

SURVIVORSHIP IN YOUNG BREAST CANCER SURVIVORS

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## **Introduction:**

Breast cancer is currently the most common cause of death from cancer in women in all major categorical racial groups and is responsible for a third of all diagnosed malignancies in women (Banks et al., 2005). Breast cancer, just like any other form of cancer, brings many issues along with the diagnoses that reach outside of just those resulting from chemotherapy and radiation treatment. Physicians in the US are starting to examine closely what life after cancer looks like for survivors. Quality of life seems to be a large issue that has always been addressed, but scrutiny is now being placed on how effectively it is assessed and improved.

Quality of life is something that is difficult to gauge and improve, as it may be different for two women who have the same state of health (Ganz et al., 2003). Body image is closely related to quality of life for breast cancer survivors, as it is a person's mental image of their physical appearance, health, and wholeness (Banks et al., 2005). Both of these topics are completely subjective, making it hard to interpret based off of their physical ailments.

Young breast cancer survivors have been found to be affected by body image greater than their elderly counterparts, mainly due to the fact that the younger a woman is, the more aggressive a treatment plan can be, leaving a devastating path of destruction on the woman's physical and mental state. Focus has begun to be placed on this now as incidence rates are rising and mortality rates are decreasing, resulting in more long-term survivors (Ganz et al., 2003). For the first time, researchers are beginning to assess quality of life in a subjective manner by allowing survivors to get their stories out about life after remission. This a key component of care during remission, as this research can improve the quality of care for survivors and allow an easier integration back into every day life.

**Background:**

Leaps and bounds have been made in the 20<sup>th</sup> century in treatment of malignancies. Not only is the medical community improving their initial treatment, they are also improving follow up care and medical adherence with their patients, ultimately increasing remission rates. In 2002, the five-year survival rate for breast cancer survivors had reached 86% and has been increasing since (American Cancer Society, 2002). While this is a tremendous accomplishment for clinicians, the quality of life post treatment is becoming an ever present problem (Banks et al., 2005).

There is an initial sense of an increased positive perception during the first year of remission, but there are few improvements after the initial year of remission (Coscarelli et al., 1996). Social roles, emotional and physical states, mental acuity, and perception of overall well-being are all factors included in a person's notion of quality of life (Levine, 1987). There are also common physical ailments that are associated with survivorship, such as an early onset of menopause, infertility, chronic pain, weight managements, and mental health disorders (Antoni and Carver, 2004). Studies published in the past decade have not been in agreement with each other, which only adds to the confusion surrounding the topic. A study conducted in 1998 reported a third of long term survivors suffer from depression (Dorval et al., 1998), while a study conducted two years later found shockingly low rates of depression in long term survivors (Gotay, 2000). This inconsistency is common in current literature, and researchers are beginning to investigate into why that is.

Many women have held complaints that their physician did not communicate all of their treatment routes to them accurately, specifically follow-up treatment once they are deemed in

a state of remission. It is a common misconception that a mastectomy is the most reasonable path of treatment, as many young women assume you can always have your breast tissue reconstructed and lead a fairly normal life. This is actually not the case for many women, as insurance companies categorize this as an elective surgery. There is also a lack of knowledge with the understanding of what to expect during remission, specifically mental health and sexuality, which are both things that affect young women more than their elderly counterparts (Ganz et al., 2003)

“Photojournalism” rose to astounding popularity during the mid 1900s in it’s effectiveness on provoking thoughts and emotions of their audience, which played a large role in the development in a new research model, Photovoice. The development of Photovoice was also strongly influenced by the increased scrutiny on social inequality around the world. Photovoice was originally created for agencies and activist groups (grassroots) who were looking for a powerful and creative way to get community and humanitarian issues on the public agenda. It gives the voice of the project not to professionals, researchers, or policy makers, but instead to the people whose lives are affected by the issue. A large ideal that was present during the creation of this model was wanting to create something that has the ability to enable people, like government officials, to understand the lived experience of an issue such as poverty or illness that they would not normally understand because they have not lived that experience. Photovoice has a profound effect on people, as it creates a reaction on an emotion and social conscious level, as traditional research reached people solely on an intellectual level (Dahan et al., 2007).

One of Photovoice's main goals is to enact positive change in a community or put a process of change into motion. The creators of Photovoice created a four step model that identifies the goals of the project; community exposure, increased awareness of issues, engagement, and social change. Photovoice also has a model for the process of change for participants that includes five stages; getting out there, being heard and validated, finding a voice, seeing the bigger picture, and personal growth. It is the facilitator's duty to identify where in the model for the process of change their participants fall and specify their aid to them in their portion of the project based off of which stage they are identified at. Facilitators have to be extremely aware of their participants, as it is vital that they balance giving direction while not influencing how the participant completes their portion of the project (Dahan et al., 2007).

**Purpose:**

The purpose of this study is to enable young breast cancer survivors to voice their story of survivorship, or what life is like post-treatment, without researcher bias. The public will be educated through this project with the aims that those in the medical community will begin to acknowledge issues that these women are all too familiar with.

**Research Questions:**

1. What does being a survivor look like to you?
2. What are the factors that serve as facilitators or barriers to a positive breast cancer experience, from diagnosis to survivorship?
3. What are our young breast cancer survivors' experiences with developing and adhering to their survivorship care plans?

**Methodology:**

Participants for this mixed methods study will be breast cancer survivors from eastern North Carolina. Many will have had multi-technique cancer treatment during their lifetime and ranging amounts of time in remission. 25 participants will be recruited from young breast cancer survivor support groups during the spring semester. These participants will participate in a focus group and health survey during phase one. The health survey will focus on many aspects of their life, such as social relations, family relations, satisfaction in the workplace, self perception, average level of pain, etc., and will be analyzed using the Statistical Package for the Social Science (SPSS). These women will be asked to volunteer to participate in the second phase of the project and be briefed individually about what is expected from them and will be given all of the necessary supplies to complete their narratives for the compilation, a participant manual, and a consent form. The participants will be given approximately two months to complete their narratives, only with my influence when needed or requested. Multiple cases will be used to produce an all-encompassing visual production that can hopefully invigorate change in the interaction between the healthcare system and young survivors' perspective on survivorship.

In addition to in-person administration, the survey will be administered via Qualtrics to the Ms. Jaime William's young breast cancer support group via a private facebook page. Ms. Williams has agreed to share the survey link, using an IRB approved email message, to assist in the recruit of breast cancer survivors for this study. The reason for an additional outreach strategy is due to the low in-person participation rates. It is expected that this recruitment strategy will help me meet my expected sample size for this study.

## Preliminary Results

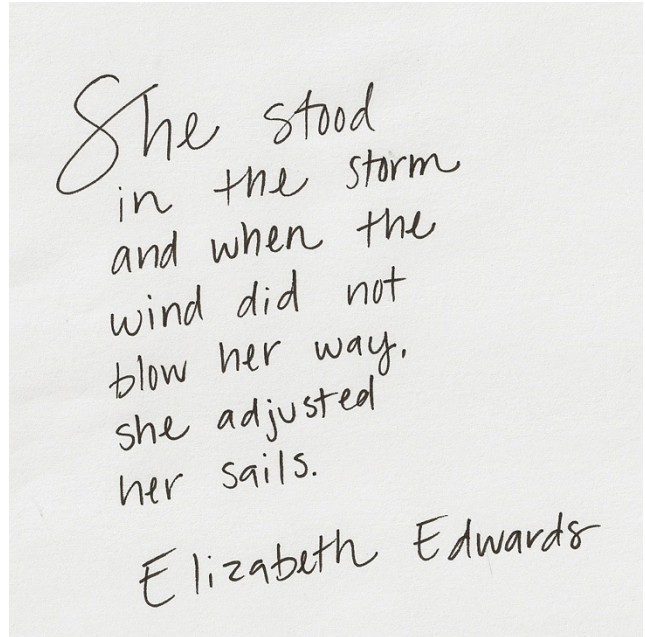
### Qualitative Data

#### Focus Group

THEMES	RESULTS	SUPPORTING QUOTES
Breast Cancer Diagnosis, How it was discovered and Appropriateness of Physicians	<ul style="list-style-type: none"> <li>The majority of the women went in for an ultrasound after discovering something abnormal on their own</li> <li>Only one woman had an appropriate experience when being told her diagnosis</li> <li>One woman was told by a stranger, not her doctor</li> <li>One woman was told over the phone</li> </ul>	<ul style="list-style-type: none"> <li><i>"I really just wanted her out of my face, I had never met this woman she was not the doctor I saw when I was there the first time."</i></li> <li><i>"Yeah I don't understand this doesn't make any sense either; well, okay, lets go tell her.' I'm hearing this outside my door and I looked at my husband and he was like "its alright its alright." He said "well, it turns out that in the five passes that I did, four came back with cancer."--And that's how he told me. Almost like he was just as dumbfounded as I was"</i></li> </ul>
Psychosocial Well-Being: Fear	<ul style="list-style-type: none"> <li>Many women report being in constant fear of cancer recurrence</li> <li>Many reported an increased fear as time goes on, as follow-up appointments become less and less frequent</li> </ul>	<ul style="list-style-type: none"> <li><i>"I'm almost half a year cancer free technically, and I just got lymphedema the other day. Luckily it has gone back down, but I was literally outside push mowing my grass and my arm swells up--First time it had done it since surgery. I mean you always worry-- You worry all of the time, and little things like that scare you."</i></li> </ul>
Psychosocial Well-Being: Coping Mechanisms	<ul style="list-style-type: none"> <li>Many women reported reaching out to women in similar situations for support</li> <li>Some women use projects and new hobbies as they are not as interested in things they spent their time on pre-treatment</li> <li>All women reported going through some form of counseling to help with reintegration back into their normal lives</li> </ul>	<ul style="list-style-type: none"> <li><i>"It is very mental. The YSC conference is the first time I walked into a room and there was like 400 women, breast cancer patients, from newly diagnosed to metastatic, and they all understood. Like, whether it was--whether you just had surgery and you had, you know, you are her too. They all understood at least part of it, and I think that your friends and family try to be there, and not that they are not good at it, but unless you have been in that situation it is real real hard to"</i></li> <li><i>"I was in a situation where I was with someone for three years, got engaged in December, then found out he was cheating on me in March--And I was going through chemo and all of these treatments. I had to go see a therapist because it affected me really badly"</i></li> </ul>
Psychosocial Well-Being: Body Image	<ul style="list-style-type: none"> <li>All women reported having a unilateral or bilateral mastectomy</li> <li>Survivors reported issues with wardrobes post treatment and finding clothing that fit appropriately</li> <li>Many claimed that the scars were more difficult to deal with than anything</li> </ul>	<ul style="list-style-type: none"> <li><i>"[T]he marks that are left behind are a constant reminder of what you had to go through"</i></li> <li><i>"Even with finding bras, it is hard to find bras that fit. I wish there were more places that worked more with women who have gone through breast cancer."</i></li> <li><i>"My body changed dramatically with treatment, I mean I gained close to thirty pounds, I have scars, I no longer have nipples, and I mean I can always go back and have them made, but you cant feel anything, like you lose all sensation. That for me was the hardest, it definitely changes you sex life too."</i></li> </ul>

#### PhotoVoice

*"It's extremely difficult to select one image that represents survivorship but this quote sums it up perfectly for me. Being diagnosed with breast cancer at 33 changed the direction of my life but even after treatment was complete, the storm didn't pass. I was left with the long term effects of treatment, a body that looked and felt completely foreign to me, and scars that would never go away. Cancer not*



*only forced me to change the plan I had for my life but it helped adjust my perspective on life as well. To me, survivorship is adjusting to the new path cancer has created for me."*

*Breast Cancer Survivor, 38*

*"When I see the colors of nature I feel very grateful to life for second chances after having fought a great battle against breast cancer. Life gave me more time to enjoy the beautiful things that God gives us in this world as seeing my son grow and be loved by my husband, Hug my mother, my sister and laugh with my friends. Now that I am a young survivor my eyes see in a different way everything that surrounds me. Thank God for second chances!"*

*Breast Cancer Survivor, Age 33*

*Quantitative Results*





N=4

Treatment	Percentage	N
<b>Chemotherapy</b>	100%	4
<b>Mastectomy</b>	100%	4
<b>Radiation</b>	75%	3
<b>Hormone Therapy</b>	50%	2

Discovery	Percentage	N
<b>Swelling</b>	25%	1
<b>Breast or Nipple Pain</b>	50%	2
<b>Nipple Retraction</b>	25%	1
<b>Nipple Discharge</b>	25%	1

Participants were asked about their screening practices before being diagnosed with breast cancer, and 75% of the women had had regular yearly breast exams before they were diagnosed (this could have included mammograms or clinical breast exams). When asked about physician communication and relationships, 50% of the participants thought their treatments were not fully explained to them by their health care team. In addition, when asked about their opinions on their lead physician, 50% of participants felt that their physician did not fully listening to them when they described symptoms they were experiencing during treatment. When asked about what part of their life was the most difficult to reintegrate into after treatment, most survivors (n=50%) described their work life and most reported taking four months or longer once in remission to return to working fulltime (n=75%). The women were asked to gauge their quality of life on a Likert scale, and all of the women (n=100%) agreed with

having a negative body image post treatment, and 75% of the women agreed that they experience anxiety in everyday life post treatment.

## **Discussion**

This study helped to us to better understand what parts of being a survivor are most difficult for young women and what aspects of remission need more development. In the focus group, the majority of the women reported not being informed of their diagnoses in an appropriate manner and felt a disconnect with their health care teams. Similarly, the women reported not being listened to fully in the survey. This shows a lack of communication and empathy from their health care teams and lead physicians. In the focus group, all of the women described experiencing fear in their day to day lives of recurrence of their cancer. This fear and anxiety does not decrease with time, as the women detailed becoming more anxious as time between follow-up appointments increase. Similarly, all of the women reported issues with anxiety in every day living in the survey. Many of the women in the focus group were not offered any direct counseling services but sought it out on their own. There is clearly a lack of focus on mental health while in remission, and physicians should encourage counseling services and new coping strategies. Survivors reported in the focus group that is it easier to connect with people in their situation compared to their close friends and family when coping with reintegration. The main issue reported with body image in the focus group was the constant reminder of their treatment from scarring, as many of the women had numerous surgical procedures during their treatment.

## **Conclusion**

The aim of this study was to expand our understanding about the quality of life after cancer, specifically among young breast survivors. This area has been studied in the past but have only resulted in inconclusive evidence. A person's battle with cancer is not over after treatment, and many people are not aware of the struggles that accompany the joy of survivorship. There is improvement needed in areas such as counseling during remission (including family counseling), patient-provider communication, follow-up appointments, and anxiety maintenance.

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