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The Impact of Emotional Support on Identity in Breast Cancer Survivors

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THE IMPACT OF EMOTIONAL SUPPORT ON IDENTITY IN BREAST
CANCER SURVIVORS

by

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A thesis submitted in partial fulfillment of the requirements
for the Honors Undergraduate Thesis Program in Sociology
in the College of Sciences
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at the University of Central Florida
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Abstract

The purpose of this study is to determine the impact that breast cancer has on identity and how emotional support affects identity formation in women after cancer diagnosis and treatment.

While there is much research on the medical treatment of breast cancer and the impact it has on women, there is a gap in research on the identity construction of women who have gone through breast cancer and the impact of emotional support and access to emotional support for them during and after treatment. This is an important aspect of research as demonstrated by the rising number of women diagnosed with breast cancer each year. Because of advances in medicine and emphasis in early intervention, more women are impacted by the emotional aftermath of cancer.

In order to accomplish this aim, this study utilizes narrative-based interviews to learn about breast cancer survivors' stories of emotional support and its impact on their identity. This study uses a sociological approach of symbolic interactionism. In addition to the participant interviews, a content analysis of web searches was conducted on topics related to breast cancer in order to understand the information and resources available to breast cancer patients. This research helps evaluate the impact of emotional support for breast cancer patients in connection with medical support.

To my mom, who taught me strength in vulnerability and faith in God. I love you.

Acknowledgements

In the name of God, the most Kind, the most Merciful.

Thank you to my parents who have believe in every dream I have, everything I am is because of what you both have taught me. To my sisters, who are always there to cheer me up and make me laugh, I am the most grateful I get to be your big sister. And to my husband, Murtaza, thank you for supporting me in everything that I do. To many more years of afternoon cake and coffee.

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Introduction

Breast cancer is the most commonly diagnosed cancer in women in the U.S.A. and became the most common cancer in 2021 (U.S. Breast Cancer Statistics, 2021). With an increasing number of women diagnosed with breast cancer every year, early detection through annual mammograms for women over the age of forty have increased, leading to earlier detection and less invasive cancer diagnosis. Breast cancer survival has increased to 90% for 5-year survival, which means there are many women who have survived breast cancer and will need to therefore deal with the physical and emotional issues of long-term survivorship (American Cancer Society, 2021). Such ramifications include menopausal symptoms like hot flashes, night sweats, vaginal dryness, and loss of sexual desires (Ganz, 2005). Beyond this, additional impacts include changes in family life and financial burdens, as well identity issues pertaining to body image impact the emotional well-being of breast cancer survivors (Osowiecka, 2020). As more women overcome breast cancer, the long-term emotional impact is an important factor to consider during and after cancer treatment.

There is an increasing importance in breast cancer research because of the prevalence in women affected by it each year. Research has been done on the medical treatment of breast cancer, but there is a gap in research on the impact of emotional support for breast cancer survivors and its impact on identity formation following treatment. The primary focus of this research is the ways in which emotional support impacts identity formation in breast cancer patients and the access to those resources. The aim of this study is to contribute to the value of resources available to help ensure better transitions post-diagnosis for breast cancer survivors. As such, this research focused on the support process, in order to better understand how primary

care supports both the physical (medicinal) and emotional (identity) components of the treatment process.

Literature Review

In order to examine the support process, this literature review will examine what has been researched on sociological literature on symbolic interactionism and interactional support integrated into and beyond medical processes. The topics examined in this literature review accordingly include identity, self-advocacy, symbolic interactionism, and support treatment. The order of review was selected in such a way as to examine the challenges that women with breast cancer may face challenges in relation to identity and self-advocacy, support treatment as resources that could be helpful in navigating this transition, and symbolic interactionism as a method of examining this research.

Identity

The diagnosis of breast cancer indicates a change in identity from a healthy person to a sick one; how they perceive themselves and their illness can have a significant impact on physical and emotional health. This is not one event or time period, but rather the diagnosis and subsequent cancer treatment can lead to lasting consequences on physical and emotional health. Since cancer is a chronic disease, this is a lifelong identity shift (Gökler-Danışman, Yalçınay-İnan & Yiğit, 2017). Identity changes according to how central the person views their cancer diagnosis and illness on their life (Gökler-Danışman, Yalçınay-İnan & Yiğit, 2017).

The stigma surrounding cancer and its implications can impact how one constructs their identity (Knapp, Marziliano & Moyer, 2014). It is not solely about having cancer, but the perceptions from others that contributes to identity. The type of cancer, visibility of the disease, and interference of illness in everyday life contribute to the impact of cancer on the person's life and consequently how significant cancer is in identity construction. Specifically in regards to

breast cancer, a major concern in identity is changes in body image (Knaul et al, 2020). These changes include loss or impairment to one or both breasts, surgery scars, skin changes from radiation therapy, weight gain from medications or treatments and hair loss (Falk Dahl et al, 2010). Poorer body image is associated with mental distress, impacting overall identity.

As patients' perception of their illness becomes more negative, their identity becomes more centralized around their illness (Gökler-Danışman, Yalçınay-İnan & Yiğit, 2017). Instead of cancer being a part of their life, it can become a significant or the most significant aspect of who they are and how they see themselves. Identification as a "cancer survivor" differs between types of cancer; those with breast cancer tend to self-identify more as a survivor (Cheung & Delfabbro, 2016). Individuals who identify as cancer survivors tend to be able to discuss their experiences more openly, use effective coping strategies, and have a better mental wellbeing (Cheung & Delfabbro, 2016).

Research demonstrates a significant identity shift occurs when women are diagnosed with and undergo treatment for breast cancer. This new identity formation is important in how breast cancer survivors navigate life after treatment and how they view themselves. There is a gap in the role support plays in these identity formations and the factors that contribute to positive identity formation in breast cancer survivors. Even so, certain research as shown that the levels of self-advocacy can help to mediate these concerns and, overall, can help to reveal the ways that self-identity influence how women experience breast cancer treatment.

Self-Advocacy and Perception of Needs

Self-advocacy is the ability and confidence to speak up for one's interest in managing chronic and life threatening illnesses (Hagan & Donovan, 2013). This includes not only medical decisions with physicians, but also with insurance, employers, and financials. Self-advocacy requires patients to assess their own needs and become an active participant in their healthcare. This can be in the form of educating themselves, reaching out for questions or concerns, and managing their health information. Efficient advocates must prioritize their own needs and communicate those with others. This concept of self-advocacy began with the HIV/AIDS and disabled population, helping to move away from a paternalistic view of medicine in which the doctor would be the contributor (Hagan & Donovan, 2013).

How medical professionals and cancer patients view self-advocacy differs. Medical providers often view patient self-advocacy as managing symptoms and receiving support from family and friends (Hagan et al, 2017). The National Coalition for Cancer Survivorship's "Self-Advocacy: A Cancer Survivor's Handbook" is the only free, publicly available patient education tool to support self-advocacy. This resource defines self-advocacy as seeking information, negotiating, communicating, and problem solving (Hagan & Medberry, 2016). While this is an important aspect of self-advocacy, survivors also emphasize the importance of trusting their medical team with important decisions (Hagan et al, 2017). The handbook focuses on being informed and doing research in order to self-advocate, while many cancer survivors prefer to research only when necessary and otherwise trust their team to accurately and effectively explain medical options. For many cancer patients and survivors in order to effectively self-advocate, they want to feel safe and comfortable with their team so that they may facilitate conversations

about their healthcare as well as have a good relationship with their provider. Self-advocacy to cancer patients and survivors is not just knowing everything about their disease, but trusting those who care for them.

Self-advocacy and perception of needs are important components of identity, especially for those who have a chronic disease. Research shows that it is important for breast cancer patients to become active participants in their healthcare to ensure positive medical outcomes. Even so, there is a gap in how identity formation impacts a survivor's ability to advocate for themselves and the influences of support on self-advocacy.

Support Treatment

The type of support that a cancer patient receives depends on what they need and what is available. Types of support for cancer patients include emotional/social, educational, financial, and organizational. Emotional and social support includes networks of family and friends, peer support groups, and therapy. The benefits of emotional support are decreased levels in stress, anxiety and depression (Osowiecka et al, 2020). Emotional support helps cancer patients in coping with the health related challenges as well as identity shifts that accompany cancer treatment. Support groups with other cancer patients benefit them by creating space to connect with others through shared experiences and feel understood (D'Agostino, Penney & Zebrack, 2011). While family and friends can provide support and encouragement, peer support facilitates connection for those going through similar experiences and may be facing similar challenges. Educational support includes informational sessions and learning from physicians.

While this does not directly impact emotional health, it does improve illness perception, which can lead to more positive emotions and identity formations (Pourfallahi et al, 2020). Organizational support aims to allow accessibility and availability to cancer services and navigate the logistical aspects of care. This can include a patient navigator (PN) program, which allows better connection to patients and eliminates barriers to healthcare, especially in underserved communities (Braun et al, 2012). Organizational support can engage health behaviors and ensure that patients are keeping up with their treatment (Reblin & Uchino, 2008). These services can include financial support, which is instrumental in helping cancer patients. The financial burden that can accompany treatment is associated with detrimental effects to mental health, so financial support is an important way to help cancer patients (D'Agostino, Penney & Zebrack, 2011). In order to effectively and better support cancer patients, there should be a combination of these types of support, which can assist in navigating the transitions and identity shifts associated with cancer diagnosis.

Symbolic Interactionism

To help address identity formation and perception of needs in breast cancer survivors, it can be helpful to evaluate the sociological approach of symbolic interactionism. Symbolic interactionism is sociological theory that explores how humans derive meaning in life through social interaction with others (Handberg et al, 2015). The importance of creating meaning guides interactions and choices throughout life. In regards to cancer patients, symbolic interactionism portrays how people with chronic illness create meaning in their lives during and after treatment. Because of the extreme changes in physical and emotional wellbeing due to cancer, the attribution of what has meaning can shift. After so many continuous and abrupt losses, the idea

of self and who they are is very uncertain and very different from who they used to be and how they saw themselves. This contributes to a new source of identity construction. Cancer patients must navigate how to reconcile their previous social identities with their current one or otherwise face a loss of self (Charmaz & Belgrave, 2013).

The symbolic interactionist approach demonstrates the importance of social interaction with others in order to attribute meaning in life. Especially for breast cancer survivors, a population that is undergoing new changes in their lives, social interaction is an important aspect of navigating life after breast cancer. Support from others, specifically emotional support, guides the way in which breast cancer survivors construct new identities and find meaning in life during and after treatment.

Research has shown the high prevalence of breast cancer in the United States and the benefits of longer survival following treatment due to early detection. While research discusses the increasing number of survivors as well as the shift in identity following this life change, little research has been done to talk to breast cancer survivors on emotional support and identity. Therefore, we will utilize an interview method for this study in order to talk to breast cancer survivors themselves about the role breast cancer plays in their identity and emotional support following treatment.

Methods

The focus of this study is to better understand the experiences of and support for women who have been diagnosed with breast cancer. To help address this, requirements for participation included first, that participants must have had breast cancer and completed treatment, including any radiation, chemotherapy or surgery that they may need. Completion of treatment was required so that participants has had sufficient time to process their diagnosis. Additionally, requirements for participation included being able to understand and speak English, along with being at least 18 years of age to follow IRB protocol. Participants were excluded if they are too unwell to do the interview. Patients with severe depression or anxiety were not included in this study as it may be distressing to them (see Appendix for IRB approval). In order to better understand participant experiences, a content analysis was performed in relation to resources on medical and emotional support.

Data Collection

First, because this population can potentially be hard to reach or identify, a convenience sample was utilized for this study. This sampling technique ensured that participants are comfortable with participating in the study and speaking about their experience. While employing a convenience sample, the recruitment process was targeted to breast cancer survivors, which will help to delimit the population that the study will be advertised to. A recruitment message and flyer was sent via email and social media to appropriate local healthcare professionals and organizations. Those organizations reached out to their network and gave an email to contact if an individual was interested. Once participants emailed us, we replied with an email further describing the study to confirm their interest and to schedule an interview at their preferred timing.

The recruitment process resulted in a total sample size of 5 participants. Participant demographics are in Table 1. The median age of participants was 38 years old and ages ranged from 29-51. All participants had breast cancer and had completed active treatment, including surgery, radiation and chemotherapy. In terms of race and ethnicity, two participants identified as white, one identified as Caucasian, one identified as Jewish and one identified as Mexican and Italian. Two participants did not have a spiritual philosophy, one identified as an Atheist, one identified as a believer and one believed in a Higher Power and Mother Nature.

Pseudonym	Gender	Age	Race/Ethnicity	Religion/Spiritual Philosophy	Income Level	Current Employment
Fiona	F	29	White	None	Average	Marketing Director
Reese	F	34	Caucasian	No	Average to above average	Social media creator
Marilu	F	46	Jewish	Atheist	Average	Disabled
Elle	F	51	White	Higher Power, Mother Nature	Below average	Self Employed
Beatrice	F	38	Mexican/Italian	Believer	Far below average	Unemployed

Table 1. Participant Demographics

As the study is based in identity construction frameworks, qualitative and narrative-based interviews were used to help garner stories of participants' perceptions of support and identity construction following breast cancer treatment. We used semi structured interviews on Zoom to discuss the impact of emotional support on identity formation in breast cancer patients. Interview questions were focused on their experiences with breast cancer, the ways in which their lives changed, identity construction, self-advocacy and emotional support. The questions were sensitized by established literature on these topics, yet also included additional probes that could help to connect and expand on the literature. The interview questions were open ended, allowing

for in depth discussion. This data collection method allows flexibility for participants to talk about experiences in depth or discuss topics that are relevant to them. Alongside the interview questions, a demographic survey was asked of each participant to gain background information.

Participants were asked about their preference for time and date; as the interviews will be held via Zoom, they were additionally be able to select their interview location. At the start of the interview, participants were reminded of the purpose of the study and the informed consent form was sent through the Zoom chat. The interviewer then reviewed key points, such as the fact that they do not have to answer any questions they would not like to and that the interview can last as long or as short as they prefer. The interviewer then reviewed that they will request to record the interview with their permission and confirm their consent; this was then captured after starting the record function. The interviews were recorded and transcribed, using pseudonyms to protect confidentiality. In addition to interview transcription, memoing was done simultaneously after each interview in order to reflect on the interview and identify potential themes.

In relation to the qualitative findings, a content analysis was designed to further examine the resources available for breast cancer patients. As the internet has been seen as an equalizer in gaining information and resources, a content analysis of websites was completed. The search terms for the content analysis of this study were Breast Cancer, Breast Cancer Information, Breast Cancer Support, Breast Cancer Services, and Breast Cancer Emotional Support. Only the first two pages of each search were used and the ads were disregarded.

Data Analysis

Data was analyzed by performing line-by-line coding using a semi-grounded approach, based in Charmaz's grounded theory. While the coding was sensitized by literature, codes were

derived organically from the data and memos and shifted as themes arose through the first round of coding. After the first round of coding, constant comparison was used to compare between the data, codes, and literature. From this constant comparison process, codes were updated for a second round of coding; another round of constant comparison occurred to create categories following this second round. Chunks of data were moved into the categories to determine the primary themes of the results. As based in a semi-grounded approach, the process of writing the results section remained a process of analysis; the analysis was concluded all categories were determined to be analytically distinct.

For the content analysis, websites from the first two pages of each search were noted down, along with the type of information and resources available on that page. After all searches were completed and noted down, it was determined which pages were duplicated across searches. After a website was noted down the first time, any subsequent appearance of that website was noted, but not used in the overall count. The websites were categorized in themes grounded in the themes found from the narrative data.

Results

The results of this section come from the qualitative/interview portion of the research/data collection, alongside of complimentary quantitative analysis. The analytical process of this research found three overarching themes: changes in identity, self-advocacy, and emotional support and resources. Women diagnosed with breast cancer often go through a shift in identity after their diagnosis as they encounter many life changes associated with this chronic disease. In navigating the healthcare system, women with breast cancer learn to advocate for themselves and their needs. In doing so, there are benefits associated with emotional support and resources so that these women can better process and navigate their situation.

Changes in Identity

Participants explained a significant shift in identity following a cancer diagnosis and becoming a cancer patient, which is consistent with the findings of Gökler-Danışman and Yalçınay-İnan & Yiğit, in which cancer patients must integrate a new concept into their identity (2017). This prior research has shown that we make sense of both small and major adjustments through narratives, helping to both explain and make sense of these shifts through a process similar to story-telling. Just as Fiona says: “When you're diagnosed, it's like suddenly everything in your identity is really replaced with like cancer patient.” This sudden and dramatic shift for breast cancer patients can be overwhelming, as they are navigating not only an unfamiliar world of medical terminology and life-changing decisions, but also a new sense of self and purpose.

The data finds that although the shift to becoming “a breast cancer patient” is a difficult one, the shift to a breast cancer survivor can be even more challenging. This identity shift becomes even more prominent following the conclusion of active treatment. The identity of a

breast cancer patient is very prescribed and medical, with the focus on survival. Support from family, friends, healthcare professionals and the greater community is greatest directly after diagnosis and during active treatment. The busyness of this portion of the patient's life can overtake the emotional processing of the identity shift. In contrast, a breast cancer survivor (in which 4 out of the 5 participants identified as) is much more complex. For example, Reese says "I feel like for me that the after period after treatment was much harder than the active treatment."

Since cancer is a chronic illness, the identity of breast cancer survivor is a lifelong one for most survivors (Gökler-Danışman, Yalçınay-İnan & Yiğit, 2017). Many participants could no longer work following their breast cancer treatment or worked in different capacities than prior to their diagnosis. For Elle, who was a fitness instructor, the physical pains and implications of breast cancer impacted her ability to perform her job. Elle's identity as a fitness instructor or physically capable in a general sense was impacted by the effects of breast cancer:

"The whole not being able to teach a fitness class which is even more vigorous than taking a fitness class. Yeah, not being able to do more than just walk the dog is killing me, it's really hard. I've gained weight, my muscle mass is gone, my lungs and my heart.... I'm moving over here. My lungs and my heart are not where they used to be. And I have no idea how long it's going to take to get all that back."

The side effects of medications from breast cancer can also cause mental impacts, like loss of memory. Marilu has had trouble remembering things after having cancer and the medications she took subsequently. This impacts her ability to do her job that she had done for so many years.

If a person defines themselves by their physical abilities or their professional capacities, that identity may be eliminated or extremely impacted if their physical and mental capabilities change. Having to rely on others as caregivers and financial support when one can no longer work can be an extreme change for women and to their identity. Women might no longer be as independent or capable at their jobs and that can impact how they see themselves and their value.

Because of the nature of breast cancer, most women go through significant changes in relation to body image. This can include a single or double mastectomy and loss of hair due to chemotherapy. This leads to a physical identity shift as well as an emotional one. According to Falk Dahl et al, body image is closely linked with identity (2010). These physical consequences of breast cancer can affect how survivors see themselves. Fiona says,

“I didn't have reconstruction like looking at myself in the mirror is still very difficult. Like changing at the gym is like feels very weird and I get stared out a lot more and like some people ask questions. Like buying certain clothes like wearing certain fabrics like clinging to me and weird and uncomfortable ways and like kind of show off a concave chest”

Similar to Fiona, another participant, Reese, also states how “losing your hair, losing your breasts. It's like, well, of course you're not going to fit in, like you're not what's normal.” Specific to women with breast cancer, these physical changes are to parts of the body associated with femininity and attractiveness. The issue then arises of women no longer feeling beautiful or less of a woman because they do not have breasts or hair. Body image and self-consciousness can impact how a woman with breast cancer sees herself and therefore identifies with her body.

The post-treatment time period, in which the patient has completed active treatment such as chemotherapy, radiation and/or surgery, was of more importance for many participants than during treatment. The support during treatment is accessible. The patient is continually seeing their doctors, family and friends are rallying with them and the steps of treatment are often clearly laid out in a methodical way. In regards to this, another participant describes how, “I feel like during treatment you're so focused on just like survival and like having those immediate needs met of that of like getting through the day or like getting to your next appointment. And you know, that's all you can focus on”

After treatment, the patient no longer visits their doctors as frequently and support from family and friends drops off. But this seems to be the most important time for emotional support, in the shift from breast cancer patient to breast cancer survivor. The identity shifts discussed earlier must now be reconciled with and processed as women now try to live their lives. Fiona speaks of the aftermath of treatment and the processing of her diagnosis: “I feel like I just kind of blocked out the like processing of everything that was happening until after treatment finished and that was another like slap of reality of like oh, this is really traumatic what I've been through, and I have not spent an ounce of energy like recognizing what's actually happened to me.” Processing the diagnosis and the impact that it makes on the patient’s identity is a journey. As Beatrice says,

“It wasn't necessarily processing the fact that you know I had cancer. It was processing the fact that the person who I wanted to be didn't get a chance. The person that I thought I was going to be changed. My plans didn't get to happen.”

These changes in identity created new needs for breast cancer survivors after treatment in order to process these life shifts. Processing the emotional and physical trauma that one has endured is essential, yet is often met with limited resources. Emotional resources and their impact on identity formation will be discussed later in the results.

Self-Advocacy and Emotional Needs

Although the literature emphasizes the difficulty for breast cancer patients to advocate for themselves in medical settings, this was not a challenge found with the participants of this study. While Hagan & Medberry found that cancer patients are hesitant to lead in their own healthcare management, participants of this study were able to navigate challenges of advocacy with their doctors, even if at times it was a difficult process (2016). Reese described how:

“I definitely felt that I could advocate for myself and I definitely felt like my husband was a huge advocate for me of like always seeking more information, always making sure like I felt empowered to ask questions and make decisions.”

Beyond this, Marilu supported this statement when she said, “And so I've learned to be an advocate, not to let things get blown off.” Elle expressed a similar statement when she said,

“I feel like I'm being good about speaking out. And I find that through the journey I've gotten more vocal over time of what I already or will allow or am okay with. In the beginning I just did whatever they told me and now I'm like no, I don't think so.” We found this to be a particularly strong sentiment, as Beatrice also stated,

“I'm definitely not afraid to speak up and say you know this is not how you do it. I feel like I've had enough experience to know the right and wrong way of doing things”

While literature upholds patients having difficulty, Hagan & Medberry describes difficulty in patients voicing preferences, participants found other challenges when it came to navigating the healthcare system. While medical information was readily available and participants trusted their healthcare team, there was less recognition and emphasis on emotional and mental health. Elle described complications arising when she asked for sleeping pills. Time after time, she inquired about help from her healthcare team on difficulties with sleep and her desire for something to help. She was referred to many professionals, none of whom addressed her difficulty sleeping. After many attempts, her primary care doctor told her that perhaps she was not prescribed sleeping pills because she was showing signs of depression. Elle was unaware of her possible depression and this was not brought up previously. Elle questioned “why didn't someone say something to [her] and we could have dealt with that aspect instead of you know [her] crying [herself] to sleep because [she] was not sleeping and then feeling like no one was listening to [her] or helping [her].” Elle’s situation shows that her issues with mental health and depression were not addressed or assisted.

Another facet to advocacy that many participants expressed was the differences between male and female doctors or healthcare professionals. Participants felt as though male doctors did not fully understand their experience and therefore advocacy was a greater challenge when it came to male doctors. The following quotes help to exemplify this:

“Things like that where it's like it if I had a female on my team like I think those talks would go a lot differently.” -Fiona

“But the care of a woman, of a female oncologist and a female breast surgeon, it's really different than a man.” -Beatrice

“There's just something different when you talk to a female about female things. Because they have the parts that you have.” -Elle

The participants of this study felt comfortable advocating for themselves in a medical sense. Over time, they became comfortable speaking up for themselves and asking questions to be an informed and involved member of their team. But in terms of emotional and mental health, advocacy was more difficult. The traumatic experience of breast cancer as well as the major identity transitions that accompanies diagnosis is already a difficult challenge for many women. Therefore, having to advocate for their emotional needs plays an important role in their identity going forward. If their identity as strong, capable and supported women match the identity that they have with their healthcare team, then advocacy and interactions become much easier and seamless. If women face difficulties in advocating for their emotional needs, this may cause their identity shifts that they are already processing to face even more setbacks. Thus, advocacy with healthcare team in terms of emotional care can have a direct impact on the identity formation in women with breast cancer.

Emotional Resources

Participants did not find a lack of information or distrust from their medical team. From a medical standpoint, they were able to advocate from themselves in getting the information and treatments that they felt comfortable with. But from an emotional and mental health aspect, there were less resources available and offered. Two participants described the need for therapy as a way to process their journey and trauma. But constant therapy was not offered to many

participants through their healthcare team. Participants claimed that their hospitals offered resources that were sometimes outdated or unhelpful to their particular situation. For example, Beatrice expressed, “The social worker, the resources that she provided were outdated, and so the organizations that she had given me to contact for whatever resources I needed were no longer active.”

The population of participants that we interviewed were younger than average breast cancer patients. Most women who are diagnosed with breast cancer are over the age of 50, while the average age of women in this study was 39.6. Emotional health can be even more important in dealing with a cancer diagnosis as younger women with different needs than older women with breast cancer. Young women diagnosed with breast cancer, like the participants of this study, also face issues pertaining to fertility and medical menopause. These additional challenges not only require medical attention, but also emotional and mental help. Every participant spoke on the benefits of connecting with other breast cancer patients or survivors, including Beatrice, who expanded on the prior sentiment by explaining that, “the coolest thing is that when you find another cancer survivor and you're like, oh yeah, we're cancer survivors. There's like this instant connection that like you instantly love each other. You're instantly like drawn to each other and like connected in this weird like family vibe thing. It's incredible. It's really incredible.”

The importance of support groups found within the data is consistent with the literature. D'Agostino, Penney & Zebrack found that in young adults with cancer, support groups can minimize the disruption to life that is caused by cancer and help to maintain normalcy (2011). Participants spoke of the sense of community they found within support groups and the ability to speak on topics pertaining to medical effects as well as emotions and identity shifts following

diagnosis. The literature identifies and elaborates on the benefits of support groups. Although caregivers are an important aspect to a breast cancer survivor's healing, research and interviews have shown the value of breast cancer patients and survivors in connecting with each other. The shared experiences and emotions between them provide meaningful connections and safe spaces. Because of this researched importance of support groups, there should be more emphasis and outreach for breast cancer patients and survivors. But the support groups that the participants joined were found through means outside of their hospital: social media (Facebook and Instagram), outside organizations, etc. Doctors and healthcare teams place importance on physical healing, while emotional healing is left for the patient to deal with alone.

Emotional resources like support groups, therapy, and counseling have been found to be important to a breast cancer survivor's emotional, physical and mental healing. These resources have a profound impact on identity as a patient and survivor navigates these changes in their life. Emotional resources guide the processing of trauma that accompanies cancer diagnosis and treatment. As mentioned earlier, patients and survivors must reconcile who they were before and who they are now. Merging this new identity of breast cancer survivor is done more seamlessly with the help of professionals or others who have been in similar situations. They often have to acknowledge and validate feelings of anger and sadness from cancer in order to move on. Fiona speaks on the benefits of therapy in her identity transition:

“But when I finished treatment, I would say like 3 months after I finished treatment, I started seeing a therapist to just yeah, like figure out like what had happened and like how you move forward from it. And that's been hugely beneficial. Like it took finding the right therapist, but once I did like, uh, it's been huge to just help me kind of like formulate like who I am now.”

According to Pourfallahi et al, coping is best done when patients are given honest and sensitive information (2020). These modes of delivery include not only the healthcare team, but also support groups and therapists. This helps in coping mechanism and managing care as well as identity shifts. In validating feelings, support groups and therapists as well as other emotional resources enable these women to reconcile the identity shift and not feel so alone. Marilu speaks on the benefit of speaking with other women with breast cancer:

“I feel like I learned a lot more from them [support group] than I did from my oncologist as far as what my cancer, what my diagnosis meant, but also what kind of treatments that were out there and also what to expect like as far as side effects and that sort of thing.”

The emotional resources are imperative to women in navigating their identity shifts after being diagnosed with breast cancer. Research shows that support groups are helpful to connect women with shared experiences together so that they can relate to the physical and emotional effects of breast cancer. It is shown that many women with breast cancer are navigating similar identity shifts and challenges, so this helps women feel less alone.

Quantitative Content Analysis

In order to better understand the resources available to breast cancer patients, a content analysis of websites was conducted. Since participants spoke on the difficulties of obtaining resources and emotional support from their doctors and healthcare teams, the internet was used to see if more and better resources were available to patients in that way.

Website URL	Number of Times Mentioned	Content Categories
https://www.cancer.org/cancer/breast-cancer.html	3	Informational, Contains Resources

https://www.cdc.gov/cancer/breast/basic_info/index.htm	2	Informational
https://www.mayoclinic.org/diseases-conditions/breast-cancer/symptoms-causes/syc-20352470	3	Informational, Emotional
https://www.cancer.gov/types/breast	3	Informational, Emotional
https://www.breastcancer.org/	4	Informational
https://my.clevelandclinic.org/health/diseases/3986-breast-cancer	2	Informational, Emotional
https://medlineplus.gov/breastcancer.html	2	Informational, Emotional
https://www.medicalnewstoday.com/articles/37136	2	Informational
https://www.mdanderson.org/cancer-types/breast-cancer.html	2	Informational
https://www.cancer.net/cancer-types/breast-cancer/diagnosis	3	Informational, Emotional
https://www.webmd.com/breast-cancer/default.htm	2	Informational
https://www.cancerresearchuk.org/about-cancer/breast-cancer/living-with/resources-books	2	Informational
https://www.cancercare.org/diagnosis/breast_cancer#:~:text=Get%20Support&text=Contact%20us%20at%20800%E2%80%91813,877%2D880%2D8622).	2	Contains Resources
https://www.komen.org/support-resources/support/support-groups/	3	Informational, Contains Resources
https://www.floridabreastcancer.org/	3	Informational, Contains Resources
https://moffitt.org/cancers/breast-cancer/support-information/	2	Informational, Contains Resources

Table 2. Repeated Websites

87 websites were found through five google searches using the terms: Breast Cancer, Breast Cancer Information, Breast Cancer Support, Breast Cancer Services, and Breast Cancer Emotional Support. 24 websites were found to be repeated multiple times, leading to a sample size of 65.

Out of those 65, 50 websites included information on breast cancer, including medical information primarily on the types, causes, symptoms, and treatment options. These websites used medical terminology such as classifying cancer “ductal carcinomas, which starts in the ducts, or lobular carcinomas, which starts in the lobule glands” (Breast Cancer, 2022). While medical terms like “breast cancer in situ” “lobular carcinoma in situ” and “invasive ductal carcinoma” are used to describe the types of cancer, much of the jargon is then described in

language that can be understood by people without a medical background. For example, when describing invasive ductal carcinoma, which is one of the most common types of breast cancer, the CDC says:

“The cancer cells begin in the ducts and then grow outside the ducts into other parts of the breast tissue. Invasive cancer cells can also spread, or metastasize, to other parts of the body”(CDC: Breast Cancer, 2021).

So although many breast cancer patients may not understand the medical jargon related to their conditions, it seems as though the internet provides ample resources to further understand their disease. These resources use language that can be comprehended by patients that are not familiar with medical terminology, so that they may better understand their diagnosis and treatment.

In addition to medical information, only 18 of the 65 websites discussed emotions and changes relating to breast cancer, about 28% of the websites. This is much lower than the percentages of websites that contained medical information, which was about 77%. Websites that discussed emotions used phrasing like “coping with the difficult emotions that may come up with breast cancer” and providing tips on ways to deal with these emotions (Breast Cancer: Coping With Your Changing Feelings, 2022). Some websites discussed overall feelings that may occur after diagnosis as well as resources and steps to take when one is facing these emotions. Other websites, like [verywellhealth.com](https://www.verywellhealth.com) discussed feelings relative to different stages of breast cancer, such as after diagnosis, during treatment, and after treatment (Stephan, 2021). Participants of this study found that post-treatment processing was sometimes more difficult than active treatment, so this distinction between different emotions during various stages is particularly helpful. These

websites provided some valuable help and tangible steps in aiding with emotional struggles. But because such few websites discussed emotional issues, it may be hard for breast cancer patients to find these websites and benefit from them.

From the websites of the content analysis, 46% or 30 out of the 65 provided resources to emotional support. These resources included support groups with other breast cancer patients and survivors as well as therapy, counseling, helplines and public forums. Most often, websites provided links to external organizations that provided support. This means that patients must then follow these resources to additional pages to find help. In addition, many of these resources were nationwide. This is helpful in terms of access, but difficult because they are not personal. Very few websites have specific resources and this is challenging for those who would like to connect with resources in their area.

In line with the interviews, the content online shows that medical information is readily available for breast cancer patients and there are many informational resources available. Breast cancer patients therefore do not appear to have a lack of information accessible to them on the technical side. Patients can make informed decisions based on this medical information and the information given by their healthcare team. The results do show a lack of discussion when it comes to emotions and changing of identity as well as a lack or difficulty in finding emotional support. Further implications of the results of this study could be training medical professions in discussing emotional difficulties with their patients. Required training for medical students on how to navigate patient emotions as well for doctors will breast cancer patients would allow healthcare teams to be better equipped to help their patients.

In terms of resources, though they are available online, there are major limitations. Some resources were outdated and no longer worked, as Beatrice says “the social worker, the resources that she provided were outdated, and so the organizations that she had given me to contact for whatever resources I needed were no longer active.” In addition, some resources were only based in certain areas and therefore not available to much of the population. With the many repeated websites across the various searches, this limits the number of resources available for breast cancer patients. The emotional struggles associated with breast cancer diagnosis are hardly discussed online and from the participants’ interviews, it seems that they are not talked about in person either. The resources are difficult to find either because of the scarcity of resources and the need to search through many broad or unhelpful resources to identify resources that could be beneficial to patients and survivors.

Discussion

There has been much research in breast cancer and many medical advancements in recent history that have allowed the survival rates to increase greatly. This leads to a great need for research on the effects of breast cancer on survivors, not only physically but also emotionally and mentally. To help advance this research and explore these challenges, this study examined the shifts in identity in breast cancer patients and survivors as well as the impact of emotional support on identity.

While prior research has found that breast cancer survivors encounter many transitions within identity, this study expands on this by focusing on the impact and availability of resources to help navigate this. Findings suggest that participants faced many struggles after treatment as they processed their diagnosis and learned to incorporate new changes in their life. This included the new identity of “breast cancer survivor” and the ways to assimilate this new identity and move forward with their lives. This new identity caused participants to live differently than before their diagnosis and therefore impact their lives on a daily basis. This research shows that participants did not have trouble advocating for themselves with their team in terms of medical decisions, but when it came to emotional struggles the resources and support were less than sufficient. Current research shows that emotional support in the form of supportive doctors, support groups, and therapy have immense benefits for breast cancer survivors. Yet there is not widespread availability and access to these resources and participants often had to seek these out on their own instead of being offered through their doctors or hospitals. The content analysis also

determined that medical information was readily available, but information on emotional struggles or resources was much less accessible.

Participants in this study found that most often doctors were willing to help with the physical side effects of their treatment and they felt informed enough to make decisions regarding their care. But many participants wished their healthcare teams were more upfront when talking about emotional struggles. This highlights the need to train doctors to be more open about the emotional challenges associated with chronic diseases and talk to their patients about possible struggles they may have in relation to this. When healthcare teams empower patients by validating their feelings, patients will feel less alone in their difficulties and can be more equipped to deal with issues when they arise. In addition, their identity formation in processing their breast cancer diagnosis and treatment will be more focused on empowerment and support.

The study also observed the benefits of emotional support resources for breast cancer patients in processing their diagnosis and evaluating their new identity shift. These resources include support groups and therapy. But participants in this study had to seek out these resources on their own and the content analysis found these resources were more difficult to find. Future studies can determine the best ways to give access to emotional support resources to breast cancer patients, specifically through hospitals so that the resources are centralized and accessible to the individual patient. Participants also mentioned using social media to find access to resources like support groups and this intersection between social media and emotional support is another highly applicable topic for future research.

This study's limitations include its small sample size, but despite this the religious beliefs of the participants varied. Yet no participants mentioned the impact on religion or lack of on their outlook or identity as a breast cancer survivor. An interesting direction for future research would be to examine the impact of religion on identity in breast cancer patients. In addition, most participants faced financial difficulties due to their breast cancer diagnosis. During active treatment, it is difficult for many breast cancer patients to work. Some medications cause mental side effects like memory loss and this can impact an individual's ability to contribute to their financial earnings. Future research might examine the way in which financial burdens affect breast cancer patients' outlook and quality of life.

Appendix A: IRB Exemption

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UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board

FWA00000351 IRB00001138,
IRB00012110

Office of Research

12201 Research Parkway

Orlando, FL 32826-3246

EXEMPTION DETERMINATION

August 25, 2021

Dear Amanda Koontz:

On 8/25/2021, the IRB determined the following submission to be human subjects research that is exempt from regulation:

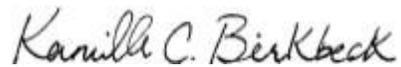
Type of Review:	Initial Study
Title:	Impact of Emotional Support on Identity in Breast Cancer Patients
Investigator:	Amanda Koontz
IRB ID:	STUDY00003232
Funding:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none">• Consent-Explanation of Research, Category: Consent Form;• Interview Questions, Category: Interview / Focus Questions;• Protocol-Request for Exemption, Category: IRB Protocol;• Recruitment Materials, Category: Recruitment Materials;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB

system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

A handwritten signature in black ink that reads "Kamille C. Birkbeck". The signature is written in a cursive style with a clear, legible font.

Kamille Birkbeck
Designated Reviewer

Appendix B: Interview Questions

Appendix B: Interview Questions

1. How would you describe yourself in 3 words?
 - a. Depending on response, may probe for them to talk more about the descriptors
 - b. Based on responses: Could you tell me more about the ways that your cancer diagnosis affected this?
2. Can you please tell me about your cancer journey, such as when you were diagnosed?
 - a. Probe: Did you know anyone with breast cancer?
3. What are the most significant changes to your life since being diagnosed with cancer?
4. Do you feel as though having cancer impacts your everyday life? Or has it taken up your life in different ways over time?
5. During or after cancer treatment, what were some of your needs that needed to be met?
 - a. Were they met? How?
6. Were there any programs or services offered to you that helped with the treatment process?
7. How did your family, friends or community play a role in supporting you?
 - a. Do you feel like it was adequate?
8. How do you feel your doctor/healthcare team supported you?
 - a. Were you able to advocate for yourself?
 - b. Do you feel like your team was approachable and comfortable?
 - c. What is most important to you in a healthcare team?
9. Did you have support from others who had cancer, like a support group?
 - a. If yes, did you find that helpful in navigating cancer treatment?
 - b. If no, why not?

10. How did you navigate the logistical aspects of cancer, like finances and keeping up with treatment?
 - a. Was your hospital able to assist you in navigating these challenges?
11. What was the most helpful for you in terms of emotionally dealing with your diagnosis and treatment?
12. Do you view life differently after having cancer?
13. Do you identify as a cancer survivor?
 - a. If they included this in question 1, the question will be: Earlier you identified as a cancer survivor, could you tell me more about why you identify as a survivor?
14. Are there any other points that we did not talk about that you think would be helpful for this study, or additional questions you think we should ask others?

Appendix C: Demographic Questions

Appendix C: Demographic Questions

1. Sex/Gender: _____

2. Age: _____

3. Race/Ethnicity: _____

4. Religion/Spiritual Philosophy: _____

5. Compared to American (US) families in general, would you say that your family's income is:

(please circle one):

a. Far below average

b. Below average

c. Average

d. Above average

e. Far above average

f. Don't know

6. Highest degree earned: _____

7. If currently in college:

a. Year in school: _____

b. Declared major(s)/minor(s): _____

8. Current Employment: _____

Appendix D: Content Analysis Websites

Appendix D: Content Analysis Websites

Webpage Title	Year	Date Accessed	Website Address (URL)
Breast Cancer – Symptoms and Causes *	2021	02/08/22	https://www.mayoclinic.org/diseases-conditions/breast-cancer/symptoms-causes/syc-20352470
Breast Cancer	2022	02/08/22	https://www.breastcancer.org/
Breast cancer: Breast Cancer Information and Overview *	2022	02/08/22	https://www.cancer.org/cancer/breast-cancer.html
Breast Cancer – Patient Version *	N.D	02/08/22	https://www.cancer.gov/types/breast
What to Know about Breast Cancer	2021	02/08/22	https://www.medicalnewstoday.com/articles/37136
Breast Cancer *	2022	02/08/22	https://medlineplus.gov/breastcancer.html
What is Breast Cancer?	2021	02/08/22	https://www.cdc.gov/cancer/breast/basic_info/what-is-breast-cancer.htm
What is Breast Cancer?	2022	02/08/22	https://www.cancer.org/cancer/breast-cancer/about/what-is-breast-cancer.html
Breast Cancer *	2022	02/08/22	https://my.clevelandclinic.org/health/diseases/3986-breast-cancer
WebMD / Breast Cancer	2022	02/08/22	https://www.webmd.com/breast-cancer/default.htm
Breast Cancer	2020	02/08/22	https://www.webmd.com/breast-cancer/understanding-breast-cancer-basics
Breast Cancer *	2020	02/08/22	https://www.cancer.net/cancer-types/breast-cancer
Breast Cancer	2022	02/08/22	https://www.mdanderson.org/cancer-types/breast-cancer.html
BCRF	N.D.	02/08/22	https://www.bcrf.org/
Types of Breast Cancer and Related Conditions	2020	02/08/22	https://www.cancerresearchuk.org/about-cancer/breast-cancer/stages-types-grades/types
Breast Cancer	2022	02/08/22	https://en.wikipedia.org/wiki/Breast_cancer
Breast Cancer	2022	02/08/22	https://emedicine.medscape.com/article/1947145-overview
Breast Cancer *	2022	02/08/22	https://www.cancercenter.com/cancer-types/breast-cancer

Breast Cancer *	2021	02/08/22	https://www.cancerresearchuk.org/about-cancer/breast-cancer
Breast Cancer *	2022	02/08/22	https://www.mountsinai.org/health-library/diseases-conditions/breast-cancer
Overview / Breast Cancer in Women	2019	02/08/22	https://www.nhs.uk/conditions/breast-cancer/
A Comprehensive Guide to Breast Cancer	2022	02/08/22	https://www.healthline.com/health/breast-cancer
About Breast Cancer	2022	02/08/22	https://www.komen.org/breast-cancer/
Breast Cancer	2019	02/08/22	https://scdhec.gov/health/diseases-conditions/cancer/breast-cancer
Breast Cancer	2022	02/08/22	https://www.hopkinsmedicine.org/health/conditions-and-diseases/breast-cancer
ACS Patient Programs and Services *	2022	02/09/22	https://www.cancer.org/treatment/support-programs-and-services.html
Treating Breast Cancer *	2022	02/09/22	https://www.cancer.org/cancer/breast-cancer/treatment.html
Breast Cancer *	2022	02/09/22	https://www.cancercare.org/diagnosis/breast_cancer
Breast Cancer: Types of Treatment	2020	02/09/22	https://www.cancer.net/cancer-types/breast-cancer/types-treatment
Breast Care Center *	N.D.	02/09/22	https://www.orlandohealth.com/services-and-specialties/orlando-health-cancer-institute/specialty-centers/breast-cancer
Breast Cancer Care *	2022	02/09/22	https://www.martinhealth.org/breast-cancer-care
Support Information *	2018	02/09/22	https://moffitt.org/cancers/breast-cancer/support-information/
Florida Breast Cancer Foundation *	N.D.	02/09/22	https://www.floridabreastcancer.org/
Breast Cancer Care	2022	02/09/22	https://healthcare.ascension.org/specialty-care/cancer/breast-cancer
Breast Cancer	2021	02/09/22	https://www.bonsecours.com/health-care-services/cancer-care-oncology/conditions/breast-cancer
Breast Cancer Services	2022	02/09/22	https://www.ucihealth.org/medical-services/breast-cancer
Breast Cancer	2022	02/09/22	https://www.mhs.net/services/cancer/types/breast
Breast Oncology Program *	2022	02/09/22	https://www.dana-farber.org/breast-oncology-program/

Where can I find a Breast Cancer Support Group? *	2021	02/12/22	https://www.nationalbreastcancer.org/breast-cancer-support-groups
National Breast Cancer Resources *	2022	2/12/22	https://www.breastcare.org/national-breast-cancer-resources/
Breast Cancer Support Groups *	2021	2/12/22	https://cancerlifeline.org/services/support-groups/breast-cancer-support-groups/
Breast Cancer Support Group *	2022	2/12/22	https://www.adventhealthcancerinstitute.com/cancer-support-resources/cancer-support-groups-programs/breast-cancer-support-group
Support Groups *	2022	2/12/22	https://www.mdanderson.org/patients-family/diagnosis-treatment/patient-support/support-groups.html
Florida Breast Cancer Foundation	2020	2/12/22	https://pickupsforbreastcancer.org/
Resources to help people impacted by breast cancer *	2022	2/12/22	https://www.lbbc.org/
Giving Help and Hope to Families Impacted by Breast Cancer	2022	2/12/22	https://www.bcfcf.org/
Breast Cancer Support Groups in Florida *	2020	2/12/22	https://www.accuboot.com/accuboot-for-patients/breast-cancer-resources/breast-cancer-support-groups/southeast/breast-cancer-support-groups-in-florida/
Special Populations with Breast Cancer *	2022	2/12/22	https://psc.ucsf.edu/special-populations-breast-cancer
Coping with Breast cancer Emotionally *	2021	2/13/22	https://breastcancer.org/information-support/facing-breast-cancer/living-beyond-breast-cancer/life-after-breast-cancer-treatment/coping-breast-cancer-emotionally
Breast Cancer: Coping With Your Changing Feelings *	2022	2/13/22	https://www.cancercare.org/publications/88-breast_cancer_coping_with_your_changing_feelings
Support Tool Helps Women Emotionally Adjust After Being Diagnosed With Early-Stage Disease	2015	2/13/22	https://www.breastcancer.org/research-news/support-tool-helps-after-diagnosis
Breast cancer: How your mind can help your body	2011	2/13/22	https://www.apa.org/topics/behavioral-health/breast-cancer

The Emotional Impact of Breast Cancer *	2021	2/13/22	https://www.webmd.com/breast-cancer/features/emotions-related-to-breast-cancer
Emotional Stages of Breast Cancer *	2021	2/13/22	https://www.verywellhealth.com/emotional-stages-during-breast-cancer-diagnosis-430254
Feelings and Cancer *	2021	2/14/22	https://www.cancer.gov/about-cancer/coping/feelings
Managing the emotional effects of breast cancer *	2019	2/14/22	https://www.lbbc.org/recently-diagnosed/your-emotional-concerns/managing-emotional-side-effects
Support After a Breast Cancer Diagnosis *	2020	2/14/22	https://www.komen.org/wp-content/uploads/Getting-the-Support-you-Need-1.pdf
Coping with Breast Cancer *	2020	2/14/22	https://www.cancerresearchuk.org/about-cancer/breast-cancer/living-with/coping
How We're Providing Support *	2022	2/14/22	https://www.cancer.org/about-us/what-we-do/providing-support.html
Your Emotions after Treatment *	2022	2/20/22	https://www.dana-farber.org/for-patients-and-families/for-survivors/caring-for-yourself-after-cancer/your-emotions-after-treatment/
Emotional “Patient-Oriented” Support in Young Patients With I–II Stage Breast Cancer: Pilot Study	2018	2/20/22	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6290028/
Breast Cancer Support: Mental Health Resources *	2021	2/20/22	https://www.goodrx.com/conditions/breast-cancer/breast-cancer-mental-health-resources
Emotional Support *	2022	2/20/22	https://www.breastinstitutehouston.com/category/emotional-support/

*Demarcates that the website included references to emotions and/or contains emotional support resources

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