Published in final edited form as:

Ann Surg Oncol. 2013 February ; 20(2): 675–679. doi:10.1245/s10434-012-2635-5.

Illness-Related Distress in Women with Clinically Localized Cutaneous Melanoma*

Thomas M. Atkinson, PhD¹, Nikki S. Noce², Jennifer Hay, PhD¹, Brian Rafferty³, and Mary S. Brady, MD³

¹Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY

²New York University School of Medicine, New York, NY

³Department of Surgery, Gastric and Mixed Tumor Service, Memorial Sloan-Kettering Cancer Center, New York, NY

Abstract

Purpose—Women may experience distress or changes in their quality of life following treatment for early-stage melanoma. In order to plan future interventions and identify areas of primary concern, we conducted a cross-sectional survey to describe the experiences of women treated for clinically localized melanoma.

Methods—We examined quality of life, levels of distress, appearance perceptions, body image, fear of recurrence, and reproductive concerns in 100 patients (Age 21–90, $M = 54.34$). Most (61%) had melanoma of the extremity, with a median depth of 1.1 mm (range 0–10.5 mm).

Results—Significant depressive symptomatology occurred in 10% of patients, and 12% reported a clinically-established high level of intrusive thoughts related to melanoma. Quality of life scores indicated more disruption on psychological, compared to social and physical functioning. Sixty-four percent of women rated their appearance as worse post-treatment; 23% were unsatisfied with the appearance of the surgical site. Recurrence concerns indicated significant worry about health and death. Most patients (>85%) were not concerned about fertility, but 52% worried that future children would have an increased risk of cancer.

Conclusions—Some women treated for clinically localized melanoma reported high levels of distress associated with their altered body image and fear of recurrence. Improvements in patient education prior to surgical intervention may reduce the distress associated with the diagnosis and treatment of melanoma.

INTRODUCTION

Cutaneous melanoma is a rapidly growing health burden [1, 2]. This is especially true in women, where cutaneous melanoma has been identified as the second most common cancer and the most prevalent cause of cancer death in women aged 25–39 [3]. Between 1980 and 2004, the incidence of cutaneous melanoma increased by 50% in women aged 15–39, whereas no significant change was observed for males in this age group over the same time period [4].

*The authors have no potential conflicts of interest to disclose.

CORRESPONDING AUTHOR: Thomas M. Atkinson, Ph.D., Department of Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 641 Lexington Ave., 7th Floor, New York, NY 10022, USA. Phone: 646-888-0089. Fax: 212-888-2584. atkinsot@mskcc.org.

The psychosocial impact of a diagnosis of cutaneous melanoma may disproportionately affect female patients. Several studies have shown that women experience more distress associated with the diagnosis and treatment of melanoma than men [5, 6]. For example, one study drawn from an outpatient pigmented lesion clinic showed that 27% of women had clinically significant high stress, as compared to 10% of men [5]. Additionally, research has demonstrated that melanoma has a more detrimental impact on quality of life in women than men [7]. Further, women are more likely than men to report dissatisfaction with the appearance of their surgical scar [8, 9]. Finally, a focus group study indicated that some female melanoma survivors have a reduced desire for having children in the future [10].

The purpose of this study was to examine the impact of diagnosis and treatment of clinically localized melanoma on quality of life and distress in women. In addition to standard, validated assessments of quality of life and distress, we also include assessment of constructs that may uniquely influence quality of life and distress in women, including body image, perception of appearance, and family functioning and planning.

PATIENTS AND METHODS

Patients

One hundred women within ten days to two years of completing surgical treatment for primary cutaneous melanoma at Memorial Sloan-Kettering Cancer Center (MSKCC) participated in this study. Informed consent was obtained from each of these patients. All were patients from a single surgical practice. Nearly 90% of those who were approached (i.e., 112 patients) agreed to participate. Patients were ineligible for enrollment if they were < 18 years old, had metastatic disease, or had a history of prior cancer (with the exception of squamous or basal cell carcinoma of the skin). This study was approved by the Institutional Review Board at MSKCC.

Measures

Quality of Life

Quality of Life Scale [11]: The Quality of Life Scale is a 35-item measure of physical, psychological, social, and spiritual well-being. Each item uses a 0–10 numeric rating scale ranging from worst to best outcome. For each domain, items were summed and averaged to create respective subscales. For the purpose of the present paper, the spiritual well-being subscale was not included.

Distress

Mental Health Inventory [12]: The Mental Health Inventory is a 5-item measure of psychological distress and well-being. The questionnaire contains a series of statements rated on a Likert-type scale from 1 (all of the time) to 6 (none of the time). Raw scores are converted to a 0–100 point scale, with scores < 52 indicative of significant psychological distress [13].

Concerns About Recurrence Scale [14]: The Concerns About Recurrence Scale is a measure of patient-reported fear of recurrence, with separate death, health, social role, and womanhood subscales. These subscales employ a 0–4 numerical rating scale (i.e., 0 = not at all, 4 = extremely) with higher scores indicating increased levels of fear or worry.

Impact of Event Scale [15]: The Impact of Event Scale is a 15-item measure of patient-reported distress related to a specific event and has separate intrusion and avoidance subscales. Items were scaled with verbal frequency descriptors (i.e., not at all, rarely,

sometimes, often), with items rated as having higher frequency being related to increased distress. For the purposes of the present study, only the intrusion subscale was retained for interpretation. Cutoff scores for the Impact of Event Scale are as follows: 0–8 indicates no meaningful impact; 9–25 indicates an impact event, 26–43 represents a powerful impact event, and scores 44 are indicative of a severe impact event.

Other Concerns

Body Image Scale [16]: The Body Image Scale is a 10-item measure of patient-reported feelings about their appearance post-cancer treatment. The items were designed to capture affective, behavioral, and cognitive aspects related to their appearance, with responses scaled from 0 (not at all) to 3 (very much). The overall scale was scored 0–30, with higher scores indicating increased distress related to the patient's appearance.

Perception of Appearance Scale [17]: The Perception of Appearance Scale was designed to measure patient-reported perception of appearance in individuals with choroidal melanoma. This scale consists of five items scored from 0–100, with higher scores indicating favorable outcomes.

Family Functioning/Planning Questionnaire [18]: The Family Functioning/Planning Questionnaire was designed to assess childbearing attitudes of cancer survivors. This measure consists of 13 statements that patients rate on a 5-point Likert-type scale from 0 (agree strongly) to 4 (disagree strongly). In the present study, this questionnaire was only administered to patients of reproductive age (i.e., 18–45).

Study Design

Eligible patients were identified by the treating physician or research study assistant when they returned for post-operative or oncologic follow up after treatment for clinically localized cutaneous melanoma. If they agreed to participate, patients were asked to complete the study questionnaires.

Statistical Analysis

Descriptive statistics for each of the administered measures were calculated relative to their respective established scoring thresholds. Given the heterogeneous nature of the sample, we explored the relationship between patient subscale scores and potentially important demographic and clinical covariates (time since diagnosis, Breslow thickness, and tumor site). Time since diagnosis and Breslow thickness were treated as continuous variables, with relationships expressed in terms of Pearson's r ; tumor site was designated as a categorical variable (distal extremity, proximal extremity, and trunk or head and neck) in one-way Analysis of Variance (ANOVA).

RESULTS

The study consisted of 100 female patients ages 21–90 ($M = 54.34$, $SD = 15.44$), with an average time since diagnosis of 194.15 days ($SE = 20.81$). All patients were Caucasian, and none reported a strong history of familial melanoma (i.e., 3 first degree relatives on the same side of the family). The majority of patients were married ($n = 64$) and/or had at least one child ($n = 75$). These and other characteristics of the patients are displayed in Table 1.

The clinical characteristics of the melanoma are presented in Table 2. Most patients ($n = 64$) had a sentinel lymph node biopsy (only patients with negative nodes were eligible for participation). The most common primary tumor sites were the trunk or head and neck ($n =$

39). Approximately half (45%) of patients had early melanoma (Breslow thickness ≤ 1 mm), and 74% of patients had a primary lesion with a Breslow thickness ≤ 2 mm.

For the Quality of Life Scale, patients had an overall average score of 6.87 ($SE = 0.16$), which indicated good quality of life for the sample. With respect to individual Quality of Life Scale subscales, patients scored significantly lower on the psychological ($M = 6.33$, $SE = 0.18$), as compared to the social ($M = 7.75$, $SE = 0.20$) and physical ($M = 8.10$, $SE = 0.16$) dimensions. Quality of life was higher in women who had been diagnosed in the more distant past ($r = 0.25$, $p = 0.01$), and among those women where the disease had been diagnosed on the proximal ($M = 7.49$, $SE = 0.23$) rather than distal extremity ($M = 6.36$, $SE = 0.29$; $F(2,97) = 4.25$, $p = 0.02$). Breslow depth was not related to quality of life.

Next we examined levels of distress in the sample. Ten percent of the patients scored below 52 on the Mental Health Inventory, a clinical indicator of high psychological distress. On average, the sample was not highly distressed, with a score of 71.77 ($SE = 1.82$). Patients were moderately fearful about cancer recurrence ($M = 3.16$, $SE = 0.13$), and were most concerned about death ($M = 2.00$, $SE = 0.14$) and their health ($M = 1.75$, $SE = 0.12$), compared to a change in their womanhood ($M = 0.56$, $SE = 0.09$) and their societal role ($M = 1.19$, $SE = 0.11$), though each of these subscales scores fall in the moderate to minor concern range. However, 12% of patients had been severely impacted by their disease (as assessed through the Impact of Events Scale), while 27% fell into the moderate impact or powerful impact event range. Sixty-one percent of patients' scores fell in the low impact event category. Neither time since diagnosis, Breslow depth, nor tumor site were related to distress, fears of cancer recurrence or impact of the disease, with the exception that there was a less severe impact of cancer reported among those who had been diagnosed in the more distant past ($r = -0.25$, $p = 0.01$).

For the Body Image Scale, patients ranged in score from 0–30 ($M = 4.43$, $SE = 0.59$), indicating low overall distress related to physical appearance. Women with distal extremity ($M = 6.18$, $SE = 0.97$) tumors, however, indicated significantly more distress related to their body image than those with proximal extremity ($M = 3.36$, $SE = 0.61$) tumor sites ($F(2,97) = 3.62$, $p = 0.03$). Time since diagnosis and Breslow depth were not statistically related to body image score. Body mass index and age were not correlated with aesthetic satisfaction, and thus are unlikely to confound these results.

On the Perception of Appearance Scale, patients scored within the “do not know or unsure” to “somewhat satisfied” range for their overall appearance post-surgery ($M = 64.65$, $SE = 2.18$); the treated site ($M = 59.60$, $SE = 3.10$); and their comfort around others ($M = 77.50$, $SE = 2.18$). Patients reported that they did not avoid social situations ($M = 92.35$, $SE = 1.75$) and did not change what they would wear on a given day ($M = 69.95$, $SE = 3.17$) following their surgical procedure. Compared to before surgery, patients felt their post-surgical appearance was in the “somewhat worse” to “about the same” range ($M = 34.1$, $SE = 2.77$). Breslow depth, time since diagnosis, and tumor site were not significantly related to any of the Perception of Appearance subscales.

Twenty-nine women in the sample (i.e., those aged 18–45) completed a family functioning/ planning questionnaire [18]. Of these women, 15 did not have children. When asked whether their future children would have a higher than normal risk of developing cancer, 51.7% of women completing this survey agreed, though 96.6% saw themselves as healthy enough to be a good parent and 53.6% agreed that their cancer experience would make them a better parent. Additionally, the majority of these women (85.2%) were not concerned that future parenthood would lead to recurrence, cause future medical concerns during pregnancy (88.9%) or that their future children would have birth defects (96.4%).

DISCUSSION

Our study describes psychosocial concerns in women diagnosed with clinically localized melanoma and identifies the areas of most concern for future large-scale examination. There are limited data for comparison, though several studies provide information about other cancer populations and help put our findings in context.

Ten percent of patients had severe depressive symptomatology and 12% reported a severe level of intrusive thoughts related to melanoma. This incidence of depression is similar to levels for females in the general population [19] and is consistent with findings reported in women treated for colorectal cancer, although these patients are much more likely to require chemotherapy and radiation therapy in addition to surgery, as well as have a more guarded prognosis [20].

The levels of fear of recurrence found in our sample of women treated for melanoma was comparable to the findings from a study of breast cancer survivors who had no recurrence [14]. Severe psychological distress was seen in both our sample of patients within two years of diagnosis (12%) and breast cancer patients (16%) two years after diagnosis [21]. Since the treatment of cutaneous melanoma is generally less invasive than that for breast cancer; these results were not expected.

As expected, our patient sample had a more positive body image compared to breast cancer survivors. Unexpectedly, however, those in the present sample scored more negatively post-surgery with regard to “satisfaction with the treatment site”, as well as “overall appearance” and “comfort level around others” when compared to choroidal melanoma patients; whose sequela of surgery could have resulted in enucleation (i.e., removal of the eye), ptosis (i.e., falling of the eyelid), etc [17].

With regard to family planning, it is encouraging that the majority of the patients surveyed believed their cancer experience would make them a better parent, with very few reporting concerns of their disease would negatively impact fertility or future pregnancy. These findings are positive when compared those previously reported by cancer survivors [18].

For our covariate analysis, women who were more distantly removed from their diagnosis reported better overall quality of life and less of an impact of their disease. These findings fit logical expectation and are similar to those reported in a study of patient satisfaction and quality of life in breast cancer patients that had undergone breast tissue reconstruction [22]. Quality of life and distress related to body image was observed to be worse for women who had distal rather than proximal extremity tumors. This finding may be reflective of the increased visibility and vulnerability of the distal extremities to subsequent trauma, as well as a lack of available skin in these distal regions for reconstruction [23].

We note some limitations of our current work. Though there was no statistical relationship between the outcome measure subscales and Breslow depth, this finding may have been impacted by the lack of range in Breslow depth in our present sample. Our cross-sectional study design prevented the ability to examine causal relationships; this area represents an important focus for future research. While this data was collected from a single surgical practice, we are not aware of any identifiable bias that would influence the results. Lastly, baseline characteristics, including depression, anxiety, and comorbidity information were not collected, making it impossible to investigate the relationship between subscale results and these variables.

CONCLUSIONS

In the present sample, a number of women treated for clinically localized melanoma reported high levels of distress associated with their body image and fear of recurrence. Interventions to target these areas may reduce the distress associated with the diagnosis and treatment of melanoma. Emphasizing the good prognosis of early stage melanoma may help to decrease the distress related to concern about survival. In addition, educating patients about the expected size and appearance of the scar prior to surgery, as well as providing patients with images depicting anticipated cosmetic outcome of surgery may address the distress post-treatment observed in our study.

Acknowledgments

This data was collected as part of NCT00745862. This publication acknowledges Grant Number NCI P30 CA08748, which provides partial support for the Behavioral Research Methods Core used in conducting this investigation. The findings in this manuscript were partially reported at the 7th Annual International Melanoma Congress, Sydney, Australia, November 2010.

REFERENCES

1. Linos E, Swetter SM, Cockburn MG, Colditz GA, Clarke CA. Increasing burden of melanoma in the United States. *J Invest Dermatol.* 2009; 129:1666–1674. [PubMed: 19131946]
2. Reyes-Ortiz CA, Goodwin JS, Freeman JL. The effect of socioeconomic factors on incidence, stage at diagnosis and survival of cutaneous melanoma. *Med Sci Monit.* 2005; 11:RA163–RA172. [PubMed: 15874907]
3. Bleyer A, Budd T, Montello M. Adolescents and young adults with cancer: The scope of the problem and criticality of clinical trials. *Cancer.* 2006; 107:1645–1655. [PubMed: 16906507]
4. Purdue MP, Freeman LE, Anderson WF, Tucker MA. Recent trends in incidence of cutaneous melanoma among US Caucasian young adults. *J Invest Dermatol.* 2008; 128:2905–2908. [PubMed: 18615112]
5. Al-Shakhli H, Harcourt D, Kenealy J. Psychological distress surrounding diagnosis of malignant and nonmalignant skin lesions at a pigmented lesion clinic. *Plast Reconstr Aesthet Surg.* 2006; 59:479–486.
6. Missiha SB, Solish N, From L. Characterizing anxiety in melanoma patients. *J Cutan Med Surg.* 2003; 7:443–448. [PubMed: 15926214]
7. Holterhues C, Cornish D, van de Poll-Franse LV, et al. Impact of melanoma on patients' lives among 562 survivors: A Dutch population-based study. *Arch Dermatol.* 2011; 147:177–185. [PubMed: 21339445]
8. Newton-Bishop JA, Nolan C, Turner F, et al. A quality-of-life study in high-risk (thickness $\geq$ or 2 mm) cutaneous melanoma patients in a randomized trial of 1-cm versus 3-cm surgical excision margins. *J Invest Dermatol Symp Proc.* 2004; 9:152–159.
9. Lichtenthal WG, Cruess DG, Clark VL, Ming ME. Investment in body image among patients diagnosed with or at risk for malignant melanoma. *Body Image.* 2005; 2:41–51. [PubMed: 18089173]
10. Oliveria SA, Shuk E, Hay JL, et al. Melanoma survivors: Health behaviors, surveillance, psychosocial factors, and family concerns. *Psychooncology.* In Press.
11. Ferrell BR, Dow KH, Grant M. Measurement of the quality of life in cancer survivors. *Qual Life Res.* 1995; 4:523–531. [PubMed: 8556012]
12. Veit CT, Ware JE Jr. The structure of psychological distress and well-being in general populations. *J Consult Clinical Psychol.* 1983; 51:730–742. [PubMed: 6630688]
13. Berwick DM, Murphy JM, Goldman PA, Ware JE Jr, Barsky AJ, Weinstein MC. Performance of a five-item mental health screening test. *Med Care.* 1991; 29:169–176. [PubMed: 1994148]

14. Vickberg SM. The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Ann Behav Med.* 2003; 25:16–24. [PubMed: 12581932]
15. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: A measure of subjective stress. *Psychosom Med.* 1979; 41:209–218. [PubMed: 472086]
16. Hopwood P, Fletcher I, Lee A, Al Ghazal S. A body image scale for use with cancer patients. *Eur J Cancer.* 2001; 37:189–197. [PubMed: 11166145]
17. Melia M, Moy CS, Reynolds SM, et al. Development and validation of disease-specific measures for choroidal melanoma: COMS-QOLS report No. 2. *Arch Ophthalmol.* 2003; 121:1010–1020. [PubMed: 12860806]
18. Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer: A pilot study of survivors' attitudes and experiences. *Cancer.* 1999; 86:697–709. [PubMed: 10440699]
19. Weissman MM, Bland R, Joyce PR, Newman S, Wells JE, Wittchen H-U. Sex differences in rates of depression: Cross-national perspectives. *J Affect Disord.* 1993; 29:77–84. [PubMed: 8300980]
20. Kroenke CH, Bennett GG, Fuchs C, et al. Depressive symptoms and prospective incidence of colorectal cancer in women. *Am J Epidemiol.* 2005; 162:839–848. [PubMed: 16207809]
21. Bleiker EM, Pouwer F, van der Ploeg HM, Leer JW, Adèr HJ. Psychological distress two years after diagnosis of breast cancer: Frequency and prediction. *Patient Educ Couns.* 2000; 40:209–217. [PubMed: 10838000]
22. Zhong T, McCarthy C, Min S, et al. Patient satisfaction and health-related quality of life after autologous tissue breast reconstruction: A prospective analysis of early postoperative outcomes. *Cancer.* 2012; 118:1701–1709. [PubMed: 22025176]
23. Moncrieff MD, Bowen F, Thompson JF, et al. Keystone flap reconstruction of primary melanoma excision defects of the leg - The end of the skin graft? *Ann Surg Oncol.* 2008; 15:2867–2873. [PubMed: 18629589]

Table 1

Demographic characteristics of the 100 women with clinically localized cutaneous melanoma

Characteristic	No. of Patients (N=100)
Age, years	
Mean	54.34
Median	53.51
21–39	18
40–49	23
50–59	18
60–69	25
> 70	16
Time since diagnosis	
Mean (days)	194.15
Body mass index	
Mean	27.39
Marital status	
Single	22
Married	64
Domestic partner	1
Divorced or separated	6
Widowed	7

Table 2

Clinical characteristics of the melanoma in 100 women with clinically localized cutaneous melanoma

Characteristic	No. of Patients (N=100)
Sentinel lymph node biopsy	
Yes	64
No	35
Unknown	1
Primary tumor site	
Distal extremity	33
Proximal extremity	28
Trunk/head/neck	39
Breslow thickness (mm)	
Mean	1.86
Median	1.10
< 1.0	44
1.0–3.9	43
4.0	13
Scar Length (cm)	
Mean	8.32
Median	9.00
6.0	27
6.0–9.9	40
10.0	29
Unknown	4
Scar Width (mm)	
Mean	3.91
Median	4.00
< 3.0	19
3.0–4.0	48
> 4.0	30
Unknown	3
Method of closure	
Primary closure	75
Skin Graft	19
Rotation Flap	5
Amputation	1
Clark level	
I	8
II	11
III	12
IV	58
V	7

Characteristic	No. of Patients (N=100)
Unknown	4