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Prevalence and correlates of adherence to skin examination among adolescent and young adult survivors of melanoma from the Project Forward Study*

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Abstract

Background: Melanoma is a common cancer among adolescents and young adults (AYAs) yet adherence to recommended surveillance and factors related to adherence are not well understood in this population. This study assessed the prevalence and correlates of physician-conducted skin examination (PSE) and skin self-examination (SSE) among AYA-aged long-term survivors of melanoma.

Procedures: Melanoma cases were identified from the Los Angeles County cancer registry and surveys were then completed by 128 respondents diagnosed between the ages of 0–24, with stage 1 melanoma or higher, at least 5 years from diagnosis, and who were between the ages of 18–39 at time of survey.

Results: 82% of AYA melanoma survivors reported SSE within the past six months, while 65% reported annual PSE. Greater health care self-efficacy was positively associated with adherence to

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Conflict of Interest Statement

The authors report no conflict of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

PSE, SSE, and both types of skin examinations ($P<0.01$). Higher socioeconomic status (SES) and having a regular source of primary health care were positively associated with annual PSE and adherence to both surveillance practices ($P<0.05$ and $P<0.01$, respectively). Hispanic ethnicity was negatively associated with annual PSE compared to non-Hispanics ($P<0.01$), and greater depressive symptoms were negatively associated with adherence to both skin examinations ($P<0.05$).

Conclusions: High rates of SSE were observed but PSE adherence was lower than optimal in this sample. Interventions to improve PSE are needed for at-risk AYA survivors of melanoma, and strategies that help melanoma survivors navigate the healthcare system and access primary care may facilitate greater adherence.

Keywords

Adolescent; young adult; melanoma; survivorship; surveillance; skin examination

Introduction

Adolescents and young adults (AYAs; aged 15–39) diagnosed with cancer represent a distinct population with unique challenges and needs due to their age and life stage.[1] Melanoma, the most lethal type of skin cancer, is one of the most common AYA cancers and its incidence is increasing in this age group.[2] Melanoma is the third and fourth most common cancer in AYA females and males, respectively, and the second most common cancer among those aged 15–29.[3–5] While survivors of melanoma have a 9-fold increased risk of developing a subsequent melanoma compared with the general population, those diagnosed with melanoma prior to age 30 are at 13 times greater risk of developing a second primary melanoma.[6]

The risk for recurrent or new primary disease is highest within the first five years following diagnosis for all melanoma patients and is likely attributable to both genetic susceptibility and melanoma-related risk behaviors, primarily exposure to ultraviolet (UV) light.[7] However, patients are at risk for a new primary melanoma and/or recurrent disease throughout their life.[8] Thus, lifelong prevention practices, including the avoidance of excessive sun exposure via sun-protective behaviors and regular follow-up surveillance for earlier detection are important for survivors of melanoma, particularly for AYA who are at risk over a longer lifespan.

Post-treatment surveillance for survivors of melanoma includes physician-conducted skin examination (PSE) and skin self-examination (SSE). Groups such as the National Comprehensive Cancer Network (NCCN) and the American Academy of Dermatology (AAD) have issued common follow-up guidelines for asymptomatic survivors of melanoma diagnosed at all stages of disease.[9–11] These include annual history and physical examination with emphasis on comprehensive, total body clinical skin examination for early detection of new or recurrent disease. Guidelines by NCCN and AAD also state the need for patient counseling for regular SSE.

Despite the increasing burden of melanoma, few studies have focused on long-term follow-up among melanoma survivors of any age.[12] Rates of adherence to follow-up care are thus not well known. One prospective European study spanning 67 treatment centers and 1,006 patients found a follow-up rate of 92% within the first two year of diagnosis, but did not report on age-related differences in rates of adherence.[13] A US-based retrospective single-institution study found that 74% of melanoma survivors were adherent to recommended physician follow-up at five-years post-diagnosis, with decreasing rates over time.[14] Notably, the study found that younger survivors of melanoma (< age 50) were twice as likely to be non-adherent compared to older survivors. However, neither study focused specifically on AYA-aged survivors as a distinct subgroup, nor included both PSE and SSE as outcomes.

AYA cancer survivors across cancer types are more likely than older age groups to discontinue cancer-focused follow-up care in general.[15] AYAs face substantial barriers to obtaining follow-up care, including financial costs of and access to care, patient knowledge regarding follow-up care after cancer, and deficits in patient-provider communication and the coordination of care.[16,17] Thus, although adherence to follow-up care for AYA survivors of melanoma is not well known, it would be expected that it is less than recommended. Further, factors associated with adherence have not been examined in this population. The aim of the present study was to characterize the rates of adherence to PSE and SSE among a population-based sample of AYA-aged long-term survivors of melanoma 5 years or more from diagnosis (and therefore not in active surveillance), and to identify correlates of adherence to surveillance.

Methods

Data source

Data were from the Project Forward study, a cross-sectional population-based study evaluating follow-up care among childhood cancer survivors and AYAs diagnosed with any type of cancer in Los Angeles County between 1996–2010 (N=1,248). The present study represented a substudy with additional survey questions for melanoma survivors (N=128). For the melanoma substudy, eligible participants were diagnosed at stage 1 or greater between the ages 0–24 years and were between ages 18–39 years at the time of survey in 2015. All participants were 5 or more years from diagnosis.

Study participants were identified through the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry covering Los Angeles County, and were mailed a survey to complete which was available in both English and Spanish. To enhance recruitment and achieve a representative sample, the Dillman Survey Method was used which utilizes multiple methods to locate and recruit participants including telephone follow-up, re-mailings of survey materials, post card reminders, and option for a telephone interview.[18] Participants were also incentivized to participate with $20 provided after receipt of a completed survey and were entered into a lottery with a chance to win $300. The study was approved by the California Committee for the Protection of Human Subjects of the California Cancer Registry and the Institutional Review Board at the University of Southern California.

Measures

Outcomes: PSE and SSE—Participants were asked 1) when they last had their skin examined (PSE) by a health care provider (primary care physician, dermatologist, or any other health care professional); and 2) when they last performed SSE to check for unusual moles, freckles, or skin changes. Response options included 6 categories ranging from "I never have" to "2 years ago or more." Based on guidelines established by the NCCN[19] and AAD[20] for surveillance of survivors of melanoma, responses for PSE were dichotomized to "within the past 12 months" vs. "greater than 1 year." For SSE, responses were dichotomized to "more recently than six months" vs. "greater than six months." As the guidelines for SSE state "regular" skin self-examination, the latter outcome intended to identify those respondents who engaged in more frequent, e.g., guideline-adherent SSE.

To capture respondents who were adherent to both types of skin examination, we considered those who practiced both examinations vs. those who practiced only one type of skin examination.

Independent variables—Sociodemographics including age and sex were obtained from cancer registry data. Race and ethnicity were self-reported by study participants. Quintiles of socioeconomic status (SES; 1=Lowest SES, 5=Highest SES) were estimated using an established area-based composite index comprising multiple socioeconomic indicators (education, occupation, employment, household income, poverty, rent and house values) from census sources, as described in previous literature.[21–23] In this sample surveyed after enactment of the Affordable Care Act, 95% of respondents reporting having health insurance and 87.39% reported having private insurance; only 6 respondents were uninsured at time of survey. Thus, health insurance was not included in this analysis due to low variability.

Clinical variables obtained from cancer registry data included stage of diagnosis and years since melanoma diagnosis. Because the majority of cases were diagnosed prior to 2004, before American Joint Committee on Cancer (AJCC) staging was available in SEER data, stage of diagnosis was characterized using SEER summary stage as localized, regional, and advanced stage at diagnosis. The intensity of prior cancer treatment was categorized by the four-level Intensity of Treatment Rating Scale 3.0 (ITR-3; 1 = least intensive to 4 =most intensive),[24] but was not included in the analysis because 94% of the sample was ITR level 1 (limited to surgery only). Participants were asked whether they had received a written summary of their melanoma treatment from their doctor following cancer survivorship recommendations from the National Academy of Medicine,[25] and whether they had a regular source of non-cancer, e.g., primary care (both variables dichotomized yes/no).

Depressive symptoms were assessed using the 20-item Center for Epidemiological Studies Depression Scale (CES-D).[26] Respondents indicated how often they had experienced symptoms during the previous week on a 4-point ordinal scale ranging from "rarely or none of the time" (less than 1 day) to "most or all of the time" (5–7 days). A total score was calculated ranging from 0–46 with higher scores representing higher levels of depressive symptoms. The Cronbach's alpha for this sample was 0.90.

Health care self-efficacy (HCSE) was adapted from the Stanford Patient Education Research Center Chronic Disease Self-Efficacy scales.[27] The scale included three items related to survivors' perceived confidence in navigating the health care system. Responses comprised a 3-point Likert-type scale ranging from "not at all confident" to "totally confident." Items were summed to form a continuous composite score ranging from 3–9 with higher scores indicating greater HCSE. The Cronbach's alpha for this sample was 0.72.

To assess perceived risk of a melanoma recurrence, respondents were asked to rate their chances of developing melanoma again in comparison to another person of the same age, sex, and similar diagnosis using a self-developed item. The scale ranged from 1–5, with response options ranging from "much less risk than others" to "much greater risk than others," with higher numbers indicating greater perceived risk.

Statistical Analysis—Descriptive frequencies and means were used to describe the sample. Bivariate logistic regression was first conducted with variables selected for their theoretical significance to the outcomes; *P* less than 0.10 was the entry threshold for the multivariable model.[28] Current age, sex, and stage at diagnosis were included in all models as covariates of theoretical importance to the relationship between the independent variables and the outcomes. All tests were two-tailed, with an alpha less than 0.05 and conducted using SAS statistical software Version 9.4 (SAS Institute; Cary, NC, USA).

Results

Response rates

The response rate (i.e., the rate of response among all eligible cases) for the melanoma sample was 48%. In comparing responders vs. non-responders with registry data, no significant differences were found by gender, SES, stage at diagnosis, current age, age at diagnosis, or years since diagnosis. A significant difference was found by ethnicity, with Hispanics less likely to respond than non-Hispanic whites ($P<0.008$).

Selected characteristics of sample

Sample characteristics are presented in Table 1. Sixty-one percent of respondents were female and 10% were Hispanic. The mean age of the sample at time of survey completion was 32 years old. Mean time from diagnosis was 12 years, and the majority of respondents were diagnosed at stage 1. Most respondents were in higher SES quintiles, and had a regular source of non-cancer care, although only 29% reported receiving a written summary of their treatment for melanoma.

Prevalence of skin examination

Prevalence of skin examination is shown in Table 2. Approximately two-thirds of respondents reported PSE at least annually or more frequently than annually, and over 80% reported SSE more recently than the past six months. Close to 60% of respondents were adherent to both types of skin examination.

Factors associated with PSE

Correlates of adherence to PSE are shown in Table 3. In bivariate analyses, higher SES, having a written treatment summary, having a regular source of non-cancer care, and greater HCSE were significantly positively associated with PSE adherence. Hispanic ethnicity and greater depressive symptoms were significantly negatively associated with PSE adherence.

In multivariable analyses, higher SES, having a regular source of non-cancer care, and greater HCSE remained positively associated with PSE adherence. Hispanic ethnicity remained negatively associated with PSE adherence.

Factors associated with SSE

Correlates of adherence to SSE adherence are shown in Table 3. In bivariate analyses, only greater HCSE was significantly positively associated with SSE adherence.

In multivariable analyses, greater HCSE remained positively significantly associated with SSE adherence.

Factors associated with adherence to both skin examinations

Correlates of adherence to both PSE and SSE are shown in Table 3. In bivariate analyses, higher SES, having a written treatment summary, having a regular source of non-cancer care, and greater HCSE were significantly positively associated with adherence to both examinations. Greater depressive symptoms were significantly negatively associated with adherence to both examinations.

In multivariable analyses, higher SES, having a regular source of cancer care, and greater HCSE remained significantly positively associated with adherence to both examinations. Greater depressive symptoms remained significantly negatively associated.

Discussion

Our cross-sectional, population-based study examined the frequency and correlates of adherence to skin examinations among AYA survivors of melanoma. We observed high rates of adherence to skin self-examination but lower rates of physician-conducted skin examination, and significant associations between skin examination adherence and several sociodemographic, clinical, and psychosocial factors.

The high rate of frequent SSE in this sample is encouraging, as more than 50% of melanomas are detected by patients or significant others.[29–31] While self-surveillance is important for early detection, however, the lower rate of AYA melanoma survivors engaged in yearly PSE in this study is concerning. Annual PSE ensures that survivors receive comprehensive, full-body skin examinations along with other clinically indicated surveillance procedures (e.g., imaging), and practicing both SSE and PSE are associated with thinner lesions at diagnosis.[32] Our findings align with recent research identifying greater likelihood of nonadherence to PSE in younger survivors of melanoma, and further highlight this young age group as at risk for not adequately meeting melanoma surveillance recommendations.[14]

Health care self-efficacy was most consistently associated across all skin examination outcomes. Emerging research has identified the importance of HSCE in adherence to guideline-based cancer follow-up care for AYAs across cancer types.[33,34] The learned process of building confidence in health care navigation and care self-management after a cancer diagnosis may prove to be a key factor in facilitating long-term adherence.

Similarly, having a regular source of non-cancer care was associated with PSE and adherence to both exams. As nearly half of AYA survivors disengage from long-term cancer follow-up,[15] maintaining a relationship with a primary care provider may provide a critical safety net in counseling and navigating young melanoma survivors towards specialized cancer care (e.g., dermatologic or oncology).[35–37] Although primary care providers express willingness to care for young cancer survivors, these practitioners report substantial knowledge gaps, including a lack of familiarity with surveillance guidelines.[38,39] Thus, targeted medical education and training for primary care practitioners in addition to coordinated transitions to primary care after treatment (including survivorship care plans and/or shared care models) may continue to strengthen the role of general providers in facilitating adherence to follow-up care among young adult melanoma survivors.

Greater depressive symptoms in the past week were associated with less uptake of PSE and adherence to both exams. Although younger age has been identified as a predictor of greater psychological distress in younger patients with melanoma,[40] the relationship between depressive symptoms and adherence to surveillance has not been extensively studied among AYA survivors of melanoma. Our findings emphasize the need for screening of AYA survivors of melanoma for depression and other mental health issues, as undertreatment of psychological distress (cancer-related or otherwise) may impair adherence to recommended surveillance.

Both SES and Hispanic ethnicity were associated with adherence to skin examination in this sample, with higher SES consistently associated with greater adherence. Young survivors of melanoma from lower SES and/or Hispanic backgrounds may have distinct barriers which lead to suboptimal surveillance, including cost of care, lower health literacy, poorer physician-patient communication, lack of proximal services, or lack of culturally competent care.[41] Hispanic survivors in this sample were 88% less likely to engage in annual PSE in comparison to non-Hispanics (the majority of which were non-Hispanic white). As Hispanic ethnicity and lower SES have been linked to more advanced melanoma at diagnosis and decreased survival,[41–44] both sociodemographic factors necessitate further research to understand potential barriers that these highly at-risk AYA survivors of melanoma may face.

Several limitations of this study should be noted. The cross-sectional design limits our ability to make causal inference. Participants were drawn from Los Angeles County, which limits the generalizability of the results to large metropolitan areas with similar demographics. Because non-Hispanic white individuals were more likely to respond to the survey than Hispanics, and due to the low number of Hispanics included in the sample, generalizability is limited and interpretation must be drawn with caution.

SSE was frequently reported in our sample, potentially limiting our ability to detect important correlates with low variability. We did not ascertain the extent to which survivors performed SSE (e.g., specific areas of the body), so it is unknown whether self-skin examination was performed comprehensively or effectively by these survivors. Further, information about patient counseling regarding the need to perform SSE, or other aspects of patient-provider counseling and communication was not available.

Additionally, while melanoma is one of the most common AYA cancers, it remains a relatively rare cancer and sample size limitations may have reduced power to detect significant effects. Nevertheless, the use of well-validated scales and population-based design are important strengths of the study. The use of cancer registry data enabled comparison of responders to non-responders and mitigates the selection bias inherent in clinical recruitment where patients are already in care. Finally, although our response rate was 48%, this figure exceeds the response rate for similar population-based studies of the target AYA population.[45]

In summary, we found high adherence to SSE but lower uptake of PSE among young survivors of melanoma and identified several correlates to guide future research. Studies that examine the discrepancy between rates of PSE and SSE, and that explore disparities by SES and ethnicity and barriers to surveillance adherence may be beneficial to developing interventions to improve adherence in these at-risk groups. In addition, the role of primary care providers as potential facilitators to adherence should be further explored. Interventions that increase HCSE (for example, survivorship care plans or patient counseling tailored to younger melanoma survivors) may boost survivors' self-confidence and willingness to engage in follow-up care. Finally, screening for and treating depression and other mental health conditions may increase adherence to guideline-recommended surveillance in AYA survivors of melanoma.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations key:

AYA	Adolescent and young adult

UV	Ultraviolet
PSE	Physician-conducted skin examination
SSE	Skin self-examination
NCCN	National Comprehensive Cancer Network
AAD	American Academy of Dermatology
SEER	Surveillance, Epidemiology, and End Results
SES	Socioeconomic status
AJCC	American Joint Committee on Cancer
ITR-3	Intensity of Treatment Rating Scale 3.0
CES-D	Center for Epidemiological Studies Depression Scale
HCSE	Health care self-efficacy

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Table 1.

Characteristics of sample (N=128)

	N (%)
Mean age at survey (M[SD])	31.74 (4.47)
Age group at survey	
≤30 years	46 (35.9)
>30 years	82 (64.1)
Gender	
Female	78 (60.9)
Male	50 (39.1)
Stage at diagnosis	
Stage 1 (Local)	111 (86.7)
Stage 2 (Regional)	2 (1.56)
Stage 3 (Distant)	12 (9.38)
Unknown	3 (2.34)
Ethnicity	
White, non-Hispanic	107 (83.6)
Hispanic	13 (10.2)
Mixed race/other	8 (6.25)
Socioeconomic status	
1st quintile (lowest)	10 (7.81)
2nd quintile	13 (10.2)
3rd quintile	28 (21.9)
4th quintile	33 (25.8)
5th quintile (highest)	44 (34.4)
Years since diagnosis (M[SD])	11.82 (3.58)
Provided a written treatment summary	
Yes	37 (29.4)
No/Don’t Know	89 (70.6)
Regular source of non-cancer care	
Yes	97 (77.6)
No	28 (22.4)
Depressive symptoms (CES-D) (M[SD])	9.53 (8.81)
Health care self-efficacy (M[SD])	8.33 (1.24)
Perceived risk	
Much less	5 (4.27)
Less	4 (3.42)
About the same	17 (14.5)
Greater	47 (40.2)
Much greater	44 (37.6)

Table 2.

Frequency of skin exam among young adult melanoma survivors (N=128)

	N (%)
Physician-based skin exam	
More frequently than yearly	37 (29.8)
Approximately yearly	44 (35.5)
Less frequently than yearly	35 (28.2)
Never	7 (5.65)
Not sure	1 (0.81)
Skin self-exam (SSE)	
Less than 6 months ago	100 (82.0)
6 months to 1 year ago	10 (8.20)
More than a year ago, but less than two years ago	6 (4.92)
2 years ago or more	2 (1.64)
Never	1 (0.82)
Not sure	3 (2.46)
Both exams	
Both exams within recommended guidelines	71 (58.7)
Neither exam	12 (9.92)
Physician exam but no SSE	9 (7.44)
SSE but no physician exam	29 (24.0)

Table 3

Bivariate and multivariable models of correlates of skin examination among young adult melanoma survivors (N=128)

	Physician skin exam		Self-skin exam		Both exams	
	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable
	OR [95% CI]	AOR [95% CI]	OR [95% CI]	AOR [95% CI]	OR [95% CI]	AOR [95% CI]
Characteristic						
Current age at time of survey[a]	1.04 (0.96–1.14)	1.01 (0.85–1.21)	0.93 (0.82–1.05)	0.91 (0.80–1.03)	1.02 (0.94–1.11)	1.02 (0.87–1.18)
Sex (ref group, male)	1.41 (0.64–3.10)	1.55 (0.44–5.44)	0.78 (0.27–2.28)	0.66 (0.21–2.07)	0.93 (0.43–2.03)	0.84 (0.28–2.58)
Stage at diagnosis[b]	0.83 (0.45–1.52)	0.57 (0.23–1.50)	1.54 (0.52–4.56)	1.87 (0.57–6.17)	0.78 (0.43–1.41)	0.64 (0.28–1.48)
Hispanic (ref group, non-Hispanic)	0.22 (0.06–0.82) *	0.12 (0.02–0.98) *	0.45 (0.10–1.99)	–	0.28 (0.08–1.03) +	0.22 (0.03–1.56)
Socioeconomic status (lowest to highest quintile)[b]	1.72 (1.24–2.38) **	1.71 (1.01–2.90) *	1.43 (0.97–2.10) +	1.44 (0.97–2.14) +	1.66 (1.21–2.27) **	1.61 (1.01–2.58) *
Years since diagnosis[a]	0.89 (0.78–1.02) +	0.84 (0.69–1.03) +	0.93 (0.77–1.11)	–	0.89 (0.78–1.01) +	0.85 (0.71–1.02) +
Written treatment summary (y/n)	4.41 (1.55–12.54) **	3.55 (0.61–20.82)	1.70 (0.51–5.62)	–	4.38 (1.63–11.75) **	2.02 (0.51–7.94)
Regular source of non-cancer care (y/n)	5.24 (2.05–13.42) ***	8.59 (1.94–37.98) **	1.66 (0.51–5.45)	–	4.23 (1.61–11.09) **	4.99 (1.29–19.37) *
Depressive symptoms[a]	0.94 (0.89–0.98) **	0.94 (0.87–1.01) +	0.74 (0.23–2.36)	–	0.93 (0.88–0.98) **	0.93 (0.87–0.99) *
Health care self-efficacy[a]	3.02 (1.87–4.88) ***	3.60 (1.57–8.25) **	1.55 (1.05–2.31) *	1.58 (1.05–2.37) *	2.63 (1.65–4.17) ***	2.46 (1.21–5.01) *
Perceived risk[b]	1.23 (0.85–1.79)	–	0.99 (0.60–1.67)	–	1.16 (0.79–1.71)	–

All models adjusted for age, sex, and stage at diagnosis

[a]Continuous variables

[b]Ordinal variables

+P<.10;

*P<.05,

**P<.01,

***P<.001