UNDERSTANDING SURVIVORSHIP:
THE SHARED EXPERIENCES AND THERAPEUTIC FACTORS IN YOUNG BREAST CANCER SURVIVORS’ USE OF ONLINE COMMUNITIES

by

JESSICA CERES HOBBS

(Under the Direction of Jeong-Yeob Han)

ABSTRACT

The growing number of individuals living many years after a cancer diagnosis continues to increase, which results in a growing need to promote and ensure the physical, psychological, social, and economic well-being of cancer survivors. An understanding of the common experiences and shared meanings of young breast cancer survivors can inform the development of interventions aimed at meeting the needs of young women affected by breast cancer and, as a result, contribute to improved coping and quality of life. This study used a mixed-methods approach using quantitative and qualitative methods to determine themes that emerge from the dialogue of young breast cancer survivors. Results indicate that many young breast cancer survivors experience fears of recurrence and leaving their children behind, fertility issues, difficulties discussing cancer with children, feelings of guilt, emotional struggles, and the expectation that there are no hardships with survivorship.

INDEX WORDS: breast cancer, young women, survivorship, internet, online, phenomenology, text analysis, health communication
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JESSICA CERES HOBBS
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JESSICA CERES HOBBS

Major Professor: Jeong-Yeob Han
Committee: Jeffrey Springston
Pamela Orpinas

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
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DEDICATION

This thesis is dedicated to anyone who has been affected by cancer – especially those who have fought or are fighting cancer and their loved ones.
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I would like to acknowledge my thesis committee for their support through this thesis and in my academic career. I would also like to acknowledge my family for their unending support and encouragement.
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CHAPTER 1
INTRODUCTION

Due to medical advances, people are living many years after a cancer diagnosis, and there are nearly 12 million cancer survivors in America (Centers for Disease Control and Prevention, 2011). Objectives for Healthy People 2020 include increasing the proportion of cancer survivors who are living five years or longer after diagnosis and increasing the mental and physical health-related quality of life of cancer survivors (U.S. Department of Health and Human Services, 2012). As the number of cancer survivors increases, there is a growing need to promote and ensure the physical, psychological, social, and economic well-being of cancer survivors. While most programs focus on early detection and prevention, research foci are expanding to include cancer survivorship (Centers for Disease Control and Prevention, 2012).

According to the National Cancer Institute, a cancer survivor is defined as an individual who has been diagnosed with cancer at any point in his or her life (National Cancer Institute, 2012). Because family, friends, and caregivers are also impacted by an individual’s survivorship experience, they are also included in this definition (Twombly, 2004). While family, friends, and caregivers are not included in cancer research statistical reports, they are often referred to as “secondary survivors” because of the impact of a loved one’s diagnosis and experience on them. The National Coalition for Cancer Survivorship (NCCS) began using this term in 1986 as a way to empower people and send a message that cancer was a disease that people needed to fight – in terms of
both autonomous treatment decisions as well as research agenda. While there is some
debate regarding this definition, it is generally agreed upon that an individual is
considered a survivor despite the presence or absence of the disease – regardless of when
the diagnosis was made and if the cancer was successfully treated (Twombly, 2004).
However, to many people, especially outside of the cancer field, “survivor” suggests
someone who has previously had cancer but is now cancer-free (Twombly, 2004).

Each year, approximately 70,000 men and women aged 15 to 39 are diagnosed
with cancer (Adolescent and Young Adult Oncology Progress Review Group, 2006). In
2009, the American Cancer Society predicted more than 190,000 new cases of breast
cancer in women and estimated that roughly 18,600 of these women would be younger
than 45 years of age. This research defines young adults as those younger than 45 years
of age, however many organizations, such as The American Society of Clinical Oncology
and LIVESTRONG, combine adolescents and young adults in one category of those 15 to
39 years of age (American Society of Clinical Oncology, 2010).

Furthermore, young women face unique challenges because of their age and other
factors. More evidence suggests that breast cancer in women under the age of 40 differs
biologically from the cancer faced by older women (Young Survival Coalition, n.d.b).
Young women generally face more aggressive cancers and struggle with many issues
either not present or much less severe in the lives of older women (American Cancer
Society, 2009). These issues can include the possibility of early menopause, effects on
fertility, pregnancy challenges after diagnosis, concerns about body image, and
challenges to financial stability (Young Survival Coalition, n.d.b). In order to develop
interventions aimed at meeting the needs of young women diagnosed with breast cancer, their support and informational needs must first be assessed and understood.

One method cancer survivors use to exchange support and information is the giving and receiving of information and social support in online communities, such as cancer community forums. Because breast cancer survivors make up the largest group of cancer survivors, this sample will consist of a young breast cancer survivor community, the Young Survival Coalition. The Young Survival Coalition (YSC) is the premier global organization dedicated to the critical issues unique to young women who are diagnosed with breast cancer. YSC offers resources, connections, and outreach so women feel supported, empowered, and hopeful. YSC identifies higher mortality rates, fertility issues, and the possibility and ramifications of early menopause as challenges unique to pre-menopausal women with breast cancer (Young Survival Coalition, n.d.a). Additionally, this network has addressed these challenges as opportunities to advocate for more research about young women and breast cancer, educate young women about the importance of breast self-awareness and knowledge, and serve as a community of support for young women with breast cancer.

This research seeks to identify the common experiences and shared meanings of young breast cancer survivors through their involvement in online communities. The study of their experiences can inform the development of interventions aimed at meeting the needs of young women affected by breast cancer and, as a result, contribute to improved coping and quality of life. The questions this research seeks to address include how young breast cancer survivors use online communities, which topics are frequently
discussed, which therapeutic factors are present in this area of support, and whether the overall affect of posts is positive or negative.
CHAPTER 2
LITERATURE REVIEW

Many researchers have sought to understand the role that online support groups play in people's lives through the study of content on discussion forums. Online communities and forums offer accessibility to those experiencing similar situations, such as breast cancer and other types of cancer. Through utilizing discussion forums, participants can give and receive support and information, share experiences and narratives, connect with others, and learn about other resources.

Social Support

Research has sought to examine both the communication patterns and the exchange of social support through online communities. Kim et al. (2012) defined computer-mediated communication according to two different communication attributes; providing support was conceived as the act of writing supportive expressions, while receiving support was conceived as the act of reading these messages. Through these interactions, a reciprocal relationship between giving and receiving social support exists; those who received emotional support were more likely to provide emotional support (Kim et al., 2012). Moreover, those who received higher levels of support from others had fewer breast cancer-related concerns, while those who gave higher levels of support to others reframed their own situation in a more positive light or adopted positive coping strategies (Kim et al., 2012).
There are a multitude of positive health-related outcomes that result from online communities. To differing extents, women have identified enjoying each other’s company and trusting, caring about, identifying with, and feeling supported by each other as perceived benefits of online support groups (Vilhauer, 2009). Additionally, women with metastatic breast cancer indicated that benefits included direct alleviation of anxiety, getting better medical care, reduction of the need for outside support, increased openness to others, becoming more active in treatment, reduced ambiguity, downward social comparison, becoming more appreciative of their own situation, realizing their situation was shared, feeling more hopeful, helping other women, and a sense of community (Vilhauer, 2009).

*Online vs. Face-to-Face Support*

The usefulness of online communities compared to face-to-face support groups has also been examined. Using factor analysis, support scores of “emotional expression” and “advice” were greater in online communities than in face-to-face support groups (Setoyama, Yamazaki, & Nakayama, 2011). Furthermore, online communities offer benefits that face-to-face interactions do not, including greater accessibility in terms of time and geographic proximity, anonymity, and the ability to obtain information without face-to-face interaction (Chen, 2012). Online communities are available and easily accessible regardless of physical and psychological distress. While both support methods have respective benefits, breast cancer patients can receive the same functions of peer support from both online communities and face-to-face support groups (Rodgers & Chen, 2005; Setoyama, Yamazaki, & Nakayama, 2011; Vilhauer, 2009). However, findings
have indicated that face-to-face and online support resources are complementary to each other, and individuals that utilize both methods will experience the most social support (Setoyama, Yamazaki, & Nakayama, 2011).

Online support groups also offer benefits based on the anonymity of interactions. Users who felt stigmatized especially appreciated the anonymity of online forums, while people who identified themselves as restricted in mobility appreciate the possibilities for network expansion (Tanis, 2008). These online interactions still proved beneficial for patients in their daily lives. Those who used only online communities rather than face-to-face support groups felt they could openly discuss their condition and had more insight into their condition. They also “calmed down” after their interactions in online communities because of meeting patients with similar experiences (Setoyama, Yamazaki, & Nakayama, 2011). Additionally, online support group users received advice on a multitude of topics related to their cancer experience. Individuals were most likely to value advice about relationships with family members or workplace colleagues and advice about decision-making on treatments and associated side effects (Setoyama, Yamazaki, & Nakayama, 2011).

Informational Needs & Topics

Literature has also demonstrated the high value patients place on practical and experiential information from other patients. Breast cancer patients often share information on particular treatments or procedures, including biopsies, MRIs, chemotherapy, radiation treatment, breast reconstruction, mastectomies, and side effects of treatment (Chen, 2012). Additionally, women shared their own experiences and
offered insight from a personal perspective about particular issues they have faced, such as finding a lump, coping, waiting for results, and relationship issues. When comparing cancer survivor needs across ages and genders, greater need was identified among cancer survivors who were young females (Knobf et al., 2012). However, there has been little focus on the online practices and needs of young women, specifically.

Cancer patients valued access to practical and experiential information from other patients (Rozmovits & Ziebland, 2004). In a qualitative study of informational needs, Rozmovits and Ziebland (2004) found that experiences of other patients provided both reassurance and access to a wealth of practical information that health professionals did not address. Chen (2012) found that experiential information in online communities included coping techniques, advice about relationships, experiences with finding a lump, and biopsy results. Similarly, Gooden and Winefield (2007) concluded that patients preferred information such as others’ experiences, how they dealt with effects of the disease, and others’ disease and treatment progress. In research involving women with metastatic breast cancer, participants reported being able to discuss many concerns freely, yet they had difficulty discussing death and dying, which is a critical issue for this category of women (Vilhauer, 2009).

In addition to experiential information, individuals sought medical information on a multitude of issues. Treatment and procedure information included pain and other side effects, biopsies, MRIs, surgeries and mastectomies, chemotherapy, radiation, and breast reconstruction (Chen, 2012). Blank et al. (2010) identified initial diagnosis and treatment, treatment side effects, long-term effects, lifestyle issues, recurrence, and relapse as frequently posted information. Other generic information included study
solicitation or results, invitations to online events, tips, and informational resources (Chen, 2012).

Previous research has also highlighted critical time periods for informational needs. In focus group results by Rozmovits and Ziebland (2004), participants regarded the period between diagnosis and treatment as a vital time for information. Immediately after diagnosis, many were too shocked to take in information but within a few days their information needs were very great. The period after treatment also brought new information needs to light; individuals wanted to know how they could better their recovery by changing their diet or lifestyle. Additionally, focus group participants identified this information as very hard to come by, and the lack of it left them feeling frustrated and disempowered (Rozmovits and Ziebland, 2004).

Financial concerns were also a common topic discussed within online support groups. Online resources allow patients to discuss the difficulty of finding out about the financial consequences of their illness with others experiencing similar situations (Rozmovits and Ziebland, 2004). Participants were likely to share information about financial help and benefits, insurance, work issues, and financial problems (Blank et al., 2010; Chen, 2012; Rozmovits and Ziebland, 2004; Vilhauer, 2009).

**Gender Differences**

Previous literature comparing male and female cancer discussion boards has noted gender differences especially within single-sex online support groups. Mo, Malik, and Coulson (2009) reviewed literature to identify gender differences in messages posted to online health-related support groups. Results indicated that gender differences occurred
in single-sex online support groups, but similarities in communication patterns occurred in mixed-sex online health support groups (Mo, Malik, and Coulson, 2009).

Most literature comparing gender differences notes that women are more likely to focus on emotional words, while men focus on treatment associated words. When comparing breast cancer and prostate cancer patients’ use of online discussions, breast cancer patients were more likely to use words related to emotional disclosure and cognitive processing, whereas prostate cancer patients were twice as likely to use words pertaining to cancer information (Owen et al., 2004). Additionally, Seale, Ziebland, and Charteris-Black (2006) found that women prioritized emotional communication and discussed a wider range of feelings than men. Women expressed more interest in more pleasurable aspects of their lifestyle and were more likely to use words associated with feelings, people, clothing, and appearance. Men were more likely to use words associated with treatments, tests, diagnosis, symptoms, side effects, and actual and potential progression of their disease (Seale, Ziebland, and Charteris-Black, 2006). Moreover, findings from Blank et al. (2010) demonstrated that breast cancer sites were more likely to offer emotional support, while prostate cancer sites focused on informational support.

**Clinical Care Guidelines**

Survivor-based research can have a profound impact on guiding clinical care. As the number of individuals living five years or more beyond their cancer diagnosis continues to grow, providing guidance about potential late treatment effects is increasingly important. Hudson, Landier, and Ganz (2011) emphasized the growing need
to anticipate health risks among survivors. Late treatment effects are commonly experienced by cancer survivors, and they increase in prevalence with aging. Additionally, late treatment effects produce substantial morbidity and predispose survivors to early mortality (Hudson, Landier, and Ganz, 2011). Findings from survivorship research enable providers to anticipate health risks among predisposed survivors; in doing so, they facilitate survivor access to interventions to prevent, detect, treat, or rehabilitate cancer-related morbidity (Hudson, Landier, and Ganz, 2011).

**Therapeutic Factors**

Therapeutic factors were identified by Yalom through his extensive research and practice in group therapy (Yalom & Leszcz, 2005). Yalom, a group therapist, writer, and professor of psychiatry, is viewed by many as an authority on the mechanisms of change in group therapy (Erdman, 2009). His texts include empirical data and clinical observations centered on the common changes that take place in group interventions. Originally referred to as “curative factors,” he has since referred to these underlying mechanisms as “therapeutic factors” because of the term’s more accurate description of the change or growth rather than cures that happen as therapeutic benefits. Therapeutic factors identified by Yalom include universality, instillation of hope, imparting information, altruism, imitative behavior, group cohesion, interpersonal learning, development of socializing behavior, recapitulation of the family, catharsis, and existential factors (Yalom & Leszcz, 2005). The occurrence and impact of these therapeutic factors varies among groups and environments.
Universality is the realization that one’s experienced is shared by others and not unique or rare (Yalom & Leszcz, 2005). This can result in affective or cognitive modifications. In addition, through discovering that one is not alone, an individual might feel an immense sense of relief and be less likely to catastrophize one's experience or illness. Positive results can include a reduction in anxiety, concern, embarrassment, fear, shame, or sadness. These affective and cognitive changes are key in reducing self-perceived stigma. This process requires self-disclosure from group members, which is fundamental to the therapeutic process (Yalom & Leszcz, 2005). For young breast cancer survivors, meeting others experiencing their unique issues at a young age, can help dispel feelings of helplessness and inspire feelings of hope.

Instillation of hope is a critical element in the therapeutic process. According to Snyder’s theory of hope, pathway thinking and agency thinking are facets of hope that lead to goal attainment. This initial instillation of hope is influenced by and sustained by meeting others who have benefited from group interactions, interacting with group members who are making progress in resolving their issues, and achieving success in resolving one's own difficulties (Erdman, 2009). As progress is made, belief in the therapeutic process and in one's own self-efficacy leads to hope.

Acquiring new information can be of significant therapeutic value to individuals utilizing counseling, group therapy, or even online support communities (Erdman, 2009). Groups addressing specific issues, such as young breast cancer survivor communities, often include explicit information or instructions pertaining to their needs. Explanation and clarification promotes understanding while reducing uncertainty and confusion. This understanding can facilitate acceptance and adjustment (Yalom & Leszcz, 2005).
Not only do individuals benefit from receiving information, but they also benefit from the support and advice they provide one another. This altruism can be satisfying and increase feelings of self-worth. This behavior also helps those with illnesses develop a sense of control (Holmes & Kivlighan, 2000). Ultimately, this altruistic alliance provides a foundation which group cohesiveness develops upon.

Group cohesiveness is the function of an individual’s relationship with other group members, the group as a whole, and the counselor. In the case of online environments, moderators may resemble this function. An atmosphere of empathy, trust, warmth, understanding, and acceptance is essential for successful group outcomes, and a combination of these forces attracts and keeps members in the group (Yalom & Leszcz, 2005). Additionally, groups that focus on a common issue or situation consistently rate group cohesion as an important aspect of their experience. Group cohesiveness, in its own right, is related to positive treatment outcomes, as well as a precursor to other therapeutic factors (Joyce, Piper, & Ogrodniczuk, 2007).

Imitative behavior includes the observing and listening to group counselors and members and adopting their coping strategies. If a common problem is shared, such as the case with breast cancer, adopting others’ coping strategies can be especially effective. By observing another person’s successful behavior patterns, an individual realizes that he or she may be able to achieve the same results. This also enhances self-efficacy, enabling the individual to feel that he or she is capable of making a desired change. In social cognitive theory, Bandura notes the importance of modeling and its role in the acquisition of cognitive competencies, behavior patterns, and rules for behavior (Bandura, 2006).
The concept of interpersonal learning is based on the significance of interpersonal relationships, the opportunity for instructive experiences, and the group experience as a social environment (Yalom & Leszcz, 2005). An individual can get to know oneself without distortions, understand how he or she is perceived by others, and realize how to improve interpersonal functioning (Erdman, 2009).

The development of socializing techniques allows group members the opportunity to “replace inadequate or maladaptive cognition and behaviors with more effective ways of conceptualizing their world and interacting in it” (Erdman, 2009). The simple interactive process can have the most long-lasting effect on learning for group members. Through the process of strengthening communication skills, individuals may increase their self-efficacy beliefs and better manage their illness.

Corrective recapitulation of the family is a therapeutic factor most relevant to those experiencing major family crises, such as psychotherapy for abusive marriages, victims of incest, or sex offenders. In these situations, group members use therapy sessions to understand the influence of family dynamics on their behavior (Yalom & Leszcz, 2005). This environment allows individuals “to confront issues and emotions that may have been dormant for many years” (Erdman, 2009).

Catharsis is characterized by an enlightening or liberating emotion for the individual. The mechanism of change requires reflection and processing of the emotional experience. Group members learn to express their feelings, which Yalom believes enhances group cohesion (Yalom & Leszcz, 2005).

Existential factors involve an awareness of the limitations and inevitabilities in one’s life. Whether it is a crisis, loss, illness, or other event, the existential component
includes the acknowledgement of life’s inevitabilities (Erdman, 2009). This process is inherent in resolving denial and problem awareness.

**Literature Gaps**

Literature is lacking in several areas relevant to this research. There is a dearth of research focusing on young women affected by breast cancer. Although this population may have been included in previous research pertaining to women with breast cancer, no study focuses specifically on young women. Other literature gaps include evaluations and comparisons of needs based on age, ethnicity, and other factors. Lastly, literature on survivorship in general is greatly lacking. There are a multitude of topics pertaining to survivorship, such as recurrence, long-term effects, fertility issues and preservation options, lifestyle changes, and support services, that should be examined. Overall, cancer survivors’ physical, emotional, psychosocial, spiritual, and financial challenges are not adequately addressed in the literature.
CHAPTER 3
RESEARCH QUESTIONS

This research seeks to explore how young breast cancer survivors utilize communication in an online community to give and receive information, advice, and support. An understanding of the common experiences and shared meanings of young breast cancer survivors may contribute to improved coping and quality of life. The experiences can also inform the development of interventions aimed at meeting the needs of young women diagnosed with breast cancer.

**RQ1: How do young breast cancer survivors use online discussion forums?**

This research question will examine how discussion forums are used by young breast cancer survivors. This will include a qualitative analysis of their communication environment, activity, and patterns. The structure of the community, roles of the users, reasons for participation, and process of communication will be examined.

**RQ2: What topics or keywords are most prevalent on discussion boards for young breast cancer survivors?**

This research question will identify the topics of discussion on young breast cancer survivor forums and the phenomena of their experience. The examination of forums for the specific population of young breast cancer survivors will lead to greater knowledge of their specific needs. Previous research has examined frequent topics of
discussion for female cancer patients and breast cancer patients; however, this research does not address the specific topics of discussion of this population. Because the incidence of breast cancer in young women continues to increase, this is an important area of research.

**RQ3: What therapeutic factors occur in the online dialogue of young breast cancer survivors?**

This research question will identify the presence of therapeutic factors in the group discussion of young breast cancer survivors. Therapeutic factors identified by Yalom include universality, instillation of hope, imparting information, altruism, imitative behavior, group cohesion, interpersonal learning, development of socializing behavior, recapitulation of the family, catharsis, and existential factors. The occurrence and impact of these therapeutic factors varies among groups and environments. This question used qualitative analysis to identify the presence of therapeutic factors in the discussion of young breast cancer survivors.

Previous research has compared online support groups to face-to-face support groups (Chen, 2012; Rodgers & Chen, 2005; Setoyama, Yamazaki, & Nakayama, 2011; Vilhauer, 2009). Because therapeutic factors contribute to the overall positive impact of support groups, this research seeks to examine whether or not these factors exist in the online dialogue of young breast cancer survivors. Additionally, this research seeks to identify which factors are present on each forum, since this may differ according to topic of discussion.
**RQ4: What is the affect (positive or negative) of the dialogue of young breast cancer survivors?**

This research will identify the overall affect (positive or negative) of posts within the Young Survival Coalition website. It will also identify other dimensions such as self-references, social words, and cognitive words. It is important to examine the affect of speech and the expression of emotion because it allows researchers to interpret a person’s emotional response. As Tausczik & Pennebaker (2010) stated, “the degree to which people express emotion, how they express emotion, and the valence of that emotion can tell us how people are experiencing the world.” Because positive emotion words (love, nice, sweet) are used in writing about positive events and negative emotion words (hurt, ugly, nasty) are used in writing about negative events, this research can examine the overall impact of the experience of breast cancer and the degree to which users are handling it.
CHAPTER 4

METHODOLOGY

The purpose of this research was to identify the unique needs of young breast cancer survivors through the dialogue within online communities for young women with breast cancer. This study used a mixed-methods approach using quantitative and qualitative methods. Phenomenological analysis and computerized text analysis were used to explore how young breast cancer survivors utilize communication in an online community for young women with breast cancer.

Sources of Evidence

Data for this sample consisted of forum posts on the Young Survival Coalition (YSC) community forums located on the YSC website. All information posted on YSC boards is public information and is available for viewing by anyone. Users are made aware of this through a statement of privacy on the YSC website. The forum posts contained in the sample were published between the dates of 10/29/08 and 3/27/13.

The Young Survival Coalition was selected as an outlet because of its prominence within the target audience. YSC is a global organization dedicated specifically to young women with breast cancer, and forum topics are specific to this population. Forums for analysis were selected based on their popularity with the target audience, as this is the only community dedicated solely to this audience. Forums were selected based upon the following criteria: 1) the topic pertained to young women who had been diagnosed with
breast cancer and 2) the forum was indicated as popular based on page views, replies, and YSC designation as “hot” or “pinned.” Forums are labeled “hot” or considered “pinned” if users find the information particularly important or useful. A user might comment stating that a forum should be “pinned,” and a moderator makes the designation.

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*Phenomenology*

Phenomenological approaches are useful in understanding experiences of human healing, caring, and wholeness. Phenomenology as a philosophical perspective has shed
light on previously ignored phenomena of the human experience, reformulated philosophical questions, and enlightened thought in almost all fields of scholarship (Tymieniecka, 2003). This method consists of descriptive and interpretive approaches. Descriptive phenomenology is most helpful to guide studies that aim to describe the universal structures of a phenomenon and when the researcher’s ultimate goal is to develop clinical interventions. On the other hand, interpretive phenomenology is most useful when the goal is to interpret contextualized human experiences (Wojnar & Swanson, 2007). The results of this study could inform clinical interventions; therefore, it will utilize descriptive phenomenology.

**Qualitative Analysis**

Data was analyzed qualitatively using Colaizzi’s method of phenomenological analysis. Colaizzi’s method of phenomenological analysis includes reading and rereading of descriptions of the phenomenon to acquire a feeling for the participant’s experience and to make sense of their account; extracting significant statements; formulating meanings into clusters of themes and validating with original text; describing topics, themes, and meanings; returning to participants; and incorporating any changes based on informants’ feedback. Because this study utilized online content, analysis did not include participant feedback to the researcher and incorporating changes based on informants’ feedback.
Computerized Text Analysis

Computerized text analysis was processed using Linguistic Inquiry and Word Count (LIWC) software. Linguistic Inquiry and Word Count (LIWC) software counts words in psychologically meaningful categories and determines the overall affect of the text (Tausczik & Pennebaker, 2010). Depending on the context, LIWC language correlates may include attentional focus, emotional state, social relationships, thinking styles, and individual differences.

LIWC software has two distinctive features – the processing component and the dictionary component. The processing component is the program itself, while the dictionary component is the heart of the program (Tausczik & Pennebaker, 2010). The dictionary allows the program to access a collection of words that define a particular category. Additionally, LIWC analyzes style words rather than content words. Style words, which account for 55% of the words spoken, heard, or read, reflect how people are communicating. On the other hand, content words convey what people are saying (Tausczik & Pennebaker, 2010). Through analyzing the text, LIWC results indicate the percentage of words in each category. For example, a value of nine for positive emotions would indicate that nine percent of text analyzed contained positive emotion words.

Emotionality is a major component of LIWC software. Because people react to traumatic events very differently, analyzing their emotional response may contribute to an understanding of how people cope with a particular event and the extent to which the event plays a role in the future (Tausczik & Pennebaker, 2010). Additionally, “the degree to which people express emotion, how they express emotion, and the valence of that emotion can tell us how people are experiencing the world” (Tausczik & Pennebaker,
Because positive emotion words (love, nice, sweet) are used in writing about positive events and negative emotion words (hurt, ugly, nasty) are used in writing about negative events, this research examines the emotional impact of the experience of breast cancer and the degree to which users are handling it.

The limitations of computerized text analysis include its inability to identify context, irony, sarcasm, and idioms. Also, since LIWC analyzes style words, the overall content of the data is not analyzed. This is one reason why qualitative analysis was used to determine the topics and overall content of the data. Other text analysis program focus specifically on content words; however, many do not evaluate the emotional component.

Table 2: LIWC Dimensions

*This table includes examples of words in each LIWC category and psychological correlates from published research studies.*

<table>
<thead>
<tr>
<th>LIWC Dimension</th>
<th>Examples</th>
<th># of Words in Category</th>
<th>Psychological Correlates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-references</td>
<td>I, me, my, mine</td>
<td>12</td>
<td>Personal, emotional, informal</td>
</tr>
<tr>
<td>Social words</td>
<td>Mate, talk, they, child</td>
<td>455</td>
<td>Emotionality</td>
</tr>
<tr>
<td>Positive emotions</td>
<td>Love, nice, sweet</td>
<td>406</td>
<td>N/A</td>
</tr>
<tr>
<td>Negative emotions</td>
<td>Hurt, ugly, nasty</td>
<td>499</td>
<td>N/A</td>
</tr>
<tr>
<td>Overall cognitive words</td>
<td>Cause, know, ought</td>
<td>730</td>
<td>N/A</td>
</tr>
<tr>
<td>Articles</td>
<td>a, an, the</td>
<td>3</td>
<td>Use of concrete</td>
</tr>
<tr>
<td>Big words</td>
<td>All words &gt;6 letters</td>
<td>N/A</td>
<td>nouns, interest in objects and things</td>
</tr>
</tbody>
</table>

(Tausczik & Pennebaker, 2010)
CHAPTER 5

RESULTS

RQ1: How do young breast cancer survivors use online discussion forums?

This research question sought to understand how discussion forums are used by young breast cancer survivors through the qualitative analysis of their communication environment, activity, and patterns.

Structure of the Community

The community forums are located on the Young Survival Coalition website as part of the community section and organized according to topic. The community provides a multitude of topics that pertain to young breast cancer survivors. Within each topic area there are threads featuring more specific topics. For example, a user can search the “Treatment” board and find threads about a specific medication, chemotherapy type, radiation, surgery, or side effect. Forums include the following titles: Technical Support and Admin; Newbies; General; YSC Regions (Midwest, Northeast, South, West); Under 30; Recurrence; C4YW 2013 (Conference for Young Women); Metastatic Disease; Treatment; Reconstructive Surgery; Fertility After Breast Cancer; Risk and Genetics; Exercise, Fitness, and Nutrition; Premature Menopause; Post-Treatment Issues; Inflammatory Breast Cancer; Support for Friends & Family; Remembrance; Pregnancy, Single/Dating; Advocacy; Lesbian, Bisexual, and Transgender Topics; Black/African Descent Topics; Asian Topics; Latina Topics; Treatment Groups; and Archives. Each of
these titles contains threads that feature more specific information. When users find a particular board or thread to be particularly useful, they can request that a moderator “pin” the board, which moves it to the top of its section. Moderators can also label a board as “hot” because of its popularity. “Hot” boards are designated by a colored label that is placed next to the forum’s replies and views counter.

**Roles of the Users**

Users serve a variety of roles within the community. Some are moderators, while others are labeled as members. Members can create the original post on a forum, reply to another user’s post, or view the forums without interactions. Users share information or their own experiences and offer encouragement or hope.

**Reasons for Participation**

Users participate to interact with other individuals in similar situations. Although the incidence is increasing, many young women do not know other young women who have experienced or are experiencing breast cancer. The community provides a network despite location. Users are able to search for a specific topic and visit forums pertaining to a variety of issues. After interactions in the community, users form relationships with each other that take place outside of the community as well; many users interact with each other through social media sites and in person. Forums that are labeled by geographic area provide a means for meeting other users in a user’s area and to share relevant information, such as clinics and services in close proximity.
**Process of Communication**

The process of communication includes a post within one of the forums, which are organized by topic. A user or a moderator posts the initial post, which might include a question, statement, or a poll. The poll feature allows registered users to vote and then shows percentages and a bar chart representing the responses. Other users then reply to the original post and the conversation continues. Even with a poll, users are able to comment below the poll and discuss their selection or the topic of the poll.

A new user can visit the “Newbies” forum and introduce herself. Often times, a user will find the Young Survival Coalition website after a diagnosis or even before a diagnosis is confirmed. The initial post can include information regarding the diagnosis, age, and any other relevant or personal information. Other users or a moderator will welcome the user to the community and respond to the inquiry. The response can include answering a question or a probe for more information. Users will ask about the new user’s diagnosis and offer encouragement or helpful information. If the new user asks a question that has already been addressed in another board, the users responding will provide information about the other forum.

At the bottom of each post, the user has a signature containing information such as their name, age, diagnosis, treatments, surgery dates, marital status, number of children, links to their own website or blog, and pictures. Their pictures can include a picture of the user with her family members or pictures of the user before she had cancer and after she was diagnosed, such as when the user lost all her hair. Sometimes the pictures include just the user’s children.
RQ2: What topics or keywords are most prevalent on discussion boards for young breast cancer survivors?

This research question sought to identify the topics of discussion on young breast cancer survivor forums and to identify the phenomena of their experience.

<table>
<thead>
<tr>
<th>Table 3: Cancer Acronyms</th>
</tr>
</thead>
<tbody>
<tr>
<td>This includes commonly used acronyms on YSC forums.</td>
</tr>
<tr>
<td>Acronym</td>
</tr>
<tr>
<td>ACT</td>
</tr>
<tr>
<td>BC</td>
</tr>
<tr>
<td>FAC</td>
</tr>
<tr>
<td>NED</td>
</tr>
</tbody>
</table>

Forum A: Fertility – Pregnancy Post-Breast Cancer

This thread started with a poll with the corresponding conversation regarding the topic listed below the poll. The poll asked, “What do you think about post-[breast cancer] pregnancy?” Most users shared their experience or concerns, in addition to statements of gratitude for others sharing their experience. One user stated, “This post hit a cord with me in so many ways...augh!!! I needed to hear from others that have similar feelings/thoughts/anxieties/frustrations.” Of the 43 replies, less than five reflected feelings or thoughts of anger. Most statements expressed worry, concern, and fear about
being able to have a baby, while many others discussed the duration of Tamoxifen
treatment before trying to conceive and the possibility of recurrence related to pregnancy.

Several users did not feel happy for their pregnant friends and felt an increasing
amount of their friends were pregnant. They expressed feelings of guilt for feeling this way.

I am feeling stressed out because four women in my life have told me they are
pregnant in the past week. It is getting me down because I should feel happy for them, but I don't. I don't have children, but was planning to have one when I was diagnosed. I go back and forth on the issue, even though I just started on Tamoxifen and feel I need to be on it for at least two years before pregnancy. I know no one can tell me what is best for me, but I am just curious about how other women are thinking about this.

Users also discussed the option of a mastectomy before pregnancy, although they would not be able to breastfeed. Others reminded them that a woman does not need breasts to have children, or they discussed their own children being healthy despite only having formula.

Users discussed the medication Tamoxifen frequently and how long they should be on this medication before trying to conceive. Others were more worried about recurrence after pregnancy and leaving children behind without a mother. Users with children felt guilty for wanting another child and that the decision to get pregnant might jeopardize their own health and cancer status, thus leaving the child they already have without a mother. One user explained, “I voted that I want another baby but probably won’t because I am just too scared - would never forgive myself if it came back.”
contrast, one user explained her experience in which her doctor found a very small recurrence and was able to discover it because of her frequent doctor’s visits during pregnancy. This user concluded with, “So the way I see it, pregnancy may very well have saved my life. I don't regret any of it.”

Many women shared their post-breast cancer pregnancy experience, and others found encouragement or hope in this. One user described how “it has been a great thing” when other users have been able to have babies post-breast cancer. Others explained that age was becoming more of a concern because of duration of treatment and waiting an adequate amount of time after treatment before trying to conceive. One user stated, “These days I am feeling pretty positive about a future pregnancy despite my hormone status. I am more worried about my age causing problems than the cancer coming back.” Similarly, another user said, “It kind of blows to have the biological clock start ticking after the BC time bomb has already exploded.”

*Forum B: Parenting – Talking About Cancer or Surgery in Front of Kids*

This forum served informational purposes including practical advice on how to approach talking about cancer and associated topics, such as treatment and surgery, in front of children. Many users expressed the need to be honest and shared their opinions on the level of information to disclose depending on the child’s age. One user discussed her issue of not having shared her cancer experience with her son and how she was unable to have people over to help her after surgery because her son would know something is wrong. Many other users were in favor of honesty and provided examples of how they shared the topic of breast cancer with their children.
Overall, users agreed that younger children need less details and a description in terms they would understand. For example, one user said,

I used their language wherever I could and empathized as much as I could. There were times when things I said made my girls say ‘ew!’ and I'd say ‘I know! Ew!’ Because really, a lot of this stuff is pretty gross.

Another user had a similar approach,

...If you are careful and offer simple, minimal answers, they'll signal what they've had enough-- ew! means enough of that. Or they'll translate to the world they can understand. (We've joked about bionics and Lego ziggurat reconstruction options.) Or they'll press for more information/reassurance.

They let their children know it is okay to talk about it and let the children make references that were familiar to them. One child associated people’s hesitation to talk about cancer with a character from Harry Potter (Lord Voldemort or “he who must not be named”), which allowed him to better understand the situation and even make light of the situation. The user shared how her son joked, “...you've got the Dark Lord in your right breast-- that can't be good!’ We laughed. It was the first of many jokes about my [breast cancer] that have gotten us through all kinds of hard days.”

Older children, on the other hand, required more details and were more receptive to having more information. Many users discussed that children know when something is wrong, and keeping information from them would be more fearful for them. They were also concerned that they would hear about other people’s cancer experiences, such as those that were worse or resulted in death, and make assumptions about their mother’s
Users urged each other to be honest and open in communicating with older children about breast cancer. One user explained,

It is part of my life in a big way right now, and thus it’s a part of hers, too. I want her to be comfortable asking about it and not be afraid of what it means. I'm going to be dealing with appointments and things related to cancer for the next few years, and I'd rather have her get her information from me than from other people who may be knowledgeable in general, but not informed about my case and my care.

*Forum C: Post-Treatment Issues – Grief and Feeling Exhausted*

This forum was centered around post-cancer blues and the feelings associated with coming out of “survivor mode.” The initial post explained:

No one warned me about post-cancer treatment blues or anything. I felt so alone until I started reading about how more and more women feel like I do. I was lucky that I stayed in survivor mode during surgery and treatment/radiation, but know that I reflect on it, I realized how much it all hurt, physically, emotionally, and spiritually.

Other users agreed that they had also experienced post-treatment blues and had been in survivor mode as well. Many offered suggestions on possible diagnoses and tests that they should ask their doctor about. These included thyroid levels, depression, and anxiety. Users felt guilty that they were survivors, while their friends or other women were battling cancer or had lost their battle. Even in their bad experience and new version of normal, they still felt guilty for their survivor status.
Some users expressed they are “quiet survivors” because it is too painful to relive their experience repeatedly. Many felt they were not prepared for the emotional healing. One user explained, “Dealing with the emotional suffering/side effect of cancer - dare I say - is worse than the treatment itself?? I don't know... I am encouraged by those of you who say it will get better.” Another user agreed:

Yeah, it sounds weird to say "this part is worse than the cancer" but I also feel the same way. At least with the cancer itself, I felt like there was a plan, and that I was actively attacking it and fighting it off. The emotional crap I'm not sure how to do that, and I keep getting blindsided by out of control emotions.

Although users agreed that their post-cancer experience feels worse than cancer itself, they also shared encouragement. “Post treatment sucks. I think it actually sucks worse than treatment. It does get better, though. It really does!”

Users expressed the experience as a form of Post Traumatic Stress Disorder and acknowledged the battle they have been fighting. “It must be some kind of PTSD. Sometimes I feel like I'm going to jump out of my skin and sometimes I can barely keep my head up at my desk. If I didn't have the kids I don't know that I would even bother.” They cite feelings of depression, lack of energy, fears of recurrence, medical issues, and bills looming as other stressors during this time. Users identified scars, hot flashes, and other symptoms as constant reminders of the experience.

While some users did not expect the negative symptoms of their post-cancer experience, one user said she was warned. “My surgeon came out to talk to my twin sis and said...'now begins the hard part...' That has been so true. Months and months of feeling so down and wondering what the HELL just happened to you.” Users described
the expectation that their experience was over and that other people did not understand their post-cancer experience. One user explained, “There really isn't anyone else who understands except for other survivors.”

Since others did not understand the experience, users felt the need to portray a façade that everything was okay. Other people had the expectation that since the cancer was gone, the negative aspects were gone as well. Users expressed that in addition to their handling their fears, they did not want to share how they were actually feeling. “I am worried about recurrence... but spend so much of EVERY day convincing everyone who asks how great I am doing and how great I feel and how happy I am that breast cancer is over with.... No one in real life wants to hear how I still struggle every single day.” Another user added:

I try not to show it, but the fear is overwhelming. There are days I get upset and ask why God left me here. Who wants to feel like this everyday? I don't want my children to remember me this way. Then I get over my pity party and move on. I know now I must find a breast cancer survivor group. I believe being around other women who understand how I feel and what I've been through will help. Plus meeting women who have overcome this fear will hopefully give me strength to move forward.

Forum D: Long-Term Survivorship – Recurrence

After a cancer recurrence diagnosis, many users expressed the need to hear from others who had a breast cancer recurrence and were long-term survivors. One user referred to herself as a “walking time bomb,” because she never knew if she would have
another recurrence. Users shared their experience of their initial diagnosis, but discussed how tough the second diagnosis was – even if the treatment was less severe. One user explained, “I have had a harder time emotionally the second time around even though treatment was easier on me since I did not have chemo this time.” Another user said, “You want to believe that you will never hear that "C" word again, but when you hear it 6 months after dose dense ACT and a mastectomy, it is hard not to believe that it is a death sentence.”

Another common concern was not being able to watch their children grow up. The thread’s original post included,

Physically, I am working out and getting stronger and eating better, yada, yada, yada - which is helping my emotional well-being, but I just feel like I have been beaten down. Mother's Day was one of my toughest days yet...... I cried almost all day, because all I could think of was my little boys growing up without their mom.

Another user added,

I understand your fears because I have them as well as I have a 5 year old daughter. I worry everyday that I am not going to be around for her. But I tell myself that I have beaten the beast 5 times and I am still around kicking.

In addition to this concern, long-term survivors offered hope.

I'm a long term survivor. I was diagnosed in 1990 at age 35 and had a modified radical mastectomy and 8 rounds of FAC. 18 months later I had a local recurrence in the same area my original tumor was located. The tumor was removed and I had radiation. I'm now 55 with 2 grown children and 3
grandchildren. I had the same fears as you...that I wouldn't be around to see my children grow up. There is hope.

Users expressed feeling hopeful after hearing about other women who had multiple breast cancer diagnoses and were able to conquer breast cancer, or “the beast,” each time. Many also said that they would be referring back to the forum or printing the posts our when they needed encouragement.

Thank you, thank you for such inspirational, "cancer ass-kicking", stories. My prayers are with you to keep fighting and winning... I will print out your replies and keep them with me for those days when I feel there is no hope.

Another user added,

I love hearing stories about long-time survivors that had a recurrence, but I think they don't come around here much because they are out living their lives with NED. That's my hope anyway and it helps me sleep at night!

Forum E: Long-Term Survivorship – The Impact of Being a Breast Cancer Survivor

This thread begins with the questions, “How much does BC [diagnosis] define the rest of your life? Do you ever stop being a person with BC? Does it ever just fade to black? What is the long-term impact of a BC diagnosis?” Other users answered and expressed their frustration that other people do not understand the recovery process and that it is not as simple as other illnesses.

One of the things that I find most frustrating about survivorship is that no one seems to understand that it's not like recovering from the flu… The problem is that others don't understand that. They think it's okay for me to keep going at
breakneck speed and that I should be able to handle this no problem. That's probably the biggest issue I'm having.

Another user defined survivor and explained that it includes opposition, hardship, or setbacks. “As a ‘survivor,’ I know that I have gone/am still going through hell.”

Some users acknowledge that being a cancer survivor defines them, while others consider it more as a badge of honor. Being a survivor includes a new normal to adjust to. Most users express frustration about this, but a few embrace that their life is now different. Many mention their fear of recurrence and their scars as reminders of the disease.

I read so many upbeat, chipper stories about survivorship... but, it's not all that pretty in my perspective... I think the reality is, my risk is high for recurrence, its normal to fear it coming back, I don't obsess constantly about it and can enjoy my life...I thank God each day I am free and clear of the disease and pray it does not come back.

Overall, users feared recurrence, felt that others did not understand the meaning of being a survivor, and that the experience gets better with time.

**RQ3: What therapeutic factors occur in the online dialogue of young breast cancer survivors?**

This research question sought to identify the presence of therapeutic factors in the group discussion of young breast cancer survivors. Therapeutic factors identified by Yalom include universality, instillation of hope, imparting information, altruism, imitative behavior, group cohesion, interpersonal learning, development of socializing
behavior, recapitulation of the family, catharsis, and existential factors (Yalom & Leszcz, 2005). The occurrence and impact of these therapeutic factors varies among groups and environments. This question used qualitative analysis to identify the presence of therapeutic factors in the discussion of young breast cancer survivors.

*Forum A: Fertility – Pregnancy Post-Breast Cancer*

Therapeutic factors: universality, instillation of hope, altruism

Through sharing concerns regarding pregnancy after breast cancer, users are able to experience universality. They realize that other women share the same concerns and fears, such as questioning their Tamoxifen duration, the feeling of jeopardizing their own life to have children, and advancing age being a factor because of breast cancer. This forum also included many users sharing their experiences with pregnancy after breast cancer and how it did not jeopardize their health status. This resulted in the instillation of hope for those worried about fertility and pregnancy issues. It also leads to a sense of altruism, as users knew sharing their experience could be helpful to others.

*Forum B: Parenting – Talking About Cancer or Surgery in Front of Kids*

Therapeutic factors: imparting information, imitative behavior, altruism

This forum mainly concerned the imparting of information. Users shared their own experiences of talking to their children about breast cancer and associated treatments. This also provided a source of imitative behavior, as other users were able to learn from these experiences and use this information in their own lives. Altruism can result from users sharing their experiences and helping others in doing so.
Forum C: Post-Treatment Issues – Grief and Feeling Exhausted

Therapeutic factors: universality, instillation of hope

This forum allowed users to experience universality, as other breast cancer survivors are experiencing the same issues of fatigue as well. The instillation of hope took place as users shared that these issues improve with time and that they are not alone in this experience.

Forum D: Long-Term Survivorship – Recurrence

Therapeutic factors: universality, imparting of information, instillation of hope, altruism

Universality was experienced as users shared feeling similar to a “walking time bomb,” as the cancer could recur at any time. Imparting of information took place as users shared their experiences of living many years after their diagnosis, and instillation of hope occurred when others found hope and encouragement in this. Even after a recurrence, these women were able to beat the disease and live beyond their diagnosis. This also inspires altruism, since users were able to help each other by sharing the number of years they were cancer free.

Forum E: Long-Term Survivorship – The Impact of Being a Breast Cancer Survivor

Therapeutic factors: universality, existential factors

Users experienced universality as many felt depressed after coming out of “survivor mode,” and that everyone else expected them to be back to normal since the cancer was gone. They discussed a new normal and that the only people who understood
were those who had experienced breast cancer. For other people, users had to act portray the image that everything was okay again. Existential factors existed as users realized that this was an inevitable part of having breast cancer.

**RQ4: What is the affect (positive or negative) of the dialogue of young breast cancer survivors?**

This research question sought to identify the overall affect (positive or negative) of posts within the Young Survival Coalition website.

<table>
<thead>
<tr>
<th>LIWC Dimension</th>
<th>Forum A Fertility</th>
<th>Forum B Parenting</th>
<th>Forum C Post-Treatment</th>
<th>Forum D Recurrence</th>
<th>Forum E Survivorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-references (I, me, my)</td>
<td>9.85</td>
<td>8.13</td>
<td>10.49</td>
<td>8.03</td>
<td>9.61</td>
</tr>
<tr>
<td>Social words</td>
<td>6.25</td>
<td>14.84</td>
<td>7.02</td>
<td>7.12</td>
<td>6.52</td>
</tr>
<tr>
<td>Positive emotions</td>
<td>1.77</td>
<td>2.87</td>
<td>3.01</td>
<td>2.52</td>
<td>2.79</td>
</tr>
<tr>
<td>Negative emotions</td>
<td>1.74</td>
<td>1.61</td>
<td>3.61</td>
<td>1.61</td>
<td>2.15</td>
</tr>
<tr>
<td>Overall cognitive words</td>
<td>7.73</td>
<td>9.39</td>
<td>8.39</td>
<td>5.66</td>
<td>6.35</td>
</tr>
<tr>
<td>Articles (a, an, the)</td>
<td>4.31</td>
<td>4.06</td>
<td>4.70</td>
<td>4.51</td>
<td>4.77</td>
</tr>
<tr>
<td>Big words (&gt;6 letters)</td>
<td>14.81</td>
<td>13.00</td>
<td>12.03</td>
<td>12.32</td>
<td>11.79</td>
</tr>
</tbody>
</table>

Post-Treatment Issues (C) had the most self-references, followed by Fertility (A) and Survivorship (E). Social words were overwhelmingly higher in the Parenting forum (B). This forum included several examples of how users talked to their children about cancer, and these could have included many social words. The most positive forums included Post-Treatment Issues (C), Parenting (B), and Survivorship (E). The most negative forums included Post-Treatment Issues (C), Survivorship (E), and Fertility (A). The most cognitive words were found on the Parenting (B) and Post-Treatment (C) forums. Article counts were very similar for each forum. Lastly, Fertility (A) and Parenting (B) had the largest amount of large words.
CHAPTER 6

DISCUSSION

This research sought to identify the common experiences and shared meanings of young breast cancer survivors through their involvement in online communities. The study of their experiences can inform the development of interventions aimed at meeting the needs of young women affected by breast cancer and, as a result, contribute to improved coping and quality of life. The questions this research addressed how young breast cancer survivors use online communities, which topics are frequently discussed, which therapeutic factors are present in this area of support, and whether the overall affect of posts is positive or negative.

RQ1: How do young breast cancer survivors use online discussion forums?

This question was focused on how online discussion forums are used by breast cancer survivors, which included the examination of the communication environment, activity, and patterns. Previous research has noted that cancer patients value access to practical and experiential information from other patients (Rozmovits & Ziebland, 2004). Additionally, research has also suggested that women prioritize emotional communication and discuss a wider range of feelings than men (Owen et al., 2004; Seale, Ziebland, and Charteris-Black, 2006). Women expressed more interest in more pleasurable aspects of their lifestyle and were more likely to use words associated with feelings, people, clothing, and appearance (Seale, Ziebland, and Charteris-Black, 2006).
This research was similar to previous research in that users prioritized emotional communication (Owen et al., 2004; Seale, Ziebland, and Charteris-Black, 2006). Just as other women in previous research discussed emotional topics, this study found that young breast cancer survivors also prioritize this emotional communication (Owen et al., 2004; Seale, Ziebland, and Charteris-Black, 2006). Users discussed emotional topics and offered emotional support. Many users discussed how they were feeling about their diagnosis or issues related to breast cancer. They also discussed how the experience after breast cancer impacted them emotionally. Overall, this is very consistent with previous research.

How discussion forums are used is what makes this study and this community unique. It is not simply a forum to post a question or response; users connect on a much deeper level. The community forums allow a place of community, as the name suggests. Users become friends and share personal details of their experience and their feelings. Future research should examine how these forums compare to other forums and if other online communities offer the same atmosphere of community.

These findings indicate that forums are used to share practical and experiential information from others and that users find this information useful. This is evident by their requests to pin boards or label them as “hot,” which assures that other users will see the board and benefit from it as well. Similar to previous research, users prioritized emotional communication and interacted with others discussing emotional topics (Blank et al., 2010; Seale, Ziebland, and Charteris-Black, 2006). Their customary practice included welcoming other users to the boards, making sure their questions or concerns were addressed, and offering encouragement as needed.
Overall, this research contributes to the body of research examining how online communities and support groups are utilized by those with cancer or other diagnoses. This research contributes a different perspective because of two factors – users are young women with breast cancer and also survivors. Breast cancer research in young women is an important area of research. Many people have the perception that only older women get breast cancer, which leads to many issues. First of all, diagnoses may be missed, which impacts health outcomes. Second, younger women have different needs than an older woman with breast cancer. Many aspects of their experience may overlap, but there are specific issues to this population that should be explored. Researchers should take note of this population and consider how research can advance interventions for this population.

RQ2: What topics or keywords are most prevalent on discussion boards for young breast cancer survivors?

This research question focused on the topics discussed by young breast cancer survivors that are specific to their experience. This is important because the examination of forums for the population of young breast cancer survivors will lead to greater knowledge of their specific needs. As stated before, previous research has examined frequent topics of discussion for female cancer patients and breast cancer patients; however, previous research does not address the specific topics of discussion of this population. Because the incidence of breast cancer in young women continues to increase, this is an important area of research.
Topics varied according to each forum. Similar themes across forums included fears of recurrence, fears of leaving children behind, difficulties discussing cancer with children, fears associated with pregnancy, feelings of guilt (manifested in different situations), emotional struggles, and the expectation that there are no hardships with survivorship.

This was very similar to previous research in regard to topics but more focused on emotional needs (Seale, Ziebland, and Charteris-Black, 2006). Previous research suggested breast cancer patients often share information on particular treatments or procedures, including biopsies, MRIs, chemotherapy, radiation treatment, breast reconstruction, mastectomies, and side effects of treatment (Chen, 2012; Gooden and Winefield, 2007; Rozmovits & Ziebland, 2004). Additionally, women shared their own experiences and offered insight from a personal perspective about particular issues they have faced, such as finding a lump, coping, waiting for results, and relationship issues.

This research was similar in that users shared their own experiences and insights. However, they also offered emotional support to each other rather than just sharing information.

Topics differed slightly, but this could also be due to the forum selection. Forums specifically focused on chemotherapy or radiation would overlap more with previous research than this study does (Chen, 2012). This study relates more to social support literature. To differing extents, women have identified enjoying each other’s company and trusting, caring about, identifying with, and feeling supported by each other as perceived benefits of online support groups (Setoyama, Yamazaki, & Nakayama, 2011; Vilhauer, 2009). This research suggests that young breast cancer survivors also
experience these same benefits through their interactions on the Young Survival Coalition website.

This is an important area of research because it shows how women utilize online support groups. There are many benefits evident in previous research and in this study. Future research should explore important topics of discussion for these women in an environment they are comfortable sharing. Many users expressed how they felt other people did not understand their experience, so it is best to research this information in a setting where they are likely to share. Only then, will research be further advanced and accurately portray the topics young breast cancer survivors are concerned with.

**Forum A: Fertility – Pregnancy Post-Breast Cancer**

Forum A focused on fertility concerns, such as how long to stay on the medication Tamoxifen before getting pregnant. Users were worried that they would jeopardize their own health by having a baby. This led to worry and guilt. Users were worried about leaving their children without a mother. They felt guilty for wanting another child, because they worried that getting pregnant put their own life at risk and increased the probability of their children growing up without their mother. However, they still thought about wanting another child. Interventions could be targeted at educating women on the actual risk of pregnancy and its relation to a breast cancer recurrence. Oncologists could also discuss Tamoxifen recommendations more in depth with these women. Previous research does not focus on this issue of weighing the importance of medications with the desire to have a baby.
Forum A also focused on worries about advancing age because of the time breast cancer consumed. Users also felt guilty because they were not happy for pregnant friends. On a positive note, many users were encouraged by reading about other women’s post-breast cancer babies. This is important to note, because it shows that women benefit from learning about other young breast cancer survivors’ experiences. Interventions could be aimed at networking young breast cancer survivors with each other because of their specific needs.

*Forum B: Parenting – Talking About Cancer or Surgery in Front of Kids*

Forum B focused on parenting and how to communicate cancer topics with children. Users expressed that honesty was essential, especially because children usually know when something is wrong anyway. This also allows users to access resources and help, since the children are aware of the situation. Users agreed that fewer details should be shared with younger children, while older children could handle more details. Using the child’s language and references was helpful, too. Interventions should anticipate that young women experiencing breast cancer should be counseled on dealing with this appropriately with children. Tools and resources to help children understand their mother’s experience could be very helpful as well and possibly reduce the mother’s burden. Research should address the best ways to handle situations such as these and the implications of each.
Forum C: Post-Treatment Issues – Grief and Feeling Exhausted

Forum C dealt with post-treatment issues such as the emotional effects experienced after cancer. Many users felt down and depressed after coming out of what they referred to as “survivor mode.” Only one user explained that she was warned about this, and it still did not prepare her for the emotional experience post-treatment. Users compared the experience to Post Traumatic Stress Disorder, citing breast cancer as their battle. Although many were proud to be survivors, they identified scars and surgeries as constant reminders of the disease, how horrible the experience was, and that recurrence was possible. They felt the need to act like everything was fine and that they were happy now because of being cancer-free. They did not think anyone else understood.

To combat these post-treatment blues, women need to be aware of the emotional experience that can take place after cancer. Many are led to believe the battle is over, and find themselves very surprised at how hard it can be even though they are cancer-free. Just as healthcare professionals educate women who have given birth about the possibility of post-partum depression, women experiencing breast cancer should also be aware of the feelings of depression after cancer. As many women expressed, it gets better with time, and breast cancer survivors should be reminded of this.

Previous research did not address post-treatment blues or depression and how to cope with it. Future research should include exploring this phenomenon and addressing how the situation can be improved upon. Whether it is a counselor referral or support group recommendation, breast cancer survivors could drastically benefit from interventions in this area.
Forum D: Long-Term Survivorship – Recurrence

Forum D focused on recurrence and how users felt similar to a “walking time bomb.” They explained how they were constantly scared of recurrence, and they worried these feelings would never go away. They were also scared that a recurrence could cause their children to grow up with out their mother. Those that had experienced a recurrence agreed that their second cancer experience was worse than the first; they explained how difficult it was to receive a second diagnosis when they had just recovered–physically, spiritually, or emotionally–from the first diagnosis. Young breast cancer survivors should have support as they find the balance between being aware of signs of recurrence but also not living in constant fear of recurrence. This research adds a different perspective of survivorship by examining some of the fears these women face.

Forum E: Long-Term Survivorship – The Impact of Being a Breast Cancer Survivor

This forum focused on the overall experience of survivorship and the long-term impact of being a breast cancer survivor. Users thought other people did not understand that the experience was not like getting over another illness; they described how being a survivor was sometimes terrible. They described others’ perception of survivorship as very positive and upbeat but not always representative of reality. Support services should be available to breast cancer survivors even after their cancer experience is over. Practitioners can intervene by educating family members and caregivers about this issue as well. Similar to the previous forum, this research adds a perspective of survivorship that includes the common concerns of young breast cancer survivors. This includes many fears and negative emotions after their cancer experience.
RQ3: What therapeutic factors occur in the online dialogue of young breast cancer survivors?

This question focused on therapeutic factors in online communities of young breast cancer survivors. While therapeutic factors are traditionally evaluated in group therapy settings, online support groups can exhibit many of the same benefits. Previous research has compared online support groups to face-to-face support groups (Chen, 2012; Rodgers & Chen, 2005; Setoyama, Yamazaki, & Nakayama, 2011; Vilhauer, 2009). Because therapeutic factors contribute to the overall positive impact of support groups, this research examined whether or not these factors exist in the online dialogue of young breast cancer survivors. Therapeutic factors include universality, instillation of hope, imparting information, altruism, imitative behavior, group cohesion, interpersonal learning, development of socializing behavior, recapitulation of the family, catharsis, and existential factors (Yalom & Leszcz, 2005). Previous research examines therapeutic factors in relation to other diagnoses, such as audiology (Erdman, 2009). This research is important because it examines therapeutic factors in breast cancer support groups.

Therapeutic Factors

Several therapeutic factors were identified through qualitative analysis. These included universality, imparting of information, instillation of hope, imitative behavior, altruism, and existential factors. Universality was experienced as users realized that they are not alone in their experience. Many may not know other young women affected by breast cancer, so the community forums allow them to connect with each other regardless
of location. Users imparted information as they shared advice or details of their experience and how they handled certain aspects of it. Hope was also instilled through this sharing; users repeatedly discussed how much something someone else shared helped them. With topics such as explaining cancer to kids, imitative behavior will result as users learn behaviors from each other. Many were glad they could be of help to others through offering their input, thus altruism resulted. Existential factors occurred when users realized that some aspects of their experience are inevitable. This especially applies to their life after breast cancer, and the “new normal” they discuss.

These are important factors to consider, because it allows researchers to extract benefits users may experience through these online communities. Because this research addresses a specific population, it is worth noting how these women benefit from their online involvement. Future research should attempt to explain how these factors differ according to topic and how they differ for different populations.

**RQ4: What is the affect (positive or negative) of the dialogue of young breast cancer survivors?**

This question focused on the overall affect of posts by young breast cancer survivors. The most positive forums included Post-Treatment Issues (C), Parenting (B), and Survivorship (E). Although these forums, especially Post Treatment Issues (C), would seem to be predominately negative, each of them includes users encouraging each other. These positive discussions could account for use of positive emotion words. The most negative forums included Post-Treatment Issues (C), Survivorship (E), and Fertility
(A). These forums suggest areas of hardship for young breast cancer survivors, as each discussed struggles within each particular area.

Post-Treatment Issues (C) had the most self-references, followed by Fertility (A) and Survivorship (E). This could be due to the fact that people are often referring to themselves and how they feel when talking about issues such as treatment symptoms or effects. Social words were overwhelmingly higher in the Parenting forum (B). This is probably because this forum included several examples of how users talked to their children about cancer, and these could have included many social words. The most cognitive words were found on the Parenting (B) and Post-Treatment (C) forums. Both of these forums include a lot of cognitive processes and words such as cause, know, and ought. Article counts were very similar for each forum. Lastly, Fertility (A) and Parenting (B) had the largest amount of big words. This could be the case for Fertility (A) because the forum mentions several medication and procedures relevant to fertility. Parenting (B) could have several large words because it includes several description of the cancer experience, such as medications or procedures.

Overall, emotionality percentages were very low, with most less than three percent. For this reason, a larger sample or different method could better answer the emotionality of this data. However, percentages indicate that four out of five forums had greater degrees of positive emotionality rather than negative emotionality. The only forum with a greater degree of negative emotion was the post-treatment issues forum, which discussed feelings of depression as survivors. Because of this, it is not surprising that the results of this forum would have a negative valence.
Future research should involve large samples of data to gain a more accurate understanding of the emotionality of this data. The sample in this research was limited in that forum threads were very specific to a certain topic and often included less than 20 responses. More data would give a more reliable indication of the emotionality of the dialogue. Ideally, other text analysis programs could be used for research such as this. Text Smart by SPSS would be a preferable option, however; it is not available at his institution and very expensive to purchase.

**Implications & Call to Action**

Overall, the needs of young breast cancer survivors are neglected. This could be due to the fact that many people have the perception that young women do not get breast cancer. People also have the perception that the battle is over once the cancer is gone, and this is simply not true. Just because the cancer is gone does not mean that these women do not have new battles in their lives. Interventions should be directed at understanding these experiences and creating programs and services that can improve outcomes and quality of life for these women.

The U.S. Department of Health and Human Services has identified survivorship as a research priority, and researchers should follow suit. Healthy People 2020 objectives include increasing the proportion of cancer survivors who are living five years or longer after a cancer diagnosis and increasing the mental and physical health-related quality of life of cancer survivors (U.S. Department of Health and Human Services, 2012). A major theme of each forum included the positive effect of other survivors’ input, so connecting with other young breast cancer survivors is essential. A variety of programs, support
groups, and information resources could prove very beneficial for these young survivors. A major theme of each forum included the positive effect of other survivors’ input, so connecting with other young breast cancer survivors is essential.

Healthcare professionals should educate young women and the community on the risk of breast cancer in this population. This serves two purposes – contributing to early detection and treatment and also raising public awareness of the issue. Healthcare professionals, especially in areas that deal specifically with young women with breast cancer, should be aware of groups such as the Young Survival Coalition and refer their patients to these areas of support. Additionally, professionals should increase their knowledge in this area by visiting the forums. An increase in knowledge could inform clinical guidelines and allow practitioners to better understand the survivorship experience, which leads to better care and services for these women.

Raising public awareness about survivorship in general could contribute to an improvement in the body of research available. While early detection and prevention are very important areas of research, research foci should consider the many people who are living beyond their diagnosis. This group of individuals includes nearly 12 million people and is expected to grow as more and more people are living five or more years beyond a cancer diagnosis. In order to promote and ensure the physical, psychological, social, and economic well-being of cancer survivors, survivorship must become a priority.
CHAPTER 7

CONCLUSION

Results indicate a variety of issues relevant to young breast cancer survivors. In this research, overall themes included fears of recurrence, fears of leaving children behind, difficulties discussing cancer with children, fears associated with pregnancy, feelings of guilt (manifested in different situations), emotional struggles, and the expectation that there are no hardships with survivorship. Another theme that emerged was that all of these issues were alleviated to some degree through interactions with other young breast cancer survivors. An understanding of these common experiences and shared meanings of young breast cancer survivors can contribute to improved coping and quality of life.

Interventions should be aimed at addressing these issues and helping breast cancer survivors anticipate and cope with them. Interventions suggested in this research include educating women on the actual risk of pregnancy and its relation to breast cancer recurrences. They should also discuss ideal Tamoxifen medication durations with their oncologists, as this is a major concern when breast cancer survivors decide to have children. To help children understand their mother’s experience, tools and resources could be developed to facilitate understanding and possibly reduce the mother’s burden.

Emotional coping is a critical issue for this population; therefore, interventions should be directed at helping breast cancer survivors cope with these issues. Practitioners can provide education on possible depression after cancer and common survivorship
experiences. Also, interventions should include connecting them with support in their community or online.

Overall, interventions could be aimed at networking young breast cancer survivors with each other because of their specific needs. In this research, users valued the interaction with others and were encouraged or uplifted by hearing of these experiences. They also appreciated reminders from women who had experienced similar situations that everything gets better with time. This was a theme evident though each forum analyzed.

Future research could examine additional forum topics on Young Survival Coalition community forums. Forums are very organized and specific to each topic, so perhaps future research could target several forums within one area (e.g., fertility, parenting, treatment). This research could be greatly enhanced by utilizing other text analysis program, such as SPSS Text Smart. This program would allow counts of the most popular words. Because it does not rely on an existing dictionary, all data is from the text, which makes it capable of detecting popular keywords that might not exist in another dictionary (e.g., Tamoxifen).
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