THE ROLE OF SOCIAL MEDIA IN CANCER RECOVERY

by
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Abstract

This study investigates the role of social media during cancer treatment and recovery. Qualitative research methods were used, which included semi-structured, in-depth interviews with 20 cancer survivors. Findings indicate cancer patients are motivated to use social media as a therapeutic tool for coping and managing emotions during their illness. Cancer patients use both social networking sites and blog sites during treatment and recovery, but prefer to use blog posts to discuss their illness. Data shows cancer patients use social media to seek and share information with family and friends, other cancer patients, and even health care providers. Further, participants report positive benefits from social media conversations about faith and spirituality during their illness. Results also suggest social media use during illness can lead to posttraumatic growth in cancer survivors, leading to deeper meaning and understanding. This study has implications for future patients, patient caregivers, health care providers, communication practitioners, and cancer organizations. Future cancer communication campaigns should seek to promote the use of social media by cancer patients to improve their quality of life.

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Preface

Acknowledgements

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Bracketed Experience

In 2005, I was diagnosed with ovarian cancer. At the time, Facebook was only a year old, and most of my friends and family members had not yet joined. However, I was familiar with a patient care blog site called CaringBridge and decided to give it a try as a way to effectively communicate with my social network of friends and family around the country. Additionally, I was working in television news at the time and did not have the energy to respond to all the emails from viewers, so blogging enabled me to keep my social network informed of my progress. I found blogging to be a beneficial outlet as a way for me to process my feelings about the disease, my mortality, and future. The response to my social media posts was overwhelming. Not only did people send positive messages of support, but they also sent inspirational, faith-based messages that I found comforting and uplifting. The experience of posting these blogs on this social media site and the messages I received empowered me to start a nonprofit organization to raise money for cancer research, specifically to fund the development of standardized tests for earlier detection in cancers without such routine screenings, and the development of cancer vaccines for prevention. My CaringBridge blog site became an effective platform to turn followers into volunteers and donors.

As a television personality, my situation was obviously unique in that I had the television medium to help build and support my online social network. Over the years I saw other cancer survivors who were seemingly transformed by their cancer experience. It made me question why individuals respond differently to a traumatic illness like cancer. Some people struggle to get their life back to normal; yet, others not only bounce back, they bounce forward to turn their adversity into something positive for the greater good. Tedeschi and Calhoun (1995) call this posttraumatic growth, which inspired me to investigate the role social media plays in cancer
treatment and recovery. My personal experience helped to frame the design of this research study, including my choice of methodology and the development of the interview questions. In bracketing my experience, I am able to honor the subjective nature of qualitative research, while also ensuring the study’s rigor. By combining personal narrative with information gleaned from a comprehensive review of the literature and findings of in-depth interviews with cancer survivors, I am better able to ensure trustworthiness and lend credibility to the findings of this study.
The Role of Social Media in Cancer Recovery

More than 14 million cancer survivors live in the United States, a number expected to increase by more than 30% over the next decade (National Cancer Institute, 2012). Cancer patients face daunting challenges following diagnosis and are increasingly turning to social media for shared information and social support (Baldwin, 2012). Social media is defined as “interactive Internet platforms” that include social networking sites (SNS), blogs, Tweets or microblogs, and online forums that allow users to participate in various topics of conversation (Centers for Disease Control and Prevention, 2013). More than two billion people use social media to engage with others online (Kemp, 2015), yet researchers know little about the effects of social media on cancer recovery and posttraumatic growth.

Social media changes the way we see ourselves, and the world around us. Online interaction with others helps people to gather information and share experiences. Research indicates social media engagement can lead to feelings of empowerment for people suffering from an illness (Househ, 2014). Additionally, cancer patients are increasingly turning to online blogging as a therapeutic tool to aid in their recovery (Morgan, Graves, Poggi, & Cheson, 2008). Heilferty (2009) defines illness Weblogs, or “blogs” as, “the online expression of the narrative of illness” (p. 1539). Cancer blogs often take on the format of an online journal as a way to update others, express opinions, seek advice, and release emotions, generating a therapeutic effect (Graham, Rouncefield, & Satchell, 2009; Nardi, Schiano & Gumbrecht, 2004). By sharing poignant examples of their experience through online social media formats, cancer patients can benefit from the cathartic effects, both physically and emotionally. Graham et al. (2009) describes it as “personal translucence” or the act of sharing commentary about the past, present,
and future to reflect on the value of life and to help others think about their mortality and life experience (p. 268).

Cancer patients can use social media as a way of sharing stories associated with their disease experience, and to stay connected with friends and family for emotional support (Kim, 2009). Sharing posts with online social networks helps patients bridge physical and psychological isolation gaps that may arise during cancer treatment and recovery, allowing patients to receive the necessary support from friends and family in real-time (Kim & Gilham, 2013).

This study explores the use of social media for cancer recovery. Research indicates that not only can social media be used enhance a patient’s quality of life, but can also be used as an effective way of sharing information with other cancer patients and health care providers. This study also investigates what role social media plays in the construct of survivor empowerment and whether social media support serves as a positive transformative experience for cancer survivors during and after recovery. Sheilds (1995) defines empowerment as, “the emergence of an internal sense of self and the ability to take action,” and as being “integral” (p. 3). Health care professionals and communication practitioners can use this research study as a roadmap for developing future strategies for effective cancer patient care plans.

**Literature Review**

Social media plays a positive role in cancer recovery and survivor empowerment. A review of the literature supports this argument and focuses on five primary areas of research: social media as a therapeutic tool, social media as a means of social support, social media as a means of sharing information with cancer patients and health care providers, social media conversations about faith, and social media and posttraumatic growth.
Social Media as a Therapeutic Tool for Cancer Recovery

Research indicates narrative expression through writing can aid in enhancing a cancer patient’s quality of life by helping them cope with changes brought on by this life-threatening disease. Expressing oneself through blogging can be cathartic, promoting healing through online social support (Cepeda et al., 2008; Merz, Fox, & Malcarne, 2014). Heilferty (2009) suggests illness blogs help patients “express the experience of illness” by sharing it with others via the Internet, welcoming but not requiring comments from readers (p. 1542). In addition, Winer (2005) suggests blogging is a forum where someone’s thoughts can stand alone without being challenged, giving the writer, “a kind of relaxation not available in other forms” (p. 3).

In an exploratory study of blogging, Graham et al. (2009) presents empirical evidence that indicates online writing can have unexpected, “surprising,” therapeutic effects (p. 268). While this study focused on blogging for smoking cessation, the authors posit the health benefits can be generalized to other forms of life change, such as the kind cancer patients encounter, with participant comments regarding goals such as, “wishing to live longer for my child” (Graham et al., 2009, p. 270). As part of a larger research project funded by the National Medical and Research Council in Australia, the authors conducted a small, qualitative study of three participants, following them through three months of blogging using “LifeBlog,” a mobile device software that encourages ease of use and frequency of posts (Graham et al., 2009). The authors hypothesized that blogging would promote self-awareness and support from others, but upon evaluating the participant posts, and conducting both interviews and a focus group, say they did not anticipate such strong psychological benefits of expressing pent-up emotions (Graham et al., 2009). One participant commented that “blogging made a great therapy tool for those who do not
have access or the funds, or are just too embarrassed by the stigma” associated with seeking therapeutic treatment (Graham et al., 2009, p. 273).

Cepeda et al. (2008) conducted a randomized control study of 234 cancer patients recruited through the Javeriana University Oncology Center and the Colombian National Institute of Cancer. The researchers randomized the patients into three different groups: 1) Narrative: patients wrote at home for 20 minutes each week over a three-week period about how cancer affected their lives; 2) Questionnaire: patients completed a pain questionnaire at home; 3) Controls: patients simply attended weekly medical visits for usual care (Cepeda et al., 2008). In measuring well-being, the authors used two independent raters, using a six-point Likert scale that concluded all three groups were similar, with the narrative group reporting a slightly greater sense of well-being (Cepeda et al., 2008). However, the authors found that patients who disclosed a high level of emotion in their narratives reported lower pain intensity at a level the researchers found to be “clinically meaningful” (Cepeda et al., 2008, p. 629). This is critical insight for health care providers; cancer patients cope with pain better when they blog about their illness experience, leading to an increase in their psychological well-being and an improved quality of life.

The importance of using blogging for therapeutic benefits was also demonstrated in a study of cancer patients at a chemotherapy infusion clinic who participated in expressive writing. The study by Morgan, Graves, Poggi, and Cheson (2008) reinforces the benefits of writing to vent frustrations and express emotions, effectively improving a cancer patient’s quality of life. After completing a baseline quality-of-life survey, 71 leukemia and lymphoma patients participated in a single 20-minute writing exercise with more than half of the participants reporting that the exercise changed how they felt about their illness by helping them take a step
back to reflect on it differently (Morgan, et al., 2008). The authors conducted a bivariate analysis of affect words, including words that express distress, acceptance, gratitude, and transformation as they relate to quality of life. The findings point to the therapeutic effects of expressive writing; writing created a sense of empowerment during a time when so many other things were out of the patient’s control.

Some of the therapeutic effects of blogging also stem from the reflective nature of expressive writing. In an analysis of cancer blogs by young adults nearing their end-of-life stage, Keim-Malpass, Adelstein, and Kavalieratos (2015) suggest that blogs offer a “legacy making” space for narratives that help patients process the therapeutic modalities of anticipatory grief (p. 209). The researchers conducted a qualitative analysis of five public blogs written by young women under the age of 39 who started blogging after their diagnosis and who later died from their disease (Keim-Malpass et al., 2015). The research shows young adult end-of-life stage cancer patients face anxiety and grief over the anticipated loss of their “unlived life” and can find blogging therapeutic in leaving a legacy behind as a way to be remembered (Keim-Malpass et al., 2015).

Through the literature reviewed above, health communication practitioners can identify the ways blogging works as a form of therapy for cancer patients (Graham et al., 2008), creating a platform for sharing reflections on life and for leaving behind a legacy (Keim-Malpass et al., 2015). Additionally, the act of expressive writing through blogging offers cancer patients a valuable outlet to express emotions and vent frustrations about their illness (Morgan et al., 2008); improving a patient’s quality of life by increasing the psychological sense of well-being and decreasing the intensity of their physical pain (Cepeda et al., 2008).

**The Role of Social Media in Strengthening Positive Social Support**
Cancer patients use social media, including social networking sites and patient care blog sites, to express concerns and share personal stories about their disease experience, to connect with friends and family, and to feel supported (Kim, 2009). Cancer patients who use social media to communicate with friends and family during their illness, help family and friends gain a better understanding of the patient’s experience so that they can respond in real-time to the patient’s changing needs with positive support (Echlin & Rees, 2002). Social media blog posts give cancer patients a platform to engage others, giving users a sense of support and belonging (Baldwin, 2012; Chung & Kim, 2008; Kim & Gilham, 2013; Ressler et al., 2012).

Baldwin (2012) conducted a quantitative study of newly diagnosed breast cancer patients to find out whether they used Facebook for social support, and whether using Facebook reduced stress brought on by the illness. Participants completed questionnaires while waiting to see their oncologists, with a total of 38 surveys returned (Baldwin, 2012). Results indicate participants gained meaningful social support by communicating with others through Facebook, especially in areas of trust, quality of friends, and understanding (Baldwin, 2012). Additionally, the study found participants used Facebook to escape the loneliness and isolation while enduring cancer treatments (Baldwin, 2012).

Kim and Gilham (2013) conducted a qualitative content analysis of 164 blogs written by 46 young adult cancer patients in a one-month period on the website “Planet Cancer.” The authors determined that blogging can help cancer patients interact virtually with others at a time when they may not be able to do so physically, giving patients a forum to share their illness experience and express their feelings about it (Kim & Gilham, 2013). The authors identified the most common blog content themes as relating to physical burdens, concerns about the future and mortality, with blogs being particularly helpful when patients feel detached due to treatment or
physical isolation (Kim & Gilham, 2013). When it came to descriptive images of cancer, several bloggers referred to the disease as the “devil,” and themselves as “warriors” fighting a battle (Kim & Gilham, 2013, p. 381). This study sheds light on the importance of online blogs to help bridge the isolation gap for cancer patients who feel physically and psychologically removed from their social support networks during cancer treatment and recovery.

Many themes identified by Kim and Gilham (2013) surfaced in an earlier study by Chung & Kim (2008), which explored the gratifications of using cancer blogs. The researchers conducted an online survey of 113 participants of mainly women whom they identified through a Google blog search, and who responded to a request to participate in a survey (Chung & Kim, 2008). Four themes emerged as gratifications for using blogs: prevention and care, solving problems, managing emotions, and sharing information. Of these, emotion management and information sharing were considered to be the most gratifying reasons for cancer patients to use blogs (Chung & Kim, 2008). The authors offer these findings as support for the Uses and Gratifications Theory, a communication perspective outlined by Katz, Blumler, and Gureveitch (1974). Cancer patients, who use blog posts to voice their fears and frustrations, effectively alleviate emotional distress by sharing this information with their social networks to encourage understanding and support (Chung & Kim, 2008).

A study by Anderson (2011) also examined the Uses and Gratifications Theory at work on patient care sites such as CaringBridge, a website that offers personalized web pages for patients to write blog posts and which provides opportunities for visitors to comment on each post. CaringBridge also features an option for patients to connect with other patients, creating online communities of like-minded individuals sharing their experiences (Anderson, 2011). The author sent 1,646 invitations to CaringBridge users to participate, receiving 378 completed
online questionnaires from a sample of 80% females with a mean age of 39 (Anderson, 2011). Participants cited important gratifications, or benefits, of using CaringBridge as feeling encouragement from others, in addition to feeling the therapeutic value of writing about challenging topics (Anderson, 2011, p. 554). Anderson’s study indicates that cancer patients, who use a patient care site such as CaringBridge to write posts about their experience, receive encouraging comments from friends and family and are able to connect with similar others about their experience.

Smartphones and mobile devices help patients receive support in real-time and serve as a valuable tool for data sharing, especially in the form of “microblogs.” Microblogs, such as Twitter, are defined as “a combination of blogging and instant messaging” that allows users to send and receive short messages that create an almost instantaneous dialogue (Nations, 2015, p. 1). A study of Twitter accounts of Japanese-based cancer patients indicates a growing patient network made up of individuals who share information about their medical conditions (Sugawara et al., 2012). For this study, Sugawara et al. (2012) identified 731 Twitter accounts that had cancer terminology in their profiles. Of those, the authors analyzed the tweets of 51 accounts with 500 or more followers. By classifying tweets into categories, Sugawara et al., (2012) demonstrated that patients exchanged information through microblogs in real-time, creating a social media “information exchange network” characterized as promoting positive psychological encouragement (p. 5). Contrary to the authors’ hypothesis that tweets would center on medical information, they found the majority of tweets focused on treatment and psychological support (Sugawara et al., 2012). Using a smart phone or other handheld device, followers of a Twitter user can easily view and respond to a tweet in real-time, creating faster response times when a cancer patient feels the need for instantaneous feedback, making Twitter a
valuable medium for cancer patients to feel empowered and supported (Sugawara et al., 2012). That kind of immediate response and benefit to cancer patients supports the applicability of the Uses and Gratifications Theory (Katz, Blumler, & Gurevitch, 1974).

The studies summarized above indicate social networking sites, patient care site blogs, and microblogs can strengthen positive social support for cancer patients, reduce physical and psychological feelings of isolation during treatment, and serve as a valuable platform to connect with others who face a similar diagnosis (Anderson, 2011; Chung & Kim, 2008; Kim, 2009; Kim & Gilham, 2013; Narimatsu, 2008; Sugawara et al., 2012).

The Use of Social Media in Sharing Information with Other Cancer Patients and Health Care Providers

According to a 2010 Pew Research Center survey of 3,000 Americans, one in four individuals diagnosed with a chronic illness such as cancer reported searching online for information from others who share a similar diagnosis (Fox, 2011). In an analysis of 25 cancer-related websites, Narimatsu (2008) determined that online visitors have diverse needs, making it necessary for health care providers to ensure sites are easy to use and contain relevant content. The researcher also points to cancer blogs as effective forums for sharing information among patients that may not otherwise be available through health care providers, due to privacy concerns. The analysis found cancer patients more frequently visited cancer blog sites, especially breast cancer and pediatric cancer blogs, than information-based sites offered by cancer centers, hospitals, or pharmaceutical companies (Narimatsu, 2008).

Health care providers can also benefit from reading a patient’s blog to strengthen the patient-provider relationship, to monitor treatment effectiveness, and to address a patient’s specific needs (Heilferty, 2009). Hilan (2003) points out additional ways that medical facilities
can make the information sharing process easier, by integrating password-protected online journals to help patients communicate with others who share the same condition and to exchange information seamlessly with members of the patient’s care team.

Ziebland and Wyke’s 2012 conceptual literature review identified peoples’ motivations to use the Internet for health reasons. The researchers suggest online resources are the primary source of health information in the digital age, identifying five significant reasons that patients go online: information, support, relationships, behavior, and online health services (Ziebland & Wyke, 2012). Two additional reasons: storytelling and disease visualization, were not as prevalent and are areas the authors suggest have important implications for health care providers in understanding the role patients play in their health care decisions (Ziebland & Wyke, 2012). The authors theorize that blogging and posting through online social networks will drive the future of electronic health, or “e-health,” in large part due to the value of first-person storytelling as patients share their illness experiences.

Internet searches for information can be challenging based on the search criteria (Kim, 2009). In a content analysis of 485 cancer blogs, Kim (2009) explored word frequency and tag words assigned by bloggers (Kim, 2009). The research revealed the most common topic discussed in cancer blogs is “breast cancer,” followed by “prostate cancer,” “lung cancer,” and “breast cancer awareness” (Kim, 2009, p. 262). Cognitive, emotive, and medically related concepts indicate cancer patients write blogs to seek emotional support and share medical information that may help others (Kim, 2009). However, the researcher points out that online searches become challenging due to breadth of cancer subtopics. For example, if someone is searching for information on “radiation” the researcher indicates the need to also look for subtopics such as, “radiation treatment,” “dose of radiation,” and “radiation oncologist” which
impact the way other cancer patients and health care providers may find relevant information (Kim, 2009, p. 265). These are important findings for health care practitioners searching for first-hand information on the effectiveness of various treatment options.

Gualtieri and Akhtar (2013) also point to the valuable information that cancer blogs can provide to oncologists and other clinicians regarding treatment effects on patients, despite the fact that health care providers are unlikely to know about a patient's blog. The researchers propose the creation of an online repository of blogs written by cancer patients and accessible by other patients when searching for information about cancer diagnoses and treatment options. In addition, oncologists and other health care providers, as well as researchers, could access rich, qualitative data to guide treatment plans and research on new, alternative treatment options (Gualtieri & Akhtar, 2013). This kind of information cache could help clinicians gain a better understanding of treatment side effects, to improve quality of care and lead to better health outcomes such as patient satisfaction and improved life expectancy.

Ressler, Bradshaw, Gualtieri, and Chui (2012) explored health outcomes by studying the psychosocial effects of illness blogging, such as coping, isolation, and support. The researchers conducted an online questionnaire with a snowball sample of 230 mostly well-educated women and determined that blogging about illness increases connections with others and gives bloggers a sense of purpose by sharing experiences that can help others facing a similar diagnosis (Ressler et al., 2012). Through written narratives, the authors found that illness blogs served as a way to reflect on the experience, to validate suffering, to feel connected, and to find meaning in illness and life (Ressler et al., 2012). The majority (89.7%) of participants shared their illness blogs with friends and family, yet only 42.1% shared them with their medical team. Participants cited several reasons for not sharing their blogs with health care providers.
including fear of judgment of patient feelings, fear of judgment of patient behaviors and lifestyle, confidentiality, and a perceived lack of medical staff time and interest (Ressler et al., 2012).

A review of the literature highlights the benefits of using cancer blogs to share information with other cancer patients who have received a similar diagnosis, and with health care providers to keep them informed of a patient’s well-being. This can aid patient recovery by giving a voice to patients struggling to cope with their cancer experience (Hilan, 2003). Fewer than half of the cancer patients who participate in illness blogging share their posts with health care providers (Ressler et al., 2012). This is an activity that health care practitioners can actively encourage to strengthen patient-provider relationships (Gualtieri & Akhtar, 2013; Heilferty, 2009; Narimatsu, 2008; Ressler et al., 2012).

The Impact Social Media Messages about Faith and Religiosity have on Cancer Patients

Cancer survivors searching for meaning during their illness frequently turn to religious and spiritual beliefs as a way of coping (Vachon, 2008). Nearly two-thirds of online Americans use the Internet for spiritual or religious purposes, including sending or receiving emails with faith-related content and making or responding to online prayer requests (Hoover, Clark, & Rainie, 2004). According to a study by the Pew Internet and American Life Project, the 82 million people who use the Internet for faith-related purposes are devoutly religious with half attending church weekly, compared to less than half of all Internet users (Hoover et al., 2004). Demographically, the study found the online faithful are more likely to be white, college-educated women, who are married, living in households earning $75,000 or more, in the South and Midwest (Hoover et al., 2004). Another study by the Pew Center for Research found 1 in 5 Americans post their religious beliefs on social media (Cooperman, Smith, Alper, & Ritchey, 2014), yet there is a gaping hole in the literature regarding how many cancer survivors are
posting, or receiving, religious and faith-based messages on social media, and the impact those messages may have on a patient’s recovery.

Psychological trauma occurs when individuals face unexpected events in which they experience a significant loss of control (Ehlers & Steil, 1995). Vachon (2008) found that cancer patients, confronted with the uncertainty surrounding a life-threatening illness, often embark on a quest for meaning, resulting in a redefined sense of self and life purpose. That search for meaning can include spiritual transformation (Hirshberg & Barasch, 1995), or conversely spiritual doubt when experienced by people who have lived a life adhering to religious principles, now feeling a sense of injustice upon contemplating the question, “Why me?” (Brennan, 2001, p. 13).

Research indicates cancer survivors rely on spirituality as a coping mechanism and to derive meaning from the lived experience (Ferrell et al., 2003). Spirituality is defined by Breitbart (2002) as a construct composed of faith and meaning. Ferrell et al., (2003) set out to explore spiritual well-being in ovarian cancer survivors, by conducting a content analysis of six years of correspondence with an online ovarian cancer support forum. The analysis included more than 21,000 letters, cards, and emails, and found that many of the women expressed a belief that God controlled their fate, reporting spiritual growth as a result of the ovarian cancer diagnosis (Ferrell et al., 2003). Some survivors reported negative feelings of uncertainty and hopelessness, commenting that they were angry with God that it was so unfair. However, the researchers also found survivors who remained grounded in faith, expressing confidence that God was in control, as their one certainty in the chaos of the illness. In addition to hopefulness, some also expressed a newfound sense of purpose post-cancer. One survivor commented, “I
wouldn’t take a million dollars for the experiences I have had…only those who have had cancer understand that” (Ferrell et al., 2003, p. 252).

Research by Sherman et al. (2001) found religion and spirituality rank among the highest coping mechanisms reported by cancer patients. The researchers measured religious faith in participants by using the *Santa Clara Strength of Religious Faith Questionnaire*. With a sample of 95 breast cancer patients and 53 healthy adults, results showed strong correlations with intrinsic religiosity, and moderate correlations with measures of both organizational, and non-organizational religious practice (Sherman et al., 2001). The researchers found that religious faith moderately correlated with strength and comfort, and was significantly associated with optimism. The instrument was not linked to perceived social support, which the researchers found consistent with slightly weaker correlations between faith and organized religion (Sherman et al., 2001). This would suggest that, in this group of cancer patients, faith was less tied to social relationships within organizational religion, than to intrinsic, internalized values. The study also found that cancer patients who were further into their recovery reported stronger religious faith than those who had recently been diagnosed. The researchers point out that this is consistent with theoretical models that recognize shifts in existential or spiritual perspectives following traumatic experiences (Sherman et al., 2001).

One of those theoretical models, put forth by Holocaust survivor and neurologist, Viktor Frankl, suggests individuals cannot be fulfilled until they find meaning in their reality; that people cannot live an authentic life without self-transcendence (Frankl, 1966). Frankl calls self-transcendence, the very “essence of existence” (Frankl, 1966, p. 104). The idea of expanding one’s consciousness to identify with something bigger than a frail human body stems from spiritual traditions. Frankl shared the idea that belief in a higher power can free a person from
limiting perspectives on their current life-situation (Frankl, 1946). As cancer patients grapple with the uncertainty that the illness brings, some individuals may struggle with finding ways to cope with the changes, deepening their search for purpose and meaning outside of the human capacity.

Coward (1997) explored the lived experience of self-transcendence in an exploratory study of five women with Stage IV breast cancer. Using a phenomenological research method, Coward (1997) asked the participants to describe a situation, in which they experienced self-transcendence, defined as “an experience of a sense of well-being, purpose in life, and interconnectedness with others” (p. 163). The question resulted in participants citing several instances that prompted them to search for new purpose in their lives after experiencing traumatic life events that caused pain or loss (Coward, 1997). The researcher concluded that despite living with a life-threatening disease, the participants found meaning and purpose in their lives in three ways: (1) by reaching out beyond themselves to help others, (2) by allowing others to help them, or (3) by simply accepting that they cannot change the situation (Coward, 1997). This study reinforces Frankl’s theory that human capacity for self-transcendence is inherent in individuals, with acceptance being one of most difficult struggles to resolve, when situations cannot be altered (Coward, 1997).

Cancer survivors often struggle with long-term adjustment difficulties, which is something Gall and Cornblat (2002) explored as part of a cross-sectional, quantitative study regarding adjustment factors in long-term breast cancer survivors. The researchers conducted a qualitative content analysis with a subsample of 39 of the 52 survivors who responded to a request to write down how religious and spiritual factors played a role in their ability to cope with the disease (Gall & Cornblat, 2002). Of the participants, 31 of the 39 women wrote that
their relationship with a higher power, mainly referred to as God, was important in helping them adjust to their breast cancer diagnosis, primarily for support, comfort, and guidance through the difficulties they were facing (Gall & Cornblat, 2002). The study found the most common religious coping strategy was prayer, asking God for strength and courage, in addition to understanding and meaning. The researchers concluded that social support is integral to a survivor’s overall view of spirituality; that relationships with family and friends, as well as support from members of the church community are seen as “manifestations of God’s presence” (Gall & Cornblat, 2002, p. 529). The study found most survivors do not blame God for their cancer, but believe the cancer is part of God’s plan, serving as some “Divine purpose” (Gall & Cornblat, 2002, p. 529). Half of the women in the study reported a new awareness, or reaffirmation of life, as a result, of their cancer experience. More than half of the participants also characterized their cancer experience as setting the stage for personal growth and transformation, allowing them a reason to reflect, process, and reprioritize their values (Gall & Cornblat, 2002). The researchers concluded that religious and spiritual beliefs provide a “stable, cognitive framework” for survivors, to reduce emotional distress and make meaning of the trauma (Gall & Cornblatt, 2002, p. 531). Additionally, Gall & Cornblat (2002) determined that the concept of faith is not shaken by a cancer diagnosis; rather, it is strengthened, empowering survivors to live without undue fear.

In contrast to the prior research indicating a positive role of spirituality in coping with stress during cancer, Gall, Kristjansson, Charbonneau, and Florack (2009) found only partial support for the role spirituality plays in relation to positive attitude and well-being. In a longitudinal study of 93 breast cancer patients recruited prior to receiving their biopsy results, participants completed questionnaires at three stages: (1) pre-diagnosis, (2) end of treatment (six
months post-surgery), and (3) recovery (one year post-surgery), and were assessed on measures such as image of God, social well-being, positive attitude, and emotional distress (Gall et al., 2009). The authors concluded that a measure of religious salience before diagnosis predicted an increase in emotional distress for participants at the one-year, post-surgery mark (Gall et al., 2009). The researchers suggest this increase may stem from disappointment from prayers “unanswered,” leading to feelings of betrayal by God (Gall et al., 2009, p. 183). The results also suggest cancer patients who are less religious or spiritual before diagnosis, and who attempt to activate these resources while undergoing treatment may experience negative doubt and a spiritual struggle that may have long-term effects. The researchers noted that this sample reported religion as being less important in the participants’ daily lives, compared to the women who dropped out of the study (Gall et al., 2009).

In a systematic review of the literature, Thuné-Boyle, Stygall, Keshtgar, & Newman (2006) examined the effects of religious or spiritual coping on patients with cancer. Of the studies examined, 17 reported evidence that religious coping can be beneficial to patients in terms of reducing emotional distress and empowering illness adjustment (Thuné-Boyle et al., 2006). Additionally, one of those studies determined that higher frequency of church attendance led to decreased feelings of anger, hostility, and social isolation, with increased transcendent meaning (Thuné-Boyle et al., 2006). The researchers identified three studies that found religious coping to be detrimental to cancer patients with seven additional studies indicating patients experienced no significant effect by turning to religion during their cancer experience (Thuné-Boyle et al., 2006).

Garland, Carlson, Cook, Lansdell, and Speca (2007) conducted a study to examine the positive outcomes of psychosocial interventions for cancer patients when it comes to the measure
of posttraumatic growth and spirituality. In this study, patients were not randomized to groups, but rather individually chose which intervention program to participate in, 51 chose to participate in the healing through creative arts program, with 79 participating in a mindfulness-based stress reduction program (Garland et al., 2007). Through questionnaires and qualitative interviews, the researchers concluded both interventions proved helpful in terms of learning to accept change and having a “better appreciation of life” (Garland et al., 2007, p. 956). Participants in the mindfulness-based stress reduction program also encountered increased feelings of gratitude, compassion, and interconnectedness with others (Garland et al., 2007). Additionally, the researchers found that increases in spirituality led to decreases in stress and mood disturbance for both groups (Garland et al., 2007).

A Pew Research Center survey shows 1 in 5 Americans share their religious beliefs on social media, with young adults (ages 18-29) being twice as likely as adults over the age of 50 to discuss their faith online (Cooperman et al., 2014). While there is limited research on the impact of religion and spirituality on cancer, there is a gaping hole in the literature regarding the ways in which cancer survivors are using social media to create and receive faith-based messages during their treatment and recovery.

**Impetus for Survivor Empowerment and Posttraumatic Growth**

A traumatic event such as a cancer diagnosis can shatter an individual’s perceptions of the world and the measure of one’s role in that world. Being forced to face mortality can lead to feelings of intense fear. Yet, in the process of confronting adversity, research of illness narratives indicates that some people experience feelings of empowerment and undergo positive transformations as a result.
When American swimmer Eric Shanteau was diagnosed with cancer in 2008, he told reporters, “Whether you want to admit it or not; cancer gives you a new identity” (Shipp, 2008). Shanteau came back to win a gold medal at the 2012 London Olympic Games. Fellow Olympian and two-time cancer survivor Jake Gibb had this to say about life after cancer: “It’s even better after. That’s hard to see at the moment, but that’s how it was in my case” (Errickson, 2013). Hockey legend Mario Lemieux shared a similar reaction to questions about his cancer experience: “As I went through the treatments for Hodgkin’s disease in the winter of 1993, I began to realize how fragile life can be. I felt that I had to give something back to the community, and this is when I decided to form the Lemieux Foundation” (Fayed, “10 Famous Olympic Athletes,” 2016).

Scrignaro, Barni, and Magrin (2012) call this the “paradox of cancer,” where the trauma brought on by a life-threatening illness can also trigger varying levels of growth (p. 823). Researchers suggest this “paradox” can parallel other kinds of life stressors such as the loss of a loved one, heart attack, or sexual assault. The difference is that cancer is not a single incident; rather, it is a chronic stress that can disrupt life for long periods of time, forcing individuals to re-examine life and offering an opportunity for change (Scrignaro, et al., 2012).

Posttraumatic Growth

The understanding of human suffering as a catalyst for transformative change dates back thousands of years to some of the earliest Hebrew and Greek texts, and can be found in the narratives and teachings of several religions including Christianity, Hinduism, Buddhism, and Islam (Bowker, 1975; Tedeschi & Calhoun, 1995). A review of recent literature highlights the challenge researchers have encountered in constructing a universal term for the kind of posttraumatic growth phenomena that can occur following a crisis, such as a cancer diagnosis.
Psychiatrist Norman Finkel first coined the term *stren*, as an antonym of the word *trauma*, which he defined as “an experience in an individual’s life that builds strength into his personality” (Hollister, 1967, p. 197). While subsequent researchers failed to adopt Finkel’s term, they did build on the concept of searching for meaning in misfortune, as a cognitive process for individuals trying to make sense of their experience (Greenberg, 1995; Proulx, Kroverola, Federowicz, & Kral, 1995; Silver, R.L., Boon, C., & Stones, M.H., 1983). Some researchers referred to it as a strategy for *coping* (Silver, et al., 1983), while others used the phrase *posttraumatic adaptation* (Horowitz, 1986). In the 1990’s, researchers labeled the concept of positive growth stemming from adversity as *thriving* (O’Leary, 1998) and *flourishing* (Ryff & Singer, 1998). Tedeschi and Calhoun (2004); however, dismissed the use of the terms *thriving* and *flourishing*, arguing that ongoing personal distress can “coexist” with growth (p. 2). This paradox was later confirmed in a study by Pat-Horenczyk et al., (2015) which found that “posttraumatic distress did not necessarily decrease as adaptive coping capabilities increased (p. 221).

In 2004, Tedeschi and Calhoun chose to define the phenomena as *posttraumatic growth*, characterizing it as “the experience of positive change that occurs as a result of the struggle with highly challenging life crises” (p. 1). The researchers developed a cognitive model that shows that growth after a traumatic life event depends on an individual’s level of constructive reflection (Calhoun & Tedeschi, 1998). Tedeschi and Calhoun (1996) created the Posttraumatic Growth Inventory, an instrument for identifying growth factors following a traumatic event, including changes in the sense of self, more meaningful relationships, new possibilities, spiritual change, and life philosophy.
As one of the first researchers to employ the Posttraumatic Growth Inventory, Weiss (2002) conducted a study of 41 breast cancer survivors to examine posttraumatic growth and to corroborate the levels of self-reported measures with the survivors’ spouses. Through open-ended questions, 98% of the participants reported: “significant positive changes” following their diagnosis with breast cancer, with 88% of the spouses also reporting “long-lasting changes” (Weiss, 2002, p. 73). The most common change was an appreciation of life and mindful living, which allowed participants to ignore daily struggles and focus on the joyful aspects of life experiences (Weiss, 2002).

Cognitive theorists suggest individuals have “overly positive views of themselves,” and reframe their traumatic life experience under “positive illusion” (Taylor & Brown, 1994). Others argue that, in some cases, perceptions of positive growth are simply an individual’s denial of reality and failure to respond to the situation appropriately (Shedler, Mayman, & Manis, 1993). Yet, for cancer survivors who report positive changes through posttraumatic growth, the results are very real (Tedeschi & Calhoun, 1996). Pat-Horenczyk et al. (2015) conducted a self-report study of 94 breast cancer survivors as part of a group intervention to build resilience and enhance social support. More than half of the study participants reported greater posttraumatic growth than those who were not included in the intervention. Furthermore, the intervention participants had higher levels of “constructive growth” with improved coping, and less “illusory growth,” than non-participants (Pat-Horenczyk, et al., 2015, p. 220). The researchers point to increased social support as a leading factor, with “peer-group support and the special solidarity of patients with similar challenges” as important factors for future cancer intervention plans (Pat-Horenczyk et al., 2015, p.220).
Danhauer et al. (2013) looked at how posttraumatic growth changes over the two-year period following a cancer diagnosis. In a longitudinal study of 653 breast cancer patients, participants filled out surveys within eight months of diagnosis and again at six, twelve, and eighteen months after diagnosis. The researchers discovered posttraumatic growth levels were greater in women with higher education levels, as well as in women who had been cancer-free for a longer period post-treatment, and who had increased levels of social support and spirituality (Danhauer et al., 2013). Another longitudinal study by Scrignaro, Barni, and Magrin (2010) investigated what, if any, role social support plays in enhancing posttraumatic growth. The researchers sent questionnaires to 41 participants at two time points. Findings indicated that cancer patients who received support from friends and family experienced greater levels of short-term posttraumatic growth, yet, did not see significant growth change six months later (Scrignaro, Barni, & Magrin, 2010).

Castonguay, Crocker, Hadd, McDonough, and Sabiston (2015) conducted a study of 470 breast cancer patients to examine physical self-worth, or feelings about one’s physical being influenced by changes such as disfigurement and limitations in abilities, to determine how those perceptions may link to ongoing cancer stressors and posttraumatic growth. The researchers found that participants on average reported moderate to high levels of perceived posttraumatic growth and high levels of perceived physical self-worth. Additionally, the results indicate moderate positive links between enduring cancer stressors and posttraumatic growth such as personal strength, spirituality, and new possibilities (Castonguay et al., 2015).

Despite burgeoning research in the area of posttraumatic growth and social support, little research focuses on the impact that online social support may have on posttraumatic growth in cancer survivors. Amichai-Hamburger, McKenna, and Tal (2008) say social media and other
online engagement can lead to individual behavior change, or “E-empowerment” (p. 1776). The researchers say interactions with a responsive online community can empower individuals on four levels: personal, interpersonal, group, and citizenship (Amichai-Hamburger, McKenna, & Tal, 2008). Those changes include the ability to reframe one’s identity, in addition to strengthening old relationships and developing new connections. The authors suggest that Internet communication empowers average citizens to find their voice, with the opportunity to project their thoughts throughout the world, much more easily than in the offline world (Amichai-Hamburger, McKenna, & Tal, 2008).

**Survivor Empowerment**

Researchers generally agree that empowerment is a process by which individuals are motivated to accomplish a goal. Thomas and Velthouse (1990) characterize empowerment as “a label for a nontraditional paradigm of motivation” (p. 667). The researchers posit that “to empower means to give power to” and that power could mean authorization, capacity, or energy (Thomas & Velthouse, 1990, p. 667). Kieffer (1984) refers to empowerment as intuitive, a construct that encompasses an individual’s cognitive, affective, social, political, and spiritual being. Bandura (1977) argues that empowerment stems from the motivational concept of self-efficacy, a sentiment echoed by Conger and Kanungo (1988). Meanwhile, Spreitzer (1995) points to a nomological network theory, suggesting that empowerment is neither logical nor explicable, but simply accepted as a process shaped by both context and personality characteristics that, in turn, “motivate individual behavior” (p. 1444). While there are several definitions for empowerment as a construct, research indicates a lack of agreement on a universal measure of empowerment. However, Rappaport (1987) suggests it “may not be a feasible or appropriate goal” to develop a global measure of empowerment (p. 581).
Sheilds (1995) conducted a qualitative study to determine how individual experiences shape the meaning of empowerment. Through in-depth interviews with 15 participants, Shields discovered three themes that embody the construct of empowerment: self-value, self-acceptance, and self-knowledge; self-efficacy; and connectedness (Sheilds, 1995). Self-value, self-acceptance, and self-knowledge are based on the “internal sense of self,” while self-efficacy is based on one’s ability to take action based on that internal sense of self (Sheilds, 1995, p. 15). The researcher describes the theme of connectedness as being “the most intangible,” occurring on two levels: intrapersonal and interpersonal (Sheilds, 1995, p. 29). Findings indicate perceptions of relationships change after a cancer diagnosis, with an increased commitment to one’s self, as well as to others (Sheilds, 1995).

Skeath et al. (2013) conducted a qualitative study to investigate the self-reported changes that cancer survivors characterize as “life-transforming” (p. 1155). Using a grounded theory approach, the researchers interviewed nine cancer survivors and found that more than half described positive life-transforming changes such as increased inner strength, stronger relationships, deeper spiritual connections, and greater meaning and purpose in life (Skeath et al., 2013. The findings indicate supportive interventions can help cancer patients “decrease suffering and enhance positive psychosocial and spiritual outcomes” (Skeath et al., 2013, p. 1155).

**Literature Review Summary**

Research indicates the use of social media during a cancer illness can provide patients with a therapeutic platform for coping and managing emotions, leading to an increase in psychological well-being and improved quality of life (Cepeda et al., 2008; Morgan et al., 2008). Additionally, social media blog writing can be a legacy-making space for patients, as a platform
to reflect on life, and as a way of being remembered (Keim-Malpass et al., 2015; Morgan et al., 2008).

Social media can be used as a convenient communication tool for sharing information, helping friends and family gain a better understanding of the patient’s experience, and encouraging effective social support, in real-time (Echlin & Rees, 2002; Kim, 2009; Kim & Gilham, 2013). The use of social media during cancer treatment and recovery also serves to bridge the isolation gap, helping patients feel connected even when they are physically apart due to treatment or illness (Baldwin, 2012; Kim & Gilham, 2013, Ressler et al., 2012).

Cancer patients use social media, in particular, cancer blogs, to seek information and confirm what they are hearing from their health care providers (Ziebland & Wyke, 2012). Gulateieri and Akhtar (2013) suggest cancer patients should share their social media blog posts with health care providers to give them a more complete picture of the patient and prescribed treatment effectiveness.

Research indicates cancer survivors turn to religious and spiritual beliefs as a way of coping with the illness, reducing emotional distress and empowering illness adjustment (Ferrell et al., 2003; Gall & Cornblat, 20020; Thuné-Boyle et al., 2006; Vachon, 2008). A cancer diagnosis can also lead to a patient needing to find meaning in their new reality (Coward, 1997).

The concept of integrating the cancer experience into one’s identity often results in a renewed or even new sense of self (Zebrack, 2000). This suggests that a cancer diagnosis sets patients on a new trajectory, moving forward on a changed life path. Research indicates posttraumatic growth changes occur in cancer patients who receive social support from friends and family (Scrignaro et al., 2010; Sheilds, 1995).
This study seeks to fill the gaps in the existing literature; to examine the role social media plays in cancer treatment and recovery, patient platform preference, and motivations for use. The study will also explore the impact of religious and spiritual conversations on social media for cancer patients, and what role, if any, social media has on survivors’ posttraumatic growth and empowerment.

**Research Questions:**

RQ1: What role does social media play in cancer patient treatment and recovery?

RQ2: What motivates cancer patients to use social media during treatment and recovery?

RQ3: What barriers prevent cancer patients from using social media during treatment and recovery?

RQ4: How do social media conversations about faith and spirituality affect cancer recovery?

RQ5: How can social media use lead to posttraumatic growth experiences for cancer survivors?

This study’s findings will offer insight into the use of social media during treatment and recovery from chronic illness. In addition to benefiting cancer patients, health care providers, and communication practitioners can use the results of this study to develop strategies for effective patient care plans.

**Methods**

This study examines the perceived benefits of using social media during cancer recovery thus this study requires the collection of qualitative data. Qualitative research is less concerned about finding averages than in understanding phenomena, focusing on a subject’s “depth” rather than “breadth” (Rubin & Rubin, 2005). Over the past few decades, qualitative research has proven instrumental in advancing the understanding of health and illness, in large part because qualitative methods help researchers gain deeper perspective of a participant’s experience
(Morse, 2012). This context is unique to qualitative research and is particularly effective when attempting to understand the experience of a chronic illness such as cancer, and the meaning of illness to the patient (Morse, 2012; Glaser & Strauss, 1965).

This study includes a purposive, snowball sample of participants who responded to an invitation to share their experiences through semi-structured, in-depth interviews. Interviews with open-ended questions create an opportunity for participants to provide detailed narratives about their opinions, attitudes, and perceptions (Harrell & Bradley, 2009). Other qualitative research methods, such as focus groups, were ruled out in an effort to avoid group pressure that could inhibit responses (Debus, 1989). Additionally, data collected by large numbers of interviews are more credible than focus groups (Harrell & Bradley, 2009).

Morse (2012) points to the importance of gaining a participant’s trust before beginning the data collection process. A strong rapport can enable an interviewer to delve more deeply into the participants’ experience. Participants often find in-depth interviews to be cathartic, as interviewers acknowledge the participants’ struggle and allow their voices to be heard (Mack, Woodsong, MacQueen, Guest, & Namey, 2005, p. 29)

**Participant Recruitment**

Participants were cancer survivors over the age of 18, who used social media during their treatment and recovery, and whose cancer has been in remission for a minimum of one year. The exclusion criteria are included to ensure adequate time for posttraumatic growth experiences. The Johns Hopkins University Homewood Institutional Review Board (HIRB) reviewed the research protocol to ensure ethical treatment of participants.

Using a snowball sample to recruit participants, I posted an invitation to cancer survivors on social media sites, including Facebook, and Twitter, asking contacts to share the invitation.
with other individuals who may qualify to participate. The social media recruitment notice can be found in Appendix A.

In addition to these recruitment methods, I also sought out participants through an email invitation sent to database members of a cancer research nonprofit organization. Before inviting these members to participate, the organization’s Board of Directors was contacted and granted permission to communicate via email with database members. It is important to note that I have personal connection to the organization, having served as the founder and Executive Director for 10 years. See Appendix A for these recruitment materials.

Participant screening was conducted during the recruitment phase. While recruitment letters included criteria for participation, I also screened participants to ensure they met the criteria for inclusion. I did this via a series of questions by phone, as indicated in the screening call script outlined in Appendix A.

**Procedures**

In-depth, confidential interviews were conducted in person, via phone, and Skype, an online video platform. Interviews took place between September 15, 2016, and October 10, 2016.

Participants were interviewed using the tree and branch method, with an interview guide (see Appendix C) to lead the conversation. The tree and branch method was preferred because it was chosen by the interviewer to maintain the flow of the discussion by focusing on several main questions and then using logical transitions and follow-up questions to elicit rich details in a more elaborate response (Rubin & Rubin, 2005). The tree and branch method is more effective in determining how a participant responds to a specific question rather than an overview of a subject. This method relies on the interviewer’s ability to keep the conversation focused on the
interview guide, rather than allowing a participant to veer a conversation off-course (Rubin & Rubin, 2005). Since a participant’s experience with cancer can be emotionally consuming, the tree and branch method helped participants focus on the research questions, which asked about the role social media played in the participants’ recovery, instead of creating a situation where the participant digresses into a response focused more generally on diagnosis and treatment of the disease issues. The interview guide can be found in Appendix C.

In compliance with the Homewood Institutional Review Board approval, all of the research study participants completed informed consent forms or issued oral consent before participating in this study. As part of the informed consent process, participants received assurances of confidentiality and were advised that they could stop the interview at anytime and refuse to answer any questions that make them feel uncomfortable. The researcher went over the informed consent form with the participants and asked the participants if they were comfortable with the study conditions and answered any questions the participants had before beginning the study. Participants were provided with a copy of the research statement (see Appendix B), and a copy of the informed consent script (see Appendix B). Interviews began after the participants read the research statement and verbally affirmed that they understood and agreed to participate in the research. The participants were recorded giving their verbal consent prior to the interview beginning.

Methodological Approach

Qualitative research studies are inherently subjective due to the interpretive methods used to identify and understand the themes found in the data. Further, the researcher’s own lived experience, can potentially bias results (Strauss & Corbin, 1998). These potential weaknesses should not overshadow the significant benefits of qualitative studies in producing a level of
understanding that can only be achieved through this type of research (Strauss & Corbin, 1998). The methodology guiding this research study is descriptive phenomenology, which depicts the core of one’s lived experiences. First identified by German philosopher, Edmund Husserl, phenomenology differs from positivist research in large part due to the belief that researchers have inherent presuppositions and cannot pretend that they will completely detach themselves from those assumptions (Groenewald, 2004). Moustakas (1994) outlined this qualitative methodological approach, suggesting the researcher study the interview data, identifying descriptive statements that are relevant to the phenomenon. Through this process, researchers can then develop a synthesized description of the essence of their common experience with the phenomenon (Moustakas, 1994). Lincoln and Guba (1998) argue that a researcher’s personal experience can help audiences understand the phenomenon. Strauss and Corbin (1998) also encourage qualitative researchers to provide a narrative of their experience, relying on that experience to explore emergent themes in the data to allow for comparison of the phenomenon.

My narrative describes my experience with using social media after my cancer diagnosis, as outlined at the beginning of this study. I followed the data analysis strategies outlined by Creswell (2007), bracketing my own personal experiences, collecting data from several individuals, clustering the statements into recurring themes, and breaking down the themes into two categories: textual descriptions of what the participant experienced, and structural descriptions of how that participant experienced the phenomenon. This methodological approach is designed to help the reader better understand “what it is like for someone to experience” the phenomenon (Polkinghorne, 1989, p. 46).

Data Analysis
Immediately following each interview, I transcribed the recorded data, assigning each participant a pseudonym to help protect their anonymity. Audio-recordings were kept in a safe behind a locked door and only I had access to the data. After data analysis was complete, I deleted the recordings to further protect participant identity. Transcripts were kept on a password-protected computer in a locked home office, which is protected by a monitored home security system.

Using a data-driven, constant-comparison approach (Glaser & Strauss, 1967), I carefully read and reread the data, looking for themes and ideas that would help to create an outline for the analysis, before the actual analysis could take place (Namey et al., 2007). With multiple research questions and 20 participants, this qualitative study resulted in a large qualitative data set, making data reduction essential. Miles and Huberman (1994) suggest data reduction is an essential part of the analysis, helping the researcher to sort, focus, and discard data to draw final conclusions that can be verified. Additionally, to make the large data set more manageable, I used NVivo qualitative software. This aided in applying structural codes to the transcript data based on the questions repeated to all of the participants. The labels created through this step helped in the data reduction process and in the subsequent thematic analysis. I organized the data by identifying analogous language, opinions, and ideas shared by various participants (Glaser & Strauss, 1965; Pope, Ziebland, & Mays, 2000). Namey et al. (2007) characterizes these kinds of data-driven approaches as having greater validity because they are open to new ideas that previously have not been considered.

To ensure validity, I chose to identify implicit and explicit ideas in the data and then marked those ideas for further review and comparison to similar themes within the data set (Namey et al., 2007). I carefully reviewed each transcript several times to absorb the data and
then returned to the recordings to make detailed notes regarding important language characteristics such as inflection and tone, that further impact participant data. Benaquisto (2012) refers to this process as open coding, breaking down the data, searching for recurring concepts and themes in the data, and creating categories that best describe the phenomena. I highlighted patterns of recurring ideas and concepts, which aids in identifying themes that emerge from the data (Rubin & Rubin, 2005). Additionally, I employed the methods outlined by Glaser and Strauss (1967) by using a constant comparative process of identifying a concept and then constantly comparing that idea with data from other participants. Looking for similarities in the data helped me to generate themes and categories to support each research question until saturation was reached. Saturation was reached when no new themes were identified from the data.

After I created my initial categories and subcategories of themes from the data, I moved on to what Strauss and Corbin (1998) describe as axial coding, in which the phenomenon is more thoroughly examined in terms of the context in which it occurred, the conditions it happened under, and the consequences that happened as a result. This allowed me to further investigate each category through inquiries of the data. Strauss and Corbin (1998) point to the importance of this phase in identifying differences and contradictions in the data, ultimately adding depth to the understanding of the phenomenon.

Upon completion of the axial coding, my final step in the coding process was that of selective coding which helped me to build substantive theories, grounded in the data (Strauss & Corbin, 1998). This process included delimiting data that I did not find relevant, focusing instead on selecting data that supported the core ideas behind answering each research question (Glaser,
This systematic method of data analysis was necessary to ensure reliability and replicability (Miles & Huberman, 1994).

NVivo qualitative research software aided in helping me to organize and manage the large amounts of transcript data. While software cannot analyze qualitative data, it can assist a researcher with the analysis process (Zamawe, 2015). I found it to be an efficient method of coding the data for easier retrieval. I also used the software to run queries of the data to identify common words. A word cloud based on word frequency from the interview data can be found in Appendix D.

Using the data and analysis of the data, I then developed the written report, organized by each research question, and backed by evidence, including direct quotes and detailed narrative to support the findings.

Rigor

I employed several strategies to ensure rigor in this qualitative inquiry, based on Guba’s (1981) model which includes identifying four aspects of trustworthiness: (1) truth value, (2) applicability, (3) consistency, and (4) neutrality. Sandelowski (1986) suggests truth value is the most important criterion, deeming qualitative research credible when it presents descriptions of a human experience that are easily recognized by others who share that experience. To achieve this level of credibility, I identified and documented recurrent patterns and themes, using reflexivity and triangulation via my personal narrative, review of literature, and findings of this study.

Applicability is not as relevant in qualitative research due to its basic purpose of gaining understanding of an experience or phenomenon, rather than generalizing it to others (Krefting, 1991). Consistency is ensured in qualitative research when replication of the test procedures can result in similar findings (Krefting, 1991). For the final criterion of trustworthiness, neutrality,
Lincoln and Guba (1985) suggest that it is more important to look at the neutrality of the data than the neutrality of the researcher in qualitative inquiry.

To achieve this level of credibility, I identified and documented recurrent patterns and themes, using reflexivity and triangulation to ensure credibility and confirmability. Aamodt (1982) suggests that a researcher is part of the research, not separate from it. Reflexive analysis was used to assess the researcher’s own background and perceptions on the research process to ensure it only dictated the framework in which the findings were organized and analyzed (Ruby, 1980). A field journal was also used by the researcher to maintain a record of personal thoughts and observations immediately following participant interviews.

To protect the study’s validity, I chose to triangulate the data as outlined by Lincoln and Guba (1985). By using my personal experience with using social media after my cancer diagnosis, coupled with themes identified through a review of the literature of prior studies, I was able to identify and compare commonly occurring themes in the data set. Patton (1990) points out the need to triangulate the data in qualitative studies to ensure trustworthiness. First, to ensure credibility, I incorporated well-established qualitative research methods including semi-structured, in-depth interviews using an interview guide with open-ended questions as my instrument. Additionally, I followed the instructions of Shenton (2004) by employing data analysis methods used in comparable qualitative studies. Lastly, to ensure confirmability I took employed specific coding techniques to ensure the findings emerged directly from the data and were not derived from the predispositions outlined in my bracketed experience.

Results

The data obtained through in-depth interviews with cancer survivors illustrates the role social media plays in cancer treatment and recovery. While each cancer survivor’s experience is
inarguably different, the process of narrative inquiry helped to illuminate the commonalities shared by participants.

A total of 20 cancer survivors participated in this research study, including 19 women and one man, with ages ranging from 19 to 73. Among the participants, the majority were breast cancer survivors (70%), with leukemia survivors (15%), endometrial cancer survivors (10%), and prostate cancer survivors (5%) making up the remainder of the sample. Interviews averaged 45 minutes and were conducted in-person, via phone, and through Skype.

By using the qualitative research methodology known as phenomenology, the researcher categorized these shared experiences into themes related to the research questions. In the sections below, data appears as it relates to each of the research questions, with illustrative quotations to support each theme. All of the participants received pseudonyms to protect their identities.

**RQ1: What Role does Social Media play in Cancer Patient Treatment and Recovery?**

This research question aimed to explore how individuals who are diagnosed with cancer are using social media during cancer treatment and recovery and the impact that social media use has on their treatment and recovery. All of the participants in this study reported using some form of social media after their cancer diagnosis and acknowledged that it was easily accessible to them through various tools such as computers (90%), iPads (30%), and smartphones (60%). Laptop computers were the overwhelming tool of choice for participants who chose to blog about their cancer experience, while smartphones were preferred for shorter posts on social networking sites.

*Cancer patients use social networking sites, but prefer blogs sites to discuss their illness.* Facebook was identified as the social networking site of choice by 85% of the sample. Four individuals also pointed to participation in various Facebook groups, which allowed them to
connect with others who shared a similar diagnosis. Only two participants reported using Twitter and Instagram. Additionally, 70% of the participants wrote blog posts, most frequently using patient care sites such as CaringBridge, CarePages, and MyLifeLine, while two of the participants chose to blog directly on Facebook, and one chose to use the Word Press blog site.

More than half of the sample reported using both Facebook and a blog site, yet few participants were able to directly identify their preference. It was not until they were asked to specify their reasons for social media use that a clear pattern emerged. Several participants stated they liked to use Facebook for shorter communications with their social networks, including moments they found humorous and more applicable to aspects of their everyday life, while providing more details about their cancer experience through lengthier blog posts. Clara, 62, described the desire to post lighter moments on Facebook, like when she started losing her hair during chemotherapy treatments:

I drive a convertible and I was looking in my rear view mirror, and there was hair flying behind me. I wrote, all I can think about is all the accidents I’m probably causing where the hair was probably hitting people’s windows!

Haley, 54, felt she was able to get more support, both physical and emotional, from her network through blog posts on CaringBridge:

It allowed me to blog and to send things out; it enabled us to create a schedule because I could not do everything. I didn’t have a community or a village, and if I hadn’t had CaringBridge, I don’t know what I would have done.

Several of the participants say they would only post about their cancer on their blog sites, including Leslie, 58: “Facebook is not for medical. I would only talk about my cancer on CaringBridge.” Sara, 47, echoed a similar sentiment: “I sort of felt like CaringBridge was for the
sickness, but that Facebook was for the part of just my regular life.” Sara also shared that she would not have felt comfortable openly sharing photos of her breasts post-surgery and during reconstruction on Facebook, and felt less vulnerable doing so with her network on CaringBridge. “I wanted people to see what this looks like when you get your boobs cut off, what does it look like in recovery, and what does it look like when you decide to get plastic surgery.”

Only four participants used Facebook exclusively to discuss their illness. Clara, 62, said that her preference was based simply on ease of use because it was where her social network was already gathered. “I had a couple of thousand friends on Facebook at that time, so it just made sense.” Jen, 55, gave a similar explanation:

> CaringBridge would have been too much extra work. My network was on Facebook. I just think Facebook is bigger than people thought it would be for these sorts of things because people are so supportive…and it helps dramatically.

When it comes to levels of engagement based on frequency of use, participants in this study reported varying levels; more than half posted as often as daily, or every other day, while others recalled writing lengthier blog posts only once a week, or just occasionally.

Several of the participants also linked social media sites that enabled volunteer sign-up pages to help with meals, transportation, and childcare duties during treatment and recovery. Additionally, Lea, 43, used the social networking site GoFundMe to raise money to pay for the expenses associated with her year-long leukemia treatment: “Really, without social media, we would have lost our house - 100% - we would have lost our house for sure.”

While the vast majority of participants relied on social media to help them through their ordeal, one participant, Len, 61, said he shared very little to maintain his privacy. “I didn’t blast it all over creation; most people didn’t even know I was getting treatment.” This one case proved
to be an exception. The remainder of the sample overwhelmingly characterized social media as
playing a significant role during their cancer treatment and recovery, describing it as an
important communication platform to stay connected with friends and family in real-time. The
difference may be gender-related. Research indicates men are less willing to engage in health-
related discussions due to gender roles and societal constructs of masculinity (Ek, 2013). Further
research shows male cancer patients prefer large-scale informational meetings, while women
prefer to communicate more intimately with a smaller peer support group (Gray, Fitch, Davis, &
Philips, 1998; Zakowski et al., 2003).

**Therapeutic tool during cancer treatment and recovery.** Participants overwhelmingly
agreed that social media aids in enhancing a cancer patient’s quality of life by helping him or her
cope with changes brought on by this life-threatening disease. Venting frustrations, expressing
fears, and receiving support were among the reasons listed, with one participant, Sara, 47,
comparing the benefits to those received from in-person support groups. “It’s probably not
feasible to go to a support group more than once a month, but it is feasible to post something and
to get it out into the universe and it gets out of your body and becomes something else.” She goes
on to describe it as an essential release.

It’s like a balloon full of air –you’re walking around with all of this anxiety and emotion
and fear – but this allows it to leak out and spread so it’s not only on your family. My
husband can only take so much emotional content at one time; he’s Nordic, right? He told
me, ‘you take a village and I can only give you so much of what you need.’

Gwen, 42, described receiving similar therapeutic benefits: “It’s a way to vent to discuss what
your feelings are, which helps you mentally because sometimes you just have to get it off your
chest.” Marie, 46, explained how she believes social media helped her recover more quickly:
You might be stuck in your home all by yourself, but so many people are online encouraging you that you didn’t feel alone, and I think it just kept me from getting down into the well of self-pity. When you go into the well of self-pity it’s a longer recovery process. So, I think I healed faster because I had the resource.

Several participants noted they felt less worry and stress after posting updates on social media, in part, due to the positive, supportive responses received, and in part because it helped them to process what was happening.

**Narrative writing can help patients process the experience of cancer.** Participants identified narrative writing as one of the distinct benefits of writing blog posts on social media. Haley, 54, characterized writing as essential to her recovery:

> It was my therapy, it was a really, vital aspect of going through this “journey.” No, no, no, it’s not a fucking journey, it’s a challenge. Blogging was a way to explore my feelings and my raw emotions. I didn’t want to talk about, it was much easier to write.

Leslie, 58, also described the benefits of blog writing during her illness:

> It clearly was cathartic in a lot of ways, you could step back for a moment and then step through and think about what does this really mean, what do I want to share, and how do I deal with what it says.

Other participants shared similar reflections. Anne, 19, characterized writing as an effective way to work through her feelings: “Sometimes it was like a way that I could process what was happening.” Additionally, some of the participants found that writing their stories as they were experiencing difficulty provided valuable perspective. Carrie, 47, recalled:

> It helped me, sort of like, photographers say having the camera between them and the subject helps them to not get caught up in it so much, for me it kind of had that effect,
you know? Looking at it objectively...like, okay this is an experience I am having and I want to share that with other people, what kind of words would I put on this.

Alli, 40, shared similar insight and says part of the writing process included forcing her to look at the experience through the eyes of her audience. Alli explained:

When you’re forced to put things down into words it helps you to process things and it helps you to think through how the audience is perceiving what it is that you are posting, which is a whole ‘nother side of the journey you need to be sensitive to.

Clara, 62 referred to blogging as an opportunity to help reframe her perspective by trying to see how her words would affect her readers.

We go through things and we think oh, that was crazy but if you sit down and write about it and explore what your feelings are it really puts it in better perspective for you as well.

Then when you post it and see the comments, it takes it to another level because...it gives you insight into how it helps other people understand what is going on as well.

Kelly, 60, also shared the importance of detachment during writing to help process the experience:

Not to just go through it, but to write about it, you have to think about it and go into it deeper but you also have to detach from it, so that you are kind of looking at your own experience almost as an outsider or as a narrator, a first person narrator, but still you have to give word and voice and detail and description to what you’re feeling. It’s different than when you talk about things in person; you just blurt it out or say these things and when you write about it you move things around and you process it. It helped me to kind of process what I was going through but I don’t think I would have, had I not been writing about it.
Several participants commented that they felt they could open up more freely in print than they felt comfortable verbalizing to their friends and family in person. Carrie, 47 said:

I would talk about my feelings, my doubts, fears, and even though what I am saying is very personal, it also made me feel kind of anonymous too, because when you are in the act of writing you are by yourself, it’s very private. And some people would come up to me at work and say ‘oh gosh I really reacted to what you wrote’ and there were face to face comments, but it just feels a little less… you know you’re not going to verbally have those deep conversations about your feelings.

Sara, 47, shared Carrie’s sentiment. Sara explained that writing made it easier for her to work through personal feelings that were hard to share with other people. She said, “some days I was mad and I didn’t want to burden them with my feelings of grief or anger and so sometimes writing that would help.” Sara also commented that she wanted a written record of what she went through for her family history, in case her daughter someday finds herself in her mother’s shoes. Sara’s own mother died from breast cancer and she says she became extremely frustrated at the lack of medical information available to her about her mother’s diagnosis.

It is clear by the illustrative quotations outlined in this theme that participants are passionate about discussing the detailed benefits of narrative writing through their illness blogs. All of the participants who blogged say they would highly recommend blog writing to future cancer patients during treatment and recovery.

**RQ2: What Motivates Cancer Patients to use Social Media during Treatment and Recovery?**

This research question investigates the motivating factors that drive cancer patients to use social media during treatment and recovery.
To update family and friends. All of the participants chose to update friends and family through social media channels, preferring the ease of communicating the information in real-time, just once, to a large group of people. Haley, 54, stated: “I didn’t have to deal with phone calls, they could read it and know what I’m going through, don’t call me to make me repeat it, I hate living through it and I don’t want to have to repeat it.” Carrie, 47, also noted that social media saves time and energy: “[I] realized I cannot tell the same story 50 times, that would be emotionally draining to me and I just didn’t have the time.” Jen, 55, also commented on the emotional reprieve she received by using social media:

This was just so much easier. Otherwise, you have to tell your story a million times, people would have to call which is so sweet, but then there you are crying for the hundredth time. It’s emotionally draining, this way you can respond and be emotional but not necessarily as emotional as it would be in person or over the phone.

In addition to the emotional savings, participants like Teri, 58, say social media became a necessity for her from a physical standpoint:

I didn’t realize how weak and sick you get when you go through chemo and people care, and they wanted to send me messages. People tried to call, but I was too tired to answer their calls…it was really nice to just open my laptop every morning and see those messages on CaringBridge.

Several participants commented that they are not sure how they would have gotten through their cancer journey without social media for the sheer ease of communication with their friends and family.

To communicate with global networks. Participants were quick to point out the benefits of communicating via social media with members of their social networks who do not live in
close proximity. Leslie, 58, states: “In our case, distance was an issue and the fact we had worldwide community support because we had lived in a number of countries…realizing we couldn’t keep track of the global group just by email.” Molly, 51, echoed that sentiment: “I live in Minnesota but have family all over the place, part of it was an easy way to keep people up to date on what was going on.” Kate, 43, also commented on how social media makes time zones less relevant:

We have family all over the U.S., I have an aunt living in Hawaii, and you know, time zones didn’t always match up. So it was an easy way to share with people here and others not necessarily in Minnesota or a neighboring state.

To seek help. Most participants say they were motivated to use social media during their cancer treatment and recovery as a mean to seek help from others. One participant, Lea, 43, even used social media to find, and connect with, a cancer specialist at Johns Hopkins.

I took to social media with this statement, ‘I need your help right now…I need to find the best doctor at Johns Hopkins. I need to get in, so if you have a connection, please share this post, and find me the best doctor possible.’ Friday was the day of my diagnosis, by Sunday I had so many people call this doctor that he called me and said: ‘Hi, I’m Dr. Mark Levitz and apparently you need my help?’ I said, ‘Yes, I do!’ and he said, ‘Well you sure know how to find somebody.’

A similar social media experience occurred for Leslie, 58, who had an old acquaintance post on her CaringBridge page that he was good friends with a specialist at Mayo, and was able to get her in to see him.

Other participants said they used social media to seek out cancer patients with similar diagnoses to ask questions and validate suffering. Marie, 46, says she used it to compare notes
with other cancer patients whom she found online: “I definitely needed it; you get so much info
thrown at you from doctors and nurses so quickly, it was nice to have these people who have
already been through it, to ask questions.” Carrie, 47, pointed out the benefits of that shared
experience:

It’s really helpful because I feel like I can help them too. Someone will post something
going on and if I’ve had that experience I can say, ‘oh, go to your dentist and ask for this
medication for your mouth sores because your oncologist won’t know about it,’ or, ‘yeah
that totally sucks, I’ve been there too.’

A few participants noted that they appreciated the ability to read the social media blogs of
other people with similar diagnoses, without having to feel obligated to actually talk to the
person. Gwen, 42, says she is not ashamed to admit she was a “lurker” who wanted information
she could not find in books:

I did this with multiple people, what did they go through, what did they do and I was able
to remain anonymous on my end…voyeuristic, lurking, checking things out, kind of
creepy but trying to get information without getting depressed.

That potential for experiencing depression after reading other cancer blogs was one shared by
several participants including Kelly, 60, who says she had to learn to steer clear of some of the
worst cases: “There are people who are processing the idea that they are going to be dead soon
and I didn’t want to read about that.” A vast majority of the participants say they openly shared
details of their cancer journey with the hope that it could help future cancer patients.

To provide valuable information to health care providers regarding treatment
effectiveness. Eight of the participants chose to share their social media blog posts with their
health care providers. Anne, 19, said she was glad she did. “I think they could better see how I
was handling it and my perspective on things.” Carrie, 47, remarked on the benefits of sharing blog posts with health care providers.

I think the benefits are, seeing a really different side of me – because when you are in the physician’s office you have specific health questions and even if the doctors don’t make you feel rushed, you know they are on a time schedule so with this they can maybe see more of the psycho-social issues that are going on and kind of get a little more full picture of the patient.

Marie, 46, concurred, suggesting that sharing social media posts is an effective way for health care providers to see the true details of a patient’s cancer experience, as opposed to the glimpse they get during office visits. Marie stated, “I know my surgeon said he was shocked by some of the feelings I went through.”

Two participants thought they would have more heavily edited their posts had they known their health care providers were reading them. However, several other participants said they wish they had thought to share their posts to help doctors evaluate the effectiveness of their treatment plans, and suggest health care professionals recommend it to future cancer patients.

**To strengthen social support.** The most common motivation for using social media was shared by all of the research study participants: the need for social support during cancer treatment and recovery. Marie, 46, described it as not wanting to fight the enemy alone. “Those messages daily help you to fight at times when you want to give up…it felt like it gave you an army beside you and kept you going.” Molly, 51, got tears in her eyes when she started to talk about the impact her social network had on her recovery.

People say you fought cancer and won. I’d say no we fought cancer and won, I was so supported by a community of people that I knew but had no idea how much I could count
on them to hold me up and lift me up for me and my daughter and that’s how I beat cancer - it wasn’t me - it was all of them.

Kayla, 46, used this descriptive narrative to illustrate how social media support helped in her recovery:

I felt like I fell down a hole. Then the doctor gives you more news, and the hole got deeper and deeper, and I looked up, and the opening got smaller and smaller, and dimmer and dimmer, and I felt like all the people around me created a ladder that helped me climb out and my sister was down there pushing my butt telling me to ‘get up, get up we’re going to get this’ and everybody else me was part of my ladder to get me out of the hole.

Participants also commented on the surprising benefits of receiving support through social media in real-time. Carrie, 47, framed her situation in the following way:

I used to be alone in my life, if I had a problem I’d fix things on my own, but with putting things on CaringBridge, and saying ‘oh the shit’s hitting the fan right now,’ people come out of the woodwork, people I didn’t expect to be super helpful…a community of support.

To bridge the isolation gap. Several participants described social media as a way to feel connected with their friends and loved ones, even when they were physically apart due to compromised immune systems. Marie, 46, described the loneliness cancer treatments create:

I was on a pretty tough chemo regimen which decreased my white blood cell count and basically kept me from human interaction because you can’t be around people when your white blood cell count is so low, you’ll get sick. So the only outlet I had outside my own family, was social media.
Molly, 51, called social media an important lifeline. “I truly knew that even if I was sitting home alone, I wasn’t really alone because at any point in time there would be someone there who I could reach out to if I needed it.” Patients like Lea, 43, who had to be hospitalized for months at a time, concurred, saying social media helped her to feel less alone.

I was fighting for my life in a city where I knew nobody, my support system was in Texas, I knew one person in the D.C. area and my husband was holding down jobs and my parents were taking care of my son, so I was staring at four walls everyday, I’m going to die, I need people to fuel me to give me strength and lift me up.

Social media is the communication platform of choice for the overwhelming majority of cancer survivors in this study, with the motivating reasons outlined above, many of which ultimately tie into the need for social support during illness.

**RQ3: What Barriers Prevent Cancer Patients from using Social Media during Treatment and Recovery?**

This research question asked about the obstacles that prevent cancer patients from using social media during treatment and recovery. Accessibility was not an issue; all of the participants stated that social media was easily accessible to them during their cancer treatment and recovery, with the exception of one participant who was diagnosed in 2000, before Facebook.

**Illness as a barrier.** One common barrier was physical limitations brought on by the disease. Marie, 46, remarked that her family had to post updates for her at times: “My daughter did it for me then like whenever I went to surgery my daughter would access and comment as me from my phone to let people know that I was alright.” Kate, 43, had her husband post for her at times during the treatments: “Once I kind of got through the chemo fog I became more active.”
**Emotional barriers.** In addition to physical limitations, some participants found themselves feeling more alone, watching other peoples’ lives being played out as usual on social media. Anne, 19, said she had to prevent herself from using social media at times to avoid becoming depressed.

Just looking at Facebook, looking at other people’s lives and that was sometimes lonely if you’re in the hospital and everyone else is out there having fun, so I feel like I had to be careful not to be jealous of everyone else going about their lives.

Anne’s feelings were shared by many participants, who said they often had to limit their screentime during various stages of their treatment and recovery to avoid obsessing about how perfect everyone else’s lives seemed at a time when they were struggling so intensely.

**Negative comments and opinions posted by others on social media.** Many of the cancer survivors discussed their frustration over negative comments made by friends and family members. Molly, 51, recalls being annoyed, and slightly mortified, about one conversation in particular:

I remember posting a message about my reconstruction… and was not necessarily comfortable with the debate over whether or not I should have reconstruction openly debated on Facebook. I let them do it because everybody got to get their say out there but I’m thinking, really? You’re debating my boobs.

Sara, 47, shared similar feelings of annoyance and frustration over some of the vociferous opinions shared by members of her network regarding cancer causes and cures:

People can get really militant in their presentation of drug protocols and advice; I think it’s all with good intention, but you know at the time you are fighting for your life essentially, someone telling you, ‘you shouldn’t eat meat,’ is not real helpful advice.
Participants reported these types of barriers as more of an annoyance than a barrier, only temporarily deterring them from wanting to actively engage on social media.

**RQ4: How do Social Media Conversations about Faith and Spirituality affect Cancer Recovery?**

This research question aimed to explore how discussions on social media relating to faith and spirituality affected participants. Despite having varied religious backgrounds, 80% of the study participants reported receiving social media messages during their treatment and recovery that were related to faith or spirituality. The reported effect of those messages varied for each participant, but the vast majority described a positive impact.

**Feeling uplifted through faith and spirituality.** Sue, 59, said she received messages daily from people who were praying for her. “I’m a strong believer in prayer, and I can say when I read those posts, I had a positive, uplifting feeling knowing I had that many people praying for me.” Anne, 19, shared a similar experience: “If I hadn’t used CarePages I wouldn’t have known how many people were praying for me and that was cool to see the support that I had.” Alli, 40, openly talked about her faith on social media and said the Bible verses, songs, and messages she received from her network helped to fuel her: “My experience was very positive. I will say there are some verses that are a little trite and I get a little bit of an eye roll. It’s like, ‘dig a little deeper here, peeps.’”

For Clara, 62, talking about her faith on social media helped eliminate her fears: “When I found out I had to have a biopsy I sent something out just saying that I needed prayer for my health and people started rallying around and I knew God was going to bring me through it.”
**Seeing God in others.** Anne, 19, described her experience with posting and receiving faith-based messages as extremely meaningful because she was able to see God working through others.

I was very open about my Christian faith and how that was an important part of helping me cope with everything and people would post Bible verses and say they were praying and that was cool to see God working through them in that way, too.

Carrie, 47 echoed a similar sentiment: “I guess it went from me thinking of God as a spiritual entity, to seeing God in other people and the things they would do for me and thought wow, this is amazing.” Molly, 51, also remarked about her surprise at seeing such an unexpected outpouring of support from her spirituality group:

A lot of them came to help so I wouldn’t have to be alone. They’d bring meals or clean my house, and they just did it, and to me, that is an incredible expression of community, it was the basis of our spirituality. The more positive energy you put into the universe the more there is for everyone.

**Social media as a platform to openly discuss faith.** Several participants used social media as a platform for discussing their faith openly during their cancer treatment and recovery. Allie, 40, described why she chose to use social media as a platform to talk about her faith:

One of the things I really faced thinking I was dying was, have I really actually been open with people about my faith and this became a platform for me and social media gave me a method by which I was able to talk to my friends, present and past, in a very honest way.

Clara, 62, described how her use of social media to talk about faith not only inspired her but had a positive impact on her social network:
I thought it was the ultimate opportunity to really let people know my faith and my focus on how God will take me through anything. It’s really interesting because some of the comments were, ‘I felt I was having a bad day and then I read this and your faith is amazing, I want what you have’ – and that encouraged me even more because my mission was being accomplished.

Terri, 58, described a similar experience regarding the benefits of posting about her faith on social media:

I realized how much God was using my cancer for other people’s spiritual life. People just kind of looked at me would be like ‘how can you be smiling?’ And that’s when it hit me, okay God use me.

While a number of participants considered their conversations on social media about faith and spirituality to be wholly positive, cancer survivors like Gwen, 42, recall being occasionally annoyed at some comments. “‘Stay strong, this is God’s will,’ you just chuckle and think ‘okay, they mean well, their heart is in the right place,’ but you are going through an emotional rollercoaster, and that is not what you need to hear.”

**RQ5: How can Social Media use Lead to Posttraumatic Growth Experiences for Cancer Survivors?**

This research question investigated how the use of social media during cancer treatment and recovery can empower survivors and encourage posttraumatic growth. An overwhelming majority of participants came out of their cancer experience with what they described as a newfound understanding of life and purpose in the world.

**Using social media as a platform for meaning-making.** Cancer survivors in this study shared their appreciation of social media as a tool to engage their friends and family in deeper
discussions about life and one’s role in the world. Many described viewing life after cancer as a “second-chance.” Alli, 40, says she no longer takes things for granted post-cancer:

My diagnosis was so severe initially that one can’t help but wonder if it was going to be the end but then, to climb yourself back out of there, you just know that your life has been given to you as a gift again.

Alli and several other participants say social media played an important role in helping them develop that perspective and develop meaning from their illness experience. Lea, 43, remarked that she used social media to talk to friends about her desperate need to find meaning in the experience:

There has to be a reason that I went through this horrific journey, if there was no purpose for the purpose to the hell I just went through. If there was no reason behind it, I would be really pissed off. I have to feel there is a bigger picture and a bigger reason.

Kate, 43, shared similar thoughts about how social media posts and comments helped her find her way toward a new meaning of?:

I’m here for some reason, and if I can make a difference I’m going to. I post about breast cancer frequently, and I do post about friend’s struggles. I think that’s kind of why I’m here, to spread the word.

While some of the cancer survivors harbored feelings of sadness regarding the lasting physical effects of their cancer and treatments, the vast majority were overwhelmingly positive about life after cancer and openly shared how they did not want to waste their second chance at life. Several participants described their cancer experience as life-changing, both psychologically and physically. Participants said cancer made it impossible to go back to the life they once knew.
Using social media to mobilize networks to turn individual illness experiences into positives for the greater good. All of the participants in this study have meaningful accomplishments to add to their post-cancer curriculum vitae, with many crediting social media as playing a significant role in their progress. For example, Lea, 43, started a nonprofit after her cancer experience. Lea’s nonprofit encourages people to exercise to stay fit in an effort to prevent illness and to speed up the healing process when someone becomes ill.

I took to social media…to help people get fit and as accountability to me, I needed something to wake up everyday. So I launched my campaign and everyday I would post how far I walked, what I did…and other people started posting saying I took a yoga class, or a I went on a walk, or I played tennis, or I went to Zumba and people from all over started using the hashtag. Instead of helping me, I needed to help other people, and that helped to fuel me.

After her recovery, Nan, 73, also started a nonprofit focused on teaching individuals breathing methodologies to reduce stress and enhance health and wellness. She is also a published author who has gone on to use her vast social media network of more than 4,500 women to expand her efforts to help others.

I think it’s part of your DNA and how you’re put together, some people do the ‘woe-is-me’ and feel sorry for themselves and don’t go further. I didn’t have time to feel sorry for myself, immediately upon being a survivor, it just makes you appreciate every day even more. It made me want to give back and help others.

Molly, 51, started a Facebook group during her treatment and recovery to help other cancer patients. Currently in its sixth year, the group hosts an annual fundraiser, raising thousands of dollars to fight breast cancer:
The best way to give back for what was done for me is to give forward. I think it is a core attribute of a person; I think the seed has to be there within them, to begin with and maybe this is what awakens the seed - you survived, hot damn right?

Sara, 47, has become a popular media personality and frequently emcees for cancer organization fundraisers. When she was diagnosed with breast cancer she did not find enough information about it online, which spurred her to help future breast cancer patients access information. She used social media to share photos and comments about the breast cancer experience.

I thought maybe by living out loud so to speak, maybe I would be able to find healing through other people’s experiences and maybe also give that back to others.

Kelly, 60, is a former women’s radio show host who openly shared information about breast cancer awareness and prevention with her listeners:

Every month on the 11th of each month, we did an on-the-air self-exam, which I narrated and had people do with me, and a woman actually found her breast cancer while doing that.

Kelly left radio but continues to be a breast cancer advocate, emceeing cancer fundraisers. She also helped launch a nonprofit that focuses on art as a healing mechanism, which uses social media to grow support. Kayla, 46 was one of the first to volunteer to join her as a breast cancer model for that project; her likeness now hangs in health care facilities to inspire future cancer patients. Kayla also wrote a children’s book about cancer to help children cope with the changes: “I wrote a book for my boys because being a mom is part of my identity, but being a breast cancer survivor and sharing with the world - those are huge pieces of my identity now too.” Kayla promotes her book through her social media network. Kate, 43, also
credits her vast social media network for her success as an author after her cancer experience. She is currently in the process of writing her third book in a series of fiction stories inspired by her breast cancer journey.

We all have different perspectives. You can either crawl in the corner and be upset or choose to look at your second chance and do something about it; do something with it. I’ve lost two friends to breast cancer, and I’m here for some reason and if I can make a difference I’m going to. Women have called me and wrote to me and said thank you because of your book I went in to get a mammogram and that to me is the best gift of all. Clara, 62, is yet another breast cancer survivor who went on to publish a book after her experience.

I just don’t believe that one thing is the sum of your life…everything is a piece of your life and cancer was just a piece of my life…the purpose was not to make money off it is but to give it to people who are going through cancer or have relatives who have cancer. Clara is also a singer and performer who uses her artistic talents to give back.

Two years after her bone marrow transplant, Leslie, 58, was able to connect with her donor via Facebook. She then became a spokesperson and advocate for an international nonprofit that matches bone marrow donors and is using social media to grow the registry, raising more than $130,000 in the process:

Now I need to help others. It was interesting, I had a really hard time receiving so much love, it’s hard to be on that end when you can’t give anything back when so many people are sending good wishes my way, and I couldn’t handle that. I felt guilty. Isn’t that crazy? I wanted to help back. I couldn’t then, so now, okay, I’m going to help people because it will help me.
Not all of the participants are paying it forward so publicly. Many are finding their purpose by volunteering their time. Alli, 40, gives back by helping individuals obtain jobs. Gwen, 42, volunteers as a softball coach for kids. Helen, 61, became a guide for the Firefly Sisterhood, an in-person and online breast cancer support and mentor program. Teri sold her business and became an aesthetician, helping students learn how to do lymphatic drain massages on cancer patients. Len, 61, is also working on the legacy he will someday leave behind post-cancer. He left his career in teaching and has since composed the music for his first off-Broadway musical production in New York. The youngest participant, Anne, 19, has big aspirations for her future. Her piano skills helped her cope with cancer and was the one thing she felt she could control during her treatment. She now teaches piano and wants to use her music to help kids with cancer. She also plans to volunteer with the Make-a-Wish Foundation.

Findings Summary

This results section reported on the findings of a phenomenological analysis of in-depth interviews with 20 cancer survivors regarding their use of social media during cancer treatment and recovery. The data illustrates the many benefits cancer patients receive when using social media, including perceptions of increased quality-of-life. The findings show survivors in the digital age prefer social media to phone and in-person communication during cancer treatment. The results also indicate cancer patients are motivated to use social media to share details of their cancer experience with the primary purpose of informing family and friends, and a secondary purpose of sharing information with their health care providers and other cancer patients. In addition to the many therapeutic benefits highlighted by these findings, cancer survivors most notably reported positive feelings associated with conversations about faith and religiosity on
social media during their cancer treatment and recovery. Lastly, the use of social media by cancer patients serves as a strong impetus for empowerment and posttraumatic growth.

Discussion

Current literature does not identify the social media platforms preferred by cancer patients during treatment and recovery; however, this study clearly pinpoints blog sites as being preferred over social networking sites for discussing the cancer experience with friends and family. Several additional findings emerged from these interviews. First, nearly all participants reported feeling that social media served as a valuable therapeutic tool during cancer treatment and recovery. Second, cancer survivors in this study preferred social media over phone calls as their communication platform of choice for social support during their treatment and recovery. Third, participants chose to seek out and share information online with other cancer patients with similar diagnoses. Some participants also chose to share their blogs with their health care providers to give them better insight into treatment effectiveness. Fourth, social media accessibility was not a barrier reported by cancer patients, but severity of illness and emotional distress led some participants to step away from social media at various times. Additionally, this study found that social media conversations about faith and spirituality during cancer treatment and recovery contribute to positive support and sense-making for an overwhelming majority of participants. Finally, the study indicates social media engagement with strong support networks can lead to survivor empowerment and meaningful posttraumatic growth.

Social Media as a Therapeutic Tool for Cancer Recovery

All but one of the cancer survivors said they felt that using social media during cancer treatment and recovery enhanced their quality of life in terms of venting frustrations, expressing fears, and receiving support. This result corresponds with earlier studies that found online
narrative blog writing offers therapeutic effects (Cepeda et al., 2008; Graham et al., 2009; Heilferty, 2009; Merz, Fox, & Malcarne, 2014; Winer, 2005). Participants characterized narrative blog writing as cathartic and as an effective way to help them process the illness experience. One cancer survivor felt so strongly about the positive benefits she claimed that posting blogs on social media during her illness helped to speed her recovery. These findings correlate with the results of a randomized control study by Cepeda et al. (2008), which found that cancer patients who disclosed high levels of emotion in their narrative writing reported meaningfully lower pain intensity. The majority of participants in the current study reported experiencing psychological benefits by posting blogs on social media about their illness, not only in helping them process the experience but to help them engage with loved ones regarding serious topics not frequently discussed in person.

This study’s findings also corroborate the themes identified by Chung and Kim (2008), regarding the gratifications of using cancer blogs. Offering findings that support the Uses and Gratifications Theory (Katz, Blumler, & Gureveitch, 1974), the authors determined that emotion management was one of the most gratifying reasons for cancer patients to use blogs, a finding that was clearly identified in this study with participants sharing the need to vent frustrations with their social networks to gain support. Several participants characterized their blog posts and the comments received in response as “free” therapy. This supports a study by Graham et al. (2009) that found using LifeBlog mobile device software served as an effective therapy tool for people who could not afford, were too embarrassed, or did not have access to, traditional forms of therapy.

Similarly, these results mirror an earlier study by Anderson (2011) regarding the benefits of using patient care sites, such as CaringBridge, to connect with other patients, friends, and
family. This study’s participants echoed those results, with participants claiming to experience gratifications such as encouragement from their social networks and appreciating a platform that allowed them to safely discuss challenging topics without feeling vulnerable or uncomfortable.

Nearly all of the cancer survivors in this study said they felt much more comfortable opening up and sharing deeper feelings about their cancer experience by writing it in blogs than they felt comfortable verbalizing to their friends and family in-person. Some cancer survivors remarked that posting blogs on social media empowered them to have uncomfortable conversations about mortality and other sensitive topics. These conversations, made easier online, made participants feel emotionally vulnerable when had in-person. These findings correlate with the results of a quality-of-life study by Morgan et al. (2008) which indicated cancer patients feel differently about their illness by writing and reflecting on it, creating a sense of empowerment when so much is out of a patient’s control.

In addition, some participants used their social media posts as a way to create a legacy-making space, using the opportunity to tell friends and family how they feel and to try to make a difference in the time they have left. One recurring comment from participants related to wanting to be remembered in a positive way, as having lived a life not defined by cancer. This study’s findings correlate with the results of a Keim-Maplass et al. (2015) study which found blogging helps end-of-life stage cancer patients process the therapeutic modalities of anticipatory grief, offering a place to reflect on life and to leave a legacy behind. In addition to wanting to be remembered, some cancer survivors also found value in maintaining a written record of their cancer experience for future generations of family members who may also battle cancer due to genetic predisposition. One participant wished her mother had kept a similar online journal of her own cancer experience so she could have had a measure of comparison.
Seventy percent of the sample posted blogs on social media, all of whom recommend blogging to future cancer patients. Health communication practitioners can benefit from this study’s results and use them to shape future campaigns directed towards newly diagnosed cancer patients. All of the participants reported the need to seek out additional information upon diagnosis and all participants reported turning to social media to confirm information they had received from health care providers, and to seek out additional cancer-specific advice regarding next steps. Cancer nonprofit organizations, health care facilities, and oncology providers can use this information to design future information campaigns, encouraging newly diagnosed cancer patients to consider writing and posting blogs about their cancer experience for the therapeutic health benefits it provides.

Social Media as a Communication Platform for Social Support During Illness

Cancer survivors in this study said their interactions on social media during their cancer treatment and recovery helped them to strengthen old relationships, create new connections, and reframe their post-cancer identities. These are three benefits related to positive behavior change as identified by Amichai-Hamburger et al. (2008). Several participants commented on feeling less restraint in expressing their feelings on social media, preferring this form of communication to in-person or phone conversations about their illness. For many, social media served as a lifeline, bridging the isolation gap created by distance from loved ones, both geographically and due to the vulnerability of a patient’s immune system while undergoing cancer treatment. These findings corroborate the study by Kim and Gilham (2013) which found that posting blogs on social media can help cancer patients feel connected virtually with their friends and family at a time when they may feel physically isolated from their social support networks during treatments.
An overwhelming number of participants in this study remarked on how quickly their social networks grew during their cancer treatments, with old friends, classmates, and even marginal acquaintances connecting and commenting on their social media posts. Several participants commented on how pleasantly surprised they were at the level of support they received from people they did not expect. In addition to emotional support, some participants used social media to help raise funds to help them during their battle against cancer, with one woman claiming it saved her from losing her house. Many others claimed they benefited greatly by linking volunteer signup sites to their social media posts to help them with meals, transportation, and childcare duties.

Contrary to the Sugawara et al. (2015) study of Japanese-based Twitter accounts, which indicated a growing number of patients using Twitter to microblog about their condition, only two of the participants in the current study chose to share information on Twitter. Participants in the current study overwhelmingly preferred Facebook as their social networking site of choice, mainly using it for short, non-cancer-based communications with their social networks. Further study is warranted to determine whether this departure is influenced by cultural preferences. The one similarity discovered in this study that supports the evidence found in Sugawara et al. (2015) is participant appreciation of the real-time benefits of using social media. While the preference of platforms varied, the real-time response for using social networking sites remained the same. The need for instantaneous feedback, and the ability to receive it, aids in helping cancer patients feel empowered and supported. This need for immediate feedback is another significant example supporting the premises of the Uses and Gratifications Theory (Chung & Kim, 2008; Katz, et al., 1974).

**Social Media as an Effective Format for Information Sharing**
Nearly all of the participants used social media to seek out and share information with other cancer patients who shared a similar diagnosis, citing the need to confirm information they had received from their doctor, evaluate and compare treatment effectiveness, and validate suffering. This supports evidence found by Narimatsu (2008) that cancer patients visited cancer blog sites more frequently than information-based sites offered by cancer centers, hospitals, and pharmaceutical companies. In this study, several participants sought information from organizations such as the Susan G. Komen Foundation, the American Cancer Society, and the Mayo Clinic, but most preferred to search other cancer patients’ social media blog posts. A few sought information from other cancer patients but chose only to “lurk” on their social media sites, gaining relevant information, but choosing to remain silent rather than communicate with the other patient. One participant commented on how grateful she was that social media allowed her to act as a silent observer without having to engage with someone else who was sick.

Only 40 percent of the participants in the current study chose to share their blog posts with their health care providers. Those who did share found their blogs found this disclosure to be a valuable opportunity to give their health care providers a better picture of their cancer treatment effectiveness and progress. These results mirror a Ressler et al. (2012) study in which the majority of the sample reported sharing their posts with friends and family, yet only 42.1% of the participants reported sharing their blogs with medical staff. These results also correlate with the findings of the Heilferty (2009) study that determined health care providers benefit from reading a patient’s blog by allowing providers to monitor treatment effectiveness and address patient needs, ultimately strengthening the patient-provider relationship. In this study, of the 60% of participants who did not share their posts with medical staff, nearly all said it just never crossed their minds to do so. Two of those survivors said they likely would not have shared even
given the chance for concern that they would have had to edit themselves, rather than freely venting about the painful process of enduring their cancer treatments. However, the remainder of the sample openly said they wish they had shared with their provider, recognizing the value in providing that information outside of their short office visits.

As Hilan (2003) pointed out, this information is valuable to medical facilities and health care provider groups which could make the information sharing process easier by integrating password-protected online journals. This would allow patients to communicate with others who share similar diagnoses, and aid in the exchange of information with the patient care team. It also correlates with a Ziebland and Wyke (2012) study suggesting that online resources are the primary source for health information in the digital age. The authors theorized that blogging and posting via online social networks will drive the future of e-health, primarily due to the ease of use, accessibility, and value of narrative storytelling by patients as they share their cancer experience.

**Impacts of social media conversations about faith and spirituality on cancer recovery**

While there appears to be a significant gap in the literature regarding the use of social media to discuss spirituality during a cancer illness, participants in this study reported a positive experience in receiving faith-based messages on social media, leading to increased feelings of support by family, friends, and church communities. Participants said receiving these messages helped them to cope with the fear brought on by a cancer diagnosis, filling them with hope and comfort at a time when other parts of their life felt out of control and uncertain. This correlates with the findings in studies by Ferrell et al. (2003), and Sherman et al. (2001), which concluded that cancer patients rely on religion and spirituality as a coping mechanism. Additionally Ferrell et al. (2003) determined that cancer survivors who remained grounded in faith, with the belief
that God is in control, found meaning in their cancer experience. Participants in this study cited the need to find meaning in their cancer experience as one of the most important, albeit difficult, issues to grapple with during their treatment process.

Participants also reported pushing down feelings of doubt that crept up during their suffering, in part due to positive comments from their social media network. These comments served as reminders to participants that there is a higher power in control with a long-term plan. These results mirror comments from a Gall and Cornblat (2002) study regarding adjustment factors in long-term breast cancer survivors. The researchers concluded prayer was the most common religious coping strategy and that social support was an integral component of a survivor’s view on spirituality with examples of support seen as “manifestations of God’s presence” (Gall & Cornblat, 2002, p. 529). A recurring comment from participants in the current study was that they were able to see God working through others during their cancer experience, helping in ways they did not expect. Several participants also viewed social media and their cancer illness as an opportunity to share their own religious viewpoint, aiding in their posttraumatic growth. While this did not appear to be addressed in prior research, it was a recurring theme of participants in the current study.

Vachon (2008) suggests that future cancer patients could benefit from care that integrates “the body-mind-spirit connection,” to examine how the individual’s religious or spiritual beliefs may affect the recovery of the individual, and to encourage reflection on meaning and understanding (p. 224). The current study adds to this body of literature, with cancer survivors sharing illustrative details of how these conversations on social media play a positive role in treatment and recovery.

**Social Media as a Tool for Posttraumatic Growth**
This study’s findings indicate social media acts as a unique utility for addressing the physical and emotional limitations of cancer patients. In addition to providing patients a platform to discuss the illness and its impact, social media enables them to control their levels of engagement, offering them a choice at a time when so many things feel out of their control. Further, social media engagement can lead to patients having increased feelings of connectedness in real-time. These changes in perception fulfill the three themes of empowerment as identified by Sheilds (1995): (1) an emergence of a core sense of self, (2) control over choice, and (3) connectedness.

Similar to the qualitative study with participant interviews by Skeath et al. (2013), this study investigated the positive changes that cancer survivors characterized as being life transforming. Analogous to the findings in Skeath et al., (2013), participants in this study reported significant transformative changes such as deepening of faith, a stronger sense of self, a closer connection to friends and loved ones, and a profound understanding of the meaning of life. These changes embody the definition of posttraumatic growth, a phenomenon first defined by Tedschi and Calhoun (2004), as “the experience of positive change that occurs as a result of the struggle with highly challenging life crises” (p. 1). This phenomenon was later confirmed in a study by Pat-Horenczyk et al., (2015). It is clear that the personal distress experienced during a traumatic experience such as cancer can be ongoing and may coexist with growth based on an individual’s adaptive coping capabilities (Pat-Horenczyk et al., 2015; Tedschi & Calhoun, 2004).

All of the participants in the current study reported having experienced this kind of posttraumatic growth phenomena. While each survivor chose to express that in different ways, the majority of the sample reported feelings of wanting to make a difference or “pay it forward.” More than half of the sample got involved with nonprofit organizations after their cancer
treatment. A handful of participants also used their creative talents as an outlet for posttraumatic growth, writing books, songs, and even a musical. Results are similar to the those found by Weiss (2002) in which 98% of breast cancer survivors reported significant posttraumatic growth following their cancer experience and found a greater appreciation for life.

Participants in this study point to social support and faith as driving factors in their posttraumatic growth. This mirrors the Danhauer et al. (2013) study which identified social support and spirituality as two of the factors that influenced posttraumatic growth. Spirituality was also identified as a positive indicator for posttraumatic growth in the Castonguay et al. (2015) study of 470 breast cancer patients, along with personal strength, both of which were also indicated in this study by the sample majority. While Danhauer et al. (2013) also discovered posttraumatic growth levels were greater in women with higher levels of education and when more time had passed since the end of treatments, those specific measurements were not investigated in this study.

When it comes to posttraumatic growth, the current study reflects Spreitzer’s (1995) suggestion that the construct of empowerment does not necessarily make sense as an argument that is logical or explicable. Rather, empowerment is a byproduct of the behaviors shaped by various factors such as context and personality. When asked open-ended questions regarding motivations for self-identified posttraumatic growth actions, participants shared similar responses such as faith, spirituality, social support, meaning-making, and social media as an effective platform for new growth opportunities. However, when evaluating the differences in participant responses, it is clear that context and personality characteristics are a significant part of posttraumatic growth. During the in-depth interviews conducted for this study, I was able to get a snapshot of participants’ individual personalities, and it became clear that participants who
were more extroverted, with outgoing, gregarious personalities, were more likely to turn their traumatic cancer experience into something positive with the hope that they could somehow impact the greater good. Several participants outwardly characterized their situation as an “opportunity” to make a difference in the lives of others. Cancer survivors in this study who were rather shy or quiet during their interviews reported wanting to simply put the cancer experience behind them, choosing to make a difference on a smaller scale, primarily within their own social networks. Future research could benefit from participant personality tests to determine whether personality proves to play a more significant role than anecdotally.

Research indicates that young adults, ages 18 to 29, are the generation most likely to use social media (Perrin, 2015). However, in this study social media has proven extremely valuable in the lives of all of the participants in the study, regardless of age. While the 19-year-old survivor, Anne, had never known a world without social media, her experience of using social media during cancer treatment and recovery was no different than for those who were three times her age. Many of the older participants commented that they preferred social media to telephone calls, appreciating the ease of updating everyone in their social network all at once, in real-time.

**Limitations of this Study**

As with all studies, while best efforts were taken to reduce limitations, some did emerge from this study. One limitation relates to the sample population. Using a snowball sample to recruit participants, the researcher posted invitations to cancer survivors on social media sites, including Facebook and Twitter, asking contacts to share the invitation with other individuals. Additionally, participation invitations were sent out via email to database members of a cancer research nonprofit. Despite the potential for a sampling of individuals with various cancer types, 70% of the study participants were breast cancer survivors, the majority of whom shared the
experience openly on social media, providing in-depth health-related information with some even posting photos on their blogs. This was a trend common in the recent literature, in part due to efforts to de-stigmatize breast cancer, the media’s role in sharing and the many stories of breast cancer in the media, and the work of breast cancer nonprofits like Susan G. Komen Foundation and pink ribbon awareness. While the sample was mostly comprised of breast cancer survivors, thus limiting the opportunity to capture the social media experiences of other types of cancer survivors, these findings are undoubtedly important for breast cancer survivors and physicians, especially as breast cancer is so common, with one in eight women diagnosed with invasive breast cancer (Breastcancer.org, 2016).

Another limitation of this study was related to sample demographics. The sample was predominantly female. Only one male cancer survivor volunteered to take part in this research study. Also, nearly all of the participants in this study lived in the same geographical region and were not racially or ethnically diverse as a whole. Geographic location may also influence social media platform preference. The majority of the participants in the study lived in the Upper Midwest and preferred to use the patient blog site CaringBridge, which is based in Minnesota.

This study also did not seek to measure how active participants were on social media before their cancer diagnosis. Participants may have self-selected into the study because they were already active on social media with no real measurement of how much, if at all, their activity levels on social media changed after their cancer diagnosis.

An additional limitation of this study is that it did not seek to answer how emotion and personality played a role in posttraumatic growth. During interviews, participants’ emotional responses and personality traits were recorded in the interview notes; however, this study’s focus
encouraged the use of anecdotal data for theme saturation and the relationship between emotional response, personality, and posttraumatic growth was not explored.

Finally, due to factors including participant time and geographic location, not all interviews were conducted in-person. While many researchers rely on interviews that are not conducted in-person, this is a limitation worth noting as contextual matters such as time of days, space, and a rapport can impact participant responses.

While these issues do present limitations, these limitations provide insight into ways future research might improve upon this study.

**Implications for Future Research**

The revelation that all of the cancer survivors found social media to be a valuable therapeutic tool, helping them to cope with the life-threatening disease by venting frustrations, sharing fears, and receiving social support, is especially important. Additionally, findings that participants who engaged in faith-based conversations on social media can be valuable for future cancer patients, as well as the discovery that nearly all of the cancer survivors in this study experienced posttraumatic growth. While qualitative research allows for invaluable, detailed illustrations of participant experience that cannot be gleaned from quantitative research, future studies could benefit from a mixed methods study that incorporates a survey of a broader sample of participants recruited through multiple testing sites, with in-depth interviews conducted at a later date. Researchers should also consider contacting cancer organizations with a national pool of cancer survivors. This would allow researchers to potentially conduct surveys at various cancer survivor events across the nation, which draw participants of varying demographics and with various cancer types and allow access to a broader participant recruitment pool for qualitative studies.
Future studies should include a broader sample of cancer types and participants. Research indicates that men and women communicate differently on social media, especially regarding health concerns. Several studies show that men are less likely to seek help as men fear seeking help is an admission of weakness and contradicts core elements of the male gender identity such as self-reliance and control (Moynihan, Bliss, Davidson, Burchell, & Horwich, 1998; Reevy & Maslach, 2001; Zakowski et al., 2003). Future studies on the role social media plays in cancer recovery could aim to incorporate a greater number of male participants to provide further insight regarding gender differences in social media use.

Additionally, future research should draw from a wider geographic base to investigate whether cancer patients in other areas of the country receive exposure to patient care sites as valuable resources during treatment and recovery. Findings from more geographically diverse studies can be compared to the findings of this study, thus providing insight into the role of geography in social media use during cancer treatment and recovery.

The majority of participants in this study described themselves as extroverts with large social networks, unafraid of sharing the graphic details of their illness, including before-and-after photos of the breast cancer experience. Further research could benefit from an investigation of the influence of both emotion and personality traits on posttraumatic growth in cancer survivors.

Additionally, future investigations should gather information about participant social media use. Specifically, studies should include information on participants’ social media network numbers, including friends, followers, and comments. This will enable researchers to make meaningful comparisons about the use of social support influence in posttraumatic growth. A longitudinal study that begins at diagnosis stage and follows patients into recovery could also prove valuable in assessing posttraumatic growth results over a longer period.
Conclusion

The American Cancer Society estimates the number of cancer survivors living in the United States will grow to more than 20 million over the next decade (Simon, 2016). At the same time, digital technology continues to rapidly evolve, creating a significant need for comprehensive research to guide future use. The overall goal of this qualitative research study was to expand the body of knowledge in the area of social media and its application in cancer treatment and recovery.

This work highlighted the positive role social media plays in cancer treatment and recovery. The findings show cancer patients are motivated to use social media during their illness as a therapeutic tool to update family and friends, gain valuable social support, and bridge the isolation gap frequently created by the cancer illness. Cancer survivors seek and share information with other cancer patients as well as their health care providers, generating valuable new information that can have an impact on future cancer care. Conversations about faith and spirituality on social media during cancer recovery are beneficial to participants, improving their coping mechanisms. Finally, findings indicate that social media use can lead to posttraumatic growth in cancer survivors, not only aiding in the development of deeper meaning and understanding but serving as a platform to motivate individuals to turn their illness experience into something positive for the greater good.

Oncology health care providers and cancer organizations have many opportunities along a patient’s care trajectory to help shape the experience of their illness. By guiding individuals to explore social media use during treatment and recovery, future cancer patients may improve their perceived quality of life. Health care providers, communication practitioners, and cancer organizations can use this research to promote social media use by cancer patients during cancer
treatment and recovery. By encouraging patients to share their disclosures with health care providers, cancer care teams receive a fuller picture of a patient’s treatment effectiveness in real-time. This additional layer of communication may lead to better health outcomes and improved physician-patient relationships. Additionally, health communication practitioners can use this data to develop future health initiatives designed to improve the cancer experience.

Communication scholars can also benefit from the rich, qualitative data gained from participants of this study to aid in the development of future research. Social media scholars can benefit from the research to gain a deeper understanding of the motivations and preferences of cancer patients for using social networking sites and blog sites. Cancer organizations like the Susan G. Komen Breast Cancer Foundation and the American Cancer Society are popular websites for newly diagnosed cancer patients seeking information. These types of organizations can benefit from the illustrative data of this research for use in future campaigns designed to improve the cancer outcomes such as improved quality-of-life and increased knowledge. Finally, patients and patient caregivers can benefit from the invaluable experiences shared by cancer survivors in this study.

The research indicates cancer patients can benefit from using social media: (1) as a therapeutic tool for emotions management; (2) a communication tool for seeking and sharing information; (3) a bridge to prevent feelings of isolation; (4) an arena for coping through religious and spiritual engagement; and (5) a platform to promote posttraumatic growth. This study provides a deeper understanding of how social media can be used effectively in cancer treatment and recovery.
Appendix A

Recruitment Materials

Participation Invitation Sent to Personal Network via Email and Posted on Social Media Sites such as Facebook

Graduate student seeks other cancer survivors for research study:

As a graduate student at Johns Hopkins University, I am conducting a research study about the role social media plays in cancer patient treatment and recovery. I am seeking participants 18 year of age and older who are cancer survivors, meaning those who have been cancer-free for a minimum of one year, and who used social media during their treatment and recovery. Interviews will be confidential and can be conducted in-person, by phone, or via an online platform such as Skype. If you meet the criteria for this study and would be willing to share your experiences in an interview, please contact the researcher, Kristin Geer, at kgeer2@jhu.edu. Additionally, please share this invitation with your friends or family who may be interested and able to participate.

Invitation Posted on Twitter

Need help! Grad student studying the role social media plays in cancer recovery needs participants. Email kgeer2@jhu.edu for info.
E-mail to Cancer Nonprofit Database Members

Good morning:

My name is Kristin Geer, and most of you know me through our work together at the Cancurables Foundation. I am currently a graduate student at Johns Hopkins University, planning my Thesis research study about the effects of social media on cancer survivors. For the research study, I hope to speak with cancer survivors about their use of social media during cancer treatment and recovery.

I will be conducting in-depth interviews with each participant, in-person at a mutually agreed upon location within the Twin Cities metro area, by phone, or via an online platform such as Skype; thus, participants do not need to be local to the Twin Cities area to be interviewed. The Homewood Institutional Review Board at Johns Hopkins has approved this study, and all participant interviews will remain confidential.

To qualify for this study, participants must be cancer survivors aged 18 or older, who used social media during their treatment and recovery, and who have been cancer-free for a minimum of one year.

If you are interested in participating, please email your contact information to me, and I will be in touch to coordinate an interview time and location. If you know someone who may qualify to participate, feel free to forward this email. Please let me know if I can provide additional information, and thank you for considering my invitation to participate in the research designed to help. This study may benefit future cancer patients by providing health care and communication professionals with valuable insight in the development of effective cancer treatment strategies.

Sincerely,

Kristin Geer
612-760-0806
kgeer2@jhu.edu
Cancurables Foundation Board Approval Letter

June 8, 2016

Kristin Geer
5808 Northwood Drive
Edina, MN 55436

Dear Ms. Geer:

On behalf of the Cancurables Foundation, I am pleased to inform you that the Board of Directors has granted you permission to send out an email invitation to the foundation's database members, requesting participation in your Johns Hopkins University thesis research study regarding the role social media plays in cancer treatment and recovery.

We appreciate your ongoing dedication to cancer research and wish you all the best with this project.

Sincerely,

Dorsette Sonnenfeld
President
Cancurables Foundation
P.O. Box 24006
Minneapolis, MN 55424-0006
612-889-9847

www.cancurables.org
Phone Conversation with Potential Participants

Hello. Thank you so much for contacting me about the research study I am conducting as part of my graduate studies at Johns Hopkins University. The study includes in-depth interviews related to the effects of social media on cancer survivors. I am studying whether social media plays a role in cancer patient treatment and recovery. I have just a few questions to ensure you are part of the group I am hoping to study.

Screening Questions

- Are you a cancer survivor?
- Are you over the age of 18?
- Did you use social media during your treatment and recovery?
- Have you been cancer-free for at least a year?
- Would you be able to speak with me during an interview?
- Do you live in the United States?

[If yes, then continue with the following.]

I can meet with you at the [place] on [date]. I can meet with you in person if you live in the Twin Cities area or, if it’s easier I could conduct the interview by phone, or via an online platform such as Skype. What works best for you and when would be most convenient? The conversation will be recorded, but the interviews are confidential, so I will not record your name. What is the best way for me to get in contact with you? Thank you again for agreeing to participate in my study and I look forward to seeing/talking to you soon.

[If no to the first three exclusion criteria.]

That is perfectly fine. Unfortunately, because you do not meet X criteria, I am not authorized to interview you for this study. Thank you for contacting me. Please feel free to share this research opportunity with others who may qualify to participate.

If no to participating in an interview:
That is perfectly fine. However, in order to participate in this study, participants must be willing to be interviewed about their experiences with social media during their cancer recovery and treatment. Thank you for contacting me and please let me know if you change your mind.
Appendix B

Research Statement (for participants to read before providing consent)

Johns Hopkins University
Research Statement

<table>
<thead>
<tr>
<th>Title:</th>
<th>The Role of Social Media in Cancer Recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Investigator:</td>
<td>LaKesha Anderson, Ph.D.</td>
</tr>
<tr>
<td>Student Researcher:</td>
<td>Kristin Geer, M.A. Communications Candidate</td>
</tr>
<tr>
<td>Date:</td>
<td>9/9/2016</td>
</tr>
</tbody>
</table>

INTRODUCTION:

My name is Kristin Geer and I am a student researcher from Johns Hopkins University, conducting research for my thesis project to complete a Master of Arts degree in Communications, with a dual concentration in health and digital communications. Dr. LaKesha Anderson is supervising this research study and serves as the principal investigator.

PURPOSE OF RESEARCH STUDY:

The purpose of this research study is to examine the role social media plays in cancer recovery. No more than 40 people will participate in this research study.

PROCEDURES:

To participate in this study, you must be a cancer survivor, in remission for a minimum of one year, and aged 18 or older. You will be asked a series of questions about the role social media played in your personal cancer journey. You will be invited to give your opinions and perceptions of different platforms and types of messages. The interview will be conducted in person, by phone, or via an online platform such as Skype. The interview will be recorded to ensure accurate transcription of the conversation.

RISKS/DISCOMFORTS:

Since this research study delves into a sensitive health topic, thinking about your cancer recovery might make you feel anxious. You may choose not to answer any questions that make you feel uncomfortable, and you are free to end the interview at any time. If I see that you are distraught, I may decide to end the interview, even if you wish to continue to avoid further distress. If you experience any undue emotional distress as a result of this interview, I can provide you with list of professionals you may wish to contact who can help. There is also a confidentiality risk present by participating in this study, primarily that your cancer diagnosis and treatment could be disclosed to individuals not involved
with this study. In order to minimize this risk, your name will not be linked to your interview answers and a pseudonym will be used. An audio recorder will be used to record our conversation, but your responses will remain confidential. Please refrain from using your name once the recording begins. I will report your age, gender, and geographic location, but your name will not be associated with your interview. The audio-recording of the interview will be destroyed after this study is completed.

**BENEFITS:**

Sharing your experience could make you feel empowered knowing you may be helping someone else in his or her cancer recovery. This study may benefit future cancer patients by providing health care and communication professionals with valuable insight in the development of effective cancer treatment strategies.

**VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW:**

Your participation in this research study is voluntary. You choose whether to participate. If you decide not to participate, there are no penalties. If you choose to participate in this research study, you can stop your participation at any time during the interview. Furthermore, you are not obligated to answer any questions with which you are not comfortable. If you would like to withdraw from the research study, please let me know by phone, 612-760-0806 or email kgeer2@jhu.edu within a week following the interview.

**CONFIDENTIALITY:**

Any records of this study that identify you will be kept confidential to the extent possible. The records from your participation may be reviewed by people responsible for ensuring research is conducted properly, including members of the Johns Hopkins University Homewood Institutional Review Board (HIRB) and officials from government agencies such as the National Institutes of Health and the Office for Human Research Protections. All of these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study which include only myself and the primary investigator.

Every effort will be made to protect the confidentiality of the information provided insofar as it is legally possible. I will audio-record the interview. After the interview, I will personally transcribe the data, assigning each participant with a pseudonym. I will then erase the audio recording of the interview. Transcripts will be locked in a safe in my home and I will password protect the digital version of the transcript file.

**COMPENSATION:**

There is no compensation for participation in this research study.

**IF YOU HAVE QUESTIONS OR CONCERNS:**
You can ask questions about this research study now or at any time by talking to the student researcher Kristin Geer via email at kgeer2@jhu.edu, or phone 612-760-0806. You can also ask the primary investigator in charge of this study, Dr. LaKesha Anderson at Johns Hopkins University, any questions you may have about the study. Dr. Anderson may be reached via email at lander73@jhu.edu, or phone 202-534-1103.

If you have questions about your rights as a research participant or feel that you have not been treated fairly, or that you have been harmed in any way, please call the Homewood Institutional Review Board at Johns Hopkins University at (410) 516-6580, or email hirb@jhu.edu.

**SIGNATURE:**

Your signature below means that you understand the information in this consent form. Your signature also means that you agree to participate in this study. By signing the consent form, you have not waived any legal rights you otherwise would have as a participant in a research study.

<table>
<thead>
<tr>
<th>Participant Signature</th>
<th>Date</th>
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<tr>
<th>Student Researcher Obtaining Consent</th>
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Oral Informed Consent Script

I have given you a research statement that informs you about this research study. Please take a moment to read it. Do you have any questions about this research study?

[If yes, answer the question(s).]

[If no, continue.]

You should be aware that there is a confidentiality risk associated with participation in this study, primarily that your cancer diagnosis and treatment could be disclosed to individuals not involved with this study. To minimize this risk, your name will not be linked to your interview answers and a pseudonym will be used. I will use an audio recorder to tape the interview, but your responses will remain anonymous. You should not say your name once I begin recording. I will report your gender, age, and geographic location, but will not associate your name with our conversation. After I transcribe the interview, I will erase the recording of our conversation.

Your participation in this study is voluntary, and you must choose to participate. If you decide not to participate, there are no penalties.

If you choose to participate in the research study, you can stop your participation at any time during the interview. You are free to refuse to answer any questions that make you feel uncomfortable. If you would like to withdraw from the research study, please let me know by phone, 612-760-0806 or email kgeer2@jhu.edu within a week following the interview.

Do you understand what I have just explained?

[If yes, continue.]

[If no, answer any questions.]

Do you agree to participate in this research study?

[If yes, begin interview.]

[If no…]

That is absolutely fine. Thank you for your time, and please feel free to contact me if you change your mind.
Appendix C

In-Depth Interview Guide: Cancer Survivors

Introduction:

My name is Kristin Geer, and I am a graduate student at Johns Hopkins University. I am also a cancer survivor, which is where my interest in this topic stems from. I was diagnosed with ovarian cancer in 2005. The purpose of this study is to examine the role social media plays in cancer treatment and recovery. The data collected during this interview will remain confidential. I will be audio-recording this interview to ensure accuracy, but I will destroy the recording as soon as I have transcribed the data. Your identity will remain anonymous, with the exception of gender and age.

I want to assure you that there are no right or wrong answers to my questions today. I want you to feel comfortable in sharing your thoughts and opinions, without fear of judgment or expectation. I am interested in hearing about your experiences, so please feel free to be open and frank in sharing your point of view.

I have given you an informed consent document to sign, but I also need to record your verbal agreement to participate in this study. Please state your name, age, and verbal confirmation of your agreement.

Before we begin, do you have any questions?

Questions:

1. Tell me about your cancer diagnosis.
   • When were you diagnosed with cancer?
   • What type of cancer?
   • With what stage were you diagnosed?
   • How would you characterize your treatments?
   • What was the length of your recovery?
   • When did you doctor announce you were cancer free?

2. What motivated you to use social media during your treatment and recovery?
   • How accessible was social media to you during your cancer treatment and recovery?
   • Did you actively seek support from other cancer patients online?
   • How would you characterize your need for online support and information from other cancer patients?
   • How would you characterize your participation in social media during your recovery? (Actively engaged in dialogue? Passive viewer? Information seeker?)
• What tools did you use to access social media during your recovery (i.e. computer, tablet, smartphone, etc.)?

3. Which social media platforms did you use during your cancer recovery and why?
   • Why did you prefer those particular platforms over others?
   • Did your social media platforms include blog sites?
     o Why, or why not?
     o How much of your blog site participation was in posting blogs written by yourself, rather than reading other cancer patient blogs?
     o How frequently did you write and post blogs about your cancer journey?
     o Describe any benefits you gained from doing writing blog posts and by posting them on social media?
     o Describe any negative aspects of writing and posting your blogs about your cancer experience.
     o What motivated you to read other cancer patient blogs?
     o Describe any benefits did you gain from reading other cancer patient blog posts?
     o Describe any negative aspects of reading other cancer patient blogs.
     o Who comprised your blog reader audience?
     o Did you invite your health care providers to read your cancer blog posts? Why, or why not?
       o If yes, what benefits did you gain from having your health care providers read your cancer blog posts.
       o Describe any negative aspects of knowing your health care providers may be reading your cancer blog posts.

• Did your social media platforms include patient care sites like CaringBridge, CarePages, or PostHope?
  o Why or why not?
  o Which patient care site did you choose?
  o Why did you choose that site over any others?
  o How did you hear about the site?
  o Were your health care providers invited to participate in your patient care site?
    ▪ Why, or why not?
    ▪ Describe any benefits you experienced from having your health care providers as visitors of your patient care pages?

• Did the social media platforms you participated in during your treatment and recovery include any online support groups?
  o If so, which online support group did you choose?
    ▪ Describe the benefits of using that site over others.
    ▪ What negative impact, if any, did you experience during participation in an online cancer support group?
• What kinds of information were you seeking from other cancer patients in these online support groups?
• What level of support were you seeking from other cancer patients in these online support groups?

• Choosing amongst social media platforms, patient care blogs, or online support groups, which did you prefer to use and why?
  o How did you decide to split your time between them?
  o What were the benefits of using your favorite platform?
  o What did you like most about using your favorite platform?
  o What did you dislike most about your favorite platform?
  o What did you like most about your least favorite platform?
  o What did you dislike most about your least favorite platform?

4. How much of your diagnosis did you share on social media?
• What motivated you to use social media to share details of your treatment and recovery?
• What were the positive effects of using social media during your cancer recovery?
• What were the negative effects of using social media during your cancer recovery?

5. What kinds of barriers did you face in using social media during your cancer recovery?
• Describe any obstacles or challenges you faced in using social media during your recovery.
• How were you able to overcome those?
• What could have alleviated those barriers?
  o Were any of those barriers or challenges a result of health care providers or the health care system?
  ▪ How could health care providers have changed that?

6. How would you characterize the messages you received on social media during your cancer recovery?
• Describe the level of positivity you encountered in messages both to you, and from you, on social media during your cancer recovery.
  o What kind of impact did positive message have on you emotionally?
• Describe any negative messages to you, or from you, on social media during your cancer recovery.
  o How did that affect you emotionally?
• How much do you remember about the actual content of those messages, positive or negative, versus remembering the overall feeling of how you felt when you read them?
  o Are there any examples that you can share with me?
7. How would you describe how your religiosity played a role in the way you shared and received information via social media?
   - Describe what kinds of faith-based messages you received on social media during your recovery.
   - How did those messages affect you?
   - PROBE: Can you give me an example of a message that made an impact on you?
   - How did those messages play a role in your recovery?
   - How would your describe the conversations you had about faith on social media during your recovery?

8. What other experiences did you encounter on social media related to your illness?
   - How did your interactions on social media during your cancer recovery affect you emotionally?
   - When it comes to social media use during cancer recovery, what would you recommend to someone who is newly diagnosed?

9. How has your cancer journey changed you?
   - Who or what do you credit for that change?
     - How would you characterize social media’s role in that change?
       - Can you give me an example of that?
   - What do you do now that perhaps you did not do before your cancer diagnosis?
     - How much of that change would you say came out of your social media engagement during your cancer recovery?
     - How much of that change would you characterize as positive, leading to feelings of empowerment?
     - How much of that change would you characterize as negative, leading to feelings of sadness or emotional difficulty?

10. Before we end, I want to summarize some of the key points that I have taken from our discussion.
    - Is there anything else you would like to add?

11. Do you have any questions?

Conclusion:

I want to thank you for sharing your thoughts with me today. I will be in touch if I have any follow-up questions as I am transcribing the data. Do you have a preferred phone number or email address that you would like me to use?

Thanks again for talking with me today!
Appendix D

NVivo Word Cloud Based on Frequency of Text from the Interview Transcript Data
References


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Curriculum Vitae

Kristin Geer earned her B.A. in Communications with a minor in Political Science from Concordia College in Moorhead, Minnesota. A three-time Emmy Award winning Investigative Reporter, Kristin spent 16 years in television news before an ovarian cancer diagnosis prompted her to leave t-v and start a nonprofit organization to raise money for cancer research, serving as the organization’s Executive Director for ten years. Kristin also ran a television production studio, producing syndicated programs and corporate videos before launching a communications consulting and speaking business. In 2016, she was invited to present on the TEDx stage on the topic of “pivoting.”

When her daughter started school full-time, Kristin decided it was time for her to go back to school to obtain a Master’s Degree in Communications at Johns Hopkins University with a dual concentration in health communication and digital communication. Her research interests are in cancer, health communication, and digital communication.

Kristin lives in Minneapolis with her husband Brad, and their daughter, Gabriella.