

Distribution Agreement

In presenting this thesis as a partial fulfillment of the requirements for a degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to achieve, make accessible, and display my thesis in whole or in part in all forms of media, now or hereafter now, including display on the World Wide Web. I understand that I may select some access restrictions as part of the online submission of this thesis. I retain all ownership rights to the copyright of these. I also retain the right to use in future works (such as articles or books) all or part of this thesis.

Pamela Chopra Beniwal

April 10, 2023

The Effect of Commercialization, Militarization, and Stigmatization of the Breast Cancer
Awareness Movement on Breast Cancer Patients

by

Pamela Chopra Beniwal

Dr. Melvin J. Konner

Advisor

Anthropology and Human Biology

Dr. LaTonia Taliaferro-Smith

Committee Member

Dr. Robert Paul

Committee Member

Dr. Kathryn Bouskill

Committee Member

2023

The Effect of Commercialization, Militarization, and Stigmatization of the Breast Cancer
Awareness Movement on Breast Cancer Patients

By

Pamela Chopra Beniwal

Dr. Melvin J. Konner

Advisor

An abstract of

a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Science with Honors

Anthropology and Human Biology

2023

Abstract

The Effect of Commercialization, Militarization, and Stigmatization of the Breast Cancer Awareness Movement on Breast Cancer Patients

By Pamela Chopra Beniwal

The purpose of the current study was to investigate the impact of symbols, vernacular, and discourse associated with and used regarding the Breast Cancer Awareness Movement as well as how these social devices impact breast cancer patients. An initial Likert Survey was used to assess general knowledge and criticism of the BCAM in $N=161$ female breast cancer patients. An additional ethnographic interview was conducted with eight of the survey respondents two weeks post-survey to further understand the involvement of the BCAM and to gain a deeper understanding of the patient experience with Breast Cancer Awareness, including its strength, pitfalls, and areas for improvement. The interviews were conducted on Zoom and MaxQDA was used to analyze the Zoom-generated audio transcripts for outstanding themes. According to the Likert survey, all respondents were aware of the BCAM, 89% indicated that it provided them a source of social support, and 86% indicated that they have purchased pink ribbon merchandise. 80% of respondents indicated that they believed “pink ribbon” themed merchandise is helpful and 79% of respondents indicated that they were at least partially critical of the Breast Cancer Awareness Movement. The results of the ethnographic interviews indicated that the women with breast cancer interviewed were critical of the use of the pink ribbon as a marketing tool for products that may contain carcinogens and products that have little to no palliative benefit. Patients diagnosed with more aggressive and difficult-to-treat cancers appear more critical of militant terminology used in BCA discourse. All patients interviewed were critical of the representation of breast cancer patients in advertisements and the BCA hyperfeminine narrative. These results indicate that there are several problem areas associated with the discourse and funding distribution of the BCAM, and that surveying the populations for which the movement advocates may illuminate solutions and improvements such that the needs of breast cancer patients are better addressed.

The Effect of Commercialization, Militarization, and Stigmatization of the Breast Cancer
Awareness Movement on Breast Cancer Patients

By

Pamela Chopra Beniwal

Dr. Melvin J. Konner

Advisor

A thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Science with Honors

Anthropology and Human Biology

2023

Acknowledgements

I would like to dedicate this project to my mother, who introduced me to both the positive and negative sides of the Breast Cancer Awareness Movement but also demonstrated to me from a very early age what true strength and work ethic are. I would like to thank my former research mentor and current committee member, Dr. LaTonia Taliaferro-Smith, who introduced me to Triple-Negative Breast Cancer research and enlightened me on the academic critiques of cancer research and the disparities that continue to pervade breast cancer patients, especially minorities. This introduction to breast cancer research was crucial to my interest in oncology and my passion for breast cancer, and I am grateful that she enlightened me with the knowledge and tools to pursue such a passion. I would like to thank my faculty advisor, Dr. Melvin J. Konner, who was the first to believe in my project idea and gave me the resources and confidence to make this project a reality, and whom I consider a kindred spirit through our shared experiences and passion for the themes pursued in this study. I would also like to thank Ms. Heather Carpenter for her assistance in the initial stages of my project and continuous and valuable guidance throughout my years pursuing anthropology as my field of study. She was and continues to be an essential resource for the department and a warm and welcoming resource to whom I have turned for help countless times in the past few years. I would like to thank my former professor and current committee member, Dr. Robert Paul, both for introducing me to the impact and importance of ethnography as an art form and research tool, and for his kindness and understanding of my extenuating circumstances when I was his student. He served as a calming presence and a mentor when I was in a fragile state of mind and continued to support me as I grew from my experiences and decided to use them as inspiration for my senior thesis. Lastly, I would like to thank Dr. Kathryn Bouskill whose dissertation *The Globalization of the Breast Cancer Awareness Campaign in Austria, 2012-2014* inspired and influenced my project. Her work on Breast Cancer Awareness demonstrated to me the possibility of pursuing a critique of BCA as a senior thesis and provided me with a visualization of how an investigative critique might look like. Without her guidance, this project would have never left the ground, and I hope this study serves as a continuation of her academic legacy.

Table of Contents

1. Personal Statement and Motivations.....	1
2. Introduction	
a. Rationale and Relevance.....	4
b. Background and Literature Review.....	5
c. Experimental Approach.....	17
3. Methods	
a. Study Design.....	19
b. Quantitative Measures: 5 Point Likert Survey.....	19
c. Qualitative Measures: Interviews.....	21
4. Results	
a. Quantitative Data Analysis (Figures 1-14).....	24
b. Qualitative Data Analysis (Table 1).....	33
5. Discussion	
a. The Commercialization of the Pink Ribbon and Capitalist Influence on the BCAM.....	52
b. The Militarization of Terminology Used in Breast Cancer Discussions and Discourse.....	55
c. Stigmatization due to the Breast Cancer Awareness Movement.....	57
d. Solutions.....	59
e. Study Limitations.....	62
6. Concluding Remarks.....	65
7. Works Cited.....	67
8. Appendix.....	70

1. Personal Statement and Motivations

Before delving into the existing literature on the stigmatization, militarization, and commercialization of breast cancer and the Breast Cancer Awareness Movement (BCAM), I would like to discuss why I am pursuing this topic and what I hope to gain from this project. My mother was diagnosed with triple-negative breast cancer (TNBC) in 2016. In the breast cancer community, this diagnosis is often viewed as a death sentence because there is no targeted treatment available for TNBC patients. As a result, the documented prognosis and survival rates are quite poor. I observed throughout my mother's treatment how she interacted with the rest of the breast cancer community as well as symbols of breast cancer. While she always appreciated the general support that the pink ribbon and the BCAM provided, I noticed that she never openly shared that she was a patient, even around others with breast cancer. When I asked her about it, she explained that, unless one has TNBC, it's difficult to understand her unique outlook on the disease. Breast cancer, being the most common cancer in women, has had extensive research invested into developing treatments for most patients. When you receive a TNBC diagnosis, however, things are different. She said that the idea of "survivors" is more fitting for patients with treatment options because it places the agency of the disease in the hands of the patients when, in her case, it most certainly was not. "That's why", she said, "it has been difficult to attend the breast cancer walks and find support within the community."

After that conversation, I started paying more attention to how she interacted within the sphere of breast cancer discourse. She always liked cute things like toy dogs and teddy bears, yet I never saw one pink ribbon-branded stuffed animal enter our house. There were no BCAM endorsed Estee Lauder or other makeup products in her vanity box and no medals from Susan G.

Komen's Walk for the Cure or the American Cancer Society Breast Cancer Awareness month 5K adorned her personal spaces. She did donate to funds for breast cancer research and endorse breast cancer-sponsored events, but she was always very hesitant to do so. "These [BCAM] donations only last for October," she remarked to me. "On November 1st, most corporations move on to the next cash cow. It's not really about breast cancer. If it was, I'd imagine it would have more of an impact on me."

Pink is a soft color. Pink represents new life, a path ahead. Pink cheeks indicate vitality and liveliness and pink lips indicate femininity. Throughout her treatment, my mom did not have blushing cheeks and rosy lips. Her fingernails were not pink; her toenails were hardly present. Despite being a shy but lively woman with an unquestionable spirit, a more fitting word for her ever-deteriorating state was gray. Her skin started to lose color, her hair showed streaks of silver. This is not to say that she ever gave up. She never took off work, during her initial treatment or remission. Even in her last few weeks, she indicated that she wanted to "find a solution to her condition." She wasn't uninformed, she was a physician herself. Her determination was what kept me hopeful even when the oncologists said that there was nothing more to be done. This doesn't change the fact, however, that pink was not a representative color of how she felt. The color pink sugar-coated a deadly condition that, in the end, caused her a great deal of suffering, and me, a great deal of sorrow.

So then, why is pink the representative color of this disease? Other than pink being historically associated with girls and breast cancer being historically associated with women (even though some patients are men) it can sometimes be difficult to feel hopeful once we acknowledge the reality of a situation. It might be easier to live and continue wearing our cottoncandy-colored glasses, convincing ourselves to infantilize our condition to trick our minds

that we have a lot more life left than what actually may be. It might just be easier to live that way, and, in all honesty, that is perfectly alright. But, in the meantime, I would like to see whether more patients feel the same way that she felt. In doing so, perhaps we can start to build a better support system for those who are suffering, rather than leaving them to convince themselves to subscribe to a movement that doesn't truly represent how they feel just because it is much less harrowing than dealing with the truth.

2. Introduction

a. Rationale and Relevance

Breast cancer is the most common cancer in American women, consisting of about one-third of all female cancer diagnoses every year (Taylor and Knibb, 2019). Breast Cancer Awareness (BCA) campaigns, in response to the rise in diagnoses in the past few decades, raise money for and promote breast cancer research and prevention (Lock, 1998). Contrary to the stated aim of these movements, very few proceeds are directed toward research. For example, in 2011, only 16% of the 470 million dollars raised were used for breast cancer research (Orenstein, 2013). Commercializing the BCA movement has also resulted in phenomena such as pinkwashing, where “a company or organization that claims to care about breast cancer by promoting a pink ribbon product...at the same time produces, manufactures and/or sells products that are linked to the disease” (Taylor and Knibb, 2019). Even the use of militarized terms such as “breast cancer survivor” is problematic as it shifts the responsibility of survival onto the shoulders of the patient when she most often does not have much agency over her disease.

There is very little recent literature on how the Breast Cancer Awareness movement has impacted the perspectives and experiences of current or former breast cancer patients. In addition, most of the existing literature focuses on quality-of-life measurements but does not explore the impact of both the positive and negative aspects of the BCA movement on the community of patients at an individual level.

The overall goal of this study is to add to the existing knowledge by providing a more up-to-date picture of how the BCA movement impacts breast cancer patients as well as providing a more in-depth exploration of the intersection of key themes of BCA movement discourse at an

individual level to garner a more holistic picture of the impact of the BCA movement. Because of its controversial past, it is important to assess whether the BCA movement serves as a form of support, social or otherwise, for the patients who have, are, or will suffer from breast cancer. This study will serve as an important step in the investigation of whether the discourse and approach of the BCA movement are truly helpful to those whom it claims to help, and, if not, better elucidating how changes can be made to further aid patients already struggling with such a deleterious disease.

b. Background and Literature Review

Limitations of Existing Literature

In most of the existing literature on this topic, one of the main recurring limitations is a small sample size. As such, the external validity, specifically the generalizability, of previously performed studies and analyses is questionable. Although this study also has a small sample size, the importance of adding to the existing body of literature on Breast Cancer Awareness and discourse given the scarce amount of information grants this study additional merit. In the existing literature, there have been narratives of the experiences of current and former breast cancer patients. There are also criticisms of many aspects of the Breast Cancer Awareness movement; however, the impact of the commonly-critiqued issues of the BCAM on patients has not been thoroughly explored. Of course, there have been highly influential narratives written by current and former breast cancer patients elaborating on how various symbols, motifs, and discourses associated with breast cancer culture, pinkwashing, and the BCAM have impacted their experience, but such narratives are few and few between. Barbara Ehrenrich's *Welcome to Cancerland* and Audre Lorde's *The Cancer Journals* are two of the most well-known and influential narratives written by and for breast cancer patients that have touched on the discourse

of BCAM and the phenomenon such as pinkwashing, but it is difficult to say whether the experiences documented in these texts are generalizable to the millions of people who have been diagnosed with breast cancer. Furthermore, there has hardly been a narrative review conducted to search for common themes and patterns that are associated with such narratives. This is the gap in research that this study intends to address.

Awareness, Screening, and Detection

One of the most controversial aspects of the efforts of the Breast Cancer Awareness movement is the extent to which screening and detection have been impacted by BCA initiatives. While the BCAM has increased general knowledge of the disease as well as mammography (MG) screening rates, “the widespread use of routine screen screening programs” arguably makes furthering awareness initiatives beyond what is already being done obsolete (Karaby and Kadioglu, 2017) (Nishimura and Acoba, 2022). One argument is that the BCAM has almost reached saturation for the targeted audience of their campaign and with the addition of routine screening programs, investing more money and effort into even grander awareness events may not be as helpful as expected (Karaby and Kadioglu, 2017). It must be acknowledged, however, that awareness of the disease is not in itself a bad thing. Compared to the Lung Cancer Awareness Movement (LCAM) and the Pancreatic Cancer Awareness Movement (PCAM), the BCAM has indeed successfully improved public awareness of breast cancer in the US (Nishimura and Acoba, 2022). On the other hand, BCAM has been criticized for contributing to the overdiagnosis of breast cancer with a rise in false positive test results that may cause patients additional unnecessary financial burden and psychological distress (Nishimura and Acoba, 2022). This perspective argues that the “increase in screening rate does not coincide with an increase in detection,” bringing into question the beneficial effect of screening campaigns

(Karaby and Kadioglu, 2017). One reason for this may be that the audience of the BCAM has an average, or even low, risk of breast cancer (Karaby and Kadioglu, 2017). One aim of this study, then, is to investigate whether patients believe that the Breast Cancer Awareness campaign has increased both rates of screening and rates of detection, and how participants' opinions change with knowledge about recent trends in screening and detection.

Quality of Life

For most patients diagnosed with breast cancer, the outlook and prognosis of the disease are rather positive. Excluding those diagnosed with particularly aggressive forms of breast cancer, those who have relapsed, or those whose cancer has metastasized and unfortunately have a high five-year mortality rate, an exploration into how the BCAM may impact the long-term quality of life is pertinent to making the experiences and daily lives of those diagnosed with breast cancer more bearable. Breast cancer has often been associated with a series of mindset changes where those afflicted have new opportunities to find "positive meaning" in "enriching and affirming [experiences] during which women with the disease are rarely "patients" and mostly "survivors." (Bower et al, 2005) (King, 2003) (Leopold, 1999) (Pezullo, 2003). While existing studies have found that a significant portion of post-treatment patients find "forms of positive meaning" in their cancer experience, this variable is positively correlated with feelings of vulnerability and negative affect, with over 50% of women in one study expressed fears about recurrence and relapse (Bower et al, 2005). This finding brings up an important point of contention that critics of the BCAM movement have regarding terms used to refer to patients who have undergone treatment and are in remission, namely the term "breast cancer survivor." In much of the humanitarian and scientific literature on breast cancer, "survivor" is frequently used to refer to former breast cancer patients. Quality of life studies, however, reveal that, as so many

“survivors” are concerned about their cancer returning, “survivor” is in no way a permanent label (Bower et al, 2005). While women do label themselves this way, they have deep-rooted and understandable fears about losing their survivorship status (Bower et al, 2005). There also exists some discrepancy about who qualifies as a survivor. Some may define cancer survivors as those who have undergone treatment and are in remission, but the National Cancer Institute defines “cancer survivor” as “anyone who has ever been diagnosed with cancer no matter where they are in the course of their disease” (National Cancer Institute, 2022). This goes to show that the way former patients are labeled may have a significant impact on their mental state and day-to-day quality of life, be it a confusing or helpful one. It is also worth noting that the results of such quality-of-life assessments may not reflect the same patterns depending on at what point in time the subjects were assessed post-diagnosis (Bower et al, 2005). The way the BCAM affects survivors as opposed to patients still undergoing treatment is different; it may be helpful in some cases but hurtful in others.

There is a large gap in the existing literature regarding the in-depth and long-term quality-of-life assessments that are not purely quantitative. While this study is also making use of a 5-point Likert survey which is a rather objective quantitative analysis tool, that may not effectively capture the nuances and subtleties of the impact of the subjects’ quality of life, the use of the one-on-one interviews seeks to fill this gap where the Likert survey may fall short. The interview discussion with current or former breast cancer patients is an attempt to fill in the gaps that traditional quality-of-life instruments fail to address or accurately capture. One limitation of this method is the small sample size. The advantage of using traditional and/or quantitative quality-of-life measurements is that a larger cohort may be used that could be more representative of public opinion. Acknowledging this limitation, this study will not attempt to generalize thoughts, opinions, and experiences associated with breast cancer discourse and the BCAM, but rather to

gain a more profound understanding of select experiences provided by individual study participants. A larger investigation of similar depth may be in order given a study with a longer time and greater means to complete such a robust analysis.

Militarization:

The militarization of breast cancer discourse and the Breast Cancer Awareness movement has primarily manifested in two ways. The first, more explicitly, is the use of the pink ribbon to promote the sale of products that adhere to and encourage a war-like mindset or that may lend a hand to violence in a militant fashion. This includes the sale of pink ribbon artillery and ammunition, but also the use of pink ribbon branded machines in the U.S. military, such as tanks plastered with a large pink ribbon mainly used by the U.S. armed forces during national Breast Cancer Awareness month. As gun restrictions are already a point of contention in the U.S., a pistol with a bright pink handle, for example, is an ironic image (Fernandez, 1998) (King, 2010). Smith & Wesson's Breast Cancer Awareness initiative, a 9 mm pistol with a pink handle, was heavily criticized for using a symbol of violence to promote initiatives to save lives the sale of this product was ridiculed by the phrase "saving lives by taking lives" (King, 2010).

The other manifestation of militarization concerning breast cancer is exemplified by the terminology used to refer to members of the breast cancer community and phrases describing events that may have happened to breast cancer patients or actions that such individuals may have taken. Problematic terminology includes words such as "survivor" and "victim" and phrases such as "the fight against breast cancer" and "winning/losing the battle against cancer" (Cone Communications, 2012) (Harvey and Strahilevitz, 2009) (King, 2010). The former two terms are problematic because they incorrectly and ironically assume the degree of agency that a person diagnosed with breast cancer may have. "Survivor" and "the fight against breast cancer "

indicates that the patient performed some action and had free will over their condition such that they could control the outcome. Implicit in that is that in the reverse situation, where a patient passed away due to breast cancer, they may have not done enough on their part or are partially to blame for the outcome of their situation when the outcome may have rested on several different factors. If they did not pursue treatment, they may not have had the means to do so, and even if they did, developing resistance is not under the control of the patient and may be inevitable. While the point of such terminology is to make patients feel less hopeless and encourage the feeling of control over their condition, such terminology runs the risk of blaming patients for their situation. “Victim” has the opposite effect, where the patient is no longer an agent of their condition and is subject to the whims of a mass of cells uncontrollably proliferating inside them as well as the choices of the healthcare system and providers who make decisions on their behalf (Cone Communications, 2012). While slightly more accurate (in some cases), this term may not have a beneficial psychological impact on the patients, further emphasizing their feelings of helplessness and despair. In the most ironic outcome, whether the discourse assigns agency of the disease to the patient or surrounding factors, “roughly the same number of people die as they did before the pink ribbon juggernaut took hold” (King, 2010). Despite this, both “survivor” and “victim” are frequently used terms in existing literature, perhaps due to the lack of other simple, non-awkward terms to describe breast cancer patients (Harvey and Strahilevitz, 2009). Noting this, a pertinent exploration of this study would be to discuss the implications behind common phrases in Breast Cancer Awareness and the potential for a new label for this population.

Consumerism and Marketing:

An important criticism of the Breast Cancer Awareness movement is the heavy commercialization of the disease and the pink ribbon symbol. It has been argued that the

widespread usage of the pink ribbon to sell products corrupts the movement and grants the corporation a “chic”, “respectable”, and “white, middle-class” cash cow to increase sales of their products while often only contributing a marginal, negligible portion of the profits to Breast Cancer Awareness (Harvey and Strahilevitz, 2009). The free access to the pink ribbon opens the door to potential abuse of the symbol, especially in the for-profit marketing industry (Harvey and Strahilevitz, 2009). In many cases, the proceeds of Breast Cancer Awareness campaigns are no more than 1%, requiring a great deal of profit for the donated amount to reach a sum that could help further research, treatment, and prevention. There has also been backlash about the lack of Breast Cancer Awareness throughout the whole year, and companies who chose to use pink ribbon advertising have been encouraged by critics to support the campaign to a greater extent for the whole year (Cone Communications, 2012) (Taylor and Knibb, 2019) (Harvey and Strahilevitz, 2009). In addition, the overuse of the pink ribbon may have desensitized consumers to the symbol, detracting attention away from products that contribute a more significant portion of the proceeds to breast cancer research and treatment (Harvey and Strahilevitz, 2009).

Much of the literature is also focused on pinkwashing, defined above in the *Rationale and Relevance* portion of the introduction. To combat extensive pinkwashing and promote a more critical eye toward consumerism and marketing in the name of breast cancer, the “Think Before You Pink” campaign has made a list of questions to ask before “buying pink” (Think Before You Pink, 2016):

1. Does any money from this purchase go to support breast cancer programs? How much?
2. What organization will get the money? What will they do with the funds, and how do these programs turn the tide of the breast cancer epidemic?

3. Is there a “cap” on the amount the company will donate? Has this maximum donation already been met? Can you tell?
4. Does this purchase put you or someone you love at risk for exposure to toxins linked to breast cancer? What is the company doing to ensure that its products are not contributing to the breast cancer epidemic?

The Think Before You Pink Campaign has been the major voice pointing out numerous examples of pinkwashing. In 2007, they criticized Ford, BMW, Mercedes, and other car companies for advertising cars that raise money for breast cancer but at the same time produce “air pollutants linked to breast cancer” (Harvey and Strahilevitz, 2009) (Westerveldt, 2011). In 2008, it was Yoplait that was under attack for using pink lids to sell yogurt that was made from cow milk treated with the hormone rGBH (this hormone has been linked to breast cancer as well) (Harvey and Strahilevitz, 2009) (Westerveldt, 2011). Disturbingly, some of the most prominent organizations for Breast Cancer Awareness have endorsed products that may contribute to cancer, such as when Susan G. Komen endorsed a Kentucky Fried Chicken initiative that sold fried chicken in pink buckets despite evidence that high-fat diets contribute to developing breast cancer (Harvey and Strahilevitz, 2009) (Westerveldt, 2011). Similarly, Avon, one of the more influential corporations that promoted the BCAM has had a dark history of plastering a pink ribbon on carcinogenic products, exemplified in 2001 during their “Kiss Goodbye to Breast Cancer” campaign where they sold lipsticks that “may have contained ingredients that disrupt hormone function, which is in turn linked to breast cancer” (Fernandez, 1998) (Harvey and Strahilevitz, 2009) (Lubitow and Davis, 2011) (Westerveldt, 2011).

In this study, it would be pertinent to explore the degree to which participants are aware of pinkwashing and whether the pink ribbon advertising has influenced some of their financial

decisions. Another important point to discuss is the impact of pink ribbon advertising specifically during October and the stark contrast on November 1st when it is no longer national Breast Cancer Awareness month. One of the themes to explore within this is corporate breast cancer, where participants are assessed on the degree to which they believe a corporation or company using pink ribbon or Breast Cancer Awareness marketing cares about the cause and how big a difference such initiatives make.

Representation

The BCAM has had issues in accurately representing the group of people it advocates for in various social spheres including age, race, socioeconomic status, and cancer type, to name a few. One of the more unaddressed issues in the existing literature is the latter sphere, type of cancer. While on occasion the discourse 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. The BCAM had made efforts to promote self-presentation that starkly contrasts with “the weak, pale, bed-ridden cancer that has in prior decades stood as the dominant signifier of the disease,” but, in doing so, results in a rhetoric best described as a “tyranny of cheerfulness” where one would think that breast cancer is a fully curable condition (Bode, 2010) (King, 2004) (King, 2010). Of course, the movement should not promote a bleak outlook on life, however, by fully embracing an upbeat and optimistic attitude, one disregards the true image of what the disease does to such an extent that the representation of the breast cancer survivor may be unrecognizable when compared to the real version (Bode, 2010) (King, 2004) (King, 2010). There is little room in contemporary breast cancer discourse for anger and dissent, two historically feminist emotions, which may be why the current perception of the BCAM is “prowomen, but not pro-feminist” (King, 2010).

Race is also an important, potentially alienating factor for some members of the breast cancer community. In general, ethnic minority women are diagnosed with more advanced diseases and experience greater morbidity and mortality, yet the more contemporary depiction of a breast cancer survivor is “youthful, ultrafeminine, slim, [and] light-skinned if not white” (Ashing-Giwa et al, 2004) (King, 2010) In studies that have surveyed members of the breast cancer community for recommendations and advice regarding representation, a common theme is encouraging advertisers to “depict breast cancer survivors to be as diverse as they are, including older women, women of color, and women who are not necessarily thin or glamorous,” once again suggesting that the breast cancer community is being misrepresented (Taylor and Knibb, 2019). In one study, 69% of the media representations of breast cancer patients were of white/Caucasian women, which has the potential to influence how ethnic minority women view the disease (Berry et al, 2016). More specifically, media representation of patients with breast cancer may affect both how frequently women of color go for screening and whether the ideal or standard version of the breast cancer patient is representative of their physical appearance (Berry et al, 2016).

One question to address in this study, then, is to ask participants to describe what they believe is the archetypal breast cancer patient or breast cancer survivor, and if they believe that they are represented by the description they provide. This study also aims to address the sorrow patients may have felt and continue to feel regarding the major change that affected their lives apart from the unbridled optimism that “demands conformity” to the mainstream depiction of the “model breast cancer survivor” that continues to promote a white, middle-class agenda that works to misrepresent people of color (POC) with the disease. (Bode, 2010) (King, 2004) Of course, such conversations would be more relevant with participants of color.

The Color Pink

The last major area of contention that has been promoted by the BCAM which this study will be investigating is the use of the color pink as the U.S. (and increasingly universal) representation of Breast Cancer Awareness. One problematic aspect of the choice of pink as the color to represent breast cancer is that it was not the original color chosen for Breast Cancer Awareness Movement when it was at the grassroots level. In the early 1990s, Charlotte Haley, a former breast cancer patient, began hand-making peach-colored breast cancer awareness ribbons to inform the general public that “only 5% [of the National Cancer Institute budget] goes to cancer prevention” (Fernandez, 1998) (Fernandez, 2019). Several executives from large corporations, including Estée Lauder and Self magazine, approached her asking for permission to use her ribbon, but she turned them down because of their intent to use the ribbon as a commercial tool (Fernandez, 2019). Self magazine then proceeded to choose pink as the representative color for its “soothing, comforting, and healing” nature and Haley’s grassroots movement died out (Fernandez, 2019).

Most of the existing literature on the problem with pink stems from narratives and articles about the potential impact of using a “soft” and “feminine” color to represent breast cancer. This study intends to garner opinion on this perspective of pink to see if participants feel that pink is “infantilizing” and weak, lacking the power to “demand change” (Elliott, 2007) (Harvey and Strahilevitz, 2009). The issue with the color pink as proposed by Lorde and Eherenrich in their respective narrative texts, as well as some additional publications on the subject, is that pink cannot connote the reality of a breast cancer patient. It does not communicate the hair loss, the chemotherapy-induced illness, or the body wasting that the majority of patients experience at one point during treatment (Eherenrich, 2001) (Elliott, 2007) (Fernandez, 1998) (Lorde, 1980). Pink

also acts against the diverse body of the breast cancer community because it only represents gender but fails to distinguish between “survivor, struggler, or supporter” (Elliott, 2007). Pink was chosen because it is “the quintessential female color” with a “calming effect” (Fernandez, 1998). However, in choosing a color that is “everything cancer is not,” you run the risk of patients feeling alienated and misrepresented by the color. There is a fine line between using a color like “150 pink” (the original color code chosen by Estée Lauder) to transcend beyond breast cancer and entirely misrepresenting the way those afflicted by the disease feel (Fernandez, 1998).

Another interesting approach that could be taken in this study is to show participants different representations of breast cancer and the breast cancer ribbon to observe how inherently this symbol and color is intertwined with the participant’s identity as a member of the breast cancer community. For example, BCA Ottawa in Canada flipped the ribbon upside down and lined it with black to represent tears shed during diagnosis and remember patients who have died, respectively (Fernandez, 1998). The “Cancer Sucks” button used by San Francisco BCA would also be an interesting symbol to garner opinion on (Fernandez, 1998). The study essentially aims to explore the extent to which the pink ribbon is integral to the experience of a breast cancer patient, and whether changing that logo to one implying less optimism and more realism makes a difference in the way the participant interacts with breast cancer discourse and the BCAM.

Contemporary Critiques of the Movement

Most of the critique addressed above regarding the Breast Cancer Awareness Movement was brought to public attention decades ago. The earliest patient-driven narratives, namely Barbara Ehrenrich’s *Welcome to Cancerland* and Audre Lorde’s *The Cancer Journals*, were published in 2001 and 1980, respectively, making it clear a critical perspective of the Breast

Cancer Awareness and pushback of the pink ribbon is no new concept (Ehrenrich, 2001) (Lorde, 1980). Since then, there have been several initiatives and organizations established to address the issues brought up by those pioneering authors as well as additional problem areas identified in the 1990s and early 2000s, resulting in a reduced production of cosmetic-pushing marketing and pink-washed products. Given the preexisting critiques of the BCAM, this study serves as an update to the earlier criticisms and can provide a sense of how perceptions may have changed over time.

c. Experimental Approach and Hypotheses

This study was performed independently from any preexisting lab or project and was created by the researcher herself to investigate the militarization, stigmatization, and commercialization of the Breast Cancer Awareness movement, the pink ribbon, and any associated language or symbols that related to Breast Cancer Discourse that affects the experience of women diagnosed with breast cancer. $N=161$ English-speaking cisgender women above the age of 18 and diagnosed with breast cancer were surveyed using a 5-point Likert Survey that was shared with them through the reposting of a Facebook post on the Georgia Clinical and Translational Science Alliance (CTSA) Facebook page to several public and private Breast Cancer Awareness and support Facebook groups. The participants accessed the Likert Survey by interacting with the repost on Facebook and, at the end of the survey, were asked if they would be willing to take part in a one- to two-hour follow-up interview, and if so, to provide their contact information so the researcher could reach out to them. Given the short time frame of the study, $N=8$ follow-up interviews were conducted, assessing the participant's thoughts about diagnosis, social support, the impact of the BCAM, the pink ribbon, pinkwashing, and critical discourses, the militarization of Breast Cancer Awareness, and stigmatization regarding the

disease. This was an exploratory study observing how women who have been diagnosed with breast cancer interact with the pink ribbon and the Breast Cancer Awareness movement. We had some expectations regarding the outcome of the study based on preexisting critiques of BCA, so this study also examined if those critiques were still true of the breast cancer community. We expected that all participants would have issues regarding the visibility of commercial marketing using BCA symbols such as the pink ribbon and that they would be concerned with the visibility of the profits that corporations collect using BCA symbols to increase sales. Similarly, we expected that all participants would have an issue with the militant terminology used in breast cancer discourse. Finally, we expected that women with poorer prognoses would have a more pessimistic and critical view of the femininity and commercialization associated with the Breast Cancer Awareness Movement compared to women whose disease prognosis was more optimistic.

3. Methods

a. Study design

The design used to assess the questions addressed in this study consists of two portions: a Likert Survey and an optional follow-up interview.

b. Quantitative Measures: 5-Point Likert Survey

Setting

The Likert survey was accessed by study participants by scanning a QR code or clicking a link.

Participants

Recruitment

The link to the Likert survey was shared on Facebook in private and public support groups for breast cancer survivors and groups providing general information about cancer awareness with permission from the Facebook group moderators. Potential participants were recruited using public and private Facebook breast cancer support groups and cancer awareness groups with permission from group moderators/administrators. The participants made the initial contact by electing to take the Likert survey. The source of participants were former cancer patients who were members of public or private breast cancer support groups and cancer awareness groups on Facebook. None of the groups were thematically associated with critiques of the BCAM. With approval from the moderator and/or administrators of the Facebook group(s), the link to the survey and the QR code was shared with the group and any member of the group who met the demographic criteria willing to participate was eligible to participate.

Eligibility

The first few questions of the qualtrics survey purposed to determine the eligibility of potential participants. If the participants opened the survey and answered “no” to questions asking about age and diagnosis of breast cancer, then the survey was terminated, and these participants were not included in the research. Eligibility was recorded by asking if the participants are above the age of 18, female, identify as women and have been diagnosed with breast cancer. The diagnosis of the women was recorded so that during the data analysis, women with different types of breast cancer could be analyzed to account for potential mediating, moderating, and/or confounding variables. The names of the women were not recorded as part of the Likert Survey. No study members accessed patient records as part of this study. IRB Approval from the Emory Institutional Review Board was obtained for this study because of the use of human subjects.

Timing of data collection

The Likert survey was designed to last approximately 10 minutes.

Protocol for data collection

Materials that were used to recruit participants include a Georgia CTSA Facebook post with both a link to the survey and a QR code that participants could scan using a smartphone camera. Potential study participants could interact with recruitment materials through Facebook. The Facebook recruitment materials were shared (reposted, no primary post on any personal social media accounts) through the personal social media accounts of research team members in breast cancer support groups and cancer awareness with approval from the group moderators. Participants could use the QR code or tap on the link that is embedded in the Facebook post to be taken to the survey. Participants were not recruited (and recruitment materials were not shared)

through Winship Cancer Institute or Emory Healthcare-associated Facebook groups, support groups, physical locations, or other Winship Cancer Institute/Emory University-affiliated means.

If the participants chose to take the Likert survey (administered on Qualtrics), they were asked a series of questions and asked to rate their response to those questions on a scale of 1-5, a rating of 1 being “strongly disagree” and a rating of 5 being “strongly agree”. The survey questions aimed to garner a reading of the participants’ attitudes to the Breast Cancer Awareness Movement, the extent to which they know about it and its related discourse, and how it has impacted their quality of life and perspective. If participants elected to do a follow-up interview, the aim of the interview is essentially the same as the survey, however, topics will be explored qualitatively and in much greater depth. All interviews were conducted via Zoom (Zoom Inc., 2023). Following the interview, the responsibilities of the study participants were complete. If they did not elect to do an interview, the subjects’ responsibilities were complete. There were no plans for a long-term follow-up. No cognitive testing of survey participants was performed as the researcher believed extensive screening measures would deter potentially emotionally fragile patients from participating.

Measures

Source of survey: Emory University Qualtrics Account

Content of survey: Likert Survey Questions

c. Qualitative Measures: Follow-Up Zoom Interview (Optional)

Setting

All interviews were conducted on Zoom (Zoom Inc. 2023).

Participants

Recruitment

If the survey participants indicated that they wished to participate in a follow-up interview, then they were asked to provide their email, phone number, or both. Then the researcher reached out to these participants.

Eligibility

See eligibility criteria used for Likert Survey. IRB approval was obtained for this study because of the use of human subjects.

Timing of data collection

Each interview lasted from 1-2 hours.

Protocol of Data Collection

Once the researcher received a survey response where the name of the participant and their contact information was provided (phone number and email), the researcher reached out to the survey participant to set up a time for the interview. Most of the interviews were set up using iMessage, and some were set up using email. Once a desirable interview date was found (about one week after the initial survey response, in most cases), the researcher scheduled a zoom call and sent the meeting invitation to the study participant.

The interviewer joined the zoom call 10 minutes early and when the study participant joined, the interviewer obtained oral informed consent before starting the interview. The interviewer also obtained consent to record the interview. The interviewer posed a general list of discussion questions, but the interviews were mainly patient-directed and evolved in the direction of topics that the patients themselves wanted to discuss.

After the interview concluded, the interviewer transcribed all recordings into audio transcripts, and assigned pseudonyms to all interview participants, and 24 hours after the

conclusion of the interview, all recordings were discarded, and personal identifiers were assigned pseudonyms to protect the anonymity of the study participants.

Measures

Source of interview software

Zoom Inc.

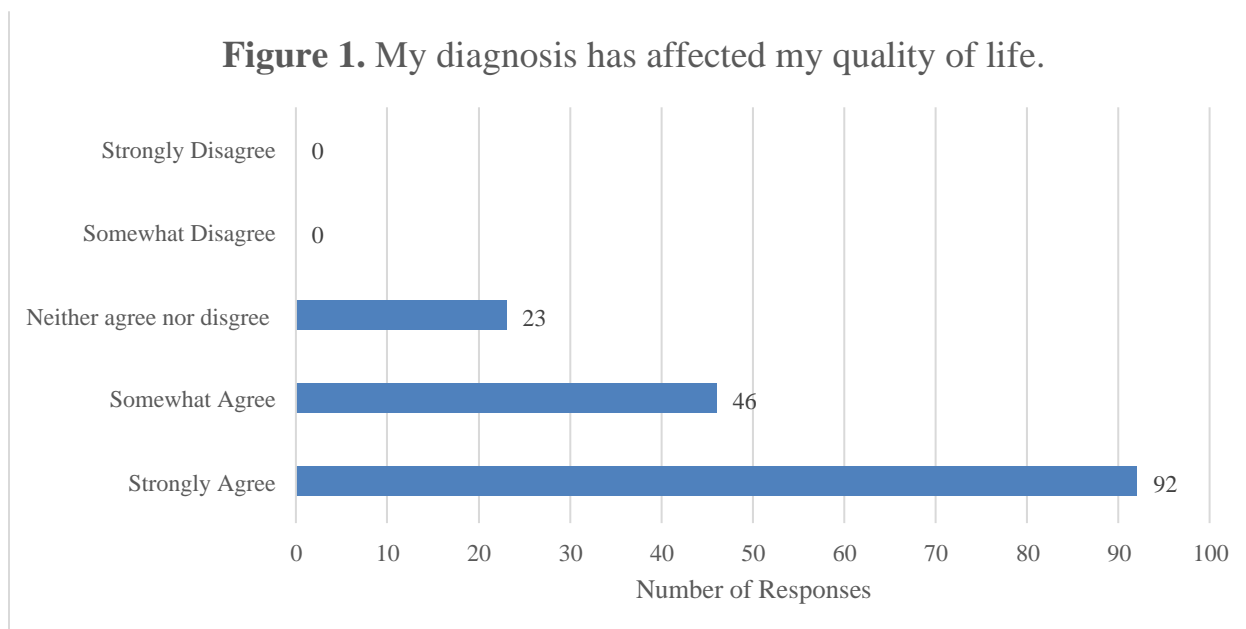
Content of Interview

Interviews were conducted following a series of discussion questions meant to guide the conversation, however, often the interviews went in another direction because of the subjects that the patients themselves wanted to discuss. Therefore the interview questions used for the followup interview only served as a guiding tool and sometimes not all questions were asked. Other times, not all questions were applicable as each interviewee had a different experience with breast cancer. A list of the interview questions utilized can be found in the appendix.

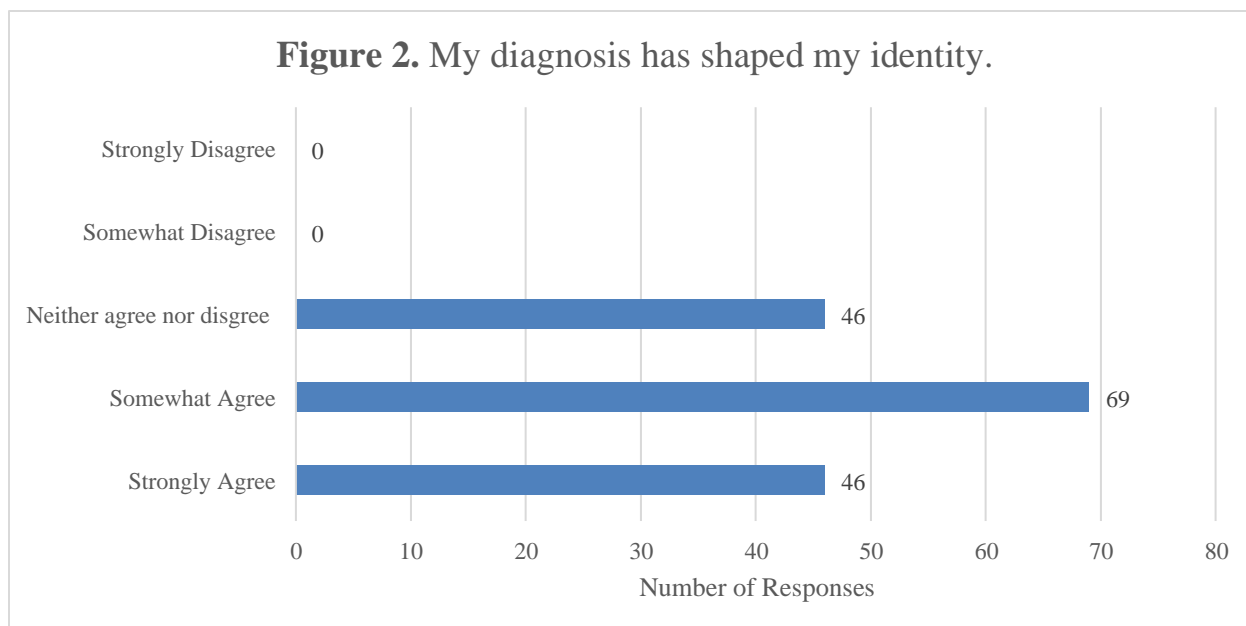
4. Results

a. Quantitative Data Analysis: Likert Survey

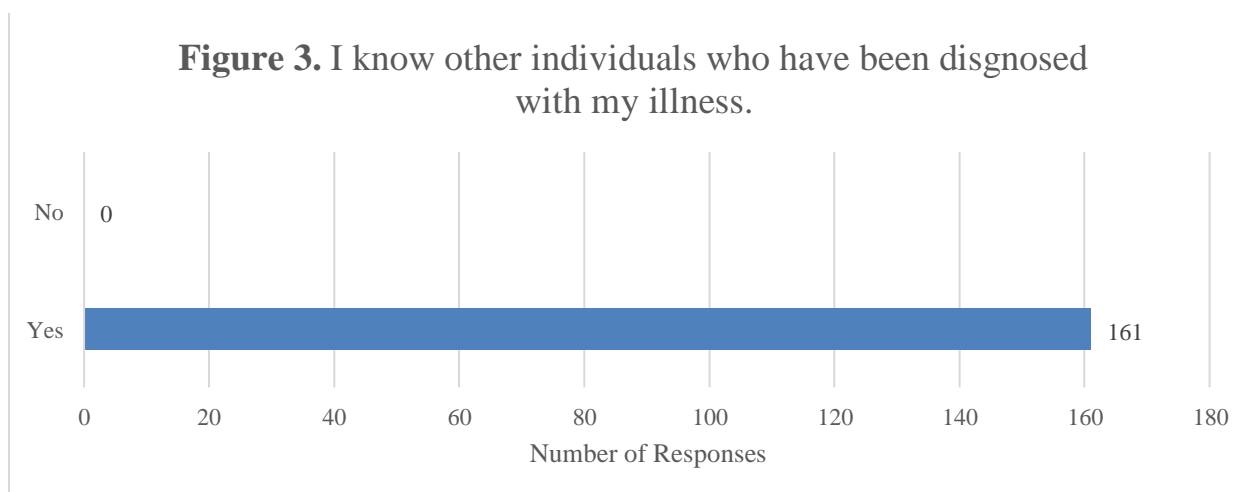
The distributions of responses to each question addressed in the 5-point Likert survey are shown below. To find the original Likert Survey questions, please refer to the Appendix.



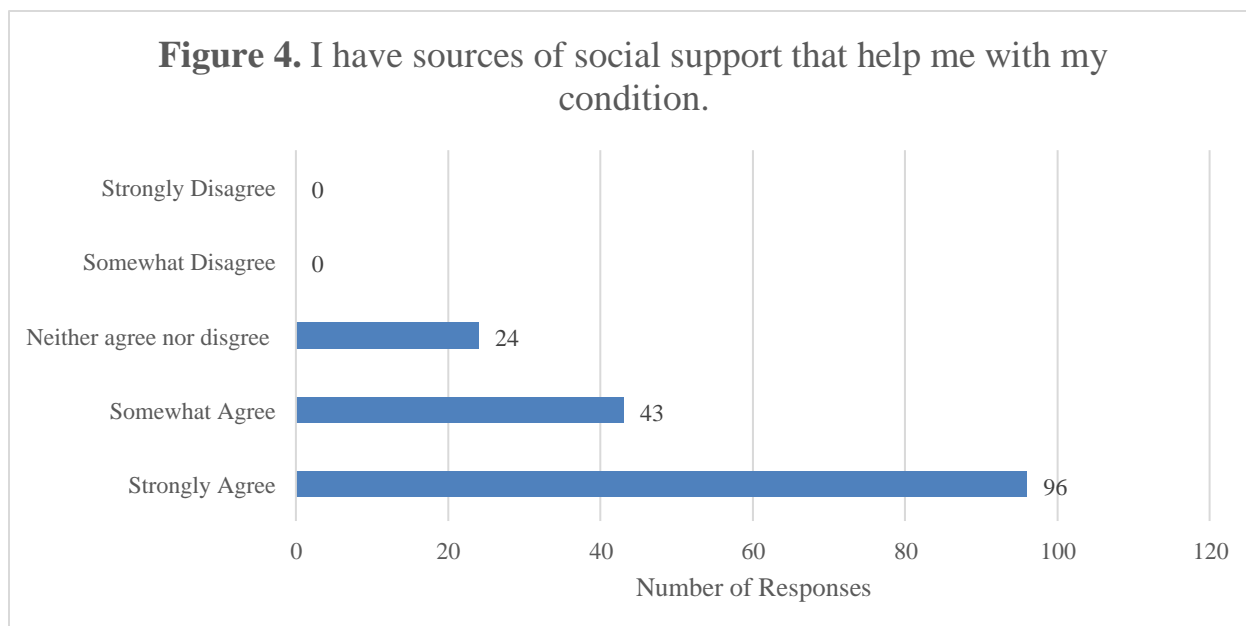
This figure describes the extent to which the survey participants feel that their diagnosis has affected their quality of life. No survey participant indicated that the diagnosis has had zero effect on their life and the majority of responses at least partially agree that a breast cancer diagnosis had impacted their quality of life.



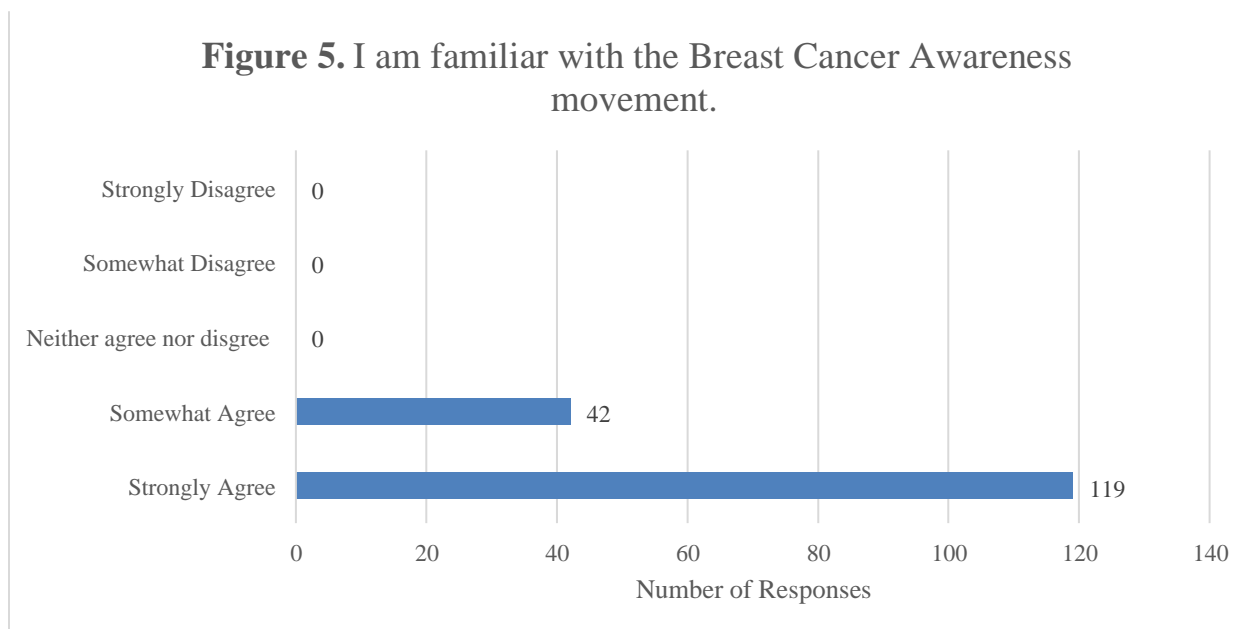
This figure describes the reported impact of a breast cancer diagnosis on the participants' identity. Once again, the majority of the participants felt that their diagnosis has at least partially shaped how they view themselves.



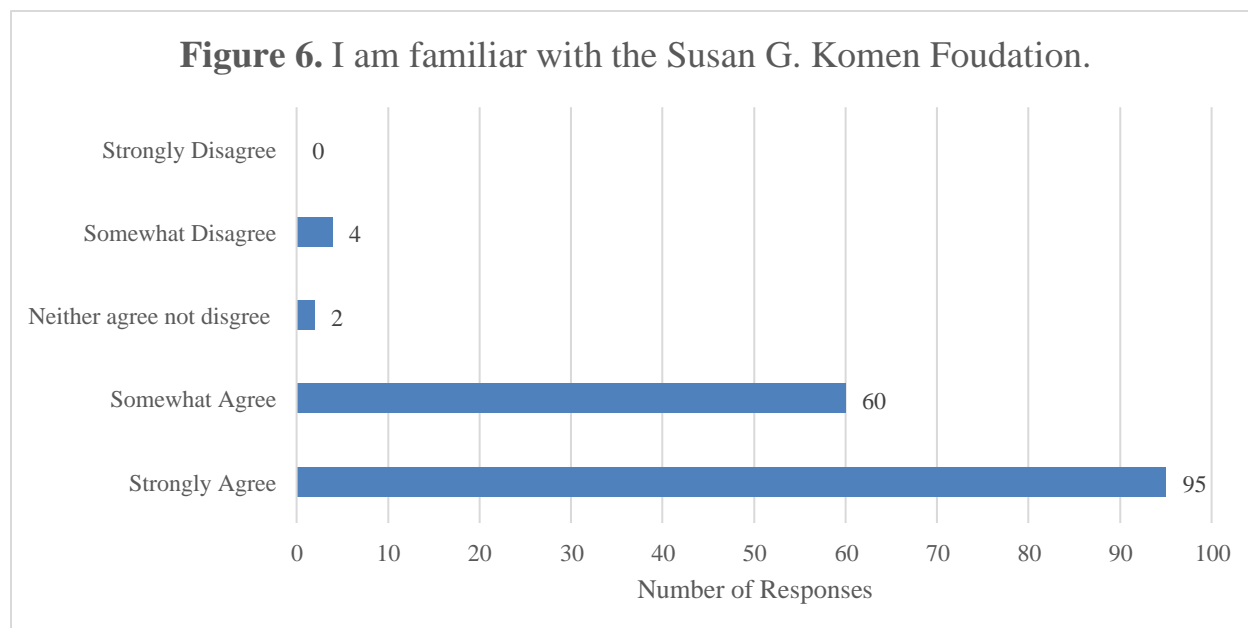
This figure described the number of women who know other individuals diagnosed with their illness. Every single survey responded reported that they know of others with their diagnosis.



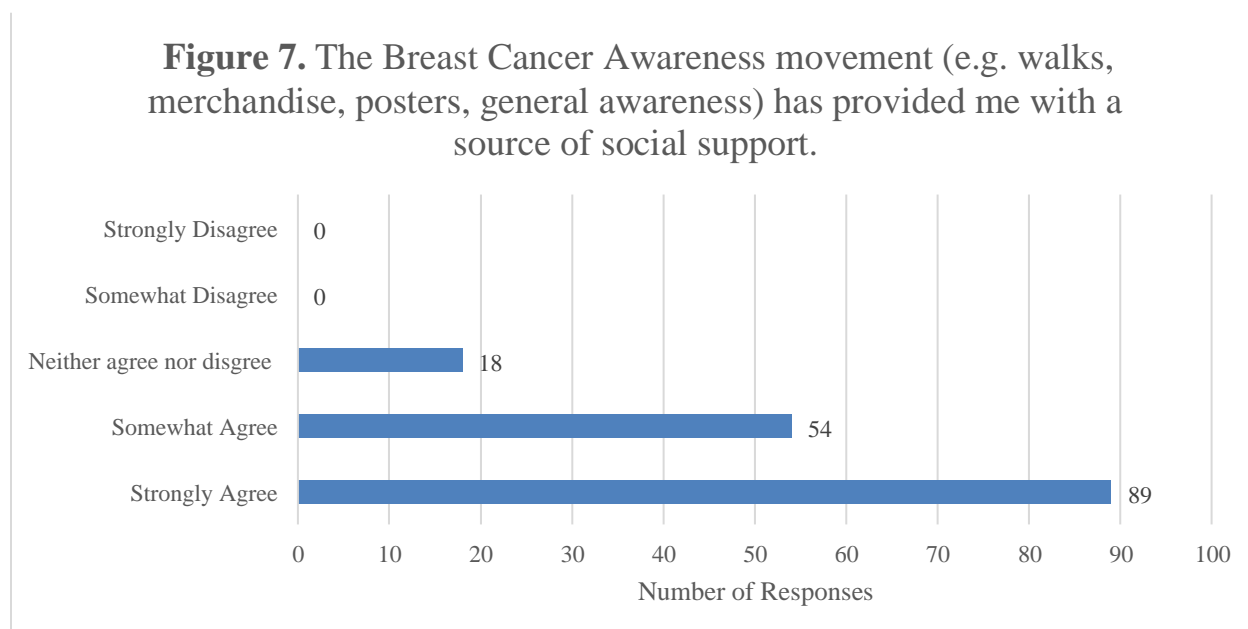
This figure describes whether or not the respondent believes she has sources of social support that serve a purpose related to her breast cancer diagnosis. Once again, the majority of respondents feel that they have at least some social support.



This figure describes the visibility of the Breast Cancer Awareness Movement to the respondents. 100% of the respondents indicate that they are at least somewhat familiar with the BCAM, indicating that visibility and knowledge of this movement are widespread.

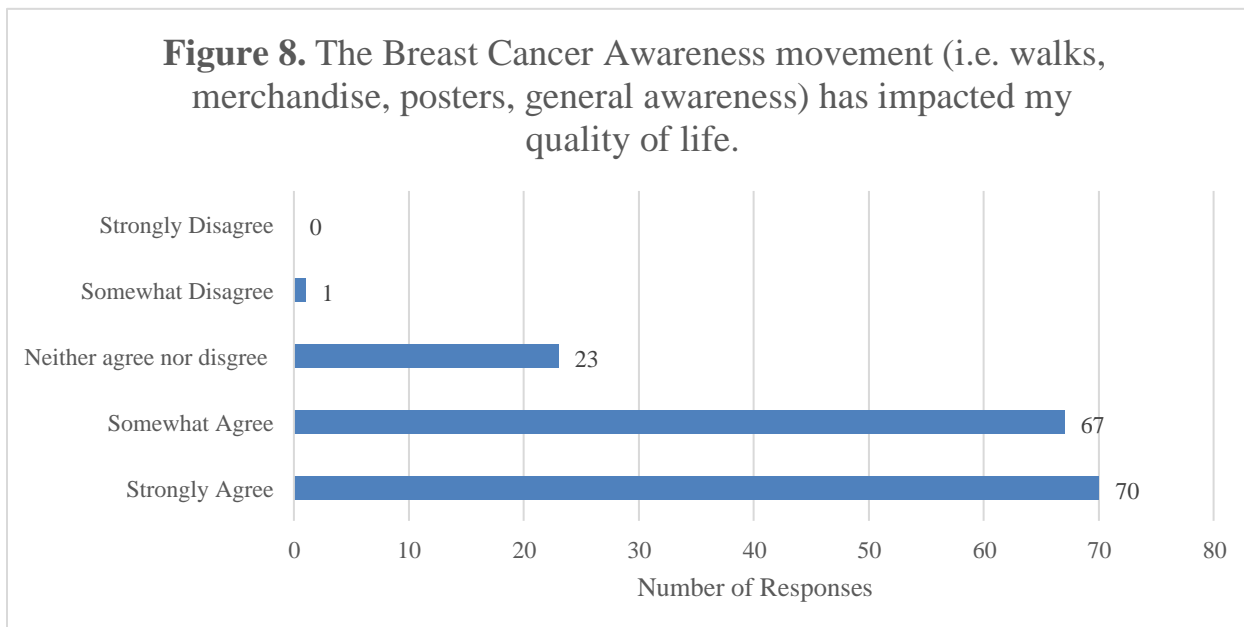


This figure describes the visibility and reach of one of the major Breast Cancer Awareness organizations, the Susan G. Komen Foundation, to the respondents of the survey. The Komen Foundation claims to “focus on navigation and advocacy, providing resources for breast cancer patients to understand the American medical system...and...[fund] research into the causes and treatment of breast cancer”. Within the participant group, knowledge regarding the Susan G. Komen foundation is almost as widespread as knowledge of the Breast Cancer Awareness movement itself.

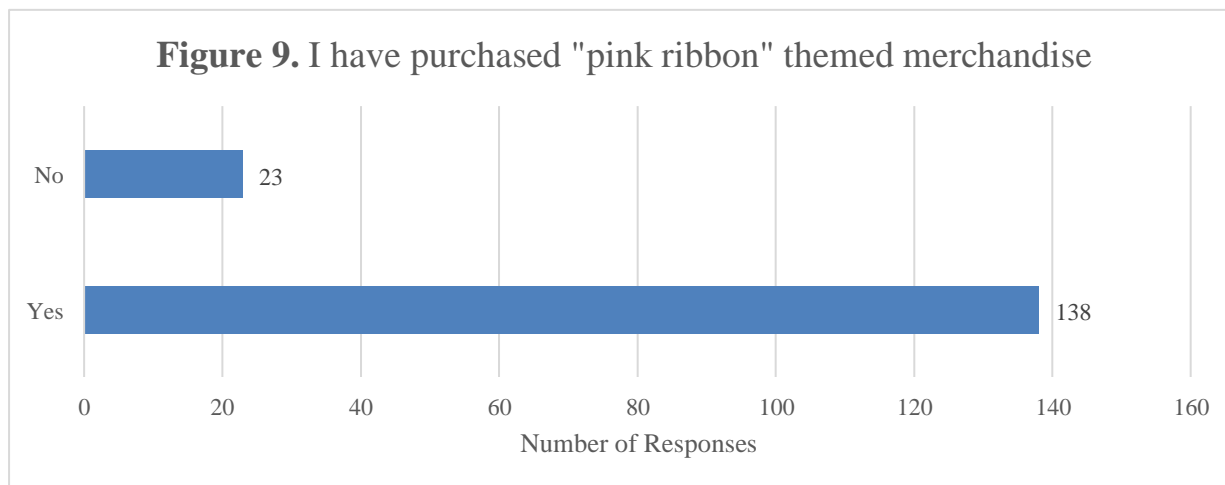


This figure describes the degree to which the survey respondents feel the BCAM provides a sense of social support. The distribution of responses in this figure can be compared to the distribution

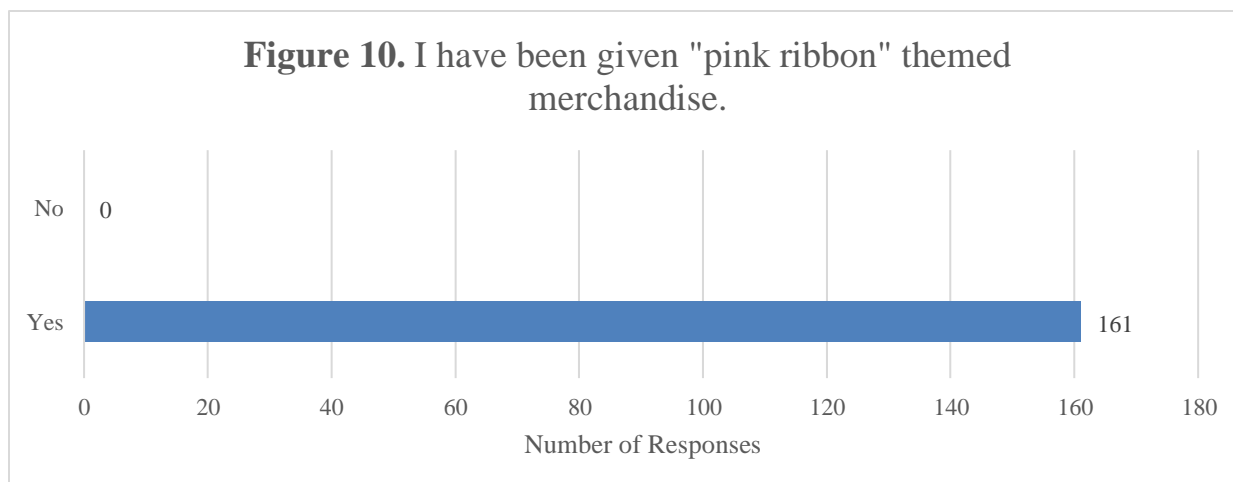
in Figure 3 to determine if there is an overlap between general social support and social support provided by the Breast Cancer Awareness Movement.



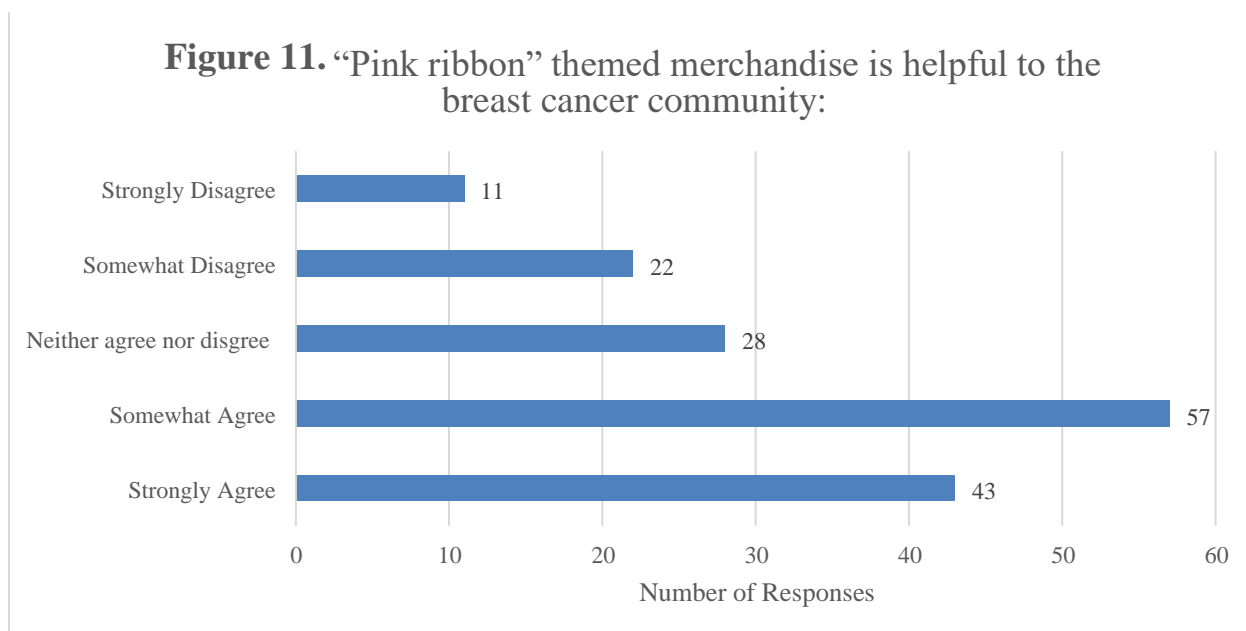
This figure describes the degree to which the survey respondents feel the BCAM has impacted their quality of life. The distribution of responses in this figure can be compared to the distribution in Figure 1 to determine if there is an overlap between the impact on quality of life due to diagnosis as compared to the impact of quality of life due to the Breast Cancer Awareness Movement.



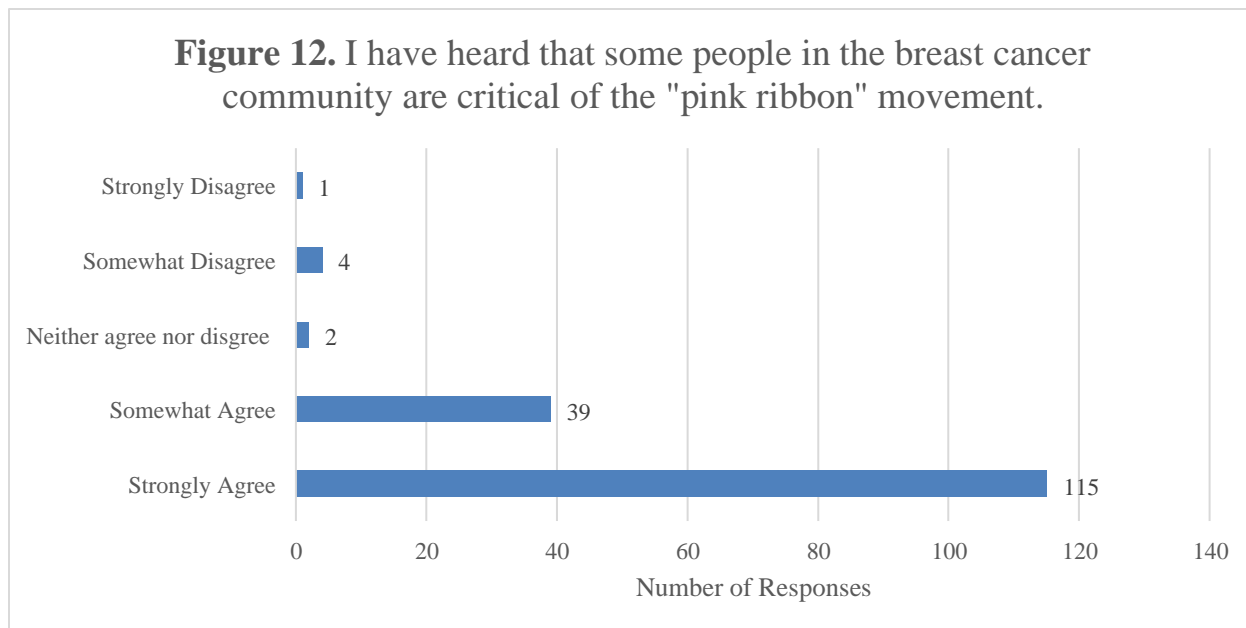
This figure describes the degree to which the population sampled has purchased BCA-themed merchandise in a commercialized manner.



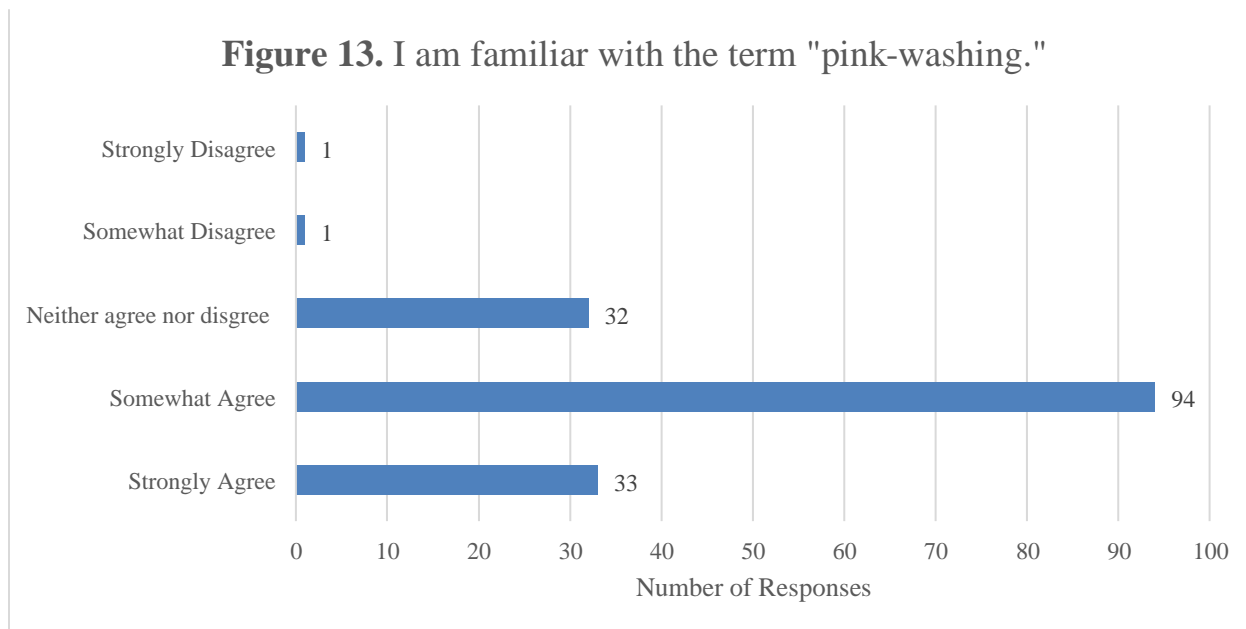
This figure described the proportion of individuals who have been given “pink ribbon” themed merchandise. All survey participants indicated that they had been given at least one pink ribbon product.



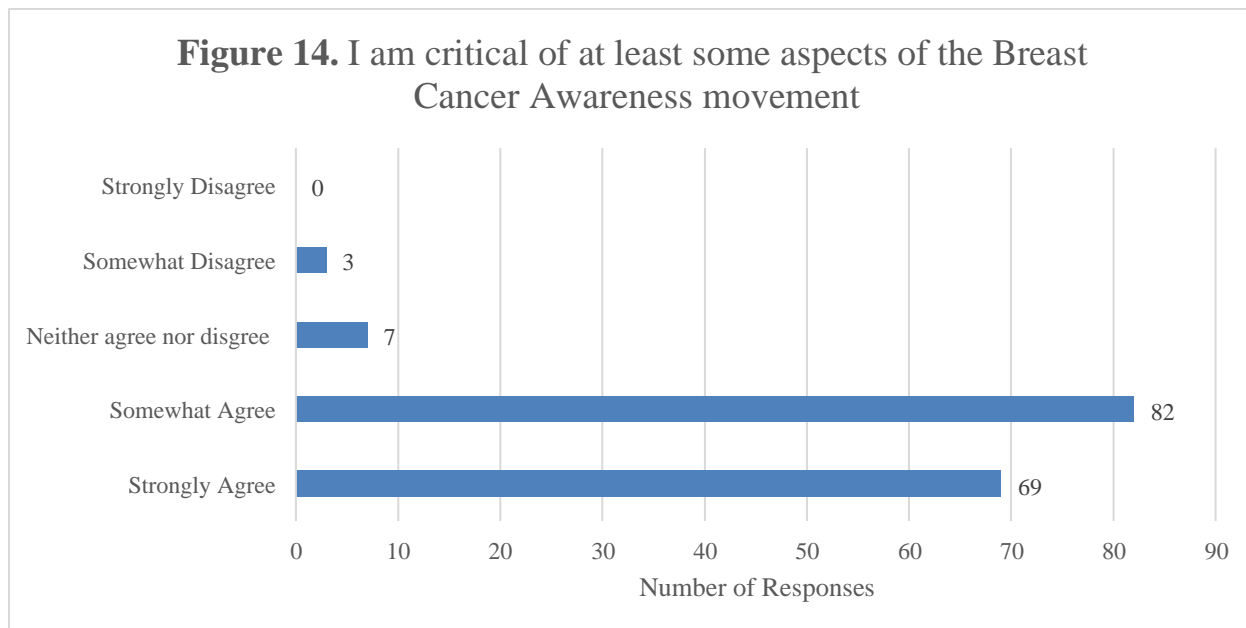
This figure describes the opinions of the population surveyed on whether BCA-branded merchandise is helpful to their community. The distribution of this question is more varied compared to the distribution of other questions, indicating that the subject matter addressed in this question may be more controversial.



This figure describes the visibility of existing critique of the BCAM to the population surveyed. The results of this figure indicate that most of the population surveyed is aware that there exist criticisms of the Breast Cancer Awareness movement.



This figure describes the extent to which the population surveyed is familiar with more specific critical terminology used in the mainstream critique of breast cancer discourse and the BCAM.



This figure describes the prevalence of critical thought present in the population surveyed. This figure shows that although the majority of respondents indicated that the Breast Cancer Awareness Movement provides them social support, they have at least partial criticisms and indicates that there are aspects of the movement that may need to be fixed.

The Likert survey received $N=161$ responses. 100% of respondents reported that they knew other individuals who have been diagnosed with breast cancer (Figure 3). 100% of respondents also reported that they have been given “pink-ribbon” themed merchandise by another party (Figure 10).

According to the results of the Likert survey, most breast cancer patients who participated appeared to be aware of the existence of the BCAM (100% of responses indicated that they were at least partially aware) (Figure 5). The distribution of responses also indicates that the BCAM has had some impact on the respondents' lives, be it in the form of social support (88.8% at least selecting “Somewhat Agree”) (Figure 7) or quality of life (85.0% at least selecting “Somewhat Agree) (Figure 8). 95.5% of respondents indicated that they were aware that the BCAM has some criticisms (Figure 12) and 93.7% of respondents indicated that they are at least partially critical of the BCAM (Figure 14).

In addition, the distribution of responses to the survey questions about the pink ribbon, pink ribbon marketing, and pinkwashing indicates that most respondents are at least aware of the historical pitfalls that the pink ribbon symbol has been associated with. Despite this, the respondents seem to have a generally positive opinion of the Breast Cancer Awareness movement, with 62.1% of respondents reporting that they believe that “Pink-ribbon” themed merchandise is helpful to the breast cancer community (Figure 11). Likely, at least some of the respondents who indicated that they are partially critical of the BCAM have also participated in pink ribbon commercialism, as 85.7% of respondents reported that they have purchased “pinkribbon” themed merchandise (Figure 9).

b. Qualitative Data Analysis: Interviews

Eight interviews were conducted with eight current and former breast cancer patients. Three of the patients interviewed were diagnosed with breast cancer pre-menopause and five were diagnosed post-menopause. In general, patients who receive a diagnosis post-menopause have more successful treatment options and lower mortality than those who are diagnosed before menopause (Surakasula et al., 2014). The majority of the patients interviewed were white/Caucasian, but the interview cohort also included one Hispanic patient and one Black patient. It should be noted that, to avoid researcher bias during the interviews, the interviewer did not view the distribution of responses to the survey until all eight interviews were completed and the survey was closed. With the informed consent of the study participants, the interviewed were recorded on Zoom via the Zoom recording software (Zoom Inc, 2023). The researcher used the Zoom-generated audio transcript to document the topics discussed during the interview (Zoom Inc. 2023). Then, the researcher used the Zoom-generated mp4 recording of the interview to manually ensure the accuracy of the audio transcript (Zoom Inc. 2023). The quotes presented

below were extracted from this audio transcript. The final version of the audio transcript was analyzed using MaxQDA to code and analyze recurring themes throughout the interviews (MaxQDA, 2022). The demographic information collected for all patients interviewed can be seen in Table 1.

Table 1. Demographic Information for all Interviewees. The table includes the assigned pseudonym that will be used to refer to individual patients, the initial diagnosis, the current treatment plan, whether or not the patient is in remission, and whether the diagnosis was made pre- or postmenopause. Arimidex is a hormone-based chemotherapy drug that needs to be administered on a regular basis. The chemotherapy cocktail is a mixture of different chemotherapies that need to be administered in a regular basis, often used if the patient has developed resistance to one chemotherapy, or if their diagnoses is particularly aggressive. If a patient has no current treatment, there is no pharmaceutical or other intervention to monitor and maintain their current physical health in regard to the management of cancer.

Patient Number	Pseudonym	Diagnosis	Current Treatment Plan	Remission Status	Pre- or postmenopausal
1	Linda	Ductal Carcinoma In Situ	Arimidex	Not in remission	Postmenopausal
2	Rena	Invasive Ductal Carcinoma, Stage 1	Arimidex	Not in remission	Postmenopausal
3	Halema	Invasive Ductal Carcinoma, Stage 1	Arimidex	Not in remission	Postmenopausal
4	Regina	Ductal Carcinoma In Situ	No current treatment	In remission	Premenopausal
5	Yara	Invasive Lobular Carcinoma, Stage 1	No current treatment	In remission	Postmenopausal
6	Maya	Invasive Ductal Carcinoma, Stage 3	Chemotherapy Cocktail	Not in remission	Premenopausal
7	Theresa	Triple-Negative Breast Cancer, Stage 2	Adriamycin (Chemotherapy Cocktail)	Not in remission	Premenopausal

8	Sophia	Triple-Negative Breast Cancer, Stage 2	Taxol (Chemotherapy Cocktail)	Not in remission	Postmenopausal
---	--------	--	-------------------------------	------------------	----------------

All recordings of participants were discarded after 24 hours and all participants interviewed were assigned pseudonyms as listed in Table 1.

Participant 1

Patient 1, “Linda,” was diagnosed with Stage 0 ductal carcinoma in situ (DCIS) of the left breast following the investigation of calcifications that appeared on a routine mammogram in 2011, postmenopause. She was treated with a lumpectomy followed by 30 rounds of radiation therapy. She had two recurrences, one on the left side of the left breast in 2013 and one on the right side of the left breast in 2017. Linda had no genetic risk factors for breast cancer and following the second recurrence in 2017, she has been on Arimidex, which lowers estrogen levels, for the past five years. Linda exhibited a generally positive outlook on her condition. She spent a lot of time during the interview talking about her initial reaction to her diagnosis and the extent of confusion and isolation she felt at that time. She indicated that she kept her social circle small, did not inform many people of her diagnosis, and chose not to join any support groups, instead choosing to fill her time by taking on more responsibilities at her teaching job:

“I didn't use a lot of the resources that were available. There were, I remember, some very welcoming, lovely women that came from the American Cancer Society to tell me about their program and that they would support me, but my feeling was: I've got to get back to work.”

When asked why she did not want to join any support groups, she responded that,

“It was horrible, but that was my own problem. I really chose to just do this independently as much as possible, just gleaning whatever I could from the doctors, and sometimes being a little stubborn. I had a really great oncology radiologist. He was the one that told me the importance of doing the radiation. So I did that. There was a group starting a support group, so I was made aware of it. But I didn't take part, and I didn't tell too many people. When you work with a lot of women, I work in a very large school where I knew people that had it.

We've lost several young teachers and I kind of thought that the pink ribbon didn't appeal to me. I just felt, you know, it was good that it was pushing research. I just didn't feel like I should be running around with a pink ribbon on my chest. Look, I teach adolescents, so I also felt I didn't want to show any weakness, so I never told any of my students, obviously that I was going through the radiation, and I would just run out during lunch and have it done”.

Linda recalled that her biggest forms of support were from other women. One major problem she repeatedly brought up during the interview was the lack of information available to her upon diagnosis. She recalled that the oncologist was very nice, however, he used words that were unfamiliar to her and she spent a lot of time after her initial diagnosis doing research on her condition and the terms used during her doctor’s appointments. She expressed during the interviews that she “was very curious about nutrition” and “wished [she] knew more about exercises.” When asked if there was anything she wished she knew before undergoing treatment, Linda elaborated extensively on the management of symptoms and side effects. She expressed that although “[she] only had radiation treatment, which is nothing compared to the brave women who go through chemotherapy,” she wished more information was available about how to care for her body outside of treatment and provide it with enough sustenance to “prepare [herself]” for the next round of treatment.

When asked specifically about whether she has supported pink ribbon products, Linda responded,

“I bought some things that I thought I would wear, but it was more or less....to support it, not to advertise it so much myself. Even if I bought a pair of leggings I might not wear them out in public...people become skeptical, even supporting it in that way, because they don't know what's really behind it. It's like giving to a charity. But you know that most of the money is going to the corporate CEOs that run that charity. You know you know what I mean? You just gradually realize the money is not going where it's supposed to, and it's not well researched in its sources.”

Linda further elaborated that although she used to purchase more pink ribbon products, she has slowly stopped over the years after having doubts about how the profits of pink ribbon products were being distributed. Toward the end of the interview, she began making more

suggestions about where the money should be going and brought up the idea of allocating funding to more research grants for preventative care, rather than palliative or curative care. She expressed to the interviewer that, in her opinion, it would be easier to “nip the problem in the bud, before it develops into full-fledged cancer” rather than try to target the issue after a cancerous lesion has already developed.

When asked about the use of militant terms such as “survivor”, “battle”, and “warrior” that are frequently used in discussions of breast cancer survivors, Linda expressed no negative attitudes towards the terminology and mentioned that she believed the terms were meant to be empowering to women during and after treatment. When the interviewer asked whether she would have thought differently if her prognosis was poorer or if her cancer was more advanced, she replied that she had never thought of the terminology from that perspective before, but she could understand how it could be more upsetting to individuals in those situations.

Participant 2

Patient 2, Rena, was diagnosed with Stage 1 invasive ductal carcinoma (IDC) of the right breast, postmenopausal, in October of 2018 and was treated with an adjuvant chemotherapy cocktail following lumpectomy. Currently, she takes Arimidex every day and visits the oncologist’s office to receive a shot of Zoladex every three months. So far, Rena has had no recurrences.

Rena indicated that she believed the pink ribbon was “a sign of weakness”, and she did not purchase any pink ribbon products because, as a hairdresser, she interacts with the same people on a regular basis and did not want to show “weakness” in front of them. She said that she believed wearing a pink ribbon stole on her chest or branded on her clothing may be interpreted as a sign of weakness, and her reputation within her career was very important to her:

“I didn't tell my customers, even because in business sometimes people are weird about things like that right away. They're looking for a replacement because they think something's gonna happen, and you're not going to be there for them, and that's sad.”

She did not have any strong feelings regarding the commercialization of the pink ribbon or its use as a marketing tool. She was more concerned about the microsocial effects of the presence of a pink ribbon than the macrosocial use of the symbol.

Rena did not join any breast cancer support groups and instead relayed to the interviewer that her main source of social support was her family, her sister in particular. She appeared to value the “advantage” of having a healthcare worker in the family because,

“A lot of times like I was in [the oncologist's office], and I was just, like, in shock. And they're talking about all these medical terms, and I leave the room, and I'm like, “Oh my God!” And then my sister's like, “No, no, no,” she explained it. So I wish everyone had somebody like that to tell you like, cause it's really it's like a lot when you're in the moment, even now, like the doctor will say something up, and she'll come with me, and then she'll be like, “oh, yeah, you know when he said this, and that's that meant,” and I'm like, “Okay, I get it now, I get it.”

She expressed to the interviewer that the slew of medical jargon “thrown into [her] head” during her first oncologist visit did not help her to understand her disease and, instead, made her feel like the situation was out of her control:

“[The oncologists and other healthcare professionals] don't understand, like, they think that giving you all the proper names for your sickness and the percentages and stuff will make you feel like you know more about it so it feels less foreign and scary, but I think that realizing how much you don't know about what's going to happen to you is even scarier. And the way they explained it to me...I was terrified.”

Rena further elaborated on the value of understanding one's condition when asked about what parts of the Breast Cancer Awareness movement could be improved. She indicated that although the focus on mammography is important, there needs to be more assistance provided to women after receiving a daunting diagnosis:

“I feel like knowledge is power. Or at least, it makes you feel powerful. But you need to understand that knowledge. You need to contextualize it.”

Rena had a more positive outlook on the use of militant terminology in breast cancer discourse. She did not place much literal emphasis on the use of “warrior,” as though she or others were actually going to fight a battle, but chose to view the terminology as a tool to aid the state of her mental health:

“I feel like I am somewhat responsible for [my physical health and treatment]. I don't know. I felt strength. I feel strength going in there saying like, “Okay, I'm going to fight this. I'm going to get through this. We're going to make it”...it's just something to keep you uplifted and keep you going.”

Rena seemed to enjoy the fact that she had more responsibility over her disease because it gave her more agency over factors that she previously felt were out of her control, regardless if things were in actuality within her control or if the empowerment and responsibility delivered to her through the use of militant terminology was just a psychological sedative to combat darker and more unproductive thoughts.

When asked whether she thought differently regarding common militant terminology in the case of patients who have little to no realistic hope of recovery due to historically poor prognosis or about those who have passed away due to breast cancer, she felt that the terminology was still unproblematic:

“Well, no, I feel like they were warriors, and I never would think that they were to blame for anything like that. I don't see it that way, but I think they were warriors, and they did the best that they could.”

Rena's final thoughts regarding the Breast Cancer Awareness Movement were that it has good intentions, but she would like to see a larger portion of the funds that are produced from sponsored events allocated to minimizing the side effects that accompany treatment and a greater emphasis on making sure patients fully understand their diagnosis, treatment, and the slew of side effects that go hand-in-hand with a breast cancer diagnosis.

Participant 3

Patient 3, Halema, was diagnosed with Stage 1 invasive ductal carcinoma of the left breast, postmenopausal, in September of 2017 and was treated with a lumpectomy followed by 35 radiation treatments. She is currently on Arimidex and visits her oncologist every six months.

Halema appeared to have very strong feelings regarding the use of the pink ribbon and the Breast Cancer Awareness Movement in general as exemplified by the following conversation she recounted with her oncologist:

“I can remember going into my oncologist in October, and he had a tie on with pink ribbons on it, and I can remember saying to him, ‘You know Dr. Perry, pink ribbons make me want to puke.’ I said, ‘because, it's not enough. It's not enough.’ ”

Halema was very outspoken with her dissatisfaction at the efforts of the pink ribbon and the BCAM. Being a relatively healthy, active woman, she profoundly felt the effects of the radiation treatment in her personal life and on her physical body:

“I mean I went from somebody who was running 5Ks every weekend to somebody who had horrible radiation burns. The radiation burns were so horrible that they had to stop my treatment and let me heal. I just physically and mentally couldn't handle being around a lot of people.”

She further described that she felt a need to hide her scars because she did not want to disturb anyone with her “disfigurations.” She seemed dissatisfied with the lack of representation of the toll various forms of treatment take on the bodies of women diagnosed with breast cancer and expressed that she was further angered by distributions of lipsticks and cosmetics with “pink ribbons slapped on.” When asked what an alternative form of awareness could be, she responded that:

“There needs to be more real talk. Pretty pink ribbons pretty it up too much. It needs to get more real. They need to see the scars. Maybe that will shock people. Have you seen the commercial with the guy with lung cancer? You see him gasping for breath, sitting at his kitchen table. They've been playing that one over and over and over on television for the past week, and

it's just heartbreaking. But Breast Cancer Awareness? Pink ribbons? It's not enough. It's too pretty. They need to show the scars.”

Halema went on to say that there needs to be more prioritization on self exams and early detection. She suggested that women should be more outspoken about how their cancer was found and repeated on several instances that it would be a good idea to show their scars and depict to others the “devastation” that breast cancer patients experience during and after treatment. She was not impressed by the use of pink garbage trucks and pink footballs during NFL games because such measures are only taken during October and the effort is not consistently sustained throughout the year.

When asked about her thoughts on the militarization of the BCAM, Halema replied that “it seems a little contradictory” to use words like “warrior” and “survivor” for people who are “struggling just to get by.” Other than commenting on the antithetical nature of militant terminology, Halema had no further remarks and seemed to have little to no qualms with the use of such terminology simply because “what other words could we possibly use? Victims? That type of negativity won’t help anybody, and there is a line between being realistic and being pessimistic.”

She concluded the interview by discussing measures which different organizations could take to improve the experience of all breast cancer patients. She first addressed the lack of support from insurance companies regarding financial aid to get mammograms in the first place. “It’s fine if people know about it,” she said, “but if you don’t have the financial flexibility to act on your knowledge, what good is Breast Cancer Awareness anyways?” She ended that thought by suggesting that some of the profits of the BCAM be allocated to making mammograms more affordable. She explained that the reach of the BCAM may have reached saturation within one

financial demographic, but poorer communities may not have the means to get mammograms and that there still exists a significant amount of healthcare inequity which may why minorities, specifically Black and Hispanic patients, are diagnosed at later stages of breast cancer and, hence, tend to have poorer prognoses (Yedjou et al., 2020).

Halema also expressed a desire to see more frequent sharing of information. Rather than lipsticks, journals, and teddy bears being handed out in hospital waiting rooms, Halema suggested to “give [patients] a laminated card with resources and common terms” that would help them understand and feel more control over their condition.

Participant 4

Patient 4, Regina, was diagnosed with Stage 0 DCIS of the right breast in November of 2006, premenopausal, and has been in remission for almost 12 years. Despite her premenopausal diagnosis (which is strongly associated with more aggressive breast cancer), Regina’s prognosis was one of the most optimistic within the cohort interviewed. She is no longer on any treatment plan and has achieved “survivor status,” as she states.

In general, Regina had a positive outlook on the efforts and achievements of the Breast Cancer Awareness Movement as well as the discourses that surround it. She had few to no issues with the use of the pink ribbon as the symbol for Breast Cancer Awareness, exclaiming that “pink is [her] favorite color, and it’s so pretty too! [She’s] happy to have it around [her] as much as possible.”

Although she did not join any support groups, she participated and even encouraged others to participate in Susan G. Komen’s Race for the Cure as well as the American Cancer Society’s Making Strides Against Breast Cancer 3- to 5-mile walk. She expressed that she was

quite content at such celebrations and makes attempts to participate in several such events every year:

“I was with a group of friends who were survivors and I was happy to be doing something with them more than actually doing it. Does that make sense? We were there for each other more than to raise money for the walk. I remember taking a bag of, like, 25 pairs, hot pink leggings, and just giving them to people. As I was walking around I was delighted to greet and congratulate those women who had survivor sashes on. I felt good to be there to support them and to support each other. I felt better about that than the fact that we were walking to support the organization.”

Regina had no issues with the way non-survivors approached the walk. Although she acknowledged that for many people, supporting breast cancer may have been a secondary reason for going, they were still contributing to the atmosphere of the events and the profits that the events brought in, so, in the end, she felt that every individual's presence was helpful in spite of the primary reason they may be in attendance:

“They were having a fun day out together, you know, like, they weren't crying as they walked. They were uplifting. They had fun. They were planning where they were going to have a glass of wine afterwards. It was social, and there's nothing wrong with that.”

Although Regina was, for the most part, content with the way the BCAM has contributed to her experience as a patient and as a survivor, she was aware that the mortality rate of breast cancer has not decreased to the same degree the mammography rate has increased, the latter trend in part being due to the efforts of the BCAM. She suggested that:

“If mammograms are not the way to go, we need to come up with something that is going to help people. Maybe having a way, like with your genetics, to see if you have a pretty high disposition to it, and I mean that, like having research on that, so that it could even be avoided, or letting you know. So you can make the right decisions for yourself.”

She further elaborated that more effort into preventative research, specifically genetic screenings, would go a long way, especially for those who get diagnosed with untreatable forms of breast cancer.

Regina indicated that she was aware of pinkwashing and the fact that some products at the supermarket that are marketed with pink ribbons also have known and/or potential carcinogens in them. She felt it was okay for such companies to continue using those symbols because she felt it was too unrealistic to mandate them to stop, however, she suggested that those companies be required to label the products which may carry carcinogenic risk, even the ones with pink ribbons.

Participant 5

Patient 5, Yara, was diagnosed with Stage 1 Invasive lobular carcinoma in June of 2009, postmenopausally. She was treated with a single mastectomy followed by adjuvant chemotherapy and hormone therapy. Despite having both the BRCA I and BRCA II genes, Yara never had a recurrence and has been in remission for about eight years. She was the only other participant interviewed who was in remission.

Yara did not appear to have a negative opinion of the militarization of breast cancer discourse. She indicated to the interviewer that she actually found such terminology empowering and a relatively accurate description of the process of undergoing treatment:

“What do I call myself other than somebody who survived treatment? What do I call myself? I'm not a patient anymore. I mean, I don't know. I don't even know that I call myself a survivor. But then, what else am I?”

According to Yara, it seems that the term “survivor” is so popular because there is no alternative terminology to describe those who are no longer going through treatment, and she seemed okay with this fact. She elaborated that “it just sounds more upbeat” to call someone a “warrior” rather than saying “oh, she's sick,” although she did acknowledge that “there's nothing upbeat about it, honey.” In spite of this, Yara seemed to feel that militant terminology provided breast cancer patients more agency than they would have otherwise because “at least [they] feel

like they can do something, anything” to help themselves. She compared the militarization of the Breast Cancer Awareness Movement to the use of the pink ribbon as the representative symbol of breast cancer:

“[The militarization] doesn't coincide...especially with the lipstick or whatever. You're barely making it during the day, and you don't feel feminine. I didn't feel feminine. Yeah, I'd rather take the warrior way of it than trying to do like the pink, the pinkness of it.”

Yara then juxtaposed the use of the pink ribbon to specifically calling breast cancer patients warriors. She suggested that it causes some cognitive dissonance within the minds of those undergoing treatment as, on one hand, organizations that use pink ribbon marketing “make [patients] feel like little girls,” but at the same time “claim that [they’re fighting] some kind of war.” She indicated that the militant terminology was more true to her experience as a breast cancer patient and expressed dissatisfaction with the symbol of the pink ribbon in itself as well as with its widespread use as a marketing tool.

Yara explained to the interviewer that she wished there were more accurate depictions of breast cancer patients in the advertisements used for BCA. She felt that there exists some societal pressure to conceal the effects of treatment on her body when she, herself, was more comfortable with her physical appearance compared to those around her:

“At first, I was trying to get a wig and try to cover [my head] up and everything, but I just didn't feel good from the chemo, and I was just like, “forget this”, so I just didn't even wear it. I mean I wore it one time because my son had a performance, he was in a play, and I didn't want to stick out that much, so I wore it that one time, but otherwise I wore a hat.”

Yara mentioned that she felt the pressure to retain her mainstream femininity was multipronged. Not only did she suspect that the general population around her felt uncomfortable with the physical and cosmetic consequences of her treatment, but she was also suspicious of corporations that were supporting the BCAM and using the pink ribbon whom she felt were applying pressure on her to hide the side effects of her chemotherapy:

“Sometimes they'd have, like, people coming giving out things for Breast Cancer Awareness, and it was like lipstick. It's just, I didn't like that. I don't want to put makeup on right now. I can barely keep food down and I don't feel well. So it felt contradicting to what someone is actually going through.”

When asked about what measures could be taken by the BCAM to make her feel more supported (if lipstick was not the answer), she answered that she would like “more information about what is actually going on,” both in relation to her own treatment and regarding the commercial activities and profit distribution of the BCAM. She put forward that she would like to see whether the increase in mammography rates are actually impacting patient mortality. She also mentioned the importance of targeting breast cancer before it develops into a full fledged tumor and asked if there was genetic testing that could “see if people have something that might trigger [the development of cancer] so that [the oncologists] could target it before” the tumor actually formed. Overall, she encouraged greater transparency of the organizations involved with breast cancer regarding their commercial activities as well as clarity about her own condition.

Participant 6

Patient 6, Maya, was initially diagnosed with Stage 3 invasive ductal carcinoma of the right breast in January of 2019, premenopausal. She was treated with a full mastectomy followed by adjuvant chemotherapy and immunotherapy. At the time of surgery, the cancer had metastasized to the left lobe of her left liver. She is currently undergoing a new chemotherapy regimen after developing resistance to Adriamycin.

Maya indicated that she did not support the use of the pink ribbon as a marketing technique nor did she feel that the companies which use the pink ribbon as a marketing tool prioritize the patients first and the profits second. She mentioned that “they make all this

hullabaloo” about breast cancer during October, but for breast cancer patients, “it’s a full-time thing,” not just something to advocate for during one month of the year:

“It’s just an ad, and they’re just trying to sell. They’re trying to get money, you know what I mean? The support for research—that I’m all for. But, like, all this stuff with the pink? I don’t get wrapped up in that. Or, like, trying to buy something. Like a pink ribbon collar around a dog’s neck or something, but breast cancer happens all the time. It’s not just October, right?”

She proceeded to explain that the use of the pink ribbon needs to be more focused on research rather than miscellaneous products that “have no real value.” Maya seemed to believe that extensive research is what saves most of the lives that are affected by breast cancer. She was aware that only a small portion of the proceeds are donated to research and indicated that she wanted that percentage to increase:

“I just wish it was more focused on the research. You know, in helping women instead of just trying to sell us more stuff.”

Maya appeared to have a more negative opinion of the militarization of the BCAM than the three other patients interviewed who had invasive but non-TNBC cancer diagnoses. She disapproved of how combative the language is, but she also expressed that she would prefer the “warrior-ness over the pink.” She said that at least when things are portrayed as a battle, a breast cancer patient is not perceived as “girly” or “feminine,” which are both qualities that she felt the pink ribbon represents and promotes:

“When I lost my hair, my eyebrows, my eyelashes...when I had to do surgery. I definitely didn’t feel—no, I didn’t feel girly or feminine. It was hard. I didn’t feel like a warrior because I didn’t feel like I had anything to fight back with at that time, but at least [that narrative] was better than the pink.”

Maya, herself, wanted to share with the interviewer some things that she felt were the most helpful during her treatment. She explained that her oncologist recommended yoga and meditation, both of which were very helpful. She also enjoyed walks outside in the sunlight

because it helped her feel more upbeat. The most helpful person she mentioned was her middle daughter:

“She took me to concerts, took me out. Kept me happy. Fed me when I was not feeling well, took me out on a cruise. She took care of me, and she was newly married, very newly married, and her husband was so understanding of her having to take care of me. They even explained it all. I didn’t totally get it at first, but she did the research for me.”

She elaborated further that having someone care so deeply about her was the most supported she felt during her treatment, and that she did not feel anything to that degree to the support groups and information session she attended. She also stated that the information provided to her was not enough and, without the supplemental research her daughter did, she would have been “in the dark.”

Participant 7

Patient 7, Theresa, was diagnosed with Stage 2 triple-negative breast cancer of the left breast in December of 2021, premenopause, and was treated with a double mastectomy followed by adjuvant chemotherapy (Adriamycin) and immunotherapy. Theresa’s diagnosis was likely due to genetic factors, given the fact that she had inherited the BRCA I gene from her mother, who also had breast cancer.

Theresa was very critical of the Breast Cancer Awareness Movement and the way the pink ribbon has been used by corporations such as Avon and Estée Lauder. She spent a significant portion of time during the interview voicing her thoughts on the “unhelpful” and “inappropriate” nature of the pink ribbon products that were handed out in the waiting rooms before her chemotherapy infusion sessions. She lamented that, rather than making her feel supported, the pink cosmetic products, notepads, and stress balls that were included in the baggies were “insulting” and not reflective of how terrible she was feeling in those moments:

“I just sat there and thought to myself, “What is this really doing?” Trying to emphasize softness and femininity when it feels very harsh and cold. Yeah, you're trying to be like a warrior. You're trying to survive. It's the opposite of what you actually feel at that moment. I don't even know what they could have given out that would have made me feel better. But they didn't hit the mark on that.”

Theresa articulated to the interviewer that she believed the goodie bags given out in waiting rooms and as gifts to breast cancer patients were a waste of money and resources. She shared the opinion that more money needed to go to research rather than being “wasted on toys that [she] would give to [her] daughter.” She acknowledged that to fund preventative research would be against the interests of the companies who were using the pink ribbon to sell their products (as it would reduce the demographic to which the market), but still felt that breast cancer would be an issue for a long time and that the ultimate focus of such companies should be on eradicating the disease altogether:

“I think more money needs to go to research instead because, if we had more research, maybe we wouldn't even need the awareness because it could be prevented, or, at least, prevented as much as possible. I think that's backwards the way they're dividing [the profits] up.”

When the interviewer followed up by asking what color would be appropriate, if not pink, she seemed at a loss for words before suggesting a different type of ribbon altogether:

“I don't think there's an appropriate color for Breast Cancer Awareness. I think they should make a ribbon with the faces of ladies who've gone through treatment on it, or something. I don't know but pink isn't it.”

The way Theresa understood the pink ribbon, neither the color nor the ribbon itself were meant for breast cancer patients in the first place, but rather, “for everyone else.” She does not own “anything with a pink ribbon on it” and has even developed an aversion to wearing the color itself, even sans ribbon. She vehemently expressed that adding a pink ribbon to a product, no matter what it was, would not necessarily make a breast cancer patient feel better and that the pink ribbon was “more of a feel-good operation” for philanthropists and massive corporations

that “want to appear generous and kind” to the public. She supplemented this by sharing stories of how, even though members of her family bought her pink ribbon products to show their support for her condition, she still felt the need to censor herself and did not disclose the details of her treatment or side effects to any of her family:

“I didn’t want to scare them. I know they wanted to help. I mean, they took the time to buy the pink stuff, but that wasn’t what I really needed. I needed someone to talk to, and they couldn’t fulfill that.”

Thresea also had a major issue with the use of “survivor” as a way to describe breast cancer patients and explained that she does not attend the walks for breast cancer because of how frequently they “celebrate survivors.” Her emotional affect at this point during the interview was noticeably more despondent than the first six interviews conducted, as noted by the interviewer. She expressed that she would,

“never attend one of those walks again. I understand why people go, for sure, but it’s more of a social thing—a fun thing to do on a random weekend in October. The few events I have been to didn’t feel like they were about me at all. My experience just wasn’t and isn’t the same as all those other women, but no one really talks about it. You don’t wanna bring down the mood, you know? You don’t want to be the downer when everyone is trying to be happy. I just felt like—like kind of irrelevant.”

She explained that her experience as a TNBC patient was significantly different from patients with more “curable illnesses” and that the “narrative [the BCAM] presents was not “[her] narrative.” She did not feel that the militant terminology was or would ever be reflective of her experience and continuously served to make her feel like an outsider when she should have been getting most of the support due to the severity of her condition.

When asked what changes could be made to improve the BCAM or her individually as a patient, she emphasized the importance of research and practical applications of the funding:

“I see local businesses painting their trucks pink. And this is painful. They should take that money and write a check to a research hospital. Take that money and write a check to a lady who is going through treatment. We have several organizations here in

the county that take that money and actually use it for patients. One is *To Ride To Survive*. They provide gas cards. Take your money and give it to them instead of donating it to Avon to make everything pink, you know? That's just the way I feel about it.”

She was aware of how few organizations donate a significant portion of the funds to research and expressed her dismay at that fact. She concluded the interview by requesting the interviewer to emphasize the importance of research to breast cancer patients who do not have many options in this study, to which the interviewer replied that she would.

Participant 8

Patient 8, Sophia, was diagnosed with Stage 2 triple-negative breast cancer in the left breast in April of 2018. She was initially treated with a lumpectomy and adjuvant chemotherapy. She discovered a recurrence in her liver via PET scan in 2022 and is currently being treated with Taxol and immunotherapy.

Like Theresa, Sophia also had a slightly more negative outlook on the Breast Cancer Awareness movement compared to the six other participants who were diagnosed with relatively more treatable breast cancer types. She felt that the heavy emphasis on pink was a waste of time and resources that could be allocated to more “healful measures”. She expressed her disgust at the big displays of pink showcased at BCA events:

“Have you ever seen those pink balloon arches? They probably cost \$300+. Take that money and give it to somebody who needs it. That's the way I feel about all of the pink crap.”

She also shared the opinion that more money should specifically go into research “into what's causing it,” and not just “how to treat it once it’s happened.” She explained that, like herself, there are many women who receive a diagnosis, yet have no options after that because the cancer diagnosis is “too aggressive” or too “unknown.” For these women, she explained,

curative treatment is no longer applicable, lest the oncological team find a specific cure to their cancer:

“I believe that prevention is always better than a cure. Prevention is more universal. It can help everyone, both the people who get diagnoses that can be treated and those who get the untreatable ones. Why? Because you might avoid the diagnosis altogether. Even if you get rid of the cancer, it can always come back, but it can’t come back if it never happened.”

Sophia indicated that she thought more severe and graphic commercials should be used to promote Breast Cancer Awareness because it more accurately reflects the reality of patients’ situations:

“I know it's sad when you watch those commercials when they have people the way they actually look with cancer. But I think that is more realistic. Then you have someone that just looks like you, because that’s what happens when you're [in the infusion room] and you're going through it. When I was going through it I was like, “Why can't I look like [the hyper-feminine depictions of breast cancer patients]?” It's not reality. They’re trying to say “Oh, you could go through chemo and everything, and you could have, like, beautiful hair, and and your eyebrows look great all the time,” but that’s just a fantasy—it's not realistic”

Sophia was intensely critical of all militant terminology used in the Breast Cancer Awareness Movement. She talked extensively about how the terminology was not all-encompassing and makes her feel excluded:

“People really need to think about these terms. Warrior? Am I fighting a battle? It's not a battle. I'm not because I don't have the proper weapons. You don't even know what the weapons are to fight. You typically go armed and ready for a battle. So even that term, you know, “we're warriors! We're fighting this battle!” Okay, but some people lose the battle. you know. What about those people who did not make it, you know? So what? They’re losers? Yes? No? Well, that’s kind of what you’re saying. Words are important.”

When asked what initiatives could improve her experience, she said that the companies who support BCA need to “give [patients] what they really need.” She told a story about how, before she was diagnosed, she received a pink ribbon candle at a mammogram and she thought it was “pretty cool,” but after diagnosis, she felt that it was a reminder of her condition rather than a product that granted her stress relief. She said that even a “cup of tea” or “something that’s going to make her feel good” would be better than the “junk” that much of the pink ribbon branding sells.

Additional comments and trends

The interviewees had varying degrees of knowledge regarding the allocation of funds that are raised by the Breast Cancer Awareness walks and pink ribbon products. Six of the interviewees were not aware that the majority proceeds from much of the Breast Cancer Awareness movement are not donated for research purposes. Both TNBC patients were aware of this information. All interviewees excluding one, Regina, reported that they do not regularly participate in pink ribbon events such as walks and 5K races.

5. Discussion

a. The Commercialization of the Pink Ribbon and Capitalist Influence on the BCAM

Both the data from the quantitative and the qualitative portions of this study supported the prediction that the study participants would have issues regarding the visibility of commercial marketing and profits that corporations collect using symbols of the Breast Cancer Awareness Movement, such as the pink ribbon. According to the 5-point Likert Survey, although 86% of survey respondents indicated that they have purchased pink ribbon merchandise (Figure 8), 94% of respondents indicate that they are at least partially critical of the Breast Cancer Awareness Movement (Figure 14), although the percentage of respondents who answered “Yes” to the former question may have been lower if it was asked after the latter. One reason for this apparent discrepancy could be that patients become disillusioned with the efforts and effects of the BCAM after experiencing the struggles and hardships that accompany a breast cancer diagnosis; the problematic aspects of the movement may not be visible to them at first, which is why so many respondents indicated that they had indeed purchased something with a pink ribbon. This interpretation is supplemented by Sophia’s story about the pink candle she received at a mammogram which, post-diagnosis, she thought was distasteful and became critical of the

decision on the behalf of the corporation to give out something “so trivial.” Only after diagnosis did she develop such critique, however, so this could be a potential explanation for the Likert Survey results.

Every single woman interviewed in this study was critical of at least some portion of the commercialization of BCA. From the interview responses, it appears that one prominent issue with the way major corporations such as Avon, Estée Lauder, and Susan G. Komen approach the issue of breast cancer is that, when they do give funding to research institutions for breast cancer (not that the funding given is close to the majority of profits they make off of their pink ribbonbranded merchandise and events), most of the grants are given to research proposals addressing curative measures rather than preventative ones. Dr. LaTonia Taliaferro-Smith, an instructor of hematology and medical oncology for eight years at the Winship Cancer Institute of Emory University and who held her own lab shared during a discussion of BCA profit distribution that she had never witnessed a grant for preventative research receive funding from any BCA source in the entirety of the time she worked for Winship. The pink ribbon movement has outgrown the values and influence of a grassroots social movement and has become intimately intertwined with a capitalist agenda that pushes the interests of major corporations. If the research grants funded by companies who wish to support breast cancer were used for preventative investigations or genetic testing, the research itself would be dipping into and potentially decreasing the main demographic that such corporations market to, so it is innately not in their best interest to fund such research, in an ironic twist working against the populations that the Breast Cancer Awareness Movement is supposed to help.

Perhaps it may be that a more comprehensive approach to cancer treatment would not only help decrease the mortality rate from its standstill level but also more fully benefit breast

cancer patients at every stage of the disease, not just those who have been diagnosed with treatable cancer and are currently undergoing treatment or are in remission. For example, it is quite doubtful that a patient diagnosed with triple-negative breast cancer for which the average survival rate is five years and against which there is no effective targeted cure would be interested in running 5Ks and purchasing pink ribbon-branded products, all of the profits of which are donated to curative treatment for other types of breast cancer with higher survival rates and more optimistic prognoses.

In addition, interview participants shared a consensus that, in many instances, the pink ribbon is misused. The patients in this study were dissatisfied with what products were permitted to use the pink ribbon for two reasons. First of all, some products which showcase the pink ribbon that are distributed to patients, such as the candle mentioned above, teddy bears with pink ribbons on their feet (such as the Susan G. Komen Dakin Bear), and mini notebooks and journals are not inherently helpful to the specific needs of a breast cancer patient. Several women described such products as “useless” and “junk” because adding a pink ribbon to a product does not necessarily address the bona fide needs of patients, indicating to the patients that the companies which use the pink ribbon to market to them do not consider the actual breast cancer patients’ experiences and their primary concern are the profits that they keep for themselves. Secondly, many corporations that use the pink ribbon as a marketing device do not clearly state what percentage of the profits go to research and awareness. The lack of transparency that pervades the commercial activities of several BCA initiatives instills a false sense of aid and action in the consumer who makes the purchase. Furthermore, although 79% of survey respondents indicated that they were familiar with the term “pinkwashing,” only two of the interview participants, Theresa and Sophia, were able to accurately define the term when asked,

indicating that perhaps there exists a misunderstanding of the term “pinkwashing.” The other six women defined pinkwashing as the overuse of the pink ribbon but had little-to-no knowledge about the use of carcinogenic materials in BCA-marketed products. Half of the interview respondents had never heard of corporations using cancer-causing substances in the pink ribbon merchandise at all. This suggests that there may exist a pervasive lack of knowledge about potential pinkwashed products. When pink ribbon purchases are made, therefore, transactions may be uninformed, and companies whose products may cause cancer continue to profit off those they claim to want to help.

b. The Militarization of Terminology Used in Breast Cancer Discussions and Discourse

Not all participants had issues with the militant terminology used in breast cancer discourse. Within the patients interviewed, there seemed to be a positive correlation between poorer prognosis and more critical views of militant terminology. The data suggested that those with poorer prognoses based on initial diagnosis had stronger negative opinions of militant terminology, which was a trend we predicted to see in the stigmatization of breast cancer patients, rather than with militant terminology.

Linda and Regina, the two patients diagnosed with in situ (non-invasive) cancer with objectively the best prognosis, did not appear to have any issue with terms such as “survivor” and “warrior,” nor did they see an issue with the use of “battle” to describe the mechanism of patients undergoing treatment and dealing with the side effects of breast cancer. Even when the interviewer presented a situation where their prognosis may not have been as optimistic, both Linda and Regina maintained their positive and even encouraging attitude towards the use of this terminology, suggesting that the prognosis of the breast cancer type may have some effect on how terminology is interpreted.

Rena, Halema, Yara, and Maya, the four patients who were diagnosed with invasive but hormonally targetable (IDC and ILC) breast cancers appeared to be slightly critical of the militarization of the terminology but also shared the opinion that specific terminological concerns are not the most problematic parts of Breast Cancer Awareness discourse and were more focused on the distribution of profits made through the use of breast cancer marketing to preventative research or palliative treatment that addresses the side effects of the disease. The use of specific terminology while appearing “a little contradictory” and “not making much sense, when you think about it,” at least according to Halema and Yara, was not perceived by the patients interviewed as psychologically harmful or inherently bad for breast cancer patients. When the interviewer followed up their nonchalance by asking whether their opinions would change if the breast cancer they were diagnosed with had a poorer prognosis, all four appeared to be slightly more critical, or at least more thoughtful, about the terms used to describe breast cancer patients. A few patients also raised the point that the use of “battle” to describe the struggle of breast cancer patients at least indicates that the process is something extraordinarily difficult and does not “pretty it up” as a symbolic pink ribbon would suggest. This suggests that the use of militant terminology is not necessarily a priority for women whose prognoses have a higher likelihood of long-term survival but is something they understand may have flaws and may be worthy of critique.

Theresa and Sophia, the two patients who were diagnosed with triple-negative breast cancer (a notoriously difficult cancer to treat due to no hormonally targetable sites resulting in a poor prognosis) were both dissatisfied with the term “survivor,” although Theresa did not seem as negatively affected by the term “warrior” as Sophia, who had a metastatic recurrence after her initial treatment and, as such, her prognosis was objectively bleaker according to reported

survival rates for TNBC patients whose cancers have metastasized (American Cancer Society, 2023). According to Sophia, “survivorship status is not a guarantee, and, for some of us, is more of a medical miracle,” so she would not “feel any sort of solidarity” at celebrations of survivors during the BCA events. In the case of a poor prognosis, terminology can serve as a reminder of the severity of one’s illness rather than a status to strive towards.

c. Stigmatization due to the Breast Cancer Awareness Movement

In this study, two major sources of stigmatization originating from the Breast Cancer Awareness Movement and pink ribbon marketing were identified as problematic for the breast cancer patients interviewed. Contrary to our hypothesis, there was no correlation between diagnosis and critical opinion of this topic; all patients interviewed felt similarly about the stigma around pink ribbon marketing. There were mixed opinions about how breast cancer should be represented, although no detectable correlations according to diagnosis or prognosis.

The first was the goodie bags and supplemental gifts given to breast cancer patients in waiting rooms and by family, friends, and organizations who want to support them during treatment and post-treatment. Several participants expressed that the goodie bags handed out in waiting rooms which contain cosmetics with pink ribbon branding, pink teddy bears, journals with small pencils or crayons attached, and various other small trinkets have little to no practical value. Not only are the items contained in such “gifts” infantilizing, but they are also a waste of the profits being collected through the use of breast cancer marketing. As Halema put it,

“A pink teddy bear isn’t going to do much for my radiation burns. Crayons aren’t going to draw away scars. Do you know what would be more helpful? A tub of Aquaphor.”

She went on to suggest that if it were a necessity for pink-ribbon branded products to be purchased and distributed, it would be more helpful to include pink-ribbon-branded sample-sized

products such as Aquaphor Healing Ointment in those goodie bags rather than miscellaneous pink items which “just serve as a reminder that [she has] become more helpless over [her] health than ever before.”

The other source of stigmatization was the representation of patients used in Breast Cancer Awareness Marketing. Several participants interviewed had mixed opinions on what imagery should be on posters, promotional materials, and advertisements for the Breast Cancer Awareness Movement campaign. For example, Halema felt that the Breast Cancer Awareness organizations] “need to show the scars” to “shock people” into getting mammograms and contributing positively to the movement, however, others, such as Rena and Regina, felt that showing radiation burns and mastectomy scars on advertisements was taking the shock factor too far.

The disagreement on whether such imagery should be displayed to the general public is understandable given the history of censorship of secondary sex characteristics such as breasts in the majority of Western media. On one hand, showing graphic images of breasts would certainly be a shocking image to people who have never seen the true side effects of cancer treatment. Both chemotherapy and radiation therapy are very harsh treatments that take a tremendous toll on the body and making the imagery more familiar to both breast cancer patients and the general public could make those “disfigurations,” as Halema’s oncologist put it, more acceptable to look at. It seems that the patients who were interviewed were continuously frustrated by the hyperfemininity that was pushed forth by the Breast Cancer Awareness Movement. For example, including cosmetic products with pink ribbons on them may subtly encourage their usage rather than making patients feel more comfortable with the natural state of their bodies. This effect may be intensified by the deterioration of the human body that cancer treatment causes, which may

exacerbate feelings of insecurity about hair loss and neuropathy, to name a few physical side effects.

On the other hand, the Breast Cancer Awareness Movement has been in effect since the mid-to late-20th century and, in the time since its conception, the mammography rates have increased threefold while the mortality rates have not decreased (Karaby and Kadioglu, 2017). These conflicting trends indicate that although more people are aware of the importance of mammograms and are indeed acting upon that awareness, the outcome is still the same, regardless of whether the cancer was detected or not. This supports the claim that the Breast Cancer Awareness Movement is hyper-focused on only one part of the life cycle of a breast cancer patient, diagnosis, and neglects prevention (pre-diagnosis) and treatment and palliative care (post-diagnosis). As a result, although showing graphic imagery of breasts may indeed deliver shock value, the benefit of such shock value is minimal as the majority of the demographic to which the Breast Cancer Awareness Movement caters (namely white, middleclass women) are already aware of the importance of getting mammographies. The value of diversifying representation and making the graphic nature of breast cancer more visible, then, is to make breast cancer patients feel more comfortable with the way their bodies look and any way their body may change so that the psychological stress of impeding and/or ongoing physical changes does not compound on the already existing physical stress of treatment. *d. Solutions*

One important aspect of the interviews was surveying the participants on potential alterations or solutions to problems identified with the Breast Cancer Awareness Movement. Throughout the interview process, there were several problems identified with how much and where the profits from Breast Cancer Awareness campaigns were distributed as well as some potential solutions that could help make life more manageable for current and future patients.

Potential areas of improvement based on the interview responses are henceforth listed below:

1. A greater portion of the profits from Breast Cancer Awareness marketing needs to be distributed to research. Of the funds that are given to promote more research, a greater proportion should be dedicated to preventative research and treatment. Cancer is a disease that can be very difficult to treat once diagnosed. Increasing the rates of diagnosis is good in itself, but once a patient has received a positive diagnosis, there must be treatment options available to them. Unfortunately, some cancers such as triple-negative breast cancer, are not targetable and therefore have no known effective treatment other than general chemotherapy or radiation therapy. For such untreatable cancers, the best method to save lives is to prevent a positive diagnosis in the first place. Including funding for genetic testing is also another suggestion that two patients provided. As the majority of cancer patients do not have a family history of cancer, a greater emphasis on genetic testing for spontaneous cancerous mutations could nip a tumor in the bud before it develops (National Cancer Institute, 2022). For those with a family history, such as the notorious BRCA genes, early genetic testing has the potential to save lives as well.
2. A greater proportion of profits should be redistributed to promote products that help breast cancer patients manage the symptoms of their treatment. Pink ribbons on trinkets that have little practical value (as discussed in the *Stigmatization* section of the discussion) are not very helpful to the management of breast cancer in the quotidian lives of patients. Adding pink ribbon branding to products such as Aquaphor which provide relief to patients who develop radiation burns from

radiation treatment, or food products that help promote metabolism, strength, and immunity (such as green tea) may be more productive for breast cancer patients. Funding exercise, yoga, and meditation classes for patients currently undergoing treatment were also mentioned as more helpful than pink ribbon goodie bags (Janelsins et al., 2011).

3. The information regarding what the patient's diagnosis means, what treatment they will be receiving, the mechanisms that treatment entails, what the symptoms and side effects of such symptoms are, the duration of treatment, and future plans needs to be made more clear to patients upon initial diagnosis and throughout the treatment process. Every single patient interviewed mentioned that they wish they had more comprehensible information available to them when they were first made aware of their diagnosis. Heavy use of medical jargon appears to be daunting to women diagnosed with breast cancer, especially to those who have no prior experience in the healthcare field or have no close friends and/or family members who are healthcare workers. Halema suggested a laminated card (with a pink ribbon on it—if that's what it takes to get it funded) with a list of national and local resources for patients diagnosed with breast cancer. These resources could include a community or source where they could ask questions, a wig supplier, various support groups, general information about Breast Cancer Awareness, and any other resources that could prove helpful.
4. The companies that use the pink ribbon to market their products must be more transparent about pinkwashing potentially carcinogenic products or products containing known carcinogens. Four of the participants did not know about

controversial pinkwashing scandals, for example, how Yoplait's pink lidded yogurt "was made with dairy stimulated with the hormone rBGH," which significantly increases levels of human growth hormone and may contribute to the development of cancer, or KFC's "Buckets for the Cure" campaign which included a partnership with the Susan G. Komen foundation, despite extensive research on how fried food contributes to obesity and obesity being a risk factor for cancer (American Cancer Society, 2014) (Breast Cancer Action, 2022). Although the manufacturers may not be entirely certain whether a product has the potential to cause or contribute to the development of cancer, if they are adding a pink ribbon to the product, it should be made clear, in layman's terms, that the product may contain cancer-causing properties. It should also be made clear what percentage of the profits are donated to Breast Cancer Awareness to avoid situations such as "Buckets for the Cure", where, hidden at the bottom of the website, it was stated that the individual consumer purchase did not directly contribute to the total profits for BCA, but, rather, that the percentage of funds allocated to BCA would be determined by the KFC restaurant operators (Kinsman, 2010).

e. Study Limitations

It should be noted that the results of this study cannot be generalized to reflect the opinions of all breast cancer patients. As only one researcher was conducting interviews over a few months, only eight interviews were able to be completed, transcribed, and analyzed. It should be noted that 47 more requests for interviews were submitted through the Likert survey, however, the interviewer did not have enough time to interview, transcribe, and analyze such a

massive amount of data in the timeframe available for this project. The greater value of this study was to identify key themes, patterns, and problems with the Breast Cancer Awareness Movement from the perspective of the patients themselves that could be used in future research and subjected to longer, more comprehensive investigations than what could have been realistically accomplished in a year-long senior honors thesis.

Although the Likert survey had significantly more respondents ($N=161$) than patients interviewed ($N=8$), the survey was also subject to sampling bias. The survey was available in various Facebook support groups that may attract a certain demographic of patients to join. The patients who see an opinion survey on the Breast Cancer Awareness Movement and choose to spend their time taking the survey also may share more critical opinions on the Breast Cancer Awareness Movement and make certain trends identified in the quantitative analysis section more widespread and/or skewed than what the actual distribution of criticism and support for the BCAM may be. In future studies following up on themes addressed in this one, it may be better to recruit from waiting rooms, infusion areas, and information centers in a cancer clinic or hospital system using a QR code or a link to the survey on the flyer. Recruiting patients through social media alone may produce a biased and overly critical sample. In addition, most of the patients who were interviewed were white Caucasian, a trend that may be linked to the recruitment methods used as many Facebook support groups show overrepresentation of a white, middle-class, and female demographic. In the future the Likert survey should also include cognitive testing of the survey questions.

One of the Likert survey questions was problematic as well. In Figure 10, the survey question detailed asked respondents if they believe that pink ribbon merchandise is “helpful” to the breast cancer community, however, the Likert survey did not define “helpful” to the study

participants. The survey responds may have interpreted this phrasing in different ways, such as helpful in term of raising awareness, proving research funding, or offering a source of emotional support. As such, this study may also have an issue of construct validity and, in future explorations, potentially ambiguous terminology should be clearly defined.

In hindsight, the Likert survey should have included a few more open-ended questions for survey participants who were not able to complete an interview or not comfortable doing so to share their opinion or any comments on the topic that they had. Another way that the quantitative data collection could have been improved is by stratifying the data based on breast cancer type. Although there was space in the survey to include which type of breast cancer the patient was diagnosed with, this question was too open-ended and resulted in a slew of broad categories that were not very meaningful. Example responses included “Stage 1,” “Stage 2,” “Metastatic,” “Grade 3,” and various other classifications of breast tumors and cancers that do not all follow the same scaling system, which made any comparative approach to those responses difficult and not very meaningful due to lack of consistency. In future research, the directions on the survey should more clearly indicate what type of breast cancer identification/scaling system the researchers are looking for so that the survey responses can be stratified by diagnosis to observe any trends based on factors such as invasiveness and prognosis.

6. Concluding Remarks

Although not necessarily generalizable, this study has provided an updated narrative review of major problem areas previously identified with the Breast Cancer Awareness Movement, especially by addressing potential disparities between women with pre- and postmenopausal cancers. While we do not advocate for the destruction and abandonment of the pink ribbon as a symbol of Breast Cancer Awareness, it is clear that the pink ribbon needs some rebranding, namely in the products which use it as a marketing tool and the somewhat false representation of women who have received a breast cancer diagnosis and who went through or are currently enduring treatment. In addition, there appears to be an unaddressed discrepancy between the information provided to patients and the information they truly understand, given that most patients have little to no medical knowledge or training. As every participant we interviewed expressed that she would have appreciated more information, the communication between healthcare professionals and the tools available to breast cancer patients to understand what is happening to them seems to be in dire need of improvement. As far as commercialization goes, corporations that ascribe to the BCAM and use the pink ribbon must become more transparent about where their profits are going. Surveying the women whom they wish to support could shed light on the types of research that their primary demographic would find most helpful, not to mention the types of products patients themselves could get the most use out of. While there may be many more criticisms of the current state of the BCAM, these were the most universal among the patients interviewed. There is great importance in taking time to listen to what breast cancer patients want out of the BCAM. For those whose cells have betrayed them and whose physical health is largely out of their control, listening to and incorporating their

actionable suggestions may provide them with a much-needed, much-appreciated sense of agency.

7. Works Cited

- American Cancer Society (2014). Recombinant Bovine Growth Hormone. <https://www.cancer.org/healthy/cancer-causes/chemicals/recombinant-bovine-growthhormone.html#:~:text=The%20available%20evidence%20shows%20that,the%20risk%20of%20developing%20cancer>
- American Cancer Society (2023). *Triple-Negative Breast Cancer*. <https://www.cancer.org/cancer/breast-cancer/about/types-of-breast-cancer/triplenegative.html>
- Ashing-Giwa, K. T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., & Hills, D. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psychology of Women Quarterly*, 28(4), 408–428. <https://doi-org.proxy.library.emory.edu/10.1002/pon.750>
- Bell, K. (2014). The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease. *Social Science & Medicine*, 110, 56-63. <https://doi.org/10.1016/j.socscimed.2014.03.031>.
- Berry, T. R., Stearns, J. A., Courneya, K. S., McGannon, K. R., Norris, C. M., Rodgers, W. M., & Spence, J. C. (2016). Women's perceptions of heart disease and breast cancer and the association with media representations of the diseases, *Journal of Public Health*, 38(4), 496–e503. <https://doi.org/10.1093/pubmed/fdv177>
- Bode, R. (2010). The sense of an illness and breast cancer culture. *Canadian Woman Studies*, 28(2), 95–98.
- Bower, J. E., Meyerowitz, B. E., Desmond, K. A., Bernaards, C. A., Rowland, J. H., & Ganz, P. A. (2005). Perceptions of positive meaning and vulnerability following breast cancer: Predictors and outcomes among long-term breast cancer survivors. *Annals of Behavioral Medicine*, 29(3), 236–245. https://doi.org/10.1207/s15324796abm2903_10
- Breast Cancer Action (2022). *Campaigns*. <https://www.bcaction.org/about-think-before-you-pink/campaigns/>
- Carlson, C. R. & Le, U. (2017) Trim the Ribbon: Reconsidering the Ethics of Breast Cancer Campaigns. *Journal of Media Ethics*, 32(3), 168-178. <https://doi.org/10.1080/23736992.2017.1329018>
- Cone Communications. (2012) *Beginning to doubt 'pink': Consumer perceptions of breast cancer cause marketing*. <http://www.conecomm.com/insights-blog/beginning-todoubt-pink-consumer-perceptions-of-breast-cancer-cause-marketing?rq=breastcancer>.
- Ehrenreich B (2001) Welcome to Cancerland: a mammogram leads to a cult of pink kitsch *Harpers Magazine*, 11, 43-53. <https://archive.harpers.org/2001/11/pdf/HarpersMagazine-2001-11-0075358.pdf?AWSAccessKeyId=AKIAJUM7PFZHQ4PMJ4LA&Expires=1568333045&Signature=HWjBLPajQSIfCgZFD11dhshivZc%3D>
- Elliott, C. (2007). Pink: Community, contestation, and the colour of breast cancer. *Canadian Journal of Communication*, 34(3/4), 521–536. <https://doi.org/10.22230/cjc.2007v32n3a1762>
- Fernandez, S. M. (1998) Pretty in pink: the life and times of the ribbon that tied breast cancer to corporate giving *Mamm* 52, 54–55, 64
- Fernandez, S. M. (2019). *History of the pink ribbon*. <http://thinkbeforeyoupink.org>

- Ferraro S (1993) You can't look away anymore: the anguished politics of breast cancer
New York Times Magazine 25–27, 58–60
- Harvey, J. A., & Strahilevitz, M. A. (2009). The power of pink: Cause-related marketing and the impact on breast cancer. *Journal of the American College of Radiology*, 6(1), 26–32.
<https://doi.org/10.1016/j.jacr.2008.07.010>
- Janelins, M. C., Mustian, K. M., Peppone, L. J., Sprod, L. K., Shayne, M., Mohile, S., Chandwani, K., Gewandter, J. S., & Morrow, G. R. (2011). Interventions to Alleviate Symptoms Related to Breast Cancer Treatments and Areas of Needed Research. *Journal of cancer science & therapy*, 2(2), 1-14. <https://doi.org/10.4172/1948-5956.s2-001>
- Kasper, A. & Ferguson, S. (2000). Breast cancer: society shapes an epidemic. *St. Martin's Press*
- Karabay, O., Hasbahceci, M., & Kadioglu, H. (2018). Impact of Breast Cancer Awareness month on detection of breast cancer in a private hospital. *Journal of International Medical Research*, 2, 619-625. <https://doi.org/10.1177/0300060517699988>.
- Kimberly A. T. & Jana N. K. (2019). Don't give US pink ribbons and skinny girls: Breast cancer survivors' evaluations of cancer advertising, *Health Marketing Quarterly*, 36(3), 186-202, <https://doi.org/10.1080/07359683.2019.1618007>
- King, S. (2004). Pink Ribbons Inc: breast cancer activism and the politics of Philanthropy. *International Journal of Qualitative Studies in Education*, 17(4), 473-492, <https://doi.org/10.1080/09518390410001709553>
- King, S. (2010). Pink Diplomacy: On the Uses and Abuses of Breast Cancer Awareness. *Health Communication*, 25(3), 286-289, <https://doi.org/10.1080/10410231003698960>
- Kinsman, K. (2010). *Activists call foul on KFC bucket campaign*. CNN.
<http://www.cnn.com/2010/LIVING/homestyle/04/28/kfc.pink.bucket.campaign/index.html>
- Klawiter, M. (1999). Racing for the cure, walking women, and toxic touring: mapping cultures of action within the Bay Area terrain of breast cancer. *Social Problems*, 46(1), 104–126.
<https://doi.org/10.2307/3097164>
- Leopold, E. (1999). *A darker ribbon: breast cancer, women, and their doctors in the twentieth Century*. Boston, Beacon Press.
- Lorde, A. (1980). *The cancer journals* The Spinster's Ink
- Lubitow, A., & Davis, M. (2011). *Pinkwashing: Corporate sponsored cancer*. Forbes.com.
<http://www.forbes.com/sites/meghancasserly/2011/07/11/pinkwashing-corporatesponsored-cancer/#4475c1aacdc6>
- National Cancer Institute (2022). *The Genetics of Cancer*.
<https://www.cancer.gov/about-cancer/causesprevention/genetics#:~:text=Up%20to%2010%25%20of%20all,of%20getting%20cancer%20is%20increased>.
- Nishimura, Y., & Acoba, J. D. Impact of Breast Cancer Awareness Month on Public Interest in the United States between 2012 and 2021: A Google Trends Analysis. *Cancers*, 14, 10. <https://doi.org/10.3390/cancers14102534>
- Pezullo, P. C. (2003). Resisting 'National Breast Cancer Awareness month': The rhetoric of counterpublics and their cultural performances. *Quarterly Journal of Speech*, 89(4), 345–365. <https://doi.org/10.1080/0033563032000160981>
- Solomon, A. (1992). The politics of breast cancer. *Camera Obscura*, 259, 157–177.

- Stabiner, K. (1997). *To dance with the devil: the new war on breast cancer*. Delacorte Press.
- Surakasula, A., Nagarjunapu, G. C., & Raghavaiah, K. V. (2014). A comparative study of pre- and post-menopausal breast cancer: Risk factors, presentation, characteristics and management. *Journal of research in pharmacy practice*, 3(1), 12–18.
<https://doi.org/10.4103/2279-042X.132704>
- Think Before You Pink (2016). *4 questions to ask before you buy pink*.
<http://thinkbeforeyoupink.org/resources/before-you-buy/>.
- Westerveldt, A. (2011). The pinkwashing debate: Empty criticism or serious liability? *Forbes.com*.
<http://www.forbes.com/sites/amywestervelt/2011/11/04/the-pinkwashingdebate-empty-criticism-or-serious-liability>.
- Yedjou, C. G., Sims, J. N., Miele, L., Noubissi, F., Lowe, L., Fonseca, D. D., Alo, R. A., Payton, M., & Tchounwou, P. B. (2019). Health and Racial Disparity in Breast Cancer. *Advances in experimental medicine and biology*, 1152, 31–49. https://doi.org/10.1007/978-3-03020301-6_3
- Zoom Video Communications (2023). *Zoom* (5.13.11) Zoom Video Communications.
<https://zoom.us/support/download?os=android>

8. Appendix

The following appendix contains a list of acronyms and/or terms used as well as the landing pages and following questions administered as part of the Likert Survey as well as a list of ethnographic questions posed to interviewees during the one- to two-hour conversational interview for qualitative analysis. Both the Likert Survey and the list of ethnographic questions were IRB-approved before being introduced to study participants.

a. List of Terms and Acronyms

BCA = Breast Cancer Awareness

BCAM = Breast Cancer Awareness movement

DCIS = ductal carcinoma in situ

IDC = invasive ductal carcinoma

LCAM = lung cancer awareness movement

MG = mammography/mammogram

PCAM = pancreatic cancer awareness movement

TNBC = triple-negative breast cancer

b. Likert Survey

Block 1

Introduction and Study Overview

Thank you for your interest in our breast cancer discourse research study. We would like to tell you what you need to think about before you choose whether or not to join the study. It is your choice. If you choose to join, you can change your mind later on and leave the study.

The purpose of this study is to investigate the impact that the breast cancer awareness movement (BCAM) has had on breast cancer survivors. Our research team aims to learn from and understand the BCAM from the perspective of actual breast cancer survivors. The study will survey opinions on perspectives, symbols, successes and criticisms of the BCAM, including common phrasing or tones used when talking to or about breast cancer survivors, the commercialization of breast cancer and pink ribbon products, and any impact the BCAM has had on the experience of a breast cancer survivor. This study will take between about 10 minutes to 2 weeks to complete.

If you join, you will be asked to complete a short survey asking you to rate your opinions on a scale of 1 to 5 in response to a list of statements, 1 being strongly agree and 5 being strongly disagree. At the end of the survey, you may have the option for a one-hour follow-up interview regarding your responses. If this question appears at the end of your survey, you will be asked to indicate your response before completing the survey. If you wish to participate in the follow-up interview, a team member will contact you within the following week to schedule a time to meet. The meeting can either take place on zoom or on the phone and an audio transcript of the meeting will be recorded. Once the meeting is over, the study team member will uncouple your responses with your personal information and all your identifying information will be discarded within 24 hours. At the beginning of the meeting, the interviewer will provide you contact information if you wish to redact any portion of your responses following the conclusion of the meeting. Please note that, as audio recordings are personal identifying information, these will also be discarded 24 hours following the conclusion of the interview. If you wish to redact any of their responses, you must contact the research team within 24 hours after the conclusion of the interview.

The topics discussed in the 5 point survey and the follow-up interview may be triggering

The topics discussed in the 5 point survey and the follow-up interview may be triggering for some individuals. While it is difficult to quantify the psychological impact of such discussions on study participants, it should be noted that the subject matter to be discussed may be sensitive, including recalling memories of diagnoses and personal feelings on certain events of phenomena related to discourse surrounding the disease that the study participant have been diagnosed with.

You may not benefit from joining the study. Your condition may improve while you are in this study or it may get worse. This study is designed to learn more about the relationship between the breast cancer awareness movement and breast cancer patients. The study results may be used to help others in the future.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents.

Storing and Sharing your Information

We will store all the data that you provide using a code. We need this code so that we can keep track of your data over time. This code will not include information that can identify you (identifiers). Specifically, it will not include your name, initials, date of birth, or medical record number. We will keep a file that links this code to your identifiers in a secure location separate from the data.

We will not allow your name and any other fact that might point to you to appear when we present or publish the results of this study.

We will not share the data, linked by the study code, with other researchers at Emory, or with researchers at other institutions that maintain at least the same level of data security that we maintain at Emory. We will not share the link between the study code and your identity.

We will not place your data in public databases.

Confidentiality

Certain offices and people other than the researchers may look at study records.

Government agencies and Emory employees overseeing proper study conduct may look

at your study records. These offices include the Office for Human Research Protections, the funder, the Emory Institutional Review Board, the Emory Office of Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

People who will use/disclose your information

The following people and groups will use and disclose your information in connection with the research study:

- The Principal Investigator and the research staff will use and disclose your information to conduct the study.
- Emory may use and disclose your information to get payment for study related activities and to run normal business operations.
- The Principal Investigator and research staff will share your information with other people and groups to help conduct the study or to provide oversight for the study.
- The following people and groups will use your information to make sure the research is done correctly and safely:
 - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research
 - Public health agencies.
 - Research monitors and reviewer.
 - Accreditation agencies
 - Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your information may be shared with that new institution and their oversight offices. Information will be shared securely and under a legal agreement to ensure it continues to be used under the terms of this consent

Contact Information

If you have questions about the study procedures, appointments, research-related injuries or bad reactions, or other questions or concerns about the research or your part in it, contact Pamela Beniwal at (973) 519-9527 or at pbeniwa@emory.edu:

This study has been reviewed by an ethics committee to ensure the protection of

3/9/23, 2:45 PM

Qualtrics Survey Software

research participants. If you have questions about your **rights as a research participant**, or if you have **complaints** about the research or an issue you would rather discuss with someone outside the research team, contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu.

To tell the IRB about your experience as a research participant, fill out the Research Participant Survey at <https://tinyurl.com/ycewgkke>.

Do you agree to take part in this study? By selecting "yes", you indicate that you have read the informed consent discussion and wish to proceed with the survey.

- Yes
 No

Default Question Block

Are you above the age of 18?

- Yes
 No

Are you female?

- Yes
 No

Do you identify as a woman?

- Yes
 No

Have you been diagnosed with breast cancer?

- Yes
 No

Please indicate what type of breast cancer you have been diagnosed with:

My diagnosis has affected my quality of life:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

My diagnosis has shaped my identity:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I know other individuals who have been diagnosed with my illness:

- Yes
- No

I have sources of social support that help me with my condition:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I am familiar with the Breast Cancer Awareness movement:

3/9/23, 2:45 PM

Qualtrics Survey Software

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I am familiar with the Susan G. Komen Foundation:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

The Breast Cancer Awareness movement (i.e. walks, merchandise, posters, general awareness) has provided me with a source of social support:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

The Breast Cancer Awareness movement (i.e. walks, merchandise, posters, general awareness) has impacted my quality of life:

- Strongly Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I have purchased "pink ribbon" themed merchandise:

- Yes

3/9/23, 2:45 PM

Qualtrics Survey Software

 No

I have been given "pink ribbon" themed merchandise:

 Yes No

"Pink ribbon" themed merchandise is helpful to the breast cancer community:

 Strongly Agree Somewhat agree Neither agree nor disagree Somewhat disagree Strongly disagree

I have heard that some people in the breast cancer community are critical of the "pink ribbon" movement.

 Strongly Agree Somewhat agree Neither agree nor disagree Somewhat disagree Strongly disagree

I am familiar with the term "pink-washing:

 Strongly Agree Somewhat agree Neither agree nor disagree Somewhat disagree Strongly disagree

I am critical of at least some aspects of the Breast Cancer Awareness movement

 Strongly Agree

3/9/23, 2:45 PM

Qualtrics Survey Software

- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Would you be willing to participate in a follow-up interview? Interviews can be conducted over the phone or on zoom. The purpose of the interview is to get a deeper understanding of how the Breast Cancer Awareness movement has impacted your experiences and perspectives. Please select yes if you would be willing to be contacted for a follow-up interview. Interviewees will be compensated modestly with a \$50 VISA gift card.

- Yes
- No

Please indicate your contact information to be used if you are willing to be selected for a follow-up interview:

Phone Number

Email

Powered by Qualtrics

c. Ethnographic Questions

Note: These interview questions are meant to guide the interview. Not all of them may be covered and not all of them may be relevant for every individual interviewed. The main purpose in writing a list of questions is to guide the conversation into a natural flow.

1. Do I have your consent to record this interview? You can choose to redact (take back or erase) anything you say at any time and I will keep your name anonymous.
2. Just for me to get some background, what is your diagnosis and your current treatment plan?
3. Can you give me a sense of what you are going through (emotionally) during this time?
4. Can you tell me about some sources of (social) support in your life?
5. What makes [forms of social support] helpful for you?
6. Do you have any acquaintances who are going through a similar struggle to yours? How does the time you have spent with this person compare to time you have spent with others?
7. Is there any activity or behavior that makes you feel lighter? This can come from within, or it can stem from another person or organization.
8. How well do you feel your experience of breast cancer is portrayed?
9. When I say the color “pink,” what comes to your mind?
10. What Breast Cancer Awareness organizations have you heard of? How did you hear about them?
11. Do you participate in pink ribbon events? Why or why not?
 1. (If yes) can you describe your feelings at such events?
12. Do you subscribe to or support the BCA movement?
 1. What do you think this movement does well with regard to your specific experience as well as the discourse or conversation about breast cancer as a whole?
13. Do you believe your quality of life has been impacted by the discourse surrounding breast cancer?
14. How do your [previously mentioned forms of social support] interact with the breast cancer movement?
15. What do you think of “pink ribbon” marketing?
 1. *After showing them some examples of pink ribbon marketing, namely a pink teddy bear, [insert other examples].* What comes to mind when you see these items?
 2. Have you heard of “pinkwashing”? [If yes] How do you feel about that?
 3. [If no] Are you aware that some in the breast cancer community are very critical of “pink ribbon” marketing? How do you feel about that?
 4. Are you aware of the fact that up until a few years ago pink ribbon marketing was exercised by some companies that produce carcinogenic (cancer-contributing) goods? How do you feel about that?
16. If the current method isn’t the right form of support, what is? (Only if they indicate dissatisfaction with the status quo, otherwise this is a leading question)

17. How would *you* want the topic of breast cancer to be approached by mass media and companies that wish to support the cause?
18. Is there anything else you want to add that we haven't already discussed regarding your experience as a breast cancer patient or with the Breast Cancer Awareness movement?