

# **HHS Public Access**

Author manuscript

Pediatr Blood Cancer. Author manuscript; available in PMC 2017 March 01.

Published in final edited form as:

Pediatr Blood Cancer. 2016 March; 63(3): 554–557. doi:10.1002/pbc.25811.

# Skin Cancer Surveillance Behaviors among Childhood Cancer Survivors

Jerod L. Stapleton, PhD<sup>a,b,c</sup>, Kristina L. Tatum, MS<sup>a</sup>, Katie A. Devine, PhD<sup>a,b,c,e</sup>, Sue Stephens, LCSW, ACSW<sup>a</sup>, Margaret Masterson, MD<sup>a,e</sup>, Amna Baig, MPH<sup>c</sup>, Shawna V. Hudson, PhD<sup>a,c,d</sup>, and Elliot J. Coups, PhD<sup>a,b,c</sup>

<sup>a</sup>Rutgers Cancer Institute of New Jersey, Rutgers, The State University of New Jersey, New Brunswick, NJ, USA

<sup>b</sup>Department of Medicine, Rutgers Robert Wood Johnson Medical School, Rutgers, The State University of New Jersey, New Brunswick, NJ, USA

<sup>c</sup>Department of Health Education and Behavioral Science, Rutgers School of Public Health, Rutgers, The State University of New Jersey, Piscataway, NJ, USA

<sup>d</sup>Department of Family Medicine and Community Health, Rutgers Robert Wood Johnson Medical School, Somerset, NJ, USA

<sup>e</sup>Department of Pediatrics, Rutgers Robert Wood Johnson Medical School, Rutgers, The State University of New Jersey, New Brunswick, NJ, USA

#### **Abstract**

The risk of developing skin cancer is elevated among childhood cancer survivors (CCS), particularly among those treated with radiation. This survey study examined the skin cancer surveillance behaviors of 94 CCS. Approximately 48% of CCS had ever conducted skin self-examination and 31% had ever received a physician skin examination. Rates of physician skin examination were 2.5 times higher among CCS treated with radiation compared to those without radiation. However, rates of skin self-examinations did not differ based on treatment history. These findings highlight the need to promote skin cancer surveillance as an important aspect of CCS survivorship care.

#### Keywords

childhood cancer survivorship; skin self-examination; physician skin examination; skin cance
surveillance; cancer screening and early detection; melanoma

#### Introduction

The development of secondary malignancies is an important health concern for childhood cancer survivors (CCS). Non-melanoma skin cancers (NMSC) represent 41% of all secondary cancers in CCS [1] and melanoma, the most fatal skin cancer, accounts for 4% [2]. The incidence of NMSC among CCS between the ages of 35 to 44 years is comparable to individuals aged 75 and older in the general population [1]. Melanoma rates are 4 times higher for CCS compared to the general population [3]. CCS treated with radiation are 6.3 times more likely to develop NMSC compared to CCS receiving other treatments [1]. It is important that CCS engage in skin cancer surveillance and early detection behaviors, including skin self-examination (SSE) and physician skin examination (PSE). Routine skin surveillance by skin cancer patients and physicians are associated with diagnosis of smaller skin tumors [4,5]. Lower rates of lethal melanoma have been observed among patients who monitor their skin [6].

The Children's Oncology Group recommends that CCS with a history of radiation treatment conduct monthly SSE and receive annual PSE [7]. The National Cancer Institute encourages annual PSE for all CCS [8]. Little is known about CCS skin cancer surveillance rates aside from a few studies that report suboptimal rates of PSE and SSE [9–11]. This survey study provides additional data on the prevalence of SSE and PSE among CCS and expands the literature by: (1) examining the prevalence of physician conversations about skin cancer early detection; and (2) examining whether CCS who report recent SSE are doing so in a thorough manner, defined as comprehensively examining all body areas and utilizing partner assistance to examine hard-to-see body locations [12]. In addition, this study is the first to examine whether CCS treated with radiation, and at higher risk for skin cancer, are more likely to report skin surveillance behaviors compared to CCS who did not receive radiation treatment.

#### **Methods**

Participants were CCS enrolled in the long-term follow-up (LTFU) care program at Rutgers Cancer Institute of New Jersey. This program provides risk-based survivorship follow-up care based on COG guidelines and communicates as needed with patients' primary care providers. Patients are referred from the institute and local pediatric cancer treatment facilities to the LTFU program when they are two or more years post cancer treatment. Most patients are seen annually. For skin cancer prevention, LTFU patients receive information and referrals for skin cancer surveillance and sun protection. LTFU providers may perform a skin exam of fields of radiation per COG follow-up guidelines but referrals are made for full body PSE. Study eligibility criteria were: 18 years of age or older; diagnosed with cancer before age 20; no severe cognitive deficits; and English speaking. The University's Institutional Review Board approved all procedures and all participants provided informed consent before completing the survey.

All eligible CCS on the LTFU clinic's newsletter mailing list were mailed a study invitation letter and instructions for completing the survey either online (a link and personal identification number) or with an enclosed paper survey. A total of 175 recruitment packets

were mailed between December 2013 and February 2014. Non-responders received postcard reminders, telephone calls, and a follow-up recruitment packet mailed approximately one month after the initial recruitment material. Participants received a \$25 gift card for completing the survey.

Survey measures included standard demographic items and a series of questions about SSE and PSE. To assess SSE, participants indicated whether they had ever examined the skin on any part of their body for skin cancer, and if so, the length of time since their last SSE. Participants who reported conducting a recent SSE (i.e., in the past 2 months) answered additional questions related to the thoroughness of their SSE practices [12], including whether they deliberately and systematically examined a variety of body area locations for skin cancer, whether they typically receive assistance when doing SSE, and what they look for during SSE. To assess PSE, participants indicated whether a doctor or other health care professional had ever examined their skin for signs of skin cancer, and if so, when they last received a PSE. Participants also indicated whether they had talked to a doctor about various skin cancer surveillance and preventive behaviors since their childhood cancer diagnosis.

#### Results

13 of the 175 mailed invitation packets were returned as undeliverable and 7 participants were deemed ineligible. Of the remaining 155 invitations, 94 participants completed the survey (60.6% completion rate). Participants were 46% female with a mean age of 24.6 years (SD = 4.45). Racial characteristics were: 79.8% White, 7.4% Black, 7.4% Asian, and 8.4% other. Hispanic ethnicity was reported by 14% of participants. Most participants had a 4-year college degree or higher (52.1%) followed by some post-high school education (31.9%), high school degree or equivalent (9.6%), and partial high school (including current enrollment) (6.4%). Most participants were single (86.2%). There were no significant differences in age, race, or ethnicity between participants and non-participants.

Among all participants, 47.9% had ever conducted a SSE and 30.9% had ever received a PSE (Table I). Among those who had ever conducted SSE, 44.4% had performed SSE within the past 2 months. Among those who had ever received a PSE, 62.1% reported a PSE in the past 12 months. Although many participants reported a doctor conversation about their risk of skin cancer (63.0%), it was less common to have conversations about conducting SSE, how to perform SSE, or scheduling a PSE. Comparison tests between CCS with a history of radiation treatment and those without revealed non-significant differences on the likelihood of ever conducing SSE, conducting SSE in the past 2 months, and doctor conversations related to SSE. However, participants treated with radiation were more likely to have ever received a PSE (p = 0.002) and to have doctor conversations about skin cancer (p = 0.012) and scheduling a PSE (p = 0.054). With respect to SSE practices, only 30.0% of participants who performed recent SSE reported thoroughly examining all body locations and 65.0% did not receive assistance from a partner (Table II).

### **Discussion**

Despite the importance of skin cancer surveillance among CCS, a majority of participants had never conducted a SSE or received a PSE and only 1 in 5 met recommendations for monthly SSE or annual PSE. These findings are consistent with prior studies that show 27% of CCS ever had a PSE [11], 13% had a PSE in the past year [9], and 27% performed monthly SSE [10]. A novel finding was more than 1 in 3 CCS did not recall talking with a doctor about skin cancer. Doctor conversations about skin surveillance were even less common. Such conversations may have occurred with caregivers rather than CCS following treatment resulting in lower recall among CCS. The findings also suggest that CCS with a history of radiation treatment were more likely to have received a PSE, talked with a doctor about PSE, and talked with a doctor about their risk of skin cancer. However, the overall PSE rate was suboptimal. Participants were not asked to report whether they had a general physician examination in the past year. Thus, we are not able to determine the rate of receiving a PSE among individuals who had received general physical exams. Rates of SSE and doctor conversations about SSE were also suboptimal and were not significantly different based on radiation treatment history. In addition, many participants who reported recent SSE did not report conducting a thorough SSE by systematically checking all body areas and utilizing partner assistance.

Study participants were enrolled in a LTFU program. However, the majority of CCS treated in the United States do not receive survivor-focused care [13]. Survivor-focused medical care has been linked to higher levels of screening behavior [13] and knowledge about late effects risk [14]. Thus, the rates of skin cancer surveillance observed among study participants may overestimate rates of the general CCS population.

There remains a dearth of evidence-based interventions designed to improve skin cancer surveillance among CCS with the notable exception of an ongoing efficacy trial of patient and physician activation interventions in increasing PSE and SSE among CCS [15]. Future CCS interventions could be modeled after existing efficacious skin cancer surveillance educational interventions targeting high-risk groups with low rates of skin screening, including relatives of melanoma patients [16,17] and transplant patients [18,19]. It is also important to consider the benefit of engaging CCS with newly developed technologies for skin monitoring, such as teledermoscopy, that allow for patients to take photographs of skin lesions found during SSE and share them with physicians [15]. The study results underscore the need to develop and test behavioral interventions and to promote skin cancer surveillance and prevention as an important aspect of CCS survivorship care, particularly among CCS treated with radiation.

#### Acknowledgments

This research was supported by a Cancer Prevention and Control Pilot Award from The Cancer Institute of New Jersey (Stapleton & Coups) and by National Cancer Institute grants K07CA175115 (Stapleton) and P30CA072720 (Rutgers Cancer Institute of New Jersey). The authors would like to thank Katie Darabos, Dawn Carey, Richard Drachtman, Stephanie Samuel, and Sharon Manne for their valuable contributions.

## Abbreviation key table

**CCS** childhood cancer survivors

NMSC non-melanoma skin cancer

SSE skin self-examination
PSE physician skin-exam

#### References

- Perkins JL, Liu Y, Mitby PA, Neglia JP, Hammond S, Stovall M, Meadows AT, Hutchinson R, Dreyer ZE, Robison LL, Mertens AC. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study. Journal of Clinical Oncology. 2005; 23:3733–3741. [PubMed: 15923570]
- Friedman DL, Whitton J, Leisenring W, Mertens AC, Hammond S, Stovall M, Donaldson SS, Meadow AT, Robinson LL, Neglia JP. Subsequent neoplasms in 5-year survivors of childhood cancer: The Childhood Cancer Survivor Study. Journal of the National Cancer institute. 2010; 102:1083–95. [PubMed: 20634481]
- 3. Curtis, RE.; Freedman, DM.; Ron, E.; Ries, LAG.; Hacker, DG.; Edwards, BK.; Tucker, MA.; Fraumeni, JF., Jr, editors. New Malignancies Among Cancer Survivors: SEER Cancer Registries, 1973–2000. National Cancer Institute; Bethesda, MD: 2006. NIH Publ. No. 05-5302
- 4. Swetter SM, Pollitt RA, Johnson TM, Brooks DR, Geller AC. Behavioral determinants of successful early melanoma detection. Cancer. 2012; 118:3725–3764. [PubMed: 22179848]
- Aitken JF, Elwood M, Baade PD, Youl P, English D. Clinical whole-body skin examination reduces the incidence of thick melanomas. International Journal of Cancer. 2010; 126:450–458.
- Berwick M, Armstrong BK, Ben-Porat L, Fine J, Kricker A, Eberle C, Barnhill R. Sun exposure and mortality from melanoma. Journal of National Cancer Institute. 2005; 97:195–199.
- The Children's Oncology Group. Establishing and enhancing services for childhood cancer survivor: Long-term follow-up program resources guide. 2007.
- 8. The National Cancer Institute. [Accessed June 10, 2015] Late effects of treatment for childhood cancer. http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient/page2
- 9. Rebholz CE, Rueegg CS, Michel G, Ammann RA, Von Der Weid NX, Kuehni CE, Spycher BD. Clustering of health behaviours In adult survivors of childhood cancer and the general population. British Journal of Cancer. 2012; 107:234–242. [PubMed: 22722311]
- Hudson MM, Tyc VL, Srivastava DK, Gattuso J, Quargnenti A, Crom DB, Hinds P. Multicomponent behavioral intervention to promote health protective behaviors in childhood cancer survivors: The protect study. Medical and Pediatric Oncology. 2002; 39:2–11. [PubMed: 12116072]
- 11. Nathan PC, Ness KK, Mahoney MC, Li Z, Hudson MM, Ford JS, Landier W, Stovall M, Armstrong GT, Henderson TO, Robinson LL, Oeffinger KC. Screening and surveillance for second malignant neoplasms in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Annals of Internal Medicine. 2010; 153:442–451. [PubMed: 20921543]
- 12. Weinstock MA, Risica PM, Martin RA, Rakowski W, Dube C, Berwick M, Goldstein MG, Acharyya S, Lasater T. Melanoma early detection with thorough skin self-examination: The check it out randomized trial. American Journal of Preventive Medicine. 2007; 32:517–524. [PubMed: 17533068]
- Nathan PC, Greenberg ML, Ness KK, Hudson MM, Mertens AC, Mahoney MC, Gurney JG, Donaldson SS, Leisening WM, Robinson LL, Oeffinger KC. Medical care in long-term survivors of childhood cancer: A report from the childhood cancer survivor study. Journal of Clinical Oncology. 2008; 26:4401–4409. [PubMed: 18802152]
- 14. Lindell RB, Koh SJ, Alvarez JM, Koyama T, Eshbenshade AJ, Simmons JH, Friedman DL. Knowledge of diagnosis, treatment history and risk of late effects among childhood cancer

- survivors and parents: The impact of a survivorship clinic. Pediatric Blood Cancer. 2015; 62:1444–1451. [PubMed: 25894324]
- 15. Daniel CL, Armstrong GT, Keske RR, Davine JA, McDonald AJ, Sprunck-Harrild KM, Coleman C, Haneuse SJ, Mertens AC, Emmons KM, Marghoob AA, Elkin EB, Dusza SW, Robinson LL, Geller AC. Advancing Survivors' Knowledge (ASK) about skin cancer study: study protocol for a randomized controlled trial. Trials. 2015; 16:109. [PubMed: 25873142]
- Geller AC, Emmons KM, Brooks DR, Powers C, Zhang Z, Koh HK, Heeren T, Sober AJ, Li F, Gilchrest BA. Randomized trials to improve early detection and prevention practices. Cancer. 2006; 107:806–814. [PubMed: 16832795]
- 17. Manne S, Jacobsen PB, Ming ME, Winkel G, Dessureault S, Lessin SR. Tailored versus generic interventions for skin cancer risk reduction for family members of melanoma patients. Health Psychology. 2010; 29:583. [PubMed: 21090893]
- Robinson JK, Rurrisi R, Mallett KA, Stapleton J, Boone SL, Kim N, Riyat NV, Gordon EJ. Efficacy of an educational intervention with kidney transplant recipients to promote skin self-examination for squamous cell carcinoma detection. Archives of Dermatology. 2011; 147:689–695. [PubMed: 21339418]
- Feuerstein I, Geller AC. Skin cancer education in transplant recipients. Program Transplant. 2008; 18:232–241.

TABLE I
Skin Cancer Surveillance Behaviors and Doctor Conversations Among the Full Sample of Childhood Cancer Survivors and by Radiation Treatment History

	Full Sample (n = 94) %	History of radiation treatment (n = 29)	No history of radiation treatment (n = 65)	$p^c$
Ever conducted a skin self-examination (SSE)				0.344
No	52.1	44.8	55.4	
Yes	47.9	55.2	44.6	
Time since last $SSE^a$				$0.224^{d}$
Within the past 2 months	44.4	31.2	51.7	
More than 2 months	55.6	68.8	48.3	
Ever received a physician skin examination (PSE)				0.002
Don't know	22.3	10.3	27.7	
No	46.8	34.5	52.3	
Yes	30.9	55.2	20.0	
Time since last $PSE^b$				$0.702^{d}$
Within the past 12 months	62.1	56.2	69.2	
More than 1 year	37.9	43.8	30.8	
Doctor talked to you about your risk of skin cancer				0.012
No	37.0	17.9	45.3	
Yes	63.0	82.1	54.7	
Doctor suggested that you regularly examine your skin for signs of skin cancer				0.174
No	50.0	39.3	54.7	
Yes	50.0	60.7	45.3	
Doctor talked about the best way to examine your skin				0.223
No	72.8	64.3	76.6	
Yes	27.2	35.7	23.4	
Doctor encouraged you to schedule a physician skin exam				0.054
No	59.8	44.0	66.7	
Yes	40.2	56.0	33.3	

<sup>&</sup>lt;sup>a</sup>Among participants who reported ever conducting a SSE.

b Among participants who reported ever receiving a PSE.

<sup>&</sup>lt;sup>c</sup>p-values from comparison tests between CCS with and without a history of radiation treatment (chi-square tests were performed except where noted)

 $d_{\mbox{\sc Fisher's}}$  Exact Test was performed due to lack of cell size for comparison

TABLE II

Thorough Skin Self-Examination Practices among Childhood Cancer Survivors who Conducted Skin Self-Examination in the Past 2 Months (n = 20)

	%		
Body locations examined deliberately and systematically for skin cancer			
Front from the waist up	80.0		
Calves	70.0		
Front of thighs and legs	75.0		
Upper back	75.0		
Back of thighs	60.0		
Buttocks and lower parts of the back	70.0		
Bottom of feet	60.0		
Scalp	35.0		
All of the above	30.0		
Who helps perform skin self-examination?			
No one	65.0		
Parent	25.0		
Spouse or partner	5.0		
Sibling	5.0		
What does CCS look for when doing skin self-examination?			
New moles or skin growths	85.0		
Moles that look suspicious	65.0		
Your moles	55.0		
Birthmarks or freckles in general	35.0		
Nothing in particular	5.0		
None of the above	10.0		