

**Article title:**

When the Risks are High: Psychological Adjustment Among Melanoma Survivors at High Risk of Developing New Primary Disease

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## **Abstract**

In this study we explored the psychosocial experiences of melanoma survivors at high risk of developing new primary disease. Twenty survivors (9 men, 11 women, mean age 57.6 years) completed a semistructured telephone interview, exploring melanoma-related beliefs and experiences, psychological adjustment to melanoma risk, and supportive care needs. Participants perceived melanoma as potentially terminal and reported persistent worries about the possibility of developing new or metastatic disease. Fear of developing a new melanoma endured for years after treatment completion and, for some, created a pervasive sense of uncertainty. Still, not a single participant sought formal emotional support to address their melanoma-related concerns. Belief in the benefits of early intervention, including self- and clinical skin examination, provided a sense of control and a recommended course of action in an otherwise uncontrollable situation. The expertise of the High Risk Clinic physicians was perceived as instrumental in creating a sense of reassurance.

**Keywords:** cancer, psychosocial aspects; cancer, screening and prevention; coping and adaptation; interviews, semistructured; risk, perceptions.

Prognosis for patients with localized primary melanoma is good, especially when detected early, with 5-year survival rates estimated at 98%. However, individuals who have had melanoma live with an increased risk of developing new primary disease. Melanoma survivors are approximately eight times more likely to develop a second primary melanoma than the general population is of developing a first melanoma (Bradford, Freedman, Goldstein, & Tucker, 2010). In Australia, the estimated 10-year risk for the development of a second primary melanoma is approximately 13%, and for patients with two melanomas, the risk of developing a third is 28% (Doubrovsky & Menzies, 2003). Therefore, for patients who live in regions such as Australia, where there is heavy sun exposure and increasing survival rates as a result of early medical intervention, the risk of developing subsequent primary melanomas is possibly much greater than the risk of a thin lesion developing into metastatic disease (Doubrovsky & Menzies, 2003). Furthermore, it is estimated that the risk of developing new primaries remains elevated for more than 20 years post original diagnosis (Bradford, et al., 2010).

In addition to a personal history of melanoma, the presence of multiple atypical moles (or dysplastic nevus syndrome, DNS) is a known risk factor for the development of primary melanoma (Halpern et al., 1991; Kelly et al., 1995). Past research has shown that the presence of dysplastic nevi as a risk factor for developing melanoma has an odds ratio of 2.5 to 8.8 (Halpern, et al., 1991). Holly et al. (1987) reported a relationship between the number of dysplastic nevi and the subsequent development of melanoma, with a relative risk of 3.8 for participants with one to five dysplastic nevi and 6.3 for participants with six or more dysplastic nevi. This relationship was confirmed in a more recently published meta-analysis (Gandini et al., 2005). Given these established risk factors, a significant proportion of melanoma patients are considered to be at high risk of developing new primary disease. Very little is known, however, about the

subjective experiences and risk perceptions of individuals at high risk of developing another melanoma. The need to assess subjective, risk-related concerns and fears in this group is justified given their known high-risk status and ensuing vulnerability to increased melanoma-related distress.

Fear of cancer recurrence (FCR) is the fear that one might develop cancer again, either in the same place or another part of the body (Vickberg, 2003). FCR has been explored in a range of different cancer groups, including survivors of breast, ovarian, colorectal, prostate, lung, and head and neck cancer (Baker, Denniston, Smith, & West, 2005; Hodges & Humphris, 2009; Mehta, Lubeck, Pasta, & Litwin, 2003; Northouse, Schafer, Tipton, & Metivier, 1999; Stanton, Danoff-Burg, & Huggins, 2002; Stewart, Duff, Wong, Melancon, & Cheung, 2001). Overall, between 24% and 40% of cancer survivors report a moderate to high need for greater support in coping with FCR (Armes et al., 2009; Katharine Hodgkinson et al., 2007; K. Hodgkinson et al., 2007; Sanson-Fisher et al., 2000). FCR has been associated with hyper-vigilant health checking behaviors (Lasry & Margolese, 1992), poor planning for the future, and decreased psychological well-being (Northouse, 1981). Longitudinal cohort studies also indicate that FCR is a relatively stable variable, which might not necessarily diminish over time (Deimling, 2002; Mast, 1998; Stanton, et al., 2002).

FCR has not yet been investigated among individuals affected by melanoma, though it might be an important area of enquiry given this group's elevated risk of developing new disease. The experience of FCR might also be unique in this population compared to other cancer survivors because melanoma survivors typically have multiple scars from the removal of suspicious moles and melanomas (Kneier, 2003; Missiha, Solish, & From, 2003; Sollner, Zingg-Schir, Rumpold, Mairinger, & Fritsch, 1998). This scarring, as well as a skin phenotype that

identifies these individuals as above-average risk (including the presence of moles or fair skin), might serve as an ever-present cue for risk-related thoughts. The risks associated with sun exposure for people with fair skin are well known in western countries with frequent sunshine; however, the impact of this psychologically is still largely unknown. There remains a dearth of evidence specifically focused on these issues for individuals at high risk of developing melanoma and it has not yet been determined whether these cues increase a melanoma survivor's vulnerability to developing FCR.

Though FCR specifically has not yet been investigated in this context, distress, anxiety, and depression have been assessed among individuals affected by melanoma in numerous studies. Overall, approximately 30% of patients with melanoma report clinical levels of psychological distress (for review, please see (Kasparian, McLoone, & Butow, 2009; Kasparian, McLoone, & Meiser, 2009). Melanoma patients report similar levels of distress compared to individuals affected by breast or colon cancer, but on average, report higher levels of distress when compared to patients with gynecological or prostate cancer (Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). Anxiety is also quite prevalent among melanoma survivors. A recent review of the literature found that about a quarter of melanoma patients (ranging from 18% to 44% across studies) fell within the clinical range on survey-based measures of anxiety (Brandberg, Bolund, Sigurdardottir, Sjoden, & Sullivan, 1992; Brandberg, Kock, Oskar, af Trampe, & Seregard, 2000; Trask et al., 2001).

Furthermore, approximately one fifth of patients newly diagnosed with non-metastatic melanoma experience depression (Gibertini, Reintgen, & Baile, 1992) and overall, studies have found that 6% to 28% of melanoma patients report clinically-relevant levels of depression (Bergemar, Nilsson, Hansson, & Brandberg, 2004; Brandberg et al., 1992; Brandberg,

Bergenmar, Michelson, Mansson-Brahme, & Sjoden, 1996; Kelly, et al., 1995). Though extensive research has examined psychological adjustment among melanoma survivors in general, the subjective experiences and psychological adjustment of melanoma survivors at high risk of new disease have not been clearly delineated.

Though an individual's risk of developing melanoma can be calculated in medical terms, subjective evaluations of one's risk might be more complex to assess. Subjective evaluations of risk might be determined by a range of different factors and might also influence an individual's psychological adjustment, coping responses, and health behaviors. The Transactional Model of Stress and Coping provides a theoretical framework which might be useful in thinking about and exploring individual experiences of health threat, and the ways in which people understand and act in relation to medical risk (Lazarus & Folkman, 1984). According to this model, stressful experiences are construed as person-environment transactions, and these transactions depend on the perceived impact of the stressor. When faced with a potential stressor (e.g. the threat of developing another melanoma), a person is likely to evaluate the potential threat (primary appraisal) and form a judgment about the personal significance of the event. Subsequent to the primary appraisal, a secondary appraisal follows; this involves the assessment of one's coping resources and options. Efforts to regulate the stressor, one's perception of the stressor, or the resources available, are part of the coping process and, if effective, will result in increased emotional well-being and health-oriented behaviors.

Guided by the Transactional Model, one would predict that the likelihood of experiencing psychological stress is greater if a person is at higher risk of developing melanoma and if he or she perceives the threat as severe. The theory would also predict that an individual who did not think they had adequate resources at their disposal to manage the threat of developing melanoma

would experience greater stress (Folkman & Greer, 2000). When considering adherence to melanoma-related health behaviors such as sun protection and skin examination in light of this model, an individual is considered more likely to engage in these behaviors if he or she perceives him- or herself to be at risk of developing melanoma, if he or she believes them self or their physician are capable of performing recommended actions, and if so, that these actions will be effective in reducing melanoma risk. However, application of this model within the context of high melanoma risk has not been investigated.

Thus, the purpose of this investigation was three-fold. First, to explore the subjective experiences, risk perceptions, and coping responses of melanoma survivors known to be at high risk of developing new disease. Second, to evaluate perceptions of emotional and practical support received and needed by individuals at high risk of developing another melanoma. And third, to consider the findings of the study in light of the Transactional Model of Stress and Coping.

## **Methods**

In this study we adopted a qualitative data collection strategy, because this method is best suited to the exploration of relatively new areas of inquiry (Denzin & Lincoln, 2000).

### *Participants*

We recruited study participants using the clinical database of the High Risk Clinic (HRC) at the Sydney Melanoma Diagnostic Centre, located within a major teaching hospital, the Royal Prince Alfred Hospital, Sydney, Australia. To ensure the heterogeneity of the sample and the comprehensiveness of experiences reported, a purposive sampling methodology was used (Patton, 2002). In accordance with this approach similar numbers of men and women, as well as

individuals from a range of different age groups and with differing clinical features, were recruited.

The clinical criteria used for admission to the HRC was also used for this study. “High-risk” was defined in both instances as having either multiple diagnoses of primary invasive melanoma or the diagnosis of one primary invasive melanoma and the presence of DNS. In addition, so that participants had sufficient familiarity with the HRC to be able to comment on it, participants were required to have attended a minimum of at least three clinical skin examinations (CSE) at the HRC. Sufficient English language skills to complete the semistructured interview without the aid of an interpreter and being of adult age (18 years or older) were additional criteria.

Individuals with a strong family history of melanoma, defined as three or more first- or second-degree relatives diagnosed with melanoma or found to carry a *p16* mutation, were excluded from the study on the grounds that substantial work investigating the psychosocial and behavioral experiences of this group has previously been undertaken by our research team (Kasparian, Butow, Meiser, & Mann, 2008; Kasparian et al., 2010; Kasparian, Meiser, Butow, Job, & Mann, 2007; Kasparian, Meiser, Butow, Job, & Mann, 2006; Kasparian, Meiser, Butow, Simpson, & Mann, 2008; Kasparian, Meiser, Butow, Simpson, & Mann, 2009). Exclusion criteria also stipulated that individuals receiving active treatment for locally advanced or metastatic melanoma were not included, so as not to burden those who were unwell.

### *Procedure*

Potential participants were sent a letter of invitation from the Director of the HRC. Those who opted into the study took part in a semistructured telephone interview. A guide was used to conduct each interview and was developed on the basis of a thorough review of theoretical



models in health psychology, including the Transactional Model of Stress and Coping, as well as previous research in this area conducted by the research team. Results from early interviews were used to suggest additional lines of questioning in subsequent interviews and sampling was discontinued once informational saturation was achieved; that is, interview data were collected until no new information or themes were disclosed during interviews (Marshall, 1996; Morse, 1995). The semistructured interview was designed to explore participants' beliefs about melanoma, personal experiences of the disease, psychological adjustment and coping, perceptions of one's risk of developing another melanoma, adherence to health behavior recommendations, including skin surveillance and sun protection, and perceptions of clinical care and support as received at the HRC. In Table 1 we present a summarized version of the semistructured interview guide. All interviews were conducted by the same interviewer, lasted an average of 47 minutes (range 23-63 minutes), and were audio-taped and transcribed verbatim. The interviewer collected demographic data immediately following the interview using a verbally-administered questionnaire. Clinical data were obtained from the HRC database. Data were collected as part of a larger qualitative study; however, only responses directly relating to participants' psychosocial experiences and support needs are reported here. Approval was obtained from the relevant Human Research Ethics Committees and informed consent was obtained for all participants prior to participation.

[INSERT TABLE 1 ABOUT HERE.]

### *Data Analysis*

We employed the conceptual framework of Miles and Huberman (1994) to guide data analysis. Conventional content analysis was used, with coding categories derived directly from transcribed text (Hsieh & Shannon, 2005) and organized using the qualitative data analysis software, QSR NVivo 8.0 (QSR International, 2008). To establish a reliable system of coding, three members of

the research team collaboratively coded four, randomly selected interviews (20%). Each transcript was reviewed line-by-line for concepts, themes and ideas from which the preliminary coding scheme was constructed. Preconceived codes and categories were not used; rather these were derived inductively from the data (Kondracki, Wellman, & Amundson, 2002; Mayring, 2000). The codes were sorted into hierarchical categories to form organized and meaningful clusters. This facilitated the development of a clear structure, or coding tree (Coffey & Atkinson, 1996; Morse & Field, 1995; Patton, 2002). The thematic coding model was then reviewed by experienced analysts within the research team before the remainder of transcripts was independently coded by two coders. At the completion of coding, random passages of each transcript were re-coded by the alternate coder, who was blind to the original coding. Any discrepancies in coding were discussed with the team until a consensus was reached. This multilevel consensus coding method has been applied in multiple settings (Hruschka et al., 2004; Sankar, Wolpe, Jones, & Cho, 2006) and meets criteria for methodological rigor in qualitative research (Denzin & Lincoln, 2000). Emergent themes were cross-tabulated by sample characteristics including sex, age, and clinical characteristics, using the query function of QSR NVivo 8.0. During analysis, counts were used to minimize researcher bias (Morgan, 1993) and participant responses which differed from the general consensus were considered carefully for the additional insights offered.

## **Results**

Of the twenty-two individuals approached, twenty participants (9 men, 11 women) completed the semistructured interview. The mean age of the sample was 57.6 years (SD=11.8; range 34-74 years). Eight participants (40%) had completed a university degree, 17 participants (85%) were

married, and 13 (65%) reported that they and their parents had been born in Australia. The clinical characteristics of participants are shown in Table 2.

[INSERT TABLE 2 ABOUT HERE.]

In this study we explored the subjective experiences, risk perceptions, coping responses, and support needs of individuals at high risk of developing another melanoma. The study findings are presented below according to themes, and a concise summary of the results is displayed in Table 3.

[INSERT TABLE 3 ABOUT HERE.]

### *Perceptions of Melanoma Risk and Personal Susceptibility*

For the majority of participants, melanoma was perceived as a potentially terminal disease, and presented a significant risk to life; “If I’m really lucky it won’t be what kills me, but it might be.” Participants consistently reported that risk-related worries or concerns persisted over many years. For several participants, the possibility of developing new primary disease was a constant concern.

Each time I get another one I have a real sense of “Oh God, here we go again” and I wonder if this is going to be the one that gets me. It’s not really a burden but it’s kind of like a shadow I guess and progressively it gets a little bit darker each time. . . . It’s going to be this constant I guess worry or concern in my life.

Many participants described a chronic sense of fear or anxiety with regards to melanoma, and this fear had “no sort of peak to it” but remained “constantly on my mind”. For these participants, the risk of developing new primary disease remained an ominous threat, like “a sword hanging over my head . . . it’s scary.” This fear of melanoma recurrence or the development of new disease did not diminish over time, but was experienced over many years,

with clinical consultations serving to keep melanoma at the forefront of individuals' minds.

“Whenever I go back to [Doctor], he says, ‘Well it is 7 years, but don't forget it could reoccur at any time.’ . . . and I suppose all the time I wonder when it's going to happen.” Throughout this time, participants reported living with a pervasive sense of uncertainty regarding if or when melanoma would manifest again. “I keep my eye on my glands in my legs and under my arms . . . all the time I wonder when it's going to happen.”

### *Ongoing Fear about the Possibility of Metastases*

Some participants reported feeling “terrified” of the risk of developing metastatic melanoma and believed that “if melanoma gets loose in your body, you've had it.” Most participants believed that current treatment options were insufficient to cure metastatic melanoma and if metastasis occurred, the chances of survival were perceived as low.

I don't want to [get melanoma again], it terrifies me. Because I know that there's a lot of treatment now, but still, bottom-line is if it's already spread and it's not got really soon, really quickly, there's no treatment for it. They can't fix it.

For the majority of participants, the belief that current treatments are ineffective for advanced melanoma underscored a strong desire to receive up-to-date information on the latest clinical research findings. Indeed, research was perceived as a potential source of hope and reassurance. “I know I've got a problem, I know I've got a danger. It would be nice to get something to outline what's happening in the research; what they're doing, the improvements in treatment, etc.”

### *Beliefs about the Causes of Melanoma and How These Relate to Personal Risk*

Sun exposure was perceived as a primary cause of melanoma by the majority of participants and therefore, being “caught out” in the sun was a source of anxiety for many. “I have active melanin and the sun is acting like a switch.” A small proportion of participants reported behaviors indicating significant fear about the potential danger of sun exposure, even in a very limited quantity. For example, one woman experienced such fear of sun exposure that when outside she described hiding in the shadows, “When I’m standing at an intersection I sort of find the shadow of a post” believing that even the smallest amount of sun exposure could trigger another melanoma.

For some, these fears interfered with daily life, including the location and timing of family activities and pleasurable outdoor events. “It changes holidays. That for me was difficult because I loved those holidays where I jumped in the pool. You know, those lovely sort of tropical holidays. That’s out of the question for me now.” The majority of participants, however, reported a more balanced attitude toward UV exposure and an ability to integrate sun protection practices and lifestyle choices. “I lead a very outdoor life. We kayak, we backpack, we walk, we cross country ski, everything outdoors and I don’t intend to shut myself away. So, we take the best precautions that we think will work.”

For most participants, the relationship between sun exposure and melanoma was perceived as a simple cause and effect relationship. For some survivors, however, this causal relationship was perceived as complex and confusing. Many believed that the sun-worshipping culture of their younger years was the primary cause of their melanoma and that “the damage was done when I was younger.” Some expressed regret that they had not learned about sun protection earlier, for “in your twenties . . . perhaps you could have done more to turn it around.” The sense that this had created a “ticking time bomb” for melanoma risk was a compelling fear

for these individuals. Yet, this did not seem to be associated with fatalism and many participants reported vigilance when it came to the uptake of recommended sun protection practices. Most participants were highly motivated to protect themselves and their family members from the sun, believing that even the smallest amount of additional sun exposure could trigger their "dormant" melanoma. Confusion was often expressed if melanoma presentation was incongruent with one's pattern of sun exposure, for example, if a melanoma developed after years of living in a cold climate or on a part of the body never exposed to the sun. "[The melanoma was] in a place that you would not be able to find. I mean no sunlight gets there. I can tell you, I'm not a nudist." Melanoma was, for some, inexplicable and unpredictable in its presentation, and these perceptions were associated with uncertainty and anxiety. "I mean my question was why did it happen then, when I had been out of the Australian climate for 6 years?"

Furthermore, in addition to personal fears, several participants also spontaneously reported worries concerning their children's or grandchildren's risk of developing melanoma and almost half of the sample reported strongly encouraging younger family members to use adequate sun protection and have regular skin examinations.

I know with our grandchildren that what isn't covered by the new modern swim suit, my daughter makes sure there's cream everywhere. I think through my experience it's really brought all my family to really look [for melanoma]. I've got three children and all their children go to check-ups regularly.

### *Skills and Resources Used To Try To Cope with Melanoma Risk*

The majority of participants' fears about melanoma occurrence or recurrence seemed to be attenuated, at least to some extent, by positive beliefs about the benefits of early intervention.

Participants gave numerous specific examples of positive beliefs that facilitated healthy emotional adjustment to their high-risk status. One such example was the belief that if detected early, melanoma could be successfully treated and cause minimal life disruption; “I know it's not severe at all if you have it removed quickly.” Some participants even reported a sense of feeling “lucky” that their cancer was outwardly visible, aiding early detection and intervention. “It's probably one [cancer] that's a blessing in that if you do get it, it's going to leave a paper trail there, or a skin trail, that you've actually got it.”

Regular skin self-examination (SSE) and CSE were another form of active coping reported by this group. For many, SSE and CSE provided a sense of control and a recommended course of action in an otherwise uncontrollable situation. Vigilant self-screening behavior was reported by many participants as a means of alleviating anxieties about melanoma. “I do it every time I think of it. Yeah it could be weekly. It's very scary. By checking I feel much more comfortable after I've done it.” For some participants, however, self-screening did not provide the same emotional benefits. Indeed, a subset of participants expressed a reluctance to rely on their own ability to detect changes in the appearance of lesions or moles through SSE. Rather, these individuals expressed a clear preference for relying on the highly trained HRC clinicians to examine their skin for changes suggestive of cancer. “I want to pay somebody who has studied this problem for years and who can diagnose it at the drop of a hat. I don't want to be relying on myself. I wouldn't be confident at all.” Indeed, the expertise of the doctors at the HRC was perceived by almost all participants as instrumental in creating a sense of safety and reassurance in the context of their melanoma risk status. “I get a lot of comfort from the experience and the reputation of the Sydney Melanoma Unit to deal with those sort of things, and . . . if you go there, you're getting the experts.” Many participants reported increased confidence and

decreased anxiety after CSEs which found no new disease. As such, adherence to recommended CSE regimens was reported by the majority of participants.

Through the combined approach of routine CSE at the HRC, regular self-screening, and healthy sun protection practices, most participants remained positive regarding their future health, despite their high risk status.

I think it would be very unlikely and unlucky if one was missed. I mean, as unlucky as just being hit by a bus. I actually don't feel fearful. Because I have a fantastic team that look after me and I check myself and I'm now really careful, I'm always covered.

However, the need for life-long sun protection and skin screening practices affected individuals differently. Those who could integrate recommended health behaviors into their health regime and “just get on with life” adjusted well; “I just pretty much kept on going with my life as per normal. Except, I . . . obviously avoided the sun - excessively, not completely.” For some though, the implementation of melanoma-related health behaviors was seen as a considerable impingement on their lifestyle; “For me it is a complete hassle because I’ve got so many bloomin’ moles on me. . . . I have got to live with this skin for the rest of my life, be always monitoring it.” For those whose life choices were more substantially impacted by their melanoma risk, coping with living at high risk of developing new disease was experienced as more difficult.

[The doctor] said, “Look, we will never tell you not to have any more children but it's extremely obvious from your case study that . . . it's because of pregnancy”. . . . I want to have a third child, but if I'm going to have another melanoma or another problem, I don't think I will do it. I think, ‘Oh my God I might die!’ and my baby won’t even know me



and she will be brought up by somebody else. . . . I remember I would sit on the lounge and cry of a night to my husband going, ‘What if I die? What will happen to her?’

### *Self-concept and Perceptions of Physical Disfigurement after Melanoma Treatment*

Several participants who had had multiple melanomas and suspicious lesions removed described their experience of treatment as being, “like death by a thousand cuts”. However, even these participants appeared to cope relatively well with the ensuing scarring, reporting limited distress or loss of self-esteem or self-confidence; “Oh, they're just a part of me now.” Indeed, all but one participant demonstrated healthy adjustment to the appearance of scars resulting from incisions made during treatment; “Oh look, I couldn't care less about scarring. I would rather a scar than, you know, be dead.” Some even found a positive side to having either a melanoma or a lymph node removed.

Hey, I'm alive, who cares. One of the boys down at the beach thought a shark had got me. . . . Where they've cut away there it just gives me a little bit more length between the hand and the armpit. It's the only side I can tuck the [surf]board under comfortably.

### *Views on Supportive Care and Areas of Unmet Need*

Few participants identified themselves as a “cancer survivor”, which in turn limited their sense of legitimacy in seeking emotional or practical support.

I don't think I've had any [support] . . . I don't even go to things like the cancer afternoon teas. . . . I guess in a weird kind of way I don't think of myself as a cancer survivor . . . because it's not the same as, you know, breast cancer or liver cancer . . . so I would feel

like a bit of a fraud there I guess. And perhaps that's why I haven't felt the need to go and seek counseling or anything like that.

Although friends were cited as a source of support, they seemed to offer little empathy for the patient's cancer-related concerns. This might have been because of a lack of awareness of the risks inherent with a diagnosis of malignant melanoma.

There're just so many people that don't understand how dangerous [melanomas] are. Like I've had many people say, "Oh you've just had a mole removed" and I'm like, "It's actually cancer believe it or not". So yeah there's a wrong perception from most people. The actual depth of what one is I think is missed.

Not a single participant had, at any time, sought formal emotional support or counseling to address their melanoma-related worries or concerns. For many participants, the thought of accessing such support had not even been considered as an option; however, in hindsight, several participants believed that newly diagnosed patients could greatly benefit from professional support. They believed consultation with a psychologist, trained to understand and address the unique and specific needs and concerns of individuals diagnosed with melanoma, would be valuable.

## **Discussion**

### *Melanoma risk perceptions and anxiety*

Participants at high risk of developing new primary melanoma reported experiencing melanoma-related anxiety, a finding consistent with past research (Kasparian, McLoone, & Butow, 2009), and the theoretical constructs of the Transactional Model of Stress and Coping (TMSC). By

examining these issues qualitatively, the present study provides a more nuanced understanding of high-risk melanoma patients' concerns and appraisals of disease risk and threat. Participants reported persistent worries associated with thoughts of melanoma recurrence, metastases and the risk of their children/grandchildren developing melanoma sometime in the future. Many reported a pervasive sense of uncertainty and some participants struggled at times to cope with not knowing "if" or "when" they would develop melanoma again. Participants believed that their personal risk of developing what they considered a life-threatening disease, remained high for years after treatment completion. In terms of the TMSC, participants' primary appraisal of melanoma was, in the majority of cases, that the disease represented an uncertain, but potentially severe and terrifying threat. This sense of uncertainty is a common phenomenon often described by cancer patients and survivors, and is recognized in Mishel's model of Uncertainty in Illness (1988). Uncertainty in illness has been associated with increased psychological distress, decreased quality of life, and difficulty coping (Wright, Afari, and Zautra, 2009). Feelings of uncertainty are likely to fluctuate across time, making it essential to measure this construct longitudinally in order to better understand the relationship between uncertainty and adjustment to chronic or potentially recurrent illnesses, such as melanoma.

#### *Psychological Adjustment and Risk Reduction Behaviors*

As predicted by the TMSC, concerns regarding the development of new disease often prompted sun protection behaviors, including the use of sunscreen and limiting time spent in the sun. Participants who believed that sun exposure was a cause of melanoma, but also that there were viable ways to manage this risk factor, tended to report greater psychological adjustment. These findings support the TMSC which purports that during the secondary appraisal process an individual will assess what they can do about a specific stressful situation. Those who perceive

the available resources as sufficient to minimize the risk, tend to report greater emotional well-being and more proactive health behaviors.

Participants who perceived even low levels of UV exposure as dangerous were more likely to consider sun protection recommendations as burdensome and disruptive because of the high level of care required to protect oneself. The inability to successfully integrate sun protection behaviors within daily life was often reported as distressing and might have created a sense of cognitive dissonance; the unpleasant internal state that arises when individuals notice inconsistencies between their attitudes and their behaviors (Baron & Byrne, 1997; Festinger, 1962). This finding is consistent with the idea, derived from the TMSC, that negative secondary appraisals (i.e. a person's perceived inability to reduce the threat of the presenting stressor), are associated with greater psychological stress. As such, the development of an effective intervention or resource, which includes helpful suggestions regarding the integration of sun protection recommendations into a healthy and balanced lifestyle, might be beneficial for this high-risk group.

#### *Perceptions of Risk, Reassurance and the High Risk Clinic*

Patients attending the HRC viewed their clinicians as experts and as such, felt that it would be "as unlucky as just being hit by a bus" for new disease to remain undetected while in their care. The HRC, with its biannual skin screening protocol, provided much-needed reassurance for those living at high-risk of developing new disease. Participants reported that they felt safe because they were being monitored and cared for by experts on a regular basis. Fear of cancer recurrence was commonly reported among participants and the risk associated with failing to notice an important change in one's skin provoked considerable anxiety in some. As such, participants who reported low self-efficacy with regards to SSE also reported a preference for the "experts"

at the HRC to conduct all skin examinations. According to this subset of participants, the HRC provided the resources they deemed necessary to allay the threat of melanoma. Thus, stress responses were lowered and coping behaviors (i.e. CSE attendance) were increased.

Though it is important that the HRC was able to provide reassurance for these patients, their singular reliance on CSE might not be considered ideal. Self-efficacy, a person's belief in his or her ability to accomplish a given task or goal, appears important for survivors' to adopt SSE practice. Personal control and self-efficacy have been shown to explain a considerable proportion of variance in the adoption of health behaviors (Godin & Kok, 1996; Klein & Stefanek, 2007; Schwarzer & Fuchs, 2001), and a sense of control is often related to reductions in fatalistic beliefs and existential uncertainty (Lipworth, Davey, Carter, Hooker, & Hu, 2010). It might therefore be helpful for clinicians to discuss patient's attitudes toward SSE, their sense of self-efficacy, and how this may be affected by the complexity of their phenotype (for example, among individuals with DNS), within psycho-educational consultations.

#### *Implications for the Clinical Care of Patients at High-Risk of New Primary Melanoma*

Clinicians are regularly faced with the task of conveying risk-related information to patients. It is important for clinicians to relay this information clearly and to appreciate that a person's understanding of risk-related messages is often based on a number of factors additional to the medical information provided. A patient's personality, level of comprehension, and experience of stress while receiving risk information, are just a few of the factors which might impact the patient's beliefs and understanding of their level of risk as communicated by their doctor (Haines et al., 2010). Given that risk-related beliefs influence health behaviors (Klein & Stefanek, 2007), any doctor-patient misunderstandings might have important long-term consequences for patient health and well-being. It is therefore important for clinicians to verify their patients'

understanding of risk, so that inaccurate risk-related beliefs might be checked and anxieties addressed in a sensitive and caring manner. Effectively tailoring doctor-patient communication of risk to patient characteristics is essential within the clinical setting.

Clinical practice guidelines for the management of melanoma consistently recommend that structured psychosocial interventions and psycho-education be made available to all melanoma patients (Australian Cancer Network, 2008). Based on the results presented herein, it is apparent that a large discrepancy exists between the level of medical support and reassurance HRC patients receive, and the level of psychological, emotional and social support received. While the majority of participants reported healthy adjustment to their melanoma risk and described active coping responses, it is concerning that a substantial proportion also reported concurrent and persistent uncertainty, anxiety and fears regarding recurrence. Not a single participant in the current study reported seeking or receiving professional emotional support, despite a desire for such support from some individuals. It appears that this reticence may stem, in part, from patients' perception that because melanoma is a visible cancer, and therefore detectable at an early, curable stage, the term 'cancer survivor' does not apply to them. Greater support in this area, therefore, appears warranted for melanoma survivors at high-risk of developing new primary disease. When making mental health referrals, it is important to discuss psychosocial needs with patients in a way that normalizes or supports help-seeking behavior, so as to limit any stigma or concerns that might hinder seeking or receiving help. Openness around this issue, on the part of the clinician, is especially important given that some patients might believe asking for further help could be considered ungrateful or a negative reflection of the medical care they are currently receiving, and as such, remain reticent to express a need for greater support.

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## References

- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., . . . Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172-6179. doi: 10.1200/JCO.2009.22.5151
- Australian Cancer Network. (2008). Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand. Canberra: National Health and Medical Research Council (NHMRC).
- Baker, F., Denniston, M., Smith, T., & West, M. (2005). Adult cancer survivors: how are they faring? *Cancer*, 104, 2565-2576. doi: 10.1002/cncr.21488
- Baron, R., & Byrne, D. (1997). *Social Psychology* (8th edition ed.): Allyn and Bacon.
- Bergenmar, M., Nilsson, B., Hansson, J., & Brandberg, Y. (2004). Anxiety and depressive symptoms measured by the Hospital Anxiety and Depression Scale as predictors of time to recurrence in localized cutaneous melanoma. *Acta Oncologica*, 43(2), 161-168. doi: 10.1080/02841860310021518
- Bradford, P., Freedman, M., Goldstein, A., & Tucker, M. (2010). Increased risk of second primary cancers after a diagnosis of melanoma. *Archives of dermatology*, 146(3), 265-272. doi: <http://archderm.ama-assn.org/cgi/reprint/146/3/265>
- Brandberg, Y., Bergenmar, M., Bolund, C., Mansson-Brahme, E., Ringborg, U., & Sjoden, P. O. (1992). Psychological effects of participation in a prevention programme for individuals with increased risk for malignant melanoma. *European Journal of Cancer*, 28A(8-9), 1334-1338. doi: 10.1016/0959-8049(92)90512-Z



- Brandberg, Y., Bergenmar, M., Michelson, H., Mansson-Brahme, E., & Sjoden, P. O. (1996). Six-month follow-up of effects of an information programme for patients with malignant melanoma. *Patient Education & Counseling*, 28(2), 201-208. doi: 10.1016/0738-3991(96)00894-4
- Brandberg, Y., Bolund, C., Sigurdardottir, V., Sjoden, P.-O., & Sullivan, M. (1992). Anxiety and depressive symptoms at different stages of malignant melanoma. *Psycho-oncology*, 1(2), 71-78. doi: 10.1002/pon.2960010204
- Brandberg, Y., Kock, E., Oskar, K., af Trampe, E., & Seregard, S. (2000). Psychological reactions and quality of life in patients with posterior uveal melanoma treated with ruthenium plaque therapy or enucleation: a one year follow-up study. *Eye*, 14(Pt 6), 839-846.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks: Sage.
- Deimling, G. T. (2002). Cancer survivorship and psychological distress in later life. *Psycho-Oncology*, 11, 479-494. doi: 10.1002/pon.614
- Denzin, N., & Lincoln, Y. (Eds.). (2000). *Handbook of Qualitative Research* (Second ed.). California: Sage Publications, Inc.
- Doubrovsky, A., & Menzies, S. W. (2003). Enhanced survival in patients with multiple primary melanoma. *Archives of Dermatology*, 139(8), 1013-1018. doi: <http://archderm.ama-assn.org/cgi/content/full/139/8/1013>
- Festinger, L. (1962). *A theory of cognitive dissonance*. Oxford, England: Stanford University Press.

- Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-Oncology*, 9(1), 11-19. doi: 10.1002/(SICI)1099-1611(200001/02)9:1<11::AID-PON424>3.0.CO;2-Z
- Gandini, S., Sera, F., Cattaruzza, M. S., Pasquini, P., Zanetti, R., Masini, C., . . . Melchi, C. F. (2005). Meta-analysis of risk factors for cutaneous melanoma: III. Family history, actinic damage and phenotypic factors. *European Journal of Cancer*, 41(14), 2040-2059. doi: 10.1016/j.ejca.2005.03.034
- Gibertini, M., Reintgen, D. S., & Baile, W. F. (1992). Psychosocial aspects of melanoma. *Annals of Plastic Surgery*, 28(1), 17-21. doi: [http://journals.lww.com/annalsplasticsurgery/Abstract/1992/01000/Psychosocial\\_Aspects\\_of\\_Melanoma.7.aspx](http://journals.lww.com/annalsplasticsurgery/Abstract/1992/01000/Psychosocial_Aspects_of_Melanoma.7.aspx)
- Godin, G., & Kok, G. (1996). The theory of planned behavior: a review of its applications to health-related behaviors. *American Journal of Health Promotion*, 11, 87-98.
- Haines, R. J., Bottorff, J. L., McKeown, S. B., Ptolemy, E., Carey, J., & Sullivan, K. (2010). Breast cancer messaging for younger women: Gender, femininity, and risk. *Qualitative Health Research*, 20, 731-742. doi: 10.1177/1049732310367502
- Halpern, A. C., Guerry, D. t., Elder, D. E., Clark, W. H., Jr., Synnestvedt, M., Norman, S., & Ayerle, R. (1991). Dysplastic nevi as risk markers of sporadic (nonfamilial) melanoma: A case-control study. *Archives of Dermatology*, 127(7), 995-999. doi: <http://archderm.ama-assn.org/cgi/reprint/127/7/995>
- Hodges, L. J., & Humphris, G. M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology*, 18, 841-848. doi: 10.1002/pon.1346

- Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., . . . Wain, G. (2007). Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology*, *104*(2), 381-389. doi: 10.1016/j.ygyno.2006.08.036
- Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., Lo, S. K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*, *16*(9), 796-804. doi: 10.1002/pon.1137
- Holly, E. A., Kelly, J. W., Shpall, S. N., & Chiu, S. H. (1987). Number of melanocytic nevi as a major risk factor for malignant melanoma. *Journal of the American Academy of Dermatology*, *17*(3), 459-468. doi: 10.1016/S0190-9622(87)70230-8
- Hruschka, D., Schwartz, D., Cobb St.John, D., Picone-Decaro, E., Jenkins, R., & Carey, J. (2004). Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. *Field Methods*, *16*, 307-331. doi: 10.1177/1525822X04266540
- Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*, 1277-1288. doi: 10.1177/1049732305276687
- Kasparian, N., Butow, P., Meiser, B., & Mann, G. (2008). High- and average-risk individuals' beliefs about, and perceptions of, malignant melanoma: An Australian perspective. *Psycho-Oncology*, *17*(3), 270-279.
- Kasparian, N., McLoone, J., & Butow, P. (2009). Psychological Responses and Coping Strategies Among Patients With Malignant Melanoma: A Systematic Review of the Literature. *Archives of Dermatology*, *145*(12), 1415-1427.

- Kasparian, N., McLoone, J., & Meiser, B. (2009). Skin cancer-related prevention and screening behaviours: A review of the literature. *Journal of Behavioral Medicine*, 32(5), 406-428.
- Kasparian, N., McLoone, J., Meiser, B., Butow, P., Simpson, J., & Mann, G. (2010). Skin cancer screening behaviours among individuals with a strong family history of malignant melanoma. *British Journal of Cancer*, 103, 1502-1509.
- Kasparian, N., Meiser, B., Butow, P., Job, R., & Mann, G. (2007). Anticipated uptake of genetic testing for familial melanoma in an Australian sample: An exploratory study. *Psycho-Oncology*, 16, 69-78.
- Kasparian, N., Meiser, B., Butow, P., Job, R., & Mann, G. J. (2006). Better the devil you know? High-risk individuals' anticipated psychological responses to genetic testing for melanoma susceptibility. *Journal of Genetic Counseling*, 15, 433-447.
- Kasparian, N., Meiser, B., Butow, P., Simpson, J., & Mann, G. (2008). Predictors of psychological distress among individuals with a strong family history of malignant melanoma. *Clinical Genetics*, 73, 121-131.
- Kasparian, N., Meiser, B., Butow, P., Simpson, J., & Mann, G. (2009). Genetic testing for melanoma risk: A prospective cohort study of uptake and outcomes among Australian families. *Genetics in Medicine* 11(4) 265-278.
- Kelly, B., Raphael, B., Smithers, M., Swanson, C., Reid, C., McLeod, R., . . . Walpole, E. (1995). Psychological responses to malignant melanoma. An investigation of traumatic stress reactions to life-threatening illness. *General Hospital Psychiatry*, 17(2), 126-134.  
doi: 10.1016/0163-8343(94)00098-X

- Klein, W. M., & Stefanek, M. E. (2007). Cancer risk elicitation and communication: Lessons from the psychology of risk perception. *CA: A Cancer Journal for Clinicians*, 57, 147-167. doi: 10.3322/canjclin.57.3.147
- Kneier, A. W. (2003). Coping with melanoma: Ten strategies that promote psychological adjustment. *Surgical Clinics of North America*, 83(2), 417-430.
- Kondracki, N. L., Wellman, N. S., & Amundson, D. R. (2002). Content Analysis: Review of Methods and Their Applications in Nutrition Education. [doi: 10.1016/S1499-4046(06)60097-3]. *Journal of Nutrition Education and Behavior*, 34(4), 224-230.
- Lasry, J. C., & Margolese, R. G. (1992). Fear of recurrence. Breast-conserving surgery, and the trade-off hypothesis. *Cancer*, 69, 2111-2115. doi: 10.1002/1097-0142(19920415)69:8<2111::AID-CNCR2820690817>3.0.CO;2-T
- Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Lipworth, W., Davey, H., Carter, S., Hooker, C., & Hu, W. (2010). Beliefs and beyond: what can we learn from qualitative studies of lay people's understandings of cancer risk? *Health Expectations*, 13, 113-124. doi: 10.1111/j.1369-7625.2010.00601.x
- Marshall, M. (1996). Sampling for qualitative research. *Family Practice*, 13, 522-525. doi: 10.1093/fampra/13.6.522
- Mast, M. E. (1998). Survivors of breast cancer: illness uncertainty, positive reappraisal, and emotional distress. *Oncology Nursing Forum*, 25, 555-562.
- Mayring, P. (2000). Qualitative Content Analysis. *Forum: Qualitative Social Research*, 1. Retrieved from doi:<http://www.qualitative-research.net/index.php/fqs/article/view/1089>.

- Mehta, S. S., Lubeck, D. P., Pasta, D. J., & Litwin, M. S. (2003). Fear of cancer recurrence in patients undergoing definitive treatment for prostate cancer: results from CAPSURE. *Journal of Urology*, 170, 1931-1933. doi: 10.1097/01.ju.0000091993.73842.9b
- Miles, M., & Huberman, A. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. London: Sage.
- Missiha, S., Solish, N., & From, L. (2003). Characterising anxiety in melanoma patients. *Journal of Cutaneous Medicine and Surgery*, 7(6), 443-448. doi: 10.1007/s10227-002-0154-x
- Morgan, D. (1993). Qualitative content analysis: A guide to paths not taken. *Qualitative Health Research*, 3, 112-121. doi: 10.1177/104973239300300107
- Morse, J. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147-149. doi: 10.1177/104973239500500201
- Morse, J., & Field, P. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.
- Northouse, L. L. (1981). Mastectomy patients and the fear of cancer recurrence. *Cancer Nursing*, 4, 213-220. doi: [http://journals.lww.com/cancernursingonline/Abstract/1981/06000/Mastectomy\\_patients\\_and\\_the\\_fear\\_of\\_cancer.4.aspx](http://journals.lww.com/cancernursingonline/Abstract/1981/06000/Mastectomy_patients_and_the_fear_of_cancer.4.aspx)
- Northouse, L. L., Schafer, J. A., Tipton, J., & Metivier, L. (1999). The concerns of patients and spouses after the diagnosis of colon cancer: a qualitative analysis. *Ostomy Care*, 26, 8-17. doi: 10.1016/S1071-5754(99)90005-0
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

- Sankar, P., Wolpe, P. R., Jones, N. L., & Cho, M. (2006). How do women decide? Accepting or declining BRCA1/2 testing in a nationwide clinical sample in the United States. *Community Genetics*, 9(2), 78-86. doi: 10.1159/000091484
- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*, 88(1), 226-237. doi: 10.1002/(SICI)1097-0142(20000101)88:1<226::AID-CNCR30>3.0.CO;2-P
- Schwarzer, R., & Fuchs, R. (2001). *Self-efficacy and health behaviours*. Philadelphia, PA: Open University Press.
- Sollner, W., Zingg-Schir, M., Rumpold, G., Mairinger, G., & Fritsch, P. (1998). Need for supportive counselling - the professionals' versus the patients' perspective: A survey in a representative sample of 236 melanoma patients. *Psychotherapy and Psychosomatics*, 67(2), 94-104. doi: 10.1159/000012266
- Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psycho-Oncology*, 11, 93-102. doi: 10.1002/pon.574
- Stewart, D. E., Duff, S., Wong, F., Melancon, C., & Cheung, A. M. (2001). The views of ovarian cancer survivors on its cause, prevention, and recurrence. *Medscape Women's Health*, 6, 5.
- Trask, P. C., Paterson, A. G., Hayasaka, S., Dunn, R. L., Riba, M., & Johnson, T. (2001). Psychosocial characteristics of individuals with non-stage IV melanoma. *Journal of Clinical Oncology*, 19(11), 2844-2850. doi: <http://jco.ascopubs.org/content/19/11/2844.full>

Vickberg, S. M. (2003). The Concerns About Recurrence Scale (CARS): a systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioural Medicine*, 25, 16-24.

Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho Oncology*, 10(1), 19-28. doi: 10.1002/1099-1611(200101/02)10:1<19::AID-PON501>3.0.CO;2-6

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**Table I. Sample Questions from the Semistructured Interview Schedule**

Topic of Discussion	Sample Questions
Thoughts and beliefs about melanoma	What are the first two things that come to mind when you think about melanoma?
Beliefs about how melanoma is caused	What do you believe causes melanoma?
The experience of having melanoma	Can you try to describe how you felt around the time of diagnosis / treatment / follow up care?
Beliefs about risk	How would you describe your chances of developing another melanoma sometime in the future compared to others?
Sun protection and skin surveillance behaviors	What types of things do you do, if any, to try to reduce your chances of developing another melanoma?
Beliefs about moles and melanoma	How do you feel about any moles or related scars, that you currently have on your body?

**Table 2. Clinical Characteristics of the Sample**

Clinical Variables	Mean (SD)
Time (years) since:	
First diagnosis	11.7 (8.9)
Most recent diagnosis	6.2 (6.0)
Number of melanomas per person	2.4 (1.4)
Average Breslow thickness (mm)	1.0 (1.0)
Personal history of melanoma	<i>n</i> (%)
One melanoma	7 (35%)
Multiple melanomas	13 (65%)
Dysplastic naevus syndrome	<i>n</i> (%)
Yes	14 (70%)
No	6 (30%)

**Table 3. A Conceptual Summary of the Major Themes Contributing to Participants' Perceptions of Melanoma Risk and Clinical Care**

Major Themes	Participant Quotations as Evidence
Fear	It terrifies me. . . in the back of my mind there's still the risk that there could be something there.
Persistent uncertainty	I just feel like it's a sword hanging over my head. I guess because you are always keeping an eye on things, it's always there – it's like an undercurrent in your life. If I'm really lucky [melanoma] won't be what kills me, but it might be.
Threat perceived as pervasive	Even though it's 15 degrees [the sun] can still burn you. . . you can get caught out.
Causal attributions	We always got sun burnt, so that's obviously why I'm paying for it now.
Controllability	I know it's not severe at all if you have it removed quickly.
Behavioral responses to threat	I don't go in the sun, I don't take any risks. I check myself and I'm now really careful.
Low confidence in one's ability to detect melanoma (i.e. self-efficacy)	I don't trust that I will pick up on any changes [indicative of developing melanoma].
Specialized medical care	I knew I was getting the best care available. Probably in the world.
Barriers to accessing emotional support	I don't think of myself as a cancer survivor. . . because it's not the same as, you know, breast cancer or liver cancer. . . so I would feel like a bit of a fraud there I guess. And perhaps that's why I haven't felt the need to go and seek counselling or anything like that.
Feeling (mis)understood	There's just so many people that don't understand how dangerous [melanoma] are.