Abstract

This chapter explores the construction of dramaturgic characters in social movement narratives surrounding breast cancer. It contributes to developing a better understanding of the role of plotting and characterization in these social movement narratives by highlighting three primary functions. First, the authors elaborate on the functions of the plotting of the central characters of a social movement narrative and their emotional appeal, in contributing to mobilizing collective action as well as operating a disciplining tool for the biological citizen. Second, they shed light on the effects of the simplification versus complexification of the characterization of the villain on mobilizing the audience's emotions. Finally, they discuss the role of the individualization and collectivization dynamics in the various social movement narratives in stabilizing and/or destabilizing certain political realities.

Keywords

social movements, healthcare activism, narratives, characterization, individualization, breast cancer, cancer activism

7

Heroes, Villains, and Victims

Tracing Breast Cancer Activist Movements

Mohammed Cheded and Gillian Hopkinson

Introduction

Breast cancer, and those affected by breast cancer, have been defined within a contested and fluid terrain. As King (2004, 475) argues, breast cancer has evolved since the 1970s from “a 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.’” This chapter is concerned with the role that social movement narratives have played in these significant changes in the way that breast cancer is framed, how those with breast cancer are characterized and the consequences that contest between cancer activist movements has on the organization of breast cancer services. This is achieved by examining and contrasting the narratives of diverse movements. It pays particular attention to the metaphoric underpinnings of those narratives and the consequent characterization of women with breast cancer that each seeks to assert and establish in public discourse. We argue that characterization, as portrayed in social movement narratives, has significant consequences both at the individual level as it relates to women’s experiences as well as having critical political implications since the dominant characterization has repercussions for the focus of attention and resources, and the way those resources are organized, with respect to the illness.

The chapter focuses on four social movements that provide narrative framings of the terrain of breast cancer. We organize our investigation of these narratives around disease stages. First, we focus on the stage of pre-illness, where we explore (1) the dominant epidemiological narrative and the previvor, and (2) the environmental narrative and the cancerogenic pollutant. Second, we focus on the stages of peri- and post-illness, where we explore (3) the pink ribbon narrative and the survivor, and (4) the feminist narrative and the empowered collective. A deeper understanding of these narratives is generated by using a wide variety of publicly available data around breast cancer social movements. These include newspaper articles, novels, memoirs, visual art, online forums and blogs, companies' websites and social media, and journal articles. The relationship between narratives and the consequences of each and their struggle for dominance is interrogated.

The rest of this chapter is structured as follow: first, we flesh out the key concepts underpinning our approach—narrative, characterization, and the social processes/contests amongst multiple narratives. Second, we briefly discuss the disease under study, which is breast cancer, with an emphasis on its cultural hegemony amongst other cancerous diseases. Following that, we move on to discussing the narratives of social movements surrounding breast cancer mentioned above. Through this we are able to contribute in the following ways: first, we highlight the functions of the plotting of the central characters of a social movement narrative and their emotional appeal, in contributing to mobilizing collective action as well as operating as a disciplining tool for the biological citizen. Second, we shed light on the effects of the simplification versus complexification of the characterization of the villain on mobilizing the audience's emotions. Finally, we discuss the role of the individualization and collectivization dynamics in the various social movement narratives in stabilizing and/or destabilizing certain political realities. By doing so, we hope to contribute to developing a better understanding of "the role of literary devices in sociological analyses of collective action" (Polletta 1998, 419).

1. Narratives and Characterization

Social movement narratives in healthcare are important because they contribute to shaping various aspects of the overall disease regime (such as authoritative discourses, emotional discourses, visual imagery, public policies, institutionalized practices, and so on), and subsequently the illness experiences (Klawiter 2004; Willig 2011). As Fine (2002, 244) argues: "by making concrete the theoretical, stories cement individuals into group life emotionally, intellectually, and behaviorally."

According to Fine (2002), social movements constitute a "bundle of narratives." They provide critical cultural resources for connecting the personal and the collective in the experience of injustice against which the need to organize arises. As such, characterization in narratives represents the embodiment of a collective's cultural codes (Jacobs 2002). Social movement narratives can help bridge the gap between the individual and the collective through the construction and reproduction of shared cultures, values, beliefs, as well as commitments to change (Davis 2002; Olsen 2014).

Narratives are essential to mobilizing collective action and thus have a significant impact on the outcomes of social movement activities. As Jacobs (2002, 206) argues, it is through the organization of characters and events into stories that individuals and collectives are able to "develop an understanding of the past, an expectation about the future, and a general understanding of how they should act.” A credible narrative requires a logical sequencing of event and emplotment and provides clear linkages between characters and events (Czarniawska 1997). Narrative logic constitutes “powerful devices through which we understand the world” (Hopkinson 2015, 287). These devices are essential to the credibility of a narrative (Polkinghorne 1988). Additionally, narratives provide us, be it explicitly or implicitly, with hints on matters of causality, blame, and accountability (Gabriel 2000). As Fine (2002, 239) put it: “narrative permits the expression of an implicit ideology that even the parties to the discourse may not fully realise is present.”

Rather than being a monolithic depiction of events, narratives are fragile and multiple (Bakhtin 1973; Derrida 1979). Storytelling is an active exercise of emplotment, characterization, and sequencing of events, rather than a passive report of what-had-happened. Stories are in competition with each other for establishing credibility and notoriety (Boje 2001). Each story does not operate in isolation but must share the stage with other stories that present alternative accounts, emplotments, and characterization (Hopkinson 2015).

Thus, there is the potential for multiple, and possibly competing, social movement narratives to be present within the same space. In order to mobilize collective action successfully, social movement narratives need to construct an appealing characterization of collective culture so as to claim individuals’ allegiance. In addition, social movement narratives should include clear accounts of injustices against which protest must be organized, agents to blame, and measures to monitor the progress of action (Polletta 1998). Collective mobilization requires the identification of an antagonist(s) or a villain(s) within the plot. The arrangement of the relations and interactions between protagonists and antagonists are crucial to creating an engaging plot, which would help mobilize action. As Jacobs (2002, 218) put it, “the narrative ordering of character relations is a strategic resource for social movement leaders.”

Social movement narratives contribute to redefining dominant conceptions of disease and mobilizing action (Kolker 2004). This chapter explores the construction of dramaturgic characters in narratives of social movements around breast cancer. We present a brief overview of the disease in Section 2.

2. Breast Cancer: A High-Profile Disease

Social movement narratives around breast cancer have been instrumental in mobilizing funding and ultimately shaping the experience of women living with/or at genetic risk of breast cancer. Breast cancer is a high-profile disease due to both its cultural dominance and financial appeal to pharmaceuticals and biotechnology industries. As Ehrenreich (2001, 45) argues, breast cancer has become “the biggest disease on the cultural map, bigger than AIDS, cystic fibrosis, or spinal injury, bigger even than those more prolific killers of women—heart disease, lung cancer and stroke.” Breast cancer has high visibility in the media (Clarke and Everest 2006). It has become a highly political disease attracting a large amount of research funding leading some critics to call it “the pinnacle of charitable causes” (King 2004, 473). It enjoys the lion’s share of cancer community funding (Klawiter 2008), as well as the largest share of research funding from the most prominent research organizations on cancer such as the United States National Cancer Institute (King 2006). Although in appearance benign (and even positive one could argue), this cultural hegemony has important implications for the construction of women’ bodies who are at risk or diagnosed with breast cancer, as well as the framing of other non-mammary related cancers, such as ovarian cancer.

From a financial perspective, breast cancer is a highly lucrative disease. Industry figures highlight how anti-cancer drugs take a clear lead in terms of products in research and development, with a trend showing a steady increase. According to industry, this tendency is here to stay and “cancer’s pre-eminence as a therapeutic target . . . is showing all the signs of becoming as immortal as cancer cells themselves” (Pharmaprojects 2019, 14). A ranking of the diseases with the highest number of active drugs in research pipelines shows that “various cancers now account for 14 of the top 20 diseases, and of these, only prostate cancer at number eight and brain cancer at number nine have smaller pipelines this year [2019] than last year [2018]” (Pharmaprojects 2019, 18). Out of these fourteen types of cancer, breast cancer bolsters the largest pipeline with a 6.5 percent increase in the research pipeline between 2018 and 2019. The research pipeline for breast cancer is higher by nearly 33 percent to the second disease in the list, which is lung cancer.

3. Our Method

This chapter draws on a wide variety of North American and United Kingdom sources around breast cancer social movements. These include newspaper articles, novels, memoirs, visual art, online forums and blogs, companies’ websites and social media, and journal articles. It is important to emphasize that the chapter does not intend to be an exhaustive review of all the narratives around breast cancer social movements. With the large and ever expanding number of organizations involved in breast cancer social movements, such an endeavor would have been nearly impossible.

We developed our database by following the traces between texts and visuals across times and spaces, and by using online searches primarily. The process was iterative between investigating key social movements around the disease, other central actors that are either explicitly or implicitly involved in the narratives (such as governmental bodies, cosmetic companies, pharmaceutical and biotech companies, and patient support groups), as well as engaging with the relevant literature. Through this iterative process, we were constantly refining our keyword searches. We carried on following the traces between texts and visuals to media coverage, press comments, industry reports, activist group websites and reports, artistic strands of activism such as visual arts and poetry, relevant lawsuits, and so on. The methods for following the traces between texts and visuals was inspired by Izak (2014) (see also Hopkinson 2015). There was no "natural" boundary to the dataset and our snowballing technique to collect it. Thus, we had to make some decisions on the selections of material and the process of tracing the sources and information to the extent that we felt able to present our narrative of the events and draw out key dynamics of characterization of the different narratives of social movements around breast cancer.

During our data analysis, we divided the dataset into two large clusters, each containing two subclusters. The main clusters are organized around the disease stages, while the subclusters are structured around the movement narratives during each stage. The first cluster focuses on the stage of pre-illness and is subdivided into (1) the dominant epidemiological narrative and the previvor, and (2) the environmental narrative and the cancerogenic pollutant. The second cluster focuses on the stages of peri- and post-illness, and is subdivided into (1) the pink ribbon narrative and the survivor, and (2) the feminist narrative and the empowered collective.

After a first round of exploration of material around breast cancer social movements' narrative, we selected, within each cluster, examples that revolve around the themes of aesthetics and the body, empowerment, funding and access, survivorship, previvorship, responsibility(ies), individualization, collectivization, biomedical orthodoxies, and alternative forms and modes of knowledge. The data analysis primarily draws on insights from discursive psychology (Potter and Wetherell 1987), with particular attention given to the matters of attribution of blame, causality, and responsibility (Edwards and Potter 1993). The analysis of visual material was largely inspired by Van Leeuwen's (1993) multi-modal discourse analysis. The analysis is presented in Section 4.

4. Analysis

4.1 Social Movement Narratives around Pre-Illness

The initial experiences of women living with breast cancer have often been described as "relentlessly individualised" and characterized by "stigma, isolation and invisibility" (Klawiter 2004, 865–6). The experiences of breast cancer as an individual journey filled with stigma are further exacerbated by the dominant epidemiological narrative of cancer as a disease occasioned by the self. Heredity, genetics, age, and lifestyle are frequently positioned at the top of the list of risk factors for cancer in biomedical and popular discourses (see for example Centre for Disease Control 2018). Framing cancer as a disease occasioned by the self has important political effects. One such notable effect is that it sets other framings to the background, such as the political framing which focuses for instance on the relationship between inequalities and the incidence of cancer, or the environmental framing which emphasizes the role of environmental contaminants (Brown et al. 2001; Kolker 2004). Furthermore, disease framing has important implications for determining the sites of responsibility and blame, which in turn favors the legitimization of particular tools of control that are deemed appropriate to target the source of blame—i.e. the self in this case. We focus next on social movements around the BRCA gene and breast cancer as a genetic disease to illustrate the characterization work in the dominant epidemiological narratives.

The dominant epidemiological narrative and the previvor

Within the dominant epidemiological narrative, the etiology of the disease is often linked to the individual. Whether it is family, history, genetics, age, lifestyle, breast density, or reproductive history, the construction of breast cancer as “a disease ‘occasioned’ by the self” incriminates the patient in the a etiology of the disease, as Stacey (1997, 175) put it. The genetics narrative reinforces the individualistic construction of both the disease and the experiences of women who are labelled “at genetic risk” for breast cancer. Inheriting a mutation in BRCA1 and BRCA2 is considered to be linked to an increased risk of female breast and ovarian cancers. The BRCA1 and BRCA2 mutations account for about 20 percent of hereditary breast cancer, around 5 to 10 percent of all breast cancers, and approximately 15 percent of all ovarian cancers (Pal et al. 2005; National Cancer Institute 2015). Despite these fairly low figures, breast cancer is probably the most geneticized type of cancer. Furthermore, the labeling of the gene is related to breast cancer only, as BRCA is an acronym for BReast CAncer, and the genes are known as BReast CAncer 1 (BRCA1) and BReast CAncer 2 (BRCA2). This is what led the gene to be commonly known as the breast cancer gene, despite being associated with other types of cancer. The genetic determinism surrounding breast cancer has had dramatic effects with regards to the media coverage of the BRCA gene as well as the social movement narratives surrounding it—with the most notable being the objectification and emphasis of breast cancer as a disease occasioned by the self.

There is a particularly interesting characterization of patients that takes center stage within the geneticized breast cancer movement narratives: the *previvor*. The term previvor was coined on the forum of the online biosocial community FORCE to describe the experiences of women living with a BRCA mutation. We will introduce FORCE in further detail when discussing the role of online biosocial communities as supporting devices for plotting the social movement narrative of the previvor, but let's focus on the characterization of the previvor for now. The FORCE website defines the identifier "previvor" as follows:

> "Cancer previvors" are individuals who are sur*vivors* of a *pre*disposition to *cancer* but who haven't had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. The cancer previvor term evolved from a challenge on the FORCE main message board by . . . a website regular, who posted, "I need a label!" As a result, the term *cancer previvor* was chosen to identify those living with risk. The term specifically applies to the portion of our community which has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer.
>
> The medical community uses the term "unaffected carrier" to describe those who have not had cancer but have a BRCA or other cancer-predisposing mutation. The term applies from a medical perspective, but doesn't capture the experience of those who face an increased risk for cancer and the need to make medical management decisions. Although cancer previvors face some of the same fears as cancer survivors, undergoing similar tests and confronting similar medical management issues, they face a unique set of emotional, medical, and privacy concerns. (FORCE, © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved)

While the term refers to a predisposition to cancer in a broad sense, it is often used to discuss "cancer-predisposing mutations" and the BRCA gene predominantly. The previvor has a predisposition to breast cancer and knows of her propensity. She is in a liminal category of wellness, as she is "neither actually ill (yet) nor fully well" (Lupton 2012, 17). She is said to be empowered to navigate her diagnosis by engaging with biomedical knowledge around genomics. Through this engagement, she is empowered to receive genetic screening, educate herself, and monitor her breasts for malignancies in order to make informed choices that help control her risk to develop cancer. Thus, the previvor represents an empowered risky subject. She is a science-literate patient/consumer who is willing to make use of the resources available to make an "informed choice." The internet has been a driver for the shaping of the "informed/empowered" patient. The plethora of web-based health-related information is said to enable the education of patients, while the online forums provide space for support, information, and story sharing. This process of education, which is primarily concerned with the compliance with biomedical orthodoxy, allows for this form of empowerment of consumers of preventive healthcare services to be possible.

What is striking here is the alignment of empowerment goals with biomedical orthodoxy and individualization trends in healthcare (Geiger and Gross 2017; Geiger 2020), as well as notions of responsibilization and self-care (Beckmann 2013). Later in this analysis, we will explore the original forms of patient empowerment in breast cancer movement narratives, when discussing feminist social movement narratives. Next, we further illustrate the characterization work of the previvor in our analysis of the supporting plotting devices for the dominant epidemiological narrative.

Supporting devices for plotting the social movement narrative of the previvor

Mass media: Mass media has constituted an essential device for plotting the social movement narrative of the *previvor*. There have been several popular figures who have gone public, in the past decade, about their mastectomies (whether curative or preventive). Just to name a few: Christina Applegate, Olivia Newton-John, Lynn Redgrave, Katy Bates, and Sharon Osbourne all announced their medical choices to the public. Sharon Osbourne, for instance, revealed to *Hello!* magazine that she undertook a preventive double mastectomy after discovering that she had "the breast-cancer gene" (Hellomagazine.com 2012). In addition, there was another key piece that sparked a tremendous interest in the BRCA gene. The article was written by the American actress, film director, screenwriter, and author Angelina Jolie, and published in the *New York Times* on May 14, 2013. In her piece entitled "My Medical Choice," Angeline Jolie revealed to the public her decision to undertake a double mastectomy following her diagnosis as a faulty gene carrier. The article sparked enormous interest, both in terms of media coverage and reaction, as well as public interest. The public interest went beyond the revelation of Angelina Jolie onto knowing more about the faulty gene.

The most notable headline that followed Angelina Jolie's article was the "The Angelina Effect," which was the cover of the *Time* on May 27, 2013. The term was initially used to describe the "cultural and medical earthquake" caused by the star's revelation. A study appearing in the journal *Breast Cancer Research* in 2014 revealed that "the Angelina effect" more than doubled the frequency of testing for the BRCA gene in the United Kingdom following the publication of the letter (Evans et al. 2014). Similar studies were conducted in other Western countries such as Australia and Canada, revealing a similar tendency to increased screening (CBC News 2013; Hagan 2013). Another study published in the *British Medical Journal* in 2016 showed that "the Angelina effect" has indeed caused a significant increase in testing, but not in mastectomy rates. The authors argue that the information might not have reached the population that is “really” at risk and just participated in increasing the paranoia surrounding genetic diseases (Desai and Jena 2016). The piece represents an individualized form of activism around the BRCA gene and the risky subject. However, the notoriety and credibility of the narrator definitely increased the impact of the story in this case. As Benford and Snow (2000, 621) put it: “the greater the status and/or perceived expertise of the frame articulator and/or the organization they represent from the vantage point of potential adherents and constituents, the more plausible and resonant the framings or claims.”

Throughout the piece, the dichotomy hope/fear plays an important role in the characterization work of the previvor. The narrative of fear is set from the outset, with metaphors of war such as “MY MOTHER fought cancer for almost a decade and died at 56” (capitalization in original). It is also discernible through metaphors of the invisible, yet omnipresent danger in “living *under the shadow* of cancer” (emphasis added). Another device at the service of this narrative is the use of factual descriptions of risk, with the example of “My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer.” The narrative emphasizes the “reality” of the risk associated with carrying a BRCA gene mutation and the amplitude of the danger accompanying it. This can be seen for example in “I have always told them [her children] not to worry, but the truth is I carry a ‘faulty’ gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.” The previvor is aware of her risk. She is also science-literate and able to make sense of the statistics available to her. In addition, the previvor is fearful of what might happen. The source of fear is a quantified, credible statistic made available to her through genetic screening. The adjective “risky” of the “empowered risky subject” materializes through the quantification and objectification of risk.

Thus, the previvor is fearful of what is yet to come. The prophecy of her fate is written in her character name, and evidenced by "objective" science.

Power and empowerment are also key themes in the letter. These themes are used to set the scene in line with the narratives of fear, in for example "Cancer is still a word that strikes fear into people's hearts, producing a deep sense of *powerlessness*" (emphasis added). They are also positioned as a response to the narratives of danger and fear. The argument of "empowerment"-as-a-solution is visible from the title of the article itself, "My Medical Choice," which signals ownership of medical destiny and the responsibility to preserve the body. The previvor is not only aware of her risk, but also willing and able to make an informed choice based on the options available to her. This can be seen, for instance, in Angelina's statement "once I knew that this was my reality, I decided to be proactive and to minimise the risk as much as I could." The previvor is responsibilized for taking back control over her risk.

The empowerment is visible in the narrative of ownership of the medical destiny and risk reduction. It also transpires through a restitution narrative that is very similar to those present in the survivorship discourse. In narrating her post-reconstructive surgery, Angelina states "they [her children] can see my small scars and that's it. Everything else is *just* Mommy, the same as she always was' (emphasis added). Here, she asserts control over her risk, and thereby her "identity" and "self" through the control of body image by means of reconstitutive surgery. The faulty genes and defective organs are constructed as "other" to the self. What remains of this "other" after the preventive surgery is the "small scars" only. The scars are reminiscent of the defective organ. However, the subject position "Mommy" is stabilized through the qualification of the scars as "small," therefore limiting their effects. This positions stereotypical and gendered responsibilities as central to the decision to preserve the body. The previvor can and should seek to reconstruct her heterofeminine body. Otherwise, she risks losing her womanhood because of the removal of her breasts.

Online biosocial communities: Online spaces constitute another important device for plotting the social movement narrative of the previvor. These spaces include, but are not limited to, forums, blogs, patient support groups, and so on. Their digital nature helps bring together communities that can be geographically dispersed, such as the communities of carriers of BRCA gene mutations. These online spaces often reproduce elements from the discourse of survivorship, which is akin to peri- and post-illness narratives. This is visible through the usage of "branded" breast cancer colors, for example, vivid pink.

While a lot of these spaces focus on patients' support and narratives, some bring together a variety of actors such as healthcare practitioners, genetics and cancer researchers, alongside patient advocacy groups. FORCE constitutes an example of an organization which enrolls several actors around a genetic mutation. Another notable aspect of FORCE is the bridging between the online and offline, as it holds its own annual conference that gathers healthcare practitioners, genetics and cancer researchers, patient advocacy groups and patients, as well as frequently advertising clinical trials for members to enroll in. Rabinow (1992) anticipated the emergence of such collectives, describing them as "biosocial communities." He envisaged that such groups would form around "new truths" produced by the Human Genome Project and outlined the requirements for such movements to materialize. These requirements included the organization of efforts around specific DNA mutations and the mobilization of genetic experts, medical specialists, laboratories, diagnostic technologies, narratives, and support groups. Collectively these features allow previvors to "understand" and deal with an almost determined fate of disease development caused by that mutation (Pender 2012).

While her responsibility is individual, the previvor organizes collectively with other women who share her genetic identity. They gather to support but also monitor each other. Peer monitoring has critical effects on the characterization work. It implicitly sets the stage for protagonists and antagonists within the narrative. While the protagonist/hero is personified in the previvor who is an empowered risky subject, the antagonist/villain manifests in the *irresponsible risky subject*. The irresponsible risky subject does not comply with biomedical rationalities around the dominant epidemiological model. She does not take care of herself as per the guidelines, lacks awareness about her genetic risk and its implications, and exposes herself to known risk factors. In order to legitimize their membership to the collective of previvors, individuals have to avoid falling into the category of the irresponsible risky subject. This was visible in the politics of advice giving and receiving in online forums, where women were carefully crafting a narrative of their stories prior to asking for advice. In the extract below from a forum discussion board dedicated to BRCA-positive women, a participant attempts to legitimize her reluctance to undertake the preventive surgery by establishing a causal link between menopause-inducing surgery and her subsequent ability to provide care for her small children. Such crafting of the narrative was necessary for the forum participant to legitimize questioning biomedical rationalities without being labeled irresponsible.

> I will most definitely ask about breast cancer risk. I have no problem having a mastectomy, to be honest if that's what the doctor recommends. The hysterectomy scares me due to the potential body changes, hormone problems, mood issues, etc. This is mainly because I have small children. If I didn't have kids to take care of, I wouldn't care about that so much either. (Forum participant)

This binary of responsibility has important implications for collective dynamics. The arrangement of characters of a narrative in a binary relationship (antagonist and protagonist), has significant effects on the evaluative and dramatic intensity of the narrative (Jacobs 2002). Such plotting contributes to praising the previvor for her courage and determination to take control over her risk. By the same token, it frames the irresponsible risky subject as negligent and casts her back into the shadow. The spotlight is put on the previvor, which bears similarities to the narrative of survivorship, explored below.

The environmental movement narrative and the cancerogenic pollutant

The environmental movement has challenged biomedical and popular explanations of causality of breast cancer—particularly with regards to an emphasis on personal lifestyle and genetics. At the center of the environmental narrative is the situated understanding of the epidemiology of breast cancer, and a commitment to shed light on the corporate and governmental responsibility in the etiology of the disease. As Rothman (1998, 169) put it: "the social epidemiology of cancer, the role of industrial capitalism, gets glossed over as the cancer moves deeper and deeper inside the individual." The environmental movement attempts to disrupt this ideology by re-emphasizing the role of industrial capitalism.

In order to challenge the dominant epidemiological narrative and destabilize the center of blame, the environmental movement has tackled the scientific approach to researching breast cancer. It has been committed to decentering the biomedical model that focused on individualistic methods for research, treating, and preventing cancer, by drawing attention to the health effects of environmental pollutants. The environmental movement aims to shape both research and policy to a focus on environmental causes of breast cancer, as well as increase public awareness towards these issues. Since its inception in the early 1990s (Zavestoski et al.

2004; Klawiter 2008), the environmental movement has been committed to scrutinizing the effects of cancerogenic pollutants as well as the political, economic, and social structures that allowed such exposures to occur. To this end, the movement has pushed the role of transdisciplinary research models in order to include a broader spectrum of disciplines and actors in the understanding of the epidemiology of breast cancer (Osuch et al. 2012).

Environmental narratives displace the blame and responsibility from its individualized conceptualization within the dominant epidemiological narrative, onto corporations and government structures responsible for the exposure of women to cancerogenic pollutants. By doing so, they debunk the myth of the previvor/empowered risky subject as the solution to preventing breast cancer and expose the complexities of breast cancer causality to the public. Rather than relying on a simplified narrative, such as the case with the dominant epidemiological narrative (Sulik 2014), environmental narratives encourage expert and laypeople alike to acknowledge and explore the intricacies inherent to breast cancer causality and investigate the accountability of corporations and government structures for the exposure of women to cancer-causing agents. Thus, these institutions take the lead villain role within this narrative.

The villain character is overall depicted as dark, mischievous, but also full of mystery. On the one hand, the overall lack of knowledge around environmental contaminants and the causal mechanisms involved in the process participates in reinforcing both dimensions of harm and mystery. The source of harm is lurking in the background. On the other hand, the language used to describe the process of exposure participates in the de/mystification of the character of the villain. The usage of both nominalization and passivation is widespread in the mainstream narratives around the exposure to environmental pollutants. Biomedical narratives focus on discussing the effects of “environmental/chemical exposure,” “individual’s exposure,” “lifetime exposure," and so on. On the other hand, environmental activist narratives specify the focus of the effects of such exposition on their impact on women's livelihoods, as well as vulnerable communities. The two extracts below from Breast Cancer Action's factsheet on breast cancer and the environment highlight such focus.

> We cannot put the burden on consumers to buy "safer" products. Below are examples of some of the ways *we are routinely exposed*. (Emphasis added)

> Disadvantaged populations, especially communities of color, are more likely to be employed in occupations with higher levels of toxic chemical exposure such as manufacturing, agriculture, and certain service sector occupations. They are also more likely to live in more highly contaminated communities. Studies have shown that these unequal exposures result in racial and ethnic differences in chemical body burdens of certain chemicals such as flame retardants, BPA and phthalates.

The usage of nominalization and passivization performs the function of deleting agency and reifying processes (Fowler et al. 1979; Billig 2008). In this case, the process of hiding agency is either intentional (protecting the agent) or constrained by legal boundaries (insufficient evidence to incriminate the agent).

When the evidence against the institutions responsible for the exposure to cancerogenic pollutants is possible, the language adapts, and the layer of mystery of the character unveils to reveal dark and mischievous attributes. For instance in 2018, the organization Earthjustice represented a coalition of health, consumer, and environmental activist organizations in a lawsuit aimed at pressuring the United States Food and Drug Administration (FDA) to prohibit cancerogenic artificial chemicals widely used for food flavoring. The petitioners represented were Breast Cancer Prevention Partners, Center for Environmental Health, Center for Food Safety, Center for Science in the Public Interest, Environmental Defense Fund, Environmental Working Group, Natural Resources Defense Council, and WE ACT for Environmental Justice. The chemicals at issue in the lawsuit are benzophenone, ethyl acrylate, eugenyl methyl ether, myrcene, pulegone, pyridine, and styrene. They are recognized to be widely used to flavor baked goods, ice cream, candy, and so on. The legal document clearly frames the responsibility and failure of the FDA to act on these widely used cancerogenic chemicals. As the senior strategic advisor of Earthjustice states: "consumers cannot identify every ingredient in processed food and they shouldn't have to; we need FDA to do its job and protect our health and welfare."

Supporting devices for plotting the social movement narrative of the cancerogenic pollutant

Seeing that environmental causality is the least mentioned topic in media coverage of breast cancer (Zavestoski et al. 2004), activist campaigns constitute the main terrain for the plotting of the environmental narrative. An example of such campaigns is "Think Before You Pink" launched by Breast Cancer Action (a key organization of feminist cancer activism) launched in 2002. Think Before You Pink campaigns to expose corporations' *pink-washing* practices and encourages consumers to be critical and reflexive about their consumption of pink ribbon products. The campaign targeted the practices within the mainstream breast cancer movement around the pink ribbon, which we explore in depth later in the chapter. It highlighted how some cosmetics product that are part of the pink ribbon campaigns contain known cancerogenic chemicals that can increase the risk of breast cancer.

In 2013 the Breast Cancer Fund and the *Campaign for Safe Cosmetics* reviewed products from the cosmetic giant Revlon. They discovered the presence of toxic and cancerogenic components hormone-disturbing chemicals such as titanium dioxide (a respiratory carcinogen), carbon black, and polyacrylamide (which may contain traces of mammary carcinogen). The products were part of the “Revlon Cares” program, with the slogan “Your lips can save lives.” This is not an isolated incident, as the cosmetics industry has had close ties with the breast cancer mainstream movement, flooding the market with pink ribbon-derived products such as lipstick, nail polish, perfume, and so on. Environmental campaigns, such as Think Before You Pink contribute to the processes of debunking the altruistic façade of certain corporations, as well as centering the corporations and government structures, responsible for the exposure of women to cancerogenic pollutants, as the lead villain character of this narrative.

The overall language of causation is important to the characterization work as well. While dominant epidemiological narratives discuss how cancer cells are made instead of born within (Steingraber 1997), environmental narratives shift the locus of blame to cancer-causing chemicals, as well as the political, economic, and social structures that allowed exposures to the causal agent to occur. This has an effect not only on the characterization of the villain but also on the overall plotting. As such, the hope for deliverance of the disease is no longer narrated in terms of controlling individual risk factors but through the lens of hope for alternative ways of understanding and doing breast cancer care. As Potts (2004, 133) argues, there is “a ‘transformational vision’ of the physical, political, social and economic environments that currently contribute to breast cancer.”

By doing so, environmental narratives propose an ideological repositioning of the very conceptualization of “risk” when discussing breast cancer. Primary cancer prevention is achieved through the identification and elimination of the “causes” or “risk factors” leading to the development of cancer (Fosket 2010). Hence it is crucial to act on the understanding of the processes of calculation and qualification of risk factors for breast cancer, and shift them from a sole focus on the individual to include the collective risk. Next, we move onto analyzing social movement narratives around peri- and post-illness.

4.2 Social Movement Narratives around Peri- and Post-Illness

There have historically been two major distinct approaches to breast cancer activism around the stages of peri- and post-illness. On the one hand, there is activism focused essentially on fundraising. This strand has worked towards the destigmatization of the disease, as well as fundraising for research, screening, and education. It has also contributed strongly to shaping the treatments, the screening methods, and the number of spaces for support available for patients. The mobilization around the pink ribbon is a great example of such activism. However, this type of activism does not necessarily challenge the conventional approaches of its areas of action (research, screening, and education), as has been pointed out by feminist critiques (King 2004; Klawiter 2008). On the other hand, feminist activism has been geared towards political action. The primary purpose of these activists is to destabilize the dominant methods of understanding and acting on breast cancer. Some of the major topics that it addresses are the blurring of the lines between prevention and early detection, as well as issues of access to the marginalized such as poor people, ethnic minorities, disabled, and LGBT women.

The pink ribbon narrative and the survivor

Much of the mainstream narrative around peri-illness sets the scene for the central character of post-illness, that is the "survivor." The mainstream narrative swings between two domains primarily: the body as a battlefield and the hope for a cure. While the former is concerned with the individualized experience, the latter focuses on biomedical victories. Another notable difference is the emotional charge, with the former revolving around fear and the latter around hope. These domains are connected through the umbrella theme of "fight against breast cancer."

Fighting, war, and battlefield constitute essential metaphorical formulations in breast cancer narratives that are central to the plotting and characterization work of the narrative. "War" metaphors are pervasive within cancer narratives (Sontag 1978). The human body becomes the battlefield, and the language of treatment is centered on fighting against a deadly, insidious enemy. The biomedical literature talks about "bombarding" areas of the body with radiation, or treatment aiming at "killing" cancer cells. Metaphors in breast cancer possess an overtly politicized character. The metaphors of war are not purely linguistic embellishments—they actually shape practices. As Annas (1997, 68) states: "military thinking concentrates on the physical, sees control as central, and encourages the expenditure of massive resources to achieve dominance."

However, the "star" of mainstream narratives is incontestably the *survivor*. The domain of battlefield and fight against breast cancer sets the stage for the primary functions of mainstream narrative: the "hope" for a cure which requires funding, and the celebration of biomedical successes and survivors. The survivor represents this figure of hope from within the collective, who "made it" to the other side. The narrative is straightforward: "in order to have more survivors, we need a cure. And in order to find a cure, we need funding!"

Supporting devices for plotting the social movement narrative of the survivor

Marketing campaigns, media coverage, social media: The hope for a cure is the primary driver for research, and the necessity to generate funding in order to achieve this aim. Approaches to generate funding have been very diverse. Some of the primary activities of this movement are focused on generating funding to support research, which will hopefully lead to funding a cure for breast cancer. These activities range from all the pink ribbon-branded products (such as Estée Lauder's Breast Cancer Awareness range), different fundraising races and marathons (such as the Susan G. Komen Foundation's Race for the Cure), or the MacMillan free kits for fundraising events in the United Kingdom. The symbolism of the mainstream breast cancer activist movement through a vivid pink-colored ribbon was a surprising choice at first. Indeed, pink is a color constructed in our contemporary culture as girly, pretty, and healthy, which makes it an odd choice for a disease such as breast cancer that is characterized by a loss of womanhood (King 2006). Nevertheless, the cultural construction of the color pink functions as a device for the materialization of the overly positive tone of the survivorship discourse. The survivor is optimistic, upbeat, and positive. She is also feminine, girly, and bubbly.

The latest campaign from Estée Lauder carries the legacy of this colorful and optimistic tone. The slogan of the fall 2018–19 campaign was "time to end breast cancer," with a trending hashtag on Instagram and Twitter #TimeToEndBreastCancer. We analyzed the "top" posts attached to the hashtag on Instagram (in terms of likes) out of a total of 14,038 posts at the time of writing this chapter (September 2019). Our examination highlighted that alongside the "girly, pretty, and healthy," the glamorous takes center stage. The theme of glamor has been present within breast cancer social movements for over a couple of decades now. For example, in 1996 the *New York Times* qualified breast cancer movements as the "Year's Hot Charity" (Belkin 1996). The same year, the fashion model Linda Evangelista was the face of an important breast cancer awareness campaign. The visual was a head and shoulders shot of Evangelista, coiffed with her iconic haircut at the time, and with her left arm across her chest, covering her breast in a much stylized fashion pose. The narrative of the *New York Times* piece was centered on the willingness of corporations and politicians to support the cause, thanks to the work of activists and survivors on the cultural appeal of breast cancer. Thus, the survivor is glamourous as well. She is appealing culturally and visually, and thus constitutes a figure to be aspired to.

Another notorious example of the mainstream breast cancer social movements is the Breast Cancer Research Stamp that was unveiled by Hillary Clinton in 1998. The slogan of the stamp's campaign was "Fund the fight, find a cure." There are several interesting linguistic devices within this slogan. First of all, the fight is formulated as defined, and the cure as unknown. This is visible through the use of the determiners "the" and "a," respectively. Furthermore, the ordering of the sentence alludes to a causal mechanism between the acts of funding the "fight" and finding a cure; *finding a cure* is constructed as a direct consequence of *funding the fight*. It also constructs the act of *finding a cure* as a collective act.[1] This specific formulation has a function of framing the "right" ways of fighting breast cancer as established and somewhat indisputable, and the cure as a subsequent collective effort that is contingent on the funding of the fight. Such practices construct survivorship and cure as individual acts of philanthropy performed within the arena of consumer culture (King 2004). The survivor is compassionate and demonstrates this virtue through consumption practices.

Feminist critiques have pointed out the profound political effects of the practices surrounding the survivorship movement, and suggest viewing them as an exercise of the fulfillment of obligations as part of the individual's *biological citizenship* (Petryna 2004; Rose and Novas 2005; Kerr et al. 2009). Biological citizenship refers to a new kind of citizenship, which emerged with the rapid progress of biomedical research, genomics, and biotechnology. This citizenship is shaped by new subjectivities, politics, and ethics (Rose and Novas 2005). The new forms of biosocial groups organize around shared biomarkers (the online biosocial communities discussed in this chapter constitute an example of such groups). They stake claims to specific rights while sharing a set of duties and responsibilities as part of their biosocial membership (Kerr et al. 2009). The model figure of the biological citizen is framed as a compassionate consumer, but also a consumer of compassion, who is actively involved in philanthropic programs in an effort to strive to become the *ideal* biological citizen. Survivors are depicted as "courageous, self-responsible, high-order citizens" (King 2004, 489). However, this biological citizen does not challenge established methods of organizing against breast cancer. Her duties are delineated into securing funding, volunteering in events, and participating in clinical trials when applicable. Bell (2014, 62) views biological citizenship within the breast cancer movement as "the subsequent willingness of white, middle-class women with a history of breast cancer to participate in research as part of their perceived duties as 'good' biological citizens."

The feminist narrative and the empowered collective

Parallel to the mainstream breast cancer movement, feminist cancer activism was committed to providing a space for the unheard voices. Taking inspiration from the LGBT movement around AIDS, this movement has been challenging the upbeat discourse of survivorship. The movement has also questioned the centricity of the character "survivor." Indeed, the core principles of the model of AIDS activism was the organization of the fight against the demonization of people affected by AIDS. Yet, the movement was equally dismissive of the trivialization of the condition through overly positive messages. Similarly, feminist cancer activism is critical of the normalization of women bodies who are affected by breast cancer. Whilst the mainstream breast cancer movement promoted unscarred, heterofeminine—albeit cancerized—bodies, feminist activists championed making spaces available for the expression of "alternative images, alternative discourses, and alternative ways of embodying breast cancer" (Klawiter 2008, 169). Indeed, survivorship stories put forward what Frank (1995) calls a "restitution narrative," where the character who re-emerges at the end of the cancer journey is reconstructed in a way to embody heterofeminine notions of womanhood still. Such a scenario is possible thanks to the heroic acts of fighting by the survivor, as well as the technologies of reconstruction. Through technologies of the body such as breast reconstruction, prostheses, wigs, and a careful choice of clothing, the transformation of breast cancer survivors' bodies so that they can mirror the image of healthy ones is not only made possible but encouraged within the survivorship discourse. Feminist activism highlights how the dominant discourse of survivorship actually distorts the ugly realities of the experiences of women living with breast cancer. Instead of the "normalized" body, the feminist movements gave a space for the scarred, the one-breasted, and unbreasted bodies, as well as other non-conformist and marginalized identities. It "celebrated the ongoing struggles of women 'living with cancer'" (Klawiter 2008, 169), rather than the overly positive image of cancer survivors. Thus, the central character of this narrative is the collective affected by the disease. It is a collective that is characterized by its diversity, and hosts many of those deemed "misfits" by society.

The feminist movement dedicated its efforts also to mobilizing support, care, and compassion for women living with cancer, especially the marginalized such as disabled, LGBT, ethnic minorities, and poor women. Mostly, feminist breast cancer activism was committed to a culture of patient empowerment. Empowerment is understood, within this context, as giving voice to expressions of sorrow, anger, grief, and other unpleasant emotions to those who were alienated by the survivorship discourse.

It is crucial at this stage to clearly delineate the meanings and usage of "empowerment" in this context, as it has important implications for the characterization of the "empowered collective," which is very distinct from the "empowered risky subject" (previvor). Empowerment is a polysemic term and has had some contradictory applications, including in the case of breast cancer activism. The initial culture of patient empowerment in feminist activist movements in healthcare did draw on the activist movement within HIV/AIDS in the gay community (Klawiter 2008), and its meaning and applications were linked to the origins of the term. "Empowerment" can be traced to the 1976 publication of "Black Empowerment: Social Work in Oppressed Communities" by Barbara Solomon, where the term started to be formally used in research and social services (Calvès 2009). Its early usage signaled a commitment to giving a voice to the oppressed, enabling them to fight against the dominating voices to which they were subjected. The empowerment was then said to be realized through a movement from a "dominated consciousness" to a "critical consciousness" (Freire 1974). The primary tools described in these early versions were education, particularly in relation to issues of domination, through the deconstruction of dominant constructs such as race and gender. The influences were very diverse, and included Freudian psychology, feminism, the Black Power movement, and Gandhism (Sharma 2008). It was in the mid-1980s that the term empowerment started to gain increasing popularity, promoted by the feminist movement. This influence spread to the field of international development, which constituted a platform for the term to infiltrate policy and program documents pervasively (Calvès 2009). Despite the diverse influences, the focus of empowerment at the time was still addressing issues of inequality and domination; hence its suitable application in the early feminist activist movements for breast cancer. The empowered collective is critical of issues of access associated with structural inequalities. They are also motivated by the anger resulting from the inequality and injustice that some of their members might face. Furthermore, they are skeptical of the mainstream movements and their potential complicity with structures of domination.

Supporting devices for plotting the social movement narrative of the empowered collective

Visual art, memoirs, and politics: Visual art, memoirs, and mass media were strong mediums for the dissemination of feminist movement narratives. One of the most notable examples is the portrait of the breast cancer activist and artist Matuschka, which made quite an impact when it featured in the *New York Times Magazine* in 1993. The image was a self-portrait and clearly displayed a mastectomy scar in the original location of her right breast. The top-right part of the dress was cut in such a way as to make a statement with this visual. The headline reads: "You Can't Look Away Anymore: The Anguished Politics of Breast Cancer" (Ferraro 1993). The narrative of the article was very much influenced by feminist activism, addressing issues of prevention, public awareness, as well as the linkages between environmental contaminants and disease incidence rates. The tone of the image and article contrasts dramatically with the title discussed earlier proclaiming breast cancer as the "year's hot charity," which appeared only three years later in the *New York Times Magazine* (Belkin 1996). The previous image of the scarred body, which was described by some readers as "shock therapy" (Anonymous 1993), left the space to a photograph of Linda Evangelista analyzed in the previous section.

The self-portrait of Matuschka entitled "Beauty out of Damage" was part of a movement of visual art which contributed to the visibility of the struggles of women living with breast cancer from the 1970s to the 1990s. One of the most notable examples of that era is a portrait of the American poet Deena Metzger exhibiting a tattooed mastectomy scar. The poster featured a photograph taken by Hella Hammid and a poem written by Deena Metzger. We present a short extract from the poem, which features in Metzger's book *Tree: Essays and Pieces* (1997):

> I am no longer afraid of mirrors where I see the sign of the amazon, the one who shoots arrows.
>
> There was a fine red line across my chest where a knife entered, but now a branch winds about the scar and travels from arm to heart.

The theme of war and battle are central to Metzger's poem (and photograph). However, their usage is different from mainstream breast cancer movements. In this instance, the metaphors of war function as devices for the celebration of the scarred and unbreasted female body. This inclusion of alternative cancerous bodies helps us relate to the struggle of women living with cancer, which contrasts with the overly optimistic mainstream narrative that focused on survivorship and the reconstruction of the heteronormative. Other examples of visual art as a medium for representing breast cancer include "Marked Up for Amputation" by British educational photographer Jo Spence (1995), and the collection of painting *Breast Cancer Journal* by Holli Sigler (1999) illustrating her experience of living with breast cancer. The empowered collective does not shy away from the ugly truths of living with breast cancer. Instead, they mobilize the emotions of anger that can stem from looking at these realities, and utilize them as fuel to organize action.

Alongside visual art, breast cancer memoirs have been a popular medium for representing the struggles of living with breast cancer. Amongst the most notable contributions are Rose Kushner's *Breast Cancer: A Personal History and an Investigative Report* (1975), Susan Sontag's *Illness as Metaphor* (1978), and André Lorde's *The Cancer Journals* (1980). They have addressed topics such as the environmental causes of breast cancer, the stigmatization of cancer patients, and the struggle of minorities living with cancer such as those of black women and LGBT women. Breast cancer feminist narratives have also challenged hegemonic models of communication about cancer such as the military metaphors in cancer care, as well as the obsession with the restitution of the heteronormative body through reconstructive surgery (Frank 1995). Moreover, these narratives confronted the corporate complicity with mainstream cancer activism, and more recently challenged genetic testing on the grounds of ethics, access, and efficacy (DeShazer and Helle 2014). The empowered collective embraces alternative forms of representation. They mobilize their anger for a fight for broader access. The fight is collective, which contrasts with the survivor's fight against a disease occasioned by the self. It is a fight against the political and social structures that generate and reproduce inequalities of access to healthcare.

5. Discussion

To start our discussion, we summarize in Table 7.1 the list of dramatis personae as featured in the social movement narratives analyzed in this chapter. As demonstrated throughout our analysis, social movement narratives around breast cancer have been instrumental in shaping the experiences of women living with or at risk of breast cancer, as well as the modes of funding and researching the disease. There are some notable differences in terms of characterization between the various movement narratives as highlighted in Table 7.1. We further discuss these differences and their effects. For clarity, we will refer to the narratives around the survivorship and previvorship movements as mainstream narratives and those around the environmental and feminist movements as alternative narratives.

<COMP: INSERT TABLE 7.1 NEAR HERE>

5.1 The Plotting of the Central Characters and Their Emotional Appeal

While mainstream narratives center the plot around the heroes (the “previvor” and the “survivor”), the alternative narratives focus on fleshing out a detailed account of the experiences of people living with breast cancer and their struggles. These plotting strategies have important implications for the emotional charge of the narratives.

On the one hand, mainstream narratives’ emotional registers revolve around the binary of fear and hope. At the stage of pre-illness, the domain of fear is constructed around the quantification and objectification of risk. In this case, the “previvor” represents the heroic figure of hope who controls her fate by engaging with biomedical rationalities of prevention. At the stages of peri- and post-illness, the domain of fear is constructed around the narratives of war against the disease. In this instance, the domain of hope materializes around (1) the hope for a cure, which is yet to come and requires a generation of funding, and (2) the central character of the narrative, who is the “survivor”—a heroic figure of hope who won the battle against cancer. The emotional binary fear–hope serves as a disciplining tool and a mechanism of social control, which outlines the rights and duties of the biological citizen.

On the other hand, alternative narratives’ emotional registers are centered around anger. The anger results from witnessing the experiences of these women affected and/or at risk by breast cancer and their various struggles: struggle in dealing with the disease, struggle to access information and/or care, struggle of their bodies being controlled and judged, and so on. As Polletta (2002) argues, stories provoking emotions of disgust or anger can successfully lead to increasing commitment and mobilizing collective action. In this case, the anger is directed towards the corporate and governmental structures that are responsible for (1) allowing the exposure to cancerogenic pollutants, and (2) exacerbating the inequalities of access to cancer care. Thus, the appeal to emotion in social movement narratives around breast cancer not only contributes to mobilizing collective action but also functions as a disciplining tool for the biological citizen.

5.2 The Characterization of the Villain

While the villain is constructed as a complex character in alternative narratives, its mainstream counterpart is rather simplified. Indeed, the alternative narratives highlight the complexities of the causality of breast cancer and incriminate multiple actors in the process: the alternative narratives refocus the story of causality onto the cancerogenic pollutants, as well as the political, economic, and social structures responsible for not only allowing the exposure to the causal agent but also exacerbating the inequalities of access to cancer care. On the other hand, mainstream narratives rely primarily on the usual biomedical script of cancer as a disease occasioned by the self.

This characterization serves as an essential plot device for the construction of the solution to the problem in each narrative, thereby shaping the modes through which collective action is mobilized. The characterization of the villain, in alternative narratives, draws on multiple sources of knowledge. Similarly to the causal explanation (and subsequently the character), the solution is complex. It involves (1) transdisciplinary research models which include a broader spectrum of disciplines and actors in the understanding of the epidemiology of breast cancer, (2) development of embodied, situated knowledge of the experiences of the different groups of women at risk and/or affected by breast cancer (in particular minority groups), and (3) holding accountable the corporate and governmental structures that are responsible for allowing the exposure to cancerogenic pollutants, and exacerbating the inequalities of access to cancer care. Overall, the solution is framed around the hope for a transformational vision that will shape the breast cancer environment.

On the other hand, the characterization of the villain in the mainstream narratives derives its explanatory power from biomedical rationalities and returns to biomedical rationalities for a solution. In the stage of pre-illness, this solution is represented in the form of wider genetic testing and preventive procedures. In the stages of peri- and post-illness, it materializes in the search for a cure. In order to achieve these aims, there is a need for (1) the compliance of the biological citizen to biomedical rationalities, and (2) the compassion of the biological citizen in supporting the generation of funding for biomedical research to find a cure. While hardly visible in the mainstream narratives, pharmaceutical and biotech companies hold an important role in this process. As discussed in Section 3, breast cancer is a lucrative disease and holds a firm top spot in terms of research and development investment and pipeline size. Indeed, the hope for a cure is a powerful device in generating research funding. As described by Hopkins and colleagues (2007, 21), the claims underpinning the biotechnology revolution to attract funding are "rhetorical devices employed to generate the necessary, political, social and financial capital to allow perceived promise to emerge."

As for the emotional appeal, this plot device has important implications for social movement narratives around breast cancer in not only mobilizing collective action but also as a disciplining tool for the biological citizen. In addition, the complexity of characterization of the villain can demand additional cognitive effort from the audience to make sense of the narrative, but also affects how emotions are mobilized. As Fine (2002, 244) argues, the "cognitive component of stories—their analytical structure—allows audiences to generalize from their emotions to the worldview that the narrator is promoting implicitly or explicitly and to make explicit the boundaries that are otherwise implicit through the placements of heroes and villains in the narratives."

5.3 The Individualization/Collectivization Dynamics

The movement narratives explored in this chapter highlight different, and sometimes antagonist, individualization and collectivization dynamics. On the one hand, the mainstream movement narrative puts the onus on the individual, despite encompassing universalized identity categories (the survivor and the previvor). On the other hand, the alternative movement narratives create a collective of a diverse range of individual experiences of being at risk of and/or living with breast cancer.

While the identity categories of the survivor and the previvor are universalized and the survivorship narrative is collective, the social movement narratives surrounding these characters put the onus back onto the individual. They do so through the recourse to two devices: the narrative of the responsible biological citizen and the hopeful configuration of the narrative of breast cancer activism. First, the mainstream social movement narratives exacerbate the construction of breast cancer as a disease occasioned by the self. Framing breast cancer as a disease occasioned by the self has important implications for determining the sites of responsibility and blame, which in turn favors the legitimization of particular tools of control that are deemed appropriate to target the source of blame—i.e. the self in this case. While destabilizing the control of the body by conceptualizing a part of it as defective, genetics discourse fosters a sense of control simultaneously, by making additional options available to reduce uncertainty. Thus, genetic information is constructed as empowering individuals through the catering of new choices for health risk management (Hallowell and Lawton 2002). Health risk management becomes an individual moral responsibility, and failing to comply with the ethical practices to "fix" the body and control the risk is, therefore, constructed as moral negligence (Lupton 1995). This process of destabilization has various implications, including the characterization of the various actors within the associated social movement narratives. More than ever, the individual takes center stage with the multiple role of "victim," "hero," and "villain" through embodying the characters "risky subject," "empowered risky subject," and "irresponsible risky subject," respectively.

Second, the usage of positive messages and metaphors in breast cancer narratives can have important implications for the collectivization/individualization dynamics of the mainstream movement narrative. First of all, and as King (2004) argues, an overly optimistic and hopeful configuration of breast cancer has an effect on diminishing the rage of activists particularly with regards to the activism against environmental contaminants, leaving a hereditary/individualist view dominant. Second, the narrative of survivors can alienate women who are going through the side effects of breast cancer treatments, a poor prognosis, or dying from breast cancer (Kaiser 2008). As much as they can be inspiring and uplifting, success stories do not work for everybody, especially for people going through the disease. Their primary function is more geared towards the celebration of the advances and heroism of biomedical sciences, as well as the different actors involved in making the success story a reality. As Ehrenreich (2001, 48) put it: "In the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the 'survivors' who merit constant honor and acclaim. They, after all, offer living proof that expensive and painful treatments may in some cases actually work." Finally, the survivorship discourse reconfigures activists' actions through a consumer culture lens (for example, through pushing for the consumption of pink ribbon-branded products as a sign of compassion). Such reconfiguration contributes to reinforcing the processes of individualization, through attaching responsibilities of consumption to the biological citizen. The individualized tone of this movement narrative both reproduces and is complicit in reinforcing the individualization trends in healthcare (Geiger, this volume)—particularly in the realm of geneticized illnesses (Weiner et al. 2017). The fight is performed through individual acts of hopeful and "positive" consumption, rather than collective rage.

On the other hand, the alternative movement narratives put forward a collective narrative of breast cancer etiology and experience. As discussed in our analysis, these narratives are concerned with the representation of the ugly realities of the experiences of women at risk and/or living with breast cancer. The narratives create a space for representing a variety of representations of the embodiment of breast cancer, including those of non-conformist and marginalized identities. By doing so, alternative movement narratives around breast cancer create a collective out of the diverse individual experiences they represent.

As demonstrated throughout our analysis, alternative movement narratives propose an ideological repositioning of the very conceptualization of "risk" when discussing breast cancer. This repositioning has important effects on shifting the epidemiological narrative of breast cancer from a sole focus on the individual to include collective concerns. It is important to note that this shift does not deny or reduce the significance of the embodied experience of being at risk of breast cancer, such as the genetic risk linked to carrying a "faulty" BRCA gene. However, it expands and challenges this view to shed light on alternative scenarios and conceptualizations of risky bodies, as well as the possible entwinement between "faulty" nature and man-made pollutants. Thus, alternative movement narratives contribute to reframing breast cancer etiology as a public health concern rather than a set of personal risk-management strategies promoted and supported by various corporate market actors, such as those focused solely on diet, exercise, genetic screening, and so on.

Furthermore, the ideological repositioning performed by alternative movement narratives has some further implications for the perfect "docile" biological citizen. This persona is morphed into a collective of citizens who mobilize their knowledge and expertise as activists. This new collective entity comes into being with the hope to produce embodied, situated knowledge that can shape our causal understanding of breast cancer, promote alternative modes of prevention, and contribute to policy formulation.

References

Annas, G. (1997), Reframing the Debate on Health Care Reform by Replacing Our Metaphors, in John Glasser and Ronald Hamel (eds) *Three Realms of Managed Care: Societal, Institutional, Individual* (67–75), Sheed and Ward.

Anonymous (1993), You Can't Look Away Anymore, *New York Times Magazine*, September 5. Available at: http://www.nytimes.com/1993/09/05/magazine/l-you-can-t-look-away-anymore-049693.html?mcubz=1.

Bakhtin, M. (1973), Problems of Dostoevsky's Poetics, trans. R. W. Rotsel, Ardis.

Beckmann, N. (2013), Responding to Medical Crises: AIDS Treatment, Responsibilisation and the Logic of Choice, *Anthropology and Medicine*, 20:2, 160–74.

Belkin, L. (1996), How Breast Cancer Became This Year's Hot Charity, *New York Times Magazine*, December 22, 40–6, 55–6.

Bell, K. (2014), The Breast-Cancer-ization of Cancer Survivorship: Implications for Experiences of the Disease. *Social Science and Medicine*, 110, 56–63.

Benford, R.D., and Snow, D. A. (2000), Framing Processes and Social Movements: An Overview and Assessment, *Annual Review of Sociology*, 26, 611–39.

Billig, M. (2008), The Language of Critical Discourse Analysis: The Case of Nominalization, *Discourse and Society*, 19:6, 783–800.

Boje, D. (2001), *Narrative Methods for Organization and Communication Research*, Sage.

Brown, P., Zavestoski, S. M., McCormick, S., Mandelbaum, J., and Luebke, T. (2001), Print Media Coverage of Environmental Causation of Breast Cancer, *Sociology of Health and Illness*, 23:6, 747–75.

Calvès, A. (2009), “Empowerment”: généalogie d'un concept clé du discours contemporain sur le développement, *Revue Tiers Monde*, 200:4, 735–49.

CBC News (2013), “Angelina Jolie Effect” Sparks Surge in Genetic Testing: Test Referrals up by 80 Per Cent in Nova Scotia, *CBC News*, October 17. Available at: http://www.cbc.ca/news/canada/nova-scotia/angelina-jolie-effect-sparks-surge-in-genetic-testing-1.2101587.

Centre for Disease Control (2018), What Are the Risk Factors for Breast Cancer? Available at: https://www.cdc.gov/cancer/breast/basic_info/risk_factors.htm.

Clarke, J., and Everest, M. (2006), Cancer in the Mass Print Media: Fear, Uncertainty and the Medical Model, *Social Science and Medicine*, 62:10, 2591–600.

Czarniawska, B. (1997), *Narrating the Organisation: Dramas of Institutional Identity*, University of Chicago Press.

Davis, J. E. (2002), Narrative and Social Movements: The Power of Stories, in Joseph Davis (ed.) *Stories of Change: Narrative and Social Movements* (10–34), State University of New York Press.

Derrida, J. (1979), Living on: Borderlines, in Harold Bloom (ed.) *Deconstruction and Criticism* (75–176), London: Continuum.

Desai, S., and Jena, A. (2016), Do Celebrity Endorsements Matter? Observational Study of BRCA Gene Testing and Mastectomy Rates after Angelina Jolie's *New York Times* Editorial, *British Medical Journal*. Available at: http://dx.doi.org/10.1136/bmj.i6357.

DeShazer, M. K., and Helle, A. (2014), Theorising Breast Cancer: Narrative, Politics, Memory, *Tulsa Studies in Women's Literature*, 32–3:2, 7–23.

Edwards, D., and Potter, J. (1993), Language and Causation: A Discursive Action Model of Description and Attribution, *Psychological Review*, 100:1, 23–41.

Ehrenreich, B. (2001), Welcome to Cancerland: A Mammogram Leads to a Cult of Pink Kitsch, *Harper's Magazine*, 43–53.

Evans, G. R., Barwell, J., Eccles, D. M. et al. (2014), The Angelina Jolie Effect: How High Celebrity Profile Can Have a Major Impact on Provision of Cancer Related Services, *Breast Cancer Research*, 16:442. Available at: http://breast-cancer-research.com/content/16/5/442.

Ferraro, S. (1993), You Can't Look Away Anymore: The Anguished Politics of Breast Cancer, *New York Times Magazine*, August 15, 25–27, 58–60.

Fine, G. A. (2002), The Storied Group: Social Movements as "Bundle of Narratives," in Joseph Davis (ed.) *Stories of Change: Narrative and Social Movements* (229–45), State University of New York Press.

Fosket, J. (2010), Breast Cancer Risk as Disease: Biomedicalizing Risk, in A. Clarke, L. Mamo, J. R. Fosket, J. Fishman, and J. Shim (eds) *Biomedicalization: Technoscience Health and Illness in the US* (331–42), Duke University Press.

Fowler, R., Hodge, B., Kress, G., and Trew, T. (1979), *Language and Social Control*, Routledge.

Frank, A. (1995), *The Wounded Storyteller*, University of Chicago Press.

Freire, P. (1974), *Education for Critical Consciousness*, Sheed and Ward.

Gabriel, Y. (2000), *Storytelling in Organisations: Facts, Fictions and Fantasies*, Oxford University Press.

Geiger, S. (2020), Silicon Valley, Disruption, and the End of Uncertainty, *Journal of Cultural Economy*, 13:2, 169–84.

Geiger, S. and Gross, N. (2017), Does Hype Create Irreversibilities? Affective Circulation and Market Investments in Digital Health, *Marketing Theory*, 17:4, 435–54.

Hagan, K. (2013), Breast Cancer: Genetic Testing Soars after Angelina Jolie's Double Mastectomy, *Sydney Morning Herald*, November 13. Available at: http://www.smh.com.au/national/health/breast-cancer-genetic-testing-soars-after-angelina-jolies-double-mastectomy-20131112-2xelm.html.

Hallowell, N., and Lawton, J. (2002), Negotiating Present and Future Selves: Managing the Risk of Hereditary Ovarian Cancer by Prophylactic Surgery, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6:4, 423–43.

Hellomagazine.com 2012. Sharon Osbourne: "Why I Chose to Have a Double Mastectomy," *HELLO!*, November 5. Available at:

http://www.hellomagazine.com/celebrities/2012110523415/sharon-osbourne-doule-mastectomy-exclusive/.

Hopkins, M. H., Martin, P. A., Nightingale, P., and Kraft, A. (2007), The Myth of the Biotech Revolution: An Assessment of Technological, Clinical and Organisational Change, *Research Policy*, 36, 566–89.

Hopkinson, G. (2015), How Stories Make It: Antenarrative, Graffiti and Dead Calves, in Michal Izak, Linda Hitchin, and David Anderson (eds) *Untold Stories in Organisations* (285–317), Routledge.

Izak, M. (2014), A Story-in-the-Making: An Intertextual Exploration of a Multivoiced Narrative, *Tamara: Journal of Critical Organization Inquiry*, 12:1, 41–57.

Jacobs, R. N. (2002), The Narrative Integration of Personal and Collective Identity in Social Movements, in Melanie Green, Jeffrey Strange, and Timothy Brock (eds) *Narrative Impact: Social Cognitive and Foundations* (205–28), Psychology Press.

Jolie, A. (2013), My Medical Choice, *New York Times*, May 14. Available at: http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html.

Jones, Y. (2010), Peeling the Body, PhD Thesis, University of Southampton.

Kaiser, K. (2008), The Meaning of the Survivor Identity for Women with Breast Cancer, *Social Science and Medicine*, 67, 79–87.

Kerr, A., Woods, B., Nettleton, S., and Burrows, R. (2009), Testing for Food Intolerance: New Markets in the Age of Biocapital, *BioSocieties*, 4:1, 3–24.

King, S. (2004), Pink Ribbons Inc: Breast Cancer Activism and the Politics of Philanthropy, *International Journal of Qualitative Studies in Education*, 17:4, 473–92.

King, S. (2006), *Pink Ribbons, Inc: Breast Cancer and the Politics of Philanthropy*, University of Minnesota Press.

Klawiter, M. (2004), Breast Cancer in Two Regimes: The Impact of Social Movements on Illness Experience, *Sociology of Health and Illness*, 26:6, 845–74.

Klawiter, M. (2008), *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*, University of Minnesota Press.

Kolker, E. S. (2004), Framing as a Cultural Resource in Health Social Movements: Funding Activism and the Breast Cancer Movement in the US 1990–1993, *Sociology of Health and Illness*, 26:6, 820–44.

Kushner, R. (1975), *Breast Cancer: A Personal History and an Investigative Report*, Harcourt Brace Jovanovich.

Lorde, A. (1980), *The Cancer Journals*, Spinsters Ink.

Lupton, D. (1995), *The Imperative of Health: Public Health and the Regulated Body*, Sage.

Lupton, D. (2012), *Medicine as Culture*, Sage.

Metzger, D. (1997), *Tree: Essays and Pieces*, North Atlantic Books.

National Cancer Institute, 2015. BRCA1 and BRCA2: Cancer Risk and Genetic Testing. Available at: https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet.

Olsen, K. A. (2014), Telling Our Stories: Narrative and Framing in the Movement for Same-Sex Marriage, *Social Movement Studies*, 13:2, 248–66.

Osuch, J. R., Silk, K., Price, C., Barlow, J., Miller, K., Hernick, A., and Fonfa, A. (2012), A Historical Perspective on Breast Cancer Activism in the United States: From Education and Support to Partnership in Scientific Research, *Journal of Women's Health*, 21:3, 355–62.

Pal, T., Permuth-Wey, J., Betts, J. et al. (2005), BRCA1 and BRCA2 Mutations Account for a Large Proportion of Ovarian Carcinoma Cases, *Cancer*, 104:12, 2807–16.

Pender, K. (2012), Genetic Subjectivity in Situ: A Rhetorical Reading of Genetic Determinism and Genetic Opportunity in the Biosocial Community of FORCE, *Rhetoric and Public Affairs*, 15:2, 319–49.

Petryna, A. (2004), Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations, *Osiris*, 19, 250–65.

Pharmaprojects (2019), *Pharma R&D: Annual Review 2019*, Informa.

Polkinghorne, D. (1988), *Narrative Knowing and the Human Sciences*, State University of New York Press.

Polletta, F. (1998), Contending Stories: Narrative in Social Movements, *Qualitative Sociology*, 21:4, 419–46.

Polletta, F. (2002), Plotting Protest: Mobilising Stories in the 1960 Student Sit-Ins, in Joseph Davis (ed.) *Stories of Change: Narrative and Social Movements* (35–56), State University of New York Press.

Potter, J., and Wetherell, M. (1987), *Discourse and Social Psychology: Beyond Attitudes and Behaviour*, Sage.

Potts, L. K. (2004), An Epidemiology of Women's Lives: The Environmental Risk of Breast Cancer, *Critical Public Health*, 14: 2, 122–47.

Rabinow, P. (1992), Artificiality and Enlightenment: From Sociobiology to Biosociality, in Jonathan Crary and Sanford Kwinter (eds) *Incorporations* (234–52), Zone Books.

Rose, N. and Novas, C. (2005), Biological Citizenship, in A. Ong and S. J. Collier (eds) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems* (439–63), Blackwell Publishing.

Rothman, K. B. (1998), *Genetic Maps and Human Imagination*, New York: W. W. Norton.

Sharma, A. (2008), *Logics of Empowerment: Development, Gender, and Governance in Neoliberal India*, University of Minnesota Press.

Sigler, H. (1999), *Breast Cancer Journal*, Hudson Hills Press.

Sontag, S. (1978), *Illness as Metaphor*, Farrar, Strauss and Giroux.

Spence, J. (1995), *Cultural Sniping: The Art of Transgression*, Routledge.

Stacey, J. (1997), *Teratologies: A Cultural Study of Cancer*, Routledge.

Steingraber, S. (1997), *Living Downstream: An Ecologist Looks at Cancer and at the Environment*, Addison Wesley.

Sulik, G. (2014), #RETHINKPINK: Moving beyond Breast Cancer Awareness SWS Distinguished Feminist Lecture, *Gender and Society*, 28: 5, 655–78.

Van Leeuwen, T. (1993), Genre and Field in Critical Discourse Analysis: A Synopsis, *Discourse and Society*, 4:2, 193–223.

Weiner, K., Martin, P., Richards, M., and Tutton, R. (2017), Have We Seen the Geneticisation of Society? Expectations and Evidence, *Sociology of Health and Illness*, 39:7, 989–1004.

Willig, C. (2011), Cancer Diagnosis as Discursive Capture: Phenomenological Repercussions of Being Positioned within Dominant Constructions of Cancer, *Social Science and Medicine*, 73, 897–903.

Zavestoski, S., McCormick, S., and Brown, P. (2004), Gender, Embodiment, and Disease: Environmental Breast Cancer Activists' Challenges to Science, the Biomedical Model, and Policy, *Science as Culture*, 13:4, 563–86.

Table 7.1 Summary of the dramatis personae featured in the social movement narratives analyzed

	Pre-illness		**Peri- and post-illness**	
	Mainstream	**Environmental**	**Mainstream**	**Feminist**
Villain	The faulty gene Irresponsible risky subject	Corporate and governmental structures that allow exposure to cancerogenic pollutants	Heredity/nature Individuals and organizations not supporting funding for research	Corporate and governmental structures that exacerbate inequalities of access to cancer care
Victim	Risky subject	Collective at risk of the disease	Individuals affected by the disease	Collective affected by the disease
Hero	Previvor	Transdisciplinary research	Survivor Docile biological citizen	Empowered collective

---

[1] It is interesting to note how certain prominent industry actors, such as pharmaceuticals and biotech companies, disappear behind the collective "we"—despite being highly interested parties!