Published in final edited form as:

Psychooncology. 2013 January ; 22(1): 106–116. doi:10.1002/pon.2059.

Melanoma survivors: health behaviors, surveillance, psychosocial factors, and family concerns

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Abstract

Background—Little research has been conducted on melanoma survivors and important opportunities exist for research in this understudied population. The study objective was to examine experiences of melanoma survivors regarding sun protection, surveillance practices, psychosocial and family concerns using focus groups.

Methods—We identified patients (> 18 years) treated at Memorial Sloan-Kettering Cancer Center (USA) during 1996–2005 with invasive primary cutaneous melanoma, stages I–III. We stratified focus groups by age (<50 vs ≥ 50 years) and years since diagnosis (1 to <5 years vs ≥ 5–10 years). We performed qualitative thematic text analysis, which involved independent data review by multiple analysts ($n = 2$) followed by interpretation of key findings via consensus work.

Results—Forty-eight survivors composed the final sample. Most did not conduct routine skin self-examinations. Survivors became more conscious of sun exposure and expanded their sun protection; some experienced anxiety if caught unprotected in the sun. Survivors were aware of the increased melanoma risk for family members, yet many did not discuss risk reduction. Melanoma diagnosis elevated the importance of retaining health insurance and purchasing life insurance for younger survivors. We did not identify significance difference between those diagnosed more or less recently.

Conclusions—We identified areas of high priority to melanoma survivors: skin self-examination, anxiety associated with sun exposure, familial risk communication, and maintaining health insurance benefits. The implications for cancer survivors are that these behavioral data will help to design health promotion and prevention programs that are tailored to melanoma survivors' risk status.

Keywords

melanoma; survivors; health behaviors; surveillance; psychosocial factors; family concerns

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Introduction

Melanoma, the most fatal form of skin cancer, constitutes a modern cancer epidemic with rapidly rising incidence and mortality rates [1–3]. These rising rates account for the greatest increases during the past decade among all preventable cancers [1]. An estimated 68,130 people in the USA were diagnosed with melanoma in 2010 with 8700 associated deaths [4]. The recent National Cancer Institute (Surveillance, Epidemiology and End Results (SEER)) Program data show steadily increasing mortality rates for melanoma, particularly in middle-aged and older men [5].

There are an estimated 758,688 melanoma survivors based on SEER data, a number that will likely rise because of the young age at diagnosis, increased screening efforts, and improved survival with early detection and treatment [5]. Younger adults are disproportionately affected by melanoma; the median age at diagnosis is 59 years, according to the 2002–2006 SEER data [5]. Thus, these patients represent a significant group of adult cancer survivors that are still in the work force and likely to have relatively young children. Melanoma is the most common cancer in young adults and, in terms of years of potential life lost, is second only to adult leukemia [6–9].

Both genetic and environmental factors have been implicated in melanoma causation, although it is difficult to separate out these causal factors [10,11]. Family clustering of a disease suggests heritable causes but environmental factors may also play a role. In pooled analyses of existing studies, family history has been shown to be a risk for developing melanoma [12,13]. In a more recent study, Olsen *et al.* used epidemiologic evidence to estimate the fraction of melanomas attributable to a positive family history [14]. Results suggest that only a small percentage, less than 7%, are attributable to familial risk, suggesting environment and gene-environment interactions make significant contributions to the overall burden of disease.

In few studies, behavioral risk factors have been explored in melanoma survivor cohorts, and results suggest that this group is less likely to use sun protection and practice skin self-examination than survivors of breast or colon cancer and that the prevalence of these behaviors is low [15–17]. Melanoma survivors appear to have higher than average perceptions of their melanoma risk [18], and sun protection, sun awareness and, examination of moles were more common after a melanoma diagnosis [19,20]. Further, doctors' recommendations to increase preventive behavior were associated with increased preventive behavior in melanoma survivors [21]. In one study, skin cancer survivors of melanoma and non-melanoma were more physically active than people without a history of cancer [22].

In studies of psychosocial outcomes, melanoma survivors fared better than survivors of other types of cancer and the general population [23–25]; the quality of life was lowest immediately after treatment [26]. Also, doctor–patient communication was correlated with the melanoma survivors' emotional and social functioning [25]. The impact of melanoma on quality of life was more substantial for women compared with men [27], and melanoma survivors who met lifestyle recommendations based on physical activity, diet, and smoking report higher quality of life than those who had not met these recommendations [28].

Melanoma survivors continue to use coping strategies to deal with their cancer many years after diagnosis [29].

More knowledge is needed about the experiences of melanoma survivors regarding surveillance, psychosocial and family concerns; we conducted focus groups to inform future intervention studies targeting this growing population.

Materials and methods

Focus group participants

We identified patients (≥ 18 years of age) diagnosed with invasive primary cutaneous melanoma, stages I–III, and 1–10 years since diagnosis who were treated at Memorial Sloan-Kettering Cancer Center (USA) during 1996–2005. If patients had prior malignancies, they were ineligible to participate. Patients were not excluded if they had received more than one melanoma diagnosis. In our cohort, there were eight (16.7%) participants who had received more than one melanoma primary diagnosis.

We limited this study population to English-speaking patients not currently receiving treatment and who lived within a 2-h distance of the center so that they could easily travel to participate in the focus groups. We selected a random sample of eligible participants, using random number generation and ordering with a stratified sampling approach: age (<50 vs 50 years) and years since diagnosis (1 to <5 yrs vs 5–10 years).

The sampling schema is presented in Figure 1. Patients were contacted by telephone and recruited for participation in the study.

Focus group content and procedures

In total, eight focus groups were conducted during 2007–2008 with two focus groups in each stratified sample of melanoma survivors, as shown in Figure 1. All focus groups explored the same set of topics regarding the impact of melanoma diagnosis on sun protection and skin surveillance practices and overall impact on quality of life, family relationships, and economic and psychological concerns (Table 1). Specific questions used for each content area can be provided upon request.

Specifically, the domain and content areas were determined on the basis of their relevance to melanoma survivors and the paucity of literature available. Understanding recurrence and second primary cancer risk, cognitive characteristics, behaviors, surveillance patterns, economic sequelae, and family issues of melanoma survivors is imperative from a public health standpoint to promote the health of these survivors. Melanoma survivors may experience declines in functional status and quality of life, acceleration of age-related changes, and co-morbidities related to treatment. Melanoma patients are at risk of developing recurrences, second primary tumors, and other cancers. There has been virtually no research on survivors' knowledge and awareness of melanoma risk factors, skin self-examination, and sun protection practices, nor are there any data on physicians' counseling regarding follow-up care and patients' adherence with recommendations. Important

cognitive factors are likely to influence health behaviors, surveillance patterns, and family issues related to cancer survivorship.

A qualitative methods specialist trained in focus group moderation conducted all focus groups, and the discussions were audio recorded and transcribed for later analysis. Additionally, the moderator and a note taker present at all focus groups debriefed following each focus group to identify emerging themes from the discussions.

Focus group participants received a \$50 incentive for their time and costs associated with travel. The study was approved by the Institutional Review Board or privacy board at the center, and an informed consent was signed by each participant.

Data analysis

The study comprised a total of eight focus group transcripts. We performed standard procedures of qualitative thematic text analysis to analyze the focus group data, which involved a rigorous review and interpretation of the focus group transcripts [30]. Our analysis process included five phases. In Phase One, a team consisting of a study psychologist, qualitative methods specialist, and research study assistant read the focus group transcripts—two transcripts at a time from a given focus group sub-sample—highlighted content that was interesting, novel, or important to the goals of the research study and noted their reflections about salient content in the margins of the transcripts, a process known as margin coding [31]. In Phase Two, after each team member read and completed margin coding of two transcripts of a given focus group sub-sample, they each wrote a narrative identifying overall themes from the sub-sample. In Phase Three, team members met to share their independent reflections and collectively generated a set of findings for the sub-sample. We repeated this iterative process until the transcripts of all four sub-samples had been read and interpreted.

In Phase Four, we compared findings of focus groups conducted with younger melanoma survivors against older survivors, as well as compared findings conducted with survivors diagnosed 1 to <5 years ago versus survivors diagnosed 5–10 years ago, according to the following issues: skin screening practices, sun protection behaviors, effects of melanoma on quality of life, concerns about the future, family relationships, and finances. The final Phase Five of analysis entailed generating descriptive and interpretive themes that represented salient findings across all focus groups. We synthesized the outcomes of our comparative analysis and developed overarching themes that delineated our observations derived from the focus groups.

Results

Participants

We identified 220 eligible melanoma patients for each stratified random sample. The number of interested participants and those patients who agreed to participate in the focus groups are shown in Figure 1. We determined a priori that each focus group would include seven to nine patients so that each focus group participant would have sufficient opportunity to express their views within the allotted time [32,33]. Forty-eight survivors of invasive primary

cutaneous melanoma composed the final sample. Survivors were primarily female (63%) and aged 26–90 years. The mean age at the time of diagnosis was 54 years (range 20–88 years). Participating survivors were diagnosed at all stages—early stage disease to late stage disease. Stage of melanoma diagnosed included IA (48%), IB (19%), IIA (19%), IIB (4%), and IIIB (10%). The characteristics of the focus group participants are shown in Table 2.

Focus group themes

The results summarizing the findings are presented in Table 3.

Impact of melanoma on life outlook and broader health—Patients frequently discussed how melanoma diagnosis had changed their lives. Positive outcomes associated with diagnosis included a greater appreciation for their lives, as well as a strengthening or reinvigorating of their social relationships. Some of the important negative outcomes included continuing physical and psychological side effects associated with their diagnosis.

Many survivors perceived that receiving a cancer diagnosis helped them develop a more positive life outlook across multiple dimensions. Several participants noted that the diagnosis prompted them to reprioritize how they spend their time, focus on being with family, and engage in activities that make them happy. Others discussed that they gained an appreciation for what is important in life and became less concerned about everyday annoyances that they now deem trivial and mundane.

A few survivors expressed dismay that the diagnosis did not more significantly affect their life outlook. One man stated, ‘the only thing that really bothers me about the whole thing (*melanoma diagnosis*) is that I didn’t take either a good enough or a deep enough life message from it...to me it was just like, “you have melanoma,” it wasn’t—it didn’t hit me like it should have, I don’t think.’

Receiving the melanoma diagnosis also elevated the importance of being more vigilant and proactive regarding monitoring one’s health and interacting with physicians to obtain good care. Several participants were dissatisfied with their physicians who in hindsight overlooked and misdiagnosed their melanomas. These experiences left survivors with a strong need to take charge of their health in the future.

Receiving a melanoma diagnosis served to either strengthen or place stress on survivors’ relationships with romantic partners. Some survivors expressed feeling isolated from their partners, that their loved ones did not fully comprehend the seriousness of their conditions, and that they did not obtain the emotional support that they needed. Other survivors indicated that their diagnosis helped their relationships, as expressed by one woman who shared, ‘I think it strengthened my relationship, just because it was such an intense period... it definitely brought us a lot closer together. And it made us a unit, like us kind of versus everybody else.’

Some survivors were still experiencing physical and psychological after-effects from their melanoma surgery. Several individuals complained about lymphedema, discomfort experienced from wearing surgical stockings, and diminished range of physical motion post-

surgery. Others remained concerned about their body image due to surgical scars. For example, one survivor was considering leaving his position in sales as he worried that his facial scars would negatively affect his ability to perform well in his job.

Modifications to melanoma risk reduction behaviors—Study participants quite frequently discussed the importance of enhanced sun protection strategies adopted after their diagnosis. Survivors recognized the importance of ‘being more careful’ and ‘more conscious of the sun’. Importantly however, many often relapsed to less stringent protection after time had passed, were concerned that they be able to ‘live life’ normally by going outdoors, and felt barriers to sun protection presented by lack of convenience of sun protection in certain situations.

Common changes to sun protection behaviors included using more sunscreen with a higher sun protection factor, avoiding the sun during peak hours in the summer months, ceasing tanning, using more protective clothing and hats when out in the sun during mid-day, being more mindful of sun exposure when selecting vacation destinations, and refraining from outdoor activities where there are limited shade opportunities (e.g., outdoor spectator sports events, being on a boat without shade options). Personal preference was a central factor in choosing sun protection; survivors chose to use methods that they liked and with which they were most comfortable. Although most survivors made changes to their sun protection and exposure habits after diagnosis, some of these changes were not lasting or permanent. Some participants indicated that over time they ‘regressed back to old habits’ and became less diligent in using sun protection as the years passed since their diagnosis.

Many survivors shared that it was important to not let melanoma take over their lives, and thus they strove to balance engaging in enjoyable outdoor activities, such as golf or gardening, using sun protection while doing so. Survivors wanted to enjoy the outdoors and live their lives but were more careful and aware of the sun. These survivors did not want to deprive themselves from the outdoors entirely.

Some participants were more committed to everyday sun protection, and others were more mindful of protection when they were planning to be outdoors in the sun. For example, several survivors used sunscreen daily, tried to avoid the sun as much as possible when outdoors, and walked on the shady side of the street when necessary.

Many survivors identified barriers to certain sun protection methods, such as sunscreen, hats, and additional clothing. Barriers to sunscreen use included convenience factors—that it takes too long to apply and discomfort factors—that sunscreen feels greasy and heavy on skin, concerns that ingredients in sunscreen are unsafe, and doubts that sunscreen is actually useful and effective as a sun protection method. Barriers to hat use centered on difficulty maneuvering with a large-brimmed hat and that it was necessary to match a hat with one’s outfit.

Physician screening practices and skin-self examination practices

Physician screening practices: Survivors had both positive and negative attitudes associated with seeing dermatologists regularly for full-body screening. However, for the

vast majority of participants, the benefits of seeing dermatologists far outweighed the downsides that they associated with physician screening. Survivors accepted the need to see their dermatologists regularly, and the majority saw dermatologists for screening, at various time intervals, from every 2 months to once per year.

Survivors expressed that it was imperative to find a highly competent dermatologist with whom they felt comfortable. Several survivors saw multiple dermatologists who overlooked their melanomas before they were accurately diagnosed, and this experience left them with a lasting impression of the necessity to find an excellent doctor who would monitor their skin for the long-term.

Several survivors distinguished between ‘general dermatologists’ and those who deal with skin cancer. One survivor noted, ‘I know he has the equipment and he has the judgment to spot melanomas, okay? And the general dermatologists have not.’ Once survivors found a dermatologist they deemed to be competent, they were willing to incur additional financial costs and manage scheduling challenges to stay with that doctor.

Additionally, many survivors viewed seeing a dermatologist as an effective strategy to ensure that any new melanomas would be identified at an early stage and would not ultimately be a lethal disease. As one individual stated, ‘I have this feeling of relief, even if she finds something, because it’s going to be taken care of.’

The primary negative associations with seeing dermatologists centered on discomfort and embarrassment being naked during full-body examinations, especially if one’s physician is not of the same gender and anxiety prior to appointments that the dermatologist may identify a suspicious area. Some focus group participants experienced anxiety within a week or several days before their appointments. The coping strategy used to deal with anxiety was to deny the feelings. Generally, as time since diagnosis increased, patients’ anxiety was reduced.

Skin self-examination practices: The degree to which participants actively engaged in skin self-examination (SSE) varied significantly. Some survivors did not practice SSE at all, preferring to rely on their dermatologists to detect suspicious skin lesions. Many practiced SSE but in an informal, reactive, ad hoc, and spontaneous way; and several had more established, proactive, and pre-planned SSE routines. The majority of survivors would examine their skin (i) when they physically felt or experienced something different in their skin, such as a burning or itching sensation or bleeding, (ii) when they happened to inadvertently notice a change in their skin, (iii) when they happened to think about examining their skin, or (iv) were in a setting when they were unclothed, such as stepping into the shower.

Appointments with dermatologists also served to prompt many survivors to perform SSE; several individuals stated that they would examine their skin before an upcoming appointment, so they would have information to share regarding any skin changes.

Individuals who conducted SSE routinely examined their skin at regular intervals, looking for changes in shape or size in moles or other skin markings. Several individuals who had

SSE routines in place examined their skin when they were undressed and getting into a bath or shower, or had spouses or partners look at their backs or other areas of the body that were difficult to see on their own. Survivors who examined their skin frequently felt more confident that they were performing SSE effectively. As one woman said, 'I trust myself to catch it (*melanoma*) better than anybody, because I'm looking for changes.' Several survivors who performed SSE on a regular basis used photo books gained from full-body photography as a tool to assist with identifying changes in moles and markings. A couple of participants circled areas on their photo books after examining their skin to demarcate suspicious lesions and would bring their photo books to their appointments with dermatologists; the photo book became a common reference point to prompt focused examination on areas of concern.

Survivors who conducted SSE infrequently or not at all cited a range of barriers. First, many survivors lacked confidence in their ability to identify suspicious areas. This was especially prominent for those individuals who did not notice the development of their melanomas, or who initiated discussions with their dermatologists about skin markings they felt to be worrisome but were told by physicians that those markings were not suspicious. Second, several survivors were overwhelmed with the number of moles they had and did not feel they could adequately examine all of them.

Finally, a number of survivors cited melanoma to be a slow-growing cancer and had faith that their dermatologists would 'catch' a potential melanoma before it had the chance to spread. In general, individuals who perceived barriers with performing SSE preferred to rely on the expertise of their dermatologists to monitor their skin for changes.

Economic issues arising from diagnosis and treatment—The melanoma diagnosis made younger survivors more concerned about ensuring the financial security of their families and, in some cases, prompted individuals to purchase life insurance for the first time. Economic concerns associated with receiving a melanoma diagnosis were far more prominent for younger melanoma survivors; financial concerns were not a major worry for older survivors, as all survivors aged 50 years and older had Medicare or some other type of insurance coverage. Younger survivors were most concerned about securing and maintaining good health insurance and obtaining life insurance. Receiving a diagnosis of melanoma elevated the importance of having a comprehensive health insurance plan.

Several younger survivors voiced frustrations associated with 'job lock', a predicament where they felt pressure to remain in a job they disliked that provided good health insurance, for fear that they would not be able to obtain adequate health insurance or health insurance coverage at another job. Receiving the melanoma diagnosis limited younger survivors' sense of their autonomy and mobility in the job market.

In addition to the importance of good health insurance, the melanoma diagnosis also raised the necessity of securing life insurance, especially for survivors who had young families at the time of diagnosis. In some cases younger survivors were prompted to purchase life insurance for the first time. Applying for life insurance in some cases was an emotionally challenging experience, as some survivors were denied life insurance due to their melanoma

history. The experience of being denied for life insurance contradicted a survivor's sense of overall health and at times served as a reminder of one's cancer history.

Despite the challenges associated with paying for cancer treatment, the majority of younger survivors stated that staying in good health was worth any price, even if it meant paying more out-of-pocket if their existing physicians no longer accepted their health insurance. One person noted that there was not an upper limit to the personal out-of-pocket expense he would be willing to pay for his treatment and care, and another said he was willing to take out a home equity loan to pay for his medical care if necessary. This reflects the primacy survivors placed on finding and staying with competent and trusted physicians to protect one's health regardless of financial burden. Survivors were also comfortable paying for commuting costs to see doctors they valued and trusted, and sun protection products, such as sunscreens, special protective clothing, and hats.

Concerns for family members—Overall, survivors indicated that their melanoma diagnosis put their family members at risk; survivors' dermatologists informed them about genetic susceptibility for melanoma and the need for family members to see dermatologists for skin screening. Concern about genetic susceptibility was most heightened for those survivors who had more than one melanoma diagnosis in their family. After melanoma diagnosis, younger survivors tended to focus on protecting their younger children from the sun, and many older survivors had conversations with older children and occasionally grandchildren about melanoma risk and the importance of risk reduction measures. Survivors who were parents of young children did not mention prohibiting their children from spending time in the sun, but took steps to ensure their children were well protected through application of sunscreen, dressing children in hats, rash guards, wet suits, and other protective clothing. Survivors who attributed their own melanoma to severe sunburns from their youth were acutely motivated to prevent their children from getting a bad burn. Several younger survivors preferred not to discuss or emphasize genetic risk with younger children through 'scare tactics', to avoid generating undue anxiety that could create a fear of going outdoors.

Some survivors singled out certain family members for risk and prevention discussions, who they felt were at higher risk than other family members. These survivors targeted family members who had significant sun exposure history, engaged in high-risk behaviors such as tanning, were perceived to have a high-risk skin phenotype or a lot of moles, or lived in a sunny climate.

Survivors were less likely to initiate discussions with family members perceived as not having a high-risk skin phenotype, not having strong history of sun exposure, not being receptive to risk and prevention messages, or younger family members who may not have health insurance and thus would have difficulty seeing a dermatologist.

Some survivors refrained from having focused prevention discussions with older family members, because these individuals are 'old enough' to make decisions on their own, 'already know' what they should do in the area of sun protection, or would not be receptive to a prevention message. Several individuals stated that there was a limit to what they could

do to change the behavior of older family members, ‘you can have the conversation but that’s as much as you can do.’

Other family concerns were a need to ensure family’s financial stability and practice good prevention to prevent recurrence.

Awareness of genetic risk can produce psychological burden, anxiety, and guilt about the possibility of children developing melanoma and may also generate psychological burden for those survivors who have not yet had children. Survivors communicated at times to their family members about increased melanoma risk and practicing good sun protection behaviors. When these family members did not listen, survivors expressed frustration and feeling of disappointment as if their melanoma experience meant little to their family members.

The imperative to stay alive to care for one’s family also encouraged younger survivors to regard the importance of sun protection more seriously.

Anxiety post-treatment, concerns about recurrence, and thoughts about cancer status—In addition to shifting behaviors regarding sun protection and sun exposure, the melanoma diagnosis seemed to create some level of anxiety for survivors within the context of sun exposure. Some participants noted that their early stage diagnosis gave them solace and also that skin screening provided reassurance. Several survivors reported feeling socially isolated from active partners who wanted to spend time in the sun. Others indicated that they became anxious if they were caught in the sun unprepared without adequate sun protection, or if they were in an environment without adequate shade cover. Feeling one’s skin get burned also generated anxiety for survivors.

Some survivors minimized their melanoma diagnosis, regarding melanoma to be a disease that was not particularly serious because it develops on the surface of the skin, external to the body’s internal organs, as well as being a slow-growing cancer. Several individuals did not regard melanoma to be a cancer at all, as it developed externally.

Thinking that melanoma is an ‘external’ cancer and slow-growing provided comfort to some survivors. One participant noted that a nurse had told her that skin cancer is ‘slow’, and learning this provided the patient comfort, ‘if it were another kind of cancer, it’d be constantly on my mind.’ However, those survivors who knew of individuals who died from melanoma regarded melanoma to be a very serious and potentially lethal disease.

Survivors compared melanoma and the treatment they experienced with other cancers; the treatment for those other cancers was perceived as more extensive. Survivors tended to minimize the severity of melanoma; it does not count as a ‘real’ cancer, nor is it as serious as other cancers. Many participants did not consider themselves to be survivors, as they associated that term to be for an individual who went through chemotherapy, radiation, or other extensive treatment.

Some patients stated that if disease had progressed to lymph nodes, they would recognize that melanoma had become systemic and would shift thinking about the disease’s impact.

Another contributing factor to minimization or lack of thinking about the disease is if the patient did not have another melanoma.

Perceptions of cancer status and the likelihood of future recurrences varied across survivors. Some considered themselves cancer free/cured, some felt as if their cancer was still lingering on and they will never feel cured, whereas others completely ignored that they had cancer and did not want to focus on it at all.

Survivors often felt comfortable with their care (between routine visits to the dermatologist and practicing skin self-examination) especially if they did not receive a melanoma diagnosis. They perceived that any melanoma will be caught at an early, treatable stage.

Prompts that brought back thoughts of melanoma included coming to the dermatologist for regular check-ups, seeing surgery scars or moles, or hearing the word cancer. For some, awareness of having had melanoma diagnosis hit home when dealing with life insurance companies that denied them coverage or when donating blood to blood banks. However, during everyday life, survivors did not seem to dwell on the diagnosis and what that could mean for their future; daily mental pre-occupation with melanoma and possible recurrence waxed and waned. Some felt that they are unlikely to die from melanoma, that other health concerns are more serious for them, or the possibility of a random event striking them is more likely.

Receiving the melanoma diagnosis prompted a shift in attitudes regarding family planning among female survivors, either evoking a desire to have more children or decide not to conceive. Some female survivors expressed concerns about developing a recurrence of melanoma if they became pregnant; others were concerned about passing down a susceptibility to melanoma to children.

Other female survivors wanted to live their lives ‘fuller’ post-diagnosis, which led one woman to have a baby after being diagnosed, whereas another regretted her decision to have a tubal ligation prior to her diagnosis.

Discussion

There have been some emerging studies on patients recently diagnosed with melanoma and melanoma survivors; however, important opportunities exist for research in this understudied population [5,15,32,34–37]. Understanding recurrence and second primary cancer risk, the psychological experiences of these patients, behaviors, surveillance patterns, economic sequelae, and family issues of melanoma survivors is imperative from a public health standpoint to promote the health and well-being of this cohort. This is one of the first studies to explore behavioral and psychosocial issues of melanoma survivors (1 to 10 years since diagnosis). The overall objective of this study was to examine experiences of melanoma survivors regarding melanoma risk reduction behaviors, psychosocial and family concerns using focus groups. We identified areas of high priority to melanoma survivors: skin self-examination, anxiety associated with sun exposure, familial risk communication, and maintenance of health insurance benefits. We used focus group methodologies to obtain comprehensive and in-depth information.

Our results suggest that survivors regularly visited dermatologists for screening, but most did not conduct skin self-examinations on a regular basis. Survivors became more conscious of sun exposure and expanded use of sun protection measures following diagnosis, but also sought to continue outdoor pursuits. This is consistent with other studies conducted in melanoma cohorts. In a population-based sample of US adult cancer survivors and non-cancer controls, sun protection behaviors were similar between the two groups (less than 25% reported sun protection behaviors). This sample is not directly comparable with the focus group participants in our study, given that only 8.4% of the cancer survivors had skin cancer. However, these findings support risk factor interventions among cancer survivors [15].

Manne *et al.* conducted a comprehensive study of the prevalence and correlates of sun protection and SSE practices among melanoma survivors in a clinic population [35]. Low rates of thorough skin self-examination (13.7%) and sun protection practices (59–70%) were reported. In a recent study, sun protection and SSE were assessed in a population-based sample of melanoma survivors [5]. Few participated in consistent SSE practices (17%), and sun protection practices were similarly low (23%). In a study that assessed quality of life in non-melanoma skin cancer patients, the use of sun protective behaviors increased after treatment (68%) with some improvements in quality of life [37]. In a small study of melanoma patients recently diagnosed, cases were less involved in outdoor activities compared with controls and protected themselves from sun exposure more often than controls. However, the results suggest that melanoma patients engaged in outdoor pursuits without sun protection and had a positive or neutral attitude toward tanning [38].

In our study, some survivors experienced anxiety if caught outdoors in the sun without adequate sun protection. Receiving good news from physician screenings was psychologically reassuring for survivors. We found melanoma diagnosis prompted many survivors to assess and reprioritize life values and develop a more positive life outlook. Survivors were aware their diagnosis increased melanoma risk for family members, yet many did not discuss risk reduction with all family members. Melanoma diagnosis elevated the importance of retaining health care insurance and purchasing life insurance for younger survivors. We did not identify salient differences between those diagnosed more or less recently.

The results of this study provide a broad understanding of the economic issues in a cohort of melanoma survivors. Although, we used stratified, random sampling to identify the cohorts for recruitment, these focus groups served as a pilot study to inform a larger scale survey study currently underway. The cohort thus reflects a convenience sample. Information was not available about the education level or socioeconomic status of the focus group participants. Further, we learned about issues in patients with early stage disease; however, research on patients with later stage disease is warranted. In addition, more research could be performed to address related work and insurance issues when patients return to their jobs.

Several factors speak to the importance of conducting melanoma survivorship research by studying their screening and sun protection practices, cancer risk behaviors, and psychosocial and cognitive factors. These include (i) the fact that melanoma is an

understudied cancer, (ii) the very high and rapidly increasing incidence/mortality from melanoma and an especially young age at diagnosis, (iii) the increased skin cancer screening efforts and the improved survival with early detection and treatment, and (iv) the risk of recurrence and second primary cancers. It is important to lay the foundation for the development of strategies for the control of melanoma and to facilitate formal studies of the efficacy of secondary prevention programs. Further, behavioral data can help to design health promotion and prevention programs that are tailored to the patients' risk status.

Acknowledgments

This research was supported by the Harry J. Lloyd Charitable Trust. There are no financial disclosures from any authors.

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Figure 1.
Sampling schema and flowchart of recruitment for melanoma survivors focus group study

Table 1

Content areas covered in focus groups

•	Impact of melanoma on patient health behaviors, lifestyle and quality of life
•	Practices related to physician skin screening and skin self-examination
•	Patient concerns for family members, including their risk for developing melanoma
•	Economic issues arising from diagnosis and treatment
•	Anxieties post-treatment, including concerns about melanoma recurrence

Table 2Characteristics of focus group participants ($n = 48$)*

Variable	<i>n</i>	%
Sex		
Male	18	37.5
Female	30	62.5
Age at time of focus group (mean = 59.3 years, SD = 17.1)		
<50 years	18	37.5
50 years	30	62.5
Age at time of diagnosis (mean = 54.3 years, SD = 17.2)		
<50 years	18	37.5
50 years	30	62.5
Stage		
IA	23	47.9
IB	9	18.75
IIA	9	18.75
IIB	2	4.2
IIIB	5	10.4
Years since melanoma diagnosis		
1 to <5	22	45.8
5–10	26	54.2

* Eight (16.7%) participants received more than one melanoma primary diagnosis.

Table 3

Summary of focus group themes

Focus group content and themes identified	Representative quotes from focus group participants
<i>Impact of melanoma on life outlook and broader health</i>	
<ul style="list-style-type: none"> Receiving good news from physician screenings was psychologically reassuring for survivors. 	‘Coming back to the dermatologist, sort of getting that stamp of approval for me is always a positive thing. And then afterwards you sort of get—you know, it actually clears your head a little bit. So I don’t mind coming. Not just clears your head that, okay, there’s something on the plus side, but it clears you of any potential negative thoughts and worries.’ (Patient <50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> Melanoma diagnosis prompted many survivors to assess and reprioritize life values and develop a more positive life outlook. 	‘In terms of my life, I think it just made me focus down on the day-to-day and not be so overwhelmed with irritations at work... It’s just—it’s like it’s not that important. The fact that I’m alive another day is more important than this.’ (Patient <50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> Receiving melanoma diagnosis elevated the importance of being more vigilant and proactive regarding monitoring one’s health and interacting with physicians to obtain good care. 	‘So what I should have done right from the beginning was, as soon as I saw something like that, if they’re not real sure, why not just get it taken off? And why don’t you biopsy it or do something? So that taught me to be real proactive. If somebody says, “Well, don’t worry about it,” I’ll tell you what, if it bothers me, I’m not going to take that for an answer anymore. I’m going to say, “Do something. I demand it.”’ (Patient 50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> Receiving a melanoma diagnosis served to either strengthen or place stress on survivors’ relationships with romantic partners. 	‘Well I’ve been married to the same person for 42 years, and I love him dearly, but he didn’t do well with my diagnosis, which was two years ago. And it was a stage II, and it was a big—it was a fairly big deal. But for some reason he became sick when I got the diagnosis. It was almost as though I was getting more attention than he was, and this became a problem just because I sort of—I guess I’m sort of an insular person, and when this happened I sort of turned inward, and you’re trying to steel yourself and get through this, and you just don’t want to deal with—I don’t want to deal with other people and their problems. I need to focus on this. And it’s a selfish thing for me, I know that, but I couldn’t deal with him. I never took him with me to the doctor because the first time I did I came out to the waiting room and there he is and he says, “Oh, I feel awful.” Wait a minute, you know? I’m the guy with cancer, and you feel awful? So this was a problem for probably the first year.’ (Patient 50 years of age; 1 to <5 years since diagnosis)
<i>Modifications to melanoma risk reduction behaviors</i>	
<ul style="list-style-type: none"> Survivors became more conscious of sun exposure and expanded use of sun protection measures following diagnosis. 	‘The need for sun protection is just a part of life.’ (Patient <50 years of age; 5–10 years since diagnosis)
<ul style="list-style-type: none"> Melanoma survivors sought to continue outdoor pursuits but used sun protection. 	‘Because I still do the outdoor stuff... my whole thought process is I’m going to protect myself to the best I can, but I’m not going to stop doing what I want to do because I just want to do it.’ (Patient <50 years of age; 1 to <5 years since diagnosis) ‘I obviously try to stay out of the sun. I wear sunscreen every day on my face. I garden but I try to stay in the shade. I wear long sleeve shirts. I wear hats in the summer if I know I’m going to be out, but to be honest with you, one way that I do manage this illness is I don’t cover up completely, because I don’t want it to overtake my life.’ (Patient <50 years of age; 5–10 years since diagnosis)
<ul style="list-style-type: none"> A majority of survivors were more likely to engage in regular, consistent sun protection during the summer months. 	‘But since all my doctors told me what to do to reduce any kind of risk—I wear the super strength sunscreen, put it on every hour. I’m actually never in the direct sun at all ever, but if I am even in the shade I put the sunscreen on every hour, wear a hat. I wear long sleeves, long pants.’ (Patient 50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> The perception that melanoma is not a serious cancer and confidence that dermatologists will identify new melanomas at an early stage both minimized the necessity of establishing consistent sun protection habits for some survivors. 	‘I take precautions I don’t drastically change my life. If I go to ...have my skin examined twice a year, which I do now, with someone who’s very competent...They would spot it very early. So the risk of it being a serious matter is minimal, in a way... I don’t see the need to really radically change things, except to take precautions.’ (Patient 50 years of age; 1 to <5 years since diagnosis)
<i>Physician screening and skin-self examination practices</i>	
<ul style="list-style-type: none"> Survivors regularly visited dermatologists for screening and that 	‘It’s a way of life’ and ‘it’s a lifetime commitment.’ (Patient <50 years of age; 1 to <5 years since diagnosis)

Focus group content and themes identified	Representative quotes from focus group participants
seeing a dermatologist is an effective strategy to ensure new melanomas would be identified early.	'I always have little skin stuff. I have lumps over here and, you know—I don't know which of these things are things to worry about or not, so going to him regularly gives a way to check...' (Patient <50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> • Skin-self examination varied significantly across the sample but most did not conduct skin self-examinations on a regular basis. 	'I guess what I mean between formal and informal is I don't formally have a set schedule.' (Patient <50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> • Survivors believed it is important to find a dermatologist whom they perceive to be competent—some survivors had dermatologists who had missed their melanoma. 	'And there's a lot of ignorance around. Doctor says something, you think that's it. I was very ignorant with that first melanoma...' (Patient 50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> • Negative associations with seeing dermatologists were discomfort and embarrassment being naked and anxiety prior to appointments that the dermatologist may identify a suspicious area. 	'When I'd first come for the quarterly check-ups or whatever, I'd feel a little tense, realizing that I could walk out of here with a different answer, or my life could change.' (Patient <50 years of age; 5–10 years since diagnosis)
<ul style="list-style-type: none"> • Lack of confidence in ability to identify a suspicious mole was cited as a barrier to conducting skin self-examination, and some survivors preferred to off-load the responsibility to the doctor. 	<p>'I don't check myself...But my skin I don't check, because the time I said, "Look at this, this, and this," and they'll say, "It's nothing."' (Patient 50 years of age; 1 to <5 years since diagnosis)</p> <p>'But over time I've really come to rely on—same thing—I really believe that in some ways I've sort of put some of the responsibility on my doctors and the photography—and I have dysplastic nevus as well—but I don't feel like I could ever do a body check.' (Patient <50 years of age; 5–10 years since diagnosis)</p>
<i>Economic issues arising from diagnosis and treatment</i>	
<ul style="list-style-type: none"> • Melanoma diagnosis elevated the importance of retaining health care insurance and purchasing life insurance for younger survivors. 	<p>'I mean and then what do you do if you can't get health insurance? I'll have to take a lousy job that I don't want to work at so that I'll have health insurance. Yeah, that's actually a huge fear for me.' (Patient <50 years of age; 1 to <5 years since diagnosis)</p> <p>'Economically I just think I'll find the money somewhere. That's not going to be the issue that I'm going to stress over.' (Patient <50 years of age; 5–10 years since diagnosis)</p>
<ul style="list-style-type: none"> • Economic concerns were far more prominent for younger melanoma survivors; financial concerns were not a major worry for older survivors, with insurance/Medicare coverage. 	'It (<i>my melanoma diagnosis</i>) really didn't hit me until I went to apply for life insurance...it was the life insurance that made it hit home and there was a difference—I have a history that affected my life.' (Patient <50 years of age; 5–10 years since diagnosis)
<i>Concerns for family members</i>	
<ul style="list-style-type: none"> • Survivors were aware their diagnosis increased melanoma risk (genetic susceptibility) and the need for family members to be screened, yet many did not discuss risk reduction with family members. 	'I wanted to make sure that they (<i>children</i>) understood that this wasn't something that you worry about for this summer, that you have to be concerned about it. I try to teach them that their whole life they need to be aware of the effect the sun can have on them and take appropriate measures for it...I didn't want to scare them or anything like that, or make them feel like, "Oh my God, I can never go outside again." I was just kind of like, "Hey, this is something that can happen. There's a hereditary component, and you're at risk because of that," but I didn't make it—I didn't play the whole thing up like...' (Patient <50 years of age; 1 to <5 years since diagnosis)
<i>Anxiety post-treatment, concerns about recurrence, and thoughts about cancer status</i>	
<ul style="list-style-type: none"> • Some survivors experienced anxiety if outdoors without sun protection. 	'When I don't think I'm going to be out and I end up having to be out, you get stressed. Like I'm outside for a half hour and I'm like, "I've got to get out of the sun. I don't have anything on."' (Patient <50 years of age; 1 to <5 years since diagnosis)
<ul style="list-style-type: none"> • Some survivors minimized their melanoma diagnosis, regarding melanoma to be a disease that develops on the surface of the skin. 	'You said the word cured, and that's the last word I would think about, because I never thought of me as having cancer, because skin cancer is almost outside of you...It's not like something inside you, systemic or something. This is sort of like, okay, it was on my skin that had to be removed. That's not—that was on top of my skin' (Patient <50 years of age; 5–10 years since diagnosis)

Focus group content and themes identified		Representative quotes from focus group participants
<ul style="list-style-type: none">•	Perceptions of cancer status and likelihood of future recurrences varied.	‘Well, I was surprised when I got the call, because they said it was for “survivors,” and I don’t even consider myself a survivor. I mean I don’t even think about it. It happened, they fixed it and it might happen again and it might not.’ (Patient 50 years of age; 1 to <5 years since diagnosis)
	Diagnosis prompted younger female survivors to shift their attitudes toward child-bearing (decision not to have children because of fear of recurrence and passing down risk to children; decision to expand family size to ‘live more fully’).	‘It’s (<i>hearing about increase likelihood of getting a new melanoma if you get pregnant</i>) a disappointment. He (<i>doctor</i>) said there are studies showing that you can—so you’re actually taking a personal risk by getting pregnant, not to mention that then that’s a period of not being as vigilant, because I can’t do some of the screens I was doing. So it’s sort of just hard to put at odds having a family versus taking care of your own body.’ ‘I’m thirty-nine and between my age and the impact of getting pregnant with hormonal levels on melanoma—I think one of the things that’s impacted me most significantly is that I’ve decided not to get pregnant.’ (Patient <50 years of age; 1 to <5 years since diagnosis)