

“SOME WOMEN ARE JUST SO MUCH BETTER THAN ME:”
GOVERNMENTALITY ENACTED THROUGH
THE BREAST CANCER SOCIAL MOVEMENT

by

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DALHOUSIE UNIVERSITY
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Dedication Page

To my partner, Kelly, and my family, Allan, Jill, Amy, and the rest of the clan, whose love and support keep me grounded.

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Abstract

Breast cancer social movements have, in many ways, succeeded in increasing the visibility of the disease in North America, yet researchers understand little about the effects of this visibility; there is little information about how women with breast cancer navigate breast cancer discourse. Feminist relational autonomy helps us to understand that women's degree of autonomy in making treatment decisions regarding their breast cancer is affected by their understanding of the disease and available options. I draw on the results of multiple qualitative interviews and online discussion group posts from 12 women with breast cancer in Nova Scotia, Canada, to examine the interconnections between breast cancer discourse and approaches to decision-making. Many representations of the best ways to “do” breast cancer cross the boundaries of allopathic and homeopathic medicine, popular self-help literature, and support services approaches to care, making them extremely pervasive in women’s lives. An idealised subject position that portrays women with breast cancer as strong, positive survivors/thrivers connects to a context in which certain identities are more likely to be accepted than others. Constraining the identities worthy of social recognition, breast cancer discourse is taken up in ways that limit the actions participants could imagine and justify, and encourage self-governance and discipline of others. Health care practitioners and support service providers have a responsibility to support women with breast cancer in developing the capacity for autonomous action by creating opportunities for women to imagine, discuss and embody alternative visions of breast cancer.

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Chapter 1: Introduction

In Canada, we hear and see a lot about breast cancer. There are pink ribbons, pink products, marathons, walks, dances, magazine articles about risk and survival, celebrity breast cancer survivors, and hundreds of millions of Internet sites presenting health information and advice. When I began thinking about this study, friends and family started telling me about their “pink” stories. In one striking example, a woman was wearing a pink shirt one morning when her five-year-old daughter asked why she was wearing a breast cancer shirt. The shirt had nothing to do with breast cancer, except that awareness campaigns have managed to create an association between the color and the disease. For many of us, pink is now the color of breast cancer.

In one awareness-raising movement that swept social media, women began posting the color of their bras as their status updates on Facebook, for example “Mine is white” or “Blue today.” The campaign swept the globe, becoming one of the top trends on Google and receiving coverage in national and international news (see for example Donaldson James, 2010). What remains unclear is who began this campaign and what they hoped to achieve with these posts (Donaldson James, 2010). The campaign’s popularity suggests that many women felt they should be part of some kind of movement or collective action by posting their bra colors, without asking any questions about why or what this could actually accomplish. In many ways, the need to raise awareness about breast cancer has become taken-for-granted, and one of the ways many women understand breast cancer.

The effectiveness of these efforts, in terms of improving care or finding a cure, is not at issue here. Breast cancer social movements have, in many ways, succeeded in

increasing the visibility of the disease in North America (Sulik, 2011). What social science researchers understand less are the effects of this visibility (Sherwin, 2006; Thorne & Murray, 2000); there is not enough information about how women with breast cancer navigate breast cancer discourse made prevalent and reproduced in part through the wealth of attention paid to the matter. By discourse I mean a set of common, taken-for-granted, barely visible assumptions which shape public knowledge of an issue (Cheek, 2000). Better understanding is needed concerning how discourse surrounding breast cancer shape women's abilities to make health decisions that reflect their needs and wishes (Sherwin, 2006).

These campaigns are not only teaching the public that pink means breast cancer or that it is each individual's responsibility to contribute to the search for a cure. Breast cancer visibility has made women with breast cancer themselves more visible. More precisely, pink campaigns make visible a particular way of being a woman with breast cancer, thus promoting one way of understanding women's experiences of the disease over others. This idealised way of being a woman with breast cancer, and the discourse that is used to constitute this subject position, are explored in Chapters 4 and 5. This is not to say that there is only one way to "do" breast cancer, or that there are not alternatives to thinking pink. I do argue, however, that such media campaigns construct an idealised 'woman with breast cancer.' Participants in this study each engaged with an idealised way to "do" breast cancer that shaped their understanding of how to be a woman with breast cancer.

Since Parsons (1951) developed the 'sick role' to describe social dictates for those who are ill, sociologists have become increasingly concerned with the social construction

of health and illness, and accompanying expectations of individuals who become ill. These expectations are further complicated by social constructions of gender, race, class, and other social differences. While early sociological studies of health and illness tended to take a view of fixed structural power relations, more recent studies delve into complex social relations through which individuals produce, reproduce and resist understandings of health and illness. Feminist bioethicists apply a similar understanding of the individual as embedded in complex relations of power in order to redefine concepts (particularly autonomy) used to guide our judgments about good care. Within this context, I am interested in the ways our socially constructed, gendered understandings of health, illness, and disease enable and constrain particular ways of being ill.

Health social movements are often described as being important sources of resistance to the power of the medical system. While many social movements do begin in order to enact resistance to a dominant power, the movements themselves also enable and constrain particular ways of being ill. In some cases, health social movements serve as means of compliance with medical norms. The effects of social movements on individual women, then, cannot be presumed to be uniformly positive. As with any social group, social movements serve both to provide a resource for resistance and create a path for exclusion, marginalization and constraint.

In this research study, I examine a key question: How do women diagnosed with breast cancer navigate breast cancer discourse while making treatment and lifestyle decisions? I use qualitative methods to examine how women diagnosed with breast cancer negotiated breast cancer discourse while receiving treatment for the disease. Participants adopted and resisted pervasive discourses as they constituted themselves as

women with breast cancer and made important treatment and management decisions. Through an examination of the complex relations among discourse, identities, and decision-making, I argue that common approaches to understanding breast cancer constrain women in particular ways in their efforts to find alternative ways to “do” breast cancer.

For example, one woman whom you will meet more fully in subsequent chapters told me that when she was first diagnosed she felt she had little control over which treatments to choose. Later she spoke about making difficult decisions about how best to manage her risk of recurrence and whether or not to have breast reconstruction surgery. Despite her ability to critique media messages about beauty, she still found herself struggling to imagine not having reconstruction. At the same time, she worried that her commitment to reconstruction was keeping her from choosing the best treatments for her disease. I argue in this thesis that she, and other women in the study, are constrained by discourses of positivity, fighting, survivorship and thriving which tell them how best to “do” their individual encounters with breast cancer. Their ability to imagine other ways of confronting cancer is facilitated when they see alternative options portrayed in the media and was hindered when interactions with others encourage self-governance and adherence to expectations. Each woman’s perception of herself as a good woman with breast cancer affected her ability to make decisions about how best to cope with the disease.

When I first told a health care provider that my research would be about breast cancer she expressed her disappointment that more money, more time and more interest was being focused on a disease that she feels is getting too much attention already. In

some ways she is right; breast cancer is one of the best-researched diseases in North America. This study contributes something new to our understandings of breast cancer experience by focusing on the effects of this recognition. As disease-focused awareness campaigns become more common, research such as this becomes an increasingly important way of understanding the connections between disease discourses, experience, and treatment decision-making.

In the next chapter I provide a review of the literature to further contextualize the study. In particular, I situate this exploration of women's experiences of breast cancer in the context of the breast cancer social movement within broader discussions of women's health, bioethics, and social scientific approaches to conceptualizing experiences of illness. At the conclusion of Chapter 2, I describe the theoretical approaches that frame the rest of the chapters, namely Foucault's concepts of governmentality and subject positions, and the feminist bioethics concept of relational autonomy. I argue that the combination of these concepts provides an interpretive lens that allows me to view the ways in which women with breast cancer negotiate breast cancer discourse and the ways in which this negotiation enables and constrains their abilities to be relationally autonomous.

In Chapter 3, I describe the qualitative research methodology that guided the process of data collection and analysis. In Chapters 4, 5 and 6, I examine the results of this study. In Chapter 4, I describe the discourses taken up by participants following a diagnosis many experienced as shocking, focusing on discourses of positivity, fighting, the journey, and surviving/thriving. In this chapter, I begin to employ Foucault's concept of governmentality to explore the ways in which these discourses are used in women's

self-surveillance and monitoring of others. This discussion is furthered in Chapter 5, in which I examine the ways these normalizing discourses are embraced by participants as they constitute themselves as good women with breast cancer and monitor others' subject positions. In Chapter 6, I use the concept of relational autonomy to explore the ways in which the normalizing effects of discourse and subject positions serve to enable and constrain participants' abilities to be autonomous. In constraining participants' abilities to imagine other ways of being, breast cancer discourse complicated participants' abilities to act in their own interests. In Chapter 7, I integrate these findings with the literature to examine the substantive and methodological contributions of this work.

Chapter 2: Literature Review

In this chapter, I provide an overview of relevant literature in order to situate this study. Bearing in mind the interdisciplinary nature of this study, I provide brief overviews of relevant debates from sociological studies of gender, illness, and illness communities, research examining women's experiences of breast cancer and breast cancer social movements, and theoretical perspectives from sociology and feminist bioethics that will be used to frame the results and discussion. In providing these brief discussions, I oversimplify complicated debates, but my point is to establish that there is a gap in the literature. By the end of the chapter, it is clear that this study of the diverse effects of the mainstream breast cancer social movement addresses an important gap in our understanding of women's experiences of breast cancer by asking how a patient-centered advocacy movement intended to resist medical power and dominance in turn can restrict and constrain women's relations with themselves, their bodies, and each other as women with breast cancer.

2.1 Studying Health and Illness¹

In 1951, Talcott Parsons developed a structural functionalist account of illness as not just a biological experience, but a form of deviance that disrupts the functioning of a society. Through this lens, individuals who become ill must fulfill a sick role that comes with rights, including exemption from normal role requirements and not being blamed for illness, and responsibilities to seek competent help and try to get well. Parsons' account of illness has been criticized for casting illness as a temporary form of deviance which

¹ This and other sections in this chapter, provide very brief overviews of large bodies of literature. In writing these overviews, I acknowledge that I am simplifying nuanced and complicated debates for my purpose, which is to situate this study by identifying a need in the literature.

excludes experiences of chronic illness, overlooks power relations inherent in the patient/doctor relationship, and suggests that individuals are responsible for becoming healthy in order to be active members of society (Friedson, 1970; Segall, 1976; Shilling, 2002). Nonetheless, Parsons' theoretical attention cast sickness and health solidly in the realm of sociological analysis, insisting that biological and physiological functions and malfunctions are simultaneously infused with social norms and expectations.

Accounts of illness have since developed to allow for a more complex world in which power relations permeate all interactions, medicine exerts control (perhaps too much) over the lives of individuals, and individuals who experience illness may successfully integrate these experiences into the narratives of their lives. Increased rates of and attention to chronic illness in the Western world, critiques of medical dominance, distinctions between disease and illness, and the narrative turn in the social sciences have inspired new ways of understanding how individuals live with ongoing illness (Barker, 2005; Bury, 2001; Charmaz, 2000; Kleinman, 1988). In the 1970s, social scientists distinguished between disease, defined as bodily disorder agreed upon by experts, and illness, the subjective experience of disease (Bury, 2001; Charmaz, 2000; Kleinman, 1988). Accompanying this change, the focus of social science studies of health and illness included a shift to examining the subjective experiences of illness and the influences of these experiences on self and identity (Charmaz, 2000). This is accompanied by structural-level examinations of medical dominance, medicalisation, and iatrogenic—medically caused—illness that illuminate power relations that shape this subjective experience (Conrad, 2007).

At the same time, morbidity rates began to indicate an increase in chronic disease in Western countries (Bury, 2001). The distinction between disease and illness is more pronounced in the case of chronic illness, which is often associated with more social, interactional and existential problems for the patient than acute illness (Charmaz, 2000). Parsons' sick role cannot account for experiences of being chronically ill, as chronic illness does not excuse the individual from usual social expectations. At the same time, understandings of chronic illness need expansion to account for acute episodes of disease that may result in a person being labelled as "at risk" of future episodes (Nettleton, 1997). This "at risk" label places the person between healthy and ill, effectively creating a life-long state of semi-illness (Jones, 2008; Nettleton, 1997). In addition to increasing rates of chronic illness and chronic risk, ongoing movements critiquing the dominance of a biomedical model of disease and calls for patient-centred care continue to inspire social scientists to examine the subjective experience of ongoing illness. Necessarily, these subjective experiences are shaped by socially and discursively constructed notions of social difference, including gender.

2.2 Studying Women's Experiences of Illness

Social understandings of gender have been enmeshed in the development of biomedicine. In the mid-1970s, analyses of medicalisation took a turn, largely due to the work of many feminist theorists (Riska, 2003). Ehrenreich and English (1972) provide a detailed, though criticized, description of the historic struggle between female healers (witches) and university-trained male physicians, following which women's approaches to healing became increasingly marginalized while institutionalized, male-dominated allopathic medicine became the norm. Medicalisation was described by feminist scholars

as a patriarchal process in which women's knowledge and power over their bodies was superseded by male medical knowledge (Riska, 2003). With this social and economic power, the male-dominated practice of medicine came to define disease in a way that often reproduced inequitable social understandings of gender (Corea, 1985; Lorber, 1984; Roberts, 1985). Feminists argued that women's experiences were more likely to be medicalised because of the visibility of women's bodily processes, women's increased contact with the health care system as caregivers, and women's subordination to men (Riessman, 1983).

Although many feminists portrayed women as passive victims of medicalisation, Riessman (1983) argued that conceptualizing women in this way "perpetuates the very kinds of assumptions about women that feminists have been trying to challenge" (p. 3). She pointed out that women actively encourage medicalisation in some situations precisely because it provides access to resources and establishes legitimacy. For the first time, the role of those outside the institution of medicine was viewed as an important factor in the process of medicalization, and the enabling nature of medicalisation was described. Due to these analyses and debates, the study of gender, health and illness has long been of particular interest to feminist scholars.

Of particular interest here are approaches to understanding the ways in which women's experiences of illness are shaped by gender. Feminist scholars in multiple fields have examined the ways in which cultural understandings of gender, particularly femininity, and other aspects of gender-based oppression, shape interactions between women patients, their health care providers, and the health care system as a whole (see for example Sherwin, 1992). Depictions of women as emotional, hysterical and irrational

are often built into definitions of disease, both medicalising and undermining women's efforts to resist medical dominance (Lupton, 2012). In this way, women's ability to express their perspectives (Greenhalgh, 2001; Todd, 1989) and frustrations or anger (Batt, 1994; Greenhalgh, 2001) during medical consultations is limited, as such expressions risk being labelled as hysteria (particularly if they counter medical views). Ironically, this may increase women's reliance on medical perspectives to understand, justify and legitimize their experiences of illness. This reinforces the perspective that patients, and particularly patients who are women, do not bring valid and important knowledges to medical consultations.

In this context, women are more likely than men to be viewed as not having credibility in exchanges with health care practitioners and in describing illness experiences or suffering (Barker, 2005; Batt, 1994; Greenhalgh, 2001). In the context of gendered assumptions that associate femininity with subjectivity and masculinity with objectivity, both Barker (2005) and Werner, Isaksen and Malterud (2004) argue that women must try harder than men to overcome assumptions about their lack of credibility in order for their descriptions of their illness experiences to be considered legitimate by health care professionals. Women's accounts of their physical experiences are undermined by relations of power that portray women as overly emotional. Greenhalgh (2001) examines the ways in which gender hierarchy exacerbates power inequities in the physician-patient relationship: "In the medical setting gender often works to amplify the voice and power of the physician. The patient is doubly silenced and subordinated, first in the hierarchy of science and then again in the hierarchy of gender" (p. 37). In other words, women's experiences of illness are often invalidated by biomedical and

patriarchal ways of understanding, which cast women's subjective experiences as less valid than masculinist perspectives of health and disease deemed objective through medical science.

There is an underlying presumption in much of this literature that physicians are often male, or at least represent a patriarchal institution. At the same time, there appears to be an assumption that women occupy a fixed category with similar health care experiences. Building on the ideas of lesbians and women of colour (e.g., Hill Collins, 1990; Rich, 1994), a post-modern turn in the social sciences has complicated studies of women's experiences of health and illness (Potter, 2001; Shildrick, 1997). Incorporating the work of Foucault (1972; 1973; 1975; 1978; 1988; 1991) and other post-structural scholars, feminist philosophers and social scientists such as Margrit Shildrick and Sarah Nettleton examine the complex ways in which diversely situated women are embedded in power relations that shape their health and health care experiences. For example, in recognizing the complex nature of power relations, women can no longer be portrayed as a fixed group who are oppressed by patriarchal, medical dominance. Instead, within the institution of medicine, power and resistance are enabled and constrained through taken-for-granted practices and relations, such as those that function discursively. In this context, the ways in which categories of ill women are socially and discursively produced is of particular importance for efforts to understand women's experiences of health and illness.

Recognizing the effects of gendered relations on women's experiences of illness necessarily recognizes individuals as members of social groups. In understanding illness experiences, social scientists have recognized the roles of illness communities and social

support groups in shaping illness experiences and knowledges. In the following section, I discuss some ways in which researchers have sought to understand the effects of illness communities on individuals' experiences of illness and how, within these relations of power, women can make autonomous decisions about their health and health care.

2.3 Studying Illness Communities

A focus on the ways in which patients and physicians interact may hide from view the many relationships that shape the worlds of those experiencing illness. Once diagnosed, or in pursuing a diagnosis, individuals enter into an illness community with those who have received or wish to receive a similar diagnosis. Increased access to the internet and increases in disease-based advocacy may facilitate the formation of these relationships (Batt, 1994; Hardey, 1999).

Social science scholars have taken an interest in the ways in which these communities shape individuals' illness experiences. Researchers have explored the ways in which illness communities have resisted the dominance of the biomedical model by challenging the professional ownership and dominance of expert knowledges. Members of these communities struggle to gain access to expert knowledges and/or affect the production of this knowledge (Batt, 1994; Epstein, 1995). Examining the ways in which patient communities challenge biomedical dominance, Whelan (2007) describes the epistemological processes that an endometriosis patient community engaged in, arguing that embodied health movements are both political and epistemological. Whether or not these groups are successful in challenging biomedicine is not the focus here, although there is a significant body of literature on the topic (see for example Yadlon, 1997).

Literature in this area demonstrates that those suffering from illness are not isolated individuals, but often adopt illness identities that enter them into social groups (Batt, 1994; Kaiser, 2008). These groups of individuals are bonded by similar experience and may have the influence necessary to shape the biomedical knowledge production process (Batt, 1994; Epstein, 1995). As the community influences biomedical knowledge production, the ability of individuals within illness communities to create and access health knowledges is also enabled and constrained by the group. The actions of the group as a whole shape the knowledges the individual accesses and, therefore, shape the way in which the individual may understand her illness. Thus, by limiting the types of knowledges readily available to individuals within a community, illness communities may limit the ways in which individuals understand their illnesses. Pitts (2004) reviewed women's websites about breast cancer; although these sites offered the opportunity for creating new knowledges about cancer, most recreated feminine and individualistic norms. In doing this, these websites limited the breast cancer knowledges accessible to members of the corresponding online communities.

Although the health knowledges made available through illness communities have been shown to limit the illness identities made available to members of the community, individuals also interpret these knowledges and adopt illness identities in the context of their personal experiences. Kaiser (2008) provides an analysis of the ways in which women redefine or challenge the concept of the breast cancer survivor within an illness community. The discourses referenced by members of the group are interpreted and used selectively by each individual in light of her own experiences. Therefore, individuals don't simply take up the discourses provided through illness communities, but interpret

and reproduce discourses in the context of their life experiences, meaning that they take up and reproduce these discourses in varying ways.

In this study, I examine the experiences of women with breast cancer as they negotiated discourses made available through the illness community they entered as participants in the mainstream breast cancer social movement. In the following sections, I turn my attention to breast cancer, examining literature about the disease itself and women's experiences of breast cancer as an illness.

2.4 Breast Cancer: Diagnosis, Prognosis and Standard Treatments

Social, cultural and relational influences shape each woman's experience of breast cancer, yet standardized medical processes have led to some similarities in illness trajectories in Canada. Breast cancer is the most common cancer affecting Canadian women; one in nine women is expected to develop breast cancer in her lifetime. The Canadian Cancer Society (2010b) predicted that approximately 23,200 women would be diagnosed with breast cancer in 2010. In Nova Scotia, breast cancer is the most frequently diagnosed type of cancer in women; approximately 740 women are diagnosed annually (Canadian Cancer Society, 2010b). Though prognoses for breast cancer vary, the overall 5 year survival rate for women diagnosed in Canada is approximately 87% (Canadian Cancer Society, 2010b).

Breast cancer is usually diagnosed through a series of mammograms and biopsy. Women are most often diagnosed with one of two types of breast cancer: ductal carcinoma, which develops in the breast ducts, or lobular carcinoma, which begins in the lobules (Canadian Cancer Society, 2010a). The breast includes a system of ducts, which are tubes leading down from the nipples to the lobules, which are glands that have the

potential to produce milk. Other types of breast cancer, including inflammatory breast cancer and Paget's disease, are rare and require different treatment regimens (Canadian Cancer Society, 2010a). For that reason, in this research study, "breast cancer" will refer to ductal and lobular carcinomas. Ductal and lobular carcinomas are further differentiated by five stages and three grades. Stages zero to four describe the extent to which cancer cells have spread; stage zero indicates the presence of abnormal cells in the ducts or lobules while stage four indicates that cancer has spread to multiple other distant locations in the body (Canadian Cancer Society, 2010a). Grades one to three describe the growth rate of the cancer, with grade one indicating a slow-growing cancer that is less likely to spread and grade three indicating a fast-growing cancer that is more likely to spread (Canadian Cancer Society, 2010a).

There are four categories of standard treatment for breast cancer: surgery, radiation therapy, chemotherapy, and hormonal and biological therapies (Canadian Cancer Society, 2010a). Surgical options include breast conserving surgeries and mastectomies. Breast-conserving surgeries involve the surgical removal of a tumour and surrounding tissue; these options are typically include lumpectomy, wide local excision, partial mastectomy, segmental mastectomy and quadrantectomy. The amount of surrounding tissue removed varies from lumpectomy, which involves minimal removal, to quadrantectomy in which a quarter of the breast tissue is removed. During breast-conserving surgeries, lymph nodes may be removed to determine whether the patient's cancer has spread further than expected. Mastectomies involve surgical removal of the entire breast. Total mastectomy removes the entire breast, the nipple and some skin. Modified radical mastectomy removes the entire breast, the nipple, some skin and some

of the lymph nodes in the armpit. Radical mastectomy, which is now rarely performed, removes the entire breast, the nipple, skin, some of the lymph nodes in the armpit, and the muscle under the breast.

Radiation therapy involves irradiating both cancerous and healthy cells, either externally, using a beam, or internally, through placement of radioactive material.

Chemotherapy, which is administered by IV infusion, injection or pill, interferes with the ability of cells to grow. It disproportionately destroys cells that are growing quickly. With some developments, surgical, radiation and chemotherapy treatments have remained standard breast cancer treatments for decades. Some physicians, patients and researchers have critiqued the medical community for failing to develop new treatments for the disease. Famously, Love (Love & Lindsey, 1990), an American physician and breast cancer expert, coined the phrase “slash, burn and poison” to critically describe these treatments – which, in effect, either cut out or kill off diseased tissue. Love, and many other researchers in the field, hope that biological and hormone treatments will provide women with new and less hazardous treatments for breast cancer.

Both hormonal and biological therapies are newer treatments drawing on research that differentiates the ways in which breast cancer tumours grow (Canadian Cancer Society, 2010a). When tumours are hormone receptor positive, meaning that the tumour depends on hormones within the body to survive, hormone therapy to lower hormone levels in the body or block hormone receptors may be prescribed. Biological therapy, which may be used for women whose breast cancer has too much of the HER2 protein, involves the use of drugs to interfere with cancer cell growth and uses the immune

system to destroy cancer cells. Hormone and biological treatments are administered in addition to one or more of the three standard treatments.

2.5 Breast Cancer: Confronting Uncertainty

As is the case with many cancers and other chronic illnesses, selecting treatments for breast cancer can be a complicated process. Medical science provides generalized statistics about likely prognoses from treatments, but science cannot predict with certainty what the treatment outcome will be for a particular individual. In her sociological analysis of medical uncertainty, Fox (2002) demonstrates that ways of understanding and dealing with this uncertainty reproduce other social and cultural trends, meaning that in contexts of uncertainty, individuals tend to turn to biomedicine to manage this uncertainty. In the case of current biomedical practice, a tension exists between two trends: evidence-based medicine and individualized medical consumerism (Broom & Adams, 2010).

Evidence-based medicine encourages health care practitioners and patients to make decisions based on generalized statistics, preferably from randomized controlled trials (Broom & Adams, 2010). Evidence-based medicine is central to the predictive capacity of oncologists (Broom & Adams, 2010). In accounts of evidence-based medical practice, patients are often portrayed as passive recipients of evidence-based predictions from expert practitioners (Lupton, 1997). Simultaneously, patients are encouraged to take an active role in making treatment decisions thanks to medical consumerism (Lupton, 1997). Consumerist discourses employ individualism to argue that each patient must interpret evidence and make decisions on her own to ensure they are consistent with her values. Although patients are often described as either active or passive, Lupton (1997)

argues that patients are both passive and active at different times and in different contexts.

In negotiating medical uncertainty within the context of evidence-based medicine and individualism, oncologists may employ individualism to manage the indeterminacy of evidence (Broom & Adams, 2010). For example, after providing a generalized prognosis, “positive thinking” may be presented as a way to increase one’s statistical chances of survival. In the case of breast cancer, many stages of breast cancer have no clear, evidence-based treatment choices (Sepucha, Ozanne, Silvia, Partridge & Mulley Jr., 2007). In the current context of medical consumerism and patient-centred care, oncologists may respond to this uncertainty by suggesting patients select treatments based on their informed personal preferences (Sepucha, Ozanne, Silvia, Partridge & Mulley Jr., 2007). Physicians may also practice patient-centred care by working with patients to come to decisions that are consistent with their needs and values.

Unfortunately, structural constraints, such as lack of time with patients, often make it difficult for physicians to support patients throughout the whole decision-making process (Sepucha, Fowler & Mulley, 2004). In the context of medical uncertainty, patients often turn to independent information gathering to support their decisions.

Patients now have access to vast amounts of information about their treatment options. As of October 2010, a Google search for the phrase “breast cancer” returned 146,000,000 web pages. Efforts to refine the search by adding the word “treatment” increased the results to 147,000,000. The patient-centred care movement has encouraged health care providers to allow women more freedom in choosing their treatments, but it can be challenging to sift through this volume of information and use it to make

decisions. Even popular media accounts now reflect on the difficulties women experience when making treatment decisions for breast cancer with little guidance from their physicians in the context of patient-centred care (Stolberg, 2000).

The way patients make health care decisions is much more complicated than is portrayed in discussions of patients as active or passive (Lupton, 1997; Kukla, 2007). The treatment choices available are, of course, limited by current medical thinking based on evidence—radical mastectomies, for example, are rarely offered to patients (Canadian Cancer Society, 2010a). Within these constraints, patients may defer to health care providers and yet also be active inquirers, or may seem to defer and then not ‘comply’ with health care providers’ advice or may seek second opinions. Patients may require support from others to develop the skills and understanding necessary to become active inquirers and to make treatment and management decisions (Kukla, 2007; Redman, 2008). Some patients search for and receive this support in illness communities, such as the community formed within the mainstream breast cancer social movement.

2.6 Breast Cancer Social Movement: Creating an Illness Community

Many women with breast cancer find support and resources in a community of women who have experienced breast cancer. Before breast cancer politics, breast cancer was a disease shrouded in secrecy, stigma and shame. At this time, extreme treatments, particularly the Halsted mastectomy (which involved the removal of all breast tissues including the pectoral muscles) were commonplace and women had little say in the selection of treatments for the disease (Batt, 1994). The roots of activism against this form of treatment, which kicked off the breast cancer social movement, are attributed to a few different sources. Ehrenreich (2001) attributes the change in approach to the disease

to the efforts of the broader women's health movement. At the same time, famous women began to speak out about their experiences of the disease, overcoming the silence that was common at the time (Altman, 1996; King, 2004; 2006). In 1975, Rose Kushner published her story and critical analysis *Breast Cancer: A Personal History and Investigative Report*, challenging the use of one-step mastectomies and starting a decade-long campaign promoting informed choice for women with breast cancer (Kasper & Ferguson, 2000; King, 2004; 2006; Klwaiter, 2008; Ehrenreich, 2001).

Over the next two decades, more and more breast cancer organizations started up across North America (King, 2004; 2006). Many of these groups had clear political stances and were or are committed to changing understandings of breast cancer to better reflect the needs of women with the disease. Klwaiter (2008) provides a detailed analysis of breast cancer social movements in the San Francisco area, demonstrating that three separate "cultures of action" existed, including early detection and screening activism, patient empowerment and feminist treatment activism, and cancer prevention and environmental activism. Although Klwaiter (2008) disputes the idea that there is one breast cancer social movement, the context of her research is a large urban centre with a history of increased feminist and environmental activism. In other contexts, the same diversity of movements may not exist.

In her book *Pink Ribbons Inc: Breast Cancer Activism and the Politics of Philanthropy* King (2006) traces the roots of the mainstream breast cancer social movement and examines the impact of current techniques of volunteerism and philanthropy on belonging and political action. Although her account is based in the United States, it mirrors similar Canadian accounts (see for example Batt, 1994). King

(2006) describes the movement from “breast cancer politics” to “breast cancer charity,” using two *New York Times Magazine* covers to illustrate this change. In 1993, the magazine ran the now famous photo of breast cancer activist and artist Matuschka showing her mastectomy scar. The accompanying article, titled “You Can’t Look Away Anymore: The Anguished Politics of Breast Cancer” (Ferraro, 1993), examined the efforts of grassroots breast cancer activists (King, 2004; 2006). In 1996, the same magazine ran a cover story titled “This Year’s Hot Charity” (Belkin, 1996), which featured a sexually provocative photo of a supermodel and focused on the fundraising efforts of Nancy Brinker, founder of the Susan G. Komen Breast Cancer Foundation (King, 2004; 2006). In less than four years, the focus shifted from grassroots, political, and explicitly feminist coverage of the disease to an account that attributes the success of breast cancer advocates to support of the wealthy and the link between breast cancer and femininity (King, 2004; 2006).

Since Kushner called for informed choices and patient activism in 1975, public perceptions of breast cancer have changed drastically. King (2004) describes these changes in the public perception of breast cancer from a stigmatized disease to a public fundraising campaign that obscures the politics of the disease:

... the disease has been reconfigured from stigmatized disease and individual tragedy best dealt with privately and in isolation, to a neglected epidemic worthy of public debate and political organizing, to an enriching and affirming experience during which women with breast cancer are rarely ‘patients’ and mostly ‘survivors.’ In the latter of these three configurations, breast cancer survivors emerge as beacons of hope who,

through their courage and vitality, have elicited an outpouring of ‘American’ generosity—a continued supply of which will ensure that the fight against breast cancer remains an unqualified success. While on occasion the discourse of fundraising references women who have died of the disease, less optimistic, more critical perspectives on progress in the fight against breast cancer are few and far between. (pp. 475-476)

King (2004; 2006) is critical of the ways in which this new focus on philanthropy serves to obscure other important ways of “fighting” breast cancer, such as regulating the use of chemicals. She suggests that in failing to make a distinction between breast cancer activism that focuses on fundraising and that which focuses on political action, researchers fail to illuminate the ways in which these movements differently constitute the problem of breast cancer. In differently constituting breast cancer, breast cancer social movements have the potential to shape women’s understandings of themselves as women with breast cancer.

2.7 Breast Cancer and the Self

Qualitative researchers have turned attention to the connection between breast cancer experiences and the self. Betero and Chamerlain Wilmoth (2007) published a meta-analysis of 30 qualitative studies conducted between 1990 and 2003 that analyzed the connection between breast cancer and the self. Their analysis demonstrated, among other things, that breast cancer diagnosis and treatment require redefinition of self. These findings are consistent with other studies of chronic illness that describe illness and treatment as self-disruptive and requiring redefinition (see for example Bury, 1982).

These analyses provide an understanding of the disruption felt and described by women diagnosed with breast cancer. Acknowledging this disruption is important in order to comprehend the significance of diagnoses in women's lives; however, this approach is not the only way to understand the relation between illness and self. By focusing on how the self is defined before and after illness, analyses of disruption may inadvertently portray the self as fixed. In addition to acknowledging this disruption felt by women, other researchers have begun to explore the ways in which illness is experienced as both self-disruptive and self-constituting (Charmaz, 1995; Frank, 2000; Riessman, 1990). In these studies, the interconnections among experiences, knowledges, and the self are examined. These analyses provide more nuanced views of the ways in which the self is actively constituted during illness experiences.

Breast cancer's visibility makes it an ideal case for examining these interconnections. The discourses available to women diagnosed with breast cancer shape women's experiences of the disease (Thorne & Murray, 2000) and the selves that women constitute. Women constitute their selves as women with breast cancer within available frameworks (Sherwin, 2006). The selves women diagnosed with breast cancer present and the selves silenced are enabled and constrained by available discourses. Within these constraints, women have active roles in constituting their subject positions as women with breast cancer.

This approach is represented in the work of Kaiser (2008) who provides a qualitative account of women's efforts to alter or reject the concept of breast cancer survivorship as they actively craft illness meanings. The 39 participants in Kaiser's study, who had recently undergone treatment for breast cancer in the United States, did not

simply absorb and reproduce discourses of survivorship, but adapted the meaning of this identity in constituting themselves as women with breast cancer in the context of their lives. For example, some women felt that their embodied experiences of breast cancer were not severe enough to warrant the title “survivor.” Others felt that “survivor” was an inappropriate title as they continued to worry about recurrence. Some women wished for a private disease experience and felt survivorship required social action. Despite these concerns, many women still used the term “survivor,” but to them the personal meaning of this term had been tailored. This study highlights that ways in which social understandings of a disease do not necessarily reflect individuals’ experiences of illness, and overlook the ways in which individuals construct illness meanings within the context of their lives (Kaiser, 2008).

Sulik (2009) provides an analysis of the role of medical uncertainty in women’s self-constitution. She suggests that women with breast cancer construct technoscientific illness identities to cope with this uncertainty; in other words, women with breast cancer draw on biomedical information such as test results to constitute themselves as women with breast cancer. With support from health care providers, women with breast cancer may come to understand biomedical information in relation to their selves and, eventually, prioritize biomedical classifications over their embodied experiences. Women with breast cancer may judge the severity of their illness experience in relation to test results and not in relation to how they feel. This is understandable, as most women do not feel ill before being diagnosed with breast cancer following a mammogram and biopsy (Canadian Cancer Society, 2010a), and thus they may distrust bodily messages.

These studies provide a good starting point for understanding the ways in which women with breast cancer situate their selves in relation to frameworks of understanding the disease. The most complicated analysis of these experiences is theoretically-based (Sherwin, 2006). Others provide detailed analyses of how women with breast cancer constitute their selves in relation to one form of knowledge or metaphor, such as medical uncertainty or survivorship (Sulik, 2009; Kaiser, 2008). As Sherwin (2006) argues, women with breast cancer encounter multiple forms of knowledges and metaphors that must be navigated.

2.8 Examining Women's Experiences of Breast Cancer

Women diagnosed with breast cancer immediately enter into multiple frameworks for understanding their disease, just one of those being medical interpretations. The physical experiences of cancer are interpreted through social and cultural understandings, further complicating the process of knowledge negotiation and treatment decision-making. In this section, I provide a brief overview of the understandings that are likely to shape a woman's experience of her self as a woman with breast cancer.

In Western society, cancer has been described as chaotic and uncontrollable. Treatments for cancer must conquer the disease in order to return one's body to a natural order (Sontag, 1990). In this understanding of the disease, the treatment of cancer is described as a "war" or "fight" between the evil of cancer and the virtues of medicine, featuring the heroism of physician and patient (Lerner, 2001). Early accounts of fights against breast cancer featured the physician as hero, but as more women live through their experiences of breast cancer, women have begun to be featured as heroines (Bahar, 2003).

The use of military metaphors encourages focus on the struggle to overcome the disruption of diagnosis and treatment. Cancer is understood as an invasion of one's body, and overcoming cancer involves fighting the invasion to neutralize the enemy. Like stories of war, medical and popular information that draws on these metaphors often provide linear narratives in which simple progressions are drawn from a state of normalcy, to invasion, to fight, and back to normalcy. In a standard illness narrative, cancer is diagnosed, the patient faces her demons and rallies her forces, a treatment is selected and the story ends with survival or death, although death is rarely mentioned (Fosket, Karran & LaFia, 2000).

At the same time, the term "survivor" has come to describe these women who win the fight against breast cancer. Stories of survivorship often privilege an understanding of illness as a search for individual self-knowledge and self-identity that ends when one successfully overcomes the disease (Potts, 2000). That is, in addition to portraying the fight against cancer in a linear narrative form, breast cancer narratives often explore how women were transformed by the experience of fighting cancer. In these stories, the disruption of cancer provides the opportunity for finding oneself (Bahar, 2003).

Breast cancer is often portrayed as particularly disruptive because of the cultural connections between femininity and breasts (Lupton, 1994). Breasts are admired as representations of the ideal of femininity in our society, both when sexualized and when associated with motherhood. Breast cancer threatens this connection to femininity and thus threatens to disrupt womanhood. The choice of pink as a campaign color for finding a cure for breast cancer reminds the public of this connection through its link with stereotypical femininity (Sulik, 2011). In the popular media, survivorship is presented in

images of women (with breasts), clad in pink, portrayed as happy, hopeful fighters. Feelings of anger, sadness, frustration and despair are rarely portrayed (Sulik, 2011). In addition, this approach encourages beliefs that recovery from breast cancer entails restoration to proper femininity through breast reconstruction and wearing makeup (Sulik, 2011).

One can see the power of these images in the controversy created when they are challenged in the media. For example, the 1993 *New York Times* cover discussed earlier, featuring a woman showing her mastectomy scar (Matuschka, n.d.), was titled “Beauty out of Damage.” This photo is one of the most controversial covers of all time, resulting in both supportive and negative letters to the editor. Since its publication, this photo has been named one of the 100 pictures that changed the world (Matuschka, n.d.). In the same way, *Harper’s* magazine and Barbara Ehrenreich (2001) fuelled debate with the publication of her article critiquing the breast cancer experience as entering her into “a cult of pink kitsch” (p. 43). *Harper’s* published six negative responses to the article and Ehrenreich’s response to these in the Letters to the Editor section in the following issue (Segal, 2005). Following Ehrenreich’s lead, the San Francisco-based support organization Breast Cancer Action initiated a “Think Before you Pink” campaign in 2002 (Segal, 2002; see Breast Cancer Action, 2010).

Positively, this shift to survivorship has positioned women as agents in their experiences of illness (Bahar, 2003). Negatively, this shift “foregrounds triumphant individual autonomy at the expense of more socially located and disjunctive conceptions of the self” (Bahar, 2003, pp. 1028-1029). In other words, the complexity, relationality, and political nature of women’s experiences of breast cancer are hidden (Sherwin, 2006).

These forms of narrative mirror the biomedical and self-help approaches to breast cancer, emphasizing individual action and responsibility (Klawiter, 2000). While these metaphors, narratives and images may motivate some women, they do not offer the only way to understand breast cancer and may silence women who understand the disease in other ways (Garrison, 2007; Sherwin, 2006).

Frank (1995) refers to these stories of finding oneself in illness as quest narratives. He suggests these narratives be challenged by listening more closely to chaos narratives, which are typified by their lack of linearity and focus on catastrophe. Pragmatically, narratives that fall between these two types, having enough linearity to be understood and enough chaos to communicate the disruption caused by cancer, would likely be most useful in helping others develop the empathy required to facilitate empowering relations with women diagnosed with breast cancer (Bahar, 2003). Some breast cancer autobiographies have already challenged typical quest narratives by placing stories of individual survival in the context of collective struggle, social and cultural constraints and disorientation (Bahar, 2003; Batt, 1994; Ehrenreich, 2001; 2007; Kushner, 1975; Lorde, 1980; Sedgwick, 1999).

Within a broader critique of the pink ribbon movement, Sulik (2011) describes the idealised woman portrayed by the breast cancer social movement, arguing that this ideal creates a context in which many women with breast cancer feel they have failed to live up to social expectations of them to be positive, to learn from their illness, and to be strong. This breast cancer story excludes many women who may not survive or who experience sadness, anger or worry. In this study, I continue and extend existing work by examining the ways in which participants negotiated breast cancer discourse in constituting subject

positions and how these processes shaped the many treatment and management decisions they made. In the following section, I outline the conceptual framework that I use to interpret the accounts provided by participants.

2.9 Conceptual Framework: Balancing Domination and Resistance

Qualitative research is often described and differentiated by the paradigm in which the research study can be situated. Paradigms provide “a basic set of beliefs that guide action” (Guba, 1990, p. 17). That is, paradigms describe an underlying foundation of beliefs on which to construct a research study, including the questions asked and approach to analysis. This study is situated within the critical paradigm, specifically from a feminist perspective. The critical paradigm focuses on illuminating and critiquing relations of power and privilege for the purpose of transforming these relations; in other words, research from this critical perspective describes structural power relations in order to imagine opportunities for addressing the oppressive effects of these relations. In order to meet this aim, research must be conducted with political and practical applications in mind. In this research study, the political and practical aim was to better understand how some women with breast cancer reproduce, revise or undermine dominant breast cancer discourse in order to illuminate ways in which others can better support women with breast cancer. In this section, I outline my theoretical commitments.

The theoretical framework that guides this study must reflect my commitment to understanding relations of power and illuminating possibilities for resistance. It must also account for the experiences described by study participants. Two theoretical understandings of the self are often presented as incompatible: the self constituted within relations of power and domination and the autonomous self capable of resistance (Allen,

2008). It is made to appear that in order to understand power relations we must relinquish the theoretical possibility of autonomy or, conversely, in order to posit the possibility of autonomous action we must imagine our selves to be free, unencumbered by power relations. Neither of these options suits my feminist commitment to understand the practices of power and privilege in order to transform them, nor my sociological understanding that no choices or actions are devoid of social influences, yet some choices and actions move toward social change more than do others. A feminist project demands a more nuanced understanding of the self as both constituted within power relations and capable of autonomous resistance. This task requires a robust theory of both power and autonomy.

Through the concept of relational autonomy, feminist bioethicists ask us to examine the ways in which relations of power and privilege undermine or enable the development of skills for exercising autonomy, and offer opportunities for autonomous action. Having skills to act autonomously and feeling competent using one's skills to navigate knowledges and to critically evaluate values implicit in knowledges are important parts of being relationally autonomous. The ability to resist inequitable social norms requires space for imagining and choosing alternative ways of understanding and being (Sherwin, 2006). Material conditions that support autonomy and availability of options are also necessary for autonomous action. For the purposes of this study, I focus on the interactions between knowledges and autonomy as important effects on and of health experiences and health care decision-making; the constraints imposed by material conditions and lack of choice are well-documented in the literature on breast cancer (Edwards, McClave & Combs, 2000). There are fewer studies that examine the discursive

constraints within which women with breast cancer must make treatment and life decisions.

Developing a theoretical approach to the data inevitably highlights some aspects of participants' accounts and backgrounds others. There is no question that capitalist and patriarchal imperatives shape the experiences of breast cancer through both pressures around consumption in health care and in everyday life, and pressures concerning normative femininity. Socialist feminist theories help to illuminate these processes. At the same time, there is no question that experiencing breast cancer throws women outside the comfortable navigation of everyday lives, into new, disorienting, and unfamiliar social territory, exactly the kind of territory Bourdieu (1977) helps us to understand in his theories of habitus and the logic of practice. Even Parsons' (1951) functionalist notion of the sick role, and its dictates that individuals must both care for themselves and seek appropriate help in order to be 'proper' sick people, is helpful in understanding the ways breast cancer fits with and perpetuates social dynamics broadly concerning illness and health. However, in addressing the central research questions concerning navigation of knowledges which both constrain and enable, and the self-positioning of women with breast cancer in light of particular knowledges, Foucault's concepts of discursive power relations and subjectification are particularly helpful.

2.9.1 Foucault's Governmentality. In his body of work, Foucault describes the historical shift from sovereign power, which is a state of complete domination, to biopower and disciplinary power. In the social studies of health, Foucault's concept of biopower illuminates the ways in which institutions and disciplines exercise power through the categorization and surveillance of populations. Categorization is the process

through which individuals are placed into groups that are assigned social value that justifies measures of social control and judgment—for example, through the creation of the category of “madness.” individuals deemed “mad” become less credible. Surveillance of populations, through tools such as the census or mandatory reporting of communicable diseases, constitutes individuals as objects of knowledge that can be studied. This knowledge can be used to normalize individuals through discipline, government, further surveillance, and categorization. In *Discipline and Punish* (1975) and *The History of Sexuality Volume I* (1978), Foucault develops the concept of disciplinary power, which accounts for the regulation of individuals through the creation of the modern subject who is self-monitoring, “docile” and “useful.” These two types of power – categorization and surveillance – are exercised through technologies of domination and technologies of the self, respectively.

The technologies of domination and self are closely related, connecting at a point which Foucault refers to as “government” (Foucault, 1991). Accordingly, governmentality refers to the techniques through which ideal subjects are produced, not through overt wielding of force, but through networks of socially constituted shared meanings and understandings, and through self-monitoring of one’s own proximity to those ideal subject positions. Thus, governmentality functions in a way that is largely unnoticed to enable and constrain individuals.

Governmentality supports “*assujettissement*,” roughly translated as “subjectification,” which is the process through which subjectivities are created. As Heyes (2011) explains “power enables the identities we claim at the same time that it represses or limits us” (p. 160). New subject positions make available ways to be a

distinct individual, but at the same time individuals are subject to the control that accompanies these positions. To borrow Heyes' (2011) example, the creation of the subject position "homosexual" can be imposed on individuals and creates a distinction that is the foundation for homophobia. At the same time, this subject position provides a resource for social mobilization, solidarity, the creation of social spaces, and the development of skills. It can be the ground for claiming a particular identity.

Subjectification occurs on two levels: through management of the population and disciplining of the individual (Heyes, 2011). Subjects are produced at the population level through the creation and maintenance of social groups, and at the individual level through the governing of individuals who may belong to one or more of these social groups. Thus, techniques of producing the self are constrained through their connection with techniques of domination. At this junction, governmentality functions in such a way that we are each charged with the responsibility for governing ourselves. Discursive constructions reflect the appropriate way to take responsibility for ourselves. Discourse is defined as "a set of common assumptions which, although they may be so taken for granted as to be invisible, provide the basis for conscious knowledge" (Cheek, 2000, p. 23). Discourses make sense of experience in a particular way and enable us to create meaning from otherwise disconnected experiences, but the type of meaning that can be created is constrained by the discourses we can access. As Greenhalgh (2001) states, discursive selves are "actively constituted by individuals out of the discourses, or scripts available in their environment" (p. 42). Thus, the discourses available to individuals shape the ways in which they constitute their selves.

As we shall see in Chapter 4, in the case of breast cancer, discourses of militancy, surviving and thriving, the journey, and positivity were most commonly discussed. These discourses provided participants with an understanding of what a good patient, good woman with breast cancer, and good survivor should do and be. Because these discourses are reflected in the knowledges provided in the health care system, support services, and popular media, their effects went largely unnoticed by most participants, even as they conveyed moral imperatives about what women should and should not do. Resistance to such diffuse forms of domination, then, is complicated by obfuscation of the ways in which discourse constrains one's opportunities for constituting a different self.

On the social level, a category of women with breast cancer has been created, and this category is used to manage populations through statistics and monitoring that support public discourses of generalized risk and responsibility; for example, exhortations to eat in certain ways and to get regular screening identify all women as at risk and responsible for avoiding breast cancer. On an individual level, having breast cancer is no longer just having an illness; it is accompanied by a widely understood (dominant) way of being with breast cancer. This is made possible through public discourse, but also through individual practices that make use of these discourses (Heyes, 2011), such as telling one's story of breast cancer, wearing pink ribbons, and engaging in fundraising campaigns. Other aspects of women's identities, such as being a mother or being a feminist, co-exist with their identities as women with breast cancer. In a sense, breast cancer is now something that one is and one does.

Individuals both accept and resist these normalizing discourses, sometimes drawing on competing discourses as an approach to resistance. This resistance is risky,

though, as normalizing discourses create standards by which women are judged, and access to services is easier for those who meet these standards. Organizations (and ultimately the state) benefit from these normalizing discourses because they produce “good” patients who are easier to deal with in the health care system, active volunteers who contribute to breast cancer social support organizations, and family members or friends who require a type of support that may be easier to provide. When women hold themselves responsible for getting breast cancer, it becomes their responsibility to deal appropriately with the disease. Therefore, women are encouraged by others in subtle ways to reproduce these discourses, constitute socially acceptable identities and make decisions accordingly. The form of power that functions to enable and constrain women with breast cancer in this way is not one that overtly dominates, but is a taken-for-granted process through which normalizing discourses infused with morals, values and judgments become taken-for-granted understandings of what is normal and right.

Foucault contends that the forces through which the subject constitutes her self in various subject positions can be empirically studied: “The discursive and sociocultural conditions of possibility for subjectivity in a given historically specified location can be uncovered through an analysis of power/knowledge regimes” (Allen, 2008, p. 37). Examining the technologies of self, the everyday practices through which individuals construct ourselves as “good” or “moral” citizens, allowed me to better understand the ways in which culture, social structure and social relations influence the construction of illness identities and selves (Clarke & James, 2003). In particular, technologies of the self provide an understanding of the ways in which dominant discourses are reproduced through knowledge negotiation and self-constitution.

In being constituted by and constituting ourselves in particular subject positions, we give something up in order to access knowledge. For example, in being constituted as and constituting ourselves as good patients in health care interactions, we relinquish our critical capabilities in order to trust our physicians and medical technology so that we can gain knowledge about and power over our bodies. The breast cancer subject position, which is quite new, counters the less desirable subject position of the passive patient, promising both knowledge and empowerment without requiring that women give up anything. The norms, discourses and practices that create and are created by this breast cancer subject position say, “You can control cancer.”

Although critics of Foucault’s work have suggested that his understandings of power relations preclude autonomy, Foucault’s subjects are not merely determined (Heyes, 2011; Ramazanoglu, 1993). In the extent to which individuals constitute themselves as subjects and occupy subject positions, there are opportunities for the norms, discourses and practices that support these subjectivities to be viewed, revised, resisted and reinvented. The type of autonomy possible is not outside of the social, as traditional conceptualizations imply. Instead, the autonomy available in Foucault’s later understanding is one that makes the most of the enabling aspects of power relations and diminishes, as much as possible, the constraining effects. At the discursive level, this mirrors, in many ways, the understanding of relational autonomy as an autonomy that occurs within and through relations of power and privilege, which shall be discussed next.

While some theorists have celebrated the rise of the modern, autonomous subject, Foucault (1997) reminds us that this apparent increase in autonomy is often accompanied

by intensification of discipline. The technologies of self imply a measure of autonomy as subjects can, to varying degrees, interpret and resist the knowledges used to constitute their selves through critique (Allen, 2008). The discourses we accept matter because they shape our reality, but the choices we make are not entirely free, nor entirely determined (Greenhalgh, 2001). This theory offers the possibility of hope for transformation because social control is enacted, in part, through ourselves taking responsibility for good and moral action; we can choose not to act in this way and gradually redefine what it means to act morally. While one discourse may be dominant, there are alternative discourses that can be taken-up in new ways. For example, some participants in this study drew on environmentalist discourses to challenge beauty norms that encourage women to use make-up products that may be carcinogenic. That is, by imagining and acting on other ways of being, one may resist and potentially undermine dominant discourses, creating opportunities for the constitution of alternative subject positions.

It appears that opportunities for autonomy lie primarily in spaces where promises of subject positions fail to materialize, allowing subjects an opportunity to question that which was taken for granted. Taylor (2011) elaborates on a “critical attitude”, which is characterized by refusal (of norms that appear to be self-evident), curiosity (the need to analyze and to know), and innovation (to seek out and imagine other ways of being). Women with breast cancer, for example, may question the effects of the pervasive image of women with breast cancer as strong, positive survivors and try to imagine other ways of coping with the disease.

Unfortunately, Foucault’s work does not provide an adequate explanation of the ways in which power relations differently affect groups, meaning that technologies of the

self can be more constraining and resistance more difficult for members of groups facing social injustices. That is, Foucault does not explain how resistance to dominant discourses may be facilitated or inhibited by one's relations with others, material conditions, and previous experiences. For example, opting for alternative treatments for breast cancer requires discovering they exist, refusing traditional medical treatment, and being able to afford alternatives all while managing others' expectations. Foucault's limitation here may be partly because his work focuses on individual subjects, overlooking the importance of relationality (Allen, 2008). For a more robust account of the potential for resistance I turn to feminist relational autonomy.

2.9.2 Relational Autonomy. A relational theory perspective is characterized by an understanding of the self as socially embedded, interdependent, relationally constituted and embodied (Brison, 1997; Christman, 2004; Downie & Llwellyn, 2008; Mackenzie & Stoljar, 2000; Meyers, 2004; Sherwin 1998; 2003; 2009). Feminists pay particular attention to the political dimensions that shape relationships and the selves constituted in these (Sherwin, 1998). Constituting oneself as autonomous in particular realms may be constrained by these political dimensions. For example, within dominant biomedical frameworks, women with breast cancer may find it difficult to constitute themselves simultaneously as a "good patient" and an autonomous woman, since "good patient" often means a version of subjection to the dictates of medicine. In the context of enabling relations, the self can be both autonomous and socially dependent (Brison, 1997).

This understanding of the self differs greatly from the isolated and independent self characteristic of liberal individualism (Sherwin, 1998). This concept also differs from previous work by feminist theorists who use the term "relational" to refer to

decontextualized interpersonal relationships (Sherwin, 1998; see also Gilligan, 1982). In contrast, “relational” as used in this theory refers more broadly to the nature of selves as socially situated and contextualized within existing social structures and power relations (Sherwin, 1998).

Despite challenging liberal understandings of the self, feminist relational theorists agree on the value of retaining and revising liberal concepts that provide a place from which to argue for transformation (Mackenzie & Stoljar, 2000). These revised concepts are more responsive to the effects of power relations and accompanying systemic inequities than previous versions. For the purposes of this study, the revised concept of relational autonomy is most relevant.

Autonomy is a capacity or practice of acting in one’s own self-interest. Feminist relational autonomy conceives of autonomy as an ongoing process, constituted through and within interpersonal and political relationships (Mackenzie & Stoljar, 2000; Sherwin, 1998). Of particular interest to feminists are the relations of power and privilege that undermine or enable the development of the skills for exercising autonomy, and offer opportunities to exercise autonomy. From this perspective, discourses are reproduced, resisted or undermined within and through relationships with others. Relational autonomy is a matter of degrees and depends on the particular context, meaning that women may be more or less autonomous on different levels, in different situations, and at different times (Mackenzie & Stoljar, 2000).

Exercising relational autonomy requires developing autonomy competencies and skills (e.g. the ability to name and critique one’s reasons for taking an action), developing a sense of self as an autonomous agent (e.g. self-trust), empowering values on which to

base one's decisions, and supporting material conditions (Sherwin, 1998). The development of these skills, development of a positive sense of self, access to empowering values and supportive material conditions are often undermined by unequal power relations. Conversely, enabling relations support the requirements for relational autonomy.

Few studies have empirically examined the concept of relational autonomy. The issue one encounters when applying this concept is that it crosses levels of analysis that are rarely combined in social scientific studies. Examining the interconnections between competencies and skills, sense of self, values, discourse, decisions, actions and material conditions, all within the context of power relations, is no easy task for one study. Instead of trying to analyze all of these levels, I use Foucault's work to develop a detailed understanding of the ways in which women with breast cancer engaged, adopted, and resisted breast cancer discourse. While this fails to account for other factors, such as material conditions, it provides an analysis of the discursive level of power relations and can be combined with similar studies to form a better understanding of the moments in which women with breast cancer are enabled or constrained in acting autonomously.

Drawing on Foucault's governmentality and feminist relational autonomy, in this study I explore how women with breast cancer navigate among available discourses and the impact of these various ways of understanding on their approaches to decision-making regarding their treatment and lifestyle. While there are serious limitations on decision-making, all infused with power relations, women grapple with and make extremely complex decisions concerning their care—decisions that constitute them in a wide range of stances with respect to biomedically dominant ways of conceptualizing

cancer. Knowing how they employ, adopt, resist, subvert, or undermine these limiting conditions is important to both recognizing how and when women exercise relational autonomy and understanding how this might be better supported. This study extends the considerable theoretical work done on this topic, drawing on empirical data generated in discussion with women diagnosed with breast cancer. In the next chapter, I outline the methodology used to generate these data.

2.10 Ethical Commitments

Reflexivity is a practice used in qualitative research to examine the relationship between the researcher and her interpretations, often suggesting that through knowing this relationship, one can know how true the interpretations are. Pillow (2003) has challenged this approach, arguing that this comfortable form of reflexivity is underpinned by an assumption that one can know oneself, know others and know the truth. Understood in this way, reflexivity can function to hide the moments of uncertainty and discomfort that are typical of qualitative research projects (Pillow, 2003).

As a researcher, it is important to acknowledge some of the ways in which I shaped the research process. I am an outsider in the breast cancer community—I have not experienced breast cancer myself. Some participants stated that they were more comfortable with my outsider status because they did not have to worry about telling me something that would upset me. At the same time, I do not have insider knowledge and this necessarily limited my ability to fully understand participants' stories. In this study, I sought to understand the ways in which women with breast cancer experienced discursively constituted breast cancer norms. Most participants seemed to find comfort in these norms, even if they also struggled to live up to these ideals. I was most

uncomfortable in moments when I had to ask probing questions about the truth of these discourses; for example, I found it difficult when I asked participants interview questions about the connections they were drawing between positivity and risk of recurrence because participants seemed to have so much invested in their ability to control their risk of recurrence by being positive. I feared that undermining this connection would excessively upset them. At the same time, though, I did not want to underestimate what participants already understood and could handle. I continue to struggle with this balance when trying to represent participants as both enabled and constrained.

Representing others through research is not a comfortable process. Even the most complicated empirically-based representations, when written in a journal article or thesis, seem to fail to convey the complexity of the selves and the experiences discussed. And, in writing or telling, the shifting and complex nature of these selves is difficult to communicate. As Holland and Ramazanoglu (1994) explain: “In any research project, the quest for valid knowledge is at odds with a desire for order, stability and certainty in our methodology” (p. 145). In other words, our desire to put forward explanations that are easy to understand is at odds with the complexity of participants’ lives.

It can be uncomfortable to sit with what one cannot know and at the same time suggest that there is something very important that needs to be known, but this is the practice of qualitative research as it is currently understood. In conducting this research study, I made an ethical commitment to recognize this discomfort. For that purpose I drew on a concept developed by Pillow (2003) and sought to practice uncomfortable reflexivity throughout this research process. Uncomfortable reflexivity is the practice of seeking to know while at the same time situating this knowing as tenuous. To document

this process, I kept a research journal throughout that project that details my decision-making process and moments of discomfort.

Reflexivity may be facilitated by articulating the practical aims of the research study (Holland & Ramazanoglu, 1994). Critical research aims to draw conclusions that may support transformation. Consistent with this aim, I draw on Lather's (1986) concept of catalytic validity which "represents the degree to which the research process reorients, focuses, and energizes participants toward knowing reality in order to transform it . . ." (p. 272). In developing this concept, Lather (1986) places a significant burden on participants to know and transform reality. For consistency with my perspectives on responsibility for transformation in the context of oppression in privilege, I adapted this concept. Relational autonomy suggests that the full burden of transformation should not be on the individual herself. More effective transformation occurs at the levels of individuals and systems. Therefore, in addition to constructing conclusions that support women with breast cancer in better understanding the relations in which they are embedded, I aimed to generate conclusions that may help individuals working in breast cancer support organizations to better understand how to support women in exercising relational autonomy. In Chapter 3 I describe the methodology I used to generate the data for this study.

Chapter 3: Methodology

In this chapter, I describe the qualitative methods used in this research study. In doing this, I begin by outlining the research questions that guided my methodological decision-making. I continue by describing the qualitative methods and approaches to data analysis that I used to generate the data I draw on in subsequent chapters.

3.1 Research Questions

Relational autonomy helps us to understand that women's degree of autonomy in making treatment decisions regarding their breast cancer is affected by their understandings of the disease and available options. Hence, I explored how women with breast cancer navigate among available breast cancer discourse to see the impacts of these ways of understanding on their approaches to decision-making in their health care encounters. In order to do this, I sought to answer the following research question and sub-questions:

How do women diagnosed with breast cancer navigate breast cancer discourse while making treatment and lifestyle decisions?

Sub-questions:

How do women diagnosed with breast cancer decide what to believe when negotiating multiple, partial, ambiguous and/or contradictory discourses?

How do women diagnosed with breast cancer constitute their selves through the affirmation, negation, and/or revision of these discourses?

How do the knowledge negotiation and self-constituting practices of women diagnosed with breast cancer serve to reproduce, revise, or undermine dominant discourses of military, survivor and femininity?

3.2 Approaching Qualitative Health Research

Qualitative approaches to the study of health and illness became more popular in the 1970s as researchers became interested in the subjective and complex nature of experiences of health and illness (Thorne, 2011). Early qualitative health researchers drew on three major methodological approaches from the social sciences in developing their studies – phenomenology, ethnography, and grounded theory (Thorne, 2011). Although qualitative health researchers continue to struggle for recognition in a field dominated by randomized controlled trials and quantitative studies, early qualitative health researchers faced more difficulty in arguing for the credibility of their research (Thorne, 2011). Health science researchers question the value of qualitative research, and social scientists question health researchers' ability to conduct qualitative studies with little or no methodological training (Thorne, 2011). Thus, qualitative health researchers continue to struggle to develop the credibility of their field.

Thorne (2011) describes the ways in which this difficult beginning led to the development of a “rule-bound qualitative health research culture” (p. 445):

In the context of this juxtaposition of social science heritage and health science resistance, the community of clinicians working within qualitative health methodological traditions coped by creating a set of rigid and rigorous rule structures to govern what might constitute quality criteria. (pp. 445-446)

Adherence to methodological rules thought to guarantee rigor have resulted in a single-minded focus on method within the field, overlooking the importance of context for the modification of qualitative methods. The field now demands adherence to the rules of

phenomenology, ethnography, or grounded theory as proof of rigor and credibility.

Janesick (1994) refers to this trend as “methodolatry” (method + idolatry), the prioritization of research methods over other concerns in qualitative health research.

Alongside rules overshadowing the methodological needs of particular studies, rule-bound qualitative health research also suffers from significant misapplications of the rules it so strongly promotes (Thorne, 2011). Thorne (2011) examines the use of the concepts of “bracketing” developed in phenomenology, and “saturation” from grounded theory to demonstrate that qualitative health researchers’ extraction of rules from the methodological contexts in which they were developed often leads to misapplication. In this way, rules meant to extend the credibility of qualitative health research actually serve to undermine the field. In adhering to rules with few methodological reasons for doing so, qualitative health researchers may well be overlooking the methodological requirements of their projects—projects that are intended to produce results that may inform our real-world understandings of health, illness, and health care delivery. In response to these issues, Thorne (2011) calls on applied qualitative health researchers to work towards “methodological emancipation” by developing unique methodological approaches that respond to the complex and applied nature of qualitative health research.

In a similar vein, Sandelowski (2000) argues that negative views of descriptive qualitative research have resulted in qualitative health researchers claiming to use an accepted methodology when they are actually conducting descriptive qualitative research. Sandelowski (2000) argues for the value of qualitative descriptive studies, which she defines as:

A comprehensive summary of events in the everyday terms of those events ... Qualitative descriptive designs typically are an eclectic but reasonable combination of sampling, and data collection, analysis, and re-presentation techniques. (p. 334)

Caelli, Ray and Mill (2003) describe a similar approach, which they name “generic qualitative research,” defined “as that which is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies” (p. 2). This “generic” approach to qualitative research makes use of qualitative methods appropriate for answering the research question, but is not limited by the philosophical foundations of ethnography, phenomenology or grounded theory. By stating the actual methodological approach (or lack thereof), qualitative health researchers can better account for how they actually did their research – even while risking the loss of credibility that may result when they forego the safety of at least nominal adherence to methodolatry.

The concern that arises when researchers conduct descriptive or generic qualitative research is how best to judge the quality of that work. As these approaches are rarely named, discussions of how best to do this research are rare. Drawing on the literature that does exist, the first lesson is that stating what one actually did, as opposed to what a methodological orientation states should be done, is important. That is, acknowledging that one is doing generic or descriptive qualitative research is required so that one can account for the quality of their work without relying on measures of rigor developed for other methodological approaches. Caelli, Ray and Mill (2003) suggest four basic requirements for good generic qualitative research: noting the researchers’ position,

distinguishing method and methodology, making explicit the approach to rigor, and identifying the researchers' analytic lens. In the following sections, I give an account of the methods and theoretical considerations I made in the completion of this generic qualitative study.

3.3 Overview of Methods

In order to answer these research questions, I used qualitative interviews and guided online discussion groups. Qualitative methods were appropriate because they allowed me to illuminate the complex ways in which discourse, knowledges, subjectivities and experiences interact. Twelve women diagnosed with breast cancer took part in three interviews each and, in two groups of six, contributed to a weekly online discussion group for 12 weeks. A thirteenth participant was recruited, but decided to leave the study after one interview.

3.3.1 Recruitment and Participants. Inclusion criteria for this study were: women diagnosed with breast cancer who had received treatment for breast cancer in the past 12 months in Halifax (a small urban centre in Nova Scotia), were over the age of 18, were able to speak English, and had access to a computer for online discussions. Women undergoing treatment at the time of the study were welcome to participate if they felt participation would not be overly burdensome. Women may consider ongoing hormonal and biological therapies (such as daily doses of Tamoxifen) to be active treatment and were welcome to participate if they felt they could provide accounts of their breast cancer experiences. Efforts were made to recruit women who identified as coming from a range of racial, ethnic, and socioeconomic backgrounds, as well as diverse sexual orientations, for maximum diversity sampling.

Participants were recruited with the assistance of a local breast cancer support organization, Breast Cancer Action Nova Scotia, and through convenience sampling. A recruitment poster (Appendix A) was distributed in the community using listservs, Kijiji, Facebook, and bulletin boards in public locations such as libraries and malls. Posters and ads asked potential participants to contact me by phone or email. In the initial phone call or email, a screening questionnaire was used to gather demographics and screen for inclusion/exclusion criteria, listed in the above paragraph (Appendix B). Those screening forms were intended to seek maximum diversity in the sample, ensuring a range of participants in terms of disease type, treatment trajectory, age, ethnicity, socioeconomic status, sexual orientation, and relationship status. As soon as all study participants were recruited, screening forms for women who were not part of the study were destroyed.

Thirteen participants were initially recruited for the study. After the first interview, one participant decided to leave the study, citing time constraints as her reason. As that participant only took part in the first interview, I removed her transcript from the data set prior to analysis. The remaining 12 participants ranged in age from 39 – 64; most self-identified as middle class, in long-term relationships and white (see demographics table, Appendix C). Participants varied in their disease stages, some were still undergoing surgeries, radiation and chemotherapy, some had finished active treatment in the past 12 months, and some were further from than 12 months their surgical treatments but continued to undergo hormonal and biological therapies. Although efforts were made to recruit participants from diverse class, ethnic, racial and socioeconomic backgrounds through the distribution of study information in community networks, participant demographics were quite homogeneous. According to the 2006 census (Statistics Canada,

2008), only 4.2% of Nova Scotians identify as being a member of a visible minority. Thus, homogeneous participant populations are typical of studies conducted in Nova Scotia unless the researcher is a member of a marginalized community or the research is focused specifically on individuals from a marginalized community. Participants received a \$25 honorarium per interview and \$25 for participating in the online discussion group.

3.3.2 Consent Processes. It was important that participants understood the rationale for the study, time commitment involved, inclusion criteria, and their ability to withdraw from the study at any time or refuse to answer questions without consequences. When each participant arrived at the initial interview she was given sufficient time to read, review and ask questions about the information presented in the consent form, which provided information and requested consent for three interviews and participation in the online discussion group (Appendix D). The consent form reads at a Grade 9 level. I ensured informed consent had been provided before proceeding with the interview. Each participant was provided with a copy of the consent form for her records. When each participant arrived at the second and third interviews she had an opportunity to ask questions, and the main points of informed consent were reviewed and confirmed orally. Continuing informed consent was requested each time participants logged on to the online discussion group website. My email address and phone number were provided in case participants had any questions.

3.4 Data Generation Methods

Participants took part in three semi-structured interviews each over a period of six-12 months. Interviews were approximately 60-90 minutes in length and were held in a location convenient for the participant, including private rooms in public libraries,

participants' homes and private rooms at Dalhousie University. Between the scheduled interviews, participants responded to questions via a secure and private online discussion group website, with most participants posting at least weekly. A total of 36 interviews were conducted, transcribed and analyzed. The number of online discussion group posts exceeded 200.

3.4.1 Interviews. Participants each took part in three interviews over a period of 6-12 months. In the first interview, I asked each participant to discuss her illness and treatment experiences. This generated a narrative description of the breast cancer experiences, as well as health care and social support experiences (Appendix E). In the second interview, I asked each participant to discuss her health knowledge-seeking experiences (Appendix F). Prior to the third interview, participants received a copy of an overview of initial results (Appendix G). I also reviewed each person's transcripts and online discussion posts to prepare follow-up questions and probes. The final interview allowed participants to reflect on participation in the project, including interviews and online discussion groups.

In some qualitative studies, initial results are provided to interview participants for a member check, meaning that participants review the researcher's interpretations to determine if the account accurately represents their stories. The third interview in this study was not a member check in that sense; participants' responses to my analysis could not result in complete revision of the interpretation provided to participants for discussion. As my analysis was one of many possible interpretations of the data, I was asking participants for feedback that shaped the ongoing analysis of the data. Participants' responses in this interview were coded with the same scheme as the other

two interviews and discussion group results. Most participants expressed agreement with the initial analysis. A couple of participants felt their experiences were not well-represented, and I sought to address their concerns in this account. In both the third interview and the discussion group, it was valuable to document participants' responses to other women's thoughts because it allowed them to articulate their own perspectives more clearly.

The use of multiple interviews allowed me to ask follow-up questions that would not have been addressed in a single interview. It is interesting to note that in many cases, participants gave nearly identical accounts of their illness in multiple interviews. I perceived this as indicating that they had versions of their cancer stories that were to some extent "rehearsed," at least internally. In some interviews, my questions had to be more direct in order to get participants to delve deeper than these possibly-rehearsed accounts. Multiple interviews also allowed me the opportunity to document change in participants' experiences over time. In cases of participants who were still undergoing treatment or had recently ended treatment, there was significant change across the three interviews; in cases of those who had finished treatment before the interviews, there was less change. These changes were particularly clear in participants' discussions of their involvement in the breast cancer community, which tended to decrease as time passed and they began making decisions about the ongoing role of breast cancer in their lives.

3.4.2 Asynchronous Online Discussion Groups. Online qualitative data generation methods are becoming more common. Some researchers argue that these methods simply reproduce traditional methods in a new medium, while others argue that the use of these methods will transform qualitative research (Wiles, Crow & Pain, 2011). Accounts of the

use of online methods typically describe the use of pre-existing blogs or discussion groups and synchronous online discussions in which participants log on at the same time and interact via typed or oral chat. In many ways, these approaches mirror existing qualitative methods, including the analysis of texts (commonly diaries, journals or other narratives) and focus groups, respectively. This is not to say that these methods do not access unique data in a medium that is becoming increasingly important in our daily lives, but the approaches to these forms of data generation are reminiscent of other qualitative approaches.

The use of asynchronous, researcher-led online discussion groups, in which participants take part in a discussion group but post at different times, is less common. This approach draws on the methods underlying focus groups and other online methods, but provides participants with more time for review, reflection and discussion of each question. Though less spontaneous, asynchronous online discussion groups provide opportunities for participants to respond to complex questions that would be difficult to answer quickly. Also, as the question is available for response for a period of time, participants with illnesses can work around their treatment schedules and respond to the question when they are feeling well enough to do so. Two participants in this study had been previously enrolled in a study that used online focus groups and had left that study because of difficulty in scheduling the timing of focus groups. Practically, the use of asynchronous online discussion groups seemed to increase participation by overcoming the scheduling difficulties often faced in the organization of focus groups.

For the purposes of this study, a website designer built a Canadian-hosted website that included information about the study, a consent and login screen, and discussion

board. Following their first interviews, participants were divided into two groups of six, allowing for a more engaged discussion with less time commitment. Groups were selected based on timing of their entrances into the study and on whether or not participants were engaged in the same support groups and community organizations. I made efforts to separate participants who would know each other well, but in a small community it is possible that some participants knew each other before both joining the study. Initiation of online discussions was staggered by two weeks. Before beginning the discussions, participants selected online names and passwords that provided them access to the discussion board. Participants were allowed to choose their own names or pseudonyms. Most participants selected pseudonyms, but many shared their real names and contact information before the end of the study. Participants were aware that confidentiality and anonymity could not be guaranteed in the context of the discussion group.

In Weeks 2-11, I posted questions asking participants to discuss elements of breast cancer discourse that had come up in the interviews. Week 1 and Week 12 were reserved for introductions and reflection on the group (Appendix H). For the most part, I engaged in the online discussions only when I was asked a direct question or when discussion slowed. The appropriate level of moderation differed based on group dynamics. Discussion varied between groups, with members of one group very engaged in discussion with each other and member of the other group more focused on posting lengthy individual responses to the questions. It was more common that the group engaged in discussion came to some form of agreement in response to questions, often expressing their agreement with the discourses under discussion. This discussion fuelled

responses and led to significantly increased engagement. In the other group, participants tended to post their responses before reading others, which led to more diversity in the responses provided, but also fewer posts and less debate.

Asynchronous online discussion groups are not often used in qualitative research so feedback from participants in this study may be useful for other researchers hoping to use this method. During the second and third face-to-face interviews, participants were able to discuss their experiences of participating in the online discussion groups. Overall, most participants felt it was interesting and thought-provoking, and reported that they enjoyed the opportunity to interact with other participants. For some, concerns about being judged by others, time constraints, and difficulty communicating in writing kept them from participating as much as they would have liked. Pamela², for example, described enjoying the discussions, but sometimes had difficulty taking the time required to complete her posts:

I look forward to it. I look forward to seeing what the next question is, because I don't find it stressful. And there are times, like I said, I was very much engaged in the conversations. And then, these last two weeks, it's like oh my God, I just gotta get the information in there and at least participate. I think it's a good idea.

At the beginning of each week I sent a reminder email to participants and reiterated the fact that they could choose not to participate. This may have lessened some participants' concerns about their levels of engagement.

² Pseudonyms are used to refer to participants.

A small number of participants would have preferred an 8-10 week group. Pamela stated that she could have been a more active member in a shorter group:

I believe this research was excellent, however I believe perhaps a little long. I think 8 to 10 weeks would have been sufficient. I kinda got lost after 9 and just couldn't get back into the commitment of being a responsive member.

Researchers hoping to use this method should consider the participants' abilities to commit the time required to complete these discussions.

Some participants found it difficult to contribute to the group for other reasons. One participant, who was less familiar with computers and felt she didn't fit in with the other participants, struggled at some points to contribute to the group:

I'm not a big one for going online and doing things like that anyway, unless I'm doing a job search or something. So I've found it interesting reading some of the other posts. I've had a hard time trying to, I don't know. I can appreciate what they're saying. And I feel like I don't have much to offer to the subject. Maybe that's it. (Paula)

Paula felt more comfortable taking part after her second interview, during which we spoke about her contributions and I reassured her that her posts had been valuable. Face-to-face interviews (which occurred about week ___ of the online discussions) provided a good opportunity to discuss the online discussion group and support participants who were less comfortable with the format.

Participants had differing reactions to the fact that they would not meet the other participants in the group. At times, participants described being more comfortable sharing

perspectives in a more anonymous environment. At other times, participants were cautious about their contributions because they could not judge how others might react.

Alice described this tentativeness:

It's an online discussion so I find it interesting 'cause it's only been five or six chats, I don't have any clue who these people are, and I feel like there's a tentativeness. I mean, people don't want to offend anybody else. And so there's some very, very different views out there, which is interesting. But I feel like we're being somewhat tentative, not wanting to tread on the toes of another survivor. I find that really fascinating, that I mean, I can hear it, through the posts, that we're doing our best to not offend anybody else.

These efforts not to offend others clearly shaped the data that participants provided during the online discussion group. At the same time, participants' recognition and discussion of these moments of tentativeness provided a valuable starting point for interview conversations about how women with breast cancer may act around each other. As with any group-based data collection method, researchers must take group dynamics into account when using the data. I have made efforts throughout my analysis to note when this method shaped the data I am using in my interpretations.

The data provided in these online discussions constituted a valuable source of information about participants' reactions to breast cancer discourse and the ways in which they governed their own and others' reactions. Overall, the asynchronous online discussion group was a valuable, practical, and convenient way to generate a different

form of qualitative data. Participation in the group also provided topics for discussion in the interviews that took place during and following the group.

3.5 Data Storage and Transcription

3.5.1 Interviews. All interviews were digitally recorded and transcribed verbatim by a transcriptionist who had signed a confidentiality agreement. Participants were made aware of the recording and transcription procedures during the informed consent process. The original audio file was stored on a password-protected computer in my locked office. Digital recordings and transcripts were exchanged using secure file exchange. Audio files were deleted after they were used to clean the transcript by removing identifying information and correcting transcription errors. The transcriptionist was asked not to hold copies of the recording or transcript on her computer's hard drive. Identifying information was removed from transcripts before they were loaded into the qualitative analysis software, Atlas.ti version 6. I chose to use a qualitative data analysis program because it allowed me to organize large quantities of data for easy retrieval during the writing process. I selected Atlas.ti in particular because I am familiar with it and have access to the software. As required by the Dalhousie University Health Sciences Research Ethics Board, all data from the study will be destroyed 5 years after I have ceased publication of the results.

3.5.2 Online Discussion Group. Each week all comments from the online discussion group were downloaded directly from the website into a password protected Word document. The Word file was stored on a password-protected computer in my locked office. Identifying information, if provided in the online discussions, was removed before the document was loaded into the qualitative data analysis software, Atlas.ti

version 6. Discussion posts were grouped by discussion week and group before being loaded into the program; for example, the discussion posts from Group 1, Week 1 were compiled in one document, allowing for analysis of the back and forth discussion posts from that week. The website was deleted from the server following the final week of discussion.

3.6 Data Analysis

The ongoing interviews allowed me to develop rapport with participants and facilitated more complicated understandings of their experiences. In the first interview, participants had the opportunity to tell their breast cancer stories, which provided background for the following interviews. In the second interview my questions focused on knowledge-seeking and interpretation. The third interview provided participants an opportunity to respond to and further my initial analysis. Online discussions provided participants with the time to reflect on and discuss breast cancer discourse. As much of this is taken for granted in our lives, direct questions about subjectivities and discourse can be difficult to answer. During the analysis process, I paid attention to the ways in which each participant presented and governed her self in relation to discourse and others.

Interpretation takes place throughout the qualitative research process. The analysis process I used for this study was adapted from Mauthner and Doucet's (1998) voice-centered relational approach. Initially developed to reflect Gilligan's (1982) relational ontology which focuses on interpersonal relationships, Mauthner and Doucet (1998) revised the method to reflect a feminist relational ontology that focuses on relationships within constraining or enabling social structures. This approach to analysis

reflects this ontology and places the participants' voices at the centre of the analysis process. The method developed by Mauthner and Doucet (1998) requires significant time commitment; even the authors themselves did not finish the process they suggest during their doctoral work. For this reason, I revised the process to respond to the practical constraints of graduate work.

3.6.1 Phase One: Reading for Broad Themes. Combining the first four readings suggested by Mauthner and Doucet (1998), this phase involved reading transcripts to identify main storylines, which may be multiple and conflicting; how each participant experiences, feels and speaks about her self; how each participant describes herself in relation to others; decision-making moments; and how participants' accounts fit within social contexts. These areas were the focus of my first reading of each transcript. I hand coded for these themes using coloured pencils. I did not use Atlas.ti for this first step because I was looking for broad themes that did not translate well into the codes required by the software program.

3.6.2 Phase Two: Developing an Initial Report. Mauthner and Doucet (1998) suggest creating a case study for each participant in the second phase of coding. Each case study should provide a brief overview of the main storylines, self-presentation, relationships, and social constraints and enablers outlined in the transcripts. Many of this study's participants were interested in the ways in which their stories compared to others. To respond to their requests for this information, I decided to combine cases in the form of a brief initial report. Drawing on the hand coding completed in phase 1, I developed an initial report that described some of the main themes present in the first two interviews (Appendix G) focusing on those that I thought would inspire the most discussion in the

third interview. The initial report was provided to all participants by email weeks before the third interview so that they could review and respond to the content.

3.6.3 Phase Three: Breaking Down the Text: Detailed Coding. In phase three I developed a code list by drawing on the content of the transcripts, initial report, online discussion group discussions and research questions. I then assigned these codes to sections of text through repeated review of each transcript and online discussion thread. Development of the code list was iterative; as new concepts came up new codes were created if necessary. Atlas.ti version 6, a qualitative data analysis software program, was used to facilitate organization of the codes and data.

In the next stage of analysis, I selected combinations of codes that I believed would help me answer the research questions. In doing this, I used Atlas.ti to produce code reports that provided all the data that was coded as two codes of interest. For example, a report of all quotes coded as both “Others- women with breast cancer” and “Compare self to others” provided data in which participants compared themselves to other women with breast cancer. I then further grouped the quotes in these reports into common themes and drew on these to create the sections of Chapters 4, 5 and 6. Necessarily, there is much data that is overlooked in this process. I used the research questions and conceptual framework to guide my decisions about what data to include and exclude from this account.

3.7 Dissemination of Research Results

I am making efforts to communicate the results of this study to women with breast cancer, health care and support service providers, policy makers and program developers in the 12 months following completion of analysis. Dissemination activities include, but

are not limited to: a report provided to participants, supporters, and local breast cancer organizations and services; academic and policy conference presentations; and academic journal articles.

In the following three chapters, I provide an academic account of the study results. In Chapter 4 I examine the breast cancer discourse described by participants. In Chapter 5 I describe the ways in which participants adopted these discourses to constitute an idealised breast cancer subject position. From this idealised subject position, participants engaged with the breast cancer community in ways that encouraged connections between community members, but also self-governance and discipline of others. In Chapter 6 I examine participants' treatment and management decisions in the context of breast cancer discourse, arguing that participants' struggled to imagine other ways of doing cancer.

Chapter 4: Discourses: Talking About Breast Cancer

4.1 Introduction

Public discourses of individualized risk of breast cancer inform women that they can lower their risk of cancer by exercising, eating well, having children, and maintaining a healthy weight (Yadlon, 1997). Articles in women's magazines and segments on popular television shows suggest that women have the power, even the responsibility, to control cancer by controlling their lifestyle. While these public discourses raise women's awareness of their statistical likelihood of cancer, they also suggest that this is a risk that can and should be controlled through individual actions. It is no surprise, then, that participants in this study felt they should have been able to control their risk of breast cancer and were shocked to receive the diagnosis, particularly when many felt they had done everything they could to lower their risk.

Following their diagnoses, many of the 12 women who participated in this study described feeling betrayed by their bodies and losing their sense of safety in the world. Susan Brison (2001) describes one of the losses caused by trauma as a loss of "necessary illusions" (p. 50), the sense that we are safe in the world that allows us to function in our daily lives. Being diagnosed with a life-threatening illness challenges individuals' belief systems and the way they make sense of the world. Most participants struggled to make sense of their diagnoses, and senses of uncertainty permeated the time following their diagnoses. For many, this same feeling of uncertainty occurred again after treatment concluded and participants were expected to return to their "normal" lives.

In one approach to coping with this uncertainty, most participants turned to health professionals and medical literature to better understand breast cancer. For individuals

with no background in health care, participants demonstrated in-depth understandings of types of breast cancer, prognoses, possible treatments, and side effects. Most of the information participants gathered reflected a medical science and physical reductionist understanding of health and disease. Most participants found this reductionist understanding of disease inadequate in its inability to respond to some questions that concerned them, such as, “what does it mean to have breast cancer?” and “how can I live my best life with this disease?” Mind-body discourses, which connect physical experiences of health and illness with ways of thinking and being, provided more useful answers to such questions and became the foundation of most participants’ efforts to understand their lives after diagnosis.

Breast cancer discourse draws on, intersects with, and incorporates elements of coexisting discourses of living with illness, which I call mind-body discourses. These ways of talking about illness are referred to as “mind-body” because they can be used to talk about connections between one’s feelings, thoughts, and ways of being during illness and the progression or severity of physical disease. Though they are elements of larger accounts of illness, I am examining here how mind-body discourses are used in discussions about breast cancer in ways which contribute to shaping an idealised version of how to be a “good” woman with breast cancer.

In this chapter, I examine the mind-body discourses that participants in this study discussed most commonly. These include: fighting, bravery, and strength; surviving and thriving; the journey; and positivity. I provide some context for these and describe how participants defined these ways of understanding and thinking about cancer. Participants used the discourses discussed in this chapter to construct an idealised way of being a

woman with breast cancer that crosses the boundaries of medicine into everyday life. I also examine the ways in which participants exhibited resistance to these discourses, despite both the usefulness of these discourses and the risks of resistance.

4.2 Know Your Risk, Know Your Body: Your Health Is Your Responsibility

Being diagnosed with breast cancer required participants who felt healthy to adjust to the fact that they actually had a life-threatening disease. Since none of them felt ill at the time of their diagnoses, this was often a confusing transition characterized by an initial shock that eventually gave way to uncertainty. Mary explains how disorienting diagnosis was for her: “I’ve got a life threatening illness? I’m not sick at all. What are you talking about? I could run a marathon this afternoon. So it kind of hits you.” Similarly, Alice discusses the difficulty she had understanding her diagnosis: “I don’t understand how you can be healthy and have these things at the same time. To be told, ‘Well, you’re a really healthy woman.’ I’m thinking, ‘Well, then okay, then how, why do I have breast cancer?’” Diagnosis was not just shocking; it also challenged participants’ beliefs about health and illness in two ways.

In the first sense, diagnosis was shocking for participants because they drew on a common understanding of health and disease as dichotomous states; that is, a person is either healthy or ill and cannot be both. As most participants felt healthy at the time of their diagnosis, learning that they had a disease was a shock that challenged their perceptions of what it means to be ill. This is further complicated by the fact that most physical experiences of illness during breast cancer are caused not by the disease itself, but by side effects of the common treatments for the disease.

In the second sense, diagnosis was shocking because participants felt they could control their risk of cancer. This belief is supported by public discourse about breast cancer risk that suggests that women can control their cancer risk through healthy lifestyle choices (Lantz & Booth, 1998; Lupton, 1994; Robertson, 2000; Yadlon, 1997). In focusing on lifestyle, this discourse fails to represent the reality that many women with identified risk factors never get the disease, and many people with breast cancer have only one or two risk factors, most commonly being female and over 35 years of age. This study demonstrates that many women who live extremely healthy lifestyles still get breast cancer.

The shock of being diagnosed with breast cancer, especially with no obvious external symptoms of illness, was accompanied by a feeling of losing a sense of control over one's health and body. This feeling of losing control is also fuelled by public discourses of personal responsibility for one's own health, which suggest that responsible women make good lifestyle choices and maintain their health. These discourses are further intensified in discussions of women's responsibilities to sense when something is wrong in their own bodies. I refer to this discourse as "know your body."

This discourse has been used by those on the borders of biomedicine as a tool to challenge biomedical expertise (Harrington, 2008). Feminists and holistic health practitioners drew on this discourse to challenge male and biomedical definitions of disease by citing women's bodily experiences of illness that did not fit within biomedical categories, and experiences of wellness that were categorized as illness. This discourse is used today as women's health organizations continue to challenge dominant categories of disease in debates about the disease status of chronic fatigue syndrome and fibromyalgia,

arguing that women's own knowledge of their bodies informs them that they have illnesses, even if these are not recognized medically. In this way, the discourse I refer to as "know your body" is a resource for women challenging the authority of biomedicine.

At the same time, this discourse is used by health professionals to instruct women about their individual responsibility for maintaining their health. This mirrors a broader shift in approaches to health promotion that focus on individual behaviour as the primary determinant of disease prevention. Becker (1986) describes one of the consequences of this individualistic approach to understanding health and illness: "the individual-responsibility approach has helped to establish 'health' as the New Morality by which our character and moral worth are judged. 'Being ill' is redefined as 'being guilty'" (p. 19). According to this discourse, our bodies are not just resources for knowledge—it is our moral responsibility to access the information our bodies want to share with us. In the fields of public health, health promotion, and biomedicine, the "know your body" dictate becomes "responsible women know their bodies." In the field of breast cancer prevention, knowing your body is equated with conducting regular breast self-exams and identifying possible tumours or "lumps." The prevalence of this discourse imbues the practice of breast self-exams with a moral responsibility that supports the conclusion that irresponsible women fail to do breast self-exams or conduct them incorrectly. Failing to do self-exams properly becomes a failure to perform one's duties as a responsible woman with breasts.³

³ The effectiveness of breast self-exams is debated. There is evidence that breast self-exams are ineffective in decreasing mortality from the disease and some guidelines suggest that they cause more harm than good (McCready, Littlewood & Jenkinson, 2005).

Although mammograms and biopsies can identify tumours at earlier stages than self-exam (Nelson et al., 2009), participants in this study expressed a sense that they were responsible for detecting changes in their breasts that may signal the presence of cancer. Most participants who had identified a breast lump and initiated investigation and treatment felt certain they could do the same again in the event of a recurrence. Participants who did not identify their lumps themselves expressed distrust of their bodies, which was rooted in a distrust of their own abilities to access the secrets their bodies held. Joyce describes feeling unintelligent because she did not know she had cancer, even though she did seek medical treatment after sensing changes in her body that she attributed to menopause:

I lost all total trust in my body. I didn't know I had cancer. The doctor found it. If I hadn't gone to her, and just blew it off, that it was just menopause starting, I don't know where I'd be today. So now, it's, you know, you feel like an idiot, every time there's something going on.

Although all participants expressed a fear of recurrence, this distrust of one's ability to know one's body fuelled a more intense fear of recurrence for many participants. Having adopted the "know your body" discourse, participants felt an increased sense of failure and feared missing another "sign" in the future. For some, regular screening through mammograms and/or MRIs provided some certainty, but others' experience of tumours having been missed by diagnostic technologies eroded their trust in these screening tools.

Even for those participants who did find their tumours through self-exams, their inability to identify risk and act before they got cancer suggested to them that they were not doing everything that a responsible, smart, healthy woman should do. Whether the

risk factor they thought they missed or “failed” to address was stress, exposure to contaminants, social isolation, or unhealthy lifestyle choices, most participants had some moments when they attributed their disease occurrence to some part of their previous actions or inactions. Heather described many ways in which she believed her actions led to her diagnosis:

One time, about five years ago, my parents had a rental property. And they had a fridge that was really dirty and full of mould since the people had moved out. So I said, ‘Oh, I’ll clean it for you. That’s not a problem.’ And I used bleach, straight bleach. And I didn’t wear gloves. And I noticed that, the next day, my hand was swollen. And so, I think, I don’t know if I damaged the lymph nodes or if, the chemicals actually seeped into the breast tissue. ‘Cause [the doctors] said, according to my tumour, that it was, about five years along.

In addition to fear that she had caused her cancer by using bleach, Heather wondered about the contributions of her body weight, activity level, diet, stress, and self-care practices:

And, what else? Just, I hadn’t been exercising as much as I should’ve. I had put on a bit of weight, within the last, like ten years or so. Like, I did walk a lot and I was doing hot yoga. But I still had put on, like a few pounds every year. And having that extra weight, I think wasn’t good ... My diet was pretty good. Now, I switched to soy, and I was drinking like quite a bit of soy. So now, you know, there’s debate about that, right? I didn’t eat a ton of beef, but I did occasionally ... I didn’t do the self breast

exam every month, to be honest. I did it occasionally, but, you know, if I could go back in time, you know, I'd do that every month.... so the cause, I think a lot of it was, I just think, stress.

Heather was highly upset during this discussion of risk factors. She and other participants struggled with the self-blame they experienced after their diagnoses.

Although intellectually, many participants knew their risk was no higher than that of most of their friends', they nonetheless struggled with self-blame. This self-blame was emotionally difficult for many participants, yet the alternative was often more frightening. When individuals are made responsible for their own health, they may have a sense of control over their ability to remain healthy or, at least, recover from illness. The alternative, that everyone is always at risk of becoming ill, was a difficult idea that participants discussed in their interviews. Elsie describes the random and prevalent nature of cancer: "Something triggered it, but I don't know what it is. I think we all have it. I don't know, but something triggered it." At times, participants accepted this uncertainty and used it to fuel such life changes as living in the moment and eating healthier foods:

It never crossed my mind that it would prevent it from coming back. You know? If it's going to come back, it's going to come back. I don't think there's anything you're going to be able to do to stop it, if it's in your cells. Other than to try to be as healthy and happy as you can, in the interim. ... Cancer or not, just try and live healthier. (Paula)

At other times, this uncertainty was rejected and participants sought control over their health through specific lifestyle changes. Heather, for example, sought to address the lifestyle factors she believed caused her cancer and would cause a recurrence:

My main goal [in changing my lifestyle] is to prevent recurrence. I thought, okay, I need to take a hard look at my life and look at why I got breast cancer in the first place, or how, if you will. And, just make the major changes in my life that I need to. And also, I think a lot of it was stress related. So I have to look at, like psychologically, some negative thought patterns that I had. I was always very hard on myself and kind of had low self esteem.

Engaging in lifestyle changes gave some participants the sense of having control over their cancer recurrence risk, but also perpetuated a challenging form of self-blame.

In literature on health and risk, it is clear that failing to live up to the responsibilities described in public discourses about cancer can be experienced as personal failure (Yadlon, 1997). All participants in this study experienced some guilt or shame about being diagnosed with cancer, and in some ways taking on this responsibility provided moments of certainty. However, this experience of failing to do what one should have was accompanied by a stronger sense of having been failed by the health information provided to them. Most participants recognized that they had done as much as anyone else to maintain their health and lower their risk. Mary was shocked by her diagnosis, but suggested that her health practices were as good as or better than those of others who did not have cancer:

Someone [in the discussion group] said something about worrying more about toxins in our environment and worrying more about what we're eating and worrying more about what we're putting on our bodies, sunscreen or whatever, all these different things, worrying more about

stuff like that. And I'm thinking, 'Well, I know people who are careless and have terrible diets and don't look after themselves. And they're grossly overweight, smoking, whatever. And they've never been diagnosed with cancer.' And here I was, looking after my health, you know; I was a reasonable weight. And eating healthy, I don't smoke, exercising. And I was diagnosed. So, dwelling on improving all that stuff, and worrying more about it, is that going to prevent me from getting a recurrence diagnosis? I don't think so.

Despite their efforts to maintain their health, participants were diagnosed with breast cancer. In this way, many participants felt they had been failed by the health promotion and disease prevention strategies in which they had placed their trust. Of course, the dominant health promotion discourse offers no guarantee of disease prevention, but it strongly suggests through the emphasis on reducing risk by living “well” that individuals can avoid cancer.

At this point, it would be conceivable to see participants abandoning health promotion discourse altogether and accepting the random nature of health and illness. But, newly diagnosed with a life threatening illness, most participants desired information about how to manage their illnesses and, most of all, how to survive by beating cancer and preventing recurrence. In this context, participants were left with a desire for a conceptual framework that would assist them in learning how to live with their disease. Unable to rely solely upon the health promotion strategies that had failed them in their efforts to prevent illness, they were left searching for additional ways to understand health and illness. This doesn't mean that participants gave up on lifestyle

approaches they hoped would increase their chance of survival and decrease their chance of recurrence. They were, however, inspired to find additional ways to understand illness that provided guidance about how to live well with disease.

Participants responded to this uncertainty by gathering information about breast cancer, reaching out to breast cancer support organizations, meeting with health care providers, and reading as much as possible about the disease. Carolyn described the importance of meeting other women with breast cancer who understand what it is like to be engaged in the “medical world:”

People in the real world don't realize what goes on in the medical world, until you're in the place you have to be. You know what I mean? And then you meet all kinds of people that are similar to you or have different types of cancer. And you're all going through the same kind of thing.

Meeting other women with breast cancer and learning about the disease provided many participants with a way to try to resolve the uncertainty that their diagnoses created. For a few, information about illness and being ill came from a pre-existing spiritual belief system. For most, their understandings of the implications of the diagnosis were derived from popular media and books, medical information, other women with breast cancer, and support organizations.

Participants quickly gathered information about the disease, its effects, prognoses, and possible treatments. They demonstrated in-depth understandings of the medical information relevant to their care. As individuals who chose to take part in a research study, it is possible that participants in this study were more engaged with current breast cancer research than others may be. Most of the health information gathered by

participants was based in medical science and came in the form of statistics and likely disease progression or side effects scenarios. Although statistics and likely scenarios provided some certainty for participants, in their application, most recognized that the medical sciences cannot state with certainty which scenario will apply to which patient. Thus, health information based in medical science did little to address the uncertainty that plagued participants. More importantly, medical science did not support participants in learning how to live with the disease. In speaking to her physician, Jean described her uncertainty about how to live with breast cancer: “I got in to the oncologist and I said like ‘I don't know what to do. Like, I'm having big trouble here.’ And I said, ‘I don't know how I'm supposed to be normal anymore and what is normal.’” Being diagnosed with breast cancer affected participants’ understandings and experiences of themselves and how to act, their relationships to their own bodies, and their relationships with others.

Although all participants expressed unwillingness to dwell on such questions as “why me?” most did express an interest in understanding the disease in a way that would allow them to incorporate the experience into their lives. Medical information provided partial answers to some questions participants were asking: Will I survive? What will treatment be like? But it could not suggest how to live with and after breast cancer, how to renegotiate relationships, and how to relate to oneself as a woman with breast cancer. For most participants, uncertainty about how to live with breast cancer continued far into their experiences of the disease. This inspired many participants to search for a body of knowledge beyond medical science, one that would answer their most pressing questions about health, illness, and their new lives. In an online posting, Gail described looking for

information about how to live her life after breast cancer, and finding answers in a book about holistic medicine:

I was obsessed with the question of: why me? After many ups and downs, reading many books and asking numerous questions of the medical professionals, I realized that I was not going to find an answer to that question because if someone had the answer we wouldn't all be where we are today. So, I eventually came to terms with that fact and freed myself from the torment of what I may have done wrong. ... As Susan MacDonald [2007] says in her book *Balance, Balance, Balance, Nature's Way of Healing the Body*: 'Life is all about BALANCE: Be present in your life—do whatever it takes. Remind yourself to listen to the birds, watch the clouds, feel the gentle breezes. Stop making lists and over scheduling your life. Don't die with the music still in you.' My transformation was/is learning how to slow it all down. I've decided to stop and smell the roses.

Like Gail, many participants found answers to their questions about how best to live with illness in holistic medicine and similar approaches to understanding health and illness.

4.3 Physical Reductionist and Mind-Body Frameworks

Harrington (2008) makes a useful distinction between three ways of understanding health and illness: traditional approaches, including religion and myths, physical reductionist⁴ approaches, including medical science, which focus on the body,

⁴ Harrington (2008) refers to these as “physicalist” approaches. To avoid confusion with other meanings of the word “physicalist,” I use the phrase “physical reductionist.”

and mind-body approaches, which provide a holistic understanding of health and illness as a state of being in the mind and body. With the decline of religious participation, traditional ways of understanding health and illness have become less prevalent in Western cultures. These were replaced with physical reductionist understandings, which draw on medical science and place the roots and effects of disease in the body (Harrington, 2008).

Harrington (2008) contends that physical reductionist understandings of disease may be deficient in three ways: conceptually, therapeutically and existentially. Conceptually, physical reductionist understandings may be inadequate in accounting for diseases that fall outside of the norm. For example, there is disagreement about whether or not ductal carcinoma *in situ* (DCIS) should be considered breast cancer (see for example Kennedy, Harcourt & Rumsey, 2009). In describing disease as an all-or-nothing state, physical reductionist understandings of disease rarely account for physical changes that are neither healthy nor diseased; for instance, there is currently no such category as “almost having cancer.” Therapeutically, physical reductionist understandings may be inadequate in providing all safe and appropriate treatment for disease (Harrington, 2008). For example, breast cancer treatment continues to consist of four options: surgery, radiation, chemotherapy and medication. Love (Love & Lindsey, 1990) famously critiques these choices: “We currently treat breast cancer as if it were a hardened criminal leading a relentless life of crime. The only way to stop the villain is the death penalty (slash, burn or poison)” (p. 175). While these treatments are necessary, if not ideal, for survival, additional alternative treatments and management approaches are financially unavailable to most women with breast cancer in a public health care system grounded in

physical reductionist understandings of disease and treatment. In the current study, very few women sought homeopathic or naturopathic approaches and none refused allopathic interventions. Existentially⁵, physical reductionist understandings may be inadequate because they cannot provide ways of understanding experiences beyond physical manifestations of disease (Harrington, 2008). This deficiency in physical reductionist understandings of disease is most relevant for this study because it is the source of participants' uncertainty about how to live with breast cancer. Harrington (2008) suggests that mind-body understandings have become more popular in Western culture because of a demand for understandings of disease that address this inadequacy of the dominant biomedical model.

Mind-body discourses are exemplified in stories of illness that captivate us (Harrington, 2008). We have all heard stories about the woman who was diagnosed with cancer and survived against all odds because of her positive attitude and fighting spirit. Heather described this storyline: "You hear stories about people who had cancer and they said 'I'm going to beat it.' And you know, three months later it's gone, miraculously." These stories are captivating because they encapsulate a way of understanding that responds to our greatest uncertainties about maintaining control over disease, making meaning of our experiences of illness, and how best to be ill. For individuals who have already been diagnosed with a disease, and those who fear future diagnoses, these stories

⁵ Harrington (2008) does not use the term "existential" in a philosophical sense. Here, "existential" simply refers to the extent to which an approach accounts for multiple dimensions of one's experience. In this case, she argues that physical reductionist approaches often fail to account for emotional, social, psychological, and spiritual experiences of illness.

provide hope and a template for living well during illness. Carolyn spoke about how much she learned from the inspirational stories of other women with breast cancer:

I am constantly learning from others and take away what they have given me, the courage to accept change and have a positive attitude ... I have learned from other family members and friends who have gone before me and now I want to help others with cancer too.

As Carolyn has learned from others, it is now her goal to pass on her illness story in order to inspire others with breast cancer to live well.

Perhaps due to the need for explanations of how best to live with illness, mind-body discourses have become very prevalent in Western cultures and cross many borders between social groups. Harrington (2008) describes mind-body medicine as:

A far-flung and omnivorous discourse that does not respect the boundaries we try to set up between the professional and the popular, but that in different ways shapes the talk, work, and experiences of all of us alike, be we doctors, patients, health gurus, paperback writers, journalists, or web-bloggers. (p. 19)

Mind-body medicine encompasses a “patchwork of approaches” (Harrington, 2008, p. 19), many of which may seem contradictory. In crossing boundaries and approaches, these ways of understanding have come to underlie much of what we understand to be “true” about being healthy and being ill.

Mind-body discourses are prevalent in literature and talk about breast cancer and women with breast cancer; but they are not unique to breast cancer. In fact, they permeate many aspects of our lives in Western cultures (Harrington, 2008). As described in

Chapter 2, in efforts to publicize breast cancer in the search for a cure, the mainstream breast cancer social movement has enacted and embodied these discourses to an unusual extent. Combined with public discourse about femininity, mind-body discourses are used to frame discussions of wellness for women with breast cancer.

When faced with the uncertainty of their breast cancer diagnoses, participants in this study began to take up these discourses to construct knowledge about how to live with breast cancer. Due to the taken-for-granted nature of these discourses, their effects on identity constitution and decision-making went largely unnoticed. In the following sections I examine some of the predominant discourses that participants used to frame their experiences of breast cancer and make sense of their disease.

4.4 Fight, Battle, War, Brave

Disease is often conceived of as an outside invader attacking the body (Arikha, 2007; Harrison, 2004). Although cancer originates in the body's own cells, in taking up a discourse of invasion, biomedical understandings of the disease conceptualize it as an intruder. The comparison of a disease to an invader invites further comparison to war and conflict. Invaders must be destroyed, war must be waged, the battle must be won, and the body is the battlefield.

This discourse of war requires women with breast cancer to fight a battle to beat the disease (Sherwin, 2006). Participants reflected on this need to fight in order to live:

I'm not ready to go yet; there's a lot I haven't done and lots I need to see
and people to spend time with. So, watch out cancer, if I have to battle
with you again, I will fight you back into the cauldron you came from!

The need to fight seemed natural in this context because the discourse underlying

understandings of disease offered few alternative ways of conceptualizing treatment.

In describing cancer, participants drew on the discourse of an invading “radical alien,” but also extended the discourse to suggest that cancer was “evil” and, in some cases, anthropomorphised the disease into a thinking evil force that was attacking their bodies. In these cases, cancer could be “fooled” or “tricked” in order to increase the effectiveness of treatment. The break between surgery and chemotherapy was described by a few participants as a time when cancer cells left over from surgery would be fooled into thinking they were safe and come out of their hiding places only to be blasted away by the first chemotherapy treatment. Megan described this tactic:

So there's a good chance those cancer cells are just swimming around in my body now, but we're not doing anything. Yeah, let 'em go for a little while. Fool them. And then we're going to blast the hell out of them.

Lulling your enemy into a false sense of safety is a commonly understood tactic to draw out the enemy in war. In this discourse of invaders and fighting, treatments are tactics of war.

Most participants described chemotherapy and radiation treatment stages in particular as a battle or a fight. Treatments for cancer were often described as weapons that could destroy cancer invaders. Alice describes medication and radiation as virtual weapons:

The image that comes to my mind is that of someone playing a video game ... I like to think that someone very experienced with that blaster blasted away all the possible cancer cells in my body when I went through radiation.

She reflected on the value of understanding treatments in this way: “The visuals help me to stay clear.” Although predominantly violent in nature, this discourse provided participants who were fearful with a way of understanding breast cancer as something they could overcome. It was clear to them that existing weapons are advanced enough to destroy such a primitive enemy.

If treatment for breast cancer is a war, women are the battlefields on which it is waged. Aside from recounting side effects, cancer cells and reconstruction, few participants spoke about their bodies in treatment. In some accounts, bodies were the place in which a war was being waged. Physical side effects, some lasting, were seen as acceptable collateral damage in a war that must be won at all costs. Jean laughed about her serious allergic reaction to a chemotherapy drug:

All of sudden, this pain rips through my groin. I had a muscle spasm from my lower back, to my knees ... [Labour] was like having a tooth pulled, compared to this. Then it just came from my neck, straight down my back, right straight through ... I've got five nurses and a doctor, there, one writing notes on her thing, one's giving me needles, the doctor's saying ‘Do this, do that.’ So that was terrible. That lasted about ten minutes, before that subsided. And then they gave me too much Benadryl and I got high. It was actually kind of not bad. If you were going to have this, you can't be in a better place. I mean, they're ready for it.

Following this quote, Jean dismissed the seriousness of her reaction to chemotherapy: “I laugh about it now. I have three friends, we all had this reaction. And when we get

together, we laugh hysterically, because it's the reactions of the people around, 'cause we scare everybody to death right?" It became clear through her good-humoured discussion that managing side effects was important, but some damage to her body was acceptable when destroying the cancer hiding within.

While the role of battlefield was a passive one for women participants, they are also soldiers in this fight. This is different from historical perspectives of patients as passive receivers of care, a perspective often critiqued for portraying women as "victims." Through the rise of patient advocacy, women's health movements, and the breast cancer movement, female patients are increasingly viewed as active participants in their care. In this revised discourse, patients play an active role in the fight. Women are not just battlefields; they are combatants in this war. Participants countered the vulnerability they experienced during invasive treatments by carrying themselves as warriors. Alice provided an account of seeing herself as an Amazon warrior during her first day of radiation: "I'm here to bare my breast and be an Amazon. That's what I'm doing. On with it." In this account, Alice is a warrior. In another way, maintaining the demeanour of a warrior was seen as a way to manage the risk of cancer returning: "I keep the image in my mind of a warrior; calm, trained in stealth, meditation, stronger than I look" (Paula). A warrior is someone who is strong during difficult treatments and fights cancer in the ways available to them, through lifestyle changes and treatment selection.

When selecting from an arsenal of weapons, soldiers ought not to choose the least aggressive weapon to destroy their enemy. Putting up a good fight requires choosing the best weapon available, and at times choosing a "Shock and Awe" approach to battle. For many participants, fighting cancer meant opting for the most treatment, and most

aggressive treatment available. For Alice, this meant refusing the more recently recommended radiation protocol in which patients undergo fewer sessions of radiation. Although she was told that this protocol has been shown to be as effective as the older regimen, Alice refused to undergo less treatment, preferring “the whole thing.” “I don't want you doing any of 'There's a new study out' stuff, I don't want that. Just get 'er gone. . . There could be one little radical alien floating around in there. Do the whole thing.” For her, the best weapon for killing this invader was the most aggressive choice, the full arsenal.

In this context, choosing not to use a biomedical treatment was sometimes seen as harming one's family. Megan describes one woman's choice to use holistic treatments instead of biomedicine as irresponsible:

For me, it just seems like, how do you do that to your whole family? How do you tell your family, ‘You know what? I don't believe that the doctor is right. And I don't believe that I should have to do this and I'm going to have control of my own destiny and I'm going to put my faith in the hands of a farmer.’

“Giving up” the fight against cancer was depicted as akin to being a deserter and showing a lack of courage in the face of battle. In this fight, allopathic medicine is perceived as the most effective weapon.

Associated with this need to undergo all treatment available, was a relentless approach to fighting. The fight, and therefore treatment, would be undertaken as long as necessary to win. Choosing not to fight was understood as the equivalent of surrendering and letting the enemy take over. Pamela struggled with the relentlessness of this fight: “I

remember those things, like 'I don't want to stop.' Because just keep pushing. . . When it gets bad, just keep pushing on. Just like that, I can do it. I can do it. I can do it.” The language of fighting provided participants with a way of talking about this relentless and arduous ordeal as one in which they were active, engaged, and able to survive.

Some participants extended the discourse of the warrior by directly comparing their experience of cancer to war:

Definitely, it is a bit like fighting a war. It's like being a veteran. You know? Maybe you only spent ten months in the Gulf, fighting that war but boy, golly, that was ten hellish months that have impacted your life in so many ways. (Megan)

Others extended the comparison to soldiers, paralleling the emotional effects of breast cancer to post-traumatic stress disorder experienced by soldiers. For some, this comparison served to legitimate the negative emotions they were experiencing. When asked why PTSD better described her experience than depression, sadness or anxiety, Jean responded:

Because everybody seems to understand [PTSD]. And people don't look at soldiers and say they're nuts. They've been through war and they've been through hell and back. It would only stand to reason that they're suffering. Look what they've been through; look what they've seen. I could turn around to my husband and said 'This is what I have.' And he could probably look at me and say 'Oh my God, I understand now.'

Because anxiety, he doesn't know what anxiety is. He doesn't know what it feels like. Same with depression, or inner turmoil. I have been on my

own battlefield. Been to hell and back. So I just think it's just a term that everybody understands, that comes in a nice, little package. And for some reason, people don't associate mental health with it. You know what I mean? ... I get this mental image, I actually see them standing in a battlefield. I don't think of somebody, you know, stuck in their head, I actually physically see them there. Right? And I think a lot of people see the same thing.

Through the language of PTSD, being traumatized by cancer becomes a “normal” reaction to a bad event, instead of a mental illness; something even a soldier might experience. Instead of being constructed as emotional or hysterical women unable to cope with treatment, the language of PTSD evokes the image of strong (male) soldiers having a reasonable reaction to a difficult experience. This excuses the negative feelings participants were often hesitant to experience and discuss. Taking up this language allowed participants to speak about their anger and sadness without the risk of being judged as irrational.

Despite these comparisons to warriors and soldiers, most participants referred to other women with breast cancer as brave, and often said that they themselves were not. Some women encouraged others to take up this discourse of bravery. Most participants felt they spent more time waiting than fighting, but continued to insist that others having similar experiences were brave: “I, too, am told I am brave, but I don’t feel brave. I feel like I am putting one foot ahead of the other, feel like I am in ‘wait mode’ and will be until ‘mammogram day’” (Alice). The inclination to downplay one’s own bravery and idolize others fuels the sense of an ideal, perhaps unachievable, way to fight the disease.

Elsie countered this ideal when she suggested all women who fight cancer are brave:

I have my days, too, when I don't have a lot of energy. You are brave – anybody who has dealt with cancer is brave, in my opinion. You are like Rosie the Riveter – you have picked up where your war (cancer) left off. I, too, am doing what I have to to get through.

Elsie argued, and others agreed, that all women with breast cancer should recognize their bravery.

Participants were not only fighting the invader that was cancer, but also referred to the fight or struggle to get the best information and treatments in the health care system. Physicians and other health care providers were described as either allies or enemies in this fight. In some cases, information was described as a weapon when going to meet with physicians who were potentially intimidating: “I was armed with lots of information and I had my test results and I wanted answers” (Alice). In these cases, participants were often “disarmed” by unexpected kindness from health care professionals: “I don't have to have this whole thought about what the medical profession is all about. I don't have to fight for my rights. I'm going to, but they're also fighting for my rights. And, they're listening” (Alice). In these situations, participants viewed themselves and their care providers as allies fighting the battle for good treatment, and for survival.

Health care professionals were not participants' only allies in this fight. For some participants, the fight against breast cancer served to unite all people with cancer:

We [people with cancer] have a common, not an enemy, but something in common. Other than the fact that we're all women with breasts, but yeah, if you've had the cancer and you've gone through the treatment I think

there's a common thread ... And no matter where you've had it, if you've had that scare or that experience, I think you can be empathetic and appreciative of someone who's in that situation, no matter what kind they're fighting. (Paula)

For others, especially those involved in breast cancer support organizations, the fight against breast cancer was unique and created a community of women with breast cancer. Each veteran of the fight against breast cancer was fighting breast cancer individually through her own survival, but the community also united to fight the war on breast cancer through fundraising, support provision, and campaigns. To use King's (2004) distinction, this fight against breast cancer is about fundraising, not political action. The problem of breast cancer, as constituted by this movement, is to be solved with a cure that research funding can buy; and these funds are best raised not through action that addresses the controversial environmental and social roots of the disease, but through images of happy survivors who have fought the disease and won.

In war, soldiers don't just fight to save their own lives—in fact, the damage caused by fighting a war must be justified on the grounds of a cause bigger than oneself. For some participants, their personal fights against cancer came to represent the war on cancer as a whole. Pamela described cancer removed from her body during surgery as being hidden from her daughters as well: “I hope it was buried deep, so deep that it doesn't show its evil face to my two young daughters who now have to be concerned and very breast healthy.” This sense of fighting on behalf of others infuses discussions of fighting with a larger and more significant responsibility. Participants were not just fighting to live; they were fighting against breast cancer so that all women will be more

likely to survive.

In this way, individual women with breast cancer become part of the larger “war on cancer.” Presented as a concerted and organized effort to find a cure and end cancer, the “war on cancer” has been critiqued for its involvement with pharmaceutical companies, unethical distribution of funds, and overall lack of success in finding a cure (Davis, 2007). Despite these critiques, the discourse of the “war on cancer” has been taken up by many breast cancer organizations in their efforts to raise funds – and clearly, by participants as well, in their efforts to make sense of their disease.

By accepting the discourse of war, the breast cancer social movement aligns with an even greater cause, fighting cancer more broadly. This does not only motivate its members to be individually strong and survive the disease, it encourages women with breast cancer to take on this fight for reasons that extend beyond their personal experience, thus ensuring the continuation of the breast cancer social movement itself. While this discourse may benefit the individual in some ways, the benefits extend beyond the individual to the breast cancer social movement, the larger “war on cancer,” and the organizations that benefit from the funds generated by those movements.

On a more personal front, participants often described being strong and fighting cancer as a responsibility to their families. For some, the inclination to be strong while going through an illness was part of a family legacy:

I think I was brought up with strong women in my background. . . . My grandmother was very, very strong. Very, very, very strong, mentally and physically. And I see that in my own daughter. We're just, there's just, and my mother, we're just, we're [strong], you know? (Elsie)

For those with children, fighting breast cancer was part of their responsibilities as mothers. Pamela saw herself as a fierce, protective mother:

I just wanted to kick ass. I was rebellious right from the beginning, I had a rebellious outlook on cancer. And there's no way that cancer's going to kick my butt. I'm going to kick its butt. I'm a mother cub, and I protect those around me. And a part of protecting those around me was trying to do what I do, and I'm not saying that it worked, because like, you know, I see some of the repercussions, like with the girls.

Although the concept of fighting is stereotypically masculine, the representations of fighting as what mothers do for their families changes the stereotype by drawing on understandings of the role of women as caregivers and fierce maternal protectors.

When this discourse of fighting is combined with discourses of femininity also prevalent in breast cancer social movements, fighting becomes less violent and more socially acceptable. While participants may have been battlefields and soldiers behind the doors of treatment rooms, the strength they exuded in public was described differently. This type of strength is often about maintaining the image of “normalcy” by portraying oneself as positive and in control. Gail described why it was important to her to get up every day, put on make-up and dress well:

It was my way of keeping the normal routine in my life and being able to look at myself and say okay, this is the way I normally would handle things, and I'm going to keep as much normalcy in my life as I can. You know? So that it energizes me through it.

Controlling the way she presented herself to others, maintaining at least a semblance of normalcy in the face of not-normal events, was a crucial part of Gail's personal fight against cancer.

For many, the fight was specifically against a type of cancer that threatened to take away their femininity. The physical changes many undergo during breast cancer treatment, including potential loss of hair and one or both breasts, takes away what many women believe to be important symbols of their femininity. Beyond these physical effects, breast cancer threatened other aspects of participants' femininity by challenging their abilities to care for their children and/or partners and making them angry, an emotion few associated with being a woman. Fighting breast cancer can become a fight to maintain feminine virtue the disease threatens to destroy. In this way, warriors against breast cancer become "warriors in pink."

4.5 Patient, Survivor, Thriver

Many participants discussed the difference between patients who are currently undergoing treatment, survivors who are no longer at risk for recurrence, and thrivers who have learned something from their illness and are now giving back to the community. Pamela described what it meant to her to thrive:

I'm thriving. Thriver means I'm dealing with things. I'm doing very well, thank you. A survivor is I survived it. You can be a survivor and not necessarily be a thriver. There's a line that I find that, when I talk about thriving is, thriving means I'm back to work. I'm doing things. I'm, you know, not back to work full time, but I'm not going back to full time

either. But, having choices, making my own choices and living, and making a five year plan.

Thriving then, was understood as being about taking an active role in one's life. Cancer support organizations strive to run programs that assist patients in transitioning between what are depicted as stages.

The concept of the breast cancer survivor and, later, the thriver was promoted by breast cancer social movements in order to counter biomedical discourses that portrayed women with cancer as "victims," passive patients who had no control of their health (Batt, 1994). Heather argued that others continue to see her and other women with breast cancer as victims because those others are afraid:

If somebody has a heart attack, you don't think 'Oh well, there's the heart attack victim' every time you see them. Or if somebody broke their leg, you don't think 'Well, there's the one that broke her leg skiing last winter. How are you? How's your leg?' You know? Like, it's funny with cancer, there's a stigma attached to it, almost like, leprosy, in a way. I think part of it is because people are so afraid of cancer. Because you hear so much of it and you see so much of it, your loved ones and family members. Probably if you did a survey of people and said, 'What are your top five fears in your life?' Getting cancer would be one of the top five things people would fear ... So I think that it's such a big fear for so many people, when someone close to them gets it, they can't deal with them, because they see themselves. 'Oh, that could have been me. She never smoked; she never did drugs. She used to exercise. She had a healthy

diet, and she got breast cancer. Now, look at me, I'm forty pounds overweight, I don't take care of myself. You know? It could happen to me.' I think that's part of it, I think people just, there's a fear associated with cancer.

In challenging such depictions, discourses that reflect women's resilience and ability to survive and thrive can be seen as a positive shift away from an understanding of women with breast cancer as victims (Batt, 1994), one Heather describes. Participants reacted very negatively to any mention of themselves as victims of the disease, or of oppressive structures. Paula described the danger of seeing yourself as a victim of the disease:

I think if you let yourself go the other way and see yourself as a victim, there's a danger of going the other way and not coming back. You know? If you let your guard down, then you're never going to get out of that hole that you let yourself wallow in. So, perhaps that's why, I try and stay positive and do what I can for myself, while I can.

Being a victim was seen as having far-reaching consequences, not least of all the risk of descending into a depression.

Though it uniformly implies resistance to victim status, "survivor" may have multiple meanings. Thorne and Murray (2000) describe the ways in which women with breast cancer alter the meaning of the word "survivor" to fit their circumstances. In the current study, participants often drew upon the discourse of survivorship in the interviews and discussion group, but there was some confusion about what being a survivor meant. Some participants associated the word survivor with reduced risk of recurrence. Some

participants believed it was risky to call yourself a survivor before you had reached certain numbers of years post-treatment and in remission. Joyce described this feeling:

The word ‘survivor’ is not easily rolled off my tongue. When people ask me how I’m doing, I usually reply OK, I think. I still don’t feel comfortable; perhaps I feel that I would be tempting fate. I have made it this far, but hesitate to say I’ve beaten cancer.

In this way, fear of recurrence kept some women from describing themselves as survivors.

Other participants referred to themselves as survivors in public as a way of promoting the cause of breast cancer. In private, participants were much less likely to consider themselves survivors. Pamela, who was well-respected by other participants for being a survivor, described the reasons she did not yet consider herself to be one:

I guess in everybody else's point of view, I am a survivor. And to be generally politically correct, when I write it down, like when I go to the Relay, I am a survivor. Well, personally, I'd like to see my five year mark, before I say that.

Being called a survivor was described as the right or “politically correct” label, but it remained an uncomfortable word for many participants.

In health care and support literature, the discourse of survivorship has been used to create implicit and nearly invisible guidelines about when to use the word “survivor.” Participants struggled to determine how they fit into these guidelines. In the online discussions, participants early in their experiences of breast cancer asked others when they should consider themselves survivors. Megan asked others for guidance: “I am not a

survivor yet, is it something I will label myself as when I am done radiation, Tamoxifen, I don't know?? Is there a timeline I am expected to follow?" In their responses, other participants echoed Megan's confusion about when they would become survivors. Only one participant, Mary, referred to herself as a survivor. She had completed treatment many years ago and was the most confident that her cancer would not return. For her and other participants, seeing survivors and hearing their stories provided hope:

When you're going through it, it's like 'Oh my gosh, what's on the other side of this? Am I really going to get through this? Maybe I'm sicker than what I think.' And then I would see [a newscaster who survived breast cancer] on the news and I'd think 'There is life after this.' There was such hope. And I thought, 'I'm so blessed.' (Mary)

Survivors, then, are those who are confident they have beaten this disease.

Throughout the discussions an implied difference between survivorship and thriving became clear. Being a survivor was associated with living after cancer and the complication is to determine at which point one had "survived." Surviving is something to be proud of because the disease and treatment are traumatic, but it was difficult for many participants who feared recurrence to determine when they would be a survivor. For most participants, survivorship was an ideal they believed they may reach in time, but they had little control over this progression. Although the potential for becoming a survivor provided reasons for hope, it was not an ideal most participants felt they could reach solely through a concerted effort. Surviving simply meant living until you were fairly certain cancer would not recur. Thriving, on the other hand, was something you could "choose" to do or be. In this way, thriving is an ideal that can be reached through

hard work on oneself and one's life. Therefore, thriving is an ideal more closely connected with one's character than surviving.

Although being able to call oneself a survivor remained important to many participants because it suggested a lower risk of recurrence, the extension of this discourse through the creation of "thrivers" has shifted representations of women after breast cancer. Like survivors, thrivers do not look ill and are positive, but they also draw on their experiences of breast cancer to support women with breast cancer and give back to the community. They have completed the breast cancer journey and are better people because of it. Carolyn described her desire to thrive:

Don't get me wrong, at times it has been a difficult journey but when it happens to be that time I just think I want to thrive and not just survive. This experience has changed my perspective on life; to do what makes you happy and hope to accomplish all the things I plan to do yet in my lifetime.

Although "thriving" could imply various mechanisms through which to become a better person, nearly all participants spoke of the importance of giving back to the breast cancer community as a mark of being a thriver. Some participants struggled to determine if they had the character necessary to become thrivers.

Although many women with breast cancer never contribute to breast cancer support organizations, there was a sense among many participants that giving back in this way was the right thing to do, both for the movement and for one's own healing—and it marked one as being a thriver. This reflects an assumption that a woman who is giving back to the breast cancer community is no longer struggling as much with her own

experience of the disease—she has moved beyond survival. Although participants spoke about thrivers who had accomplished this, those who were considered thrivers by others often described their own struggles as continuing. Pamela, who referred to herself as a thriver, spoke about keeping busy volunteering in order to avoid dealing with the emotional effects of the disease:

I'm sure that I also do it to forget. And to keep busy, so I don't think about what happened. As much as I'm involved [in the breast cancer community], like deeply into it, it's amazing that every time you turn around— I've got breast cancer, but as long as I am helping, or am doing something, I find that I don't sit there and dwell about it, or think about it. So, I guess, being busy, for me, is a crutch. So I'm not sure if it's a healthy crutch. We'll find out I guess.

Even thrivers like Pamela questioned whether or not this was always the best way to cope with the disease.

Batt (1994) critiqued social support programs that encourage women with breast cancer to become survivors by looking better, feeling better, and moving on with their lives. She suggests that this movement serves to obscure the political and difficult aspects of the disease, making others feel better when they see happy survivors but doing little to help women with breast cancer to understand and cope with the disease or to prevent the disease through social changes. Since the publication of Batt's (1994) critique, the idea of thriving has become more common, but many of her critiques remain relevant to this new concept.

In this study, it is important to acknowledge that in efforts to support women with breast cancer to heal by becoming thrivers, support organizations benefit by producing future volunteers. Similarly, health care providers may find it easier to deal with survivors and thrivers than women who struggle to cope with the lasting effects of breast cancer. By equating healing and moving on with becoming survivors and thrivers, the discourse of survivorship creates an ideal that many participants could not consistently live up to. “Failing” to live up to this ideal has the potential to affect women’s access to support services, such as support groups, because women who do not meet this ideal find it difficult to relate to the services provided. I discuss this further in Chapter 5.

In this context, women who will not survive breast cancer likely experience further exclusion from support services and the breast cancer community. At the time of taking part in this study, all participants believed they would survive breast cancer, despite experiencing fears about recurrence. Thus, they engaged with survivorship discourse in a context of believing that they would be survivors one day. This account would be very different if undertaken with data from participants who knew they would not survive the disease.

4.6 The Journey

When someone is ill, those around them want to provide support, and they also want to know what is going on. Participants described the need to tell their illness stories over and over again. For some, the number of times they had told their story was clear in the context of the multiple interviews I conducted with them in this study, with nearly identical narratives being detailed each time. The telling of one’s illness story is often viewed as a way to make meaning and integrate the experience into one’s identity (Frank,

2000). If the meanings created were entirely individual, we could expect that each illness story would be unique. But despite the fact that many participants had different backgrounds, lifestyles, and levels of support, their illness stories were very similar. As Frank (1995) describes, this similarity may reflect the ways in which both the experience of illness itself and the format of illness narratives are socially constructed. In this case, most participants formatted their stories as “journeys” in which they overcame obstacles and learned from their illness.

As discussed in Chapter 2, Frank (1995) describes different types of illness narratives, which he titles restitution, chaos and quest. Restitution discourse, which is reflected in stories of healthy people becoming ill and then returning to their normal states of health, is reflected in the most common understandings of health and illness in Western cultures (Frank, 1995). This narrative underlies the way we understand illness as a passing experience and provides a framework for our expectations of what illness experience will be. It shapes the conceptual inadequacies of biomedical efforts to understand and treat chronic and terminal illnesses.

The idea of restitution clearly shaped participants’ expectations about the progression of their disease. Participants early in their experience of cancer looked forward to the end of treatment, when they presumed their experience of illness would end. Megan expressed her hopes that “cancer is like a two year college visit, where I learn how to be strong and take chemo and then you move on and you take that wisdom and apply it to the rest of your life.” Elsie expressed a similar sentiment when she said “Been there! Done that! Don’t want the t-shirt! It was another part of my life to

encounter, deal with and move on.” The promise of restitution gave participants hope that their experience of breast cancer would end.

Unfortunately, for most participants, this expected storyline did not play out in their actual experience. Transition, the stage at which women with breast cancer complete treatment and are expected to return to their normal lives, was the most fraught and difficult period for most participants. Some struggled with the choice to continue taking hormone therapy for five years in order to lower the chance of recurrence. Those ineligible for medication due to their types of cancer struggled with the fact that nothing could be done to lower their risk of recurrence. All participants struggled with the lasting emotional impacts of their illness, which did not suddenly end with treatment. Pamela describes the difficulty of even contemplating returning to her normal routine after transition:

But that's actually when your life starts and you start to try to figure out where you need to be. And how to deal with all the, you know, if it's going to come back or what I'm going to do, and I try not to think about that.

Joyce straightforwardly describes her experience of transition: “It wasn’t until all my treatments had finished that my meltdown began and continues through to today.” The implicit promise of restitution did not materialize for most participants. Instead, they were left searching for another way of understanding their experiences after transition.

For all participants, the promise of the restitution discourse made difficult the realization that there were lasting disease effects after transition. The fact that most of

their friends and families expected them to move on made their transitions even more challenging:

If somebody had seen me when I was pale and no hair, and you know, going through the worst of my chemo, then they might relate to it. But when they see you a little bit later you seem to be better, in one sense.

(Carolyn)

This stage of being “in-between” health and illness affected participants’ emotional health and relationships, and robbed them of the “reward” of restitution.

To better explain their experience, many participants draw on the concept of a “journey,” which is similar in many ways to Frank’s (1995) quest narrative. In a journey or quest, individuals who are ill learn something from their experience and become better people. Frank (1995) illustrates the quest with the concept of the phoenix, a mythical creature that is reborn in the ashes of its previous self. Some participants preferred to draw on examples such as Julia Roberts’ character in the film *Eat, Pray, Love*, who found her new self while traveling the world after a difficult divorce. Carolyn describes finding inspiration from the Oprah show: “[Oprah] said: ‘. . . Everybody has a calling, and your real job in life is to figure out what that is and get about the business of doing it.’” In this case, “the calling” is thriving after breast cancer. The idea that difficult experiences create the circumstances necessary for self-improvement and an opportunity to thrive were the common themes of the lessons learned by most participants. Participants provide a link between the journey discourse and the discourse of survivorship/thriving, in which women with breast cancer learn from their disease, live life to the fullest, and give back.

These lessons on this journey were accompanied by losses. The loss felt most acutely by many participants was the sense that they were safe and would live long and healthy lives. Heather describes this loss, as well as the lessons she has learned from it:

I don't think I'll ever have that sense of 'Oh, I'm going to live forever.

And I'm going to be healthy forever.' That's gone. But, having said that, it's not necessarily a bad thing either. You know? Like if I want to go to Europe, well, then I'd better plan a trip to Europe. You know? If I want to change careers, then I need to do that this year. You know? So it's, it motivates you, so it's not necessarily completely negative. It's just a matter of managing that, and not obsessing over it.

In some ways, participants experienced a loss of a sense of safety, predictability and control. Understanding this loss as part of a quest or journey provided a new way to appreciate illness as an opportunity to improve one's life by living each day to its fullest.

Most participants spoke openly about the ways they wished their life would be different after transition. Many of those who were currently working full-time expressed wishes to spend more time with their families or start families of their own. Those who had spent most of their time with their children often expressed a need to make a larger difference in the world, usually through a career or volunteering, especially in the field of breast cancer support. Pamela expressed disappointment in herself for waiting until she had breast cancer to make a difference: "I've always wanted to make a difference somehow. And I feel that, kind of, breast cancer has given me that outlet. It's kind of pathetic, when you think about it. But I mean, it's something." She, and other participants, attributed this to "fate" or the idea that everything happens for a reason: "I'm

very much spiritual, in, there's a reason for things. And this is obviously my reason somehow. That's what I believe it is anyway” (Pamela). While the ideas of fate and journey helped some participants to talk about creating meaning of a difficult time, it was accompanied by an expectation that some participants openly resented.

Two participants strongly disliked the concept of the “gift of cancer” that commonly accompanied discussions of the journey. Jean countered the idea that cancer is a gift or opportunity by minimizing the effects of cancer and comparing it to any disruptive life event:

It's made me maybe take stock. But, the same thing getting hit by a bus could do. Right? And like, anything that's going to be life altering is going to make me do that. But as far as giving it meaning, no, I just, I can't.

Nancy also rejected the idea of the gift of cancer, but recognized that she did take something from her experience: “I really resent the whole notion of looking for the gift of cancer, but I have to reluctantly acknowledge that it is a pretty good prod.” Both Jean and Nancy rejected the prescriptive nature of this journey discourse and found it difficult to engage with support services, particularly support groups that expected them to make meaning of their experience in this way. Other participants also found this pressure overwhelming at times. I examine participants’ accounts of this pressure further in Chapters 5 and 6.

For a few participants, learning something from cancer was understood as a necessary step in avoiding a recurrence. In one moving example, Heather implied the importance of learning from cancer by looking up at the ceiling during an interview and

saying “I’ve learned” in an effort to demonstrate to God that she’s learned a lesson and does not need a recurrence. As Heather explained:

I just want to learn the lesson that I was meant to learn. And not make the same mistakes. And move on. I guess that's just my goal. To kind of say ‘Okay’ to the universe, you know, ‘I’ve learned my lesson. Thank you for the lesson.’

The idea that one should learn from cancer and if one failed to do so it would revisit, provided some participants with a sense of control, but simultaneously created an idealised way of doing breast cancer and representing one’s story. For many participants, living life in accordance with these lessons was difficult, particularly given the emotional and physical effects of the disease. While it was not difficult for most participants to learn the lessons they felt breast cancer was meant to teach them, such as the need to live life in the moment, following these lessons in their daily lives was not easy. Thus, participants struggled to realign their lives in the context of the lessons they learned.

This struggle to realign one’s life was not always visible to others, nor did women always see it within themselves. Participants in earlier stages of breast cancer looked up to women who had learned something from the disease. Some worried that they would never achieve the wisdom or understanding others had. Megan wondered if she was able to learn what other women in the online discussion group had:

Some women on there, I think, are just so good. So much better than me ... I mean, they just seem to have been so, I don't know if nourished is the right word, but they seem to have taken so much from this disease that, and I'm not, I don't know if I'll ever be there. I'm, maybe not, maybe

that's not in my make-up, to be that person. But, they seem so wise. Like they've really gleaned a lot from having cancer.

The idea that one should or must learn a lesson and become a better person was present in the data, although when asked directly, most participants stated that everyone has a right to take what they want from the experience. Nancy pitied women who couldn't learn from cancer, though in expressing this she conveyed a belief that women ought to learn from the experience:

I don't know how much it makes people more introspective to have cancer if they're not able to look closely at their lives or don't know how. I think it would be scary and painful to have cancer and be unable to change; maybe that leads some people to try just to brush past it as quickly as humanly possible. It may be that you need some basic skills in being able to weigh and question issues in order to pull some meaning from this terrible experience. But I don't think you need more than basic wisdom and humility and common sense to learn these lessons—they're things anyone can learn from, I mean, with the right mindset.

The idea that women with breast cancer should learn something from the disease is also manifested in support organization programs and support groups that encourage women with breast cancer to move from patient to survivor to thriver. The organization Breast Cancer Wellness (2012), for example, states "Our mission is to support survivors to be THRIVERS. Our vision is for patients and survivors to move beyond the diagnosis of breast cancer and to live their life with renewed joy, passion and purpose."

4.7 Positivity

There were few discussions of happiness or joy in the interviews or online discussions; however, positivity was one of the most common topics of discussion. Ehrenreich (2009) notes the differences between happiness, a feeling brought on by one's circumstance, and positivity, an attitude or way of being that is performed, often despite one's circumstances. In many ways, being positive actually requires one to separate herself from what she is feeling (Ehrenreich, 2009).

Few participants would disagree with Ehrenreich's distinction. Most described positivity as a way of being that allowed for feelings of sadness or anger, or at least did not require happiness. According to the participants, in embodying positivity, women with breast cancer do not slip into the "darkness," feel pessimistic about the outcome of their illness, or feel self-pity. Gail described her commitment to positivity: "Even though I went through a time where I mourned the loss of my health, I refused to let myself go down the 'dark' road of negativity. I was 'sad' but I was not negative." More participants spoke of being sad than angry, but a few suggested that being angry is a natural part of having cancer. They did not, however, see negativity as a natural part of having cancer. Megan distinguished between anger and negativity, which she understood to be pessimism: "Who is never angry, when you have cancer? Everybody has to be angry at some point. So, yeah, I guess I'd say that's what negative is to me, is that someone who never looks on the bright side of things."

Remaining positive in the face of cancer was closely connected with making the best of a bad situation and being optimistic. Carolyn described the importance of making the best of the situation in order to move forward:

You do cry ... But, I don't know, you just have to find a way to get around it. And keep going. Because you know, as long as we're here, we're living and we have to make the best of it.

This need to keep going and make the best of the experience is connected to the relentlessness of this fight against cancer. Participants struggled to maintain positivity in order to cope with the relentless difficulties of the cancer experience.

Harrington (2008) attributes the rise of the discourse of positivity to discussions of the mind's power to heal the body. She refers to this as the "secular miracle" narrative and traces its roots to French and American medical efforts to explain Catholic healing miracles. This discourse became more acceptable in biomedicine as the negative perception of the placebo effect was reinvented to account for stories of patients healing themselves through hopefulness and laughter (Harrington, 2008). In the field of cancer support and care, "hope" is described as a necessary attitude for recovery (see for example Rutledge & Walker, 2010).

Participants spoke extensively about the reasons why it was important to be positive. The most common explanation involved a connection between negative energy and the growth of cancer cells (which are negative). For most participants this connection was uncertain and vague. Paula explained:

If negative energy helps the cells grow somewhere, I don't want to feed that at all. So, I try, not to be negative ... I kind of half believe that negative energy will make things grow, if they're going to grow.

Despite the uncertain connection between negativity and cancer growth, being positive was deemed an important part of managing the disease.

Although researchers have disproven the connection between positivity and survival of cancer (Coynes et al., 2007), medical, social support, holistic, and popular resources extol the virtues of a positive outlook. Many support programs for individuals living with cancer are designed to promote healing through positivity. Participants often quoted from women's magazines, self-help literature, Oprah, and movies which encouraged women to think positively. The self-help phenomenon of positivity is most pronounced in the extremely popular book *The Secret* (Byrne, 2006) which explains to readers that they can control their destiny through positive thinking. While no medical professional would suggest that one can control the outcome of an illness, medical literature similarly encourages a positive outlook (see for example Rutledge & Walker, 2012).

While not all participants fully understood the connection between positivity and survival, most agreed that women with breast cancer should be positive. When pushed to explain the connection between negativity and cancer, Paula said: "Thinking positive is better than thinking negative anyway. So I didn't want to be, if you think about it, you might convince your body you do have something. I don't know. I'd rather be optimistic than pessimistic." Others felt there was a more definite connection between positivity and mental health: "I believe positive and negative feelings affect your health, certainly your mental health. Negativity is very daunting, especially if you are afraid to begin with" (Joyce). Whether or not participants articulated detailed connections between positivity and cancer, the language of positivity provided a way to talk about being hopeful and living life to the fullest.

Positivity was also seen as a necessary mindset for good medical decision-

making. Nancy, who encountered difficulties negotiating the medical system, explained that it was important to set aside negative feelings:

Early on I realized I was only going to be able to negotiate it successfully if I put that [anger] aside. I did it by promising myself I could come back to it later ... I felt I had to have all my internal resources available to get through the treatment.

Nancy felt that sadness, anger, and other “negative” emotions had the potential to cloud one’s judgement when selecting treatments.

Being positive was also depicted as an important responsibility, much like fighting and thriving. Participants stayed positive for themselves, but also for others: “I stay positive for the young people I work with and for my family. I stay positive for me because it is less soul-sucking and physically exhausting than sorrow and fear” (Alice). Participants were proud when others commented on their positivity: “I constantly hear, 'You, you are so positive. And you know, you've been getting through this so wonderfully.' And, I have” (Megan). Some participants even became role models for other family members with cancer:

When I was going through mine and everybody was saying ‘It's so good that you're staying so positive.’ Now my brother in law has been diagnosed with prostate cancer. And of course, here I am, now lending support to him. And he said to me, ‘You know, Gail, I admired you because you were so positive while going through your experience.’ He said ‘So I'm going to try to do the same. That's my goal.’(Gail)

Again, mothers were most likely to speak about the importance of staying positive for

their families: “During those four or five days, or six days, whatever it would be, on each of the treatments, when I felt my worst, I still tried to make myself stay upbeat, so that my kids didn't worry” (Gail). Being positive was a way to maintain relationships with others during a difficult time.

Positivity, particularly through the use of humour, was also the best way to cope with uncomfortable changes in relationships with others. Jean, who continued to work in a male-dominated industry during treatment, joked with her co-workers to overcome potential discomfort:

I was sitting there with like, four or five guys and we'd be having a meeting and all of a sudden I looked up ‘Oh my God, I forgot my boob.’
Right? And he'd say ‘Where?’ ‘Oh it's home on the piano.’ or something
right? And of course, then they're trying not to look.

Megan used humour to confront family and friends who thought she might die: “I am constantly seeing that look, you know the one, the ‘OMG she could die look.’ I confront it head on, call them out and laugh it off.” It is important to note that in making jokes to lighten the mood with friends or family members, participants only made jokes about the physical changes associated with breast cancer; such as their hair loss or breasts. The emotional effects of the disease were deemed private, beyond the realm of humour and, in many cases, shameful. Jean described the secrecy that surrounded the emotional effects of breast cancer, which embarrassed her: “So I'm not the only one [who feels depressed]. But nobody talks about that. And I'm embarrassed by it.” Participants struggled to maintain at least the appearance of positivity.

Being a positive person wasn't limited to acting positively. The requisite

commitment to moving on and keeping on involved getting up each day, getting dressed, applying make-up, and maintaining a feminine appearance. Although few participants wore a wig because they found them uncomfortable, one participant enjoyed wearing different coloured wigs to change her appearance. Others spoke about taking the time to draw on eyebrows and selecting beautiful scarves during chemotherapy, dressing in bright colours, and/or camouflaging scars and mastectomies with carefully chosen clothing.

The positive woman with breast cancer, then, is understood as responsible to herself and to others for maintaining positive demeanour in public. Although being sad or angry was acceptable in these understandings of positivity, being negative in public was judged quite harshly by many of the participants. Managing when to express negativity was part of this responsibility to others. Pamela described when her emotional moments happened: “I guess the trauma comes back, and it haunts you. But I'm not around anybody usually, when it happens. So, I do it in my privacy.” She went on to recommend holding on to negative emotions until privacy was ensured: “The negative emotions are going to be there and I will feel them. I tend to send them back in the box at times and the shower is a wonderful place to release crying” (Pamela). Sometimes, participants expressed sadness, fear or anger to family, friends or support people, but these instances were few and far between. Participants stated that they rarely expressed these feelings to other women with breast cancer because they were worried about upsetting others and/or felt those times spent with other women with breast cancer were theirs to spend happily, socializing. Interactions in the online discussion group suggested that this is an incomplete explanation. Participants’ efforts to express anger or negativity online were

often resisted by other members of the group.

Although participants claimed that any emotional reaction was acceptable when you had cancer, interactions in one online discussion group demonstrated perceptions of a participant others deemed negative. Other members of the group blamed the “negative” participant for her inability to maintain a positive outlook. In a later interview, Carolyn said:

I saw with our negative/positive thing you had posted, some [participants] aren't as positive. I know it's not easy to be positive, but sometimes when you are, it's just your frame of mind helps your body, or helps you know, get through things.

Similarly, Elsie described the diversity of approaches women with breast cancer may take up in an online discussion post: “We all deal with things in a different way. Who is to say one is better than the other!!” but contradicted this statement in a later interview when she suggested that this “negative” participant may not have support because she was not positive: “If you are negative, you bring negative to you. [I] wanted to tell the woman on the group who wants a relationship that nobody wants to be around someone who is negative.” In this way, participants’ broad statements about how women with breast cancer could feel were often more supportive of diverse reactions, while particular responses to specific others rarely reflected this level of acceptance. In practice, expressing negativity in public was unacceptable. While participants did not directly confront the individual they deemed negative, they passively excluded her from the group by refusing to respond to her posts. Later, this “negative” participant noticed no one was responding to her and asked for a response:

Ladies, tried to connect Asked questions that I legitimately wanted info feedback or answers for. Have had no positive contact, except for one. Please respond to posts, negative or positive. We all experience this journey in a different direction. Maybe yours can help me on mine, maybe mine can help on yours. Thanks.

Despite her requests, other participants did not respond to this post. She continued to be passively excluded from the online discussions.

These reactions reflect the common belief amongst participants that being positive is something that can and should be controlled. Carolyn describes this perspective best when she states that cancer is a “test”, perhaps of one’s character:

They've [psychologists] told me I'm not, I don't have terrible anxiety or a real bad depression. And that I seem to be a tough cookie, but maybe it's because, I don't know, I guess it's, it tests your strength sort of. You know? How you want to, I guess, cope with it yourself.

She suggests here that remaining positive is a show of strength. One participant took this even further by suggesting that women with breast cancer have no choice but to be positive: “Well, what's the alternative? You die? Like, do I have choice in this matter? You know? You do your best” (Heather). Nancy was the most outspoken about her dislike of the idea that positivity created health because she felt it demonized people who died by suggesting they were not positive enough; yet she also believed that being positive was important. This requirement of positivity led to lengthy online discussion about methods to stay positive and control negativity.

One common approach for controlling negativity was to eliminate relationships with negative people: “If you've got negative people around you, it's like poison. It just goes through and it, it's not good for anybody's peace, like you know, you need your head in one place, and a focus” (Joyce). Other approaches to staying positive included exercising, talking to (positive) friends, and volunteering. Needless to say, women with breast cancer who were seen to be negative did not find it as easy to start relationships with other women with breast cancer and felt excluded from some support services. Nancy, for example, spoke openly about her anger at having received a late diagnosis and her subsequent depression. She did not see her anger as problematic in and of itself, but struggled to find other women with breast cancer with whom she could discuss her feelings about the health care system. Nancy’s efforts to reach out to breast cancer support organizations were disappointing:

Another thing I did to try to get myself out of this depression was I called [a breast cancer support organization]. And I talked with a woman and I found her really unhelpful. I was so discouraged when I hung up. And when talking to her, I almost wanted to cry. And I know I'm depressed. I'm in this swamp. But, I felt like she might be this, helpful resource or helpful voice and more or less what she said was ‘Well, what we want is for the doctors to give us hope.’ She asked me who my doctors were. And she was familiar with them, and she said ‘Well, some doctors are better than others at giving patients hope.’ And I got so angry because I felt like, she was talking about empty platitudes, and this thing that I hate so much of, she did kind of talk around this; she never came out and said

this explicitly, but she really talked about the importance of keeping your spirits up, and how you have to keep your thoughts, you know, on the right path to stay healthy.

When Nancy sought support for dealing with her feelings of depression and anger, expressing these feelings actually made it more difficult for her to find support.

A few participants spoke candidly about the effects of the struggle to ignore or push aside negativity. Pamela, who was seen by others in the online discussion group as a role model for positive thinking, described in detail the result of pushing aside her negative emotions:

It's almost like you have a toxic waste can, and all during your cancer and during the time, transition, you tried to be positive and all the stuff that wanted to come out, you kind of stuffed it into this can. And it became toxic. And, there's so much of it that every once in a while, the toxins come out and you start to weep. And you don't know why, well, you do know why. You know why, but I kind of use that as an example because I remind myself 'Oh, okay. I know. I just haven't dealt with that.' And, you know, I just can't deal with that right now. So I shove it back in and I move on.

Some participants recognized that the pressure to be positive had the potential to cause problems. But most could not see another option.

Remaining positive was often most difficult for those participants who had initially been misdiagnosed or had delayed diagnoses. Nancy, for example, believed

delays in scheduling her surgery had allowed the tumour to progress further before it was removed:

I finally had my surgery in March. So it had been six months since I had found this lump. And, there were two lymph nodes involved. Of everything that's happened, that has been the hardest pill to swallow; being stage two rather than stage one.

Nancy could not maintain her positivity given her disease trajectory. Further, some participants who didn't find their tumour by themselves had come to distrust their abilities to sense something wrong in their bodies. In these cases, a lack of trust in the medical system and/or their own ability to detect a health issue caused a great deal of fear. Joyce explained her challenges in staying positive:

I did not know I had cancer, I didn't feel the lump in my breast and I am afraid that something else will crop up and I won't know it. It's sometimes hard to be positive. Being here every day and taking my kids to school and being home after school is the best positive energy I can get. (Joyce)

Participants especially struggled to maintain their positivity when the circumstances surrounding diagnosis were particularly difficult.

A few participants spoke in more detail about positivity as something that could not always be controlled. Mary argued in the online discussion group that women with breast cancer are positive when they feel supported, in contrast to the wider held belief that positivity somehow creates the environment for support to be provided. Here, she described the reasons she was positive:

I guess I'm fortunate. I have a good life. I have a good family. I have a good husband and good kids and I'm happy with my life. And so I can look, I kind of look at it like that's an experience that I went through but I'm on the other side of it. And my life is back to normal and I feel good about things. So I don't worry about the negative.

Other participants compared their experiences of sadness to types of negativity they believed to be legitimate, such as clinical depression, the mood swings of menopause, post-traumatic stress disorder, and the grieving process. These comparisons allowed a few participants to attribute their negativity to factors beyond their control, thus avoiding some of the self-blame that accompanied these feelings.

Despite the fact that most participants were on some form of anti-anxiety or anti-depressant medication, few spoke openly about the emotional effects of the disease. In fact, most felt a shared connection to other women with breast cancer, but doubted that others were struggling as much emotionally as they were:

But I more think of the sick part of it, then, and the physical part than the emotional part. That's sad isn't it? ... I think it is that I wouldn't, maybe I'm self-absorbed, that I wouldn't think that other women really have all the same emotional problems. (Joyce)

This left many participants feeling alone in their efforts to cope with sadness, anger and anxiety. It is clear that participants recognized their own negative feelings, but tried to avoid or rationalize them away. At the same time, many seemed unable to recognize that others felt the same way. By seeing only their own negativity and the positivity of others, participants drew on an unachievable affective ideal that left them feeling alone and

susceptible to self-blame.

Positivity became more difficult when participants stopped focusing on cancer and started the transition back to their regular lives. This transition was as difficult as the initial transition from healthy to ill. Megan spoke about her concerns:

I'm definitely still positive about [surviving cancer]. Other aspects of my life, maybe not so much. Like, where my life is heading ... Now I'm here, and it's a little bit more, I have to take back my life and start focusing on what happens next. For the longest time, all I could see in my future was cancer. You know? And I feel like I'm more than mid-way through, like the initial, you know, get rid of the initial cancer.

Given prevailing uncertainty about how to live after cancer, positivity was more difficult to maintain during transition. In fact, the concepts of journeying and surviving/thriving offered much of the guidance about how to live after cancer and participants used both of these discourses to suggest that life after cancer continues to revolve around the disease through volunteering and life lessons. When they considered moving on, beyond cancer, participants were left devoid of guiding beliefs, as they could no longer easily believe in health promotion and risk avoidance, as they had pre-cancer, nor could they rely on notions of journeying or fighting that had helped them cope with diagnosis and treatment.

Pamela, who expressed a significant commitment to thriving in the breast cancer community in her first few interviews, expressed concern about needing to move on during her final interview:

The epiphany is I have to put my family first now. Because I've done a year of chemo treatment and then for a whole year I gave back to the

breast cancer community and gave all I could, but in that giving, I left a lot behind ... Your family's more important. I mean, it's important to do cancer related stuff, but not at the expense of your family and friends ... I found that I was getting into the breast cancer social network, and that's fine. And there's nothing wrong with that, but you need to also balance your life and it's got to do with balance, because it can bring you down too. Because, you know I need to move on now.

For Pamela, moving on meant leaving the breast cancer community to some extent and returning to the social networks she had before cancer. Participants had difficulty finding support and guidance for their efforts to move on after breast cancer within the breast cancer community.

Although thriving is often portrayed as moving on from cancer in order to give back, participants experienced the requirements of thriving as being in conflict with moving on with their lives, as they still kept women centred on cancer. Gail spoke about her need to stop engaging in advocacy and move on:

Initially, I had my little pink rubber bracelet that I wore all the time. Now I've actually thrown it away. The other one with the beads on it is now in the corner of my jewellery box. It's kind of funny, there are all kinds of little things that I've said to myself, 'Uh-uh.' Now I still have the ribbon on the back of my vehicle, the magnetic one. And I think I'll keep that. But as for the rest, and even with [breast cancer group], I started that; I was doing it, committed. And now, it's almost like, I don't know, I just don't want to be in the middle of it anymore. Right? It's just, it's kind of

weird. There's so much they do: they're fundraising and they're this and they're that. And I'm happy to help and I'm happy to do my donations.

But I don't want to be in the middle of it anymore. It's time to move on.

In moving on, most participants strove to retain some lessons from their experience, such as living life to the fullest, while turning their attention back to their life outside of breast cancer. Although participants who chose to move on may still describe themselves as thriving, they are no longer understood as “thrivers” within the breast cancer community.

4.8 Weaving Discourses

Harrington (2008) argues that mind-body discourses like those described in this chapter are often contradictory. In this case, these ways of talking about breast cancer have already been combined in some ways in the public campaigns created and promoted by the breast cancer social movement. At first glance, it appears there are clear connections between the discourses of journey, surviving and thriving, and positivity. Each of these discourses provides a way of talking about the importance of improving oneself, learning something, and giving back.

The fighting discourse seems least likely to fit with these others because it brings to mind violence and anger. But an examination of the ways in which participants adapted this discourse by combining it with survivorship and femininity illuminates the ways in which it connects with other ways of talking about breast cancer. Fighting became fighting cancerous cells in order to survive, and also fighting to be a feminine, positive thriver. Diverse discourses came together in participants' accounts and helped them to understand and talk about what it means to be a woman with breast cancer.

In many instances, participants adopted these discourses to talk about their breast cancer experiences in a way that enabled them to maintain a sense of control over their disease experiences, communicate their experiences to others, and become members of a social group. This does not mean that discourses did not sometimes conflict and create uncertainty. Many participants struggled to untangle diverse ways of understanding what it means to have breast cancer. Sometimes, when faced with conflicting discourses, participants were able to find ways to overlook, manage or overcome these conflicts. Of course, participants did not have to do all of this interpretation by themselves. Public discourses of breast cancer are taken up and combined in medical, social support, and holistic health settings and knowledges. In combining these ways of understanding breast cancer with their own life experiences, participants created various ways of understanding how to live with the disease. Despite the widespread acceptance and use of these discourses, participants did not wholeheartedly accept each discourse throughout their entire experience with breast cancer.

4.9 Resisting Discourses

In this section, I discuss participants' resistance to the ways of understanding breast cancer described in this chapter. While I focus on a few examples here, it is clear from the quotations in this chapter that participants often actively engaged with, questioned, and adapted breast cancer discourse to better explain their own experiences in the context of their lives. Resistance to these ways of understanding breast cancer arose most, or was most apparent, when women encountered conflicts between elements of breast cancer discourse, or between these ways of understanding breast cancer and other beliefs that were important to them.

Participants had difficulty coping during times of transition and times of uncertainty when they were most unsure how to act and who to be. While prevalent understandings of how to be women with breast cancer were restrictive and created ideals few could live up to, they also provided a certain amount of guidance and certainty for which participants were searching. Taking up these discourses provided easier access to care and support, as well as a sense of doing the “right” thing. Despite these benefits, participants did resist these discourses in different ways. Participants often resisted one breast cancer discourse by drawing on another, or by drawing on other beliefs that were important to them.

At times, participants drew on one discourse (fight, survivor/thriver, journey or positivity) in order to discredit or revise another. For example, Jean argued that the word “journey” sounded too arduous, difficult and negative. Instead, she referred to her experience as an “adventure.” Her “adventure” was described similarly to the “journey” of others, but the change in language better reflected her positive outlook. Participants made these types of revisions to better represent their experiences. In this way, they could maintain the identities that received social approval, but could also individualize the discourse to a certain extent.

Other participants drew on alternative discourses that offered other ways of being and doing cancer. Megan and Paula, for example, spoke about their experiences of poverty in a way that minimized their descriptions of the impact of cancer. For them, cancer was sometimes understood as one more difficult life event in a life characterized by uncertainty. Mary drew on her religious beliefs about mortality to lessen fears and uncertainties about recurrence. By lessening the disruption they experienced at diagnosis,

such alternative ways of understanding breast cancer provided these participants with less need for the guidance provided by other breast cancer knowledges. In some cases, this allowed them to resist the ideals of positivity and thriving. At the same time, these discourses are promoted by others as much as they are by one's own need for explanation. Accepting these discourses is often experienced as necessary in order to relate to other women with breast cancer and to tell socially acceptable breast cancer stories.

Some participants recounted actual experiences of exclusion from the breast cancer community. Nancy, for example, could not find support for dealing with her anger and depression. In other cases, participants' described knowing that they could be excluded if they acted in a particular way. This risk of being excluded was more common than actual exclusion, as most participants strove to act "appropriately." I examine these experiences of exclusion and the risk of exclusion further in chapters 5 and 6. For those living alone and in poverty, these services are particularly important.

Gail drew on a perspective she attributed to her educational background to develop her understanding of cancer. She expressed concern that the breast cancer social movement in Nova Scotia did not act on political issues such as environmental causes of the disease and chemicals in cosmetics. Due to her political stance, she felt less connection to the social movement here and distanced herself from the movement. By taking up another cause and set of lessons, Gail acknowledged the need to learn from and act on the new knowledge she gained through her illness, but did not see volunteering for an existing organization as the way to act on these lessons. For her, the risks of rejecting

these discourses were lessened due to a strong support network outside of the breast cancer community and to her own economic stability.

Some participants rejected the ways in which these discourses were taken up by women with breast cancer, support people, and health care providers to form unreasonable expectations, but at the same time made use of these ways of understanding breast cancer. For example, Nancy believed that positivity was important, but rejected the ways in which the regulation of positivity excluded women experiencing and expressing anger. It is unclear whether participants who engaged in this type of resistance wanted to make more room for alternative ways of doing cancer, or wanted existing supports to acknowledge women who struggled to reach these ideals and support them in their efforts to do so—in a sense reinstating these ideals.

All of the forms of resistance described here varied in intensity for each participant throughout their experiences of breast cancer. Although I use the word “discourse” here for theoretical purposes, participants discussed facts, knowledge, and beliefs about how to live with breast cancer. Participants rarely fully took up these understandings as truth, or fully rejected them as nonsense. Times of transition were particularly fraught as previous discourses failed to explain their experiences and participants needed to rely on others. Participants actively engaged with and negotiated these discourses to construct meaning, constitute identities, and make decisions.

4.10 Conclusions

When diagnosed with breast cancer, the discourses of risk and control in which participants had placed their trust failed to explain their diagnoses. Struggling to cope with the resulting uncertainty, participants searched for information that would help them

to understand their experiences. Physical reductionist understandings of disease characteristic of medical science could not answer some questions that were important to participants: How do I live with disease? What does it mean to be a woman with breast cancer?

Participants turned to mind-body discourses, including those of fighting, surviving/thriving, the journey and positivity, to answer these questions and create meaning. Although participants used these discourses to explain their experiences, they also created an idealised way of doing breast cancer that many participants felt they could not entirely meet, but often aspired to achieve. Throughout their experiences participants engaged with, challenged, and revised these ways of understanding breast cancer in different ways. At different times and in different situations, resistance could be risky or complicated.

Participants took up these discourses to connect with a social group of women with breast cancer, using them a resource for solidarity and a source of certainty. At the same time, these discourses were used to tell illness stories invested with moralizing tones and judge the success or failure of women with breast cancer. While participants used these discourses to serve their own needs, they also met the needs of the health care system and support service organizations which benefit from happy patients and willing volunteers. Governmentality, the techniques through which the behaviour of women with breast cancer is constrained and enabled, is enacted through the use of these normalizing discourses to set standards for self-surveillance and monitoring of others. This will be discussed further in Chapters 5 and 6.

In the following chapters I further illuminate the ways in which participants negotiate these discourses as they constitute their identities, or subject positions, as women with breast cancer and make treatment and lifestyle decisions. Throughout these discussions I highlight the ways in which participants were enabled and constrained at different times. I continue to examine the ways in which these discourses are adopted, inscribed, reinforced and resisted by participants, and the larger social processes that shape participants' abilities to negotiate these discourses in ways that serve their own interests.

Chapter 5: Subject Positions: Being a Woman With Breast Cancer

5.1 Introduction

The discourses described in Chapter 4 comprised common modes of understanding breast cancer and what it means to be a woman with breast cancer. Participants adopt these combined discourses—the fighter, thriver, positivity, and journey—to produce and reproduce subject positions that are made available to women with breast cancer. I will argue that, fuelled by a broader cultural trend promoting the search for an authentic self, this idealised position becomes invested with moral judgments that affect women’s perceptions of themselves and others.

In this chapter, I examine the ways in which participants described, engaged and resisted the subject positions made available to them. In doing this, I discuss the understandings of identity that underlie participants’ evaluations of themselves and others, and the availability or unavailability of these subject positions to various women. I conclude by examining the benefits and consequences of taking up these positions.

5.2 Searching for an “Authentic Self”

Theoretically, discussions of identity in feminist sociology and philosophy now rarely draw on understandings of identity as singular and consistent, indicating the rhetoric that our authentic self is always there, or as teleological, meaning that all of our experiences, if interpreted and dealt with appropriately, lead us to an authentic self. Instead, identities are typically conceptualized as plural, shifting, relational, embodied and contextual. While this post-modern shift is now commonplace in academia, popular and self-help literature continue to describe identity as something we are born with, lose due to social constraints, and must uncover through a search for something depicted as an

“authentic self.” In this context, disruptive life experiences, like cancer, are often described as opportunities to uncover the authentic self that may be hidden from view. In this popular discourse, identity is consistent and singular (our authentic self is always there, awaiting discovery) as well as teleological.

The cultural trend encouraging the search for an authentic self is often attributed to the separating effects of modern life—an era of increased connection to others through technology, but concurrently increased loneliness and exclusion (Potter, 2010). In this modern world, the search for a mythical authenticity provides a way to create meaning and a guide for living one’s best life (Potter, 2010). In sociology, some theorists have similarly conceptualized the modern era as one of decreased regulation and increased reflexivity, in which individuals face more opportunities and risks in constructing their identities (see for example Giddens, 1991). Whereas people once lived guided by tradition and local social norms in smaller, more pastoral societies, in late modernity options and individual choices seem endless (Giddens, 1991; Beck, 1992). Any individual is almost required to construct an individualized, reflexive self, exercising agency to challenge the constraints of social structures. While an increase in reflexivity may be interpreted as an increase in freedom from social norms, Foucault’s work draws attention to the ways in which increasingly dispersed power relations constrain and enable subjects. In modernity, our relations with ourselves and others, including our efforts to create meaning, are not at all exempt from relations of power.

Some participants equated being one’s authentic self with being free of social influences, relating their breast cancer experiences to such a notion of “authenticity.”

Alice clearly articulated a consistent view of identity, suggesting that people become less themselves if they “mould” themselves to society:

[Cancer] hasn't shaken me in who I am, because I'm dealing with it exactly as I would expect to deal with it. It's no different than I dealt with my appendix coming out ... I firmly believe that who you are at two and who you are at fourteen and twenty four is pretty much who you are at forty one. It's just, you know, whether and how much you mould according to what other people think.

In this account, authenticity is something anyone can retain if they resist social norms.

In other accounts, participants who took up a teleological understanding of identity describe the authentic self as something you uncover or become. For many participants, breast cancer was described as an opportunity to move toward being more fully themselves. Heather, for instance, described her efforts to become more assertive: “I need to deal with [cancer] head on, as opposed to running away from it, which is what I would normally do.” Her experience of cancer gave her an opportunity to become someone who faced her fears. For a few participants, this idea of improving oneself or becoming one’s authentic self through cancer was extended to suggest that cancer itself happened for a reason. Pamela, for example, suggested that breast cancer happened to teach her a lesson about happiness:

[Breast cancer] is strongly a part of who I am now. My life leading to my diagnosis had taken me down a road of unhappiness. ... Cancer comes (no surprise), but it shook me up and made me ask myself ‘What the heck are you doing? You are wasting precious time.’ It

made me fight and be strong for my kids and husband and family and friends. Through all the bravery of treatment, hair loss, and sickness I gained a sense of strength and became more self-reliant.

Even participants who did not believe cancer was a gift or opportunity often agreed that this life-threatening experience allowed them access to a perspective that others struggled to attain. For many, this perspective was something more real, genuine or authentic.

Broadly, what it actually means to be one's "authentic self" remains unclear. Potter (2010) suggests that authenticity is not a definable set of traits, but is instead "a way of talking about things in the world, a way of making judgments, staking claims, and expressing preferences about our relationships to one another, to the world, and to things" (p. 13). Authenticity, then, is a vague discourse through which we can talk about, categorize, and judge our own and others' searches for meaning. The search for an "authentic" self is not free of power or social constraints, but is instead a mechanism of governmentality that provides a way to seek fulfillment while simultaneously constraining understandings of what it means to be fulfilled. This normalizing discourse suggests that women need to be fulfilled, while at the same time providing a one-size-fits-all definition of fulfillment. The vague nature of this discourse allows "authenticity" to be interpreted in various ways, meaning that it often combines with other ways of categorizing and judging others' searches for meaning (Potter, 2010). In the case of breast cancer, participants took up the mind-body discourses described in Chapter 4 to describe what it meant to be true to themselves—authentic—while dealing with the disease.

5.3 The Idealised Breast Cancer Subject Position

As was discussed in Chapter 2, Foucault's (1973; 1975; 1978; 1988) work on the discursive production of subjects has been influential in challenging understandings of identity as consistent or teleological. Foucault examines the ways in which discourse is used to produce subjects. Individuals constitute themselves within subject positions made available to them through circulating discourses. Subject positions facilitate particular ways of being that can form the basis of social groups and also establish ideals that may be employed by individuals and groups to self-govern, discriminate, and exclude (Heyes, 2011).

From particular subject positions, individuals are conveyers of power/knowledge, which means that they have access to the benefits of successfully adopting this normalizing discourse. While some of these benefits may be material (i.e. access to resources), others may be less tangible but perhaps more important experiences, such as inclusion, belonging, and acceptance. At the same time, as individuals take up these subject positions, they are also subject to governing techniques that accompany these representations. In this way, subject positions offer subjects the opportunity to make sense of the world and gain belonging while constraining which types of meaning are available to them and what bases for belonging are legitimate. In this section, I examine the subject position I call the idealised woman with breast cancer.

Many participants struggled to provide a concise explanation of what it meant to be a woman with breast cancer. There was, however, a sense in the interviews and discussion groups, that there was a "right" way to be a woman with breast cancer, even if participants were not convinced there should be. In discussing her views on the ideas

about positivity and fighting she saw in other participants' posts, Nancy expressed confusion about the messages she received about what it means to be a woman with breast cancer:

I don't see anything there that can be measured or quantified or that can be defined in any way, this sort of, fierce, indomitable spirit, well, what does that mean? How does that translate into any kind of action or reality? So it's just this very, very nebulous concept of wanting something, almost a craving. And to try to pin down what that could actually translate into, in terms of action, seems impossible to me.

Nancy described a desire for guidance concerning how to be, a “craving” that results from uncertainty following diagnosis. Although this “spirit” is “nebulous,” it is possible to examine the ways in which discourses are taken up by participants and others to produce an idealised way of being a woman with breast cancer.

Popular culture plays a significant role in proliferating discourses concerning how one should find and be her authentic self, whether or not she does so while coping with an illness. For example, as discussed in Chapter 4, participants often mentioned the very popular book and film *Eat, Pray, Love* (Gilbert, 2006) in which the main character has every material thing she could want, but feels she lost her self in a marriage. Following her divorce, the character travels the world discovering answers to life's biggest questions in European and Eastern traditions that encourage nourishment, balance, and wisdom. In the online discussion group, Carolyn passed on a quote from the final episode of Oprah Winfrey's talk show, which she found to be inspiring:

I watched the last Oprah show and found some inspiring words that she spoke of: ‘what I know for sure from this experience with you is that we all are called. Everybody has a calling, and your real job in life is to figure out what that is and get about the business of doing it.’

As noted in the previous chapter, participants also spoke about *The Secret* (Byrne, 2006), a best-selling self-help book that claims positive thinking can change the concrete conditions of people’s lives. In such accounts, women uncover and live according to an “authentic self” that is strikingly similar to the idealised woman with breast cancer described by participants.

In this study, participants’ accounts of identity could be described as consistent, we’re born our authentic selves, or teleological, we become or create our authentic selves. Their descriptions make it seem unlikely that women would all uncover or create the same “authentic” self or have the same purposes in life; yet, in the interviews and online posts, participants often used the language of authenticity to talk in very similar ways about the importance of being positive, fighting, finding meaning, and being a survivor/thriver. In talking about positivity, for example, many participants reported being positive because that is who they were—they had always been positive people. This assertion, of course, does not mean they were positive every day; most participants struggled to maintain a positive outlook.

As taken up by participants and others, the discourses of positivity, fight/bravery, survivor/thriver, and journey outlined in chapter 4 make available an idealised way of being a woman with breast cancer. As I argue in this chapter, this ideal is then recast as “natural” through the discourse of authenticity. Members of the mainstream breast cancer

social movement have not created these mind-body discourses, nor have they created the language of being true to oneself and living according to one's purpose. They have displayed agency and evaded discursive determinism by combining existing ways of understanding illness and other difficult experiences in a cohesive and persuasive manner that explains women's experiences of breast cancer.

The idealised woman with breast cancer is positive and strong, and makes meaning from her experience of breast cancer. Many participants alluded to this ideal in their interviews and online discussions group posts during discussions of how women with breast cancer act and how they cope with breast cancer (though it was clear that they did not always believe it described them, personally). The individual characteristics most often discussed were positivity or optimism, independence or self-reliance, generosity or giving back, and wisdom.

The idealised woman with breast cancer played a significant role in most participants' understandings of living with the disease. Mary described finding comfort in seeing survivors on television soon after she was diagnosed:

I just remember, the thing that inspired me, in those times, were people that I had learned were survivors, like I know Wendy Mesley, the journalist on the news, she's got a great career, nice looking woman, she's a breast cancer survivor, she went through chemo, went through the whole thing. All kinds of people like that, that are on the other side of all their treatment and living very productive, wonderful lives. And so, I just remember thinking 'Oh my gosh, there's hope. I'm going to be there one day.'

The concern with living a productive life after surviving a life-threatening illness is an important feature of the idealised woman with breast cancer.

Heather was comforted by her sense that breast cancer made her a better person: “It gives me comfort thinking that it happened for a reason. I got through and you know, maybe one day I can help others who are going through it or I’m a better person.” The idea that cancer makes one a “better” person allowed participants to make meaning of a difficult experience. For many participants, being a better person meant being a more “authentic” person; that is, in order to become a better person through the experience of breast cancer, many participants described a need to find and/or act in accordance with their true selves. For example, Pamela described how the experience of breast cancer helped her to find her purpose in life:

My life leading to my diagnosis in Sept of 2009 had taken me down a road of unhappiness. I hated my work! I felt stuck! Boom! Cancer comes (no surprise), but it shook me up and made me ask myself ‘What the heck are you doing? You are wasting precious time.’ It made me fight and be strong for my kids and husband and family and friends. Through all the BRAVERY of treatment, hair loss, and sickness I gained a sense of strength and became more self-reliant. My non-existent self-esteem returned ... You asked, ‘Who controls your journey?’ I like to be in control, but in this case the driver is the man upstairs who gives me today and the opportunity to complete my purpose on this earth. I am finding purposes, every day!

A few participants suggested that a true self was not something that you found, but something that you created through your actions. Elsie, for example, described life as an opportunity to create yourself:

Life isn't about finding yourself, life is about creating yourself, so true. We shape our lives not by what we carry with us but by what we leave behind. There is a master plan. We are part of it. What can you do but live with the hand that was dealt! Learn what we can and move on as fast as we can (if not, faster).

Whether participants described breast cancer as an opportunity to find or create one's true self and purpose in life, the characteristics of this true self were often consistent with the ideals discussed here and in Chapter 4.

Many participants mentioned the importance of this idealised woman in the larger fight against breast cancer. In her discussion of this ideal, Megan argued for the necessity of women who take up this subject position – positive, strong and “changing the face of cancer:”

I know there are people who do it. These are the people who come up with the ideas for Relay for Life, or the fundraisers. These are the people who really do take this and make it worthwhile. If there weren't people like that in the world, there'd be no disease curing. Some people are that dedicated and are that wise. I don't think I'm one of them. I wish I could be. I wish I had it in me to sit down and write a book that would change the face of cancer, but I don't think that's me. I think it may be one or two of the women who write on [the online discussion board].

Megan articulated the sense that adopting this subject position is one option amongst many, but it is morally important that at least some women with breast cancer succeed in embodying this positive, strong ideal. Without individuals acting in accordance with this subject position, breast cancer will not be cured. At the same time, Megan acknowledged the possibility of other, perhaps lesser, subject positions that women with breast cancer could take up. As the next section will show, however, identifying with these other positions may be experienced as failing to live up to an ideal.

5.4 Living Up To This Ideal

In Chapter 4, I described the discourses of thriving. Related to that notion of thriving, in this section, I ask what it meant for participants to better themselves through their experience of illness by striving to live up to an idealised representation of women with breast cancer. Most participants struggled to embody this idealised subject position in different situations and at different times. Despite this struggle, most felt it was important to try to embody this subject position whenever possible. During interviews and online discussion group posts, many participants commented on Pamela, whom they often described as best embodying this subject position. Pamela described the need to strive for this ideal:

It's all to do with who I was before: perfectionist and trying to maintain perfectionism, sort of. But, I mean, I know there's no perfection in this world. And, nothing is perfect. But you always strive for the best that you can be right? Or the best that you can have.

Although this subject position was something participants struggled to embody, the idea that women with breast cancer should strive to be the best they could be was a common

sentiment amongst participants. This created expectations that many participants felt they failed to fulfill.

At times, all participants struggled to live up to the ideal portrayed in these representations of women with breast cancer. Sometimes this struggle caused them to work harder to live up to the ideal, at other times to doubt they ever could measure up to the ideal. Megan, who was at an early stage in her experience of breast cancer, struggled to embody this subject position; she thought other women with breast cancer she admired may have been “like that all along, or maybe it was just hidden within them and it only came out when they were forced to deal with maybe dying.” Megan was concerned that she was just not the type of person to “do” breast cancer in the best way. According to this way of thinking, some people are innately or authentically better able to cope with the disease.

Drawing on the discourse of authenticity, some participants – like Megan – naturalized the idealised woman with breast cancer, conceptualizing it as something one either can or cannot be, based on innate personal characteristics. But for others, failing to live up to the ideal led them to question the accuracy or the idealised representations themselves. Many participants expressed concern that they could not and should not have to live up to their own and others’ expectations and suggested instead that there was no right way to be a woman with breast cancer: “Is there supposed to be a stereotypical behaviour? ... Everybody's an individual” (Paula). Participants expected other women to have diverse experiences of the disease, even when they continued to discuss ideal ways of coping.

While no participants felt they could or should completely embody this ideal, most couldn't articulate another acceptable way to do breast cancer in public. As has been discussed previously, in contemplating the alternatives to being positive, Heather wondered, "What's the alternative, you die?" When participants read this quote in the initial results they were provided before the final interview, most agreed that the only way to be a woman with breast cancer was to be positive. Even if being a good woman with breast cancer was a struggle, actually rejecting this completely was difficult to imagine. Alice compared the ideal to a path:

I think having a path and knowing you can go off that path is a good thing.

I think that being the one that's at the front of the path and trying to cut through the grass is a really hard thing to do. I think it's full of panic, because you don't know if you're going in the right direction. It's just constant panic. And I think that you end up rushing through things, if you're at the lead, and you have nothing to hold onto. For me, having a path that others have walked, and I can see the other grass lines that people have walked down and I have some idea that I know people have landed at the other end. I know that they've gotten through it; I know that I can as well.

In many ways, the guidance the ideal provided was valuable enough to justify the difficulty many experienced in trying to live up to the accompanied expectations. Positivity was valuable to some participants because following it was said to increase one's chance of survival. Others rejected that claim but still believed that the ideal

provided guidance that supported their emotional well-being during their illness. Not following the path meant uncharted territory.

People within organizations supporting women with breast cancer recognize a need to support women with breast cancer in becoming thrivers (see for example Breast Cancer Wellness, 2012), which to some extent means helping women embody the idealised version of being a woman with breast cancer. To help members move towards this version of themselves, some support groups encourage members to build a “vision board.” Heather recounted her experience at a fun support group meeting during which she and other members flipped through popular women’s magazines to cut out pictures of beautiful women, exotic travel destinations, and words like “confidence” and glued them on to large sheets of Bristol board. Her vision board, and those of other participants in the study, visually represented the person the idealised woman with breast cancer is supposed to be becoming; she is beautiful, strong, positive, happy, and living a productive life. Nowhere is the influence of popular media on this ideal more visible than in accounts of finding one’s ideal self in the pages of popular women’s magazines. Organizers of the support group suggested that participants hang their vision boards in a place they see every day so they remember what they have the opportunity to become. Much like *The Secret* (Byrne, 2006) suggests, just focusing on these goals was thought to make it possible to achieve them.

Whether participants felt their skills naturally allowed them to adopt this subject position or they worked hard to try to become good women with breast cancer, the importance of being positive, wise, and strong was consistently recognized. As has been stated, many participants felt that embodying this ideal contributed to their health and to

the broader fight against breast cancer. Bettering oneself through cancer was a recurring and largely unquestioned theme in this study. It is interesting to compare this to young women's efforts to "better" themselves by conforming to gendered beauty norms. While this trend persists, many women recognize the ways in which we discipline ourselves to become "better" in this way. This recognition has not yet translated to a broad examination of the work that goes into becoming a good woman with breast cancer. The risks of examining this idealisation may be too high for many women with breast cancer. Unlike criticizing beauty norms, which may only affect how one is seen by others, criticizing the work of being good women with breast cancer is seen as a potential risk to one's health and well-being—whether through negativity (or critical perspective) feeding cancer cells, or through exclusion from or within support groups. In the following section, I examine the ways in which women's efforts to become good women with cancer required self-governance.

5.5 Subject Positions and Self-Governance

Adopting a subject position requires individuals to situate themselves in relation to the representations and meanings present in discourse. In order to situate oneself in the position from which the discourse makes the most sense, individuals must align themselves with the discursive representations and meanings. In this way, taking up a subject position requires self-governance and discipline.

Understandably, participants reacted negatively when I asked an interview question that used the word "should." All of the participants stated that women with breast cancer shouldn't be expected to do or be anything in particular. In line with this belief, many participants were struck by the frequency with which members of the online

discussion group apologized for expressing their feelings, and wished that everyone felt more comfortable discussing their negative experiences of the disease and the health care system. Jean reminded other participants that they didn't need to apologize for their posts: "I learned early on not to worry about offending others. You have the right to be who you are and need not apologize for it." In this and many other ways, participants explicitly recognized that women with breast cancer did not have to be positive, wise or strong. At the same time, their stated expectations of themselves and others, as discussed in Chapter 4, often contradicted these explicit statements.

Most commonly, participants suggested *they themselves* should not complain, express anger or be passive in their care. One participant encountered significant emotional difficulties during the study. At that time, Jean described a feeling of losing control of her self and how she was acting. During her second interview, she discussed her concern that the change in her mood would lead other participants on the online discussion group to judge her:

At first everybody was positive, and I was probably leading the charge at one point ... And then later, as I started to shift, I felt wishy washy because I knew I was switching up. I just felt like maybe I was going to be judged, by all these strangers. You know? And they're probably thinking 'What a basket case.'

Appearing to be consistently happy was important to many participants. The alternative, as Jean described, is being labelled a "basket case." This mirrors examinations of women's experiences of illness in which gendered expectations of women create a context in which women's expressions of negative emotions in health care situations are

interpreted as hysterical or irrational (Greenhalgh, 2001). This is also a result, in part, of engaging in online discussion groups with unknown others. Although some participants felt more comfortable expressing their feelings to strangers, some said that they would have preferred to know the people with whom they were engaging online.

Many participants struggled to reconcile the contradictory ideas that one needs to express anger in order to be healthy, but that expressing anger is not a good thing to do. As part of the online discussion group, participants were asked to read a blog titled “No F***** Pink Ribbons!” (Jennifer, 2010-2012) which was written by a woman with breast cancer who is openly angry. Participants reacted strongly to this task, and some refused to read the blog because they feared it might negatively affect their health. For many participants, choosing the people and ideas they came in contact with was an important way to govern themselves and protect their health. Pamela, for example, discussed leaving behind people who were not positive. Negativity, anger, and sadness were described as being contagious. An important part of governing oneself was governing with whom and what one interacted in order to avoid such contagious negative emotions. This view of negativity as contagious fuels the surveillance and disciplining of women with breast cancer who fail to control their negative emotions around others. When a woman with breast cancer fails to govern herself and expresses anger to other women with breast cancer she doesn’t just put her own health at risk, she risks contaminating others with her negativity and damaging their health.

Many participants struggled to articulate how women with breast cancer could express their anger, given that they shouldn’t do so publicly. Mary tried to acknowledge

that a woman with breast cancer can be angry, while implying that this is not a good thing to do:

As I began reading this blog, I immediately felt that [the blogger] is not a person I would not like to be around. Not only negative, but she comes across as someone extremely self-absorbed and bitter. We do need to be able to express ourselves openly and honestly, whether we are feeling angry, abandoned, ripped off or otherwise, but we cannot expect the world to change because of our own diagnosis/experiences.

Often, a woman's inability to control her anger was thought to reveal something more deeply wrong with her as a person. Joyce attributed the blogger's anger to unreasonably high expectations, selfishness, and entitlement: "I think the woman in this blog was angry about her diagnosis and felt ripped off that it was her and that the whole world should adapt to her feelings." It is clear from these reactions that participants expected other women with breast cancer to control their feelings and their expectations, especially in public. To fail to do so is to invite judgment.

Participants governed their actions so that they would not act inappropriately and reveal themselves as negative women with breast cancer. For many participants, being positive was easy when in public:

It's not hard to [look positive]. I don't feel like 'Oh my god, I have to put a smile on my face.' It's none of that. You can get caught up in it, right? But it's when you go home at night, or when you're alone with your thoughts, it's like 'No, I'm not happy about this.' (Jean)

Although it was often easy to appear to be positive in public, participants noticed some ‘side-effects’ of this portrayal. Carolyn noted that people didn’t see how she was actually coping with the disease:

Visibly you might look alright. But it's the invisible things you don't see.

You know what I mean? I think that's hard to explain to people

sometimes ... [They're not seeing] how you're coping with it; how much

you've gone through ... Maybe people just can't fathom how difficult that

is.

In some ways and at some times, participants valued the privacy provided by this invisibility. At other times, this privacy was accompanied by feelings of being abnormal or excluded. Participants struggled to balance the benefits of remaining invisible by appearing to be a positive survivor, and the consequences of feeling alone in their moments of sadness, anger and frustration. This balance is further complicated by the connections between these ideals and stereotypical femininity.

5.6 Subject Positions and Femininity

The control participants exerted over their feelings, thoughts and behaviours resembles in many ways the effects of gender norms on women in all contexts. The requirements of being positive, looking happy, and making others happy before oneself, directly mirror the requirements of normative femininity (Bordo, 1993). There are significant connections, for example, between the subject positions of mother and woman with breast cancer. Some participants drew explicit links. For example, being a mother and wife fuelled Pamela’s desire to be a positive cancer survivor:

As long as I have children, as long as I have a husband and as long as I have friends and family, you're going to see that I'm going to try to promote myself as a positive cancer survivor, if I can call myself a survivor ... I guess a role model is more, than a survivor. I just want to be a positive role model for them. It doesn't always happen. I mean, I can be pretty positive on paper and I can be pretty positive speaking. But I can have pretty negative attitudes too.

Pamela felt that the moments she failed to be a good woman with breast cancer were also moments she failed to be a good mother:

Sometimes when I don't feel positive, I really get down on myself ... I understand, but I just get upset at myself, because 'get over it.' You know? Just get over it ... Everybody tells me [I'm dealing with a lot], and I have to tell myself that, 'It's okay. I've been through a lot.' But it doesn't mean that I have to be angry; it doesn't mean that I have to snap at my kids.

In many ways, the idealised woman with breast cancer subject position is strengthened by its connection to femininity. It is not surprising that many women diagnosed with the disease are already adept at putting others first and maintaining the appearance of positivity and hiding anger.

At the same time, many participants felt the experience of breast cancer freed them from some requirements of femininity by allowing them to become less governed by feminine social norms. Many participants stated that their experience of breast cancer allowed them the opportunity to critically evaluate and resist beauty standards. Alice, for example, felt more able to resist gendered beauty requirements:

Did the ‘am I going to wear shorts this summer assessment’ yesterday and came up with ‘hell no’ and then said ‘Alice, you survived breast cancer, wear what you want, be grateful for the lopsided boob, and then decide to either accommodate them or let it ride because it will all sort out and the phases of comfort and discomfort change.’

For Alice, experiencing breast cancer provided a perspective on her looks that allowed her to overcome the self-criticism that normally would have kept her from wearing shorts. Other participants spoke about feeling less need to style their hair or wear make-up after having gone through chemotherapy. In this way, undergoing treatments provided some participants with the opportunity to critically resist gendered beauty norms.

For other participants, experiencing breast cancer provided an opportunity to reevaluate other subject positions, many of which reflected dominant understandings of femininity. Pamela described the way in which her increased self-esteem initiated significant positive changes in her relationship with her husband as she started to take a more active role in decision-making in the home. For Pamela, breast cancer was an opportunity to challenge the constraints of femininity by taking a more active role in the family decisions that affected her and her children.

For some participants, being both a good woman with breast cancer and a good woman in other aspects of their lives (at work or at home) was not always possible. Gail, for example, described how her professionalism at work was undermined by the way breast cancer drew attention to her personal life. For many participants, being seen as having increased credibility at work required overcoming assumptions about femininity that cast women as being less professionally capable than men. In this context, adopting

the feminized subject position of a woman with breast cancer further challenged participants' efforts to be credible in their places of work. For various reasons, most participants did not employ the subject position made available to them by breast cancer discourse at all times and in all places. In the following sections I examine instances of resistance, partial engagement, and the social relations that make this position more available to some than others.

5.7 Undermining "Authenticity"

In many ways, taking up the idealised subject position made available through breast cancer discourse was accomplished by acting in particular ways that differed from one's actual experience at the time. Participants often felt the need to complain, felt angry, or felt vulnerable. Yet they often refused to display those feelings in public. This difference between how one was feeling and how one was acting, undermines the discussions of authenticity outlined in the previous sections.

When 'negative' feelings were expressed, it was not always clear whether this was understood as a form of resistance to the normative standard of positivity, or failure to take it up adequately. In reference to the online discussion group, Joyce was surprised that women with breast cancer would actually express anger: "There seem to be a few people who are very angry. I understand where they're coming from, why they're saying what they say. But I find it very funny that they would actually put it all on there" (Joyce). It is not the existence of anger that surprised Joyce, but the inability or unwillingness to control or hide anger in a semi-public setting. Thus, a failure or unwillingness to self-govern often shocked participants. While women with breast cancer

may authentically experience a range of emotions, it was not necessarily considered acceptable to express these to others.

The claim of authenticity was further undermined by participants who spoke about “putting on” a survivor role in public. Pamela, for example, spoke about learning how to wear different hats in her many roles with breast cancer organizations:

[Support organization representative] taught me that I wear different hats.

And I was having a difficult time, because I didn't know how to be, what to say, because I didn't want to say anything wrong for [breast cancer support organization]. But [other breast cancer support organization] is very important to me, so there was a balance of like, a struggle I guess, because I didn't want one to be more important than the other, because they're all important, and need my [support]. But they're all serving a different purpose in my life. And she told me that I wear different hats, and that I should wear my survivor hat that night. So today, I'm wearing my survivor hat; I'm not wearing anybody else's hats. And that's one of the lessons that will stay with me.

If survivorship is a “hat” that one can take on and off, then the ideal representations of women with breast cancer promoted by the breast cancer social movement are not “authentic,” but rather subject positions that women use to fulfill their needs in particular circumstances, and the agency entailed is made evident. Women may be choosing *when* to embody the idealised woman with breast cancer.

No participant consistently personified the idealised subject position made available through breast cancer discourse; they all experienced moments of being fully or

partially outside this position for various reasons. The experience of being unable or unwilling to completely live up to this ideal may have provided a site from which participants could be more critical of the idealised subject position. In this section, I use the word “resistance” to describe the ways in which participants themselves experienced being outside of this subject position.

Many participants were concerned that breast cancer not become a dominant or permanent part of their identity. Preventing this often meant deciding when and how to present themselves as women with breast cancer. Heather spoke about the need to balance the breast cancer subject position with other ways of being:

I think if I'm at the mall, selling tickets to a fundraiser, then it would be appropriate for me, to, you know, grab someone who comes over for a brochure and say ‘You know what? I had breast cancer and I survived. And that's why we need to do research’ and have the whole sales pitch. You know? Like I think that it's appropriate for that in that forum. But yet, at the same time, there's more to me than breast cancer. You know? Like if I met someone at a dinner party, well, I could talk to them about, you know, well, I like to paint, or I like to, write poetry or whatever. You know what I mean? Like, there's, there's more to me than breast cancer. I don't want, for me, I don't want to deny that I had breast cancer, or pretend that it isn't important to educate people and advocacy is very important. But at the same time, it doesn't define who I am. It doesn't, you know, I'm not breast cancer. I'm [Heather].

Similarly, after her diagnosis, Gail stopped wearing “pink” products because she did not

want to become the subject of this feminine breast cancer discourse:

Before cancer I wore some of the breast cancer 'pink' wear as a sign of support, but now I steer away from it because I do not want it to define who I am or where I've been. It's a little confusing at times.

Mary chose when to use "survivor" language so that she could limit the extent to which and occasions in which it defined her:

Personally I use the metaphor 'survivor' at times when I feel I want to share that I had breast cancer with someone. It doesn't make me feel like I have to be part of the breast cancer 'community.' Just because I had the disease doesn't mean I want to be part of a 'Club.' I want my life to move forward after treatment, not to be my identity.

In many ways, participants employed the subject position made available through breast cancer discourse as they found it to be useful and resisted the position when it was not of use to them. At times, participants found this subject position drew so much attention from others that it overshadowed other aspects of their identities. For example, as mentioned earlier in this chapter, some participants experienced difficulties to occupying professional subject positions at the same time.

At other times or in other contexts, participants resisted the idea that the idealised woman with breast cancer even existed. Joyce, who was involved in the breast cancer community but refused to take up the language of survivor or thriver, described what she thinks is behind this ideal: "The thrivers that I've met, they're people who are not dealing with perhaps all that's gone on with them ... I daresay they have their dark moments." At the same time that Joyce questioned the reality of this ideal, she expressed concern that

her inability to be a thriver meant that she wasn't going to make a difference in the fight against cancer:

They're blazing trails and they're going to make a difference. And I'm not. Maybe it's a personality thing. I was never somebody who wanted to be out there and be the martyr, or you know, the big, I don't know, the conqueror. I just want to get on with my own life, and do my own thing, and maybe that's why I'll never be a thriver.

Even as Joyce resists the validity of this subject position, she endorses the ideal of the “thriver” and uses military language to describe other women as “conquerors.” In many accounts, there was a sense that resisting breast cancer discourse meant that one could not make a difference. Giving up the perceived obligation to contribute to the cause of breast cancer was sometimes difficult for participants.

In some contexts, resisting taking up the positive, strong subject position was necessary in order for participants to seek help. Jean discussed the moment she told support group members that she was experiencing depression and thoughts of suicide:

I thought, 'You know what? I'm going to be honest with these people. These people know what I'm going through. They've been there themselves.' Three of them stepped up and said the exact same thing as me, as far as like, suicide and stuff. We're all walking around carrying anti-anxiety drugs. You know? They're all going through the same thing ... I really believe that the positive attitude that we portray is not for ourselves, to be honest with you. It's for everybody else sitting around you.

In this moment of resistance, Jean recognized how much work she and others were doing to maintain this subject position. At the same time, Jean defended her decision to resist this subject position by attributing her sadness, anger and depression to menopause and inappropriate medications: “It's the menopause. I'm having a lot of problems with menopause. I'm having a lot of problems with my medication, in that it's making my menopause worse.” In attributing her experiences of sadness and anxiety to a medical issue, Jean moved the blame from herself to a treatable illness. In doing this, she evaded questioning the accuracy of the subject position, but instead excused herself for not living up to the ideal.

Accepting a particular subject position can allow one access to a community of individuals who have done the same; however, most participants felt that they could not or should not adopt this subject position and did not fit in with other women with breast cancer. At times, this was because their experiences of cancer did not seem serious enough to justify their involvement with the group. Elsie felt she did not have enough lasting physical effects to make her part of the breast cancer community:

You don't really like to complain because there's maybe somebody worse.

Because, like I said, the [groups] that I'm in, they seem to have either lost their breasts or the chemo side effects and I never had that ... If somebody comes up to you, they've got two broken legs, one broken arm, black and blue and you've got a sprained wrist, what do you have to talk about?

For Elsie, belonging to the community of breast cancer survivors required having survived something more significant than she had. Joyce's fear of recurrence kept her

from being what she considered a “survivor,” making it more difficult for her to feel she belonged in survivor-run organizations:

Some people are very quick to say ‘I’m a survivor. I’m a survivor.’ Does that mean that you’re finished? Was that only the beginning of this battle, if you will? ... I don’t look at myself in the mirror and say that. I just say, ‘Here again today.’

In these cases, physical or emotional experiences of the disease that were inconsistent with survivor stories made it difficult for participants to accept the subject position made available.

In one case, a participant rejected breast cancer discourse because she felt she already received comfort and meaning from her spiritual community. For Mary, there were few benefits to identifying herself as a woman with breast cancer as she had an alternative source for answers to the questions others were asking: “Even before cancer, I thought a lot about those things. Like how do I want to live my life? And what are my values? And what’s important to me?” She was evidently still interested enough in being involved in the breast cancer community that she wished to participate in this study, though the idealised subject position made available through breast cancer discourse held few additional benefits for Mary and she chose not to engage with it. For some participants at some times, the benefits did not justify the work to portray themselves as a good woman with breast cancer, or they were able to access similar benefits through other subject positions available to them.

Although participants resisted idealised representations of women with breast cancer at various points, all tried in at least some circumstances to be good women with

breast cancer. There was a sense in the interviews that being a good woman with breast cancer was important, even to those who challenged what it meant. In the next section I examine the ways in which social relations denied some women access to this subject position.

5.8 Availability of Subject Position Through Social Recognition

Foucault's account of subjectification has been critiqued by feminists as being overly individualistic and overlooking the ways in which relations with others, material conditions, and other structural power relations make it difficult for some women to accept or resist subject positions (Allen, 2008). The addition of a relational perspective allows us to better view the ways in which social relations shape an individual's (in)ability to embrace or resist a particular subject position. Discourse and identity are relational, meaning that they are not produced or maintained individually, but rather through interactions with others. In this context, social recognition is required to maintain a subject position; a woman with breast cancer cannot access the benefits of being a good woman with breast cancer if others do not believe she personifies this subject position. In order to adopt and maintain a subject position, one must govern her self and risks being disciplined by others. Governance operates through relations within and outside the breast cancer community.

Through their judgment of others, participants made it clear who they believed to be living up to this ideal and who they believed not to be. As we have seen in Chapter 4, one participant in particular was described by other members of her discussion group as negative and unable or unwilling to be a good woman with breast cancer. Gail described this participant as wasting her energy:

This one person was talking about, her family wasn't very supportive.

'Why did I have to deal with this?' 'Why me?' But no matter how you look at that, I just say to myself 'You'll never answer that question. So there is no point wasting energy on trying to answer it.'

These accounts contradict the “negative” participant’s own account of her beliefs and feelings; she described herself as a positive, strong and independent person. These accounts do explain why this “negative” participant experienced exclusion from the breast cancer community despite her efforts to reach out. Other participants also experienced instances of reaching out for support and being told that they just had to be more positive. Failure to live up to an ideal may result in exclusion from support through the breast cancer community. In this way, women with breast cancer who wish to access support learn that they must govern themselves appropriately—thought they may still refuse to do so.

Participants involved with breast cancer support organizations stated that anyone with breast cancer will receive support from the breast cancer community. At the same time, most of them also said they wouldn't be around anyone who is negative, so it is unclear who would provide this support to “negative” women. Joyce describes the non-judgmental environment of one support organization:

[Support organization] is also a place for people to cope, to learn how to be a survivor or a thriver, it's all part of the healing process. I think, because the organizers and the people who are in place have been there. They've had breast cancer and they, I don't think that you become very judgemental. You lose a lot of that and it's humbling when you see what

people will do for people. And when you've experienced cancer, you can really sit back and understand that, 'Okay, she's not there yet. She might never get there. But at least she's trying.' You know? She's not sitting at home, wallowing, worrying, all the time.

Although Joyce contends that this is a supportive environment for anyone with breast cancer, it is clear that there are judgments about not moving forward and worrying. And it is clear there is an ideal that women can aim to achieve. In order to receive support, an individual who is not living up to the ideals of survivorship or thriving must at least be trying to be more like a thriver.

The judgment that women faced was compounded by understandings of the ideal subject position as authentic and natural. Participants contributed to a discourse in which women who failed to take up this position had other morally questionable personal characteristics that influenced their inability to do so. Joyce, above, referred to women “sitting at home, wallowing.” In an online discussion group post, Nancy compared women who can’t make meaning from their experiences of breast cancer to Snooki, a reality star famous for her perceived lack of intelligence: “I don’t think you need more than basic wisdom and humility and common sense to learn these lessons; they’re things anyone can learn from, I mean, with the right mindset. (Maybe not Snooki.)” It appears from comments such as these that failure to be positive, to fight or to make meaning is attributed to an inability to self-govern, often due to a perceived lack of intelligence or laziness.

In some examples, women’s failure to take up this ideal breast cancer subject position was even used to explain some women’s inability to cope with or survive the

disease. Jean suggested that women who do not take an active role in their care (fight) are more likely to suffer emotional effects of the disease:

I find those people that just kind of lay back and just say ‘Okay, you know what? You do it all’—I don't know how to put it, it's just, maybe they didn't rebound as fast ... I think it takes them a little longer.

Through judgments like these, participants were able to attribute their own coping and survival to their personal characteristics. This provided a sense of control over the outcome of the disease, but did so at the cost of others who were disciplined and judged as failures.

Although this sample was not representative, it was interesting to note that the participant most often judged by others as “failing” the ideal was also the most demographically different from the other participants. From a disadvantaged socioeconomic background and struggling with poverty, this participant had more difficulty expressing herself in writing and often voiced concerns about not knowing what was appropriate and inappropriate to share on the discussion board. When she expressed concerns about lacking social support or struggling to start new relationships, other participants interpreted this as self-pity and criticized her inability to be positive. As we have seen, Elsie went so far as to suggest that the participant lacked social support because nobody wanted to be around someone so negative. In this way, she was cast as a “bad woman with breast cancer” and was seen to deserve the difficulties she encountered. The effects of larger social differences and inequities on one’s ability to take up and maintain a socially recognized and sanctioned subject position were rendered invisible. By making these social relations invisible, participants’ discussions of how to embody

this ideal serve to privilege those who succeed in taking up the idealised position by suggesting that their innate character has allowed them to do so, rather than any structural advantages.

Some participants did mention the effects of structural power relations, most often when talking about the costs of medications and travel to and from treatment sites and support organizations. Joyce examined the ways in which the benefits of cancer are not equally available to everyone:

Some people are not as benefitted [by cancer] as I was. I had a medical plan. I have disability [insurance]. I have a family, a husband and people around me. And then there are other people who are literally financially ruined and their families fall apart. So 'gift' is not really appropriate. I mean you gotta find a silver lining in things. And you know, I guess for some people who are less fortunate, at least they survive. Hopefully they survive and their families make it through. And I think that's the side of things that I would like to see better. For the people who can't, I mean, it's crushing, emotionally, financially sometimes.

Joyce implied that the meaning that some take from cancer is not as readily available to others. While everyone has to find a "silver lining," this may be easier for some than others. As there are real benefits for those who can access the idealised breast cancer subject position, the structural inequalities, such as living in poverty, that hinder some women from taking up this subject position are important to bear in mind. It is equally important, though, to consider the benefits in relation to the costs, and consider how this subject position may govern women with breast cancer. The following sections examine

these topics.

5.9 Benefits and Costs of Taking up Idealised Subject Position

In Chapter 4, I examine the ways in which mind-body discourses help to provide a sense of certainty about how best to “do” breast cancer following a disruptive diagnosis. In order to embody this normalizing discourse, participants must situate themselves in positions from which they make sense; in other words, the certainty that these discourses provide is only available from particular subject positions. If a participant wanted to feel a sense of certainty and control (as we all do), these discourses are among the few resources available.

I cannot overstate how important it was for participants to feel that they had some control over their disease and care. For many, this sense of control was completely entangled with mind-body discourses and being a good woman with breast cancer. At times, it was difficult for me to ask participants to talk about the positions they occupied because I felt I was undermining their ability to cope. Many participants had a lot of their hope invested in the truth of these discourses, and thus worked very hard to take up the corresponding subject positions:

I think if you're negative and you take on the victim mentality, there are studies saying that it compromises your immune system. Right? So I think if you think positive, that it helps to build your immune system, helps you to fight off cancer. And so I think, like, ninety nine percent of it is in your head. If you can keep positive and stay positive, that is your best medicine. That's your best defence. (Heather)

The most important benefit of this idealised subject position is the sense of control, certainty and hope it provided—hope not only for survival, but also for a new and more meaningful life after cancer. The idealised woman with breast cancer is a role model for other women with breast cancer, providing a path to follow and a sense of possibility. I examine the effects of moments in which this certainty is undermined in Chapter 6, but for now it is enough to say that moments of uncertainty caused significant upheaval for participants.

The benefits of this subject position did not come without costs. In order to maintain this subject position, participants had to exert a significant amount of control over their feelings, relationships and self-conceptions. For some, this required them to set aside sadness, anger and frustration that later surfaced as depression and anxiety. After transition, many participants wished that they had expressed more of their negative feelings while going through treatment:

I should have vented. I should have started letting it out. I needed an outlet. And now it's coming out now, and it's pouring out but I'm trying to get out like a year's worth and it's just, sometimes I feel like I'm tripping over my tongue. (Jean)

In addition to emotions “pouring out” later as Jean described, many participants experienced depression and anxiety for which several were prescribed anti-anxiety medications. Many participants worried that hiding their anger would have lasting health effects. In not expressing their emotions, participants also were unable to ask for help. In order to access help for the emotions they were experiencing, they would first have to admit that something was wrong. Although some received sufficient help from others,

most did not receive the amount or type of support they really wanted. In other cases, participants' efforts to meet expectations of the good woman with breast cancer by drastically change their lives by, for example, changing careers, volunteering or altering personal relationships, distanced them from their support system, strained their relationships with family and friends, and often failed to produce the change they envisioned.

The ability to adopt and maintain this subject position provided participants with a sense of control over themselves and their disease. Later in their disease experiences, many participants recognized unanticipated emotional effects. Despite this, many maintained that it was best that this subject position continue to be featured in the media. When asked if it would be better to have a more realistic representation of women's experiences of breast cancer in the public, Gail replied:

I don't think we really miss it. I think that's just part of everybody trying to stay within the definition of keeping life normal ... If somebody was out there and was just going around with the one breast, I guess it would raise the level of awareness more. But in terms of the person who only has the one breast, I think keeping life as normal as possible, is really, I think it's important for people. You know? If the spotlight is put on you, because of what you've been through, it's not necessarily a good thing, for me. Then it's a constant reminder and people are looking. I don't think it's pleasant for the person who would have to go through that.

For Gail, the normalization provided by the idealised subject position has value for women with breast cancer. Gail's opinion mirrors that of many individuals, and explains

the strong public reactions that often follow media campaigns that feature images of women following a mastectomy (see for example Matuschka, n.d.) or accounts of anger in the face of breast cancer (i.e. participants' above-mentioned reactions to "No F***** Pink Ribbons!"). In many ways, participants believed that, despite the costs, this idealised subject position was important for their own survival because it increased their chances of survival, decreased their risk of recurrence, and/or supported their abilities to cope with the disease. In calculating these benefits and costs on an individual level, the ways in which this subject position governs and services women with breast cancer as a group is not entirely visible.

5.10 How the Ideal Governs Women

In personifying particular mind-body discourses, women with breast cancer become members of a social group of women with breast cancer, providing a source of solidarity and meaning. But living up to the ideal required for group belonging comes at a cost, requiring participants to self-govern and discipline others. These techniques of governmentality simultaneously allowed women with breast cancer to create meaning from their experiences, and exercised control over their behaviour by limiting legitimate ways in which to make meaning.

It is no coincidence that the way most participants chose to make meaning was through volunteering in the breast cancer community or health care system. The pressure to do so left some participants feeling as if they were failing to be good women with breast cancer if they did not volunteer. This experience was particularly common for participants who had the most contact with breast cancer support organizations. Some of

these participants spoke about the many different ways other women with breast cancer could contribute:

Some people can't [volunteer] because of their family circumstances.

Some people do, if they can. People will donate their wigs, or donate things. I know of one person who donated a couple camisoles and a prosthesis. Maybe helping others, knowing that we are starting a group or have a group. People do it in different ways, what they can do. Right?

But I think sometimes [we feel pressure], I don't know if it's something known that we're supposed to help somebody else. You know what I mean? Maybe it's perceived that way. (Carolyn)

In this quotation, Carolyn noted that women with breast cancer might perceive that they *should* volunteer. Rarely are these calls to volunteer explicit, but many participants perceived an implicit expectation that they give back.

Participants with less contact with breast cancer support organizations were also less likely to discuss an expectation that they volunteer. As Mary noted, no one had asked her to volunteer:

I would have to do it because I wanted to. And, I wouldn't want to do it because I felt like I had to. And, maybe one day I will. I did think about, nobody ever approached me about it, so I never really did anything.

For these women with breast cancer (recruited through a breast cancer support organization), good women with breast cancer contribute to the fight against breast cancer by volunteering with breast cancer organizations.

Participants who did take up this idealised subject position—the eager

volunteers—were welcomed into the breast cancer community. Some of these participants became overwhelmed by the sheer volume of volunteer opportunities:

There's a little bit of burn out happening there, like, the overwhelming amount of stuff that you can get involved in [in the breast cancer community]. And you have to pick and choose. And unfortunately, when you're my type of personality, you pick and choose everything. (Pamela)

Although Pamela attributes her tendency to choose to be involved in too many things to her personality, many participants felt overwhelmed by the ways in which breast cancer became a larger and larger part of their lives. Once a participant was involved in one event, she received more and more requests to assist with others. Participants who actively limited their involvement in the breast cancer community did so, in part, by resisting the subject position made available to them. Nancy, for example, sought outlets for her anger in writing about her experiences with breast cancer. When participants did try to become involved in the community some experienced judgment for their previous lack of involvement. For many participants, a lack of involvement meant a lack of contact with other women with breast cancer, thus limiting (though not eliminating) the judgment they might face. In perpetuating these discourses and the idealised subject position it makes available, support service organizations further their own objectives by producing active volunteers. These governing techniques enabled participants to feel in control in the face of uncertainty, but also required them to govern themselves in an effort to live up to an ideal. Participants who could not or would not self-govern in accordance with these discourses, often lacked support for their choices and felt lost in their efforts to define what it meant for them to be a woman with breast cancer.

5.11 Conclusions

In the context of uncertainty, mind-body discourses were the foundation of a social group of women with breast cancer, providing a source of solidarity and meaning. At the same time, they were invested with moralizing tones, created an idealised way of experiencing breast cancer that many participants felt they could not entirely meet, and led to judgments of self and others. These techniques of governmentality simultaneously allowed women with breast cancer to create meaning from their experiences, and exercised control over their behaviour through discipline and self-monitoring. For participants, this ideal representation of women with breast cancer provided guidance, hope, and a way of connecting with others. Participants' efforts to live up to this ideal also benefited the health care system and support service organizations through the production of willing volunteers and good patients.

Popular media promote the idea that women should find and live according to their "authentic" selves. Participants described breast cancer as an opportunity to do just this, to thrive by living in an "authentic" way. The mind-body discourses discussed in Chapter 4 provided guidelines about how to thrive. Participants described thriving as being true to themselves and living a full life, and this language of "authenticity" served to obscure the socially constructed nature of the idealised woman with breast cancer. In this chapter, I made visible the ways in which this ideal is discursively constituted. In taking up this subject position, participants benefited from fulfilling social expectations, but this position is not always available or desirable. In moments when participants were unsuccessful in taking up this position or refused to do so, they risked being judged, excluded, or feeling a sense of personal failure.

In the context of efforts to negotiate the idealised subject position described in this chapter, participants also made significant life and health care decisions. In the following chapter, I examine the ways in which the constraining and enabling effects of these discourses and idealised subject position extend to participants' discussions of decision-making. In framing these decisions as "personal," participants strived to make decisions consistent with their identities. In doing this, the idealised subject position discussed here becomes the foundation on which many decisions are made, limiting participants' abilities to imagine other options.

Chapter 6: Making Decisions

6.1 Introduction

Discussions of informed choice in the context of evidence-based medicine and consumerist health care often focus on the need to provide medical science information to patients so they can make good treatment decisions. In practice, medical science is often unable to provide the definitive answers people hope for and other factors play a significant role in medical decision-making. In the instance of choosing medical treatment for breast cancer, many participants were faced with a decision between treatments with roughly equal statistical effectiveness. Theoretically, this leaves patients and physicians to work together to decide on the treatment plan that is best for the individual patient.

As explained in Chapter 2, in developing the concept of relational autonomy, feminist bioethicists provide a framework for considering the effects of power relations on medical decisions (MacKenzie & Stoljar, 2000). Much of the bioethics literature describes autonomous decisions as those made with a good understanding of relevant information, competence and freedom from coercion (Faden & Beauchamp, 1986). Feminist bioethicists expand on this understanding of autonomy by arguing that making an autonomous decision is about more than being informed, and requires enabling relations of power to support the decision-making process. Researchers must look inside and outside of clinical settings to view the many ways in which relations of power shape the medical decisions made by patients who are situated as members of particular social groups (based on factors such as gender, race, socioeconomic status, age, ethnicity). Embedded within complex power relations, individual patients may have access to

certain options and not others may assign different meanings to these options in their lives and may face different consequences if making an uncommon or unpopular choice.

In this chapter, I examine the ways in which participants made treatment and life decisions. I begin by examining participants' discussions of the medical decision-making process and what it means to be informed. In the absence of definitive answers from medical science, treatment decisions were framed as personal choices. I argue that this understanding obscures the many ways in which relations of power, in the form of mind-body discourses and available subject positions, shape the choices that are visible and acceptable to women with breast cancer. Throughout these discussions, I draw attention to the ways in which participant decisions are governed by efforts to live up to the ideal of the good woman with breast cancer: a woman who advocates, is strong, takes care of her family, and is positive.

6.2 Informed Medical Decision-making

Legal and moral standards of medical practice require physicians to obtain informed consent from patients before initiating any treatment option. The idea that a physician would make unilateral decisions for his or her patients reminds us of previously accepted paternalistic care provision, which is now deemed morally and legally flawed. Emanuel and Emanuel (1992) describe the extreme version of the paternalistic model as one in which the physician informs the patient which intervention is best. In doing this, the paternalistic model is founded on an assumption "that there are shared objective criteria for determining what is best. Hence, the physician can determine what is in the patient's best interest" (p. 2221). In contrast, medical consumerism reflects the idea that patients are consumers who are more actively involved in selecting which providers,

tests, and treatments they prefer. A growing body of literature reacts to and challenges medical consumerism by suggesting that the rational consumer implied in consumerist models of care overlooks the complexity of health care decision-making. Lupton (1997) argues that the conceptualization of the patient underlying medical consumerism mirrors the sociological concept of the late-modern reflexive self who rationally pursues self-improvement and criticizes expert knowledge. Instead, she argues that lay people take up both the idealised “consumerist” subject position and the “passive patient” position during medical decision-making. In this way, patients are neither entirely active nor passive, but rather adopt different positions toward decision-making in different contexts.

In the medical literature, a more straightforward reaction to medical consumerism argues that in some cases, patients don't want to make their own decisions (see for example Schneider, 1998). Following this argument, patients should have the right to choose to trust their physicians to make decisions for them. Although this differs from Lupton's (1997) argument, it is similar in suggesting that patients are not always or perhaps cannot always be active consumers. While the control exercised by active consumers is thought to be helpful compared with passive patients who make no decisions, active patients must also accept responsibility for the outcome of their health care decisions. Additionally, even passive patients often make the choice to trust their physicians. Even though the choices patients make are constrained, they may be held or hold themselves responsible for the outcomes. In some cases, avoiding this responsibility is seen to be more important than having control. In other cases, this sense of control may support healing.

In developing the concept of relational autonomy, feminist bioethicists look

beyond current standards of informed choice to examine the ways in which power relations shape women's abilities to be autonomous. This approach complicates dichotomous discussions of control and responsibility, demonstrating that enabling social relations are required for autonomy. Thus, autonomy is not contingent on being free from social relations, but of being embedded in enabling relations.

In the following sections, I examine two of the decision-making moments participants discussed in their interviews. I then discuss the approaches to decision-making that participants most often took up in making these decisions. Throughout, I begin to make use of the concept of relational autonomy to understand participants' decision-making moments. This connection is explored further in Chapter 7.

6.3 Two Types of Decisions

In this section, I describe participants' accounts of two types of decisions they made during their breast cancer experiences: selecting treatments, and managing risk of recurrence. While participants had different experiences making these decisions, they were described by participants as pivotal moments.

6.3.1 Selecting Treatments. As described in Chapter 2, in mainstream medicine women with breast cancer are treated with some combination of surgery, chemotherapy and radiation. The availability of these options may depend on the type and stage of breast cancer identified at the time of diagnosis. The extent to which women with breast cancer experience the selection of allopathic treatment as an active choice depends in part on their relationship with their physicians and the quality of medical evidence available for their type of breast cancer. It is important to note that all participants in this study underwent allopathic treatments. While some selected naturopathic and alternative

treatments for managing side effects, none chose not to engage with standard medical treatments. In earlier sections, I described participants' discussions of the need to undergo allopathic medicine in order to properly or adequately fight breast cancer. Thus, the choice not to undergo allopathic treatments is not considered here, since that was not a choice made by any of the study participants. This, of course, does limit the results of this study.

In this context, most participants with common types of breast cancer did not experience their selection of treatments as a decision that required much consideration of various options. Nancy described her experience of treatment selection: "There wasn't a lot of autonomy and decision-making required and I found that helpful." Most participants disagreed with Nancy and felt it was important to frame these decisions as autonomous choices. In many of these cases, participants' physicians suggested the treatment plan they felt would be most effective, and participants agreed with their suggestions. Most participants who selected treatments in this way described agreeing with their physicians' suggestions as a choice, arguing that making a decision to trust your doctor can be an informed choice.

When participants agreed with the treatment plans suggested by their physicians, most still spent extensive amounts of time reading about the treatments selected. Sometimes this reading took place before the treatment plan was confirmed. In other cases, participants agreed to a treatment plan in one appointment and read about the treatments they would undergo after the decision was made. Participants who took their physicians' advice were still actively involved in becoming informed about their treatments.

A couple of participants were asked by their physicians to choose between one or more available treatment plans. Mary, for example, was asked to choose between mastectomy or lumpectomy with radiation. She chose the lumpectomy because she was terrified of having a mastectomy. It was common for participants to fear one of the common treatments and make decisions designed to avoid that option. Similarly, Heather made her treatment choice to ensure she could have immediate reconstruction. In this case, it was most important for her that she not wake up without a breast following her mastectomy.

In a couple of cases, participants described choosing their own treatments from the commonly available options. Gail, who had a rare type of breast cancer, was told by her physician that he could not recommend a treatment based on medical evidence; thus, she chose the treatment plan that she preferred. In this case, as is typical of consumerist medicine, her oncologist provided Mary with all of the options and allowed her to choose her course of care:

[My oncologist] addressed the fact that mine was extremely rare and that they really didn't know how to treat it, because it was so rare. They basically put the options out to you and you make your decision. It's not 'We're going to do chemo and radiation.' It's 'Here are your options. And 'We need you to decide.'... It was my decision.

Gail described this decision-making process as a welcome opportunity to exert control over her care. It was important to trust her initial instincts when choosing without definitive information. She decided that it was safest to choose the most aggressive treatment plan available. Similarly, Jean's physician asked what type of treatment she

wanted, and then confirmed her choice was appropriate. In both of these cases, participants chose the most aggressive treatment available to them.

It is not surprising that participants chose to follow their physicians' advice or selected the most aggressive treatment. It is certainly understandable that participants wanted to survive cancer and chose the treatments they believed made them most likely to survive the disease. Participants described these decisions as being informed and not coerced, meeting the requirements of autonomy in the most common sense. Decisions such as these, made in moments when one's life is threatened, are necessarily limited. As much as they could in the limited time available, participants sought to inform themselves about the treatment options available to them. Although these choices were often guided by fear and relied on trust in physicians, talking about treatment decisions as active, informed choices was important for most participants. In the next section I describe participants' decision-making processes when choosing how to manage risk of recurrence. These decisions have fewer immediate consequences, leaving more room for participants to exert control over the lifestyle changes they decided to make.

6.3.2 Managing Risk of Recurrence. It is important to examine what it is that this fight in which “good” women with breast cancer are exhorted to participate in, is really against. Women with breast cancer are not only fighting their current battle with breast cancer—in biomedicine the focus on managing future risk also calls on them to select treatments that mitigate risk of recurrence. Beck (1992) describes modern society as a “risk society” in which lives are organized in response to perceived risk. As risk becomes something understood through scientific (or medical) knowledge, individuals become more dependent on experts like physicians to define and help them respond to risk (Beck,

1992). Luhmann (1993) extends this discussion by describing risk as a way of managing a future that is decided in terms of probabilities and improbabilities. As decisions are made long before the consequences will be known, the concept of risk allows individuals to make these decisions (Luhmann, 1993). In the case of breast cancer, considering their futures in terms of risk required participants to make decisions that would have future consequences. For many participants, risk of recurrence was a significant concern when selecting which treatment was best for them.

The statistics used to determine risk are often quite complex. For example, a statement like “this will lower your risk of recurrence by five percent” seems to mean that your risk of getting breast cancer would lower from 20 percent to 15 percent. More likely, this discussion of risk refers to a percentage of your current risk, meaning your risk will be lowered from 20 percent to 19 percent (by 5% of 20%). On top of this confusion, statistics cannot tell someone what will happen in an individual case. Carolyn discussed the limits of statistical probabilities for decision-making

The other thing is what are my options? Like, when you go into chemo, because you have triple negative breast cancer, there's thirty percent it works for you, thirty percent it doesn't, and you can be the thirty percent it may come back, and it may not work. So you've got a thirty percent chance. They just go by statistics, which is unfortunate in some cases, but that's what they have to base it on right? (Carolyn)

In reality, each individual's cancer will return or it won't. Each participant either will have a recurrence or will not have a recurrence. Thus, each individual's chance of recurrence, if we could know the future, is really zero or 100%. There is no evidence to

suggest which of these scenarios will apply to this particular person. Regardless—and unsurprisingly—managing the number assigned to their chance of recurrence became an important part of treatment for participants.

Fuelled by a fear of recurrence, for some, even a two percent benefit was worth the risk of undergoing short-term chemotherapy or radiation: “I said, ‘You know what, it's greater than one [percent]. I want [chemo].’ [The physician] said ‘You know what? I agree with you.’... For me, it was like, ‘I don't care. Get it gone.’ All of it” (Jean). Others didn't feel it was worth taking a long-term chemical control medication, such as tamoxifen or herceptin, if there was no 100% guarantee that it would prevent recurrence:

This was my body and the way I was feeling, and I couldn't understand why I had to be on this chemical for five years. You know? They couldn't tell me one way or the other if it was definitely going to prevent a recurrence. It might. The odds were, like forty percent or something like that. I thought, well, that's not enough, for me to be taking this every day.

So that was my choice. (Paula)

Even those who do choose to take Tamoxifen or other hormonal medications may later stop taking the drug without telling their physicians. And a few turned down chemotherapy because it would not bring about a large enough change in risk of recurrence. Alice, for example, felt she had already done enough to prevent recurrence:

It's not even clear whether it's one or two percent. ‘And it will make you very sick, so you need to think about that.’ And I said ‘I don't need to think about that.’ You know? If I'd gone, and the numbers went from, well, with the surgery alone, I think was eighty five percent no return rate

in the breast. With radiation as well, it was, what, ninety two, not in that breast, and with the Tamoxifen as well, it was ninety two or ninety three percent of never returning in either breast. That's enough for me. At that point, I went, no, I'm not going to make myself ill for a year and half and, no. Not doing it. Don't regret that.

For Alice, getting over 90% was important, but any additional benefits were unnecessary.

Similarly, Elsie drew on the idea of risk to argue that she was too old to need the small difference offered by chemotherapy:

I met with [my oncologist about chemotherapy]. But my percentage was not even one percent of benefit from it. And I decided I wasn't having the chemo. Because I thought, I didn't want to put my body through that. If she had told me a bigger percentage, I might have, I would have. I would have gone. ... I just said, well, if I live to be ninety or ninety five, that one percent, you know, I'm happy with ninety.

Whether or not participants used numbers to justify a decision to have or not to have treatment, the dominance of the concept of risk and numbers had affected their decision-making processes. In some cases, risk of recurrence was balanced with risk of side effects from treatments.

Many participants developed their own tolerances for risk and often justified their decisions with medical science and statistics. Decisions not to undergo short-term chemotherapy or long-term chemical control medications may seem to contradict the discussion about the need to do all one can to prevent cancer, but most participants did not describe their choices in this way. Instead, choices not to undergo these treatments

were justified because they had already done all they could do, or by suggesting that the side effects of these treatments (including other life threatening diseases) outweighed the benefit.

For most participants, developing an understanding of risk factors was an important part of engaging actively with their physicians and making treatment decisions amidst uncertainty. In some circumstances, numbers provided a way to justify decisions that would otherwise be unacceptable to themselves and others. As described above, Paula, for example, used numbers to justify her decision to stop taking Tamoxifen—a decision no other participant could imagine making. For most participants, knowing their statistical risk was important because it provided a sense of certainty during their deliberations. Quantifying risk provided a way for participants to feel like they were controlling their risk of recurrence and to talk about the lifestyle changes they were making.

When combined with the discourse of individual responsibility for preventing illness and the requirements of being a good woman with breast cancer, this risk discourse requires women to make and justify decisions in particular ways. The justificatory strategies participants used are conditioned by assuming particular subject positions. Participants could make different decisions about how to manage recurrence, but these were more likely to be accepted by others when decisions were justified in the language of risk, fighting, and survivorship.

The decision-making process leaves women with breast cancer navigating complicated risk calculations which can be confusing and overwhelming, but also offers them access to a language deemed credible in biomedicine that may allow them to refuse

treatment. Being able to confidently engage with discussions of risk is a skill necessary for autonomous decision-making, and an understanding of what risk is and what one can and cannot actually control is also important. Ways of talking about risk of recurrence in terms numbers that one can move up and down with lifestyle changes and medications obscures the real meaning of the statistics provided to women with breast cancer.

6.4 Approaches to Decision-making

In this section, I briefly describe participants' approaches to decision-making. It is important to note that no participant used only one of these approaches to decision-making in all contexts. As Lupton (1997) argues, patients are neither entirely passive nor active, but instead approach decision-making in different ways at different times. Despite this, all participants argued that making one's own medical decisions is an important part of being a woman with breast cancer.

Mirroring the debates in the literature on consumerist medicine, participants in this study varied in their perspectives on making medical decisions at different times and in different contexts. Many spoke out at times in favour of a consumerist approach to care, suggesting that it was important that all women with breast cancer be actively involved in treatment decision-making. This involvement was described as a way of maintaining a sense of control, which participants felt was important for feeling empowered throughout their experience of cancer. At the same time, trust in one's physicians provided a "safety net" that allowed participants to make decisions without feeling entirely responsible for the outcome.

Jean spoke most strongly about the need for women to make their own choices, suggesting that women who don't do this become victims who struggle to move on from

the disease:

I really believe that people need to [make their own decisions]. I mean, it's hard to force somebody who's not like that, just that meek and mild little person who just sits in the back, but I think it's probably one of the things that helped me move on too. Just that, 'Okay, there it was, I did it. Give me the next challenge.' But if you're sitting there and somebody just makes your decisions for you, I just don't know how you can be comfortable. Like I say, it makes you the victim.

For Jean, feeling in control of her medical decisions was part of coping with the emotional effects of her diagnosis. Being actively involved in decision-making was an important part of feeling empowered when her illness made her feel very dependent on others in other parts of her life. At the same time, Jean trusted that her doctor would have stopped her if her preferred treatment was unwarranted:

If I had said 'I want to have chemo.' If [my oncologist] thought it was a bad idea, he would have said 'You know what? It is going to do absolutely nothing for you.' If that was the case, then he would have told me.

For Jean, making her own decisions was an important part of being a particular type of person, a strong person who stands up for herself. Having trust that her physician would step in provides her with a level of certainty that she made an appropriate choice.

For many participants, being informed and making decisions with the support of a physician was a necessary component of respectful health care. Alice recognized that patients need to balance the control they exert over their own bodies and decisions with the need to trust physicians:

I remember saying, 'Okay, well, cause everything I'm reading and what you just told me about this, tells me I'm probably not going to be doing the chemo road.' I said 'You're going to have to be very convincing, for me to go that route.' I think there are lots of other options. But, if, and I said to [radiation oncologist and oncologist] 'You know, but if you look at me and you say 'Yes, I believe you need to do chemo.' I will jump off that bridge and I'll do it. Because I do trust you.'

Like Jean, above, Alice made medical decisions with the assumption that her physician would step in if necessary. This trust in physicians allows decisions to be made with a decision-making "safety net" which allowed participants to feel as though they were making choices, while providing them with the certainty that comes from trusting an expert. This safety net acts as a support for participants to try to enact their own values and make their own decisions while maintaining a sense of being supported by someone else.

While some participants passionately defended their right to make these choices, others were relieved that their physicians suggested or dictated a course of treatment. Nancy, for example, was relieved that she didn't have to make many medical decisions:

I found it helpful that the whole cancer thing was like that [with guidance]. It was just, all these appointments and all you have to do is get there and take some notes on an index card and remember those things and keep track of that and go to Lawton's and get your prescription filled. There wasn't a lot of autonomy or decision making required. And I found that helpful. ... [Physicians] are smart people who probably know more than I

do about everything they do, and I don't have to know it. I found that a relief, and helpful.

For Nancy, the amount of information needed to make these decisions was deemed overwhelming and inaccessible. Many participants echoed this concern about their inability to understand the amount of information needed to make treatment decisions, which they regarded as an expectation and their responsibility. This was especially true during the stress of processing a diagnosis:

I wasn't in any frame of mind to make decisions, informed decisions, because of shock. I didn't know what to do. I wouldn't have a clue what to do. I went with whatever [the physicians] said. Truly, they're not going to sit down and say their second thought first. Their first thought is what they really believe, it's what they believe is what you need to do. They know what they're talking about. I don't know anything about cancer. These people, they've studied this. They've seen the biology of this cancer or mass or whatever. I don't know anything. I have to trust that they do.

(Joyce)

Joyce was very invested in the trust she had in her physicians. When asked what she would have done if her physician had not suggested one treatment plan, she faltered before saying she would have had to ask what the physician would do. For Joyce, making this decision for herself was an impossible task.

Before their third interview, participants were provided with an initial report of the results. One section included Nancy's quote, above, in which she stated that she preferred not to make her own decisions. Other participants replied negatively to this

section of the report. Jean, for example, suggested that doing this made women into “victims” and slowed their emotional healing. Most participants stated that women with breast cancer should make their own medical decisions. Those involved in the breast cancer social movement often expressed one of the movement’s common sentiments, stating that women with breast cancer must advocate for themselves: “They say you have to be your own advocate” (Carolyn). “They” was not in reference to anyone in particular, but represents breast cancer discourse; it seems the discourse is used to dictate that women with breast cancer must advocate for themselves. Good women with breast cancer are strong enough to make their own decisions, or at least talk about the importance of making their own decisions. The alternative is to be a “victim,” as Jean describes. Participants who spoke about letting physicians make these complicated decisions were sometimes judged by others as unintelligent women with breast cancer.

6.5 It’s a Personal Choice

While many participants struggled to make treatment decisions, for most it was very important to at least state that the decision had been their own. Pamela, for example, stated that she made a choice to trust her physician and that that constituted a legitimate choice. In describing their treatment and risk management decisions, most participants suggested that these decisions had to be a personal choice. The statement “my body, my choice” is reminiscent of the women’s health movement, as well as the breast cancer social movement. This idea of owning one’s body and thus having control over what happens to it was a common sentiment in the interviews. But the idea of “personal choice” I describe here goes beyond the concept of having control over one’s body as an object.

Instead, personal choice as conceptualized by many participants seems to extend past the understanding of ownership of one's body to engage with the idea of making decisions that are authentic—consistent with one's life, values, and beliefs. As Carolyn describes: "Everybody has their own personal choice; it's who we are, and you know, how we feel about things and how we've gone through things." A personal choice is one that takes into account everything that is important to the individual making the decision, including the cumulative experiences that have shaped her life. By definition, a personal choice cannot be made by someone else. It is impossible to imagine how another person could understand an individual to the extent necessary to make a decision that is personal for her; thus, overlooking the influence of normalizing discourse that reflects larger social values and ideals, these decisions are entirely individual. By describing the source of these personal decisions as values found within themselves, participants accounts obscure the politics of breast cancer decision-making, limiting their ability to be relationally autonomous.

At certain times, conceptualizing treatment and risk management decisions as personal choices made it easier for some participants to decide which options were best. Jean, for example, immediately knew which treatments she would prefer:

When it came to my surgery and my treatment I knew right away, because I knew I wanted to do the best possible things for me. And even though I know there could be some lasting effects from chemo ... when I weighed it, for my peace of mind, it was worth the risks.

Each participant made a decision at some point that seemed self-evident to her. In these moments, participants expressed feeling that they had made the right decision for

themselves. This does not necessarily mean that they did not later regret this decision or wonder if they should have done something else, which did happen occasionally.

In some instances, personal choices were not so easy. Some participants struggled with the lack of guidance that accompanied this approach to decision-making. As Carolyn said: “Each person has to decide for themselves, and I find that hard.” At times, participants struggled to make choices, or to explain why they chose the options they selected. The pressure to make choices that reflected one’s own values was a struggle, particularly when participants may not have had the occasion to consider or articulate relevant values or beliefs in the past. While some participants could easily state what their breasts meant to them or how they felt about the use of chemotherapy, others had never thought about these things. This left some participants searching for values and beliefs with which to make these personal choices. When the corresponding searches led them to find these answers in breast cancer discourse, their abilities to be relationally autonomous could be compromised, not taking into account the sources of these values.

In Chapter 5, I examined the ways in which participants conceptualized their identities as women with breast cancer in relation to an idealised subject position that they described by drawing on a discourse of authenticity. In trying to make personal choices, participants felt compelled to make authentic decisions based on the characteristics of their “true” selves. Authenticity, in this sense, is a normalizing discourse that governs women with breast cancer by suggesting that they should improve or uncover these selves by taking up an idealised subject position produced by breast cancer discourse. But, participants experienced this search for authenticity as real and greatly important for their healing and coping.

Most participants felt unable to maintain this idealised and authentic subject position over time and across contexts, leaving some feeling lost. In these moments of “inauthenticity,” making personal choices with which they felt happy became extremely difficult for most participants. When participants felt they were not reflecting their “true” selves, they lost self-trust, seriously constraining their abilities to be relationally autonomous. Following her diagnosis, Jean struggled to be positive during moments of depression. In these moments, she felt shame for not being her true, positive self and struggled to act in her own self-interest. Jean expressed disappointment in herself for not having the self-control to eat healthy food while feeling depressed. She blamed herself for failing to make good lifestyle choices.

By casting these decisions as personal and individual, the ways in which normalizing discourse shapes treatment decision-making are made invisible. Casting treatment decisions as personal decisions may initially seem like a good alternative to a consumerist model that portrays patients as excessively rational consumers of information. Taking values, beliefs, and identities into account is important, but disconnecting these from the discourses that participants used to constitute their values, beliefs and identities only further obscures the relational nature of treatment and risk management decision-making during breast cancer.

Some participants suggested that framing medical decisions as personal decisions may privilege “choice” over quality care. Nancy articulated her concern about the reasons women with breast cancer make treatment decisions:

I said ‘I would want a lumpectomy and follow up treatment. That's the standard for twenty or twenty five years now.’ And [the surgeon] said

‘Well, some women want a mastectomy.’ And I said ‘But it's been proven not to have any benefit.’ And she said ‘Yes, but it's really important not to take away people's ability to choose.’ I can see that, if they're just so freaked out and worried that they think ‘Just cut it all off and be done with it.’ ... I guess it's good to let people be wrong, but I don't know. I would rather the doctors be right about it, it's more important to me that the doctors know what they're doing, than I be able to choose.

To Nancy, having choice is less important than the right decision being made. An informed choice, made with the support of a physician, may be preferable to an uninformed choice made independently. In this quotation, Nancy privileged medical evidence over women's personal experiences with and beliefs about these treatments. Without the skills to understand medical information, it is difficult to argue that women with breast cancer could make autonomous treatment decisions without the support of a physician. But it is also clear that individual patients' values and beliefs should have a role in medical decision-making.

At first glance, it may seem that by stating that they chose their own treatments based on personal preferences, some participants made more autonomous choices than others. Their counterparts, as Jean described, were simply “victims” unable to make decisions for themselves. It would be all too simple, though, to suggest that selecting from a list of previously determined choices while drawing on values, beliefs and identities rooted in breast cancer discourse is truly autonomous decision-making. This is not to say that feeling informed or feeling safe after having invested trust in a physician did not make participants feel better about their decisions, because in many cases it did.

But looking beyond the clinic to better understand the relations that constrain these “personal” decisions provides a better view of this decision-making process. Power relations are intensified in the context of facing life-threatening decisions without all the information necessary to make them.

6.6 Imagining Alternatives

Participants in this study did not choose from an infinite number of treatment possibilities. Many felt there were only one or two treatment plans available to them. These were often dictated by the type, stage and location of the cancer, the treatments available at the hospital where they were patients, and more broadly by the information and treatments available in allopathic medicine. For example, sentinel node biopsy, a lab test that identifies cancerous cells in the lymph nodes, is only available during surgery at one hospital in Nova Scotia. At all other hospitals, the number of lymph nodes removed during surgery is at the discretion of the surgeon who sends the cells for testing after removal. Certainly the timing of diagnosis, cancer type, and geographical location limited the choices available to participants.

Although it is important to mention the ways in which health policies and treatment availability limited choice, these types of limitations are not the focus of this study. The key focus is the ways in which breast cancer discourse and subject positions govern the options visible to participants. That is, the ways in which discourses and subject positioning make some choices available and others unavailable or even invisible. In the following sections I examine some of the ways in which participants experienced their choices as being limited.

6.6.1 Choosing to Fight and Biomedicine. All of the participants in this study sought primary treatment in the biomedical system, which limits the results of this study. Some participants wondered whether the dominance of Western medicine limited the choices they could access. This left some participants, like Carolyn, who was diagnosed with genetic breast cancer, wondering if there was something they were missing:

The doctors only give us one option, in Western medicine. I wish we had more options. Is there anything else we should be doing? Eating better?

They say sometimes it's our diet that affects our cancer, or our lifestyles, or it is just hereditary? Or it is environmental? What areas can you improve that you can improve yourself?

Participants tended to align biomedicine with treatment and holistic medicine with lifestyle changes. However, a biomedical approach to the treatment of breast cancer has directed the development of new and novel cancer treatments in a way that is limiting. As mentioned previously, biomedicine's "slash, burn, poison" (Love, 1990, p. 175) approach to treatment, which dominates approaches to care, is both limited and little-changed after many years.

A few participants were very critical of the role of pharmaceutical companies in dictating the cost of care and types of treatments available. Despite this criticism, though, most could not imagine choosing an alternative approach:

I remember thinking to myself, 'Well God, I don't know how else to treat this. What other options do I have?' I mean, you could go the natural, all of those naturopathic kind of things, but I don't know, for me, at that point in time, I'm thinking 'Oh my God of course I'm going to go have

the treatment, because really, that's my only known solution.' That's definitive. (Gail)

In fact, all but two participants stated that it was important to undergo the most invasive treatment offered by their physicians. Jean, for example, underwent every treatment she could:

I have no regrets about what I've done. Because I've done the extreme on everything. So, here's my choices? Bam, okay, let's go with this. Cut it off; poison the crap out of it; beat it to death with pills; get extra testing to get my peace of mind. There's nothing else they can do, that can give me peace of mind. I mean, I've had bone scans, MRIs, you name it. ...

Now I'm good.

For Jean, and many other participants, choosing not to undergo all available allopathic medical treatment was unimaginable. This lack of imagination is not just because information or alternatives are unavailable, nor due to a personal failure of imagination. Good women with breast cancer must fight the disease, and fighting requires accepting all allopathic treatments that have been offered by physicians. One hopes that physicians will offer only those treatments they believe improve patients' likelihood of remission. Fighting the disease is also about toughness and being able to undergo these invasive treatments and their side effects—as well as a totally understandable desire to effect remission at all costs

Given the commitment to fighting to survive by undergoing all allopathic treatments, choosing to refuse a treatment was something only a weak or irresponsible woman with breast cancer would do. For many, refusing naturopathic treatments was

seen as an acceptable option, but most chose to undergo these treatments in addition to their allopathic treatment regimen. Some participants explicitly judged women who chose not to undergo significant allopathic treatment and those who did not manage their risk by making lifestyle changes. This was particularly true for mothers, who were expected to do everything they could to survive:

I know a woman, she had the exact same cancer as me, the exact same size as me, the whole bit. And she opted for the lump[ectomy], and she said ‘Well, it was the right decision for me.’ And I said ‘Okay, that’s fine.’ And a friend of mine asked me later, they said, ‘Could you have done it?’ And I said ‘No, never in a million years.’... She’s comfortable; she can live with it. She doesn’t have children. I want to live to see my kids grow up. (Jean)

While it’s expected that all women with breast cancer will fight to survive, women with children may be most expected to survive in order to continue caring for their children. It seems to be especially unimaginable that a mother would give up “without a fight.” Refusing medical treatment, even when it increases one’s chance of survival by a small percentage, is seen as giving up the fight before it was won. In this account, the woman who opted for the lumpectomy drew on discourses of authenticity and personal choice when she said “it was the right decision for me.” Even these justificatory strategies could only be used to successfully defend her decision because she did not have children.

Women with no children also experienced expectations in terms of their treatment decision-making. Alice, who had a lumpectomy, spoke to a friend about whether or not she would choose to undergo a mastectomy if she had a recurrence. Her friend was shocked when she suggested she might choose not to have the surgery:

[My friend] said ‘Well, if it happened to me, I would just have double mastectomies. Just take them; I’m not attached to them.’ And, I looked at her and I said ‘Well, if it came to the point where I was told that that was my option,’ I said, ‘I might not do it.’ And she said ‘But they’re just flesh, just skin, it’s your life.’ I said ‘Yes, but, I don’t know whether I would make that choice. I mean, I might make the choice of not doing it.’ And she was shocked and was about to say something else. And I just said ‘Well, you don’t know until you’ve experienced it.’ And I said ‘I don’t know if the next time, if it comes up again, in my life, what decision I’d make.’

Alice felt the need to defend her decision not to have a mastectomy because she knew that others would disagree with her stance. Although the breast cancer social movement began in opposition to extreme medical treatments, the current discourse of survivorship and fighting seems to naturalize the choice to undergo all available allopathic treatment. A good woman with breast cancer is someone who makes the right choice to fight the disease, and the “right” choice is generally the most invasive allopathic treatment available. The body undergoing these treatments is the battlefield on which the fight against breast cancer is waged.

In the accepted version of decision-making, there is a need to make a personal, individual and autonomous choice that nonetheless must include allopathic treatment available. This choice then becomes a result of “human nature.”

You talk about choice and I think my answer was like ‘Really, well, what choice do I have? It’s there; I’ve got to get rid of it.’ I never thought about

the other, because it's human nature to want to live; to want to survive. I would have to be really depressed to not want to do anything. But most people that I know are the fighters. They just keep going. (Elsie)

Women with breast cancer who choose not to fight are cast as negative as well; they must be depressed to make that decision. Thus, choosing to fight—which means selecting all available allopathic treatments—is an important part of constituting oneself in the idealised breast cancer subject position. In order to occupy this position, one must make the right choices, and the right choice is always to accept medical treatment. This is, of course, likely true of individuals' experiences with potentially fatal diseases other than breast cancer; these discourses are not necessarily unique to breast cancer.

6.6.2 Avoiding Self-Doubt and Regret. According to relational theorists, self-trust is an important part of having the capacity to be relationally autonomous (McLeod & Sherwin, 2000). At the same time, the capacity for critical evaluation of one's values and beliefs is also necessary (Mackenzie & Stoljar, 2000; Sherwin, 1998). Participants in this study sought to avoid self-doubt and regret by making decisions that took into account the statistics provided to them by their physicians and, when that was not enough, through lifestyle changes they believed would help manage their risk. Although participants recognized no health or health care decision was certain, the level of confidence many wished for or tried to sustain goes beyond what can legitimately be promised by medical science.

For many participants, fighting self-doubt in making decisions was an important part of managing the emotional effects of the treatment decision-making process. Jean puts this simply: "Don't ever doubt yourself. Never doubt yourself. You can't." For her,

and other participants, self-doubt could lead to regret and regret was unmanageable. Confidence in their decisions was something participants tried to actively cultivate through trust in themselves and in their physicians. For many, this confidence was part of being a positive woman with breast cancer. The alternative was to wallow in negativity and fear.

In many cases, the elimination of self-doubt made it impossible to listen to alternative perspectives. Gail, for example, refused to hear her sister's concerns about the long-term effects of chemotherapy:

There are so many factors that control/determine one's fate that it becomes overwhelming to think about. My state of mind is the one thing I can control. I stay positive by keeping positive people around me. I remember one of my sisters asking me at one point, 'Are you going to let them put that poison in your body?' I immediately responded with, 'This is the best option I have right now considering how rare and aggressive my breast cancer is. Please stay positive with me. I can't go down that dark road.' From that point on I committed to keeping that frame of mind and the people around me did the same.

Positivity in the form of optimism and a commitment to fighting regardless of the costs required participants to overlook potential side effects in the pursuit of treatment. In this extreme form, self-trust precluded consideration of other options. Participants expressed a high level of responsibility for their medical decisions, but often felt there was little they could actually control. In some cases, I felt unable to follow-up on participants' reasons for their decisions because they had invested so much in making the "right" choice. When

they were unable to articulate reasons for their decisions, I got the sense that follow-up questions would cause their confidence to unravel by revealing options they had not considered. I feared that undermining this confidence would trigger the emotions they were so carefully managing to escape.

On the other hand, participants who lost trust in themselves also struggled to make treatment decisions. This often occurred after they made decisions that did not work out as they had hoped. This led to regret, and in a couple of cases, this regret led them to question all of their decisions. Heather, for example, was initially misdiagnosed and chose, based on that diagnosis and the assurance she wouldn't need radiation, to have a bilateral mastectomy with immediate reconstruction. Later, she discovered she had not needed a mastectomy and would need radiation, which complicated the reconstruction process that had already begun. Throughout most of this process, she maintained that she made the right decision, suggesting that it was easier to have a bilateral mastectomy because reconstruction was most important to her. Later, when Heather encountered difficulties during the reconstruction process, she questioned not only her choice to have reconstruction, but every choice that led her to that point:

Initially I was misdiagnosed. They told me that I had a different type of cancer. So I had both breasts removed. And then you know, then I'm thinking, now I have to have reconstruction on both sides. It would have been easier just to have one. But you never know. Then you think 'Well, if I hadn't had my right breast removed and then five years from now, if I had gotten cancer in it, then I would have said I made the wrong decision then.' You know? So it's really, it messes with your mind.

At the same time, Heather struggled to stay positive despite the setbacks she was facing, and she rarely spoke about feeling regret. Many participants worked to make decisions that they would never regret or doubt, or to justify decisions later so that they would not experience regret. While this is not unique to decision-making in the context of breast cancer, the way participants tried to avoid regret illuminates some of the ways in which their experiences have been shaped by breast cancer discourse.

This commitment to avoiding self-doubt and regret seriously impaired participants' ability to entertain alternative perspectives, which in turn impeded their abilities to be relationally autonomous. The form of self-trust sought by feminist relational theorists does not preclude critical thinking, but rather is secure enough to engage critically with other ideas and to imagine alternatives (Mackenzie, 2000; McLeod & Sherwin, 2000). Of course, this type of self-trust may be less available in non-ideal circumstances, which certainly includes the experience of breast cancer. The efforts to avoid self-doubt and regret that participants engaged in did not often feature a critical perspective; instead, they fuelled further reliance on breast cancer discourse. Good women with breast cancer are confident that they will survive, and they make decisions to ensure that they do; this helps to silence doubt, uncertainty, fear, anger, sadness, and regret.

6.7 Breast Cancer Community

Alternative choices are often rendered invisible or made unacceptable by the breast cancer community. Some participants acknowledged this trend, most commonly observed in the images of women with breast cancer encouraging reconstruction or prostheses and the use of wigs. Nancy, for example, discussed her realization that some

women choose not to use prostheses after mastectomy:

When I was getting close to the time for the mastectomy, I talked to a friend of mine, who watched, 'What Not to Wear' and they had profiled a woman who had had a bilateral mastectomy and decided not even to wear the prostheses. And I wasn't aware that that was even an option people considered. And he told me how they suggested wearing ruffled shirts or shirts with ruching or tucks or something. And I thought, this is true, I could do that. And I was so happy. It was just one conversation with a friend on the phone but it had a big influence on me, to realize there are other women out there who just choose to stay flat and not be ashamed of anything or try to hide anything. And so, I'm doing that. ... I'm really happy to know that there is at least one other person on the planet doing that, which means, which certainly means there are a lot. I just haven't happened to encounter them.

Nancy suggested that there are women who make the decision not to have reconstruction or use prostheses, but she hasn't "encountered" them. This reflects the homogeneity of the breast cancer community that one does encounter, and suggests that women making alternative choices are not always visible there.

Similarly, Gail expressed concern that women make hasty decisions to buy expensive wigs when their hair begins to fall out. Members of the breast cancer community may encourage the use of reconstruction, prostheses and wigs by making other options less visible. Understandably, participants were better able to challenge discourses of femininity than discourses of allopathic medicine. Perhaps this is because

breast cancer discourse includes some “unfeminine” attributes such as fighting or being strong, but do not challenge allopathic medicine directly. This may also be because feminism has created a lot of space in which to challenge beauty norms but has not challenged biomedicine in the same way, particularly in cases of life-saving medical norms. And, of course, choosing not to wear a wig is not life-threatening, while choosing not to undergo chemotherapy may be.

For many participants, breast cancer treatment was an experience with few explicit moments for decision-making, but also with the opportunity to make decisions if one wished to do so. Many participants believed that women with breast cancer need guidance, but that there should be a way to suggest that you can also make your own choices. Earlier, I quoted Alice describing the importance of having a path (or ideal) to follow during one’s experience of breast cancer. At the same time, Alice suggested that it needs to be clear that one can leave this path by making different decisions, if they wish to do so: “I think having a path and knowing you can go off that path is a good thing.” In comparing the experience of breast cancer to a path, Alice suggested that it is necessary to provide women with breast cancer with guidance and examples. By observing the decisions others have made, women with breast cancer can learn what to expect. The discourses and idealised subject positions discussed in Chapters 4 and 5 provide this path for women with breast cancer. However, Alice also suggested that women with breast cancer should know that they can step off this path to make other decisions or understand their disease in a new way. In this belief, she overlooks the fact that the discourses and subject positions available to women with breast cancer often preclude imagining other ways of doing breast cancer. In doing this, they make the likelihood of leaving the path

quite slim.

During the interviews, I asked participants how we could increase women's ability to see the availability of other options during their experiences of breast cancer.

Gail replied:

My initial response would be pair them up with a buddy to help them work through that. But I had a next door neighbour who went through the same thing and her response was 'Oh, get the wig right away.' So, I think it needs to be from a more professional point of view, to present the options. So someone who has done the research and heard the stories of people who could say, 'The women that I've studied, this is how they responded. And yet, you know, some have said 'Oh yeah, go get it right away.' But, not everybody feels the same way.' You know? Just to kind of present the options, I guess. It's like you're navigating down a preset journey. But it's not. Because it's different for everyone. You know? It goes the same for when you initially go in and they're presenting you with the options of treatment.

Gail suggested that women with breast cancer need a more balanced and diverse view of the experiences of others in order to make informed decisions. This would provide support for women with breast cancer who want to make less common treatment or lifestyle decisions. In recognizing that individual women with breast cancer may not be able to provide one another with the support needed to see other options, Gail questioned the foundation on which the current breast cancer support system is built; peer support is a standard approach to helping women through the experience of breast cancer. As Gail

noted, this approach may also continue to reproduce the same discourses and subject positions currently available. Women with breast cancer govern each other, thus limiting the critical capacities of the community as a whole to reflect upon the ways in which normalizing discourse constrains women's ability to be relationally autonomous.

Nancy went one step further to suggest that women with breast cancer should cultivate a critical understanding that allows them to question the options made available to them:

[In the book *The Help*] it's Abilene, who says 'The lines aren't there.

They're not real.' I think it's kind of like that. We see all these lines, but they're not real. It's just this made up, non-existent, fence that boxes us in. And it's completely unnecessary. ... Like having breast reconstruction, it was just so invisible to me that you don't have to have that. You don't.

You can just go around flat. I never, ever was able to see that before.

And wearing a scarf or a hat is like that.

For most participants, it was easier to see these alternatives and talk about developing a critical perspective when talking about cosmetics or lifestyle changes. They could see that reconstruction was not necessary, even if they felt significant pressure to undergo the surgery. Seeing alternatives to viewing oneself according to one's risk factor and selecting treatments accordingly often remained impossible. While feminism has made available alternative discourses that challenge beauty norms, an alternative to biomedical discourse is not yet readily available. In larger urban centres with more varied breast cancer social movements and through patient websites, breast cancer discourse based in feminism and environmentalism may begin to serve this purpose (see Klwaiter, 2008).

6.8 Conclusions

When breast cancer treatment decisions are portrayed as personal choices, the ways in which discourses constitute the values, beliefs and identities that women draw on to make these decisions is obscured. Theoretically, this has significant consequences for our understanding of what it means to make autonomous decisions about breast cancer treatment. It is likely that the freedom of women with breast cancer to choose to stop treatment and to make lifestyle choices that do not conform to expectations of the good woman with breast cancer have been overestimated. Although many participants engaged in naturopathic treatments, they were undertaken in combination with allopathic treatment regimens.

Practically, conceptualizing these decisions as personal also affects women's experiences of decision-making. They experienced significant pressure to constitute themselves as a good woman with breast cancer by making the "right" choice. At the same time, participants (understandably) did want to survive, so they were already experiencing pressure to make the choices that would lead to survival. Sometimes, even when someone made the "right" choice at the time, things didn't work out as they hoped. In these situations, the idea of having made personal choices caused participants to doubt themselves.

This fear of making the wrong choice governs women's treatment decision-making for breast cancer. In this context, women constitute themselves as good women with breast cancer by making the right choices. In return, their choices are approved by their physicians, friends, families, and other women with breast cancer—giving them the support they need to feel at peace with their decisions and cope with the emotional effects

of the disease. In this context, an unpopular choice may result in a perceived lack of support at a time when so much is required. For women who face other difficulties accessing support, such as those who are not in long-term relationships, these risks are more serious.

When those who do make alternative choices are invisible to those engaged in the mainstream breast cancer movement, women with breast cancer have difficulty even imagining what another way of handling breast cancer might look like. Living with breast cancer is difficult enough; trying to imagine options and ways of being that are not readily available while dealing with the other consequences of having this disease is unlikely. Expecting women with breast cancer themselves to create this space is expecting too much. Instead, researchers, ethicists, feminists, social scientists, physicians, support organizations, and organizations leading the mainstream breast cancer social movement must take some responsibility for recognizing the relations of power in which women with breast cancer are embedded and making some changes to better support women in making decisions that serve their own needs in the context of these relations.

Chapter 7: Discussion and Conclusions

In this study, I sought to examine how women with breast cancer navigated breast cancer discourse while making treatment and lifestyle decisions. In this chapter, I provide an overview of the findings outlined in the preceding chapters, relating them to the existing literature to advance thinking not only about experiences of breast cancer, but also about discursive constraints on relational autonomy. I also discuss the limitations of this study, my efforts to address these limitations, the implications of the study results, and future directions for this area of research.

7.1 Synthesis of Findings

In Chapter 4, I discuss the ways in which participants engaged with elements of breast cancer discourse—fighting, surviving/thriving, the journey and positivity—to talk about their experiences of breast cancer. As described in Chapter 5, these discourses are created and reproduced by subject positions through which women with breast cancer came to govern themselves and others. In this context, participants' ability to imagine other ways of doing breast cancer was compromised. The perpetuation of breast cancer discourse through the mainstream breast cancer movement and biomedicine thus constrains women's abilities to be relationally autonomous.

Historically, women's experiences of breast cancer were shrouded in secrecy and shame that marked a lack of discussion about alternatives to the extreme medical treatments used. Women's early efforts to speak out about their experiences of the disease challenged standards of care and politicized the disease. The subsequent breast cancer social movement created a community of women with breast cancer made breast cancer one of the most familiar charitable causes. King (2004) refers to this progress as a

shift from “breast cancer politics” to “breast cancer charity” (p. 475). Through this shift, the mainstream breast cancer movement began to produce its own dominant discourses, calling on women with breast cancer to fight on behalf of themselves and the cause, to be positive, and to thrive by learning from their disease and continuing to contribute to the cause.

Individuals diagnosed with an illness often adopt an illness identity that enters them into a social group (Batt, 1994; Kaiser, 2008). In this study, most participants were recruited through a breast cancer support organization. Through this organization they found a community of women with breast cancer, but were also subject to (and the subject of) already-familiar breast cancer discourse. At some time, most of the participants sought to live up to an idealised subject position produced by the discourses strongly promoted within the breast cancer social movement. Similarly to survivors in Kaiser’s (2008) study, while participants adapted the meaning of these discourses in light of their individual experience most also believed they should try harder to live up to the ideal.

In this context, participants had to make decisions that would have immediate effects, such as which treatments to undergo, and decisions that would have future outcomes, such as how best to manage the risk of recurrence. In conceptualizing these decisions as personal choices, participants overlooked the relations of power that affected their decision-making processes. This is further complicated by the fact that choosing alternatives carried greater risk and required the ability to imagine alternatives that were not readily available. Given that women with breast cancer are already struggling with

the implications of their diagnoses, others must contribute to efforts to create space for alternative ways of doing breast cancer.

7.2 Ethical Commitments

Qualitative research requires the researcher to speak on behalf of others. As I have not experienced breast cancer myself, I am interpreting and speaking from outside of this community. For some participants, my outsider status enabled them to speak freely about their difficulties in the community; at the same time, though, my status as an outsider precludes any experiential understanding of women's experiences of the disease. At times, it was uncomfortable to speak on behalf of women with breast cancer. In these moments, I tried to exercise reflexivity about why I was experiencing discomfort. In most cases, I was uncomfortable about portraying women with breast cancer as being passive, duped, or lacking autonomy. During interviews, this discomfort made it difficult for me to probe in a way that I felt would challenge participants' understanding of their active role in this process. In writing these results, this concern has led me to question the ways in which I represented participants as being "caught up" in complex power relations.

In this study, I examined the ways in which women's ability to exercise relational autonomy was constrained. While I believe it is important to focus on the ways in which we are all constrained by the power relations in which we are embedded, I do not wish to undermine the sense of control that allows women to make the decisions they must make each day. Thus, I reject such concepts as "false consciousness," which has been used to theoretically account for women's failures to understand the social relations in which they are embedded. In this study, I made efforts to represent women as doing the best they could within complex power relations often beyond their control. While these

relations need to be changed over time, women with breast cancer must make decisions now. I hope that in writing the results of this study, I was successful in representing participants in this way.

As mentioned in Chapter 3, I hoped to write these results in a way that was consistent with an adapted version of Lather's (1986) concept of catalytic validity, which requires research to enable change of oppressive circumstances. This was a challenging task. In the following sections, I examine the limitations and potential contributions of this research study. By situating the results of this study within the literature, I hope to further understandings of breast cancer in a way that will eventually enable women with breast cancer to be more relationally autonomous.

7.3 Contributions

In this section, I examine the potential substantive, theoretical, and methodological contributions of this study. I explore these contributions while recognizing that one study must become part of a body of literature that as a whole has the potential to make significant contributions to the ways in which women's experiences of breast cancer are understood. Given this, I reiterate my commitment to publishing relevant results in formats more accessible to academics, practitioners and patients.

7.3.1 Substantive Contributions. In this section I return to the literature outlined in Chapter 2 to examine some of the substantive contributions of this research. In particular, I comment on the research findings regarding gender, medical dominance, identities, illness communities, social movements, relational autonomy and governmentality.

7.3.1.1 Gender and breast cancer. In Chapter 2, I briefly describe approaches to studying the relationship between discourses of gender and women's experiences in the

health care system. Within a context that privileges objectivity and attributes this characteristic more readily to men, women are more likely than men to be viewed as not having credibility in describing illness experiences (Barker, 2005; Batt, 1994; Greenhalgh, 2001). Women's diverse experiences of illness, including that of breast cancer, are often made less visible within the context of biomedicine.

Emerging from the women's health movement, the breast cancer social movement sought to legitimize women's experiences of breast cancer. In doing this, the movement adopted discourses that challenged images of women with breast cancer as victims by portraying them as fighters and survivors (Batt, 1994; Sulik, 2011). At first glance, these discourses seem to challenge traditionally feminine norms by portraying women as strong and self-assured; however, in many ways, the movement draws on socially acceptable discourses of femininity to strengthen the cause. In discussing the need to fight, for example, participants often spoke about the need to fight for their children, evoking notions of maternal strength. The use of the color pink and discourses of motherhood, positivity, beauty and caring, further entrench discourses of femininity within the movement, even as it challenges notions of feminine victimhood. Incorporating femininity into the movement ensures social acceptability but fails to fully challenge traditional femininity.

In this context, participants' understandings of themselves as women with breast cancer were shaped significantly by their understandings of what it meant to be a woman. For some participants, experiencing breast cancer offered an opportunity to challenge traditional femininity. This was particularly true in relation to beauty norms. Gail, for instance, took this opportunity to stop dyeing her hair and wondered why she spent so

much time attending to her looks before her diagnosis. In other ways, many participants reinforced femininity throughout their experiences of the disease. While most participants reflected critically on the need to be beautiful, many also did not allow anyone to see them without makeup, wigs and prosthetics. Many participants also reflected on the relationship between their experiences of breast cancer and their responsibilities as mothers to be positive and to survive for their children.

At most times, being a good woman and being a good woman with breast cancer coincided for participants. In these situations, failing to be a good woman with breast cancer (by being negative, for example), also meant failing to be a good woman more generally. In a few situations, being a good woman *conflicted* with being a good woman with breast cancer. Pamela, for example, struggled to balance her commitments to being a mother with her new commitment to volunteering with breast cancer organizations. In such situations, participants often reflected on the transient nature of breast cancer and made decisions that would allow them to be good woman after the disease. Pamela, for example, returned her focus to her family after she felt she had survived the disease.

Discourses shared through the breast cancer social movement provided many participants with a language to speak about themselves as active, strong fighters of a disease that they feared. At the same time, these discourses reinforced traditional femininity by encouraging a focus on beauty, motherhood, and caring for others through volunteering. In some ways, these discourses may be more damaging when hidden behind language describing women as strong and independent. They make invisible the effects of gendered power relations on breast cancer experiences and treatment. This

study provides one view of the ways in which these discourses shape women's experiences of breast cancer.

7.3.1.2 Illness communities and health social movements. Many studies of illness communities have examined the ways in which illness communities and health social movements challenge biomedicine by acting as sites for knowledge creation, identity constitution and advocacy (see for example Epstein, 1995). Much of this work describes social movements as a promising avenue for challenging biomedical dominance, democratizing knowledge, and raising awareness about the subjective experiences of individuals with a particular disease. Illness communities and health social movements do provide sites individuals with an illness to come together, but in doing this, they also constrain the ways in which one can behave in order to remain part of this community. In this study, I began to examine the ways in which health social movements, when they move from politics to charity, begin to produce and reinforce dominant discourses. Health social movements are not just sites of resistance and community, but also serve to govern. A more complicated approach to understanding health social movements and illness communities as sites of both power and resistance is important for understanding individual experiences within these.

Researchers studying health social movements and illness communities have begun to observe the complex ways in which communities create space for some knowledges, identities, and ways of being ill, privileging them over others. Sulik (2011), for example, argues that breast cancer survivorship creates a context in which some women feel as though they have failed to live up to an ideal. In this and many other ways, being part of the breast cancer illness community required participants in this study to

assume a particular subject position—the strong, positive, thriver. In some cases, those who did not take up this subject position faced difficulties in connecting with other women with breast cancer and experienced self-doubt. This phenomenon complicates understandings of illness communities as creating space and demonstrates that, as is true of all social groups, illness communities create space for some ways of being and exclude others.

Klwaiter's (2008) detailed account of breast cancer social movements (or “cultures of action”) in San Francisco challenges the view that there is one breast cancer social movement, demonstrating the ways in which smaller groups are formed to challenge the largest breast cancer organizations and medical dominance. While this is certainly a more nuanced account of breast cancer social movements than those that suggest there is only one movement, it is worth noting that Klwaiter's study was based in a significantly larger city than mine was. Finding alternatives to the pink movement in Nova Scotia was not easy for my study's participants; thus, in accessing support at the few breast cancer support organizations in the province, participants were necessarily introduced to a mainstream breast cancer movement. While many found support in this space, many also experienced moments of feeling exclusion and unworthiness. Perhaps more importantly, they conveyed a perception that gaining support through this organization was dependent upon being and doing in particular ways, meeting the expectations of the idealised woman with breast cancer.

Theoretically, it is important to conceptualize illness communities as spaces that both enable and constrain identities. The concept of relational autonomy (Mackenzie & Stoljar, 2000) provides a helpful lens for understanding the consequences of this

constraint. When women with breast cancer cannot imagine other ways of being, their ability to make decisions that reflect their own interests is also constrained. Practically, this helps explain how some individuals who are ill are better able to access support services than others.

7.3.1.3 Studying “pink.” The “pink” or mainstream breast cancer social movement is attracting increased research attention as breast cancer campaigns become a more common part of daily life in North America. King (2004; 2006) and Sulik (2011) provide detailed critiques of the pink movement, particularly the capitalist and consumerist dimensions of the movement. King (2006) describes the need to look past the positivity promoted by the pink movement to view these relations of power and their effects:

Perhaps one challenge for those who seek to transform breast cancer culture, then, is to work *against* submersion in happiness and toward recognition of the deep and fundamental problems that surround us, both within the realm of breast cancer and beyond. (p. 115)

These accounts detail the damaging effects of a pink movement that privileges fundraising over challenging social norms that reinforce existing relations of power.

Importantly, these relations of power also have effects on an individual level. Ehrenreich (2001; 2009) draws on her experiences of breast cancer to critique the gendered, infantilizing, and capitalist nature of the pink movement. Similarly to my account in Chapters 4 and 5, Sulik (2011) extends these critiques by examining the ways in which idealised notions of survivorship, infused with expectations, have led women with breast cancer to feel as if they have failed when they cannot live up to this ideal.

The current study builds on Sulik's (2011) work by examining the ways in which the discourses adopted and promoted by the pink movement shape women's individual experiences of themselves as women with breast cancer and their decision-making. By focusing on discourses, identity constitution, and experience, this study provides an important perspective from which to critique the movement. Results from this study suggest that the breast cancer movement is potentially even more insidious than was once initially thought, as it gets subverted into dictating how women with breast cancer must behave and accordingly, what decisions they can and cannot make if they wish to retain the privileged positioning of "good" woman with breast cancer.

The pink movement does not only conceal the ways in which women's experiences of breast cancer are shaped by relations of power; the movement itself functions to constrain women's ability to act in their own interests by making alternative ways of doing breast cancer less accessible and potentially suspect. The movement is not only failing to challenge the relations of power that dominate women with breast cancer; ironically, it is an important part of this domination, enacted in part through women themselves. Future critiques of the breast cancer social movement must acknowledge the discursive-level effects of the movement on individual women's experiences of the disease.

7.3.1.4 Breast cancer identity. Breast cancer diagnosis and treatment require redefinition of self (Betero & Chamerlain Wilmoth, 2007). While women actively constitute their selves as women with breast cancer (see for example Kaiser, 2008), they are doing so within available frameworks for understanding the disease (Sherwin, 2006). I argue that breast cancer discourse is adopted by women with breast cancer to constitute

an idealised breast cancer subject position that encourages self-governance, judgment, and discipline of others. In examining discursively-available subject positions, this study contributes to understandings of women's experiences of themselves as women with breast cancer.

Sulik (2009) argues that women with breast cancer prioritize biomedical classifications over their embodied experiences of the disease. Similarly, many participants in this study placed great importance on their test results, as they did not actually feel ill at the time of their diagnoses. Biomedical quantifications of risk were very important for participants. Instead of discussing lifestyle changes, such as eating well, in reference to how well they made them feel, most participants spoke about lifestyle changes in terms of how much it would lower their risk of cancer recurrence. Similar to Sulik's (2009) account, in contexts of fear and uncertainty, participants came to depend on biomedical information to understand their embodied experiences of wellness and illness.

Kaiser (2008) has demonstrated that women with breast cancer adapted the meaning of survivorship to fit with their lived experiences. The results of the current study demonstrate that women did understand breast cancer discourse in the context of their own experiences, but that participants' ability to adapt these discourses in meaningful ways was limited by their need to relate to others within the context of relations of power. Mary, for example, described her commitment to her family as a way to thrive. This opposed others' accounts of thriving as contributing to the breast cancer social movement. Although Mary was able to adapt this discourse in her own life, her adaptation did make it more difficult for her to relate to other women with breast cancer;

for her, the opportunities to redefine breast cancer discourse were constrained. Living up to an idealised subject position provided more access to support and a greater sense of success. In this context, there may be consequences for adapting these idealised subject positions. Future studies of breast cancer and the self must consider the complex nature of individual meaning construction within the constraints of available discourses.

7.3.1.5 Relational autonomy and breast cancer. Women with breast cancer are understandably overwhelmed by the implications of their diagnoses. Much of their energy is directed towards the physical and emotional implications of the disease and its treatment. This is clearly not an ideal situation in which to be relationally autonomous—that is, being in a life-threatening situation makes it more difficult to act in one’s own interest within the context of oppressive power relations. Decisions to, for example, undergo potentially lifesaving treatments are not exempt from relations of power, but the expectation that a patient would consider these relations in making her decision is unreasonable. In these instances, institutional changes over time can provide women with breast cancer with more options and safer spaces in which to discuss these relations of power, but it is expected that these decisions are made quickly and while under considerable stress. Less immediate decisions, such as those regarding managing risk and contributing to the breast cancer social movement, may offer more opportunities for women with breast cancer to think critically about the ways in which these decisions are enabled and constrained. They can also be more or less supported in doing this critical thinking.

Participants in this study drew on feminist discourse to challenge femininity around lifestyle—except mothering—and appearance, but not to challenge biomedicine.

Feminist discourse has been effective in offering alternatives in some areas of women's lives, but not in many areas of allopathic medicine. This is likely due in part to the fact that the power of allopathic medicine extends to life-threatening situations. It is much more difficult to challenge a system that is required for the maintenance of our health and, at times, survival. But in treating illness and in telling individuals how to maintain health, allopathic medicine also tells individuals how to be well and how to be ill. It is at these extensions of medicine into everyday life that alternative discourses are particularly important.

In this study, I examined the ways in which women being treated allopathically for breast cancer and seeking support in an illness community, also learned how to be women with breast cancer and how to do breast cancer. Mackenzie (2000) argues that in order to be relationally autonomous, women must be able to imagine other ways of being. Breast cancer discourse made available one way of understanding what it meant to be a woman with breast cancer; in this context, imagining other ways of being was very difficult for participants. As Heather commented on the need to be positive: "Well, what's the alternative? You die? Like, do I have choice in this matter?" Participants experienced a lack of choices as to how to constitute themselves as women with breast cancer.

There is room here for feminists to challenge the discursively constituted subject positions that govern individuals who interact with the health care system. Feminism need not challenge allopathic medicine itself, but can begin to examine the ways in which allopathic medicine and support organizations create, perpetuate, and reproduce discourses that govern and limit women's abilities to be relationally autonomous.

7.3.1.6 Understanding and challenging medical dominance. Early work in the field of women's health sought to counter medical dominance by challenging the intrusion of medicine into women's lives (Ehrenreich & English, 1978). Much of this work drew on a conceptualization of medical dominance as a top-down relation of power. In challenging medicalization, many women's health scholars and activists argued for medical options and concepts that better reflected women's wishes, values and lived experiences. In doing this, women's health scholars and activists successfully expanded treatment options for diseases common among women, including breast cancer, and continue to alter definitions of disease to better reflect women's experiences of illness. This approach to challenging medical dominance focuses on the structure of medicine as an institution that has the power to name, diagnose and treat. It remains important to improving women's experiences of health and illness, but this does not account for all of the ways in which women's experiences of health and illness are shaped by relations of power.

More recently, complicated depictions of the ways in which power functions have demonstrated that challenging medical dominance is more complicated than was once thought. Power functions not only to dominate individuals, but also to constitute individuals that regulate themselves (Foucault, 1973; 1975; 1978; 1988). This dispersed view of power means that challenging medical dominance involves better understanding and changing the ways in which individuals govern themselves and the processes by which this governance is encouraged, reinforced and resisted. Further complicating this view, power is both dominating and productive, meaning that power enables and constrains individuals' abilities to act in their own interest (Foucault, 1973; 1975; 1978;

1988). Studying the ways in which relations of power serve the needs of individuals—by providing the foundation for social groups, for example—and how they dominate individuals—by providing a basis for prejudice and exclusion—is complex. Thus, challenging biomedicine involves better understanding the power relations in which individuals self-govern.

Relational autonomy asks bioethicists to look outside of the clinic to better understand the ways in which relations of power shape women's decision-making (Mackenzie & Stoljar, 2000; Sherwin, 1998). The results of this study illuminate the complicated ways in which discourses reproduced within biomedicine and support organizations, as well as the popular media, serve to limit the choices made by women with breast cancer. In this way, discourses that originally challenged medical dominance—depicting women as active warriors instead of passive victims—now also constrain women's abilities to make choices that reflect their own interests. At the same time, these discourses provide a foundation for a social group of women with breast cancer, where some women find support and strength.

In this context, challenging medical dominance in the lives of women with breast cancer is not only about demanding new and better treatment and screening options. When discourses reproduced in biomedicine enable and constrain the ways in which women with breast cancer constitute themselves and make decisions, challenging biomedicine means challenging the ways in which medicine and support organizations encourage one idealised way of being ill. Making space for alternative acceptable ways of being a woman with breast cancer is not simple.

Although the results of this study do not provide answers to the question of how best to create this space, I can speculate that an important first step is in undermining the truth-value of some discourses women with breast cancer currently draw on in constituting themselves. Participants in this study were not relentlessly positive just because it felt better—they strove to remain positive because they believed being positive increased their chances of surviving cancer. When such discourses become taken-for-granted “truths” about disease, it becomes less possible to imagine other ways of doing breast cancer. If it is true that negativity causes recurrences of cancer, then women cannot reasonably be invited to express their anger, fear and sadness. The first step in challenging this is to question the view that there is one ideal way to be ill that is better than an other. If evidence eventually shows that negativity causes cancer or cancer recurrences, then the social relations that support some women in being positive must be further examined before responsibility is placed on individuals to manifest happiness.

In theory, the knowledge explosion made possible through the internet offers a venue for challenging these taken-for-granted “truths” about illness. In practice, the emancipatory ideals of the internet may not be fulfilled. Pitts (2004), for example, argues that online depictions of breast cancer often reproduce traditional femininity. Similarly, some participants in this study refused to even visit a blog in which the author expressed anger (Jennifer, 2010-2012) because it might cause them to be negative, violating the dictates of “good-women-with-breast-cancer.” Within the context of the breast cancer social movement, Sulik (2011) argues that women with breast cancer prefer to tell socially acceptable breast cancer stories. Similarly, participants in this study often chose not to share their sadness or anger with other participants. When alternative accounts of

breast cancer were shared, they were often dismissed by the other participants. Undermining multiple alternative “truths” about breast cancer embedded in these discourses is unlikely to happen online without the support of the institutions that perpetuate these discourses, including biomedicine.

Making change does not require individuals within the medical system to reject these discourses entirely. Surely, many studies have demonstrated the usefulness of these discourses in promoting hope and providing a foundation for supporting and treating individuals who are ill. Instead, small and manageable changes must be made to undermine the constraining effects of these discourses. These changes may include acknowledging and allowing moments of sadness, recognizing and validating diverse experiences of illness and survival, and being forthright about the need to balance the side effects of treatments with the desire to survive disease.

7.3.1.7 Examining what wasn't said and by whom. In Chapters 4, 5 and 6 I provided an interpretation of the data generated in this study. I did not examine the lack of data about certain topics. Certainly, what isn't said by participants says something of importance as well. In this section, I briefly examine some of the topics that are present in the literature but were not discussed by participants.

Both Kaiser (2008) and Batt (1994) provide accounts of breast cancer social movements that engage with feminism and environmentalism. While some participants in this study did speak about the environmental causes of breast cancer, none were active in these movements; for participants, being active in the breast cancer community meant being active in the mainstream breast cancer movement. This commitment to volunteerism within the mainstream breast cancer social movement suggests that many of

the participants in this study were committed to living up to the ideal representation of women with breast cancer, perhaps more than other women with the disease. This level of involvement in the mainstream movement can be partly attributed to my recruitment strategy, but also suggests that Nova Scotia may be a unique setting in which counter movements may not be as common as in other locations. Access to alternative understandings of breast cancer may be more available elsewhere in larger centres, and that may provide more space for alternative ways of doing breast cancer.

Women who took part in this study were involved in breast cancer support organizations that had adopted the discourses typical of the mainstream breast cancer movement. In larger urban centres, women with breast cancer more commonly access alternative discourses through environmental, medical and feminist activist groups (see Klwaiter, 2008 for an exploration of these groups in San Francisco). It is possible that women with breast cancer in Nova Scotia who did not take part in this study are also involved in these causes. In attending to the political nature of breast cancer, women involved in such activist groups engage politically with their personal experiences of the disease, fuelling a critical perspective that may support relational autonomy. In smaller urban centres, breast cancer support organizations could benefit women with breast cancer by offering more opportunities to engage with these more political sides of breast cancer and by encouraging women with breast cancer to better understand the relations of power in which they are embedded. This suggestion is complicated by the fact that most support service organizations are funded by larger “pink” charitable organizations, and acting politically may threaten the funding that allows them to do such important work

(Batt, 2012). Thus, these organizations may be no more free to resist these discourses than are their members.

Participants in this study were primarily white, middle class and heterosexual. The discourses discussed in Chapter 4 reflect a larger social trend among upper middle class, white, heterosexual women to “thrive” and be “authentic” (Lamont, 1992). One participant, who experienced poverty, did not always relate to the existential issues discussed by other participants. While others asked questions like “how should I be a breast cancer survivor?” this participant was more focused on how to make enough money to buy fruits and vegetables. In many ways, this participant was more constrained materially in that she did not have the resources to live with the disease in the way she wished. In other ways, her life experiences provided her with the resources to understand that she could make it through this challenge just as she had done with all of the other challenges in her life. Hearing more from women who felt excluded from the breast cancer community for a variety of reasons would have provided a different and valuable perspective on the discourses described in Chapter 4.

One may wish to suggest that, discursively, the participant from a lower class background was more enabled to act autonomously because she was more likely to dismiss the discourses promoted by the breast cancer social movement. The data in this study cannot suggest who was “more autonomous” than others, and this was not the goal of this study. I can speculate that while some participants were less likely to take up these discourses than others, this did not mean that they did not privilege these ways of understanding the disease. Being able to see that there is more than one way of doing an illness does not necessarily mean that each of these ways is judged to be equal. Feminists

have provided accounts of the ways in which their understandings of beauty and weight norms as socially constructed and based in oppressive views of women's bodies as objects does not necessarily make it easier to challenge these norms in their daily lives (see for example Mandle, 2000). As Dorothy Smith (1987) says, understanding the social relations of power does not put us outside of them. Knowing that something is not the only way to be and living in accordance with this knowledge are very different things. Until alternative ways of being are supported more broadly within a society, it is a struggle to live in a way that challenges the discourses that tell individuals how best to live their lives. While individuals who are classed or racialized may have a better view of the ways in which these discourses fail to account for their lives, their daily experiences of oppression may make it even more difficult to assume alternative ways of being ill, rendering them even further outside of the privileged mainstream.

7.3.2 Theoretical Contributions. In this study, I drew on the concepts of relational autonomy and governmentality to illuminate the discursive-level of women's experiences of breast cancer, and the ways they may influence women's decision-making when faced with breast cancer. As described in Chapter 2, relational autonomy is a complex concept that has been used to develop in-depth critiques of the ways in which relations of power on all levels enable and constrain women's ability to be autonomous (Mackenzie & Stoljar, 2000). It suggests that women's capacities to act in their own interest are enabled and constrained within relations of power. This concept crosses boundaries typical of social science theory approaches to understanding power, thus it is difficult to take up the concept in conjunction with these. This concept has been used most commonly to examine structural-level constraints on decision-making, such as lack of access to

treatment options. Foucault's notion of self-governance (1988; 1991) helps to illuminate the discursive level constraints and enablers of relational autonomy that are less commonly examined.

In examining power and resistance, it is important to attend not only to structural power relations—such as physician-patient relations—and material bases for power such as access to resources, but also to ideological and discursive operations of power that may limit relational autonomy. In this study, I used Foucault's concept of governmentality to focus on the discursive operation of power. Relational autonomy provides a useful way of understanding the consequences of governmentality for individuals, something Foucault may have overlooked in his work. Relational autonomy and governmentality are very useful in understanding the discursive operation of power and its effects. Relational theorists may wish to examine the ways in which different conceptions of relations of power illuminate the many ways in which relational autonomy can be enabled and constrained.

In combination, the concepts of relational autonomy and governmentality allowed me to examine the complicated ways in which breast cancer discourse functions to create an idealised way of being a woman with breast cancer that limited participants' abilities to imagine other ways of doing breast cancer, and in particular limited their abilities to imagine themselves enacting such alternatives. The concept of governmentality provides a tool for conceptualizing participants' actions as shaped by discourses that encourage self-governance, judgment of self and others, and discipline of others. In neoliberal political climates, there is strong emphasis on individuals demonstrating themselves to be moral, virtuous citizens through taking personal responsibility for the pursuit of health

(Crawford, 2006). Policing oneself and others extends the capillary-like network of governmentality.

Relational autonomy provides a conceptual tool for interpreting the everyday effects of this self-governance on women's abilities to imagine other ways of being and act in their own self-interest. Autonomous decision-making may be constrained in part by women's own efforts at self-governance and their surveillance of one another to ensure adequate production of idealised women with breast cancer. This discursive-level examination is an important addition to studies that focus on material and structural constraints because it further complicates understandings of the ways in which relations of power serve to limit opportunities for relational autonomy. Interestingly, combining governmentality and relational autonomy highlights the ways in which women contribute to constraining their own and each other's decision-making. Building on the results of this study, relational theorists may wish to further examine the discursive enablers and constraints on self-trust and imagination.

Perhaps because of its complexity, relational autonomy is rarely examined empirically. This concept offers an important starting point from which to develop research questions that attend to relations of power and their effects. In using relational autonomy in conjunction with governmentality, this study may provide some guidance for researchers hoping to use this concept in an empirical analysis of discursive-level relations of power.

7.3.3 Methodological Contributions. As described in Chapter 3, in this study I used a generic approach to qualitative research. Most commonly, qualitative health researchers describe their methodologies as using ethnographic, phenomenological or

grounded theory approaches. At times, it seems that these methodological terms are used because they provide legitimacy, not necessarily because they describe what was done in the research study (Thorne, 2011). Generic or descriptive qualitative research has an important place in furthering the field of qualitative health research by generating data that is useful for health policy and practice decision-making, and by requiring researchers to clearly articulate their methodological approach (Sandelowski, 2000). This study provides one example of a generic qualitative research study as an illustration for other researchers.

Qualitative data collection using online methods is becoming more common. In the context of health research, online formats for interviews or focus groups provide opportunities to access participants that may be otherwise unable to participate due to illness, time constraints, or geographical distance. Most online data collection methods currently in use involve collecting pre-existing online content or engaging participants in synchronous interviews or focus groups, meaning participants go online and take part in a real time interview or focus group. Thus, most claims to methodological innovation using the internet actually adapt in-person methods for use online (Wiles, Crow & Pain, 2011). In this study, I used an asynchronous online discussion group in which participants contributed to a guided group discussion at times convenient for them. This method was very successful in that it provided rich data and participants enjoyed being able to engage with the group at their convenience. One drawback of this method is the research ethics requirement in Nova Scotia to create a Canadian-hosted website for the discussion board, which can be cost prohibitive. There is also little literature about how best to analyze interactions between participants. Asynchronous online discussion groups are a useful

method to add to the qualitative health researcher's methodological toolbox and it is worth reflecting on the value of this method for other studies.

7.4 Limitations

There are methodological limitations to this study that must be considered while examining the potential implications of this work. Methodologically, approaches to study design, recruitment, and data collection shaped the results recounted here. Participants were recruited with the assistance of a breast cancer support organization in Halifax, Nova Scotia. As all participants had some contact with this organization, it is likely that they were more involved in the mainstream breast cancer movement than the average woman with breast cancer. In some ways, this makes this group of participants ideal for examining the ways in which popular breast cancer discourse shapes decision-making. At the same time, this limits the transferability of the findings, as other women with breast cancer may be more or less subject to these discourses. This recruitment strategy meant that few participants articulated alternatives to the discourses discussed and none decided not to pursue allopathic treatment. Demographically, participants were reasonably homogeneous. Although this reflects the overall population of Halifax, Nova Scotia, it also fails to represent the perspectives of women from diverse social categories. It is possible that some of the norms discussed here, such as not complaining, are typical of Nova Scotian culture. Conclusions about geographical and cultural differences cannot be drawn from this study.

In conducting qualitative data analysis, researchers must make decisions that highlight some results and obscure others. In efforts to answer the research question for this study, I made decisions in the analysis that caused much of the data collected to be

relegated to the background of the analysis. While these decisions were made to allow me to answer the research question, it is possible that some excluded data may have been relevant to this study or to the reader, as it certainly was to the participants.

As with all qualitative studies, the results from this work are not generalizable. However, the implications of this work can be extrapolated beyond these participants to better understand the ways in which health social movements that aim to support women also serve to constrain them. Thus, the substantive, theoretical and methodological contributions of this study may contribute to the literature in various fields.

7.5 Future Directions

The results of this study will be disseminated to academic, health professional, support service, and patient communities. Results have been and will be presented at international academic conferences, and will be published in academic journals, in the fields of bioethics, qualitative health research, oncology practice, and sociology of health and illness. A report appropriate for health professionals, support organizations, and patients is underway. Participants will also receive a copy of this thesis. Presentations will be made to lay audiences at local breast cancer support organizations.

While the results of this study make some contributions to understandings of relationally autonomous action in the context of breast cancer social movements, these are limited by the fact that health care providers and social support providers were not interviewed. A study generating data concerning the provision of care to women with breast cancer from these perspectives would provide more insight as to how best support women with breast cancer in being relationally autonomous within the context of current standards of care and health care policies.

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Appendix A: Recruitment Poster

 **DALHOUSIE**
University

Women's Experiences of Breast Cancer: Navigating Breast Cancer Knowledges, Metaphors, and Images



A Research
Study

How do you make sense of all the information about breast cancer?
What does it mean to you to be a woman with breast cancer?

If you are a woman diagnosed with breast cancer who:

- has received treatment in Halifax in the last 2 years
- is over the age of 18
- has access to a computer and the internet

Take part in 3 interviews and an online discussion group over 5 months. Call or email for more information.



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Appendix B: Screening Questionnaire

Hello. [If by phone: May I please speak with [insert potential participant's name here]?] My name is Erin Fredericks and I'm leading the research study titled: Navigating Breast Cancer Knowledges, Metaphors and Images. I received your email/phone call expressing interest in participating. [If by phone: Is this a good time for you to discuss this? If yes, continue. If no, arrange a time to call back.]

I would like to provide you with more information about the research. I am trying to understand how women make sense of all the information about breast cancer and how this affects their interactions with health care and support service providers. Right now I am recruiting participants. Participation involves taking part in 3 interviews over a period of 5 months, plus participating in an online discussion group weekly for 3 months. [If by phone: Do you have any questions? Respond to questions] [If by email: I am happy to answer any questions you may have about the project by email or phone]

[If by phone: Do you think you might be interested in participating? If yes, continue. If no, end call and thank her for her time] [If by email: If you are still interested in participating, I have included more information below. If not, thank you for your interest.]

I am looking for participants who represent a wide range of backgrounds. In order to ensure I have this wide range, I need some information about you before I can set up an interview. I am the only one who will see this information and it will be destroyed immediately if you end up not taking part in the study right now. [If by phone: Are you willing to answer a few questions about yourself? If yes, continue to screening questionnaire. If no, end call and thank her for her time.] [If by email: If you are willing to answer some questions about yourself, they're included below. You can insert your answers in your email response]. You may choose not to answer any of the questions.

- 1) When were you diagnosed with breast cancer? What type?
- 2) When did you last receive treatment for your breast cancer? What type of treatment?
- 3) Do you feel your health will allow you to take part in the study?
- 4) Do have access to a computer with internet access?
- 5) What is your age right now?
- 6) What is your occupation?
- 7) What is your highest level of formal education?
- 8) It can be difficult to pin down, but would you say you're working class, middle class, upper class or somewhere in between?
- 9) How do you identify in terms of your race and ethnicity?
- 10) What is your current relationship status?

[If meets inclusion criteria/diversity requirements: You are invited to participate in the study. Would you like to schedule your first interview now? Or should I call back at another time? If yes: schedule interview. If not: book a time to call back.] [If does not meet inclusion/diversity requirements: I am sorry, you don't meet the inclusion criteria for the study so I'm afraid I cannot ask you to participate. Do you have any questions?] Thank you for your time.

Appendix C: Demographics Table

Pseudonym	Year Diagnosed	Treatments	Age	Class	Race/Ethnicity	Relationship status
Megan	2010	mastectomy, chemotherapy	39	Working	Caucasian	Single mother
Alice	2010	Lumpectomy, radiation, tamoxifen	49	Middle	White	Separated
Jean	2009	Mastectomy, chemotherapy	43	Middle	Caucasian	Married
Pamela	2009	Lumpectomy, radiation, tamoxifen	47	Middle	Caucasian	Married
Joyce	2008	Mastectomy, chemotherapy, radiation	47	Middle	White Canadian	Married
Elsie	2009	Lumpectomy, radiation	64	Middle	Mixed (African Nova Scotian and White)	Married
Heather	2010	Bilateral mastectomy, radiation	41	Working	White	Single
Gail	2010	Lumpectomy, chemotherapy, radiation	52	Middle	Caucasian	Married
Paula	2007	Lumpectomy, radiation	56	Working poor	Caucasian	Single mother
Nancy	2010	Bilateral mastectomy	46	Middle	White	Married
Mary	2008	Lumpectomy, herceptin	49	Middle	White Canadian	Married
Carolyn	2010	Mastectomy, chemotherapy, radiation, tamoxifen	49	Middle	Canadian	Common-law partnership

Appendix D: Consent Form



Title: Women's Experiences of Breast Cancer: Navigating Breast Cancer Knowledges, Metaphors and Images

Introduction:

You are invited to participate in a research study that involves participating in three interviews and an online discussion group. This is part of a research study examining how women diagnosed with breast cancer make sense of information about breast cancer and how they use this information to make health care decisions. Erin Fredericks, a doctoral student at Dalhousie University, is leading this study with the support of her supervisor, Dr. Brenda Beagan. Your participation in this study is voluntary and your choice to participate or not to participate will not affect your ability to access health care or support services. You may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study will not directly benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with the researcher. Participation in the interviews and online discussion group will take about 11 hours of your time over five months.

Contact Information:

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Purpose of the Study

The purpose of this study is to learn more about the experiences of women diagnosed with breast cancer and their health care and support service providers. We especially want to know how women deal with all the information they may encounter.

Study Design

In Halifax, 12-15 women diagnosed with breast cancer will each take part in 3 interviews and an online discussion group.

Who Can Participate in the Study

Women who have been diagnosed with breast cancer, are over the age of 18, speak and write English and have access to a computer with internet can participate in the study.

Who will be Conducting the Research

Erin Fredericks, a doctoral student from Dalhousie University will lead this research project. She is supported by her supervisor, Brenda Beagan. If you agree to participate, you will be interviewed by Erin.

What you will be asked to do

You are being asked to take part in 3 interviews and contribute to an online discussion group with other participants. In the first 2 interviews you will be asked questions about your breast cancer experiences. In the third interview you will have an opportunity to respond to some of the initial results of the study. These interviews will be recorded and later typed up. The interviews will take place at a time and location that is convenient for you. The 3 interviews will take place over a period of 5 months. For 3 of these months you'll also be invited to take part in an online discussion group with 11-14 other study participants. Each week, questions will be posed to the group and you can post your answers and respond to others. Below, you will be asked if anonymous quotes from the interviews and online discussion group can be used in publications from the research study.

If at any point you choose not to continue with the study, you are free to withdraw. The information you have contributed to that point will still be used, unless you ask me not to use it. Simply call or email to ask me to destroy your data. After September 2011, it will no longer be possible to withdraw your information from the study, since analyses will already have been completed.

Confidentiality and Anonymity

Anonymity: Your name will not be used in anything that is written or presented about this research. The researcher will not tell anyone your name. An identification number was assigned to you when you first contacted the researcher about possible interest in the study. You will have the option to create a pseudonym or to use your first name in the online discussion group. The one file that links your ID number, pseudonym and your name will be kept in a locked drawer in the researcher's office at the university. If you use a pseudonym, anonymity cannot be guaranteed because someone may be able to guess who you are. If you choose to use your first name, you will not be anonymous to other research participants.

Confidentiality: The digital recording of your interview will be stored on the researcher's password protected computer. It will be deleted after the interview is typed up. The typed up version of your interview and online discussion responses will also be stored on the computer, and password protected. Your name will not be in it, and anything that identifies you will be changed or taken out of the documents. All data collected during this study will be securely stored at Dalhousie University for five years after the last publication is complete. The researcher will keep everything you say in the interview private. The participants in the online discussion group will be asked not to share information from the discussion with others. Nonetheless, because someone *may* share this information, confidentiality cannot be guaranteed.

Your Rights: You can choose not to answer any question that is asked. You can take a break at any time during an interview. You can stop the interview or stop contributing to the online discussion group at any time. At that time you can tell me if you want the recording of your interview or your contributions to the discussion erased, or if I can still use what you have said so far. You can receive a, electronic copy of the final report and/or dissertation, just by indicating below that you want one. You can ask the researcher any questions you want to about the study.

Possible Risks and Discomforts

It may be uncomfortable, or even painful, talking about your experiences with breast cancer. Keep in mind that you do not have to talk or post online about anything you do not want to.

Possible Benefits

The study will not help you directly, but it could provide a better understanding of the experiences of women with breast cancer.

Compensation/Reimbursement

To reimburse any expenses and show respect for your time, you will be given an honorarium consisting of a \$25 gift card for each interview and for participation in the online discussion group. If you participate in all 3 interviews and the online discussion group you will receive a total of \$100 in gift cards. If you choose to leave during an interview or the online discussion group you will still receive the honorarium.

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Patricia Lindley, Dalhousie University's Office of Human Research Ethics Administration, for assistance at (902) 494-1462.

I have read the consent form about this study. All my questions have been answered at this time and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I have been given a copy of this signed consent form.

_____ I consent to having interviews recorded

_____ I consent to having my contributions to the online discussion group saved

_____ I consent to the researcher including anonymous quotations from my interviews and online discussion posts in publications and presentations from this study.

Participant's Signature

Date

Researcher's Signature

Date

_____ I would like a copy of the final report/dissertation [circle] from this study.

Contact information:

Appendix E: Interview 1 Guide

- 1) Tell me about yourself. (Family, friends, work, other activities)

- 2) Tell me about your experience of finding out you have breast cancer.
Probes: When did you first know you might have breast cancer? Diagnosis?

- 3) How did you tell your family and friends? What were their reactions?

- 4) After you were diagnosed what was the next step?
Probe about both medical and non-medical treatments and support

How did you decide what you would or would not do?

Has your breast cancer diagnosis changed how you think about yourself at all?

- 5) Tell me about your health care and support service team.
Probe about specific experiences- positive or negative

- 6) Is there anything else you'd like to add today?

Appendix F: Interview 2 Guide

1) Check-in about first interview and online discussion group.

2) Ideal (or right) ways of doing breast cancer.

What are they?

How do women learn about them?

3) Which of these do you identify with?

What does being _____ foreground? Background?

4) You're lots of things other than a woman with breast cancer. When have these conflicted?

5) When have you created your own way of doing breast cancer?

Appendix G: Initial Results

August, 2011

Women's Experiences of Breast Cancer: Selection of Initial Results

Erin Fredericks

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Negotiating Control: Medical Decisions and Lifestyle

Being diagnosed with breast cancer surprised most of the participants, many of whom were healthy until their diagnosis.

For many participants, this surprise made them feel as if they had lost control of their bodies.

While participants wanted to be informed and involved in medical decision-making, most took comfort in trusting their doctors to recommend the right treatment for them:

"There wasn't a lot of autonomy and decision-making required and I found that helpful."

This trust provided them with a sense of control over their treatment. It also allowed them to finish treatment without regretting any decisions they had made.

For some, trusting their doctors meant not searching for too much information. Others

read as much as they could about breast cancer. In both cases, controlling the amount of information they were exposed to played an important role in their efforts to remain calm and make decisions.

While we often focus on medical decisions, participants also managed other things that they believed would make them healthier. These included maintaining a positive attitude, and making meaning from the experience:

"Staying focused I think is a big part of having cancer, I don't think you should let it take over you. I rebel against it. I'm going to do as much as I can to move on and change it and use it as a positive instead of a negative."

Staying Positive

Most of the participants in the study felt it was important to maintain a positive attitude.

For some, appearing to be positive was difficult as they experienced sadness, anger and depression.

Some of these participants were disappointed that other women in the breast cancer community hid their negative emotions, leaving them feeling left out:

"So I'm not the only one [who feels de-

pressed]. But nobody talks about that. And I'm embarrassed by it. "

A more realistic definition of positivity that allows moments of sadness was suggested:

"Positive means thinking it will all be okay but it's okay to be sad as long as it's not all day, every day."

Others associated positivity with being hopeful, learning, and moving on.

Making Meaning

We hear stories of those who have a life threatening experience and learn valuable lessons.

focusing on one's family, having more compassion, and loving oneself.

pened for a reason. I got through it and I'm a better person."

thing from having cancer. Despite this, even the most hesitant took some meaning from the experience:

Participants in this study often discussed the lessons they learned, or meaning they've made from their experience of breast cancer.

Some participants felt that making meaning was one of the most important steps in healing from cancer and moving on after cancer:

Others struggled to make meaning as they continued to experience the emotional effects of the disease.

"So, I really resent the whole notion of looking for the gift of cancer, but I have to reluctantly acknowledge that it is a pretty good prod."

Ways of making meaning included changing careers, volunteering,

"Because for me, it gives me comfort thinking that it hap-

Some participants were upset with the implication that they had to learn some-

Choosing From Limited Options

As described here, the initial results of the study demonstrate that many participants made similar decisions about how to be women with breast cancer.

felt they chose to act this way, many would consider asking for more help and sharing their emotions with others if they had to face cancer again.

like Do I have choice in this matter? You know? You do your best."

these choices were shaped significantly by the options available and visible to them.

Participants did not feel that others required them to act in a particular way. Instead, many suggested that they wanted to act that way because it was for the best:

When asked if they would do anything else differently, many participants didn't see other options available to them.

Another described her reaction when she realized she didn't need to have a prosthesis or reconstruction after bilateral mastectomy:

In cases where options were severely limited, participants made the best of the choice they had to make.

"I tried to stay positive, for me, because I knew it was the best thing."

For example, when asked about the option of not being positive and brave, one participant said:

"You know, I'm a bright person and honest to God, it never, ever crossed my mind that that was an option."

Although participants

"Well, what's the alternative? You die?"

Participants decisions about how to act were their own choices. But,

Appendix H: Online Discussion Questions (sample)

Week 1

Welcome to the online discussion group. In this group we will be discussing common knowledge, images and metaphors about breast cancer.

Images are pictures or representation of breast cancer or women with breast cancer. Metaphors are comparisons. We use metaphors to compare the experience of having breast cancer to other experiences to help us explain what it's like to others. For example we might say "I'm fighting breast cancer," or "I'm on a breast cancer journey."

While there are many popular metaphors and images about breast cancer, I want to start by talking about the ones that mean something to you.

Is there a metaphor or image that you use to describe your breast cancer experience?

If so, what is it? Has it been helpful to you in better understanding your experience or in describing it to others?

If not, do any particular images or metaphors come to mind when you think about breast cancer?

Week 2

The pink ribbon has come to represent all things related to breast cancer. Now the color pink has come to identify products, services and events that fundraise for breast cancer organizations.

What do you think about the pink ribbon?

Why do you suppose the colour pink was chosen?

Week 3

When many people talk about breast cancer they use words related to war and violence. These include "fight", "victim", "enemy", "battle", and "winning". This language is common in media campaigns and medical brochures.

Do you feel like you're in a fight against breast cancer? Why or why not?

Should we be using this language? Why or why not?

Week 4

The word “survivor” is connected to the idea of breast cancer as a battle that one can survive.

What does the word “survivor” mean to you?

When, if ever, will you consider yourself to be a survivor?

Week 5

Many women refer to their experience of having breast cancer as a journey. For some women, this is connected to understanding the experience as having happened for a reason, or as leading to something else. Some women describe the breast cancer journey as being transformative, or changing them in important ways. In this description, the journey doesn’t really end because their lives are permanently changed as a result of breast cancer.

Do you feel like having breast cancer is a journey? Why or why not?

Week 6

Last week we talked about breast cancer journeys. Many women describe the breast cancer journey as being transformative, or changing them in important ways. In this description, the journey doesn’t really end because their lives are permanently changed as a result of breast cancer.

Do you think having breast cancer is a life changing event? If so, in what ways?

Do you want your life to be different from what it was before you had cancer? Or do you want to go back to the way things were? Why?

Week 7

We hear a lot about the importance of positivity for women receiving cancer treatment. But, we also hear about the health risks of not expressing negative emotions.

Do you think being positive or negative affects your health?

How should women deal with all of the emotions associated with a cancer diagnosis?

Week 8

There are many programs and products designed to help women look better while they have cancer. These include the “Look good, feel better” program, prostheses, and wigs. Some websites advertise ways to “hide” the results of breast cancer treatments.

Do you think “looking better” makes women with breast cancer feel better? Why or why not?

Do you think women want to look better for themselves, for others, or both?

Week 9

There are many breast cancer related products for sale in stores in Nova Scotia. Breast cancer is often mentioned in movies, books and on television.

Do you often notice reminders of breast cancer in stores, movies, books and on television?

How do you feel about these reminders?

Week 10

We’ve talked about the importance of positivity when it comes to having breast cancer. In the media, we see many positive images of women with the disease. But, there are some things we don’t see very often- anger, sadness, frustration, and pain, for example. Here’s a link to a blog written by a woman who is sharing her anger with the world:

<http://nofnpinkribbons.blogspot.com/2010/05/wanted-new-metaphors-and-analogies-to.html>

You can read more of her posts by clicking the titles on the right side of her blog page.

What do you think about her posts?

Week 11

There are a lot of politics surrounding breast cancer. For example, pharmaceutical companies make decisions about which treatments to make affordable, non-profit organizations campaign against each other for funding, governments provide funding for some services and not others, and researchers compete to produce new treatments first.

Do you think women with breast cancer should be engaged in the politics of breast cancer? If so, why should they be involved? And how should they be involved? If not, why shouldn’t they be involved?

Week 12

You've all mentioned how important it is to see experiences of breast cancer in the media because it raises awareness. I would suggest that the experiences of breast cancer we see in the media are often one-sided. We see the positivity, survivorship, and activism, but we don't see the negative physical and emotional effects of the disease.

Do you feel like representations of breast cancer in the public represent your story? Why or why not?

What are the consequences of representing breast cancer in this way? (positive and negative?)