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“It’s Not JUST Skin Cancer”: Understanding Their Cancer Experience From Melanoma Survivor Narratives Shared Online

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Abstract

Cancer survivors narrate their experiences in unique ways, articulating different aspects of the cancer journey. The purpose of this study was to analyze the content of cancer narratives that melanoma survivors share online in order to present the ways that survivors narrate their cancer experience, to identify survivors’ motivations for sharing, and to better understand the ways in which survivors are impacted by and cope with the diagnosis and treatment of cancer. The sample consisted of 95 unique melanoma survivor narratives, accessed from the Melanoma Research Foundation in November 2015, that were inductively and deductively coded for key themes and subthemes. Emergent themes described different aspects of the melanoma experience during prediagnosis (identification of selfphenotype, searching for causes, suspicious findings, delay in diagnosis), diagnosis (communication of diagnosis, emotional responses), transition from diagnosis to beginning treatment (second opinion), treatment (positive reframing of attitude, proactive cancer management, side effects), and posttreatment phases (social support, vigilance behaviors posttreatment). Two themes that cut across all phases of the cancer journey included recognizing and dealing with uncertainty and survivors’ motive for sharing narrative. These findings have implications for understanding how melanoma survivors may benefit personally from sharing their cancer experience online and for the potential for survivor narratives to motivate behavior change and facilitate coping among readers.

Cancer survivors have important narratives to tell that can be extremely helpful to other survivors. In a large number of virtual communities (generated via online support groups and blogs), thousands of cancer survivors share their experiences on a regular basis to not only inform others, seek support themselves, and build supportive virtual relationships (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007), cope with stress, uncertainty, and identity changes brought upon by cancer (Heilferty, 2009; Kim & Lee, 2014), but to also model coping skills, provide perspective, and share valuable information and resources (Eddens et al., 2009).

Previous work on analysis of cancer survivor narratives has included linguistically based narrative analysis of video-based YouTube narratives by cancer survivors (Chou, Hunt, Folkers, & Augustson, 2011), thematic and linguistic analysis of cancer narratives shared by adolescents and young adults (Howard et al., 2016; Kameny & Bearison, 2002), and content

analysis of personal narratives written by stem cell transplant survivors (Symes et al., 2016). Prior studies have described themes such as physical and emotional effects of the disease and treatment, coping strategies, and/or advice given to peers undergoing similar treatments, whereas research has not described these themes during different phases of the cancer journey. The purpose of this exploratory study was to investigate the different themes associated with melanoma diagnoses and treatment during different stages of the cancer trajectory.

Why Cancer Survivors Share their Experience Online

Through a large number of virtual communities (e.g., online support groups, blogs), cancer narratives are increasingly available as sources of health information for patients and the public (Eddens et al., 2009; Khangura, Bennett, Stacey, & O'Connor, 2008). Recognizing the power and reach of online cancer narratives, researchers have focused on the unique capabilities of cancer narratives to enhance understanding, model desirable behavior, deliver social support, guide decision making, and facilitate adaptive coping (Hinyard & Kreuter, 2007; Kreuter et al., 2007, 2008). Kreuter et al. (2008) note that "Cancer survivors' direct experience with the disease and demonstrated success living with cancer makes them especially attractive and credible as messengers of cancer information" (p. 33). In a study of the motivations of people who seek information online, Powell, Inglis, Ronnie, and Large (2011) found that the desire for reassurance, increased understanding, and a second opinion were key factors leading individuals to utilize the Internet as a source of health information. Furthermore, in a study of online medical bloggers, motivations for blogging included sharing practical knowledge or skills with others, influencing the way others think, and expressing oneself creatively (Kovic, Lulic, & Brumini, 2008).

Blogging about one's health and medical experience has recently been described using the term "cybercoping." Cybercoping refers to engaging in problem solving and connecting with others via virtual communities (Kim, Park, Yoo, & Shen, 2010). Whether cancer survivors share their unique experience in a narrative form once online, or write regular blogs about their cancer experience, the process of sharing one's personal experience with others can be helpful in two distinct, yet interrelated ways.

Individual Benefits

First, sharing one's personal experience can be beneficial for the cancer survivors themselves. Online sharing can enhance personal empowerment and self-esteem and reduce social isolation and distress (Kim & Gillham, 2013). Writing about a traumatic event can also have inherent biopsychosocial benefits (Pennebaker, 2004). The social cognitive model of restorative well-being (see Foster & Fenlon, 2011; Hoffman, Lent, & Raque-Bogdan, 2013) can inform the process by which online sharing of a personal narrative can serve as a coping strategy for cancer survivors. The model integrates a number of factors that have been linked to coping and emotional recovery, beginning with awareness of significant stressors and including coping strategies, perceived self-efficacy, personality factors, and environmental supports that may affect psychosocial adjustment. Since the experience of

cancer typically disrupts well-being, the focus of this model is on strategies for improvement in relative coping and emotional recovery (Hoffman et al., 2013).

Benefits to Others

Second, describing one's cancer experience through online narratives can also have beneficial effects on those reading them. Kreuter et al. (2007) described that cancer survivors' narratives may influence prediagnosis outcomes (e.g., cancer-related lifestyle and screening behaviors) and postdiagnosis outcomes (e.g., informed decision making and coping) in others. Long-standing national cancer control programs like Reach to Recovery, Man to Man, and The Witness Project are designed around survivors sharing their experiences. Evidence suggests that these programs increase public awareness of cancer, impact cancer screening and health behaviors, and encourage the provision of support and hope to other cancer patients (e.g., Coreil & Behal, 1999; Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996; Rogers, Bauman, & Metzger, 1985).

Several theoretical perspectives, such as social cognitive theory (SCT; Bandura, 2001), the theory of reasoned action (Ajzen & Fishbein, 1980), and the transportation-imagery model (Green & Brock, 2000), can be applied to understand why survivor narratives can have benefits for those reading them. For instance, SCT is a learning theory that postulates that people learn by both observing and imitating others, as well as through positive reinforcement. Survivor narratives can provide vicarious learning exemplars for those reading them (learning by observation), stressing that not all cognitive, affective, and behavioral learning happens from direct experience (Bandura, 2001; Yoon & Tourassi, 2014). Alternately, the transportation-imagery model describes that when readers are "transported" in the narrative world, they can have cognitive, affective, and behavioral changes because (a) transported individuals are so absorbed in the narrative that they are less likely to counterargue and therefore believe the narrative propositions; (b) transportation makes the narrative seem more like authentic experience; and (c) transported individuals may identify with or develop strong emotions for the characters of the narrative, increasing the influence of the perspective on the reader's beliefs (Green & Brock, 2000). These theoretical approaches—with varying degrees of explanatory utility—explain how a person faced with cancer can reap cognitive, affective, and behavioral benefits by reading experiences of other cancer survivors (Hinyard & Kreuter, 2007).

This Study

Before we can harness the widely available cancer narratives for self-help or help to others, we must develop an understanding of what cancer survivors share online. The purpose of this study was to describe the content of melanoma survivor narratives across distinct phases of the diagnosis and treatment trajectory, and to find thematic similarities including (but not limited to) a description of communication between clinician and patient around diagnosis, an identification of melanoma survivors' motivations for sharing their narratives online, and a description of ways in which melanoma survivors are impacted by and cope with the diagnosis and treatment of the disease. In order to accomplish the objective, we conducted a qualitative analysis of melanoma survivor narratives posted online.

Contextualization Around Melanoma

We contextualized this study around melanoma survivor narratives. Melanoma, once considered a rare cancer, is disproportionately increasing in young adults, with vast differences in survivorship outcomes. Melanoma is one of the most common cancers in people younger than 30 years (especially younger women; American Cancer Society, 2016). Latest reports from the Surveillance, Epidemiology, and End Results (SEER) program add that about 84% of melanomas are diagnosed at a localized stage, when they are highly curable. The 5-year relative survival rate is 98% for localized melanoma, 62% for regional disease, and 18% for distant-stage disease (Howlader et al., 2016). Despite increasing rates of melanoma, education about limiting ultraviolet (UV) exposure and screening for melanoma continue to be severely underutilized (Geller, Swetter, Brook, Demierre, & Yaroc, 2007; Riker, Zea, & Trinh, 2010). However, advocacy organizations for melanoma research are burgeoning and often include patient narratives (Black & Brockway-Lunardi, 2013). Cancer survivors can choose to narrate their experiences in unique ways, articulating different aspects of cancer experience; an analysis of common themes in these narratives was the main objective of the current study.

Methods

Sample Selection

The sample consisted of 95 unique melanoma survivor narratives, accessed from the Melanoma Research Foundation (<https://www.melanoma.org/find-support/patient-community/patient-stories>). The website has a library of survivor narratives and we selected all of the narratives available in November 2015. We used the National Cancer Institute's definition of a cancer survivor as "One who remains alive and continues to function during and after overcoming a serious hardship or lifethreatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life" (National Cancer Institute, 2015).

Table 1 presents descriptive characteristics of the survivor, as described in the narratives. A majority of the narratives were about White (77%) and female (66%) melanoma survivors. About 50% of the narratives clearly mentioned age of the survivor (range 2–79 years; $M = 35.4$, $SD = 14.3$). The overwhelming majority of narratives were written by the survivors themselves (90%). The narratives varied in length (range 70–2,490 words; $M = 603.4$, $SD = 445.8$).

Qualitative Analysis

Our coding of melanoma survivor narratives included a combination of inductive and deductive coding (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). First, the narratives were reviewed by using inductive thematic textual analysis, an iterative process of review, interpretation, and consensus discussions (Patton, 2002). The analysis team consisted of a clinical health psychologist specializing in melanoma (Hay), a behavioral scientist (Banerjee), and two research fellows (D'Agostino and Gordon). Each coding member read the same narrative independently, identifying important content and emerging themes (Miles & Huberman, 1994). Next, the entire team met to share their independent coding results and

collectively generated overarching themes that emerged. Higher order descriptive and interpretive themes were then generated to summarize key inductive findings. Finally, we used deductive coding and focused on categorizing our themes within the narrative structure (i.e., framing of events prediagnosis, framing of the diagnosis event, transition from receiving diagnosis to getting treatment, the treatment journey, and posttreatment phase). The project's qualitative framework prompted the use of group consensus building over statistical tests to ensure reliability.

Results

Data are organized according to the deductive categories. Next, inductive, emergent themes within melanoma survivor narratives are described, with frequencies (where applicable), illustrative quotes, and sex of the survivor to provide insight into melanoma survivors' written experiences; parenthetical numbers refer to the narrative identification (ID). We also analyzed gender differences in themes and have highlighted significant differences in narratives of male versus female survivors, wherever applicable.^{1,2}

We reached thematic saturation about midway along the analysis (Fusch & Ness, 2015), and added frequencies to the applicable categories to demonstrate reoccurrence of themes and subthemes. Figure 1 provides an overview of themes and subthemes across the following phases of the cancer journey: framing of events prediagnosis, framing of the diagnosis event, transition phase between diagnosis to beginning treatment, treatment phase, and posttreatment phase. Additionally, one theme, recognizing uncertainty, did not clearly fit into a narrative structure and cut across different phases of the cancer experience.

Framing of Events Prediagnosis

The description of events before diagnosis encompassed varied levels of detail, and recurring themes focused on four broad areas: (a) identification of self-phenotype, (b) searching for causes of melanoma, (c) suspicious findings that led to the visit with the dermatologist, and (d) delay in getting a diagnosis. Table 2 presents the themes and subthemes in framing of events prediagnosis.

Identification of Self-Phenotype

One-fifth of the melanoma survivor narratives included a description by the patient about his or her observable risk factors. A majority of those who reported their self-phenotype noted high-risk characteristics such as fair skin, blond or red hair, blue eyes, and freckles.

¹We ran chi-squared tests to test for differences in cancer narrative themes by gender, and found significant differences in 6 of 12 thematic categories (i.e., identification of self-phenotype, searching for causes of melanoma, suspicious findings, emotional responses, proactive cancer management, and social support). We present a descriptive account of gender-based differences in the article.

²In addition, we ran chi-squared analyses to examine themes by cancer stage (early versus advanced). Results indicated that emotional responses, proactive cancer management, and social support differed between early and advanced cancer stages. For emotional responses, the results indicated that a higher number of narratives from patients in the early stage of cancer (75%) included an emotional response as compared to narratives from patients in the advanced stage of cancer (42%). For proactive cancer management, the results indicated that a higher number of narratives from patients in the advanced stage of cancer (79%) included proactive cancer management information as compared to narratives from patients in the early stage of cancer (21%). Finally, for social support, the results indicated that a higher number of narratives from patients in the advanced stage of cancer (51%) included a description about social support as compared to narratives from patients in the early stage of cancer (13%). More details are available from the first author.

Alternatively, a handful of survivors noted that they had an atypical phenotype such as dark skin, dark hair, and no freckles or moles. Gender differences were evident, with identification of self-phenotype coming more frequently from female survivors (89.5%).

Searching for Causes of Melanoma

About one-third of survivors described behaviors that were likely contributors to the melanoma diagnosis (35%), with significant gender differences. Of the survivors who described searching for putative causes of the melanoma diagnosis, 82% were written by female survivors (82%). Although a history of sun exposure was noted quite frequently, it was mentioned in different contexts: survivors who did not expose themselves in a harmful way versus survivors who voluntarily exposed themselves to the sun without adequate sun protection.

In general, the incidence of getting a melanoma diagnosis when people did not engage in risky exposure was described as a shocking, surprising, or unexpected event, while the description of harmful sun exposure and inadequate sun protection was typically fraught with emotions such as guilt or regret. A few survivors also discussed their indoor tanning behavior as a possible cause of their disease. These descriptions—laden with expressions of guilt and regret—were often framed as cautionary tales for others who may feel invulnerable to melanoma.

Suspicious Findings That Led to Initial Visit

Sixty-five percent of the survivor narratives included a description of the event that initially led to a visit with a health care provider. In particular, the narratives clearly described the person who noticed the suspicious mole/lesion that prompted the survivor to make an appointment with their primary care physician (PCP) or dermatologist. In a majority of cases, the patients noticed the suspicious mole/lesion themselves, and included vivid descriptions of the changes in a preexisting mole, or appearance of new moles. Additionally, survivor narratives included detailed descriptions of a close friend/family member who noticed the suspicious mole/lesion. In many of these cases, the discovery of the mole was made incidentally (e.g., when taking off clothes or wearing a swimsuit). Finally, only a handful of cases described instances where the dermatologist or PCP noticed the suspicious mole/lesion and raised a concern. Additionally, there were significant gender differences evident in the description of the suspicious findings, and in naming the person who noticed the suspicious mole/lesion. Among narratives that included this description, 74% females and 26% males self-noticed the mole/lesion, 33% females and 67% males described a close friend/family member as the first person who noticed the mole/lesion, and 75% females and 25% males described instances where the dermatologist or PCP noticed the suspicious mole/lesion.

Delay in Diagnosis

A little less than one-third of survivor narratives included a description of delay in diagnosis (31%), with three prominent subthemes: patient procrastinated in seeing a physician, physician was unable to detect disease clinically and therefore did not order a diagnostic test (biopsy), or medical insurance-related issues caused a delay in making an appointment. There

were no gender differences evident in the description of delay in diagnosis. Survivors who blamed the delay on the physician noted their frustration and resentment, while those who procrastinated shared feelings of regret. A couple of survivors described the delay in going to the doctor, but at the same time they expressed gratitude to the person who insisted on the visit.

Framing of the Diagnosis Event

The survivor narratives included details around the diagnosis of melanoma, including naming the medical tests they underwent and health care providers they saw. Given the focus of this article on the melanoma survivors' cancer experience, two themes emerged around the framing of the diagnosis event: communication of diagnosis, and appraisal of the emotional response to diagnosis. Table 3 presents the themes and subthemes in framing of the diagnosis event.

Communication of Diagnosis

The communication of diagnosis to the patient included a clear identification of who delivered the test results (in 47% of all narratives), with no significant gender differences. In a little more than half of the instances, the dermatologist delivered the diagnosis of melanoma, followed by the PCP and surgeon. In a handful of melanoma survivor narratives, it was noted that the diagnosis was received from "someone in the doctor's office." Most of these conversations occurred over the phone (75%). In addition, during the coding process, we noticed that some instances of the communication of diagnosis included the use of forewarning or a warning shot (i.e., alerting the patient that difficult news is forthcoming) (Akunjee, Akunjee, Siddiqui, & Mallick, 2010).

A few melanoma survivor narratives also presented examples of good and poor communication skills from the health care providers and staff members, with specific references to words/phrases used by the oncologists and other health care providers. Good communication skills included managing patient emotions and validating patient concerns as appropriate. Poor communication included heightening the alert for the patient to a level that impeded their decision making, snubbing the questions, or dismissing patient anxiety all together by disengaging.

Appraisal of Emotional Responses Around Diagnosis

As expected, about half (54%) of melanoma survivor narratives include emotional responses that survivors experienced when receiving their diagnosis. There were significant gender differences evident in these descriptions with more female survivors (78%) describing their specific emotions. The emotional responses described by survivors can be grouped into six different, yet not mutually exclusive, categories: anxiety/ stress, devastation, fear, denial/ shock, sadness, and guilt/ regret.

Additionally, about one-third of the melanoma survivor narratives included a description of how the survivor evaluated the risk of the diagnosis and the words they used to characterize the disease. About 37% of survivors characterized melanoma as a "beast"/"monster," 22% as "it was not JUST skin cancer," 19% as a "death sentence," and 22% with miscellaneous

terms that held a negative connotation, such as “evil disease,” “aggressive disease,” or “tough illness.”

Transition Phase: Diagnosis to Beginning Treatment

Survivor narratives included descriptions about how the patients made sense of their melanoma diagnosis, and got ready to begin treatment. Primarily, survivors described seeking a second opinion to confirm the diagnosis, and presented their reasons for doing so. Table 3 presents themes and subthemes in transition from receiving treatment to beginning treatment.

Second Opinion

When people described seeking out a second opinion, they described doing so because they (a) wanted to find a specialist who had experience in treating patients with melanoma, (b) were unsure of the diagnosis that they first received from the physician, and/or (c) wanted to confirm the first diagnosis and treatment offered. However, not all of the second opinions were in agreement with the first, as was evident in some of the survivor narratives.

Some survivors described supplementing a doctor’s opinions and recommendations with Web-based research to learn more about melanoma. While Internet searches proved useful in educating those survivors who went online, some described reading both helpful and unhelpful materials on the Internet. One person also wrote about going to the library for reading about melanoma (as she was diagnosed in 1980, when access to online information, if any, was very limited). There were no gender differences evident in the description of second opinion.

The Treatment Phase

The treatment phase descriptions included a description of the treatment(s) received (which have not been described here for brevity purposes). The key themes that stood out in the treatment phase focused on melanoma survivors’ treatment-related coping (positive reframing of attitude, proactive cancer management) and description of side effects. Table 4 presents themes and subthemes in the treatment phase.

Positive Reframing of Attitude

Positive reframing of attitude refers to consciously thinking positive thoughts to refocus negative cognitions and feelings. In some way, all of the melanoma survivors who shared their narratives online engaged in positive reframing. However, three-quarters of the narratives described this process more explicitly. The subthemes evident in positive reframing of attitude included positive thinking, advocating for melanoma awareness, and turning to faith. Almost all the melanoma survivors who included an explicit description about positive reframing wrote about the strength of positivity, and keeping an optimistic attitude while they were undergoing treatment. About one-third of melanoma survivors described involvement in specific initiatives to increase melanoma awareness (e.g., writing in magazines, writing blogs, giving interviews, and/or raising money to support research) that helped them in positively reframing their attitude. Some of these survivors who wrote about advocacy mentioned specific steps they had already taken, while others expressed

desire to engage in advocacy. Some survivors also expressed support for states banning tanning beds for those under 18 years. Finally, about one-fourth of melanoma survivors described finding a positive outlook by turning to faith, and reaffirming their belief in God.

Proactive Cancer Management

Proactive cancer management was evident in specific steps that melanoma survivors took to manage the cancer and treatment. About half of melanoma survivors (50%) described how they took their cancer management in their own hands, including a description of behaviors they changed or introduced to manage their care, such as adopting a general proactive stance, searching for clinical trials, starting health maintenance behaviors (such as gentle exercise and healthy nutrition), and rejecting medication/treatment offered by their physician. Of the narratives that included a description of proactive cancer management, 69% were from male survivors.

A large number of melanoma survivors described implicit and explicit behaviors that they pursued to educate themselves or to gain a better understanding of the treatments available. An almost equally large number of melanoma survivors also described their active search for clinical trials and more information from the doctor to pursue and check for their eligibility to enroll into the available trials. Some melanoma survivors described the health maintenance behaviors they adopted, including gentle exercises (e.g., walking), changes in diet and nutrition, use of sun protection, and quitting tanning beds. Finally, some melanoma survivors described refusing medication that a physician offered due to a bad experience with the drug, or as a result of their Web-based research.

Side Effects

A little less than half of melanoma survivor narratives described side effects (44%) such as scarring, pain, fatigue, loss of appetite, fevers, and lymphedema. Survivors typically described multiple side effects, and in some instances described helpful strategies to manage the specific side effects. No significant gender differences were evident in the description of side effects.

Posttreatment Phase

A description of the posttreatment phase included social support available to melanoma survivors throughout the illness trajectory, and vigilance behaviors adopted after treatment. Table 5 presents themes and subthemes in the posttreatment phase.

Social Support

Social support was mentioned by a large number of melanoma survivors and was very important in helping survivors at each stage of their illness. More male survivor narratives (50%) as compared to female survivor narratives (27%) included an explicit description of the social support they received through their cancer journey. The social support offered was helpful not only for managing the cancer, but also for professional help, as described by one survivor. Three kinds of social support were most frequently mentioned: (a) spouse/partner, (b) friends/ family, and (c) online support. In some instances, one social support agent was exclusively mentioned, while in others cases, multiples social supports were noted. Overall,

a large number of survivors who mentioned social support described emotional and functional support from their friends/family. Spouses/partners were also frequently mentioned for social support. Some social support descriptions included expressions of gratitude to their respective partner, while some described growth in relationship, as was evident in a few cases when the support from survivors' romantic partners during the treatment led to marriage and a long-term commitment as the survivors moved from active treatment to surveillance phase. Finally, some survivors described online support as their avenue for seeking social support. Additionally, a large number of melanoma survivors expressed gratitude to the hospital/clinic and/or their doctor (91%). Typically, melanoma survivors noted specific names of the doctors, often as a means of expressing appreciation.

Vigilance Behaviors Posttreatment

Approximately half of all narratives had clear descriptions of vigilant behaviors (e.g., checking for new moles, seeing dermatologist regularly, use of sunscreen, general awareness of changes in body) that melanoma survivors adopted postdiagnosis and/or recommended to others (53%), with no clear differences in male versus female survivor narratives. It was evident in these narratives that experience of melanoma resulted in teachable moments, and motivated survivors to take better care of themselves and engage in more melanoma prevention behaviors to reduce the chances of the disease coming back. A few survivors also described how their melanoma experience led them to make family-level changes so that their loved ones also engaged in melanoma prevention behaviors.

Cross-Cutting Themes Across the Cancer Phases

Finally, there were two themes that were cross-cutting between the different phases of the cancer journey: recognizing uncertainty and motive for sharing narratives.

Recognizing Uncertainty

The time period between undergoing a diagnostic test and receiving results is rife with uncertainty and anxiety. In the melanoma survivor narratives, this period of uncertainty was highlighted for three different time periods: (a) between diagnostic test and receiving results, (b) while undergoing treatment (uncertainty about efficacy of a new drug used/clinical trial), and (c) the period after finishing treatment and getting the next positron emission tomography (PET) scan to assess the effectiveness of the treatment in shrinking tumor/eliminating cancer. No gender differences were noted in the recognition and description of uncertainty.

Motive for Sharing Narratives

Motive for sharing narratives was discernible in all of the melanoma survivor narratives analyzed, without significant gender differences. In some cases, the motive was shared explicitly (along with a motivational phrase to highlight the point; e.g., "Pale is the NEW beautiful," "Pale is the new tan," "Stage IV at age 47, but staying strong and positive"), while in some cases, the motive was implicit in the narrative, but not directly mentioned. Although it was possible to find multiple motives in a narrative, we focused on the most prominent motive (and have provided frequency of narratives).

The motives can be summed across the following categories: (a) seeking advice and support from others (22%; e.g., “If you have any advice how to help my recovery, and how to move forward it is all greatly appreciated”—Female, ID 020); (b) encouraging others to engage in preventive behaviors (21%; e.g., “I can’t stress enough to all my family and friends and even people I don’t know to use sun lotion, don’t use tanning beds, and to go and have your body checked regularly. Don’t feel uncomfortable because it can save your life”—Female, ID 032); (c) advocacy efforts in fighting/planning to fight for melanoma awareness at a larger level (13%; e.g., “I’m also going to fight for melanoma awareness on the national level. I’m going to let my voice be heard and get my story out. Melanoma has met its match and its going down!”—Female, ID 069); (d) motivating others to be persistent and proactive (12%; e.g., “So, if you have a spot that YOU think is weird ... get it checked out. Now. Don’t wait. Because really who knows your body better than you do”—Female, ID 037); (e) expressing gratitude for all the support (11%; e.g., “I have fallen into a deeper love with the people around me and feel so grateful for them. I have found strength, hope, a voice, and faith I never knew I was capable of having. I am thankful for everything, even this recovery period!”—Female, ID 016); (f) finding solace in faith for comfort and strength and asking for and offering prayers (8%; e.g., “I have learned that I can truly trust in God, and to draw closer to the people that love me the most ... God bless us all and give us strength and peace”—Female, ID 050); (g) for catharsis and writing to relieve emotions (7%; e.g., “Thank you! To this site for encouraging us to share our stories. It should be a standard therapy for all cancer patients. All the best for my fellow melanoma patients and their families. We are united by uncertainty, but we can help each other by sharing our experiences”—Female, ID 066); and (h) sharing optimism and positivity to deal with melanoma (6%; e.g., “Almost one year to the day of my surgery I got the melanoma ribbon tattooed on my leg with the quote, “one day, one breath, one step at a time.” It reminds me daily of just how strong I truly am”—Female, ID 021).

Discussion

This descriptive study presents a detailed account of melanoma survivors’ cancer journey through a narrative lens, albeit limited to online narratives and those who chose to report. From framing of events prediagnosis through treatment and posttreatment phases, this study highlights key themes and subthemes of melanoma survivors’ cancer experience. Survivors emphasized their experiences with receiving a diagnosis, enduring treatment and related medical care, and coping with various changes and forms of loss. Of particular importance, survivors expressed interest in sharing their narratives for a variety of reasons, frequently related to lessons they had learned through their illness trajectory and a desire to pass on their knowledge. Many survivors additionally expressed a strong desire to improve public awareness of melanoma and to draw attention to the difficulty, and often deadliness, of the disease. This motivation to give back to the society, improve public awareness, or even engage proactively in advocacy efforts is also evident in past research (e.g., Symes et al., 2016) and describes an opportunity for personal growth and psychological health through resilience (Benish-Weisman et al., 2014).

Utility of Cancer Survivor Narratives

Cancer survivor narratives can therefore serve multiple purposes, that is, be therapeutic for survivors while enhancing personal empowerment and self-esteem and reducing social isolation and distress; help to direct development of supportive models of care for other survivors; and be an educational tool for high-risk populations and encouraging preventive health behaviors. As Rowland (2008) notes:

We need to listen to what survivors are telling us about the problems they are experiencing, resources they need, the fears, concerns and expectations they have about the future, and how they prefer to work with their healthcare teams, other clinicians and researchers to improve not just their lives, but potentially those of future cancer survivors. The clinical research community knows that some of the best ideas about questions to pursue come from patients themselves, from our observations about how they fare. (p. 367)

Theories in social psychology are important to understand the utility of cancer survivor narratives and are briefly described in the rationale. Clearly, social cognitive theory (Bandura, 2001) and the transportation-imagery model (Green & Brock, 2000) can help describe the process of modeling and learning from others' experience, and help provide a process that leads to new behavior adoption (e.g., using sunscreen) or behavior change (e.g., avoiding sun or tanning beds); we did not examine that in the current study. Given that this study was based on an analysis of melanoma survivor narratives shared online by survivors (or in some instances, their loved ones), and did not focus on examining how these narratives can be useful for others reading them, we focus on the social cognitive model of restorative well-being (Foster & Fenlin, 2011) as a useful framework for interpreting our findings.

Theoretical Justification for Interpreting Findings

According to the restorative model, emotional well-being (and the process through which an individual normally maintains that sense of emotional well-being) may become disrupted through the experience of a challenging event such as a cancer diagnosis (Hoffman et al., 2013). While the problematic event for a patient confronting a cancer diagnosis may seem obvious, what is unique about the melanoma survivors' narratives analyzed in our study is that they portray how adapting to cancer is a longitudinal process that requires continually meeting the ongoing (and often unexpected) challenges that present throughout the illness trajectory. For example, it is clear that the specific experience of receiving a cancer diagnosis was traumatic for most melanoma survivors. More than half of the narratives included a description of the survivor's initial emotional response to receiving a diagnosis of cancer. However, in sharing their experience, survivors described additional challenges that they grappled with over time. This included treatment-related side effects, illness-related uncertainty, and preventive measures adopted to protect against recurrence. These findings are consistent with research demonstrating that melanoma patients face psychosocial difficulties at multiple phases of their illness, including at the time of diagnosis, through treatment, and persisting into survivorship (Tan, Butow, Boyle, Saw, & O'Reilly, 2014).

The restorative model also proposes that individuals engage in a cognitive appraisal of stressors, as well as an evaluation of whether or not they hold the coping resources needed to

manage the issue. Cognitive appraisal has been shown to be a strong predictor of adjustment among melanoma survivors (Hamana-Raz & Solomon, 2006; Kasparian, McLoone, & Butow, 2009). An appraisal of threat or danger was apparent in the narratives analyzed in the present study, particularly as evidenced by the words melanoma survivors used to describe their disease. Many survivors characterized their cancer as a “beast”/“monster” or a “death sentence,” or used other terms that signify an appraisal of melanoma as aggressive and life-threatening. Such appraisals suggest that melanoma was perceived by patients as being likely to have a significant impact on well-being.

Interestingly, melanoma survivors’ narratives highlighted many of the coping strategies and resources used in managing stressors. A distinction between problem-focused and emotion-focused coping is well established (e.g., Lazarus & Folkman, 1984), and our findings are consistent with this differentiation. For example, melanoma survivors were able to refocus negative thoughts and feelings using positive reframing strategies. Alternatively, melanoma survivors were also problem solvers, using proactive cancer management strategies like pursuing clinical trials and adopting health maintenance behaviors.

The act of sharing one’s cancer narrative online may also function as a coping strategy for melanoma survivors (Kim et al., 2010). Kim and Lee (2014) described two forms of communicative action used by participants of online networks such as blogs and discussion forums: information seeking (i.e., accessing/receiving information posted by others) and information forwarding (i.e., sharing/producing one’s opinions and experiences). These actions have differential effects on physical and affective outcomes (Kim & Lee, 2014). In this way, the information-forwarding action of sharing one’s narrative on the Internet may be considered a form of expressive writing and contribute to biopsychosocial well-being (Pennebaker, 2004; Stanton et al., 2000). The fact that more than half of survivors’ narratives included a description of their emotional response to receiving a diagnosis of melanoma supports this point. The motives for sharing that were coded from the content of narratives also suggest that melanoma survivors seek to connect with others by posting their experiences online. This process likely enhances social support for these patients (Kim & Gillham, 2013).

Limitations of the Study

There are limitations to our current work. The study analyzed online narratives from melanoma survivors (or their loved ones), and thus generalizability to all melanoma survivors is limited. Prior research suggests that not all patients share their cancer experience online, and there are key characteristic differences in those who share versus those who don’t (Eddens et al., 2009), for example, disproportionate absence of older adults and minority survivors. Next, most of the narratives (except two) were shared by White melanoma survivors, and only two narratives were shared by minority survivors. It is important for Black, Asian, and Hispanic melanoma survivors to read/listen to experience of other survivors that are similar to them; therefore, it is important to encourage minority melanoma survivors to share their experiences online. This is challenging, given the low numbers of minority melanoma survivors. However, it is especially important because of the increasing impact of melanoma among U.S. Hispanics, where melanoma is affecting this

most rapidly growing demographic group at disproportionately higher rates and with more advanced disease than the general population (Rouhani et al., 2010).

Next, given the enormity of themes and subthemes that emerged from this data, we limited our analyses to the narratives only and did not analyze the comments and dialogue that existed between online users and person who wrote the narratives. Describing ways in which melanoma survivor narratives can influence participation from other cancer survivors in sharing personal information and information seeking could be explored in future research. Additionally, we did not stratify the narratives by stage of cancer or current treatment status, which may lead to different themes and subthemes highlighted in cancer survivor narratives. We did examine gender differences, and found some significant differences in themes that emerged. Understanding key issues for different melanoma survivors can be helpful in developing supportive models of care that are unique to the survivors' context and provide a more tailored approach to treating the patient.

Implications of the Study

There are several implications of the study. First, this study describes an empirical way of harnessing cancer survivor narratives shared online to describe key themes and motives discussed. Recent research suggests that the Internet and social media serve as an important source of accurate health information about skin cancer, especially for the young adult population (Hay, Coups, Ford, & DiBonaventura, 2009). Although we employed convenience sampling to gather melanoma survivor narratives, a method of triangulation could be employed and thematic similarities and differences can be assessed by analyzing online narratives, conducting narrative interviews with melanoma survivors, and conducting a systematic review of literature about psychosocial issues of melanoma patients and survivors. Second, this study has implications for public health researchers to harness the patient voice and the power of storytelling for developing campaigns about public awareness of melanoma risk, providing information and support to melanoma patients, and encouraging melanoma prevention behaviors (Chou et al., 2011). Despite expressed interest in providing personal narratives, and some theoretical support for this approach in improving behavioral outcomes among healthy individuals, little work has been done to elucidate its efficacy regarding skin cancer and sun protection behaviors. Future directions could make use of the themes present in these narratives to determine the usefulness of various personal narratives in the context of sun protection and skin cancer prevention. Finally, this study provides guidance for conducting twofold research to understand the benefits of sharing personal cancer experience for cancer survivors themselves, as well as the benefits of reading others' cancer survivor narratives for coping and behavior change among those going through different phases of melanoma disease and treatment journey.

Conclusion

This study presents a qualitative study of melanoma survivor narratives shared online. The results of the study provide a deeper understanding of themes relevant in different phases of melanoma journey, from pretreatment phase to treatment phase and posttreatment phase. This study presents immense potential to inform melanoma prevention health

communication campaigns and interventions, and to help inform supportive models of care for other melanoma survivors.

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Figure 1.
Phases of the diagnosis and treatment trajectory: Major findings.

Table 1

Descriptive characteristics of melanoma survivors from online narratives.

Melanoma survivor characteristic	Frequency (%)
Sex	
Female	63 (66.3%)
Male	32 (33.7%)
Age (years, <i>M, SD</i>)	35.39, 14.26
Race	
White	73 (76.8%)
Black	2 (2.1%)
Undisclosed/unable to discern	20 (21.1%)
Type of melanoma	
Melanoma (unspecified)	87 (91.6%)
Ocular melanoma	5 (5.3%)
Anal/rectal melanoma	2 (2.1%)
Nodal melanoma	1 (1%)
Stage of disease	
Early stage	24 (25.3%)
Advanced stage	53 (55.8%)
Unspecified stage of disease	18 (18.9%)
Stage of current disease status	
Completed treatment/no evidence of disease	42 (44.2%)
Under treatment	33 (34.8%)
Follow-up/surveillance	8 (8.4%)
Enrolled in clinical trials	6 (6.3%)
Waiting for test results	4 (4.2%)
Passed away	2 (2.1%)

Table 2

Themes and subthemes in melanoma survivor narratives at prediagnosis phase.

Themes and subthemes (%)	Definition	Examples of supporting quotes
Framing of events prediagnosis		
<i>1. Identification of self-phenotype: Self-identification by the patient about his/her observable risk factors (20%)</i>		
1a. Typical high-risk phenotype (84%)	Visibly identifiable risk factors for melanoma that include nevi and pigmentation indicative of a sun-sensitive phenotype such as fair skin, red or blonde hair, and blue or green eye color.	<p>"I am a blonde-haired, blue-eyed, pale, Irish/German girl. Which means that I have a lot of moles and freckles and red spots on my skin." (Female, ID 006)</p> <p>"I am the stereotype for skin cancer: very blonde hair, pale skin, blue eyes, freckles, and a history of sunburn, that, nowadays, makes me cringe." (Male, ID 39)</p>
1b. Atypical phenotype (16%)	Visibly identifiable factors that are indicative of low melanoma risk such as no moles, and dark skin.	<p>"I am Afro-Caribbean so we believe that black people are less susceptible to UV damage as compared to lighter skinned counterparts." (Female, ID 9)</p> <p>"Our Italian skin was a good enough base (or so we thought)." (Female, ID 92)</p>
<i>2. Searching for causes of melanoma: Potential behavioral factors that caused melanoma (35%)</i>		
2a. Sun exposure (49%)	Voluntary exposure to UV radiation from the sun and inadequate sunscreen use.	<p>"I grew up in a dairy farm in NE Iowa. The responsibilities of a family farm meant we didn't travel, unless it was a Sunday afternoon day trip. My summer vacations entailed picking rock and stacking bales in the barn. I admit I was young and dumb when it came to sun protection. I rarely used sunscreen. I would go out in the field in a tank top and shorts. I had numerous sunburns. I remember having trouble sleeping some nights due to painful sunburns." (Female, ID 25)</p> <p>"I have always been very active outdoors. I played sports, specifically soccer, all throughout grade school, high school, and college. This meant camps and tournaments where we would be outside in the sun all day, without shade, several days a week. I also worked as a landscaper during my summer breaks in college. I NEVER wore sunscreen when I played sports, and I NEVER wore sunscreen when I was working outside. I would let my arms, face, neck, and legs get burned until it would eventually tan. I just thought it was unavoidable. I wasn't going to quit working outside or playing sports!" (Male, ID 039)</p>
2b. Indoor tanning (30%)	Voluntary exposure to ultraviolet (UV) radiation from a tanning bed, booth, or sunlamp to get a tan.	<p>"As I got older, I discovered the tanning bed. At first, I just tanned before a dance or vacation. But then I tanned during the winter, I was addicted." (Female, ID 028)</p> <p>"As I got older, I fell in love with tanning beds and I even worked at a salon that had multiple stand up and lay down beds. I was in heaven because I could tan after every shift. I was told if you didn't burn you would be safe. Well, if we only knew then what we know now, right?" (Female, ID 037)</p>
2c. No sun exposure (21%)	Patient kept away from sun, but still got a melanoma diagnosis.	<p>"I have always been a very outdoorsy person—hunting, fishing, hiking, camping—but I have never worshipped the sun like my sisters. Actually, I used to hide from the sun, so finding out I had melanoma was an incredible shock to me!" (Female, ID 006)</p> <p>"I wasn't a sun worshipper or had many blistering sunburns as a child..." (Female, ID 62)</p>
<i>3. Suspicious findings: Description of the event that led to the visit with the health care provider (65%)</i>		
3a. Self noticed (74%)	Patients noticed the suspicious mole/lesion themselves.	<p>"I noticed a color change in a mole I had on my collar bone area on my chest. The mole I had all my life and was about 1/8 inch in diameter. It was changing from brown to having black flecks or streaks in it (not full blown black)." (Male, ID 003)</p> <p>"One of my many moles started to change. It was on my right ear. It was getting bigger and darker. I didn't think a lot of it until I woke up one morning with blood in my hair. I realized the mole had burst and bled overnight." (Female, ID 41)</p>
3b. Noticed by a loved one (19%)	Close friend/family member noticed the suspicious mole/lesion.	<p>"My mole was never elevated, matter of fact, I was never aware I had this mole until friends told me I had one. Actually being able to feel this mole on that day had me concerned. It also itched quite a bit and had been for few weeks but I was never that aware of the change till I</p>

Themes and subthemes (%)	Definition	Examples of supporting quotes
Framing of events prediagnosis		
		asked someone to check out my neck since I felt there was a bug there. It was an elevated mole." (Female, ID 009) "I was outside doing yard work with my shirt off when my girlfriend at the time noticed a strange mole on my side. It looked as if it had a zit growing in the middle of it. Kind of a nasty looking thing." (Male, ID 26)
3c. Physician noticed (7%)	Dermatologist or primary care physician (PCP) noticed the suspicious mole/lesion.	"I visited my dermatologist for a routine skin exam ... At this visit, he spotted a mole on my leg that looked suspicious, but it was still round and wasn't very big so he didn't think I should be overly concerned, thinking it might be a spitz nevus or a type of pre-skin cancer that could easily be taken care of." (Female, ID 49)
<i>4. Delay in diagnosis: Description of events and/or reasons that caused a delay in getting the melanoma diagnosis (31%)</i>		
4a. Patient-related (55%)	Patient procrastinated in seeing a physician.	"In Nov 2014 I went to see my family doctor while I was traveling in Cleveland. He told me to see a Dermatologist. I had a lot going on at that time and was moving in Feb 2015 so I put off the dermatologist (first off I found out how much of a mistake procrastinating was)." (Male, ID 003) "I knew I should get it checked out, but just couldn't seem to find the time and kept pushing it off for weeks. After all, it wasn't bothering me and I couldn't remember if it had always looked that way and perhaps it just looked more dramatic contrasted against the white hair. Flash forward to May 2014, I finally asked for a referral from my primary doctor to see a dermatologist regarding the 'mole.' But, of course I was too busy and just couldn't fit it into my schedule so I put it off even longer." (Male, ID 017)
4b. Physician-related (38%)	Physician unable to detect disease clinically so did not order a diagnostic test (biopsy).	"10 years ago I saw a dermatologist and showed her a mole on my chest. She says it's nothing. Therefore, 6 months later, I decided to see another dermatologist because I do skin care and I did not like that mole. It was a Stage II melanoma. If the first dermatologist would have known that, it would have been nothing or Stage 0." (Female, ID 013) "I had what I had thought was an age spot and had developed a new freckle on my nose. The dermatologist removed them but unfortunately did not send them off to pathology. I assumed all was well." (Female, ID 028)
4c. Insurance-related (7%)	Medical insurance-related issues caused a delay in making an appointment to see a physician.	"My network is so small, that it was hard to find a dermatologist first off, and then I tried to get into U of M melanoma clinic which my insurance was out of network. I know that money should be the least of concerns, but when you are faced with costly treatment, you guess again." (Female, ID 007) "Family members kept telling me to go get it checked because it was still growing, but I didn't have health insurance so I ignored them." y(Female, ID 021)

Table 3

Themes and subthemes in melanoma survivor narratives at diagnosis and transition phases.

Themes and subthemes	Definition	Examples of supporting quotes
Framing of the diagnosis event		
<i>1. Communicator of diagnosis: Description of the key person who communicated the diagnosis of melanoma (47%)</i>		
1a. Dermatologist (51%)	Dermatologist communicated the news of melanoma diagnosis.	“In 2 days, he (dermatologist) called me to tell me I had cancer and wanted me to come and see him the same day.” (Male, ID 003) “However, 6 days later, the dermatologist called me and said that I had malignant melanoma.” (Female, ID 006)
1b. PCP/Physician (22%)	Physician communicated the news of melanoma diagnosis.	“My doctor came into the exam room. ‘I have some bad news,’ he said. ‘That mole I removed was a melanoma. I am going to refer you to the surgical oncologist.’” (Male, ID 010) “The doctor called me two days after the operation and said that the initial pathology report showed that it was malignant melanoma.” (Female, ID 063)
1c. Surgeon (18%)	Surgeon communicated the news of melanoma diagnosis.	“So I went to a plastic surgeon and had it removed again. I got called back for results and was told it was pre-melanoma.” (Female, ID 035) “The surgeon examined me, which was extremely uncomfortable, and said ‘we need to stage this and get the histology ASAP.’ I said, you’re saying this is cancer?” (Female, ID 047)
1d. Someone in the doctor’s office (9%)	Someone in the doctor’s/ dermatologist’s office communicated the news of melanoma diagnosis.	“Took over a week to get a call from doctors office telling me I had Clark’s Level 2 melanoma and have to see a plastic surgeon.” (Female, ID 015) “However, on Wednesday, May 28, Ben received a call from the dermatologist’s office informing him that his mole was actually a ‘Malignant Melanoma.’” (Male, ID 023)
<i>2. Emotional responses: Description of emotional responses to receiving the diagnosis (54%)^a</i>		
2a. Anxiety/stress (41%)	Survivor described anxiety/stress at diagnosis.	“The ENT dr sent me off to get a neck CT because he felt a lump in my neck. Yes my stomach dropped.” (Male, ID 003) “At first the news was sickening. My blood pressure was 180 over 130 as I had not been able to sleep for days.” (Male, ID 024)
2b. Devastation (30%)	Survivor described devastation at diagnosis.	“I was distraught because I felt I was only 22 with skin cancer.” (Female, ID 009) “The call came when I was home alone, and was one of the most devastating experiences of my life. Unable to breathe, I laid on the floor shrieking in disbelief when panic crept up my spine. Although it only took 15 minutes for my family to arrive, it felt like the longest wait of my life.” (Female, ID 073)
2c. Fear (30%)	Survivor described fear at diagnosis.	“I was TERRIFIED. I called my family members crying, none of them could believe it.” (Female, ID 034) “As you can probably imagine, my heart felt like it was going to explode out of my chest and it felt like I had a brick in my stomach. I had never been so scared in my life.” (Male, ID 039)
2d. Denial/shock (24%)	Survivor described denial/shock at diagnosis.	“The news hit me like a ton of bricks.” (Female, ID 016) “I had never heard of this, and was shocked to learn how rare and aggressive it is” (Female, ID 047)
2e. Sadness (11%)	Survivor described sadness (and in some instances, hopelessness) at diagnosis.	“It’s ok sometimes that’s all you can do ... cry ... and then call a friend and cry and then hopefully you can laugh until you cry some more.” (Female, ID 016) “I was so sad and upset that this was happening again” (Female, ID 035)
2f. Guilt/regret (4%)	Survivor described guilt/regret at diagnosis.	“A stream of tears fell from my face and I almost collapsed. The guilt I felt was instant.” (Female, ID 069) “I admit I didn’t know that melanoma could kill you. I admit I didn’t know much about melanoma and thought if I got skin cancer it wouldn’t be so bad. They would just cut it off and I would go on with life. I was so wrong.” (Female, ID 083)
Transition from receiving diagnosis to beginning treatment		
<i>1. Second opinion: Description of reasons for seeking a second opinion to confirm the diagnosis (14%)</i>		
1a. Seeking a specialist (54%)	Patients wanted to find a physician who specialized in melanoma	“I went to see the local oncologist, who with consultation from Mayo Clinic, recommended I have a complete lymph node dissection of the left groin area. At this point, I knew I had to find someone that specialized in melanoma. I did a lot of research on melanoma clinics and was intrigued by MD Anderson in TX. I was able to self refer myself to MD Anderson and within five days I was on my way to Houston, TX.” (Male, ID 022)

Themes and subthemes	Definition	Examples of supporting quotes
Framing of the diagnosis event		
1b. Unsure (23%)	Patients were unsure of the diagnosis that they first received from the physician.	<p>“We got a second opinion from Dr. Stephen Trocha who is a surgical oncologist who specializes in melanoma, here at GHS Cancer Center of the Carolinas. He pretty much backed everything up that we had been told, but both Ben and I felt 100% more comfortable with a specialist doing the work.” (Male, ID 023)</p> <p>“I asked my PCP to look at this suspicious mole. My PCP said it was nothing to worry about and it was just a nevus on top of a mole. I wasn’t real happy with this response, so I decided to get a second opinion.” (Female, ID 006)</p> <p>“10 years ago I saw a dermatologist and showed her a mole on my chest. She says it’s nothing. Therefore, 6 months later I decided to see another dermatologist because I do skin care and I did not like that mole.” (Female, ID 013)</p>
1c. Confirmation (23%)	Patients wanted to confirm the first diagnosis and treatment offered.	<p>“A second opinion confirmed the first as it was the standard of care.” (Male, ID 043)</p> <p>“I sought out second opinion with Dr. Zubin Bamboat at HUMC.” (Female, ID 047)</p>

^aNot a mutually exclusive category. Multiple emotions were noted in the survivor narratives.

Table 4

Themes and subthemes in melanoma survivor narratives at treatment phase.

Themes and subthemes	Definition	Examples of supporting quotes
The treatment phase		
<i>1. Positive reframing of attitude: Consciously thinking positive thoughts to refocus the negative thoughts and feelings (75%)^a</i>		
1a. Positive thinking (96%)	Forcing oneself to think positively, and keep an optimistic outlook.	<p>“While I would not wish this on anyone, I can say that it has been a weird blessing in disguise. I’m not even sure how to describe, it maybe it’s a wake up call, a change of perspective, a real kick in the ass, or simply it’s life changing. I find myself hugging my boys tighter and longer before dropping them off at school and I whisper a small prayer for them as they walk in.” (Female, ID 016)</p> <p>“Everything went cloudy as we starting making appointments with surgeons and calling family members! The next morning I woke up just as the sun was rising. When I opened my eyes the sun’s rays were shining on me and at that moment I knew I was going to be OK.” (Female, ID 021)</p>
1b. Advocating for melanoma awareness (30%)	Taken up advocacy for melanoma awareness through a large number of initiatives, such as writing in magazines, writing blogs, giving interviews, and/or raising money to support research.	<p>“And all I can say is I am a huge advocate for states banning tanning beds for those under 18, because at that age, you just can’t comprehend what you are possibly doing to your body.” (Female, ID 033)</p> <p>“I now participate in walks when I can and I have a blog and Facebook page dedicated to melanoma. I also did my first of many, TV interviews this month for melanoma awareness month! I will always educate on the dangers of tanning.” (Female, ID 083)</p>
1c. Turning to faith (23%)	Finding a positive outlook by turning to faith, and keeping their belief in God.	<p>“Talk about some extreme praying and meditation happening. It may sound strange, but I felt God wanting me to fast at this time as well. So, I began fasting and continued to pray like I’ve never prayed before. I made the calls to my family and friends and asked for support through thoughts and prayers.” (Male, ID 026)</p> <p>“One thing I can say through all this is that the majority of my strength is coming from the big man upstairs. I asked Father Grimes one day if God gives you as much as you can handle, why me ... Has he forgotten how much he’s already given me? He answered with a big smile and said to me ‘God doesn’t give it to you.’ My problem is, I was losing trust in Him. From that day forward, I know I am not in this alone. God will continue to protect me and keep me strong.” (Female, ID 092)</p>
<i>2. Proactive cancer management: Patients taking their cancer management in their own hands, including a description of behaviors they changed or introduced to manage their care (50%)^a</i>		
2a. General proactive stance (64%)	Taking their decisions and cancer care in their own hands.	<p>“I immediately went online and did some research. I should add that I am a nurse and very well educated and I know how to navigate around all the bullsh*t on the internet and find the actual appropriate facts.” (Female, ID 006)</p> <p>“I had done some research on MPIP and found that with my Breslow depth, 2.34 and Clarks Level 4, there was a necessity for follow-up and I should NOT have had a wide excision before I had a Sentinel Lymph Node biopsy.” (Female, ID 045)</p>
2a. Clinical trials (43%)	Active search for clinical trials and seeking more information from the doctor to pursue and check for their eligibility.	<p>“All along, I was doing research for clinical studies. I had one in mind (NCT02388906) that offered either Yervoy or Opdivo in a blind study for patients that where stage IIIB and had a full lymph node dissection. That was me in a nut shell.” (Male, ID 003)</p> <p>“I had my melanoma tested for the BRAF mutation and got the news on May 30 that I do have the BRAF mutation. I will be looking into a clinical trial for Stage IIIa that is being done in Portland, Oregon, about 130 miles from my home. We will see if that is possible and to work out the travel details and how often I would need to be there.” (Male, ID 036)</p>
2b. Starting health maintenance behaviors (23%)	Description of survivor-adopted health maintenance behaviors, including beginning gentle exercises (such as walking), change in	<p>“I’m still scared to spend time out in the sun. I wear hats and use an umbrella and now I use sunscreen like cream.” (Female, ID 009)</p> <p>“With the nutritionist’s help in June learned a fairly good diet... Lots of fresh fruits and vegetables and for me lean meats like sirloin steak. Lots of juice, milk and water.” (Male, ID 056)</p>

Themes and subthemes	Definition	Examples of supporting quotes
The treatment phase		
	diet and nutrition to improve health, and others.	
2c. Rejecting medication (19%)	Patient refused medication that the physician offered due to an initial bad experience with the drug, or as an outcome of their own research online.	I “I tried one dose of Sylatron, and it made me so sick that my wife and I agreed that it wasn’t worth it. So, I told my oncologist we would continue with monitoring, and forget about interferon.” (Male, ID 008) “Our next step is to decide whether or not to pursue treatment, and if so, what that looks like for our family. With such modest statistical benefits of interferon, we are leaning towards the ‘watch and wait’ approach.” (Male, ID 023)
<i>3. Side effects: Side effects described by the survivor (44%)^a</i>		
3a. Scarring (29%)	Side effect of scarring or disfigurement, typically after surgery.	“I was a bit shocked when I removed the dressing and took a shower for the first time (3 days post-op). I had a fairly large chunk missing from my leg. I looked like a baby shark bite!” (Female, ID 006) “The first time I took a shower and took off the bandages and saw the damage it had caused I cried ... a lot.” (Female, ID 016)
3b. Pain (24%)	Side effect of pain, typically after surgery.	“I went home and rested and took a lot of Norco. I was in a lot of pain ... like A LOT!” (Female, ID 006) “... though surviving burning pain on the underside in my arm.” (Female, ID 011)
3c. Fatigue (14%)	Side effect of fatigue or loss of energy.	“The worst was the constant fatigue/hangover feeling and lack of any type of energy.” (Female, ID 086) “... which leaves you very exhausted.” (Female, ID 092)
3d. Loss of appetite (14%)	Side effect of loss of appetite or nausea.	“My biggest problem was nausea, so finally found pepcid twice a day.” (Female, ID 002) “... and my appetite has waned. Actually, that’s not quite true. I still have a decent appetite, but almost everything I eat makes me feel very sick, with crampy abdominal pain.” (Male, ID 010)
3e. Fevers (14%)	Side effect of fevers after treatment.	“It was a long 5 weeks with high fevers, and two ER visits.” (Female, ID 021) “I’ve also been running a low grade fever up to 100.5 at times and have been extremely fatigued lately.” (Male, ID 022)
3f. Lymphedema (12%)	Side effect of swelling or lymphedema after treatment.	“I’ve noticed lymphedema in my neck and near my cheek but I’ve been trying to massage it away.” (Male, ID 017) “I believe I am developing lymphedema from one of the two nodes as the sutures have begun to leak a clear yellowish fluid.” (Male, ID 071)
3 g. Miscellaneous (26%)	Other side effects like diarrhea, vision problems, general uneasiness, etc.	“My eye sight in my right eye is okay, still have double vision in my right peripheral area and some blurriness and my pupil is still very dilated and light sensitive.” (Female, ID 001) “... the radiation brought on menopause, which assisted in hair loss issues!” (Female, ID 046)

^a Not a mutually exclusive category. Multiple responses were noted in the survivor narratives.

Table 5

Themes and subthemes in Melanoma Survivor Narratives at posttreatment phase.

Themes and subthemes	Definition	Examples of supporting quotes
Posttreatment phase		
<i>1. Social support: Expressions of gratitude for different forms of social support (35%)^a</i>		
1a. Friends/family (73%)	Support from friends/family.	“I wanted to give up once but my mom was an amazing support system and helped me to stay strong even when I was weak.” (Female, ID 021) “The support of friends and family has been overwhelming and truly lifting me up.” (Female, ID 053)
1b. Spouse/partner (46%)	Support from spouse/romantic partner.	“After this fiasco, I decided, This woman (my girlfriend) is part of the reason I’m still alive’ and decided to buy a ring as I knew at this point I wanted to spend the rest of my life with her. That woman is now my wife. Not only did she find the melanoma just in time, but she stuck with me, knowing that it could’ve ended up worse and she could have lost me.” (Male, ID 026) “I have a wonderful fiancé, who, without him, I would be going crazy. He is my rock.” (Female, ID 031)
1c. Online support (18%)	Support from online forums.	“This forum has been such a wonderful resource for me. I admire all the stories of others on here and appreciate the good, bad, and everything in between stories.” (Male, ID 017) “Thank God for the Internet! It must have been horrible before the Web for patients to try and understand what they were up against. I would love to hear from people that are aware of clinical studies for IIIa.” (Male, ID 071)
<i>2. Vigilance behaviors posttreatment: Descriptions of vigilant behaviors that melanoma survivors adopted postdiagnosis and/or recommended to others (53%)</i>		
2a. Vigilance behaviors for self (85%)	Vigilance behaviors adopted to catch any recurrence early.	“We see the oncologist and dermatologist once a year and are vigilant about checking for lumps and bumps.” (Female, ID 008) “Since then, I cover up and use sunscreen. I’ve had numerous moles removed through the years. On mole on my back I had removed a few years ago was precancerous. I now see a dermatologist annually.” (Female, ID 025)
2b. Vigilance behaviors for others (15%)	Vigilance behaviors for other loved ones.	“I’ve been married for 16 years and we have three girls. I’m proud to say my daughters have never had a sunburn.” (Female, ID 025) “Obviously if you are reading this or someone you know has had melanoma, so please for my father spread awareness ... get yourself and your family and friends checked.” (Female, ID 082)

^aNot a mutually exclusive category. Multiple responses were noted in the survivor narratives.