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Exploring Women's Experiences and Family Role Shifts Superseding a Breast Cancer Diagnosis

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ABSTRACT

The purpose of this inquiry is to explore the family members' experience in a family with a breast cancer survivor. This study examined family role shifts. Our research originated from two focus groups with eight breast cancer survivors in each group. The study findings revealed coping as a core theme, which was represented by the main umbrella theme, "Ambiguous Terror" and 7 subcategories on the individual level and on the relational level by "Struggling Well is Relational" and 8 subcategories. Our findings contributed to filling a gap in the literature related to shifting roles and ways to support family members.

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Introduction

Breast cancer diagnosis

According to the Centers for Disease Control and Prevention (2020), breast cancer ranks as the second most common medical diagnosis among women in the United States. Furthermore, BreastCancer.org (2020) indicates a stunning 1 in 8 US women (12%) will be subject to a breast cancer diagnosis during their lifetime. The aggressive nature of cancer places stressors on the patient and their support system. The effects of cancer on families over time have warranted many research studies to understand this nuanced disease's implications further. Segrin et al. (2018) imply a few repercussions: psychological, familial, and financial impacts. Numerous researchers have explored the significant effect of a breast cancer diagnosis on the individual patient and their overall experience, but they have often failed to include the family and other support systems' vicarious experiences (Su et al., 2017). Due to this research gap, there lies an indication of further required research on the family support system.

Purpose of the study

The purpose of this study is to understand and explore family role shifts that occur after a breast cancer diagnosis. Shifting roles have shown to result in a family member (spouse, children, adult child, etc.) suddenly being in a caregiver role to provide support and relief to the breast cancer patient. It is essential to understand the system shifts within families who have a family member diagnosed with breast cancer. The support style in these families affects the caregivers' feelings of burden and impacts the entire family, especially the patient (Ávila et al., 2016). Families often have to rearrange their responsibilities to best support the family member with a breast cancer diagnosis. Rather than relying on the sick individual to complete all the previously held family roles, the family members take on new assigned family roles in order to meet the responsibilities needed. A breast cancer diagnosis's primary effect is on the diagnosed individual, but there is a secondary effect on those closest, such as family, coworkers, and friends. Some of these changes reorganize the family system, whereby, loved ones take on new roles and responsibilities in the family. Often, children take on parental roles either in helping care for the sick parent or their siblings or providing emotional support to the other parent throughout the diagnosis.

Research highlights that both children and adolescents have increased personal responsibilities, and a decrease in social activity thereby reducing the time with peer groups and age-appropriate activities (Shah et al., 2017). As a result of these shifting roles, adolescents may end up on a continuum of being both part of the support system and needing support. Mental health issues for the adolescent begin to emerge as a direct result of these shifting roles (Clem, 2009; Fisher, 2009; Osborn, 2007).

Another example is the strain put on marital relationships; the patient's partner not only has to navigate the emotional stressors related to the diagnosis but also the physical side effects and increased functional disability associated with the diagnosis. Thus, partners and spouses are left to manage major life decisions, financials for the family, household and childcare responsibilities, and the uncertainty of a future with their loved one. Couples dealing with a cancer diagnosis often experience significant adjustment and relationship difficulties (Traa et al., 2014; Zimmermann, 2015).

Research questions

Our study will focus on answering two questions. The first question is: 1) What is the experience of women diagnosed with breast cancer? 2) How would family roles shift along the continuum of being supportive and needing support? We seek to provide direct information about the experience with breast cancer from the perspective of the survivors and their family members.

Literature review

General family support

Research shows that if an individual does not have their support system needs met, the survival rates go significantly down (Fong et al., 2017). A drop in social support levels correlates with an increased level of depressive symptoms. Family is the most common support system for cancer survivors. That is why there has been a lot of research surrounding cancer diagnosis, and the support roles family members engage in (Shah et al., 2017). It is important to note that family systems are not binary to social norms and can include same-sex couples, single families, dyads (couples without children, etc.). Segrin et al. (2018) explored the significance of stress, particularly distress, in breast cancer patients and their families. They found the presence or lack of familial support can result in poor psychological outcomes such as depression in the family caregiver upon a role shift. Furthermore, these authors stated psychological outcomes, such as depression, directly correlate to family conflict. Additionally, due to the heightened consequence of potential family conflict, one can argue the impact of said conflict is tremendous on the breast cancer patient and their overall health (Zimmermann, 2015).

Impact of adolescent support

In light of a breast cancer diagnosis, family support could be argued as a tertiary topic for overall positive outcomes. It is important to expand upon familial support to explicitly include spouses, children (adolescents and adults), and adult siblings. Additionally, familial support could include distant family such as aunts, uncles, and grandparents. Top tiered within the family system are the implications of the adolescent experience. Children often times took on the parent role in order to help. Age factors were also present in terms of the level of help from children. But the adolescents assisted with cooking, driving, shopping, helping with getting dressed, etc. Tavares et al. (2018) highlighted a gap in current research in relation to systemic studies on the parent-child relationship considering a breast cancer diagnosis. Counteracting the avoidance patterns, these authors revealed that open communication is a key factor in having positive outcomes to an adolescent's adjustment in regard to a breast cancer diagnosis. There is a small percentage of research highlighting the relationship between child and mother following a cancer diagnosis, but the impact of mother-daughter roles is powerful (Mackenzie, 2014). Davey et al. (2005) states that adolescents dealing with the process of breast cancer find themselves being nicer to their mother as well as becoming

more protective. Additionally, these authors revealed that the adolescents took on more family responsibilities. Undoubtedly, adolescents' experiences related to being a loved one of someone with breast cancer is multifaceted. Thus, providing support for adolescents during this time is essential. Research has found that some adolescents felt special support groups should be developed to address their needs (Davey et al., 2005). There is some evidence pointing to the need for such support groups to be adolescent based only and gender specific. Additionally, adolescents feel that school support should be incorporated (Chalmers, 2021).

Spousal impact

The spousal relationship has been shown to serve as a buffer for the effects of dealing with breast cancer for women (Gao et al., 2019). Spouses typically assume more than one role within this dynamic and often are at risk of mental and potential medical challenges, such as recurrent feelings of anger and heightened worry about the future, which can manifest in symptoms of depression and anxiety. Support from family and the medical team ultimately can lead to less stress and feelings of being a burden on the individual diagnosed with cancer. The cancer patient also requires psychosocial support to ensure quality of life (Kuswanto et al., 2018).

Partner support

Cancer patients often experience individual and relationship challenges. Furthermore, these challenges have the propensity to strengthen the couple relationship or significantly deteriorate the quality of the relationship in the areas of relationship cohesion, relationship functioning, less intimacy, and overall decreased relationship satisfaction. However, the implications of a cancer diagnosis, also may have positive effects on the individual and their relationships, such as greater appreciation of life, changed priorities, closer relationships, and enhanced spirituality (Zimmerman, 2015). Additionally, spousal support has been seen to serve as a buffer for mental health concerns like depression and anxiety and may also be related to the overall psychological well-being of the patient and their spouse (Hasson-Ohayon et al., 2010). While caring for a spouse with cancer takes on many forms, and the implications of this support may vary, together couples are able to lend support to one another in various ways.

Need for support

One can conclude that partners and children play a vital role in the adjustment and overall well-being of the cancer patient. Additionally, as patients

progress through their cancer journey, family and friends should know that their needed support may change over time. Similarly, family roles and responsibilities may shift as well. It becomes imperative that family and friends adapt to the ever-changing process of the cancer diagnosis as they determine how best to support and meet the needs of their loved one.

Methodology

Research design

The participant's experience is a major part of phenomenological inquiry. The goal of this type of inquiry is to discover the individual and shared meanings of the phenomenon (Creswell, 2007). These researchers looked at the phenomenon of breast cancer. The themes that emerged came from the commonality of the descriptions of the participants' experience in relation to the phenomenon of breast cancer. The purpose of this phenomenological study is to grasp the essence of participants' experience with breast cancer.

A hermeneutically derived phenomenology is looking at the lived experience of participants and interpreting these experiences in the context of their everyday lives (Creswell, 2007). This type of inquiry does not so much depend on set rules or methods but it relies on the dynamic interplay of other research activities. In this process, the researcher looks at essential themes based on the lived experiences of the participants. Thereby, this type of inquiry is both a descriptive and interpretive process.

The particular type of phenomenological study used by these researchers is interpretative phenomenological analysis (IPA). This specific method contains an aspect of making sense of what the participants are experiencing; this is the concept of double hermeneutic (Smith et al., 2009). Additionally, the authors describe IPA as idiographic, in that; the experience of breast cancer is very specific to a certain group of the population. This study focused on a set of breast cancer survivors. Every effort was made to properly bracket (Smith et al., 2009) scientific constructs so as not to be derailed from the descriptions of the experiences and shared meanings of the participants.

Use of secondary data

Using secondary data in qualitative studies has both positive and negative implications for the quality of the study. One such limitation refers to the impact of decontextualizing the data (Andrews et al., 2012; Bishop, 2007; Corti & Thompson, 2004; Yardley et al., 2014) Thus, secondary data may be limited in adequately capturing the context in which the data was originally collected, (i.e. the cultural and/or political norms unique to that

time may have a different significance if reevaluated at another time). On the other hand, the use of secondary data may be beneficial in that, researchers may not be as connected to the data as they were not a part of the original collection process. Thus, resulting in more objectivity in conducting the research. While secondary data comes with its own challenges, the current study was prudent in taking into account these considerations.

Participants were recruited with fliers. The women who volunteered for the study received treatment for breast cancer at Dartmouth Cancer Center at New Hampshire. The age range of these women was late 20's to early 70's. This group also represented various types and stages of breast cancer. All women were currently finished with their treatment.

Reflexivity

According to Moustakas (1994), the Interpretative Phenomenological Approach allows researchers to explore and understand the context in which one's lived experiences happened. Furthermore, qualitative researchers have great understanding and respect for the relationship between the research question and the methodology being used to examine the issue. However, phenomenology also acknowledges that one cannot truly be neutral in pursuit of a deeper understanding of one's lived experience. To this extent, the research questions for this study stemmed from the review of the literature on breast cancer and its effect on all family members. One member of the research team had their own personal connection with this topic, as a survivor of breast cancer. The second, third and fourth researchers neither had a relationship with the participants or personal experience with the lived experiences of these individuals, yet simply assisted in the review of the study findings. The overall aims of the study developed through general conversations with the breast cancer survivors as well as analyzing the data. Through this process researchers noticed gaps in the literature in regard to support groups for families with a breast cancer survivor. In taking a subjective social constructionists' framework, the decision was made to look at how to best support family members of breast cancer survivors. Another unique idea that emerged in the review of the literature is that adolescents in these families have struggles that may go unnoticed.

Participants

The participants of this inquiry came from two focus groups with eight participants in each group. Participants received treatment for breast cancer

at Dartmouth Cancer Center at New Hampshire. The age range of the women was late 20's to early 70's. The women who volunteered for the study were all Caucasian. They were all married and had children. This group also represented various types and stages of breast cancer. All women were currently finished with their treatment.

Data collection

For the purpose of the current study, researchers found that a sample size of 16 participants met the aims of a phenomenological study. Thus, while reaching saturation of the data is often the goal of many qualitative studies, phenomenology endeavors to provide an accurate, comprehensive description and interpretation of the phenomenon (Mason, 2010), in this case of the lived experiences of breast cancer survivors. Charmaz (2006) suggests that the aim of the project is the ultimate driver in determining the sample size and therefore saturation. She adds that a small study with “modest claims” may reach saturation faster than a bigger study that tries to describe a process that spans disciplines (p.114). Crouch and McKenzie (2006) also mentioned that studies which used methods such as in-depth interviews with the same participants (e.g., longitudinal or panel discussions or focus groups) require fewer participants in order to reach saturation. The current study met this requirement by providing a comprehensive description of the participants' interpretation of the phenomenon.

Prior to the data collection, approval for the study has been received by the Internal Review Board of the Institution that the primary researcher attended. Confidentiality of the participants was ensured by assigning a code to each transcript and field note. The initial step of data collection for the primary researcher was collecting demographic information, age, gender, race, education, and marital status. Semi-structured interviews were conducted in a private room. Interviews were about 120 minutes. All interviews started with asking the participants: “Just so that I have context, because there are so many kinds of cancer treatment would you mind telling me what kind of cancer and treatment you had.” The researcher used consequential questions developed in the process of the interview to explore more about women's experience, perspectives, thoughts and feelings about the treatment process. Examples of these are: “So, who were the key supporters, friends, family, and other people – who would you, say were the key supporters for you during the treatment period?” “How did you see your family relationship changing? Who did what? Did the roles change? How you related to each other? How did that change? I'm going to assume there was at least some change.”, “So how would a woman know that despite the fact there's been a weird day, or there's been difficult day,

or there's been whatever kind of day that it was one of the good days too? How would a person even know that she and her family were struggling well?"

Data analysis

Phenomenological Method was used in analyzing the transcripts. The procedures that these researchers used are presented through stepwise descriptions. Step 1: The researchers read through the full transcript without making notation. Step 2: A second reading of the transcripts was done, whereby; researchers began circling units of meaning on an exploratory level (initial noting). These units of meaning (keywords) represented the participants' understanding of the phenomenon. Step 3: During the third reading, researchers underlined interpersonal dynamics. These descriptive codes represented who came closer, who went distant, and who isolated from the group. Notes were written in the process of coding. Step 4: The initial codes and descriptive codes were combined onto smaller pieces of paper or unitized cards. Step 5: Researchers developed themes based on the initial and descriptive coding. The unitized cards were then organized by major theme. Some of these unitized cards were used as bridging themes. Step 6: In reading the larger themes, researchers determined some themes were closely related. Reviewing each researcher's notes, it was decided to pool these themes into specific umbrella themes. These umbrella themes were developed through a process of abstraction, which identifies patterns of emerging themes and places them into larger themes or umbrellas of understanding (Smith et al., 2009).

In step three, the analysis focused on linguistic and conceptual comments. These are a key element of exploratory noting (Smith et al., 2009). Beginning with step three, time was given to reflecting and refining the codes as well as refining ideas that emerged. Researchers continually looked for emerging connections between themes beginning in step five. This entailed moving themes around to cluster related themes as well as search for magnet themes that would pull other themes toward each other (Smith et al., 2009).

As umbrella themes emerged, they helped to bring together a series of related themes (Step 5 and 6), which Smith et al. (2009) calls subsumption. This process was crucial to our inquiry. Another very important concept was polarization. This concept is said to occur when researchers focus on the differences between the themes instead of the similarities while setting aside the negative aspects (Smith et al., 2009). Researchers used polarization in step 6 as they identified that some of the themes would not be defined in traditional ways. More about this is explained in the following section.

Provisions for trustworthiness

No identifying information was used in the written transcript and the research article. Every effort was given for each participant's voice to be heard and each participant to be treated equally. Participants were also asked for their feedback after themes were formed to ensure their experience was captured accurately. Additionally, external audits confirmed that the interpretation of the participants' experience was used.

Results

From the focus group transcripts, two umbrella themes were extracted as well as 15 other sub themes. The umbrella themes were structured on the basis of two organizing principles:

a) individual phenomenon or individual based coping and b) relational phenomenon or relational based coping. [Figure 1](#) portrays the overall process of coping. From the focus groups transcripts, coping was formulated as a core category. Coping on the individual level was represented by the main umbrella theme, "Ambiguous Terror" and 7 sub themes/categories and on the relational level by "Struggling Well is Relational" and 8 subcategories. The main coping umbrella themes were structured on the basis of two organizing principles: a) individual struggles and ways of coping with cancer and b) relational struggles and coping as a family. Through action/interaction, intervening strategies, and consequences categories were linked, "struggling poorly" was a bridging subcategory between the individual and the relational levels of coping.

Umbrella theme: Ambiguous terror

[Table 1](#) shows all the main themes/categories and subcategories. This theme arose based on concepts that participants used to describe the process of breast cancer treatment, 'terrified', 'ambiguous terror', "some mixed feelings sometimes." Participants explained that the way they felt was confusing and "very few people understood or have experienced that level of terror." For them, this level of terror was something very different than anyone has ever experienced before.

Terrified but positive

This was a common theme among the participants. It related to the fear experienced throughout the process of breast cancer treatment and the idea of keeping a positive attitude, "I felt terrified" and "nobody really understood," "I think a positive attitude is a big thing," "made peace with

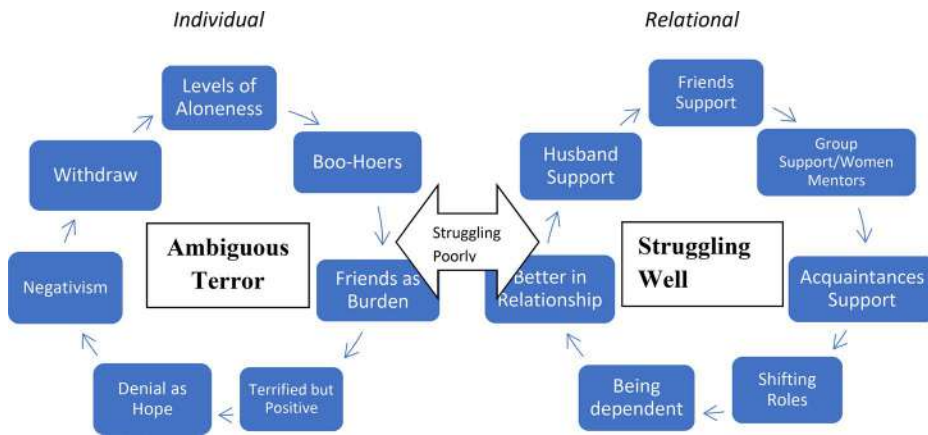


Figure 1. Theory of coping with breast cancer treatment.

that [terrified].” There was a sense of “mixed feelings.” Participants were terrified yet trying to stay positive as a way of coping, but even going to the support group added to being scared, “...added to the terror.” Staying positive helped them make peace with the terror, but being terrified was a constant part of their life even when they received support.

Denial as hope

This was a new concept that seems to contradict traditional views of denial. The cancer patients shared that denial helped them preserve their hope while struggling with the cancer treatment. They said they were determined to continue living and they did not want to face the reality of cancer, “we’re not even going there,” “...not give in to any thought I’m dying,” “If I’m going to die, it’s not going to be today,” “I don’t need to know how bad it is.” They did not want to admit this is a serious disease that might be lethal. This denial is what helped them survive, preserve their hope, and keep on living one day at a time.

Negativism

This is a very interesting idea that is also tied to the idea of denial as hope and it is in opposition to the idea of staying positive in order to survive the battle. This is a very interesting finding related to number 2: denial as hope. This result also opposes the idea of staying positive in order to survive the battle. Negativism and denial are generally not considered functional ways of coping, but for these women this was the only way of coping. Negativism was utilized as a defense mechanism and was extremely helpful for these women who were in a survival mode but not surrendering to despair. They found meaning in their suffering, but they expressed it through

Table 1. Main themes/categories and subcategories.

	Coping
Individual level /"Ambiguous Terror"	Relational level/ "Struggling well" is relational ↔ struggling poorly
Terrified but positive	"Struggling Well" Better in Relationship
-making peace with terror by staying positive	-relationships making the process better
-terrified even when receiving support	
• "I felt terrified"	• "journey is just so much better"
• "I think a positive attitude is a big thing"	• "hard to struggle well as an individual"
• "made peace with that [terrified]"	• "too hard to go through by myself"
• "mixed feelings"	
Denial as hope	• Struggling Poorly
-denial as survival instinct	-detached from family and friends
-denial helps with finding hope in suffering	-never see a positive thing
	-insensitive remarks of loved ones
• "...not give in to any thought I'm dying"	• "they're not struggling well"
• "we're not even going there"	• "never see a positive thing"
• "I don't need to know how bad it is,"	• "struggle was terrible"
	• "detached of their family and friends"
	• "I hope you have a wig or something"
Negativism	Husband Support
-freedom of not having a positive attitude	-having caring and encouraging husband
	-husband taking over everything
	-not being able to survive without their husband
• "have to be free not to have it [a positive attitude]"	• "incredibly supportive through the whole"
• "I don't have one today and I didn't have one yesterday either"	
Withdraw	Friends Support
-withdrawing and not burdening the family	-friends help the patients live through the struggle
• "withdraw for a while"	• "wonderful friends who were very supportive and helpful"
	• "they were extremely supportive"
• "wanted...to be by myself"	• "huge, huge positive"
• "no desire to be in a support group"	Group Support/Women Mentors
Levels of Aloneness	-essential to have someone there who understand
-purposefully seeking alone time	-helping each other/ passing the support to other women
-no one understood	
-no one there for them	• "everybody there knows what you've been through, or can at least relate"
• "alone"	• "I found them <i>incredibly</i> important though the whole thing"
	• "she was just incredible"
• "just didn't want them [family] around"	• "she would be there"
	Acquaintances Support
• "they really don't understand"	-support from strangers
• "set up...life in that room,"	-huge positive in one's life
Boo-Hoers	• "I got a lot of support from people I barely knew or acquaintances"
-people who had to be comforted	• "support came from virtual strangers was astonishing"
-crying and not knowing how to react	• "really amazing there was that much good will and helpfulness from people that weren't my closest friends or family"
• "didn't know what to say"	
	Shifting Roles
• "just got overwhelmed"	-family changes
	-children take on parental role
Friends as a burden	• "took over taking care of me"
-having to comfort others	
-not wanting to be a caretaker of others	• "I could just ask my oldest son to cook"
• "they look at you like... they can't help it"	• "daughter took over the parent role"
• "didn't want any negative people"	
• "I just didn't want them around if they felt that way."	• "she would take me shopping"
	• "she came over and fixed my coat"

(Continued)

Table 1. Continued.

Individual level /"Ambiguous Terror"	Coping
	Relational level/ "Struggling well" is relational ↔ struggling poorly
	<ul style="list-style-type: none"> • "kind of took over when she came home" Being Dependent -desire for equal partnership -struggling with having to be dependent to survive • "become the person he had to care for" • "took over care of me" • "I found it necessary and comforting and I hated it."

negativism. These women could not be optimistic about their situation since they did not know what to expect at the end of their treatment process. They also did not want to be cautiously optimistic, but they found it helpful to prepare for the worst and be negative in this situation. They were talking about the freedom of not having a positive attitude, which they found to be a strength in the battle with cancer, "have to be free not to have it [a positive attitude]," "I don't have one today and I didn't have one yesterday either." Along with the need of having support in their life as a way of coping, these women needed also to be in denial and be negative at different phases of the treatment process.

Withdraw

That is why as a way of coping, participants withdrew for a while from family and friends, pulling into themselves and being alone as a way to cope, "withdraw for a while," "wanted...to be by myself," "no desire to be in a support group." This is a very important part of the coping process for women. They withdrew for a while, because they did not want to be a burden for their family members and preferred to be alone, "I couldn't always tell them I didn't want them to worry more." They felt like no one could understand them and they did not want their family to feel bad watching them suffer. It is very interesting that women used "withdrawing," "denial as hope," and "negativism" to cope with what they were going through. This concept is also connected to the "levels of aloneness" subcategory.

Levels of aloneness

This concept relates to participants feeling like they did not really have anyone there for them, because no one could understand what they were going through emotionally. They were "alone," "set up...life in that room," "just...wanted to be by myself." They felt like, "I was by myself but that was ok," "did feel alone," "just didn't want them [family] around," "they really don't understand," "nobody really understood." They were left all alone with their emotions and feelings and the hurt and the pain. They

also had to comfort people who did not understand or did not know how to handle their diagnosis, the “boo-hoers.” They wanted to stay away from these “friends as burden.”

“Boo-Hoers”

The concepts “levels of aloneness” and “friends as a burden” connect with this subcategory. This is an in vivo theme that came up directly from the data. The “Boo-Hoers,” who were “typically young and sweet” people around the cancer patients “didn’t know what to say” and “just got overwhelmed.” These people who were sometimes even strangers had to be comforted by the cancer patients, “I had to comfort 5 or 6 people about the fact I had cancer.” This subcategory is an interesting concept that shows how women were surrounded by people who reacted overly emotional around them because they did not know how to handle the treatment process. The participants called these people “Boo-Hoers.”

Friends as a burden

This theme continues the story of women having to comfort other people such as their friends and purposefully seeking alone time or withdrawing so that they don’t have to do this. Participants had to be the caretaker for their friends who could not deal with seeing them go through the process of cancer treatment, “they look at you like... they can’t help it.” They did not want to be a support system for their friends and were annoyed with the absurdity of the situation, “didn’t want any negative people,” “stayed away from all people that would be pitying me,” “didn’t want them around if they felt that way.” This concept connects the individual struggles and ways of coping with cancer and the relational struggles of participants and their coping as a family via the bridging subcategory of “struggling poorly.”

Umbrella theme: “struggling well”

Participants described their need for having strong support from family, friends, support group, women mentors, and even strangers. This led to the formulation of this theme. It explains how the supportive families, friends, mentors and strangers’ relationships encouraged participants and helped them cope with the terror of having breast cancer.

Struggling poorly

This is a concept that presents the other side of the “struggling well” concept. It shows what happens when people are not struggling well and never

see a positive thing in their life,” they’re not struggling well,” “never see a positive thing,” and” struggle was terrible.” These people are surrounded by the insensitive remarks of their loved ones, “detached of their family and friends” and “I hope you have a wig or something ‘cuz you can’t walk around here bald.” This is what made the suffering more difficult for the cancer patients and made some women give up on the battle. This concept is also a bridge between the individual and relational levels of struggling and having no support from friends and family in this process.

Better in relationship

Struggling well was found to be hard for breast cancer patients to do on their own. Participants felt that being in a relationship made this process a little bit better, “journey is just so much better,” “hard to struggle well as an individual,” “too hard to go through by myself,” “they are the ones who just kept me going.”

Husband support

All the subcategories on types of support are strongly connected. Participants stated how important it was to have a caring and encouraging husband, “incredibly supportive through the whole,” “married the right guy,” “my husband was wonderfully supportive,” and “I couldn’t ask for a more caring person,” “God-send. They explained that their husband took over everything for them and helped them tremendously, “he took over everything” and “took the leadership role.” They shared that they would not have been able to survive if their husband was not there for them. They thought it was very important that there was someone there for them in their hardest moments.

Friends support

All participants addressed how important their friends’ support was while they were battling cancer, “wonderful friends who were very supportive and helpful,” “they were extremely supportive.” They said that it was a “huge, huge positive” thing in their life. Friends helped cancer patients live through the struggles. Friends’ support was not only important for the cancer patients themselves but also for the husbands, who had no other outlet or support system, “friend takes care of the patient and ... of the caregiver and other family members.”

Group support/women mentors

All women in the study said that having a support group while going through the cancer treatment and post treatment was crucial, “everybody there knows what you’ve been through, or can at least relate.” They found

it essential to have someone there to share with, “I found them *incredibly* important through the whole thing,” “they’re all women.” Women were helping each other and passing this support to other women, “she was just incredible,” “she would be there,” and “she was always in a good mood.”

Acquaintances support

This theme described the power of having support coming from strangers and acquaintances, people who were not that close to the cancer patients, but they provided them and their families with lots of support, “I got a lot of support from people I barely knew or acquaintances,” “a woman who I had a passing acquaintanceship with made 10-days’ worth of dinners,” “support came from virtual strangers was astonishing,” “really amazing there was that much good will and helpfulness from people that weren’t my closest friends or family.” Women found this as a huge positive aspect in their life.

Shifting roles

This is an important concept that shows what families did to adapt to the new changes in the family. Children took on the parent role in order to help. They did the cooking, driving, shopping, helping with getting dressing, etc. This relates to all the other subcategories of “struggling well is relational” and shows how family members were coping and what support the cancer patients had. This was revealed by “took over taking care of me,” “I could just ask my oldest son to cook,” “daughter took over the parent role,” “she would take me shopping,” “she [daughter] came over and fixed my coat,” “kind of took over when she came home.”

Being dependent

It was very hard for the participants to leave their husband and children take over all their responsibilities, “become the person he had to care for” and “took over care of me.” They realized that they needed to do this in order to survive the treatment process. They had mixed feelings about it “I found it necessary and comforting and I hated it,” but they started appreciating that there was “someone there to care for you,” “equal partnership,” “he took that all over for me.” It was the only way for them to make it through the process and they hated and liked it at the same time.

Discussion

Summary of findings

The researchers discovered two main umbrella themes: a) “Ambiguous Terror” at the individual level with 7 sub themes/categories and b)

“Struggling Well is Relational” at the relational level with 8 subcategories. Ambiguous terror referred to the “mixed feelings” and terrifying experience that participants had while battling cancer. Participants felt not understood and alone. They were surrounded by people who did not know how to handle seeing them suffer, which led them to withdraw and use “denial as hope” and “negativism” in order to survive the process. Ambiguous terror is a unique concept that came up in this study regarding going through breast cancer diagnosis, treatment, and follow-up while not knowing the outcome, which could be overwhelmingly terrifying. There is a level of feeling alone that not only causes withdrawal but also denial which, from the findings, is actually a positive process resulting in finding hope in suffering. There is also this idea that the process of treatment doesn’t end with treatment.

It was also discovered that the process of treatment didn’t happen in a vacuum. Things from everyday life continued to take place and resiliency seemed to be strengthened by having strong relationships with family, friends, acquaintances and even strangers- “Boo-Hooers.” We discovered some unique concepts that have not been previously discussed in the research literature such as “Ambiguous Terror,” “Boo-Hooers,” “Denial as Hope,” “Negativism,” “Levels of Aloneness.” In addition, participants revealed that one way to find hope in suffering is to “struggle well.”

It was also found that the process of “struggling well” had another side of it, “struggling poorly.” This was a bridging concept between the individual and relational levels, showing what happened to people when they were not understood by their family and friends and lacked support. Resiliency or “struggling well” seemed to be strengthened by having support from family, friends, acquaintances and even strangers. It was also revealed that the participants and their family members changed their roles in the family. They became more dependent upon their family members, even though this change was uncomfortable for them. Their husband took upon their responsibilities and their children became the new parent figures in the family. Participants both liked and hated these changes in the family, but they realized this was the only way for them to survive the process of breast cancer treatment. Finally, the participants felt that the process of treatment was more doable when they could associate with a survivor buddy.

Research implications

This phenomenological study sparked conversation about future topics of research related to family coping during the process of breast cancer treatment. One of these was if there exist a relationship between mothers’

and fathers' way of coping and children's dysfunctional ways of coping by taking on the parent role, which for daughters in some cases has led to the development of eating disorders (Clem, 2009). Further research could be done to explore this relationship and assess if sons also developed some psychological or behavioral issues in taking on the parental role. Additionally, the transcripts highlighted that family members felt supported by acquaintances more so than by outside professionals. As such, one source of support was through support groups for the husbands and teenagers. Hence, future research can explore more about this need of support for the whole family.

Implications for practice

The current study findings lend support to the medical and clinical field to better understand the needs and/or stressors of women affected by a cancer diagnosis. This shows the importance of having the right support system or understanding some of the challenges that loved ones and/or acquaintances might have in navigating through this diagnosis. Ultimately, clinicians can help women develop or enhance their coping strategies and its impact on the woman's well-being. Also, from the findings it is clear how indispensable support groups are in helping these women cope. Another research implication is studying directly family members who live with a breast cancer survivor in order to better understand the family role shifts that take place in these families. This study expands previous research findings related to the implications of breast cancer for the patients and their families (Segrin et al., 2018). Specifically, it showed that breast cancer patients may experience a sense of "Ambiguous Terror" or "mix of emotions" such as "Denial as Hope" and "Negativism" in coping with this diagnosis, which were found to be unique coping strategies. These findings may help clinicians better understand, validate, and support the highs and lows specific to the breast cancer patients and their families.

Limitations and recommendations for future research

Secondary data analysis is typically messy and informal (Seale, 2004). It is easily influenced by the questionnaire and sample of other primary researchers. Other issues revolve around researcher bias and personal interest. Additionally, the qualitative research methodology used by the researchers could be a limitation. Some other issues may be related to the fact that one did not know the sample well, did not choose the sample, did not design the database, or transcribe the interviews. It is also possible

that one may not have all the data available. In the case of our current data analysis, the researchers were not present for the focus group or privy to video footage of the group. The study included all white women and only heterosexual couples. Future research could be done with diverse couples and women from different cultural backgrounds. All of these are limitations of the current study.

In conclusion, this study revealed that the process of breast cancer treatment was accompanied by significant family role shifts. The breast cancer survivors became more dependent upon their family members. Their husbands took upon a lot of their responsibilities and some of the children in the family took on parental roles. Participants hated these changes and they caused significant issues in their families, but they also realized this was the only way for them to survive the process of breast cancer treatment. This article provides a look into the changes that affect these families and opens up the door for future research on this topic. More research is needed in this area in order to produce effective findings. The researchers of this study recommend that future studies explore the experiences of family members in these families and the effects of breast cancer treatment on all family members. Also, other researchers could look into the family role shifts that take place in these family and discuss how these shifts influence family members' mental health.

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