, you did not just do that. I'm not 95 years old.

Kay's doctor found humor in the situation because presumably she, as a 63 year-old woman, *should* not be having sex nor should she be concerned about treatments for sexual related discomforts. The assumption of asexuality in 95 year-old women and in Kay reflects a limited understanding of sexuality in general and disregard for female sexuality. In this case, it does not matter that Kay bleeds after sex due to dryness, she, as a pseudo asexual 95 year-old woman, does not *need* to have sex. How might this scenario

have played out differently had Kay approached her doctor with her husband's concerns? Had she framed her discomfort as his discomfort would she have been given more credibility as a sexual being? Regardless of the hypotheticals Kay was eventually given a prescription for a pharmaceutical to help decrease vaginal dryness.

Certain doctor's inability to see women as both breast cancer patients and sexual beings has additional side effects. Veronica, 58 now, was still on hormonal birth control to prevent pregnancy when she was diagnosed at 44 years old.

What they told me was because I was still on birth control that wasn't gonna work. And I'm really glad I went to see my gynecologist because he's really the one who understood that from what the diagnosis was. Because that wasn't something the surgeon talks to you about and I don't know that the oncologist would have thought much about it. But for me it was like whoa hey that's our major form of birth control we're gonna have to do something. But it worked out, because talking to the gynecologist we were able to schedule it so that he could do a tubal while I was under for the lumpectomy.

Veronica's gynecologist, but not her surgeon or oncologist, alerted her to the problems with continued use of hormonal birth control after breast cancer. Her surgeon seemingly discounted that a woman undergoing treatment for breast cancer might also be a sexual person. The lack of attention to women's sexuality, in its various shapes and forms, only serves to render invisible the multitude of experiences women have after breast cancer. The examples here cannot be said to contradict the dominant narrative, as women's sexuality plays no part in survivorship. It is an invisible, unspoken, often unacknowledged facet of life that is incompatible with pink ribbon culture and the sanctification of breast cancer survivors. The demonization of women who have sex has not dissipated; rather it has taken different forms. Finally, women who want to have sex after breast cancer and want to maintain intimacy with their partners are left to understand their new bodies and new concerns with little help from professionals. Lily,

33, shared, “We were very intimate before and now we are not and, yah, I was concerned like that. I still wanted my body, I still wanted that.” Lily still wants to have sex with her husband, even after breast cancer. For many, this fact of her life is unimportant, not a component of survivorship, and best left ignored. In order for breast cancer survivors’ sexuality to become part of the dominant narratives women’s sexuality, in general, must be recognized and then valued.

The dehumanization resulting from these medical encounters reflects the insensitivity of biomedicine and has the effect of silencing women’s stories and erasing their experiences from the repertoire in pink ribbon culture. Coupled with the imperatives of medical consumerism, which puts the burden of knowing the intricacies of various treatments on survivors, biomedicine as it is played out in pink ribbon culture contributes to the marginalization of breast cancer survivors and their narratives. However, sharing stories that conflict with dominant pink ribbon narratives is a form of resistance. It is a rejection of silence through shared experience and confronts the dominant narrative by insistence on the validity of a range of experiences.

### ***Pink Ribbon Encounters***

*“Bob McCosh loves strong women!”*

Outside of doctor’s offices, hospitals, and treatment facilities survivors experience the erasure of their experiences and stories at pink ribbon events. The strangeness of the erasure that occurs at pink ribbon events is similar to the erasure in medical encounters in that it is related to a familiar pattern of minimizing and marginalizing experiences and bodies that differ from the norm. Moreover, the persistence of stereotypes about women, people of color, what is considered healthy, youth and old age are all reflected in pink

ribbon encounters often under the guise of sisterhood. Nonetheless, erasure occurs in strange and familiar ways, like it did at the 8<sup>th</sup> Annual Pink Promise Tea.

Breast cancer survivors and supporters gathered at the tea to celebrate survivorship, support those in the throws of cancer treatment, and award grant money to an organization providing financial assistance to cancer patients. Amid the pink décor and brunch, tables of women listened to representatives from their local Komen affiliate, a local news broadcaster, an up-and-coming motivational speaker and small business owner from St. Louis, a fellow survivor, and a car salesperson from a local dealership. The diversity of industries represented was met by a largely homogenous group of attendees.

The tea represented the convergence of philanthropic charities and corporations with vested interest in association with a charitable cause (King 2006). A female car salesperson and representative of Bob McCosh—Chevrolet, Buick, GMC, Cadillac—made a short speech emphasizing the goodness of Bob McCosh the person. She joyfully explained that “Bob McCosh loves strong women!” and he also employs them. She sought to find commonality with the group by joking that “buying a car was like going to the gynecologist, you didn’t want to, but you had to!” Audience members laughed at the comparison, seemingly in agreement. Curiously, the representative did not mention breast cancer during her speech.

The absence of a statement on breast cancer while at the Komen Tea was noticeable, yet not entirely out of line with the politics of philanthropic corporate giving. As a sponsor for the event Bob McCosh paid for 50 survivors to attend. At \$15 per seat the car dealership donated \$750 in seats and had their insignia emblazoned on the pink cups

given to all attendees. The message was clear: the women attending the Komen Tea were a key car buying audience and if Bob McCosh could corner the market on concern, humor, and the values of strong women the dealership might also gain a few new customers. The effect of this sort of blatant live commercial advertising was to temporarily change the tone of the day, to shift the focus away from breast cancer awareness and to place it on the goodness of Bob McCosh, his dealership, and his employees. Consequently all sense of breast cancer as an embodied experience was suspended while in the midst of a breast cancer event.

This erasure is more obvious than other forms that take place during pink ribbon encounters. For example, during the same Tea, the Komen representative declared that breast cancer cut across the lines of race and class. The audience acknowledged this, but the composition of the audience was overwhelmingly white, middle aged, and presumably middle class. The homogeneity of the event became more apparent near the end of the program when the local news broadcaster asked everyone to stand. She then asked women that were 5 years from their breast cancer diagnosis to come to the front of the room. She did the same in 5-year increments asking women 10, 15, and 20 years from diagnosis to come to the front of the room. The room was hushed during this time giving all the attendees the opportunity to acknowledge the survivors before us and pay respect to those who did not survive. Yet, the survivors called forth were overwhelmingly white and between the ages of 40 and 60. Why were more women of color not present at the event? How are class differences apparent, or not, in Komen events?

King (2006) argued that philanthropic citizenship, of which the Komen Tea is a primary example, relies on the “erasure of power relations” between classed, racialized,

and gendered minority and majority groups. Thus the Tea, a brunch and auction, functions as a regulatory mechanism where not only are certain types of women kept out but those that are allowed in are regulated by rules of attendance. For example, most women in attendance, myself included, wore some shade of pink clothing. Pink, the color associated with breast cancer awareness, also has a strong connection to femininity (Peril 2002). The softness and delicacy of the color translates to idealistic womanhood wherein people classified as women come to embody the qualities associated with the color such as innocence and girlishness (Peril 2002). Breast cancer scholars have pointed to the ways the color and the disease are at odds since breast cancer most often occurs in women, not girls, and is neither dainty nor pretty (Sulik 2012, King 2006).

Knowledge of the racialized, gender, and class-based connotation of a “tea” renders the event an exclusive zone of erasure whereby differences between and among women are minimized in order to create a sense of cohesion under the “sisterhood” associated with breast cancer. While cancer does cut across the divisions created by class, race, and gender, pink ribbon culture does not. According to the CDC’s 2011 statistics, African American women, more than women of any other race or ethnicity, were more likely to die from breast cancer. Additionally, white women were more likely than women of other racial groups to be diagnosed with breast cancer. The discrepancy here, that white women are more often diagnosed with breast cancer yet black women are more likely to die from breast cancer is indicative of the ways pink ribbon culture masks inequalities on one hand and perpetuates inequalities on the other hand. Inequalities are masked by a discourse that constructs breast cancer to be every woman’s problem,

without acknowledging the increased risk for African American women, low income women, women with disabilities, and lesbians (DeShazer 2013).

Within pink ribbon encounters the discrepancies women experience based on gender presentation, race, and class are erased. Acknowledging difference in experiences based on factors like race, class, sexuality, and ability is the antithesis to the “sisterhood” supported through the brand of survivorship put forth by pink ribbon culture (Sulik 2012). Difference is a threat to unification under pink ribbon culture because it denies that all those categorized as women share the same lived experiences. Underneath the erasure of sisterhood are the very real discrepancies women experience based on limited understanding of gender, race, health, and age.

Thus the pink ribbon brand does an effective job of masking differences to produce a recognizable and acceptable breast cancer survivor (Sulik 2012). This ideal survivor, or she-ro as Sulik refers to her, embodies “pink femininity” which describes the contradictory qualities of “softness, innocence, and dependence” and “cunning, manipulation, and seduction” that are hallmarks of pink ribbon narratives (Sulik 2012: 90). These qualities may represent a mythical breast cancer survivor, but as Sulik explains “she-roism” is not limited to breast cancer survivors. Supporters, or women in general, can adopt “pink femininity” and thus embody the qualities of a she-ro. Barb confronted this mythical survivor in the form of a breast cancer supporter as a volunteer for Susan G. Komen. During our interview she shared:

They put me, I was on the committee, event committee, I was like a co-chair. I was with another lady, not a breast cancer survivor, very cute, vivacious cute body. We were co-chairs and I found out that they sent her to Komen in Texas because she was the image of what they wanted. It was so obvious to me. I even went to them and go "I'm the survivor, I'm the one that really cares, I want to raise money." They're like "Well, I think she'll do better." They sent her off to Komen

training and I just happened to find out about it. I went to them I was like "I'm volunteering here." They totally dissed me on that...It was like really? I'm not what you're looking for, for body image? You knew that's exactly what they were doing.

Although Barb is a breast cancer survivor, wanted to attend the training course, and had been a Komen volunteer for some time she felt that another representative was selected because her *body* more closely aligned with the image the organization wanted to put forth. Through this process, Barb's body and her story become invisible. This erasure, while likely unintentional, is still systematic. Komen relies on particular bodies to represent the breast cancer brand. Through Barb's pink ribbon encounter it is clear that there is a very particular form of gendered body produced by pink ribbon culture. Like Sulik (2011) asserts, this body need not be a survivor body; rather through a culture of survivorship made accessible by emphasis on fundraising, publicity, and solidarity even those not directly impacted by breast cancer have access to the survivor identity.

To be invisible in pink ribbon culture is to have one's body and story made unimportant. This invisibility reflects the masking of inequalities by mainstream breast cancer organizations and activists to produce an apolitical and more agreeable pink ribbon culture (King 2006). In Barb's example, she felt the other woman's "cute" and "vivacious" body approximated a norm that hers could not—or not to the extent that Komen desired in their representatives. This gendering of breast cancer survivors is paradoxically two-breasted, youthful, normatively attractive and feminine and thus the antithesis of cancer. To represent *breast cancer*, then, one must embody all that is healthy, beautiful, and whole in addition to being white, heterosexual, and able-bodied.

The whiteness of pink ribbon culture's racial politics seeps into the support group to produce various tensions that result in the erasure of African American women's

experiences. The result is that there is an acceptable African American survivor experience and *other* experiences. This dichotomous understanding of African American women's survivorship plays upon culturally salient controlling images (Hill Collins 2010), the myth of the strong black woman (Madlock Gatison 2015), and longstanding racism in the United States.

Among breast cancer survivors that I spoke with who do not attend the support group many referred to it as "Sandy's group." This association of the unaffiliated support group with a singular white woman and her friends is not outwardly problematic, but the ramifications of a close knit support group heavily populated by white breast cancer survivors can carry an air of exclusivity barring women of color from joining. As such, longstanding racial tensions and the whiteness of pink ribbon culture contribute to the erasure of black women's experiences at pink ribbon events.

Only two African American women, Francine and Rita, regularly attend the support group. Many of the members, Francine among them, knew each other from working together in the healthcare setting prior to their breast cancer diagnosis. There is great support for Francine, who recently had open-heart surgery. Sandy solicited group members to make meals for Francine as she recovered and many did, myself included. Rita received much less support outside of the support group and was upset when there was no offer of meals after her double mastectomy. The white group members felt badly that Rita was hurt, but explained that they made Francine meals because they are friends outside of the group.

Tensions surrounding Rita's performance of survivorship peaked in the March meeting but started increasing long before. Prior to the February meeting Rita requested

that she be allowed to put on a program during the last 15 minutes of the meeting. She brought bible lesson worksheets pertaining to St. Valentine and a bag of props for a photo. In March Rita again requested time at the end of the meeting, this time for a lesson on St. Patrick. There was a definite division in the room and a palpable sense of frustration among those not interested in learning about St. Patrick. During Rita's program a new woman, Crystal, quietly asked Brianna if anyone else in the group had lymphedema. Hearing this exchange Rita asked them to "keep it down" and "move to the back of the room." This was met with resistance by Crystal and Brianna with Crystal responding "I talk in a whisper I didn't think anyone could hear me." Rita maintained that it was disruptive. Alice, sitting next to me, quietly asked me what was going on. I hesitated to explain. Rita finished her program a little late and proceeded to organize the picture as another announcement was made. To describe the situation as merely tense is an understatement. At a separate event in April Alice told me she emailed Rita after the meeting to tell her the religious programs were inappropriate for a breast cancer support group.

With so few African American women represented in the group, and pink ribbon culture in general, Francine embodies the *right* kind of African American breast cancer survivor and Rita does not. Instead, she embodies not only white women's fear of the black body but also the contradictions that occur when one's lived experience conflicts with what other's believe they know to be true about the group one belongs to. Moreover, Rita is unapologetically religious and her commitment to Christianity involves sharing it with others. While there are religious undertones within certain rhetoric in pink ribbon culture it is of a primarily neoliberal bend wherein morality is equated with personal

responsibility.

Rita's experience as a religious African American woman was and is largely erased through pink ribbon culture. As a primarily secular space, pink ribbon culture does not do much with any particular religious orientation, despite the role of spirituality in survivors' understandings of the *purpose* of breast cancer as an opportunity for personal transformation. Nonetheless, the role of religion coupled with persistent myths about the strong black woman and pink ribbon culture influence the shape of survivorship for African American women (Madlock Gatison 2015). That is to say, African American women face a unique silence especially pertaining to the "ugliness" of breast cancer. This silence, reflective of ambivalence surrounding African American women's experiences with breast cancer as women *and* people of color, translates to invisibility within pink ribbon culture as well as scholarship on breast cancer.

The general invisibility of African American women in pink ribbon culture contributes to an air of uncertainty and concern for the suspected unique ways African American women experience breast cancer. White women's concern for African American women's health reflects paternalistic sentiments, long standing race based presumptions, and enduring belief in the inherent difference between African American women and white women on the basis of race, coded as culture. In reflecting on her own experience and the American culture which places such an importance on breasts and hair as representations of femininity one white breast cancer survivor explained:

...boobs are so identified with femininity that um, there's no getting around it and hair is also so...hair is unbelievable the amount of, and African American women, I think, have it more than Caucasian women, really, the hair thing is so, like, can be so devastating for them.

These statements were made not to draw arbitrary distinctions between African American women and white women, although that is the result; but rather to make sense of other women's experiences where there is a lack of knowledge. While the association of African American women with concern for hair, or beauty in general, is rooted in controlling images (Collins 2010), the failure of pink ribbon culture to represent African American women is indicative of the process of erasure. To say African American women are somehow more concerned with losing their hair than white women is to ignore that African American women are not a homogenous group and also a reflection of the invisibility of African American women in pink ribbon culture.

Another white woman, Alice, shared information she had recently learned with me during our interview.

And interestingly, I didn't know this, but African American women don't like talking about like the mammograms and well um, ...[Francine] says oh yah, she would go around to churches and talk because everyone, a lot for one reason or another don't get mammograms and then by the time they get them its really far and that's really sad

The narrative Alice reiterates says African American women do not get mammograms out of shame, a lack of knowledge, or discomfort. Attributing the high rate of breast cancer mortality to personal or individual reasons renders invisible the structures of inequality. Pink ribbon culture and the institutions that uphold and maintain it are exonerated when the problem is located in "their culture". This discourse supports individualism, whiteness as the default and proper way to be in the world, and delegitimizes African American women's experiences.

The idea that African American women are resistant to pink ribbon culture, not that pink culture is resistant to African American women, comes not only from white

women. Francine, a support group staple and 20-year survivor, is active in pink ribbon culture. During our interview she showed me a picture of herself at a breast cancer event and at an event related to heart disease. She explained, “My heart people they walk with me, open hearts. This is the onl[y]black [person] ... That's me. You don't see no, no black girls [at the breast cancer event].” She goes on to explain that while she invited African American women from her church to join the support group, none take her up on the offer.

I've invited, I have. Then they say "Oh we started a group of our own." I said, "Oh, I'll come and see." "Oh, we ain't got it started yet." I was going to come to a meeting. Nope. I don't know if it's [an] embarrassing thing to black ladies... I am the only black [person] that goes to those. I don't know, they just don't want to do it. They act like they ashamed they got breast cancer but we're not contagious and that's what I have told them.

Rita's take on this absence reflects a sense of internalized racism whereby African American women come to take on the viewpoints of white people.

I don't have any reason to think they're intentionally leaving black women out. I think sometimes in general, our, my race tends to segregate their own selves from things. They just have not...the confidence to go and participate in things like that. They don't have the desire, they don't have the, they don't really concentrate on the benefit as much as they should. Um, the um, indoctrination into feeling inferior has still some lingering [effects].

Rita's assessment of the lingering effects of historically generated feelings of inferiority is under-acknowledged by women who are not African Americans. This erasure is part of pink ribbon culture, however. It thrives on the displacement of inequalities so that “the cause” can continue to be branded as apolitical (King 2006).

Another component of survivors' experiences, and their associated narratives, erased under pink ribbon culture is living with complications that stem from breast cancer treatments. Disability is incompatible with pink ribbon culture because it defies the

normalcy imperative wherein women find a new normal that very much resembles their pre-breast cancer selves. Moreover, because of the conflation of health with beauty under neoliberalism disability, in multiple forms, is eschewed (Guthman 2011).

In their analysis of support groups Coreil, Wilke, and Pintado (2004) found that members employed a cultural model of illness characterized by recovery that emphasized optimism and personal growth. These sentiments were echoed even when telling stories of trauma and grief and were evoked in criticisms of other's emotional stories (Coreil, Wilke, Pintado 2004). Pink ribbon culture exacerbates these tensions because of the limitations surrounding what it means to have breast cancer, erasure of the complications of recovery, and a preference for light, happy narratives. There is a demand for self-censuring and self-surveillance to ensure that one's story and body conform to the carefully crafted ideal presented through pink ribbon culture. When sharing stories of the ugliness of breast cancer, to borrow Madlock Gatison's (2015) phrase, the women I interviewed often followed it up by emphasizing that they are not "throwing a pity party" and "don't want anyone's pity." Throughout the course of the development and deployment of pink ribbon culture exploring and explaining one's suffering became equated with a desire for pity. This framework was used to make sense of the behavior of one support group attendee.

I don't know if you was in there when she came. She has a heart monitor thing. She was the one that was going through this when I first started coming and we were about the same type, she's a little younger than me. She was the one that was growing no hair and it was all pity pity my hair ain't growing as fast as yours. Well she was always setting down a negative mood at least every meeting she was...It's just that pity party thing and its like you need to get over that and all you're doing is bringing yourself down and you need to pick yourself up.  
(Brianna)

The support group member referenced above developed a heart condition as a result of overly aggressive chemo-therapy treatments. Since then, she struggled to embody survivorship in a way that is appropriate for the support group and adhere to the proscriptive survivorship of pink ribbon culture. She is not a she-ro: her hair is thin, she struggles to lose weight because of a heart condition, and she often feels tired and weak from even minor physical activity. While Brianna's statement may seem mean spirited, it is part and parcel of pink ribbon culture to eschew the sort of suffering the group member faced because it does not signify survivorship. It alludes to the complications of breast cancer treatments that delving into would uncover a myriad of injustices that take place within the world of breast cancer. These sorts of embodied experiences are erased by pink ribbons, breast cancer walks, and ever present cheer.

There is a complex negotiation involved in deciding how to be both a breast cancer survivor and a person suffering complications from breast cancer treatment. Despite the cheer of pink ribbon culture these complications exist, as does the specter of the possibility of death. From time to time both come out in support group meetings. This discouraged one breast cancer survivor from returning to the meetings.

I went to one (support group), um, and it was ok. But...it's hard to hear about people and I don't know why it's so much harder with the breast cancer than it is my MS group. Probably because most MS people don't die from it. You become pretty physically disabled, unable to walk and all that; but you're not in immediate danger from dying. And I think from breast cancer that's the feeling you get. (Brenda)

The potential for death as a result of breast cancer is erased by pink ribbon culture, which is in part why so many women with metastatic breast cancer feel alienated in the movement for breast cancer awareness (Sulik 2012). Consequently, the association of breast cancer with death propelled Brenda to disassociate with the support group. The

burden of fear is less heavy among others with MS.

The visibility of disease, its physical manifestations, also impact identification with breast cancer or MS. Anne describes how the invisibility of MS informs her identification with it, given that she is known in her small town for breast cancer. She described “And my disease is invisible right now they say. Later it might be a cane or a walker or a wheel chair you don’t know or maybe not.” The invisibility and uncertainty inform Anne’s decision to publically discuss her MS diagnosis. She continued “And I live in a small town, a small community, ok so, I’m with the you know... I don’t want to say I’m the breast cancer woman but you know what I mean. Well so with my MS I have not disclosed in my community yet. My close friends know, my family knows.” Another woman in Anne’s town has MS and Nan, knowing this, is hesitant to disclose her status publically as she already occupies the breast cancer survivor status. These identities and conditions do not have to be mutually exclusive, yet, their co-existence adds a layer of complications to claiming authenticity with either identity. The erasure of other health complications by pink ribbon culture makes choosing between being “the breast cancer woman” and “the other woman with MS” a very real decision.

Darlene sums up the mutual exclusivity of breast cancer and other conditions when she explains, “ Well...it dep[ends]...it’s just that my mind set has gone from cancer to heart failure.” The shift from identification with breast cancer to another disease, to put breast cancer second so to speak, defies the dominant narrative that posits breast cancer as the greatest challenge a woman will face. To dis-identify with breast cancer, even momentarily, is to reject the widespread cultural pink washing of the disease. Constructed to be pleasant, wholesome, and feminine, those who have experienced the disease, and

others, reveal that the intricacies of the experience are anything but.

In light of the characteristics of Sulik's she-ro and emphasis on pink femininity it is certain that aging presents a challenge to dominant pink ribbon narratives. Consequently, the experience of having and being an aging body is erased in a cultural milieu that emphasizes youth and two-breasted bodies. The erasure of aging bodies from pink ribbon culture emerged during the mastectomy fitter training class. The organizer of the class spent a great deal of time considering how to properly discuss older women's breasts and how to "fit" women of advanced age. Older women were particularly hard to fit for two reasons, the organizer explained. First, the aggressiveness of the Radical Halsted mastectomy performed from the 1890s until the 1970s made women's chests concave and uneven (Love 2010). Second, many elderly women had poor posture or were primarily bent over. Both made it unlikely that the prosthetic would sit close to the chest and give the appearance of a biological breast. She went on to suggest fitting older women with prosthetics two or three sizes larger than their other breast to account for the missing tissue and muscle. A single *mature* breast presented a problem to finding a comparable prosthetics because they aren't made *pendulous*. Instead, prosthetic breasts, like finished reconstructed breasts, resemble the breasts of much younger women. These challenges indicate not only a lack of consideration of older women when designing and producing prosthetic breasts, but also a lack of language to discuss older women's bodies and their experiences with breast cancer. Pink ribbon culture was built on the existence of these kinds of bodies and stories, but since activism has been replaced with philanthropy (King 2006), they have been erased.

As a reflection of American values and beliefs about women and women's bodies, pink ribbon culture supports the devaluation of women's bodies as they age while also leaving little space for young women who don't adhere to gender norms to share their stories. The pink ribbon as a symbol of breast cancer awareness reflects the trivialization of breast cancer, the infantilization of women, and suggests newness and light heartedness that conflict with many women's lived experience with breast cancer (Sulik 2012). The primary symbol of pink ribbon culture displaces the experiences of breast cancer survivors that relate to aging. Women's feelings about their bodies, how they live in survivor bodies, and the ways young women manage experiences and bodies rapidly altered due to chemically induced menopause are not accounted for under the auspices of a pink ribbon. The result is a general erasure of the aging body and a denial of the process of aging.

One of the ways survivors' narratives about the aging body are erased is through pink ribbon culture's emphasis on reconstruction. This is not to say that the practice of breast reconstruction should be avoided or an indictment of women who opt for reconstruction; rather, the practice transforms the shape of women's breasts and thus changes the corporeality of the aging body. At the first meeting of the Mid-Missouri Breast Cancer Awareness Support Group I was met by 9 breast cancer survivors ranging in age from 39 to 74. During this first meeting each woman sitting around the table introduced herself and stated how long she had been a survivor. Kelly, 58, shared that she had just gotten her nipples tattooed on. This was momentous because it meant her breast reconstruction was almost complete. Kelly joked that one of the benefits of reconstruction was that her breasts would never sag and she jumped to demonstrate how

they wouldn't move either. The other women in the group laughed; many of them shared this embodied experience.

Kelly's decision to have breast reconstructive surgery was informed by multiple conflicting sources. Her daughter encouraged her to get reconstruction because she was interested in dating, but her ex-mother-in-law had a different suggestion.

My ex mother-in-law, we're still very very good friends. When she heard I had [breast cancer] she was like "oh me and my lady friends were just talking about this the other day," and she's 80 some years old, "we were just talking about this the other day about at age 60 you don't need em anymore, so you should just cut em off and get rid of em." Well I'm like, "I'm not at 60 yet Irene, so I'm going to have some more put on." (Kelly)

Kelly confronts pink ribbon culture's preference for youth on two fronts and her body is erased in two ways. First, the corporeal ramifications of breast cancer are erased through reconstruction. Second, her existence as a sexual being is erased by the imperative that she doesn't *need* breasts anymore; or soon will not. The conflicting messages Kelly receives from well-meaning family and friends is indicative of the sorts of messages breast cancer survivors receive about their embodiments relative to their age.

In both cases Kelly's embodiment is a social process whereby her family and friends acknowledge, however tacitly, that the way Kelly's body reflects the social world will have implications on her life thereafter. This paradox is downplayed by pink ribbon culture, which marks reconstruction as the end of the recovery process.

The embodied paradox set up by pink ribbon culture, yet rendered invisible is realized in and through the aging-reconstructed body. Francine was diagnosed with breast cancer at 52 and had a single mastectomy and reconstruction. At age 52 her reconstructed breast and her biological breast were symmetrical and similar in size. Now 74, Francine described the dissatisfaction she feels with her breasts.

I wish I could get them both back the same size but with my age now ... With my age, what can I say, it helped me [when I was young]. I'm not looking again for, what can I say, looking [for] something...to happen. I just look at what I got and it was no boobie (Francine)

When Francine looks at her breasts she sees one pendulous breast that has aged along with her but the other breast remains high on her chest and has retained the same firmness and roundness as when it was put in. Francine tried to account for the asymmetry by wearing hard cup underwire bras but after open heart surgery the scar going from her chest to abdomen has made it difficult to wear anything but soft cup and soft banded bras. In addition to speaking to the paradox of embodiment supported by pink ribbon culture Francine's story contradicts with the dominant narrative, which suggests the reconstructed body is better than the body before cancer. While Francine may have evaluated her body more positively 20 years ago as time goes on it grows increasingly difficult. Yet, aging women, like Kelly's mother-in-law suggested, are thought to be somehow beyond body image issues. Or, the concerns and confines of femininity are thought to no longer matter once a woman has passed an age where she is subject to the male gaze.

The erasure of these concerns does little to aid women in survivorship. Marilyn, 74 now, and 63 at diagnosis, opted for the flap reconstruction procedure. She endured multiple surgeries, which were ultimately unsuccessful, resulting in the implantation of silicone implants, something she hoped to avoid. During our interview she shared:

**Marilyn:** I don't like to look at [my body]; but, who knows? Good God, I'm 74 years old. Maybe I wouldn't like to look at it anyhow.

**Jenna:** Could be.

**Marilyn:** I don't know. I was always, and I still am, concerned about my appearance. I don't go out of the house without makeup; I don't go out of the house without my wig on. I don't wear sweats and stuff like that. When I go out in public, I try and look as best I can, so I still try and look as best I can, and make

this body do the best that it can do.

Marilyn tries to “make this body do the best it can do” by which she adheres to the norms of femininity by appearing two-breasted, wearing makeup, and dressing up. Consequently, whether she is dissatisfied with her embodiment because she is aging or because of breast cancer is unclear. The amalgamation of a body marked by cancer and a body marked by aging contributes to the complicated negotiation Marilyn undertakes when going out. It should be noted that Marilyn still wears a wig many years after finishing breast cancer treatment because when she lost her hair to chemotherapy it never grew back. This complication is scarcely attended to under pink ribbon narratives, which attempt to soothe women undergoing hair loss by assuring them “it’ll grow back.”

Despite the emphasis on youthful femininity pink ribbon culture enacts erasures of young breast cancer survivors as well. One way this is done is by leveling the differences women experience based on age. Yet, youth carries with it expectations regarding the shape of the corporeal body and how to best make decisions about the body.

Part of embodying breast cancer is the struggle one faces while undergoing treatment. For very young women, this can be a time where one is first made aware of the aging process. Hana, 38 now but 33 at diagnosis maintained, “chemo ages you.” Having looked, in her estimate, ten years younger than her chronological age Hana felt that she had suddenly caught up because of chemotherapy. Hana reconceptualized aging as a result of the aggressive treatments as a “badge of honor,” an affordance not granted to all women with breast cancer. Conversely, Matilda, 39 now, 37 at diagnosis, struggled to negotiate how she felt, how she looked, and the expectations put forth by pink ribbon

culture.

I don't know how to describe it, I don't know what it is about, especially since I'm not older and went through it...its definitely a whole different mindset I think (pause). Yah, I don't know and then a part of me is like maybe its just me...reacting differently than say somebody else my age that doesn't have kids, maybe I'm just the different one in the bunch, because that's entirely possible too because I feel like I've definitely experienced this in a whole different way than most people have and um yah its been really strange. Well and then another thing is that I don't look sick when I'm sick.

Not having children, youth, and her healthy looking appearance in addition to her status as a graduate student render Matilda's body and experience invisible in regard to mainstream breast cancer narratives. Matilda attributes the differences she experiences to something inherent to her, not pink ribbon culture which puts forth a particular narrative characteristic of a particular type of body and experience.

### ***Conclusion***

The narrative excerpts presented here highlight the multiple ways breast cancer survivors experience discrepancies between the narrative set up by pink ribbon culture and their lived experience. These discrepancies, couched in medical and pink ribbon encounters are largely based on the intersections of gender, race, class, sexuality, health status, and age. Each of these instances represents a break from the dominant narrative espoused through pink ribbon culture and demonstrates the role of medical consumerism and sisterhood in erasure. The bodies and stories made possible, or impossible, through these interactions are far more complicated than can be symbolized by a pink ribbon. Rather, these stories show the multitude of ways breast cancer results in experiences that differ from the normative survivor narratives.

Survivors continue to have their personhood threatened by a system that legitimizes certain kinds of female bodies by excluding or dismissing narratives that do

not support dominant pink ribbon narratives. Overt and covert racist discourse inform the invisibility of women of color and support a faulty black/white binary, which normalizes white women's experiences with breast cancer and makes African American women's experiences seem strange. Moreover, financial struggles resulting from the tie between work and health insurance, Medicare's inadequacies, and rapidly increasing medical costs are unsustainable for many women. The cost of cancer care falls disproportionately on the socio-economically disadvantaged and is all but non-existent in the sanitized world of pink ribbon culture where paying for treatment is a non-issue, but more often, an individual's responsibility.

Furthermore, using sexuality as a lens it is apparent that pink ribbon culture and medicine operate under an assumption of heterosexuality but downplay and mock female sexuality. In a similar way, both old and young women are disadvantaged by pink ribbon culture that curiously celebrates youth and beauty. In terms of age, the ideal survivor body is elusive; it shifts and changes so that regardless of her age, a woman is the wrong age. Finally, the overwhelming saturation of pink ribbon culture erases the other conditions women have due to chemotherapy treatment or simply occurring alongside breast cancer. The breast cancer diagnosis becomes a master status wherein a woman with a complex, multifaceted, identity becomes a breast cancer survivor.

The various encounters here, both within medical encounters and during pink ribbon events, represent systemic erasure of the nuances of breast cancer survivorship. By denying differences in experiences related to age, race, gender, health, sexuality and others, understandings of breast cancer become consolidated to the detriment of survivors, in general. These limitations influence the understanding of the *problem* of

breast cancer, discouraging critical engagement with pink ribbon culture, which is viewed only as the solution and not a problem in and of itself. Nonetheless, pink ribbon culture and its association with altruism are reflected in women's narratives. The dominance of pink ribbon cultural narratives produces a very particular kind of breast cancer survivor. This ideal type is never realized; yet the she-ro (Sulik 2012) takes the premier position in the survivor hierarchy, which is the focus of Chapter 3.

### CHAPTER 3: CHALLENGING AND REPRODUCING THE SURVIVOR HIERARCHY

*There's too much pink. I'm tired of pink. I really am. I'm a survivor, yes. I'm a survivor of a lot of things. Heart disease, high cholesterol, spinal stenosis. Why have we made this so different, such a big focus? Why have we done this? It's not that it's bad, but I don't know why we over do it. Especially in October, goodness gracious, it's a lot. – Marilyn*

In this excerpt from our interview Marilyn touches on the curious power of pink ribbon culture. She asks, “Why have we done this?” Why has breast cancer survivorship, symbolized by the color pink, become hyper visible and why does it subsume other parts of a woman’s identity? Marilyn’s assessment of survivorship in the context of pink ribbon culture reflects changing sentiments about cancer, the development of the survivor subject position, and the strangeness of a disease-experience influenced by neoliberal understandings of health and wellness.

The meanings associated with breast cancer survivorship have changed over time as common understandings of cancer in general have also changed. Once associated strictly with death and the unspeakably abject, cancer has been transformed into a culturally resonant charitable cause (Sontag 1977, Stacey 1997, King 2006). However, prior to the 19<sup>th</sup> century, breast cancer especially, carried a negative stigma and an association with sin (Leopold 1999). New treatments, like surgery and later radiation and chemotherapy, made the disease survivable which helped to shift the stigma (Frank 2013, Stacey 1997). This transformation intensified as neoliberal policies took hold and encouraged charitable, rather than state, support for health care (Sulik 2012, King 2006).

Since the 1980s neoliberalism has influenced the nature of capitalism and the form and shape of American citizens; breast cancer survivors are no exception (Guthman 2011). Neoliberalism is characterized by an emphasis on individual choice and

responsibility, deregulation and cuts to social services, and promoting the interest of corporate profits under the guise of preserving the wellbeing of a nation's citizens (King 2006, Harvey 2007, Gill and Schraff 2011, Guthman 2011, Dubrinwy 2013). This ideology is reflected in the development of the *cancer survivor*, which is notably different from cancer patient and cancer victim because of association with empowerment, individual responsibility, and the notion of choice.

While the “survivor” subject position is not limited to those with cancer, it has a strong connection. This connection stems from characterizations of cancer as the ultimate battle between the self and the body (Stacey 1997). Other conditions, like those Marilyn mentioned during our interview, lack this kind of dualistic mind/body battle. Therefore, the origin of cancer in the body, the literal attack of cells on cells, makes surviving cancer different than surviving other sorts of illnesses.

This does not mean, however, that surviving other types of illnesses is less difficult than surviving cancer; rather, neoliberal ideologies surrounding health make cancer a unique condition for which survival becomes a responsibility. Moreover, it indicates that one made the right *choices*: an especially neoliberal sentiment (Frank 2013). Breast cancer survivorship, then, exists at the threshold of neoliberal notions of health and well-being within the context of pink ribbon culture, which leads to the promotion of particular kinds of survivors embodied in the “she-ro”.

The ideal breast cancer survivor, Sulik's (2011) “she-ro” is also the ideal neoliberal subject. Both are white, middle class citizen consumers with interest in and the financial ability to secure particular bodies through surgeries—either cosmetic or reconstructive, all the while sufficiently “empowered” to make the right kind of choices

regarding their health (Dubriwny 2013). Importantly, the ideal breast cancer survivor also identifies as a wife and mother, detects her cancer early, receives the right kinds of treatments, and recovers successfully (Davis 2008).

The result of this confluence of forces on women's lived experience with survivorship is the existence of a survivor hierarchy. In this chapter I add to Sulik's (2011:319) analysis of the survivor model, which forces women to question their survivorship through comparison to others, by addressing how women deploy specific breast cancer narratives in effort to make sense of their embodied experiences in light of the survivor hierarchy. Illness narratives, under which breast cancer narratives fall, help to "recover voices" lost to illness and share experiences related to how illness impacts one's life (Frank 2013, Sulik 2012). The ability to tell a story reflects a shared experience with boundaries, words, and meanings that have special value within the context of an illness (Frank 2013), all of which are informed by the survivor hierarchy. Survivors' embodiment, or the physical expression of biological and social factors (Krieger 2005), informs how a narrative is shared and how one makes sense of their story in the context of the survivor hierarchy. The shape the body takes during and after breast cancer has important impact on the potential women have to embody breast cancer survivorship. Since the survivor hierarchy reflects neoliberal understandings of health as a personal responsibility (Stacey 1997), medical consumerism (Sulik 2012), and the commodification of breast cancer as a profitable cause (King 2006) it adds to the discrepancy between women's lived experiences with breast cancer and the experience produced through pink ribbon culture.

The survivor hierarchy dictates proper responses to breast cancer related situations, but also, and importantly, the appropriate treatments and recovery process. Consequently, the survivor hierarchy influences the types of treatments and surgeries that women choose when confronted with options. For example, Grace had the option to have a lumpectomy or mastectomy after her biopsy. She chose a lumpectomy at first but later elected to have a double mastectomy. Grace is not alone in her decision to have a double mastectomy when other breast conserving surgeries were available. Rates of double mastectomies have more than doubled in recent years despite no increase in survival rates compared to breast conserving surgeries (Wong et al 2016). Angelina Jolie and the subsequent “Jolie effect,” referring to Angelina Jolie’s decision to undergo preventative mastectomies upon discovering that she had the BRCA1 mutation, has been credited with the increase (Saleh 2015). Despite not having breast cancer Jolie earned a spot in the survivor hierarchy for the difficult decisions she made to *prevent* breast cancer. Jolie, and others who opt for preventative mastectomies, are termed *previvors* (Dubriwny 2013). Thus, the mode of survivorship one engages has personal and cultural significance. Other women’s surgery decisions framed in pink ribbon culture as the *right* decisions and ranked in the survivor hierarchy, inform the ways survivors’ bodies take shape and influence the ways they share their story.

The survivor hierarchy normalizes particular treatments to the detriment of survivors by promoting experiences that correspond with the values and norms in pink ribbon culture. For example, women who undergo chemotherapy treatments to reduce the size of breast tumors are viewed as having struggled more than women diagnosed with breast cancer but who did not undergo chemotherapy. Further, women who lose their hair

as a result of chemotherapy are viewed as having struggled more than those who undergo chemotherapy but do not lose their hair. The hierarchical ranking of these components of survivorship are subtle, but felt by survivors—especially those that did not undergo chemotherapy and did not lose their hair. It produces varying responses in women whose experiences conflict with the hierarchical ranking including guilt, remorse, a sense of deserving to suffer in some way, and frustration. Thus the survivor hierarchy accentuates Sulik’s “survivor model” by taking the concept further and developing not only its characteristics, but also the ramifications of such a comparison on breast cancer survivorship.

The survivor hierarchy is reflected in a proliferation of breast cancer illness narratives produced in and through pink ribbon culture, characterized by optimism and empowerment, which makes commodification of the experience and marketing of the disease possible (Sulik 2012). Importantly, the commodification of breast cancer experiences leaves little room for alternative stories because narratives that reflect dominant discourse supersede those that tell alternative stories (Sulik 2012, King 2006, Leopold 1999, Ehrenreich 2001). The space for alternative stories may be limited, but their existence is powerful because it challenges the survivor hierarchy by exposing discrepancies between lived experience and pink ribbon culture. For example, when women share stories about the amount of work that goes into survivorship or mention feeling badly about not living up to the standard of survivorship the survivor hierarchy is revealed and shown to be a mechanism to reinforce gendered disease experience.

The limitations placed on breast cancer survivorship are reflected in breast cancer survivors’ narratives. Sulik (2011:101, 317) argues that larger cultural narratives

dominated by exhibitions of “strength, hope, and courage” circulate through pink ribbon culture and also use bellicose language, emphasize successful recovery, promote consumption of pink ribbon goods, and follow quest or transcendent narrative forms. While this is the case, they also confirm survivorship, demonstrate the work that goes into survivorship in particular contexts, and fix women’s perceived flaws. As such, the following analysis details three types of breast cancer narratives that reproduce and challenge the survivor hierarchy: stories that confirm survivorship which reference hair loss, stories about the work of survivorship which detail the prevention and management of lymphedema, and stories about transformations which reflect positively on the experience.

### ***Stories that Confirm Survivorship***

Stories that confirm survivorship are based on embodied conditions associated with cancer survivorship. In this case I focus on narratives about hair loss. Stories about hair loss reinforce the survivor hierarchy by drawing connections between the experience of hair loss and survivorship, highlighting positive qualities of those that experience it, and reproducing images of breast cancer survivors that coincide with the dominant narrative. Through these stories, a strange experience: losing one’s hair due to cancer treatments becomes a familiar benchmark for survivorship.

Not all women diagnosed with breast cancer will undergo chemotherapy and lose their hair, but enough do that hair loss is a sign of survivorship. Hair loss, however, is more than a physiological response to chemicals; it can symbolize a loss of womanhood and present a challenge to femininity (Hansen 2007, Dua, Heiland, Kracen, Deshield 2015). Thus, the meaning it has within pink ribbon culture reflects a loss of womanhood

and the opportunity to recuperate a feminine gendered body through hair regrowth. These ideas circulate through pink ribbon culture and inform women's experiences and perception of hair loss (Hansen 2007). In many ways, it is the factor that confirms one's status as a cancer survivor or cancer patient.

Understandings of cancer and its nuances as an embodied experience are restricted by the limitations of language (Sulik 2012, DeVault 1999). As such, the signs and symbols that signal to outsiders that one is sick, suffering, or surviving are culturally dictated. While the stigma surrounding cancer changed as cancer culture developed (Stacey 1997), hair loss remains a powerful symbol of cancer as well as a challenging embodied experience. For Kay, a white woman age 43 at diagnosis, hair loss was "one of the hardest things" to come to terms with throughout her experience with breast cancer.

During our interview she explained:

That was awful. I thought about that a lot. I think that was one of the hardest things, is losing your hair. I remember just standing at the sink and just pulling out handfuls of hair. That was rough. Even knowing that it's going to come back in, and I have curls now, so it's okay now. That probably was one of the hardest things. I think that makes you a cancer patient when you lose your hair. I never realized you lose it on your arms. You lose it all.

Kay, like many other women in my study, cited losing hair as the most traumatic and the most difficult part of having breast cancer. For some the loss of hair was a challenge to their femininity, for others it was "looking sick" that they found so difficult. Nonetheless, hair loss cemented their status as "cancer patient" or the term more often used today: cancer survivor. And while the American Cancer Society and Susan G. Komen for the Cure advise that one becomes a cancer survivor from the moment of diagnosis, hair loss as a result of chemotherapy is a notable experience in the embodiment of survivorship.

Hair loss is a significant part of women's breast cancer narratives. For one, it allows for reflection on the experience as difficult and *over* which is vital to maintaining the survivor hierarchy. Since hair most often grows back, telling a story about hair loss and the associated trials and tribulations is a legitimating experience in the survivor hierarchy. Hair loss threatens feminine embodiment, which makes hair regrowth reclamation of femininity and a pushback against breast cancer as a threat to one's life. The value of hair, then, lies both in loss and regrowth as both provide an opportunity for personal transformations. Moreover, any experience that contains a beginning and a neat ending (regrowth) can be commodified within pink ribbon culture and reified as an exemplary breast cancer experience.

Narratives featuring hair loss and regrowth confirm the proper way to experience breast cancer, which is to undergo treatments, suffer through the side effects, and reflect positively on the experience as a whole. As a mechanism to reinforce proper gendered illness behavior these narratives indicate that the right and proper way to experience breast cancer is to have the type that requires chemotherapy. Engagement with biomedicine, pharmaceuticals, and full integration into the cancer complex solidifies this experience as valuable and *legitimate*.

The value of hair loss is not limited to the ability to share a story about recovery. It also allows other people to evaluate one's story as an exhibition of bravery. Since sickness propels one into the vulnerability associated with femininity (Stacey 1997), showing signs of bravery while sick allows the storyteller/sick person to recuperate favorable masculine traits. This feminine/masculine tradeoff is a lively part of pink ribbon culture and cancer culture as a whole (Sulik 2012, Stacey 1997). These

characteristics emerged during participant observation in the support group and in interviews with individual women.

The December 2014 support group meeting was like most others without a speaker or presentation. The attendees introduced themselves and shared where they were in their cancer treatment or recovery process. On this day the organizer, Sandy, brought wig catalogues in case anyone was interested. None of the women there that day needed a wig since they were all past the hair loss stage or did not undergo chemotherapy. Nevertheless, the conversation turned to memories about their experiences with hair loss. Two women shared that they either did not wear wigs or seldom wore them. Rita thought both women were brave. One of the women, Tonya, then shared a story about the time she was at her daughter's school program when her wig cap started to bunch up and roll off underneath her wig. She said she tried to discretely pull it out, but someone sitting next to her saw her do this. Tonya said she whispered, "It's ok, I don't have any hair, I have cancer!" Most group members laughed, but Rita did not, instead she commented on Tonya's bravery.

The evocation of bravery when confronted with stories about hair loss is common in pink ribbon culture. In the support group where women discuss wearing wigs because of hair loss due to chemotherapy Rita evokes bravery to describe Tonya who mostly went without a wig. Using "brave" to describe Tonya's wig use does several things all of which uphold the survivor hierarchy. First, it makes Tonya's situation and experience exemplary, an enviable way to act when one has cancer. Second, it separates those who wore wigs after losing hair from those who did not. To reject wigs is a rejection of the feminine components of illness. It is a means to embrace the masculine by rejecting the

vulnerability associated with wig surveillance and maintenance. In Tonya's story her bravery manifests when she reveals she has cancer and is, in fact, wearing a wig. Bravery lies in revealing one's baldness through humor and reveling in a new embodied state. Hair loss and baldness, in this sense, allows women to stake claim on survivorship through narratives where they demonstrate bravery.

Women also gain access to the survivor hierarchy through stories that reflect their stoicism during hair loss. The same way pink ribbon culture uses war rhetoric (Sulik 2012) to describe experiences with chemotherapy it also insists on exhibitions of stoicism. This was reflected in my interview with Brenda when she explained, "I think I handled it pretty good. I walked around with those lint brushes and would do this [clean off shoulders and chest] all the time and it drove me crazy to think there was hair all over my stuff and it got to the point where there was hair all over my stuff I just kept shaving my head." Handling hair loss well means taking control of the situation, hiding the sick body, and maintaining normalcy through whatever means necessary. While, carrying around a lint brush is not outrageous or damaging, it is a technology of the self whereby individuals attempt to maintain a level of normalcy in an abnormal situation (Hansen 2007).

Maintaining normalcy in the face of breast cancer is a hallmark of the survivor hierarchy. In a strange way it requires that women relish in the experience of breast cancer while also denying the embodied struggles associated with it. The conundrum makes it so that no woman's story can approximate the ideal because there are too many complexities involved with a breast cancer diagnosis and too many ideals set up by pink

ribbon culture. Nonetheless, there are women who tell stories about their seemingly textbook breast cancer experience.

Rosie, a 70-year-old 8-year breast cancer survivor, shared her story with hair loss and breast cancer, in general, as a positive experience. Her narrative, though, exists within a context beyond pink ribbon culture. Rosie was diagnosed with breast cancer during a tumultuous ten years for her husband who began to suffer the side effects of what is largely believed to be the result of exposure to Agent Orange during his Vietnam service. While Rosie had breast cancer her husband had melanoma, lung cancer, open-heart surgery, and a kidney transplant. While Rosie lost both her breasts, the combination of dominant narratives in the survivor hierarchy and caring for her husband throughout his multiple health scares it is no wonder she evaluated her experience in a positive light. She infused her story with humor, light-heartedness, and a lively tone. She had her husband shave her head, wore beautiful scarves and hats, and received overwhelming support from friends and co-workers. Her story is one of positivity and personal growth. In fact, Rosie embodied the ideal breast cancer survivor so much that her boss once commented that she “look[ed] like the poster child for breast cancer” and said “everybody will want it because you come in looking so stylish and everything” (Rosie).

With her stylish scarves and hats Rosie embodied breast cancer survivorship. Her boss’s statement that Rosie’s presentation would make other’s *want* breast cancer because of how great she looked, and how well she handled the disease, is indicative of the cultural imperative surrounding breast cancer survivorship: make it look good so that other’s will envy your position. The position can be purchased through pink ribbon commodities and one need not be a breast cancer survivor to access this identity (Sulik

2012). To be the Poster Child for Breast Cancer, however, one must lose her hair and do so in a graceful, aesthetically pleasing manner. All this, however, is divorced from the other components of Rosie's life including her husband's multiple cancers, her caretaking, and beyond. The survivor hierarchy only values bracketed stories that simplify one's life into time before cancer, time with cancer, and the time after.

The survivor hierarchy relies on narratives that are, for the most part, void of context. Narratives that reproduce pink ribbon culture through simplifications of treatment experiences, evocations of bravery, and assessments of survivorship based on surface level factors support the hierarchy of experience. However, the survivor hierarchy is not an all-encompassing, literal structure that cannot be dismantled. Instead, the survivor hierarchy is broken down and exposed as a mechanism of control when women's narratives call it into question. This is to say; when women call out the survivor hierarchy in their narratives its very existence is threatened.

Some of the women in my study who did not undergo chemotherapy and therefore did not lose their hair find they have less stake in the cultural meanings attached to survivorship. As such, their stories of struggle and suffering suggest that the narratives which uphold the survivor hierarchy fail to encompass all that is and can be breast cancer. Randi a white woman age 55 at diagnosis, had a double mastectomy with no reconstruction and did not require chemotherapy, she explained:

I think because I never had chemo and I never lost my hair people kind of look at you differently than they do when you go through the chemo and lose your hair and everything. There is something about that hair loss thing that people think you didn't have it that bad if you didn't lose your hair. And my husband he's gotten mad a couple times because like in February his brother said "oh she's just doing great" and he said "you have no idea what she's been through" and you know a lot of people that lose their hair have had a lumpectomy and when they get in you know when they recover from their cancer or their chemo they are just like they

always were. And he's like she is changed forever and she has to cope with that and so we got upset about it.

Randi's story demonstrates the cultural weight of hair-loss from chemotherapy—it means “you had it bad.” To “have it bad” is to have a legitimate experience with breast cancer. Randi explains that despite having a double mastectomy she felt like her experiences were somehow less valuable than those who lost their hair. Her brother-in-law reiterated those sentiments from an outsider's perspective. His evaluation of her experience is based on whether or not she lost her hair, not her breasts. While Randi argues that her body is permanently changed which *should* be enough to constitute her survivorship other's interpretation of her experience is rooted in hair loss. For Randi losing both her breasts and recovering from that physically and emotionally constitute her survivorship, yet she is forced to confront the survivor hierarchy through her double mastectomy and finds that there is little room for her embodiment or her story.

### ***Stories About Survivorship as Work***

Stories that focus on the work of breast cancer survivorship pertain to conditions that survivors manage on a daily basis. Women in my study rely on pharmaceuticals to prevent breast cancer recurrence, contend with developing new conditions from aggressive breast cancer treatments, and confront the rules of survivorship dictated by pink ribbon culture. Consequently, narratives that hint at the work required of survivors mean that the survivor hierarchy is both challenged and reproduced. For example, work to *prevent* further cancer or cancer related conditions fits with the dominant narrative and reproduces the hierarchy; however, when one develops those conditions despite preventative measures the survivor hierarchy, and the dominant narrative it upholds, is revealed to be a very limiting, contingent space. The stories about the work of

survivorship presented here focus on the ways women manage their bodies with the threat of lymphedema and after a lymphedema diagnosis. In both scenarios the body does not return to its prior state, instead it remains at risk.

Lymphedema is “the most serious possible long-term effect of surgery on the lymph nodes” and commonly manifests as a swollen arm, which puts women at an increased risk for infection (Love 2010:543). When lymphedema occurs swelling in the arm is managed by wearing a compression garment that can extend from the hand or wrist to the shoulder. While fewer women are diagnosed with lymphedema today than in the past, the women in my study felt under-informed about its causes, treatments, and preventative measures. Part of the uncertainty surrounding lymphedema is that there is no guarantee one will or will not develop it after lymph node removal.

Since lymphedema can happen at any time, women that underwent lymph node removal are responsible for working to prevent an occurrence, despite uncertainty as to whether any measures will *actually* lead to a decreased chance for developing lymphedema. Nonetheless, stories that depict survivors as vigilant body-monitors help to ease the self-blame that results from the diagnosis. Women who tell stories about managing their bodies and attempts to prevent lymphedema are met with positive reinforcement because it indicates that one takes personal responsibility for their health. Here, the survivor hierarchy emerges as a mechanism to control women’s bodies, and thus their stories, by insistence on responsibility for health—traits indicative of neoliberalism.

Narratives that reflect the survivor hierarchy also indicate the neoliberal imperative to take responsibility for one’s health by seeking out information when

medical professionals provide little (Stacey 1997). This is part of the professionalization of the patient, where self-knowledge is the solution to managing risk and potential health problems (Stacey 1997). Marilyn demonstrated the importance of taking responsibility for one's health when she shared a story about a time she had to correct an anesthesiologist.

I have no veins left, because you don't do anything on the arm of the mastectomy, and I practically had to get out of bed at Boone hospital and hit the anesthesiologist over the head. He had a hard time getting in, like everybody does over here, because there's nothing left. He was insisting that he could use my right arm, that it'd been long enough, and after I said, "Sir, no." You could develop lymphedema at any time, no matter how far out you are. I've never had any, and I'm not going to chance it now. We had a big argument about that (Marilyn).

In this example, Marilyn embodied ideal survivorship by demonstrating her knowledge of the survivor body and remaining vigilant. She used the knowledge honed in her career as a nurse and her lived experience with breast cancer to engage with medical professionals to hopefully prevent lymphedema. Her narrative about the work of survivorship reflects positively on her survivorship because she is shown to be pro-active, informed, and brave enough to speak up. This kind of story reinforces the survivor hierarchy, which places a great deal of value on *not developing* breast cancer related conditions. Another way women are taught to prevent lymphedema is by pre-emptively wearing compression garments. In our interview Anne shared her knowledge about preventing lymphedema.

Even if you didn't have it you have to have one of those [lymphedema sleeves]. So many people don't know it, but you have to have it to avoid getting it... When flying or sometimes maybe they'd recommend it for when you're exercising. But you have to have it while flying because of the cabin pressure... (Nan).

Anne comments that this sort of information is not common knowledge and many women are not aware that they should wear a lymphedema sleeve on a plane. In many

ways not knowing, or not being aware, is unacceptable within pink ribbon culture. The lack of knowledge and awareness of lymphedema in pink ribbon culture is met by a lack of medical research as well. Louisa, a nurse PhD whose research focuses on lymphedema, shared that it wasn't until she was diagnosed with breast cancer and later developed lymphedema that she discovered the lack of medical literature on this condition. This general lack of knowledge translates to a great deal of uncertainty and makes it difficult for women to maintain the survivor body through prevention techniques. Consequently, narratives in the survivor hierarchy that feature lymphedema also focus on managing it once it develops.

Despite attempts to prevent lymphedema through pre-emptively wearing compression garments, avoiding blood work in the arm closest to the original cancer site, and generally being careful, many women still develop the condition. Women's stories about managing their bodies with lymphedema often start with admission of guilt for failure to attend to some component of the recommended prevention techniques. During our interview Celia confessed that she could have done more to prevent lymphedema.

I think it was the sunburn and working out in the garden, getting cuts and scraps and stuff, so it's like if I had been a little more diligent, keeping my arm covered it might not have happened (Celia).

This excerpt from my interview with Celia reveals how the survivor hierarchy manifests in women's lived experience. Here, Celia's admission of guilt is a tacit acknowledgement of the survivor hierarchy. In this, she recognizes there is a correct and proper way to manage the body after breast cancer and that somewhere between diagnosis and developing lymphedema she did something wrong. None of the women in my study who developed lymphedema contributed causation to the surgical removal of

their lymph nodes; rather, all took personal responsibility for failing to remain vigilant about prevention—a reflection of post-modern and neoliberal patient imperatives (Stacey 1997).

Stories about managing the body after a lymphedema diagnosis also involve negotiating changes in embodiment and emphasize how changes to the body necessitate changes to the self. For Matilda, lymphedema challenged her view of herself as a physically strong person, which was an important part of her identity.

I do have some of that [lymphedema], so I have to be careful. And, if I exercise I have to have a sleeve for that, travel, you know planes, I have to have a sleeve for that, repetitive actions like if I'm doing dishes or cleaning I need to have that, if I'm lifting anything over ten pounds I pretty much have to have a sleeve on. And, they tell you that you can't just like lift some big piece of furniture on a whim you kinda have to work yourself up...And so I was really strong before cancer and so that was something I've had to adjust to, where I can just do everything, I used to just carry all the groceries with my hands and now I have to be really careful, so that as a huge adjustment.

The sort of adjustments Matilda refers to, wearing a sleeve to exercise and travel and avoiding lifting heaving objects, are small changes to her daily life, but they signify a break with her former self. These mundane changes conflict with the positive personal transformation breast cancer is reported to bring about in stories that reflect the survivor hierarchy. Rather, these adjustments represent changes that Matilda will have to carry on for the rest of her life, barring any major advancement in lymphedema treatments. Matilda was not made a better person because she lost the ability to exercise physical strength and no part of her story about how she's changed since developing lymphedema references a positive personal transformation. Instead, the swelling she experiences may increase or decrease based on numerous factors, but the risk for infection remains throughout her life. This is the lived reality of developing lymphedema after breast cancer.

Managing risk and reducing chances of infection require that survivors with lymphedema take extra precautions, many of which are inconvenient and uncomfortable.

Sue-Jane shared some of her struggles with lymphedema in our interview.

I wish I didn't have lymphedema. It's kind of a drag and it's been reacting lately. I've got a sleeve that I think was too much compression. I took it off and there was a red rash. I've had 3 bouts of cellulitis, which is like in the hospital, antibiotics, big big bummer. But the last time I was in Kansas City, I've gotten shingles twice on my arm, yah bizarre. It's like an AIDS arm because you don't have the right immune system and so I was driving to Kansas City and I wasn't feeling good and I was like uh oh because I know the feeling. And I went to a clinic and I told my doctor she was great the nurses were great but I just thought, I am not going in the hospital in Kansas City and so we got meds and it turned out ok...so now I have a couple scripts I carry with me in case. (Sue Jane)

In this example Sue-Jane embodies the risky subject with her “AIDS arm” that poses a constant threat of infection to a body always already at risk (Klawiter 2008). To account for this Sue-Jane carries extra medication. Her story, and others like it, shows how tentative and contingent body management can be. Stories that reveal taken-for-granted complexities demonstrate that there is more to a “successful” recovery narrative than the survivor hierarchy suggests. For example, women also shared stories about how lymphedema was an embodied reminder of breast cancer.

Lymphedema-as-reminder displaces pink ribbon culture as the mechanism for understanding, experiencing, and remembering cancer through locus in the body. This conflicts with the efforts of pink ribbon culture, which distances the cause of breast cancer from the embodied condition and experience of breast cancer. This and other conundrums such as the elusive ranking of experiences, reflect the impact of the survivor hierarchy on women’s breast cancer narratives.

Embodied reminders of cancer, like lymphedema, exemplify the uncertainty that accompanies life after breast cancer. For Celia, a lymphedema diagnosis was “more of an

issue...than anything because [she has] to wear [a] sleeve all the time and it's just a constant reminder.” Wearing the sleeve, unlike wearing a pink ribbon, firmly roots breast cancer in the body effectively undoing the work of pink ribbon culture. Lymphedema is a reminder of the embodied aspects of breast cancer: the sickness from chemotherapy, the isolation of radiation, the pain of reconstruction, or the difficulties managing a prosthetic.

As a five year breast cancer survivor a lymphedema diagnosis ushered Betsy back into the world of cancer when, after a day of gardening, she noticed her arm was swollen and bore the imprint of the afghan she was resting on.

As soon as I looked at it, I knew what it was. I knew what it was. I just thought because I was five years out I wasn't going to get it. I was not very happy, I was really not happy. I was pissed off actually... Then I just put it in perspective, its not a recurrence of cancer, it's not cancer. I think the thing that really bothered me about getting Lymphedema is not the people notice that I have a sleeve but it's the fact that it's a constant reminder of having cancer (Betsy).

Betsy’s breast cancer narrative is heavily focused on her experiences with lymphedema. While it does not surpass breast cancer as a traumatic experiences, it is a constant reminder of that traumatic experience and the fear she, and other women, associate with that time. Betsy remarks that she “put it in perspective” by recognizing that lymphedema was not cancer, but still struggles with the ever present linkage. To put things in perspective, within pink ribbon culture, means to compare an experience to cancer and declare it “not as bad.” For pink ribbon culture to sustain itself narratives in the survivor hierarchy must emphasize that having cancer, and not the lasting conditions that stem from treatments, is *the* experience. Consequently, stories that emphasize the work of survivorship have the opportunity to challenge the survivor hierarchy by rooting experiences in the body rather than in elusive ideals. To challenge the hierarchy does not mean to out-right or explicitly reject the positive transformation component. Rather,

detailing the added complexity lymphedema poses to survivorship reveals the limitations of a hierarchical ranking.

### ***Stories About Survivorship Transformations***

For the survivor hierarchy to persist narratives about breast cancer as a positive experience must circulate widely. This is done through mainstream media, social media, and the sale of pink ribbon commodities. Beyond stories of successful survival, survivorship transformation narratives highlight a personal flaw and reveal it to be fixed through one's experience with cancer. These stories are accessible because they confirm that medical science is making progress in the treatment of breast cancer, but also because they make cancer seem like an experience that helped the storyteller to become a better person.

Transformation narratives, like quest narratives, allow the storyteller to make use of their illness (Frank 2013). It gives the experience meaning and a function, which for the women in my study meant fixing a perceived flaw. Sharing stories that construct breast cancer to be the mechanism by which one became better and showing gratitude for a harrowing illness reproduces the moralistic components of the survivor hierarchy. Those who tell different kinds of stories confront the hierarchy through feelings of guilt.

Most of the women involved in my study found their experience with breast cancer to be personally transformative, but this did not necessarily prevent them from feeling guilty or remorseful at different times. Rather, positive personal transformation was characterized by adjusting priorities, motivations, and desires. The result is that those who share transformation narratives find that they want to be, and are, different in many regards. Jane shared her story during our interview and despite the struggles she faced

found that her experience gave her a new perspective on beauty and bravery.

Well I am absolutely so vain if my hair don't look good I don't feel good all over so... all my life. I saw this woman speak one time and she was an African American woman, and she had her hair shaved and she was so beautiful. She was so amazingly beautiful and I thought to myself then, what courage she had to do that and if I, I always felt like if I had that kind of courage I thought I could do anything, course I never had it. So it was forced on me that once you do that and get ok with it, it's like you can do anything.

Having breast cancer and losing her hair as a result of chemotherapy gave Jane the courage she felt she had been lacking “all her life.” Jane shared her struggles with hair loss, finding a wig, and committing to wearing the wig despite discomfort. Breast cancer transformed Jane’s body and her self, forcing her to reconceive of beauty, a burden she felt for as long as she could remember. In many ways, Jane’s prior enactments of white womanhood stifled her ability to channel the courage to go without a wig or to wear her hair short. Tacitly acknowledging the limitations imposed by traditional white womanhood, Jane found an example of courage and beauty in an African American woman. The complications of African American womanhood in the United States is not accounted for within pink ribbon culture, but evocations of strength and an emphasis on respectability politics is, as Madlock Gatison (2015) demonstrated. As such, Jane’s longing for courage embodied in the form of an African American woman reflects the strength and perseverance of the myth of the strong black woman (Beauboeuf-LaFontant 2009). The unnamed woman’s beauty stems as much from her physical form as it does from ideas about African American women and perceptions of strength.

The flaw Jane finds in herself, a lack of courage demonstrated through an emphasis on aesthetics, is ameliorated through the lessons she learned from breast cancer. Shifts in perspective and priorities allowed Jane to re-conceptualize her own beauty and

live a more courageous life. As a more recent breast cancer survivor, Tonya shared similar sentiments. Her struggle with breast cancer changed her perspective on life and made her want to “be better” in a number of forms. She explained to me during our interview:

I have noticed that I want to be a better person. I want to be better at work. I want to do my job better. I want to be a better parent. I want to be a better wife. I've had thoughts of, maybe if I could afford it, becoming a foster parent, or maybe going and volunteering somewhere to help somebody like a, I respect veterans very [much], my dad was a veteran. Maybe it's motivating me to think about different things in which to help people with ...and not just all about me and my kids.

The desire to “be better” is not necessarily a reflection of Tonya’s belief that she was “bad” before but rather a desire to live differently. Tonya explains, “I think when you face this, and it's a brush with death, it's a possible brush with death, and you come to realize that you just need to quit sweating the small stuff, and get out and enjoy life.”

Tonya’s sentiments reflect the survivor hierarchy, which ultimately reinforces ideas and expectations about gender. Specifically, it rejects feminine illness for the masculine battle/victory over illness (Stacey 1997). To constitute the subject position “survivor” women, especially, are bound by the experience to highlight how their former self improved through the experience.

“Sweating the small stuff,” is a highly gendered practice wherein a component of femininity is to focus on the details other might not notice or care about. Worry about these seemingly small things is an impediment to enjoying life and, consequently, something that is realized through the course of treatment for breast cancer. The perspective breast cancer gives women is that the way they were living prior to diagnosis was ineffective. Focus on bigger issues, like the needs of veterans, would allow Tonya to demonstrate altruism and her new perspective in a manner that benefits others and gives

credence to her survivorship. In essence, the transformation narrative insists that women didn't survive in vain; rather, through their survivorship they vow to transform from ordinary women into breast cancer survivors. Transformations, as such, are evidence of post-feminist discourse where gender is realized through constant self-evaluation (Dubriwny 2012). In post-millennial America survivorship is constituted through improvements to the self and the story of one's transformation legitimates one's experience with breast cancer.

Survivorship is constituted, then, through stories of personal transformation and a turn to altruism after breast cancer. Both expressing thanks for one's life and actively changing how one lives are prime components of survivorship. The most visible survivors "give back" by volunteering at Reach to Recovery, Susan G. Komen for the Cure, the American Cancer Society or with other organizations that seek to help those with cancer. Altruism, and demonstration of such through one's narratives, is in many ways the final step in breast cancer recovery. After one has stopped and recovered from treatments, philanthropy is a means by which one can recuperate positive components of femininity. In whatever ways one works to bring about a cure or support those in the throws of cancer, the actions of cancer survivors and lay supporters are imagined to be the way breast cancer will cease to exist (King 2006).

Louisa's story of transformation occurred in a slightly different context. She lost her husband to cancer as a young woman and found that experience to be "one of the most painful experiences of [her] life," but she "also realized that that made [her] a more compassionate person, [she] could understand the losses other people experience because [she] had been there." This context colors much of Louisa's breast cancer narrative. Her

husband's untimely passing left her the mother of two young boys when she underwent treatment for breast cancer, an experience she was not sure she would survive.

Nonetheless, Louisa's narrative centers on how these painful experiences transformed her ability to empathize, giving her new perspective on life and managing loss. She explained:

... You have an empathy and way of seeing the world that is different from how it was before and it isn't anything that you could ever, you would never know ahead of time how it will make you different, it's not anything you would ask for, but when you've been through that you understand that it was, like you say transformative, a life changing experience and it's not for the bad, it's for the good that you had to go through that to get there and maybe there's no way to get there without going through something like that in some way, some kind of a loss or uncertainty.

In this excerpt Louisa describes how the development of empathy after uncertain life experiences, the death of her spouse and breast cancer, were life changing and trying, but "for the better." Both these experiences gave Louisa different perspectives that through her allusion to a journey result in being somewhere else, or in the embodiment of a different state. This conceptualization is a way to make sense of a seemingly senseless, uncertain experience. As such, transformation narratives whether centered on developing courage, altruism, or empathy construct the breast cancer experience to be a learning opportunity. Through this learning opportunity women shed the feminine qualities that are less favorable for those that are highly valued both within pink ribbon culture and mainstream society. These include: shedding vanity for courage, selfishness for altruism, and development nurturance through empathy. Through these experiences, and the narratives that describe them, a very particular image of a breast cancer survivor emerges. Touching, transformative stories where women are able to see breast cancer as a mechanism of self-improvement are highly valued within the survivor hierarchy. Not

only because these stories resonate with other survivors and breast cancer supporters, but because they help to change the understanding of breast cancer from a deadly disease to a personal challenge that leads to great self-awareness and self improvement (Ehrenreich 2009). To be a breast cancer survivor requires more than literal survival, it requires the adoption of a transformation narrative.

This does not mean, however, that all breast cancer survivors tell stories of positive personal transformation. Yet, those stories are much less visible and do little in the way of promoting pink ribbon culture or the survivor hierarchy because they expose an experience that was not as personally enlightening and fulfilling, as it was emotionally and physically painful. Additionally, these contrary stories break away at the façade created by pink ribbon culture and reveal the survivor hierarchy to be a mechanism of control that creates competition and guilt among survivors.

While most women in my study shared stories of personal transformation after breast cancer, not all of the stories were positive. The survivor subject position is, in many ways, accessible only to those who adhere to normative post-cancer embodiments. One telling example of the power of the survivor hierarchy emerged in Lily's story. Lily was 33 and a mother to young daughters. For years she had worked as a server at a local diner until her breast cancer diagnosis and treatment left her unable to keep up with the demands of the job. As a result of losing her job and struggling to pay for breast cancer treatments with no insurance, Lily and her family experienced a great deal of financial hardship. This caused strain on her marriage and added unneeded stress to her life. For these and other reasons, Lily's attempts to tell a positive story, by emphasizing newfound religion, were betrayed by her tears. Lily internalized that her story *should* report positive

feelings and a sense of gratefulness for having survived breast cancer; yet, she struggled to get to that point.

I feel like I should be grateful and I'm having a really hard time with my emotions and stuff because I feel like um, that I should just be thankful. You know? I just...(crying) like, I'm having a hard time even dealing with that to figure that out like inside of me. So I just...I just live with this you know like...I cry and feel like I'm having a pity party.

Lily recognizes that her emotions conflict with the dominant narrative. She feels as though she should be grateful, and her story should reflect that, but her lived experience conflicts with that. Instead, she feels guilty for crying. Breast cancer permanently changed her body, has changed her marriage and family dynamics, cost her financial stability, and because of that she struggles to tell a story about a positive personal transformation. She feels guilty about this. Lily's recognition that she should tell a particular kind of story, and her feelings about not being able to do so, reveal the toxicity of the survivor hierarchy

The dominant narrative circulated through pink ribbon culture is damaging because of the positivity it insists on. Survivorship becomes an experience characterized not by embodiment, but by the espousal of certain criteria, which revolve around transformation. Further from her diagnosis Lily's story might change. She may reflect positively on her experience and cite the struggles she faced as necessary hurdles to get to an ideal state, but at the moment of our interview Lily recognized the imperative to tell positive stories and felt badly about her inability. This represents the façade of the survivor hierarchy created by pink ribbon culture. When women feel compelled to tell particular types of stories about their experience with breast cancer the stories stop creating awareness. Instead, they uphold the dominance of particular experiences and

support the limited understanding of breast cancer put forth by pink ribbon culture, to no fault of their own.

### ***Conclusion***

This chapter used narratives about three components of survivorship to argue for the existence of a survivor hierarchy within pink ribbon culture. Stories that confirm survivorship demonstrated that the embodied experience of hair loss due to chemotherapy is a litmus test of breast cancer survivorship to the extent that others challenge women who did not lose their hair. Stories about the work of survivorship focused on prevention and management of lymphedema. These stories revealed that the survivor hierarchy values prevention of lymphedema over living with lymphedema because pink ribbon culture espouses the importance of awareness and screening over the difficulties of living with the complications associated with breast cancer. Finally, stories about survivorship transformation contribute to the dominant narrative, which constructs breast cancer as an opportunity for self improvement. These narratives support the hierarchy by highlighting women's perceived personal flaws and finding recourse through breast cancer.

All of the stories shared with me contain components that support the survivor hierarchy, but also contain the tools for its destruction. Without directly acknowledging the discursive control the survivor hierarchy has over their narratives and their experiences, the women in my study shed light, however tacitly, on the problems of pink ribbon culture when they critique mainstream breast cancer organizations ad campaigns, demonstrate ambivalence about the survivor identity, mention the overabundance of the pink ribbon, and when they arrange for representatives from National Breast Cancer Coalition to speak to the members of the support group. All of these acts of resistance

break down the survivor hierarchy by showing different ways of being in the world and different articulations of breast cancer as a cultural force and embodied experience.

Breast cancer is both a gendered disease and a disease that challenges the embodiment of gender. As such, the dominant narratives produce a way of being a breast cancer survivor that maintains the status quo associated with gender embodiment while also providing a recommended path for that experience. As such, pink ribbon culture as a whole reinforces the organizing principles set up by the gender system. It produces a subject position accessible only to those who adhere to normative post-cancer embodiments. The legitimate breast cancer narrative rejects some components of femininity and adopts masculine strategies for survival all the while insisting that women perform femininity properly and undergo a transformation brought on by breast cancer.

Ultimately, the narratives reveal the façade surrounding pink ribbon culture by showing that women acknowledge the ways their experiences are ranked and yet participate in the ranking to varying degrees. This denaturalizes the notion of a given breast cancer experience accompanied by a particular breast cancer narrative. Finally, the narratives featured here demonstrate that the body is both a conduit for the transference of pink ribbon culture and also offers potential for change. Change comes from the articulation of embodied difference in narratives that run counter to dominant pink ribbon cultural narratives. When breast cancer is understood to be a complex, multifaceted disease because women's stories are complex and multifaceted a new image of the disease will emerge. One way this can be accomplished is through revelation of the various objects involved in breast cancer survivorship. The next chapter will focus on strange and familiar objects and the relationships between survivors and these objects.

#### CHAPTER 4: THE PROMISE OF STRANGE AND FAMILIAR BREAST CANCER OBJECTS

*“I do the Komen pink ribbon thing, I dress in pink in October when I go out to do a presentation for something, I pull out the pink stuff and everything because it's the way people recognize that you're representing the organization or whatever. Um it's also a way to, to find and see and identify other people who've had some sort of experience most likely with breast cancer.” -Janet*

The pink ribbon is perhaps the most recognizable object associated with breast cancer. As Janet describes, it conjures associations with particular organizations, dominates the visual landscape in October, and symbolizes a shared experience. To be sure, the pink ribbon does a great deal of work. The ease with which it is recognized and associated with the breast cancer movement allow it to be a literal brand that creates linkages between it and the object it adorns—ultimately blurring the lines between commodity and cause (Sulik 2012).

The commodification of the ribbon and the breast cancer cause is what Charlotte Haley—creator of a peach breast cancer ribbon, feared when Estee Lauder and *Self* magazine approached her in the early 1990s (King 2006). Haley’s ribbon came with information and statistics about breast cancer and urged readers to contact their legislators (King 2006). Without Haley’s permission to use the ribbon and her format for dispersion Estee Lauder and *Self* turned the ribbon pink (King 2006). In many ways, the trajectory of the pink ribbon represents the trajectory of the breast cancer awareness movement, and now, pink ribbon culture. At its core, pink ribbon culture is a commercialized, commodified endeavor to raise funds for high profile organizations. It follows that the objects that visually reinforce those associations are most prominent. Yet, this means that the pink ribbon hides the objects that aid in actual survivorship. In other words, the pink ribbon displaces the material components of survivorship by shifting the

focus back to awareness, prevention, and hope, which are organizational concerns, instead of the lived reality of breast cancer.

While the pink ribbon carries the breast cancer brand it is scarcely the only object that evokes survivorship. There are *familiar* objects, like the pink ribbon, mammogram machines, pink rubber bracelets, and a mass of other products; and there are *strange objects* like breast prosthetics, implants, wigs, and lymphedema sleeves. The former objects are commodified goods emblazoned with the pink ribbon whereas the later are largely concealed, or intended to conceal the suffering body in some way, and border on the uncanny. These objects are *like* the body, but not quite. Yet, these are the actual, material, components that aid in the lived experience of survivorship.

Both pink ribbon commodities and cancer artifacts are informed by pink ribbon culture and inform embodiment. Yet, the visibility of these objects differs. Those that offer the promise a cure—pink ribbon commodities—are highly visible both commercially and culturally. They are intentional outward signifiers of belonging, the breast cancer cause, and philanthropy (King 2006). Those that offer the promise of normalization, or a return of the body to its pre-cancerous state, are much less visible, and intentionally so. The promise of normalization relies on concealment of those efforts. Throughout this chapter I will demonstrate that the promise offered by both types of objects can never be fully realized. Both sets of objects offer the user a potential. This potential takes the form of finding a cure for pink ribbon commodities and of returning the body to a prior state for cancer artifacts. Consequently, the objects offer a promise to the user to meet the expectations associated with purchase and use, respectively. The expectations vary depending on the particularities of each object but the agreed upon

meanings associated with each object provide the user with an indication of a potential for change.

Analysis of the objects that inform breast cancer survivorship is important because the relationships survivors have with both cancer artifacts and pink ribbon commodities speak to the ramifications of pink ribbon culture on lived experiences with breast cancer. It offers a different take on the day-to-day experience of survivorship outside of the celebratory nature of pink ribbon culture. In this analysis the allure of pink ribbon cultural narratives is traded for narratives that expose the messy reality of life as a breast cancer survivor. In order to maintain interest in ending breast cancer women's narratives about the contradictory, often-uncomfortable components need to be centered lest the problems with breast cancer appear to be solved.

Objects can no longer be neglected from analysis of the social world. Whether through exhibitions of material agency (Pickering 1995), using objects to think with (Turkle 2011), or understanding the gendered nature of many daily use objects (Kirkham 1996) objects are, in many ways, materializations of the social world. Analysis of the role and use of objects in cancer culture, more broadly, and pink ribbon culture, more specifically, is especially lacking. With cancer conceived as both a material and discursive social phenomenon the day-to-day experiences of surviving and living with cancer can be subsumed under material or symbolic understandings.

Both strange and familiar objects play important roles in the material realities of breast cancer survivorship. As such, the offerings of both strange and familiar objects require greater analysis and in-depth understanding. These objects are strongly intertwined yet their relationship to one another is rendered invisible by the cultural

construction of breast cancer put forth by pink ribbon culture. For one, survivors and supporters alike spend large amounts of money on cancer artifacts and pink ribbon commodities with the hope of finding a cure for breast cancer and repairing the body after breast cancer, respectively. These exchanges fuel the pink ribbon industry, which profits off of women's suffering. Accordingly, this chapter adds to the conversation started by Lorde (1980), King (2006), Sulik (2011), Jain (2013), and others by focusing on the material components of survivorship within the context of pink ribbon culture. Focus on body/object interactions and the strange and familiar ways these objects inform survivorship adds a layer of complexity to the discrepancy between pink ribbon culture and women's lived experiences with survivorship that has received little sociological analysis.

It is important to note, the distinction I make between familiar and strange objects is more descriptive than analytic. In fact, I argue that the truly strange object in pink ribbon culture is not the uncanny breast prosthetic or lifelike wigs, but rather the pink ribbon itself. I will demonstrate how *familiar* items like pink ribbon goods embody a strangeness that often goes without notice whereas *strange* objects like cancer artifacts are more familiar to femininity and body normalization than is let on. The division between strange and familiar objects is arbitrary but based primarily on the intended visibility or invisibility of the objects, their role as commodities, and the symbolism attached to each.

It would be remiss to assume that breast cancer survivors are uncritically supportive of the deployment of the pink ribbon or pink ribbon culture for that matter. The strangeness of these familiar objects is made visible through women's critiques.

Janet describes the pink ribbon as a “marketing tool.” She explains, “It is what it is. I don’t go around wearing lots of pink ribbons all the time.” This acknowledgement, general acceptance, and a rejection of the prevalence of pink ribbons indicate the dual nature of this particular object. The ribbon is a recognizable symbol and as such, a marketing ploy, which is problematic for some survivors. However, the practice of creating recognizable brands for charitable causes is the current form of philanthropy and the crux of pink ribbon culture (King 2006). Sandy reiterates this multiplicity and ambivalence about the marketing components of the ribbon. She explained:

I don’t think it has the significance as it maybe once did. I think people see a pink ribbon and they know what it means. I think it’s still good, I don’t think it should be done away with. I think it’s kinda trite. I don’t want to say overused, but maybe in a way it is.

The pink ribbon is many things; both overused and still important. This ambivalence circulates through women’s narratives and the relationships they have with various familiar and strange objects. Both types of objects offer promises to the public and the women who engage them.

### ***Familiar Objects: The Promise of a Cure***

Familiar objects, pink ribbon commodities sold under the guise of promoting research, creating awareness, or fostering hope, offer the promise of a *cure*. Their familiarity whether due to being an existing product, like a bag of chips branded with a pink ribbon or a fashion accessory, mark these objects, incorrectly, as apolitical and thus *safe*. Their affective power, the “stickiness” of these objects (Ahmed 2004) is nonthreatening and produce feelings of empowerment, altruism, and philanthropic goodness. Essentially, familiar objects are the regular, everyday things we use often, rebranded to support the breast cancer cause.

Familiar objects rebranded to offer *hope* signify that work is done to combat breast cancer in some way. They are aesthetically pleasing and often play into the conflation of health and beauty (Guthman 2011). Here, aesthetically pleasing goods allow consumers and breast cancer supporters to access to the survivor subjectivity through consumption and beauty. As such, through consumption non-survivors and survivors alike can help find a cure. Yet, the reality of the path to a cure is elusive and the promise of a cure is not realized in any material way. However, the power of *hope* suggests capitalism has the power to cure breast cancer. This is demonstrated through pink ribbon events like the Race for the Cure.

The 2014 Race for the Cure was like others before it. In addition to the race itself, there were booths set up selling pink ribbon goods, a special tent for survivors, and various speakers throughout the day. Booths featured pink ribbon themed jewelry, knick-knacks, and clothing. One t-shirt vendor sold a memorable pink camouflage sweatshirt that read “hunting for the cure.” Access to these goods was not limited to breast cancer survivors; rather, supporters were encouraged to partake and show their support through consumption. This allowed race participants and observers access to not only the survivor identity, but also the altruism of philanthropic giving (King 2006).

The familiarity of objects sold at the Race for the Cure was compounded by the strangeness of their distance from the embodied condition of breast cancer and women’s experiences with the disease. At the Race survivors were given a free pair of earrings, free snacks, free massages, and were welcome to take the scarves and earrings decorating the tables in the survivor tent. Alice, a support group staple, gave me a scarf donated by Ford as indicated by the “Warriors in Pink: Powered by Ford” printed on one end. Any

connection between pollutants produced by cars manufactured by Ford and breast cancer was absent.

The automaker made another appearance through sponsorship at the Komen Tea. Bob McCosh, a local car dealership sponsored many of the goods available to those attending the Komen Tea in April of 2015. Included among the free goods were a pink cup with a lid and straw, a pink ribbon pin on a piece of paper that read, “Imagine life without breast cancer. It’s a vision we all share. With your help, this ribbon will make it a reality. Show your support. Wear it proudly.”

The note accompanying the pin suggests the ribbon itself can help make “life without breast cancer...a reality.” This object, a pink ribbon pin, embodies the responsibility of ending cancer without any evidence that merely wearing it will create change. This all too literal analysis of the ribbon sheds light on the strange ways that objects are used in pink ribbon culture as a stand-in for action and change. The mass of pink ribbons, argued to help make the eradication of breast cancer a reality, lend to the idea that breast cancer can and will be eradicated through the altruistic actions of caring people and corporations (King 2006). Making the statement, essentially, makes it true despite lack of evidence and the absence of a clear path from the point of purchase to changes in science and medicine. Consequently, the familiarity of this object, and others like it, hide the embodied experience of breast cancer.

Other objects given away at the Komen Tea included a pink Komen pen and Komen for the Cure tissue with a sticker that read, “Get screened.” All these goods, fairly mundane daily objects, bore the mark of the organization which cemented their connection to the breast cancer cause, but not the embodied condition of breast cancer.

Their familiarity masks the strangeness of the association of pink objects to disease and the ribbon normalizes this connection and the commodification of both the cause and various objects.

Strange and familiar objects were also prominent in support group oriented events. For the past five years, Barb, a support group attendee organized get-togethers to paint ornaments. The goal was to sell the ornaments and donate the proceeds to Ellis Fischel's mammogram program. In 2015 and 2014 the group painted white ceramic purse ornaments with small (pink) ribbons on the corner, a change from prior years where they painted a white ceramic ribbon. Barb and her sister purchased all the blank ornaments, for about \$3 each online, in addition to the paints for this project. Ornaments are sold for \$10, but in 2014 Barb had difficulty finding a place to sell them. In 2015, a local boutique agreed to sell the ornaments and host a painting party for group members and store patrons. Ornaments are dedicated to women with breast cancer and hung on Christmas trees in local cancer treatment centers.

The purse ornament carries significant symbolic weight in addition to the material work it accomplishes. The ornament itself is a representation of a highly gendered object: the purse. The purse ornament also reflects the pink femininity Sulik (2011) describes as a combination of the "softness, innocence, dependence and virtue of girlhood and true womanhood" with the dangerous "qualities of independence, cunning, and manipulative seduction." The ornament combines all the components of idealistic, particularly white and middle class femininity with the economic savvy to provide access to screening procedures for low-income women. The astuteness of the plan is not marred by the femininity of the objects, rather the juxtaposition points to the ways pink ribbon culture

makes use of white, middle class femininity while also requiring participants to exhibit masculine traits associated with the market and medicine (Sulik 2012).

The purse ornament offers the promise of a cure through early detection coupled with middle class whiteness. It allows middle class white women to solve their own problems through consumption all the while drawing out and reproducing common reductionist notions of womanhood. The purse is connected to breast cancer by the ribbon already in place and by the women that paint them. Through these material connections it becomes a conduit that transfers consumption as a means of social change and also a way to allow for white, middle class altruism to benefit low-income women without physical contact between the groups. In this way, whiteness and white middle class femininity come to be the *cure* for low-income (often women of color) women's access to care. It does not require any structural adjustments to systemic racism, insurance, or medicine. Rather, goodness and care-work provided by white middle class women can save "other" women from the horrors of breast cancer. Thus, the purse ornament takes a *familiar* philanthropic path from the hands of middle class breast cancer survivors to the bodies of low-income women.

Like the purse ornament created in honor of a breast cancer survivor, many of the women in my study received breast cancer themed gifts at various times throughout active treatment and after. The gifts are often well received for the giver's thoughtfulness and attempt to reach out and are important during times of great uncertainty, yet there is a strangeness associated with the practice. Matilda brought up the gift giving practice during our interview.

Another, you know, weird thing, you know so all these people start giving you gifts and reconnecting with you and sending letters and how they felt like they

you know they felt bad they lost touch, you know family members start coming out of the woodwork, and they send these really beautiful wonderful things you know and you're not asking for it right, this is just happening... (Matilda).

After news spread that Matilda had breast cancer family members and friends she lost touch with attempted to reach out to her through gifts and letters. While Matilda appreciated the sentiments, she found the practice strange. Overall, the objects were familiar: cards, trinkets, hats, scarves, t-shirts, etc. but through decoration with a pink ribbon they were transformed into pink ribbon commodities. The strangeness in this practice lies in purchasing a gift that symbolizes breast cancer awareness for a person who has breast cancer. Through this exchange, the person with breast cancer becomes a commodity of sorts. Not only are they intended to wear or somehow display the pink ribbon good, but the givers connection to breast cancer, while not actually having it also becomes a currency in pink ribbon culture. Now the gift giver has a name to write on an ornament and a person to honor through a Race for the Cure. In pink ribbon culture these personal connections carry value beyond human connections. They provide a *justification* for pink ribbon culture and pink ribbon culture provides ways to sustain those relationships.

Pink ribbon gifts are complicated because, as Hana described, they are both reminders of cancer and that others care. Hana was given items like scarves, hats, other head coverings, gift certificates for food, and offers to help with childcare. While Hana appreciated all the gifts, the most moving was the friend who took Hana's husband out for drinks. It brought a semblance of normalcy back to their lives. However, the shared time outside of the house was not a commodity and would not be recognized as

supporting work towards the cure; although, it helped a family find grounding in uncertain times.

Like Hana's example suggests, the types of gifts or gestures most meaningful were often not directly related to breast cancer or lacked pink ribbon branding. Instead thoughtful gifts or gestures that could be shared with others were found to be most valuable. Janet shared a story of a blue bear given to her by a friend out of state:

A friend of mine who lived in Arkansas at the time mailed me a little blue fuzzy stuffed bear... When my port was removed and everything [the medical professionals] were really cool, they put it inside a plastic bag, a baggie really and I kept it in my room. So it was mostly because Pat was thinking of me. And ironically, she was later diagnosed with breast cancer. I had never been inclined to give my blue bear to anyone but when she was diagnosed I mailed it back to her and said it's your turn for blue bear. (Janet)

The blue bear was made all the more meaningful because Janet was able to share it with her friend Pat during her time of need. It was not that the profits from the sale of the bear were purported to go to breast cancer research. Instead, it allowed both women to recognize shared embodiment and find solace in that commonality. This object promises a connection to others, not the promise of a cure. At times, gifts and goods more obvious in their connection to breast cancer elicited a different response.

**Kay:** I've had my fair share of all of that. I think they're either up in the closet or down in a bag somewhere and lots and lots of pink t-shirts have been given to me with all the different sayings on. I just took a whole bag of those to The Wardrobe downtown the other day. It's like, okay, I don't need these anymore.

**Jenna:** Why don't you think you need them?

**Kay:** Good question, because I had some that I used to wear to the gym and I don't anymore. I don't want it like, "hey, here I am, feel sorry for me" or anything like that because I don't like that part of it... I have gotten rid of some of those type of things, t-shirts, teddy bears. (Kay)

Kay brings up a point reiterated by many women in my study: that outward signifiers of breast cancer, pink ribbon goods, might signal to others that the wearer

wants pity. Pity, from others or self-pity, were admonished and to be avoided as much as possible. Pink ribbon goods may signal or represent a desire for the cure, but in practice women were concerned they might represent a desire for others to feel bad for them. Superficially, pink ribbon goods offer hope for a cure, but by wearing and through conspicuous use they give information about the wearer. In this case, objects communicate different meanings when one had cancer and when one is a supporter. This does not mean that many of the women in my study did not like wearing, having, or receiving pink ribbon goods; rather, there was an ambivalent relationship with the objects.

***Strange Objects: The Promise of Normalcy***

*“The objects in this uncanny heap had served not merely as isolated stand-ins for a body, but as crucial conduits for some semblance of a social life, for a normalcy that was by no means assured” (Jain 2013: 203)*

Strange objects, like wigs, prosthetic and reconstructed breasts, and lymphedema sleeves offer the promise of a return to normalcy. They conceal a body disrupted by surgery, compress limbs swollen from lymphedema and hide heads bald due to cancer treatments. Wearing these objects in and on the body is an attempt to make the body *normal* after breast cancer. Yet, normalcy is predicated on the concealment of these objects. They should not be revealed, exposed, or left out lest the promise of bodily harmony put forth by pink ribbon culture is threatened. Consequently, the body after breast cancer is one that should reiterate surviving and thriving. To approach the world with one or no breasts, bald headed (permanently is much less accepted than temporarily), or with arms visibly swollen threatens the sustainability of pink ribbon culture and all that it celebrates.

Cancer artifacts (Jain 2013), those objects that offer the promise of normalcy, work on multiple levels. They signify health to the outsider, offer a point of commonality with other cancer survivors, and help form the wearer's various subjectivities (Jain 2013). All this is done under the guise of a return to normalcy, whatever that might be, after cancer. Of all the items contained in a breast cancer repertoire prosthetics and reconstructed breasts, wigs, and lymphedema sleeves present interesting cases where the promise of normalcy intersects with the body to produce versions of femininity that challenge and are challenged by pink ribbon culture. The narratives that women share about these objects and their experiences point to a complexity unaccounted for with the *promise* of normalcy.

The promise of normalcy is embodied in the use of internal and external prosthetic devices. Pink ribbon culture, prosthetic manufacturers, and medical professionals alike participate in the dispersion of this promise when forms of breast restoration are presented as the final stage of breast cancer recovery (Crompvoets 2006). While it may be the final stage for many women, breast restoration cannot compensate for the experience of breast cancer. Moreover, both prosthetic breasts and reconstructed breasts are accompanied by the imperative of concealment, feelings of ambivalence, and an opportunity for different embodiments. Consequently, relationships between women and their prosthetic and reconstructed breasts are complicated since the body and objects interact in ways that fail to approximate the norms constructed by prosthetic manufactures and medical professionals. The process is most often more complicated than expected, requires more surveillance than one is accustomed to, and creates anxieties related to body symmetry and stability.

When the women in my study shared stories about their prosthetic breasts they mentioned the materiality of the prosthetics and how they moved or did not move with the body. Ultimately, stories about prosthetics paint them as a sufficient but imperfect option. Breast prosthetics serve their purpose, for the most part, but the relationship between women and prosthetics is characterized by anxieties that result in intensive self-monitoring. However, the self-monitoring that accompanies prosthetic breast use is not much different from the self-monitoring associated with other components of having and being a feminine gendered body. The concealment necessitated by menstruation, biological breasts, menopause, and childbirth is like that required of a woman who lost a breast to cancer (Young 2005). Thus, prosthetics are strange, yet familiar, as women are socialized to expect a certain amount of strangeness in regard to breasts and bras.

The imperative to conceal the one-breasted body and prosthetic device manifests in self-monitoring that goes beyond the visual and seeps into the tactile. Alice, a 64 year old white retired teacher worries about others seeing and feeling her prosthetic.

I just always, I'm kind of careful to keep it away, I don't want my granddaughter...she's only like four and if she would just see it laying around... But, in fact its probably because my daughter in law asked me the other day about it, I don't know how it, oh I think its because I said, do you think, because I was concerned about that, giving people a hug, she said "I don't even, I never notice it, I don't even know which one it is, which one is it?" And then when I told her and you know she asked me what it looked like and I, you know, I showed it to her.  
(Alice)

In this quote Alice shares that she is careful to conceal her prosthetic from her granddaughter out of fear that it might frighten her and that Alice herself is worried that others can feel or "tell" which breast is the prosthetic. The importance of maintaining normalcy after breast cancer is not limited to visual normalcy; Alice's narrative points to the importance of touch as well. Concerns about the feel of prosthetics are not limited to

external devices, women with reconstructed breasts also reported that the feel of their breasts was strange and different. Elizabeth, a white woman in her mid 50s reported that the silicone implants she was given against her wishes felt like “memory foam pillows” and were left with “divots” in them when touched.

The materiality of Elizabeth’s silicone implants contradict with the tactile sensations expected of biological breasts and differ, also, from prosthetic breasts. Nonetheless, prosthetic breasts vary in weight, texture, and material, among other characteristics. Finding the right prosthetic breast is a challenge since not only is the breast area sensitive after mastectomy, but it is difficult to simulate one’s biological breast with human-made materials. Helen, a 68 year old, white, retired teacher articulated the dilemma between presenting a two-breasted body and contending with various discomforts associated with prosthetic materiality.

Well, I got one at Kilgore's and it was like I think it's made of silicone or something and it's so heavy so I never wear it. My daughter does wool felting and she wool felted me one that is very lightweight and I just shove it in the special bra. And maybe it doesn't look exactly like a perky form would look but its a heck of a lot more comfortable. And, I also found a form made out of just foam that I ordered from Walgreens that worked really quite well, but um you know your bra doesn't really fit quite right, it slides around and stuff... Well its not the greatest but you know, you...have to make choices.” (Helen)

Helen negotiates between physical discomfort with a prosthetic and the emotional discomfort of not wearing a prosthetic. Her daughter’s innovative breast form design, however, provides her with a way around some of those discomforts. The strangeness of these various and multiple interactions highlights the lengths to which breast cancer survivors go in order to embody a two-breasted form. The objects that accompany attempts at normalcy, like prosthetic breasts, require physical negotiation and the process can be derailed at any time.

Louisa, 60 years old, white, doctor of nursing had a lumpectomy and radiation for breast cancer. At first she decided to wear a prosthetic, but had to make due with alternatives after a health scare.

... I was fitted for a very high level prosthesis and I wore it for two weeks when I traveled overseas...and that's actually where that fibrotic came above the breast so I had to stop wearing it. It was too much weight, I think, and so there are other lightweight forms that you can use but they don't stay in one place so I just found it was better to not worry about that. There are probably products you can Velcro and wouldn't move, but it's not a good thing to be wondering if that's shifted. If you reach down to get something with that, it's shifted. So I've kind of just dealt with it more with what I wear. What I wear right now is a sports bra that supports the larger breast and makes them feel like and look like they are more equivalent and so I just try to address it through the style of clothes that I wear with the patterns so I'm not trying to look exactly like I'm symmetrical with something that doesn't show a pattern. (Louisa)

Louisa's experience with a prosthetic breast resulted in the development of fibrotic tissue ultimately resulting in further health scares and her decision to forgo prosthetics entirely. The material agency of prosthetic objects cannot be downplayed or ignored. Beyond merely creating discomfort, Louisa's prosthetic interacted with her body in way that caused harm. Since normalcy could not be guaranteed through prosthetic use, Louisa chose to mask the asymmetry of her breasts using clothing. This is not in and of itself a strange process; rather, it is a component of feminine embodiment which might manifest through padded bras, shape wear, or other garments intended to shape and mold the body into particular forms (see Young 2005 for more discussion).

Since reconstructed breasts have, in many ways, replaced prosthetic breasts as normalizing objects after cancer women who wear prosthetic breasts must contend with the invisibility of their experience. However, invisibility is both desirable and damaging. As Audre Lorde (1980) argued over thirty years ago, prosthetics hide mastectomied

women from one another. While this has negative connotations for those looking for support and commonality, it allows women to by-pass the stigma associated with the loss of a body part and the association with sickness, disability, and feebleness. External and internal prosthetics offering the promise of normalcy manifest much differently, but the strangeness of both are accompanied by a familiarity with the comportment required of feminine embodiment (Young 2005).

Reconstructed breasts offer the promise of normalcy, but embody the strangeness and familiarity also associated with prosthetic breasts. Many of the women in my study found that their reconstructed breasts do not look or feel “normal;” that is, like their breasts prior to cancer. Their form, shape, and aesthetics are the result of complex embodied and surgical techniques that can, and do, malfunction to varying degrees. Positioned as an easy solution to breast loss in theory—reconstructed breasts are contentious objects in practice.

The surgery (or surgeries) can be difficult, the recovery painful, and the final results may not match the breasts a woman had before or the breasts she desired with reconstruction. Nonetheless, the women in my study experienced varying degrees of satisfaction with their reconstructed breasts. Expectations of satisfaction and beliefs about the prevalence of breast augmentation informed at least one woman in my study. For Brianna, surgically enhanced breasts among women who had not experienced cancer were prevalent.

You know it wasn't too hard considering just about everybody has fake boobs now. Everybody's just like oh I'm going to get an implants done so I can be bigger. So it wasn't you know, its just like why not. So, it wasn't hard for me you know.

Brianna's sentiments articulate a desire for normalcy that coincides with normative femininity. Having large breasts through surgery or biology corresponds with gendered beauty expectations and women with breast cancer are not exempt from these cultural messages. As such, reconstructed breasts and augmented breasts have more commonalities than differences especially in regard to discourse about beauty, consumerism, and discourse about who has the *right* to beauty (Sullivan 2001). Both reconstructed breasts and augmented breasts are adopted in order to amplify or create normality where there is a sense of its lack (Davis 1991). Brianna insists on the familiarity of augmented breasts as justification for reconstructed breasts, but her lived experience with reconstructed breasts is an articulation of the strangeness of introducing outside material to the internal body. Brianna's experience demonstrates the unruliness of these objects making them just as unpredictable as the physiological body they are intended to normalize.

I had one of the breasts, it wasn't working right so we had to go back in. So I had a few different surgeries with that. And before that I had this one that would always want to go over here [the side of her torso] I guess from being pregnant. And it just got huge and so I had him sew that up to make it stay on this side cuz I noticed it, the expander, was wanting to stay on one side and it was wanting to go over here. So I said, "can you go in and stich that up?" So he stitched that up so it wouldn't slide that way, you know, and then you got the tubes and your drains and stuff you have to deal with and I didn't want to deal with prosthetics ...because to me it would just be a hassle to put em in a bra or have a bra that already had em and you know I'm like, no I'd rather just do the reconstruction and then be more normal (Brianna).

Brianna's reconstruction process did not go as planned. With myriad of difficulties, shifting expanders, and multiple surgeries it was a much longer process than expected. Her reconstructed breast's material agency was both unexpected and unaccounted for and Brianna attributes some of the difficulties to her body, "I guess from

being pregnant” and not the object. Despite the sliding and stitching Brianna maintains that external prosthetics would be a bigger hassle than reconstructed breasts. To a certain degree reconstructed breasts retain a normalcy, because of their placement inside the body and the lack of visibility that external prosthetics cannot maintain. Here, visibility lends to normalcy and a decrease in strangeness, but not necessarily familiarity, as Brianna’s reconstructed breasts are not much like those she lost to cancer.

Later in our interview Brianna revealed that because of these difficulties and the pain of surgery and recovery she slept in a recliner in her living room for three years. She had just begun sleeping in a bed with her husband again at the time of our interview. The desire for normalcy often cannot account for the roadblocks to that point. Within pink ribbon culture reconstruction is posited as the most normal option. It is understood to be an easy, although potentially painful, alternative to living breastless, one breasted, or with asymmetrical breasts. Yet, focus on the aesthetics by medical professionals and within pink ribbon culture displaces the embodied components of the procedure and thus the material agency of these objects.

The familiarity of reconstructed breasts is threatened by visual strangeness. Barb, a white, single woman age 46 at the time she was diagnosed made the decision to have reconstruction after suggestions from her surgeon. For Barb, the promise offered by reconstructed breasts was not kept in her lived experience. The visual discord between Barb’s biological breasts, the breasts she thought she would have after reconstruction, and her actual reconstructed breasts produced a great deal of dissatisfaction. Where normalcy and familiarity were promised: the objects themselves delivered a strangeness that left Barb, like many other women, regretful. Barb explained:

The implants are flat and they're big. They've got a big base. He's [her doctor] like "What size do you want to be?" Oh I don't know B or C. I was like an A or a B. He's like oh let's go up, why not? They don't tell you that the base, maybe they've improved, it's the base where all the weight goes. It doesn't look like a normal breast.

For Barb, the promise of reconstructed breasts and the reality of reconstructed breasts differ greatly. The shape, weight, and accompanying limitations were not part of the normalcy Barb desired or part of the promise offered by reconstructed breasts. She explained:

**Barb:** You think oh yeah, they'll look okay, well they don't. You lay down ... I work out a lot so my muscles are very strong. I can move them. I can sit there and I can move my implants if I press enough. I've really gotten strong. I can sit there and lay there and you can watch the implants just slowly...

**Jenna:** Like, rippling?

**Barb:** Yeah. Then one of them is really flat. God. They're just so ugly.

Barb explains that she thought, "They'll look ok" but found that her reconstructed breasts, "well, they don't." It is not only the visual; but movement and rippling that contributes to Barb's strong negative feelings towards her reconstructed breasts. Where pink ribbon culture marks reconstruction as the final stage in recovery and a signal of successful survivorship, Barb found that reconstructed breasts brought an unfamiliar and rather strange embodiment.

Kay articulated similar sentiments, although from a different perspective. Her years of experience as a surgical nurse placed her in situations where she often saw one or no-breasted bodies.

Like I said, I had seen enough of them over the years. It's just so flat. Sometimes when we would be operating on someone that had mastectomies, you could just literally see the heart beating underneath there if someone that's thin. I think it always made me sad to see other patients that we were operating on for whatever reason that had had a mastectomy that didn't have reconstruction, the scars. I think every time you look in the mirror, even now, with the reconstruction, they're not normal looking. They look normal in a bra or a swimsuit but they're not normal

looking (Kay).

The strangeness of a heart beating through a patient's chest with no breast tissue to cover it informed Kay's decision to have her breasts reconstructed. Yet, even after that she notes that her breasts are "not normal looking". When coupled with other objects, like bras and swimsuits, reconstructed breasts can be made to appear more similar to biological breasts, but without this integration these objects are more strange than familiar. For Kay, then, reconstructed breasts offered the promise of something more normal than the concave chests she saw during surgeries. Yet, even with lowered expectations Kay finds her reconstructed breasts lacking.

The importance of "looking normal" is not only the concern of breast cancer survivors. Reconstructed breasts promise a body like other women or in Sue-Jane's case, "other moms." Sue-Jane had not noticed that her children were in tune with her experiences, yet after reconstruction she learned one of her son's had been paying attention. She explained:

One thing that was interesting, my son was 8 when I did the reconstruction and I didn't think my kids paid any attention to stuff and he said, "Mommy I'm glad you had that surgery because now you look like all the other moms." And I was like...I didn't even think he paid attention. But kids at that age just want you to look like you looked. (Sue-Jane)

Looking the same before and after cancer is part of the promise of reconstructed breasts. The promise also encompasses an embodied familiarity that signifies the end of one's breast cancer experiences. However, the promise of reconstruction is never completely kept. It fails to account for material agency, body/object interactions, and the disconnects created by pink ribbon culture, medicine, and feminine beauty norms. Other objects, like wigs, offer promises for breast cancer survivors that differ in form and

function from the promises offered by internal and external prosthetic breasts. The difference in the nature of these promises is the temporary nature of wig use contending with the intended permanence of prosthetic use and reconstructed breasts.

Wigs offer a promise of hair restoration, beauty, and normalcy. They hide hair loss due to chemotherapy on one level and mask the sick body on another. Wigs are most often intended to be temporary solutions, a normalizing device worn until the body begins to produce its own hair again. Yet, selecting and wearing a wig are much more complicated than one might think. The promise of wigs, offered up by pink ribbon culture, wig manufacturers, the American Cancer Society and other powerful cancer organizations is particularly gendered. “TLC”, the American Cancer Society’s “Tender Loving Care” catalogue, offers an assortment of cancer artifacts. One of the selling points of wigs are “no more bad hair days” (Winter 2015:19). It goes on to suggest that wearing a wig will make the wearer, and others, smile (Winter 2015: 19). The imperative to smile, and makes others smile too, all while undergoing treatment for cancer, is a uniquely gendered component of women’s experiences with breast cancer. Making someone smile with a wig is to suggest that women’s body/object interactions are about more than making sick bodies appear well, but about upholding norms of gendered embodiment. Thus, wigs present a familiarity for their proximity to physiological body hair, but also strangeness for their uncanny resemblance and the power they have to reinforce gendered body norms.

Many of the women in my study reported that they had attempted to find a wig that resembled their hair only to find it strange and not quite right. The stories told about wigs revolve around fit, replacing hair, and the importance of appearing normal by

masking the sick body. Most women feel “ok” about their wig as long as others read their bodies as healthy, and along with that—beautiful. This comes in the form of others not recognizing the wig as a wig, usually by complimenting the new hairstyle.

The narratives surrounding wigs promise a return to normalcy at best and a mask for sickness in the least. Yet, women who wear wigs during and after hair loss must negotiate the complexities of picking out a wig, wearing a wig, and growing accustomed to it. This is often not an easy process. There is much fear and anxiety due to being exposed, in that someone will recognize it as a wig, fear of various mishaps including the wig falling off, blowing away in the wind, or merely unexpectedly shifting. Sandy found the experience to be initially traumatic. Not only did it force her to confront the sick body but she also had to confront the limitations of the wig promise.

In the beginning it's tough. It was for me. That was really traumatic for me. I hated that and because I was so paranoid about it. At the time Ellis Fischel had a wig room and you could go and get wigs so I went and I picked out a couple um, the best I could find because I had long hair. So I got long hair wigs, although they didn't have my color...and my hair used to be blonde. Used to be about the color of yours. And one was kind of a real, like an ash, whitey blonde and the other was red (laughs) but that's all they had. Most the others were gray, little old lady wigs. I was 46 at the time. So I took em home and I just felt so horrible and one day I decided I'm going to put one on and see how I look and it was horrible because I still had my hair and they don't fit right when you've got hair, they just, they don't fit on your head right. So that was pretty awful. (Sandy)

Sandy remembers her initial reactions to wearing a wig to be unpleasant. She was fearful that she would not look like herself. The wigs that seemed to resemble her hair the most were the least attractive and presented the most difficulties. Thus the promise of a wig to cover or replace one's hair is disconnected from many women's lived experiences with wigs. To recover from this many of the women in my study opted for wigs far different than their hair. This is something the “TLC” catalogue reiterates, explaining

“While losing one’s hair might be frightening, many women enjoy trying new styles and colors in a wig they would never have dared to try with their own hair” (Winter 2015:19). Wigs not intended to bear any resemblance to one’s hair allowed many of the women in my study to find pleasure and fun in the experience. Circumventing the initial displeasure associated with finding that a wig might resemble one’s hair but in reality fails to approximate it led women to shorter styles in different colors, often red.

Sue-Jane initially reported her hair loss to be traumatic due in large part to the fear she had for her young children at the time. The absence of her hair communicated sickness and mortality both difficult qualities to confront as a mother to young children. However, through wig use she was able to control the degree to which her body communicated sickness and allowed her to playfully engage with various wigs. Sue-Jane shared:

But my husband oh my gosh. He went on eBay and he bought 7 wigs. It was hysterical and like yah you're real supportive you're just trying to fulfill a fantasy here. So I had short, my favorite was about your length, had bangs, copper penny pageboy. That was a fun one. And then I had this fun one called Halle Berry, real frosted, it was fun. Then of course the others were long, but they were all synthetic (Sue-Jane).

Sue-Jane had several wigs of varying quality. The variety changed the relationship between Sue-Jane and her wigs. Instead of breaking the promise of a return to normalcy, the wigs promised playfulness, change, and difference. Kay reiterated the fun, and importance, of using wigs that differed from her hair and differed from one another.

Then, I had a longer dark wig that I think someone let me borrow, and then I had I think a red one too. I had fun with that. I tried to have fun with that and wear different ones. I kept the one that I actually bought. I still have it. That’s one of those things you can’t get rid of because I’m afraid I might need it again. If I get rid of it then ... Superstition I guess (Kay)

Despite the playfulness of having and using various wigs, the experience is not without the creeping darkness that comes with a cancer diagnosis. For Kay, fear of recurrence is exacerbated by the idea that letting go of a wig could bring about cancer. Kay, a nurse, did not believe that getting rid of her wigs would cause a cancer recurrence; rather, letting go of the wig meant letting go of control and preparedness. Having the wigs means she is prepared if she needed them again. Even when wigs are fun or pleasurable it is difficult to escape the embodied context that makes wigs feel necessary in the first place. Consequently, the fun or pleasure of wigs cannot be separated out from the strangeness of losing hair and replacing it with a wig or the association with sickness and death.

The anxieties surrounding wig use come in different forms depending on context. In hindsight the worry can seem unnecessary, yet for new wig users the uncertainty of wig stability can be overwhelming. Like other women, Kay was reaffirmed by an outsider's compliment.

I wore it almost all the time. Of course you're walking outside and it's windy or by a tree, you're afraid it's going to blow off or fall or a tree is going to snag it, stupid things like that, which doesn't happen but you worry about it. One day walking down through the hospital, someone that I would see but didn't really know each other at all, she goes, "Oh, you got a new hairstyle. It really looks cute." It was like, oh, thank you. You don't know what that just meant to me. Instead of, oh, what you got a wig on for? (Kay)

The fear and anxiety Kay mentions, particularly towards the end of her story references other's asking "what you got a wig on for?" These sort of intrusive questions require an admission of cancer to justify wig use, which places some women, those invested in masking their sickness, in precarious positions. Other's perceptions of the wig as hair are vitally important to making one's experience with a wig fit the promise of

wigs put forth by pink ribbon cultural narratives.

Although questions about or comments on one's appearance are not often welcome especially for those in precarious liminal states, on occasion an unsolicited comment about a wig, confused for one's hair, results in feelings of successful articulation of survivorship. Sandy shared a story of an incident that made her feel better about wearing a wig.

But, something happened that really helped me. The first day, the next day when I had to go to work with it everybody at work was so supportive, I was so lucky, but there was a guy that used to come to the lab and he kinda always had a crush on me, he was a person that um, like a sales rep type person so you didn't see him very often. But he had asked me out once and I had to say, uh I'm married. But anyway he was a nice guy and he used to come in. But he came in that day, he looked at me and he said wow I really like your hair and that just really made me feel good. Because he was an outsider and to this day I don't know if he really thought that was my hair or what. I'm sure he found out quickly that it wasn't because you know how the rumor mills in hospitals are, but it really made me feel better about it. (Sandy)

The sales representative's compliment to Sandy was meaningful for a number of reasons. First, he confused her wig with her real hair, which allowed Sandy to exist momentarily as a non-sick person. Second, through his compliment the sales representative reinstated gender dynamics that emphasize a woman's beauty, which is often strived for, but thought to be lost during cancer treatments. The perception of a loss of beauty and its importance to gendered embodiment is the motivation behind programs like "Look Good, Feel Better" and catalogues like ACS's "Tender Loving Care." Thus, his compliment is more than a personal affirmation of beauty—it symbolizes the object's potential to subvert sickness and reinstate beauty. Jane's experience with wigs and the complexity of the relationship between beauty and health supports this.

I got a wig, and wore a wig and people thought I had just cut my hair and dyed it and they just thought I was beautiful. And, you know like, oh my god you're

going to be so disappointed, but um, I didn't want to look sick. That was my main thing and I work in the public sector and I didn't want that stigma. (Jane)

Jane's story touches on a point others have not: that people may be disappointed if they find out her hair is, in fact, a wig. The key to successful articulation of survivorship as a wig user is that no one recognizes the wig as a wig. The wig offers the promise of reinstated beauty and normalcy, but there is always a risk that it will be revealed as a removable object and not physiological hair. The body beneath the wig is then revealed to be sick, which complicates gendered articulations of embodiment. While it does not, and perhaps should not, look like one's hair a wig can facilitate survivorship by circumventing the stigma associated with baldness, which signifies cancer.

These unassuming objects, wigs, suggest a layered embodiment that complicates dominant pink ribbon cultural narratives. The promise of a wig is always one that must be worked for rather than given. A wig has the potential to fulfill one's desires but it is done within the context of much individual emotional labor and requires that others participate appropriately. Another object, the lymphedema compression sleeve, also carries complex meaning and requires women to actively work for normalcy, and promises control over the unknown.

Rather than promising normalcy, lymphedema sleeves offer the promise of control over an unruly body with a little known condition. The lymphedema sleeve indicates a contingent survivorship that is worked for and constantly engaged with. The sleeve signals to women who wear them as well as others that there is still something to be concerned about. The women in my study who wore lymphedema sleeves conceived of the sleeve as bothersome, irritating, and even embarrassing. The visibility of these

objects means the strangeness of a swollen arm, intended to be compressed with this garment, requires continuous monitoring. The visibility of the lymphedema sleeve contrasts with the visibility of the pink ribbon in that the sleeve is a reminder of the long term effects breast cancer has on the body and the ribbon is a cover for all the lasting unpleasantnesses.

For those only peripherally involved with pink ribbon culture a lymphedema sleeve is a strange object. The noticeability of the sleeve—primarily when women wear short sleeve shirts, have colorful sleeves, use sleeves very different from their skin tone, or opt for garments that cover a portion of their hands— exacerbates the strangeness of the object. Since lymphedema is a little known condition outside of those who have lymph nodes removed due to breast surgery, these garments scarcely play a role in pink ribbon culture. Consequently, the women in my study lamented having to explain the sleeve to inquiring others. Louisa shared her experience:

I would say that for me it is the more visible thing, even when I was early on in the lymphedema treatment and you are bandaged 24hrs a day. I remember going to a ball game in the evening for my son and people were quite concerned that the cancer had come back. “Oh what's happened, why do you have this bandaging?” Well it was for the lymphedema, it wasn't for the cancer at all. It does raise alarm and when I meet the people who know just a little bit that you've been diagnosed with cancer or strangers want to know what has happened that your arm is bandaged like that. It raises conversation and you kind of have to be ready to publicly acknowledge what it is or have something to...practiced that you're ready to say so that it isn't an issue. [It] could come up any given day at a cash register or in a dress store or anytime so you just kind of need to not take that as a personal query as much as its an opportunity for educating someone because it is quiet possible they know somebody with a swollen arm, but now they know what it is that's causing that. (Louisa)

As Louisa demonstrates, since lymphedema remains a hidden, yet visible, component of life after breast cancer the presence of a sleeve draws out questions about the survivor body. Does it indicate a recurrence of cancer? Is it cause for concern? The

multiple embodied conditions that characterize breast cancer survivorship are, in many ways, dismissed by the rhetoric employed in pink ribbon culture. Successful survivorship exists outside of the many objects used to return the body to normal and regain control. Yet, objects like the lymphedema sleeve play prominent roles in women's daily lives and come to shape their experience not only in the present but also in the future. Living with lymphedema, and taking part in the recommended treatments, means managing the inflicted arm with a compression sleeve. While these objects offer a promise of treatment; medically, they also offer a promise of abnormality for the women that wear them. As Louisa demonstrates, explaining one's body to others becomes part and parcel of the experience. It can also require women to educate others on the condition, explaining their body to friends and strangers alike.

The sleeves are noticeable, more so once one's attention has been drawn to their existence, often coming in shades of beige that do not quiet match anyone's skin tone or lively, colorful patterns which are not intended to blend in. However, the sleeves lack widespread cultural recognition rendering them unfamiliar to those not embedded in the world of breast cancer. Hana shared a story about a stranger that came up to her, having noticed her sleeve, and said with a knowing look that they knew what it was: a Japanese driving sleeve.

Pink ribbon culture does not adequately address lymphedema sleeves because they directly conflict with recovery and survivorship narratives. The double play of visibility and invisibility of lymphedema sleeves reflects the incompleteness of dominant narratives, masking of the body after breast cancer, and a lack of knowledge of the items that facilitate survivorship.

The desire for normalcy after breast cancer, among individual survivors and society, is reflected in the situations women are faced with while wearing a lymphedema sleeve or with a swollen arm. Louisa, a lymphedema expert, explained:

I think about society and how we respond to either someone wearing a sleeve or not wearing a sleeve or having a swollen arm and it being so visible. I don't know that I think of it in terms of beauty so much as normalcy maybe, that um we see something different and we don't want that to be different so we hide it or we say they can't wear a sleeve because it would draw attention to it and it's not the best thing for them or for people in general.

Here, Louisa references a story she told earlier in our interview about a woman whose employer barred her from wearing a lymphedema sleeve. The woman served Louisa at a restaurant, and being both a breast cancer survivor, someone with lymphedema, and a lymphedema researcher Louisa recognized her swollen arm immediately. The two women briefly discussed their shared condition and Louisa found that the woman was not allowed to wear her sleeve, which led to her noticeably swollen arm. Louisa explained that this resulted from a fear of difference and a widespread desire for normalcy. As such, the lymphedema sleeve, while intended to create normalcy—to compress the arm and regain control—indicates an embodied difference that threatens various components of our collective understanding of the body after breast cancer.

Failure to recognize and accept bodily difference renders women's bodies abnormal after breast cancer. The lymphedema sleeve then becomes not a medical device intended to control swelling and hopefully prevent infection, but a signifier of abnormality. Lack of knowledge about bodies, in general, lymphedema after breast cancer, and the sleeve are all symptoms of the masking achieved by pink ribbon culture and its dominant narratives. Since this phenomenon, which impacts approximately 2-6% of women who had sentinel node biopsies (Love 2010), is largely hidden many women

are self-conscious about their swollen arms and the sleeves intended to ameliorate that.

Kelly shared:

Because it is very possibly a life-time thing and it doesn't seem, I don't know how much you can tell, but it doesn't seem to matter if I wear a sleeve or I don't wear a sleeve, it always, it swells and I feel self-conscious about it. I've had some people say "well I didn't even notice" well I sure notice...

In Kelly's experience the sleeve does not seem to make much of a difference in regard to swelling. Consequently, the promise of the lymphedema sleeve is not realized. The strangeness of the sleeve is met with the strangeness of her arm that swells without warning. As Kelly mentioned, for now lymphedema is a lifelong condition that can occur at any point after the removal of lymph nodes. There is an air of uncertainty that circulates around lymphedema since it lacks the familiarity of conditions that biomedicine promises to cure. Questions about if and when one might develop lymphedema are only compounded by the general lack of knowledge of the condition and the objects used to manage it.

Lymphedema sleeves are physical reminders of cancer and a largely invisible, or unknown, condition associated with breast cancer. The duality of lymphedema sleeves makes the relationship between gender, bodies, and objects additionally complex. The promise put forth by lymphedema sleeves reflects the absence of this part of breast cancer from dominant pink ribbon cultural narratives.

### ***Conclusion***

Pink ribbon culture offers a plethora of objects as symbols of hope, the search for a cure, and personal strength. Yet, as this chapter demonstrates these objects offer a promise that can never be fully realized. Moreover, the realm of pink ribbon cultural objects is limited and often dismissive of the objects that promise bodily normalization—

the very objects that do the work of maintaining the recovery narrative so important to pink ribbon culture. Throughout this chapter I've discussed pink ribbon commodities and cancer artifacts as both strange and familiar. And while each grouping of objects offers some sense of familiarity and strangeness, the pink ribbon itself embodies these characteristics. Its sole purpose is discursive, rendering its power and characteristics strange. As an object it encompasses far too much. However, it is culturally resonant and lacks the strangeness of objects intended to replace or approximate missing or damaged body parts. It allows breast cancer to be separated out from the body, to be reified, as an ethereal *thing* that can be ameliorated, cured, and gotten rid of forever with enough money, research, and support. Other objects, like prosthetic and reconstructed breasts, wigs, and lymphedema sleeves firmly root breast cancer back in the body. Focus on these objects, and their promises, highlights just how much work is done in pink ribbon culture to separate the body from the cause.

The promise of a cure, embodied in the familiar objects associated with pink ribbon culture and found at pink ribbon events leaves much to be desired when examining the lived experience of breast cancer survivors. Emphasis on the cure is a political distraction from the realities of life with, and after, cancer.

The promise of normalcy, juxtaposed against the promise of a cure, accomplishes similar goals. Through distance and distraction the lived experience of having and living with cancer is displaced. Emphasis on normalcy constructs the body as a static entity that can and should be repaired in order to approximate a former state. This is problematic for numerous reasons, but it also reflects larger social and cultural values that emphasize bodily wholeness while disavowing illness and any form of disability.

## CHAPTER 5: CONCLUSION

*“I hoped becoming a survivor was the end. It wasn’t.”*

Near the end of my participant observation the support group organizer, Sandy, asked if I would share my findings with the group at the August meeting. I was honored and humbled by her request. During the talk I explained my project, the overall process, gave some background information, briefly touched on the sociological literature, and gave a synopsis of the chapters and my arguments. I shared what I hoped my research would accomplish and solicited their questions and comments. The feedback was positive and the group members seemed to especially enjoy the discussion of objects. But, overwhelmingly, the questions centered on notions of survivorship. One woman voiced the quote at the beginning of this chapter. For many of the attendees, survivorship seemed like a temporary status, but over time was revealed to be an ongoing process. The disconnect between the experience constructed by pink ribbon culture and women’s lived experiences with breast cancer was revealed once again during our conversation.

For better or worse, pink ribbon culture has helped to transform survivorship from a temporary marker to a historically and culturally contingent subjectivity that bears the mark of neoliberalism. Survivorship is at once a socially embodied phenomenon replete with pre-existing connotations and connections and something that emerges and comes into being within each new breast cancer case. The complexity of survivorship, and ramifications of occupying this position, make pink ribbon culture an entity not only worthy of study, but also critique. Moreover, the ways it supports and makes use of neoliberalism should be problematized and examined as it contributes to ever increasing inequality.

Through the preceding chapters I sought to demonstrate the myriad of ways women's lived experiences with breast cancer differed from the construction of breast cancer created by pink ribbon culture by analyzing various modes of survivorship. I addressed how pink ribbon culture perpetuates erasure and limits understanding of breast cancer in medical encounters and during pink ribbon events. The result of this erasure is a normative breast cancer experience that reflects neoliberal ideals regarding health as an individual responsibility. I also attended to the ways survivors make sense of embodiment in light of an emergent survivor hierarchy. In this chapter I showed how women use their narratives to uphold and challenge the hierarchical ranking of breast cancer experiences by focusing on the stories survivors' tell about hair loss, managing the risk and condition of lymphedema, and how they frame their experiences as positively transformational. Finally, I offered a discussion of how cancer artifacts and pink ribbon commodities inform the embodiment of survivorship. I explain that these objects are both strange and familiar and promise a path to a cure and a normatively gendered body, respectively. My analysis reveals how pink ribbon culture separates the body with breast cancer from "breast cancer" the cause through pink ribbon commodities. Taken together these chapters create a picture of breast cancer survivors, breast cancer narratives, and American pink ribbon culture in which they are couched.

Discussions of objects are weaved throughout these chapters, but dominate Chapter 4. The excerpts from interviews and participant observation often feature objects like wigs, lymphedema sleeves, and pink ribbon commodities. This theme is my primary contribution to works like Sulik's (2012), King's (2006), Jain's (2013), and Frank's (2013). Attending to the various ways objects inform embodiment gives greater insight

into how illness narratives serve both individual and cultural purposes. That is to say, focus on objects allows us to understand and navigate the world of illness by centering the techniques that make the sick and recovering body possible. Through my analysis it is apparent that breast cancer survivors are responsible for not only maintaining survivorship through any means necessary but also that their survivorship serves external purposes.

Ultimately, breast cancer survivors are asked to ease our collective conscious through their survivorship. They are asked to accept erasure, support the survivor hierarchy, and normalize their bodies with cancer artifacts while also proudly displaying pink ribbon commodities. Breast cancer survivorship serves several cultural purposes. On one level breast cancer survivorship exists for the individual as a marker of an embodied status. On another level, and perhaps it's most prominent feature, survivorship exists for those without breast cancer. Survivorship—the narratives, the embodied conditions, and the material components—exists so that women with breast cancer can ease the conscious of those without cancer. In essence, breast cancer survivors are tasked with comforting deep-seated anxieties about the nature of the social world, the environment, medicine, and the American family. In a cultural climate in which society seems to be on the verge of crisis breast cancer survivors assure the collective that everything is “ok.” Survivors do this by preserving feminine gendered bodies, telling particular types of illness narratives, and looking to the market for a cure. Through these activities breast cancer survivors become beacons of hope for their families, people in their communities, and others in general. This is not to say, however, that breast cancer survivors are individually responsible for this; rather, the *burden* is placed on them through their survivorship and

domineering neoliberal policies and practices. The distinctly neoliberal qualities of American pink ribbon culture exacerbate the gendered responsibility of nurturing and calming the collective fear of crisis that breast cancer survivors undertake.

My analysis provides important commentary on the intersections of culture, gender, and health. These ideas are woven throughout the chapters to create a picture of breast cancer that is more holistic and much more complicated than that which is presented in pink ribbon culture. The simplification of a complex experience serves several purposes. Most important, for the project at hand, is the use of women's bodies and stories to comfort and ease cultural anxieties. Filled with joy, eternal hope, and positivity, pink ribbon culture in America is the antithesis of the lived reality of breast cancer for many women. This disconnect serves the patriarchal commodification of women's bodies and experiences in order to (re)produce the status quo. The ribbon itself is a paradoxical symbol for an experience that remains characterized by uncertainty, inequality, and a compromised day-to-day survival.

This project, and others like it, is important for several reasons. First, it challenges dominant narratives and thus the dominance of pink ribbon culture. By calling into question the taken for granted components of pink ribbon culture, this project like King's (2006) and Sulik's (2011) makes space for alternate stories and thus alternate embodiments after breast cancer. Dismantling the façade surrounding pink ribbon narratives translates to a wider range of accepted post-breast cancer bodies. By doing that, I sought to minimize the harm related to the lasting stigma associated with breast cancer and, hopefully, other cancers as well.

Second, this project demonstrated how value-laden cultural norms are felt not only in women's narratives, but also in the very embodiment of breast cancer survivorship. My study showed how women's ideas about the body after breast cancer informed how they wanted and expected their bodies to look after breast cancer. Other scholars (King 2006, Sulik 2012) have devoted more time to analyzing the corporate connections to pink ribbon culture to the extent that there can be no denying the ways corporate entities (those funding breast cancer organizations) influence treatments for breast cancer and how women exist in their bodies afterwards.

Finally, this project highlights the value of unpacking the seemingly ordinary. By treating pink ribbon commodities and cancer artifacts as both strange and familiar this project challenges the appeal of pink ribbon commodities while destigmatizing the objects, and work, that goes into maintaining the survivor body. This is important because, as I have demonstrated, the material components of survivorship are largely hidden which results in not only feelings of inadequate survivorship (demonstrated by the survivor hierarchy) but also perpetuates stigma associated with disability and the loss of body parts. Moreover, questioning the value of pink ribbon commodities contributes to discussions of the ways capitalism and neoliberalism, under the guise of promoting awareness, subsume the breast cancer cause in order to profit from sickness.

This research can spur multiple future projects. Primarily, it provides a jumping off point for analyzing other cancer narratives and embodiments. The dominance of pink ribbon culture means that it is likely to influence how those with other forms of cancer tell stories and experience their bodies. This would allow sociologists and medical

professionals to better account for patient's experiences in light of powerful cultural influences.

This project also provides justification for additional studies of objects that aid in survivorship. There remains a dearth of social science research on cancer artifacts and my chapter only begins to detail the importance and complexity of the body-object relationship and the implications of continued ignorance surrounding the survivor body. Similarly, more data from events like the mastectomy fitter training class would provide a unique perspective on the ramifications of a surgical phenomenon that is becoming obsolete due to the growing prevalence of breast reconstruction.

Based on the evidence and examples presented here, this research could be useful to professionals in several areas, not limited to sociology. First, health care practitioners would benefit from acknowledging the ways pink ribbon culture is lived in and through survivors' bodies and their stories. This has the potential to change the way practitioners interact with patients and inform not only patient's experience with breast cancer, but also how they live as survivors. Support group facilitators and organizers would benefit in a similar way. Unpacking the dominant narrative with and for support group attendees would allow survivors to see themselves as part of something larger, but also acknowledge how the prevalence of certain types of stories over others is detrimental to survivorship. Finally, breast cancer organizations would benefit from re-evaluating how they present the survivor body, the impact of the events they sponsor, and using an intersectional lens when creating campaigns and looking for solutions to their cause.

As long as women's bodies remain the medium that assures us that "everything is ok" breast cancer will continue to be a conduit for race, class, and gender based

inequalities. For this, and other reasons, continued feminist research on breast cancer, and other less frequently studied cancers, is important.

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## APPENDICES

### INTERVIEW GUIDE

#### **General:**

- Education level
- Career
- Marital status
- Children?
- When were you diagnosed?
- What type of breast cancer did you have?
- What kind of treatment did you have?

#### **Decisions:**

- How did you come to decide to get reconstruction/wear a prosthetic/neither?
- What sort of things influenced your decision?
- Timing and type influence your decision?
- Genetic testing?
- Family?
- Can you tell me about the process?
- What role did reconstruction/prosthetics/decision to go without play in your recovery/healing/adjustment?

#### **Feelings about breasts and body before/after:**

- How did you feel about your breasts/body before breast cancer?
- How has the prosthetic/reconstruction/going without changed that?
- How has breast cancer changed your life and how you feel about your body?
- How have reconstruction/prosthetics/going without changed your life?

#### **Additional Questions:**

- Have you experienced, or do you think other women have experienced discrimination, after they have breast cancer? Why do you think that is?
- How do you feel about the term “survivor”? Do you consider yourself a survivor?
- What do you think caused your breast cancer?
- Some women have mentioned that having breast cancer made them a better person. What does that mean to you? Would you agree or disagree?
- Is there anything else you’d like to share with me?
- What would you like your pseudonym to be?
- And, is there anyone else you know that might be interested in participating in an interview?

## VITA

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