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Factors influencing scalp cooling discussions and use at a large academic institution: a single-center retrospective review

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Abstract

Purpose Chemotherapy-induced alopecia (CIA) is a stigmatizing and psychologically devastating side effect of cancer treatment. Scalp cooling therapy (SCT) is the most effective method to reduce CIA, yet it is underutilized. We investigated factors that may impact scalp cooling discussion and use.

Methods We performed a retrospective review of cancer patients from 2000 to 2019 who had documentation of SCT discussion in the electronic medical record. The University of Michigan Rogel Cancer Center registry was used to identify the total number of cancer patients eligible for SCT during 2015–2019. Chi-square tests were used for outcome and patient characteristic comparisons ($p < 0.05$).

Results From 2000 to 2019, 194 patients had documentation of SCT discussion. Of those, 72 (43.6%) used SCT, 93 (47.9%) did not use SCT, and the remaining 29 (17.8%) had unknown SCT use. A total of 5615 cancer patients were eligible for SCT from 2015 to 2019. As compared to those who did not have documented SCT discussions, patients who had documentation of SCT discussions in that period ($n = 161$, 3.0%) were more likely to be female, have breast cancer, be less than 45 years old, and live in a zip code with average income $> US \$100,000$ (all $p < 0.0001$). Between 2015 and 2019, 57 patients (1.02%) used SCT. On univariate analysis, patient-initiated conversation about SCT ($p = 0.01$) and age less than 65 ($p = 0.03$) were significantly associated with decision to use SCT.

Conclusion There were distinctions in the types of patients who have documented discussions about SCT. Improving patient knowledge about the availability of SCT and increasing access to this technology for all eligible cancer patients may enable more patients to achieve improved quality of life by reducing or preventing CIA.

Keywords Scalp cooling therapy · Chemotherapy-induced alopecia · Cold cap therapy · Hair loss prevention · Manual cold caps

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Introduction

Chemotherapy-induced alopecia (CIA) is a highly stigmatized and psychologically devastating side effect of cancer treatment [1]. Scalp cooling systems are the most effective, FDA-cleared method identified to date for reducing CIA, with data from clinical trials supporting their efficacy [2]. However, most hospitals only permit manual cold cap use, which requires patients to privately rent the caps and bring their own equipment to the hospital for use.

Currently, there is a difference in the options hospitals offer patients with regard to scalp cooling therapy (SCT), and there are notable barriers for patients to access centers with scalp cooling [3, 4]. Various other factors have been postulated to impact patient use of SCT, including

awareness, provider support, and effort involved in addition to financial, efficacy, and safety concerns [3, 5–8].

While it is widely known that SCT use is low in the USA, especially when compared to European counterparts, little data exist about the overall use of SCT at specific centers, and which factors impact SCT use [1, 3, 5, 9–11]. To further understand the landscape of patient SCT use, we present a single-center retrospective study of scalp cooling implementation at an academic institution that permits manual cold caps.

Methods

We conducted a retrospective cohort study of University of Michigan Rogel Cancer Center patients who have documentation of SCT discussion in the electronic health record (EHR) between January 2000 and December 2019. During this period, the SCT option offered to patients at this institution was use of manual cold caps with patient-supplied dry ice. EMERSE, a medical record search engine, was used to identify University of Michigan charts with the following key words: “cold caps,” “cold cap,” “scalp cooling,” “Paxman Scalp Cooling,” “Dignicaps,” “Dignicap,” “Paxman,” “Penguin,” “scalp hypothermia,” “ice cap,” and “ice caps” [12]. Further chart review was conducted to identify patients with documentation of SCT discussion for inclusion in this study.

Demographic, disease characteristics, and cancer treatment information was collected on the subset of patients for whom SCT discussion was documented. Each chart was reviewed to determine who initiated the SCT conversation (patient, provider, or unclear) and if the patient used SCT (yes, no, unknown). Efficacy and side effects of SCT and the medical management of side effects were also noted for those who used SCT. Scalp cooling was considered effective when the note stated that the patient was “satisfied” (or similar words that indicated satisfaction) with their result or when the provider noted that there was “little to no hair loss.” If efficacy was not clearly noted, then this was charted as “unclear.” Data were collected and corroborated by 2 independent reviewers (TN, MN).

Characteristics of cancer patients who decided to use SCT were compared to those who opted out. Cancer patients who did not have a clearly documented decision about SCT use or did not undergo chemotherapy were excluded from this analysis.

Demographic and disease specific information of cancer patients with documentation of SCT discussion were compared to those without documentation among the general cancer patient population eligible for SCT in the University of Michigan Rogel Cancer Center Registry. Eligibility for SCT was defined as patients with solid tumor cancers

who underwent chemotherapy. The analysis of this group was limited to years 2015 to 2019. Due to limitations in the data available from the registry, chemotherapy setting and chemotherapy type for the entire population could not be included in this analysis.

Descriptive statistics were used to report baseline patient characteristics. Chi-square tests were used for outcome and patient characteristic comparisons. P-values of < 0.05 were considered statistically significant. This study was approved by the University of Michigan Institutional Review Board.

Results

From 2000 to 2019, 194 patients had documentation of SCT discussion in the EHR (Table 1). Most of the documented discussions (161/194, 83%) occurred after 2015. Thirty received chemotherapy at another institution, of which seven patients were documented as having received chemotherapy elsewhere due to lack of support for cold caps (e.g., no freezers for manual caps, no machine system).

During 2015–2019, 5615 cancer patients were identified who were eligible for SCT use at the study center, of which 161 patients (2.9%) had documented SCT discussions during this period and 57 patients (1.02%) were identified as having used SCT. As compared to the patients who did not have documentation of SCT discussions ($n = 5454$), those with documentation of SCT discussions (3.0%) were more likely to be female, have breast cancer, be less than 45 years old, and live in a zip code with average income > US \$100,000 (all $p < 0.0001$) (Table 2). In addition, of those with documented SCT discussions, 82% were white and 9% Black, as compared to 90% and 5% in the population without documented SCT discussions ($p = 0.01$) (Table 2).

From 2000 to 2019, 165 (165/194, 86.6%) patients had clear documentation in the EHR of a SCT decision (Table 1). Of those, 72 (43.6%) chose to use SCT, while 93 (56.4%) did not choose this option. Patients 65 years old or younger were significantly more likely to use SCT than those older than 65 years of age ($p = 0.03$). Forty-eight percent of patients who initiated the conversation about SCT with their providers used SCT whereas only 9.6% of patients used SCT if the provider initiated the discussion ($p = 0.01$). No significant associations were identified between the decision to use SCT and type of cancer, average zip code income, living in a metropolitan versus non-metropolitan area, adjuvant (stage 1–3) versus palliative (stage 4) therapy, year of diagnosis, and undergoing anthracycline vs. non-anthracycline chemotherapy (Fig. 1).

Of the 37 patients for whom SCT efficacy could be clearly identified from the EHR, 26 (70.2%) had effective SCT. Side effects included “discomfort,” nausea/vomiting, pain, and headaches. No serious adverse events were noted.

Table 1 Characteristics of all cancer patients with documented clinical discussions of SCT from 2000 to 2019

	All cancer patients with documented clinical discussions of SCT (<i>n</i> = 194) (<i>n</i> , %)
Gender	
Male	4 (2.1)
Female	190 (98.0)
Race	
White	163 (84.0)
Black	15 (7.7)
Other	16 (8.2)
Type of cancer	
Breast cancer	154 (79.4)
Gynecologic	17 (8.8)
Lymphoma	8 (4.1)
Gastrointestinal	5 (2.6)
Genitourinary	2 (1.0)
Lung	2 (1.0)
Other	6 (3.1)
Age	
< 45	55 (28.4)
45–65	104 (53.6)
> 65	35 (18.0)
Zip code average income	
< \$100 k	110 (56.7)
> \$100 k	74 (38.1)
Out of state	10 (5.2)
Zip code metro/non-metro	
Metro	114 (58.8)
Non-metro	70 (36.1)
Out of state	10 (5.2)
Chemotherapy setting	
Adjuvant	155 (80.0)
Palliative	32 (16.5)
No chemo	7 (3.6)
Chemotherapy type	
Anthracycline	53 (27.3)
Non-anthracycline	120 (61.9)
Unclear ^a	21 (10.8)
Date of chemotherapy	
< 2010	4 (2.1)
2010–2015	29 (15.0)
2015 +	161 (83.0)
Decision to use	
Used SCT	72 (37.1)
Did not use SCT	93 (47.9)
No chemotherapy	7 (3.6)
Unclear	22 (11.3)
Initiation of conversation	
Patient	54 (27.8)
Provider	78 (40.2)
Unclear	62 (32.0)

^aPatients did not receive chemotherapy infusion at our institution and no clear documentation of what they received

Discussion

This is a single center retrospective study of scalp cooling practices at a large academic center that permits manual cold capping. In this study, a distinction was identified in the type of patients who were more likely to have documented discussions about SCT, which included younger, female breast cancer patients living in higher income areas. Our data also shows that a very small proportion of patients used SCT. Age (≤ 65 years old) and patient-initiated discussion about SCT were the significant factors found that positively impacted patient decisions to use SCT.

We identified a very narrow and specific patient population (female, breast cancer patients) that had documented discussions about SCT. To our knowledge, this is the first study to examine the characteristics of cancer patients offered SCT. However, we also found that most patients who used SCT at our institution were female, younger, and breast cancer patients. These findings are consistent with previously reported data on the landscape of SCT use and may be due to targeted offerings of SCT. In a 2012 Dutch registry study of 1411 chemotherapy patients who used SCT, 96% were women and 86% had breast cancer [13]. Both of the landmark clinical trials in the USA in 2017 also only reported on female, breast cancer patients [14, 15]. Recent data on the use of Paxman machines from 2017 to 2020 at major centers across the USA noted that 78% of patient users had breast cancer followed by 12% with gynecologic tumors, which parallels our data [9]. As a result of the expanded FDA clearance of SCT for all solid tumor cancers in 2017, all such patients should routinely be offered this technology, coupled with further studies on a broader group of cancer patients to assess efficacy with different factors including chemotherapy regimens. Furthermore, many male patients can also benefit from prevention of CIA, although they are infrequently offered and/or use SCT [16–18].

In addition to being female and having breast cancer, we found increased rates of documented SCT discussions with younger patients. Younger patients seeking privacy at work and who have young children may be more motivated to use SCT [8]. However, patients with a wide range of ages have been found to use and benefit from scalp cooling. In a 2018 registry study of cold cap use at the University of California-San Francisco, the median age of SCT use was 48, with a range from 27 to 83 years. In the Netherland Registry study, only 21% of patients were less than 45 years old [19]. The majority of patients using scalp cooling systems at major institutions across the USA were between the ages of 45–65 (55%), followed by 65–74 (18%), older than 75 (5%), and 25–44 (2%) [9]. Additional research with a larger sample size is needed to further investigate the impact of age on the decision to use SCT.

Table 2 Cancer patients with documented discussions of SCT compared to those without documented SCT discussions among total University of Michigan Cancer Center patient population eligible for SCT from 2015 to 2019 in a univariate analysis

	Documented SCT discussions (<i>n</i> = 161) (<i>n</i> , %)	No documented SCT discussions (<i>n</i> = 5,454) ^a (<i>n</i> , %)	<i>p</i> -value
Gender			
Male	2 (1)	2,464 (45)	<0.0001
Female	159 (99)	2,990 (55)	
Race			
White	132 (82)	4,889 (90)	0.008
Black	14 (9)	265 (5)	
Other/unknown	15 (9.3)	300 (5.5)	
Type of cancer			
Breast cancer	131 (81)	1,023 (19)	<0.0001
Other ^b	30 (19)	4,431 (81)	
Age			
< 45	45 (28)	555 (10)	<0.0001
45–65	87 (54)	2,925 (54)	
> 65	29 (18)	1,973 (36)	
Zip code average income			
< \$100 k	92 (57)	4,248 (78)	<0.0001
> \$100 k	60 (37)	883 (16)	
Out of state	9 (6)	323 (6)	
Metro/non-metro			
Metro	94 (58)	2,673 (49)	0.06
Non-metro	58 (36)	2,458 (45)	
Out of state	9 (6)	323 (6)	

^a5615 cancer patients were identified who were eligible for SCT use at the study center from 2015 to 2019, of whom 5454 did not have documentation of SCT discussion and/or use. Eligible patients were defined as patients with solid tumor cancers undergoing chemotherapy

^bOther cancers include gynecologic (15), lymphoma (5), gastrointestinal (GI) (4), lung (2), genitourinary (1), and other (3)

SCT is not generally covered by insurance and can be costly (approximately US \$300–\$500 per month of use). In a national survey of oncologists, the number one provider-reported reason for not discussing SCT with patients was financial concerns [5]. Although this cost may be prohibitive for many patients, we did not find a statistically significant difference in the use of SCT between patients who lived in higher versus lower income zip codes. While income by zip code may not serve as a fully accurate proxy for financial capacity, financial support programs (e.g., Hair to Stay, Cold Capital Fund, Cap & Conquer) and increased reimbursement with specific ICD and CPT codes (e.g., Z51.11, L65.9 & A9273, A9282) may increase access to SCT for patients of lower socioeconomic status. [20, 21]. Therefore, providers should not limit discussions based on presumed financial status [5]. Given the psychosocial distress of chemotherapy induced alopecia and SCT's proven efficacy for many patients, widespread insurance coverage would be ideal for all affected patients.

We also found that there was no difference between using or not using SCT based on the goal of chemotherapy (palliative versus curative), although given the small numbers

in our study this finding may be due to insufficient statistical power. Most SCT studies have focused principally on patients undergoing chemotherapy with curative intent [14, 22, 23]. Our results support discussing SCT with patients undergoing palliative chemotherapy as well.

Overall, a very small proportion of the patients at our large academic cancer center have documentation of discussing SCT from 2000 to 2019 (194 patients), with 1% of the eligible cancer patient using SCT from 2015 onward. The low discussion and usage rate is consistent with prior research noting the lack of availability and use of SCT, particularly in the USA [3, 4, 6, 8]. This may in part be due to lack of clinic protocols or known narrative language to educate patients about SCT. In a recent study, while the majority of providers were in favor of SCT, only 25% of oncology providers surveyed answered that they consistently initiated conversations with patients about SCT [5]. Similar to oncofertility programs that have increased education and provided clinical narratives to help providers discuss implementation of fertility preservation, it will be important to establish protocols for patient education about SCT [24]. The identified low rate

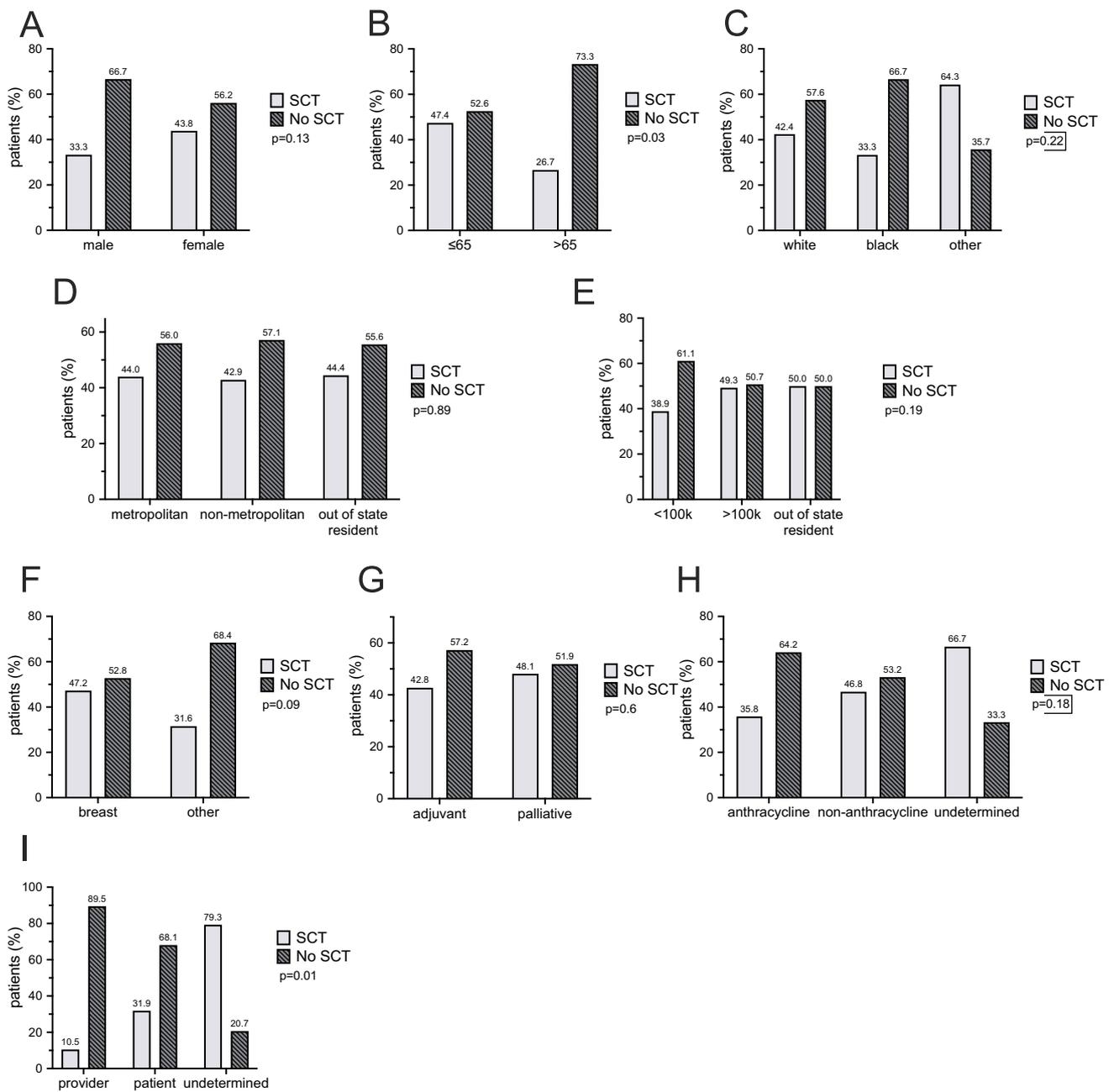


Fig. 1 Characteristics of cancer patients who decided to use SCT (gray bars) were compared to those who opted out (black bars) to determine factors influencing decision to use SCT. Patients who were 65 years old and younger (**B**, $p=0.03$) and those who initiated the SCT conversation with their provider (**I**, $p=0.01$) were significantly

more likely to use SCT. There was no statistically significant difference between patients who used SCT and those who did not based on gender (**A**), race (**C**), classification of zip code (**D**), average income of zip code (**E**), type of cancer (**F**), chemotherapy setting and (**G**), and chemotherapeutic agent (**H**)

may also be due to omission of documentation in the EMR about scalp cooling discussions with patients who did not express interest in using SCT. Further investigation into additional barriers to patient use of scalp cooling, such as effort involved, factors that impact efficacy (e.g., capping technique, chemotherapy regimen, hair care practices), and possible inconsistent or inaccurate communication about

implementation, will be necessary to increase use of SCT by appropriate candidates [3].

Limitations to our study relate to the retrospective nature of this study, which means there may be incomplete or variations in documentation regarding SCT by provider, lack of objective data regarding SCT efficacy, and inability to perform CTCAE grading of adverse events. Of note, in our

center, there were no scalp cooling systems available during the study dates, which may have influenced the lack of interest by patients and lack of discussion by staff about scalp cooling. Also, since much of the data regarding the safety and efficacy of scalp cooling was published later during the time period covered by our analysis, we may have underestimated the current rates of discussions about and use of SCT for avoidance of CIA.

In our study, we were able to identify that documented discussions about and use of SCT were limited and distinctions in the patient population was evident. Offering information about and access to SCT to all patients who are initiating chemotherapy for FDA-cleared indications could positively impact quality of life for patients with cancer through reducing or preventing CIA.

Author contribution All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by TN and MN, DP, and JG. The first draft of the manuscript was written by MN and TN and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.”

Data availability The data is located on a password-protected excel document and can be shared with the journal.

Code availability Not applicable.

Declarations

Ethics approval This study was IRB approved by the University of Michigan Institutional Review Board.

Consent to participate For the chart review, the University of Michigan Institutional Review Board approved a waiver of informed consent.

Consent for publication Not applicable. All data was de-identified.

Competing interests Dr. Jeruss receives research support from the National Institutes of Health (R01CA243916, R01214384), the Dynami Foundation, and A Sister’s Hope. She also serves as a consultant for COUR Pharmaceuticals.

Two authors (Ms. Madison Novice and Dr. Taylor Novice) are co-founders of a non-profit named Cap & Conquer whose mission is to fund scalp cooling therapy for low-income cancer patients and raise awareness about the treatment.

David Portney, Joshua Goyert, N. Lynn Henry, and Monika Burness have no conflicts of interest to declare.

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