

RESIDENT COMPETITION RESEARCH ARTICLES

The Perception of Chemotherapy-Induced Alopecia in Cancer Patients Currently Undergoing Treatment

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ABSTRACT

Background: Chemotherapy-induced alopecia (CIA) is a common adverse effect of chemotherapy. Eight percent of patients consider declining chemotherapy due to CIA risk.

Objective: To determine whether cancer patients who are actively receiving chemotherapy are interested in preventing or treating CIA.

Materials and Methods: This is a survey-based, cross-sectional study of cancer patients undergoing chemotherapy infusion at a tertiary medical center. Data including demographics, cancer diagnosis, medical literacy, quality of life, hair quality satisfaction, and costs patients were willing to accrue for CIA prevention/treatment were gathered.

Results: Sixty-two adults were enrolled, mostly 55 to 64 years of age, female (72.6%), and Caucasian (63.8%). Many patients were diagnosed with malignancies associated with a high rate of morbidity-mortality including ovarian, lung and pancreatic. In our cohort, all patients would not decline cancer treatment based on CIA risk. 94.6% of patients were unwilling to risk cancer recurrence, 80.9% additional side effects, 55.8% extra time outside of infusion and 47.9% to pay out-of-pocket for CIA prevention/treatment.

Conclusions: Patients with high cancer disease burden will not decline current treatment due to CIA risk. In addition, they are not willing to sustain additional discomfort, cost or time to prevent or treat CIA.

INTRODUCTION

Chemotherapy-induced alopecia (CIA) is among the five most common adverse events related to cancer treatment with 22% to 65% of chemotherapy patients experiencing anagen effluvium.¹⁻³ It is reported that 8% of patients consider declining chemotherapy due to CIA risk.⁷ Although most CIA does not result in permanent hair loss, hair often grows back with altered color, texture, and density.^{2,4-6}

CIA can be devastating for patients and quality of life (QOL) suffers because hair is used for personal expression and characterizes youth, health, beauty, religion and gender identity.⁸ Women are more impacted than men by CIA.^{9,10} Patients react differently to CIA depending on their values, cancer prognosis, degree of expected hair loss, physician counselling, and individual coping.^{4,8} Even if the hair loss itself is not upsetting, the constant reminder of illness can be overwhelming.^{2,4} Self-esteem declines after cancer diagnosis, and perception of body image can be exacerbated by CIA.³ It is difficult to differentiate CIA-related distress from confounding factors, such as poor cancer prognosis or treatment side effects, and may contribute to lack of significantly increased QOL in patients receiving CIA preventive measures.

Many chemotherapeutics, including some targeted therapies, cause CIA. More than 80% of patients receiving anti-microtubule agents experience CIA; the incidence of alopecia is > 60% with alkylators, 60% to 100% with topoisomerase inhibitors, and 10% to 50% with anti-metabolites. Epidermal growth factor receptor inhibitors (EGFRi) cause hair loss in 50% to 90%. Permanent

CIA after taxanes and EGFRi has been reported.¹¹

The goal of this cross-sectional study is to determine cancer patients' baseline knowledge of CIA, the effect CIA has on patients, the general interest in receiving CIA prevention/treatment, and costs patients are willing to accrue for therapy.

MATERIALS AND METHODS

Ethical Review

This study was approved by the University of California, Irvine Institutional Review Board and Chao Comprehensive Cancer Center Skin Disease-Oriented Team.

Study Participants and Data Collection

Participant enrollment took place over 24 weeks from December 2017 to May 2018. English-speaking, adult patients, currently undergoing chemotherapy infusion, who were able and willing to give verbal consent were enrolled. Patients who could not speak or read English, felt too ill or were disinterested in participating were not enrolled. Study data were collected and analyzed using REDCap (Research Electronic Data Capture).²¹

Survey Instrument

After reviewing CIA literature, three surveys were developed addressing demographics, hair quality satisfaction before and after CIA, QOL, as well as knowledge of CIA and CIA prevention/treatment (Appendix 1). Participants were asked what they would tolerate to minimize or treat CIA including time, side effects, cost, and cancer recurrence risk with predefined response categories. In cases where a 4-point Likert scale could be used, we asked patients to pick answers ranging from "not at all," "a little," "quite a bit," to "very much". In addition,

we used the only known disease-specific survey, Chemotherapy-induced Alopecia Distress Scale (CADS),²² to assess patient perceptions of body image and overall QOL (Appendix 2).

RESULTS

Demographic and Clinical Information

Sixty-two patients currently undergoing chemotherapy infusion were enrolled. The majority of participants were female (72.6%), with a mean age range 55 to 64 years. Annual household income ranged from < \$25,000 USD (32.0%) to > \$200,000 USD (12.0%). All patients were covered by medical insurance, were satisfied with coverage, and were undergoing traditional or targeted chemotherapy for cancer. The most common malignancy was ovarian (16.1%), followed by lung (11.3%), leukemia/lymphoma (11.3%) and pancreas (8.1%); a large proportion of patients were diagnosed with advanced malignancies associated with a high level of disease burden, morbidity and mortality. The most common chemotherapeutics used were carboplatin, cisplatin, oxaliplatin (38.7%), followed by docetaxel, paclitaxel (29.0%) and gemcitabine (17.7%) (Figures 1 and 2).

Hair Characteristics After Chemotherapy

Prior to chemotherapy, 46.8% of patients were “very much” satisfied with their hair. Only four patients had alopecia before starting chemotherapy [alopecia areata ($n=2$), lichen planopilaris ($n=1$) and androgenetic alopecia ($n=1$)]. Forty-three patients (76.8%) experienced alopecia after starting chemotherapy, with 70.7% reporting hair loss involving the entire scalp; 60.8% of patients reported greater than 50% loss of hair. CIA-associated symptoms included itching (32.1%), flaking and pimples (16.1% each), burning (14.8%), as well as pain,

erythema and bumps (14.3% each); 48.2% of patients did not report symptoms. Of the patients that answered “Have you experienced hair regrowth on your scalp?” ($n=34$), 61.8% reported “yes.” Hair regrew brown (35%), black (30%) or gray (30%), with the same or thinner thickness (45% each), and with the same texture (58.8%). Only 16.7% of patients each reported “very much” and “quite a bit” satisfaction with their hair regrowth, with 45.8% being only “a little” satisfied.

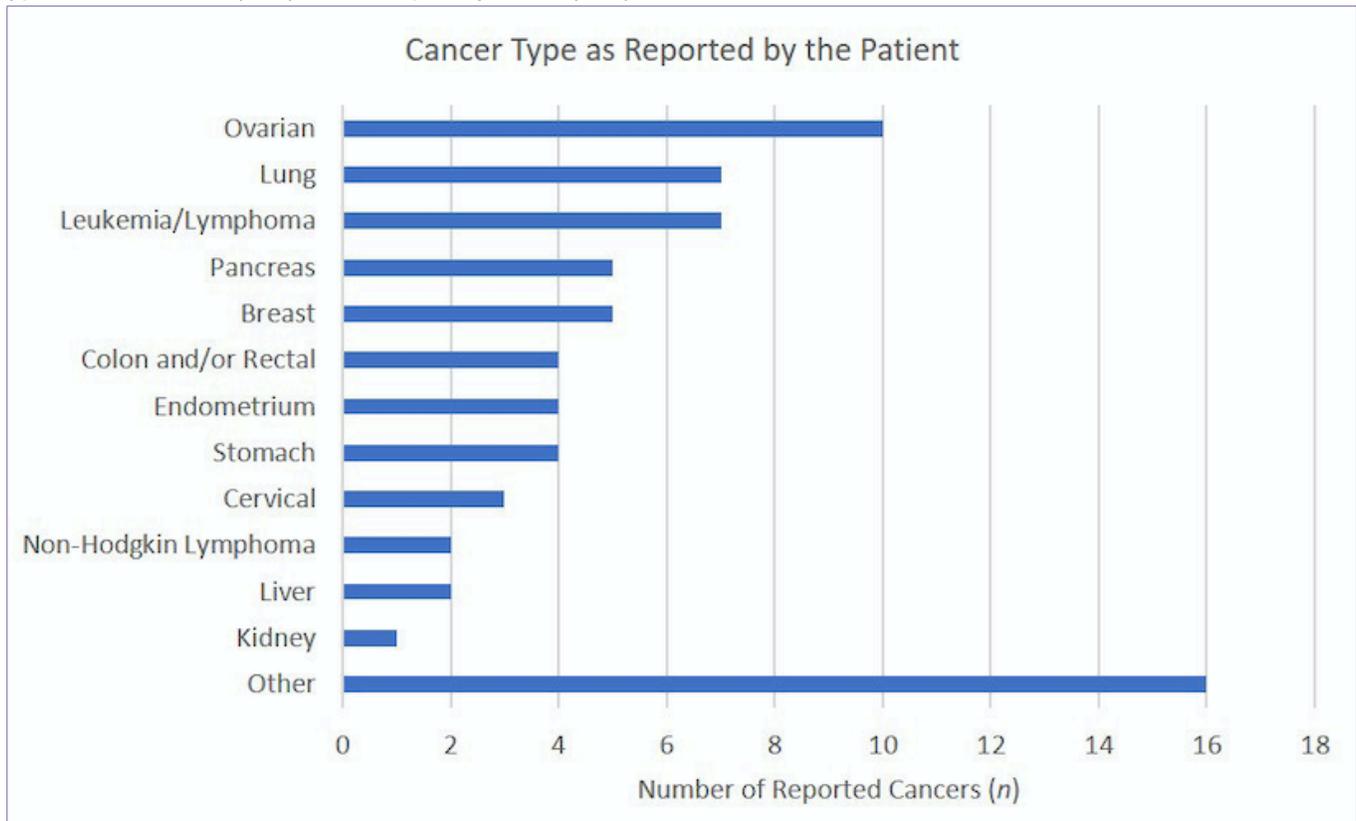
Chemotherapy-Induced Alopecia Distress Scale

The majority of patients who participated in CADS answered either “not at all” or “a little” more frequently than “quite a bit” or “very much” for the entire questionnaire demonstrating that patients were not distressed by CIA (Figure 3).

Hair Loss Treatment Knowledge

Despite having medical insurance, 77.4% of patients did not know if alopecia treatment costs were covered; of patients who knew their coverage, all patients reported that CIA treatment or prevention would not be covered. 88.1% of patients reported that someone did inform them about CIA-risk, most often by their oncologist (86.3%), but also the oncology nurse (25.5%), family/friends (23.5%), primary care physician (13.7%) or conducting their own research (13.7%); however, 33.4% reported being “a little” or “not at all” informed regarding CIA and 47.3% reported not being aware of CIA prevention/treatment. Surprisingly, 11.5% of patients reported the expectation that their hair would not regrow after chemotherapy; of those reporting their hair would regrow, 88.5% thought it would regrow differently than before. The majority of patients were “not at all” aware of hair loss therapies such as scalp-cooling (71.9%), hormonal treatments (83.9%), injections

Figure 1. Patient-reported cancer type ($n=62$ patients, 70 malignancies). The most common “other” malignancy types were cervical ($n=3$) and multiple myeloma ($n=3$).



(85.7%), immunosuppressants (90.9%), or topical and/or over-the-counter treatments (54.7%). However, subjects were most knowledgeable about head coverings, such as wigs or wraps, with 61.4% of patients answering they knew “very much” or “quite a bit”.

Hair Loss Treatment Interest

A majority of patients undergoing chemotherapy (64.9%) reported they were not interested in alopecia treatments. Only 13 participants (21%) continued past the initial question to fully complete this survey section which included measures to discern interest in specific alopecia treatments. Of those that responded, 46.2%, 69.2%, 61.5%, and 79% were “not at all” interested in scalp-cooling, hormones, injections, and immunosuppressants, respectively. On the

other hand, 46.6% and 60% of patients were “very much” or “quite a bit” interested in topical and/or over-the-counter treatments and head coverings, respectively (Figure 4).

Acceptable Risks to Minimize Hair Loss

While a large proportion of patients were not willing to dedicate additional money (47.9%) or time outside of chemotherapy (58.8%) to minimize hair loss, 31.3% were willing to dedicate less than \$100 and 26.1% were willing to temporarily dedicate time to treatment. Patients were also unwilling to endure additional side effects (80.9%) or cancer recurrence (94.6%). As compared to previous data that 8% of patients would decline chemotherapy due to CIA, 0% of our participants would have declined chemotherapy (Table 1).

Figure 2. Patient-reported chemotherapeutic regimen ($n=62$ patients, 111 chemotherapeutics used). Those chemotherapy regimens marked with an (*) indicate > 60% frequency of CIA.¹¹

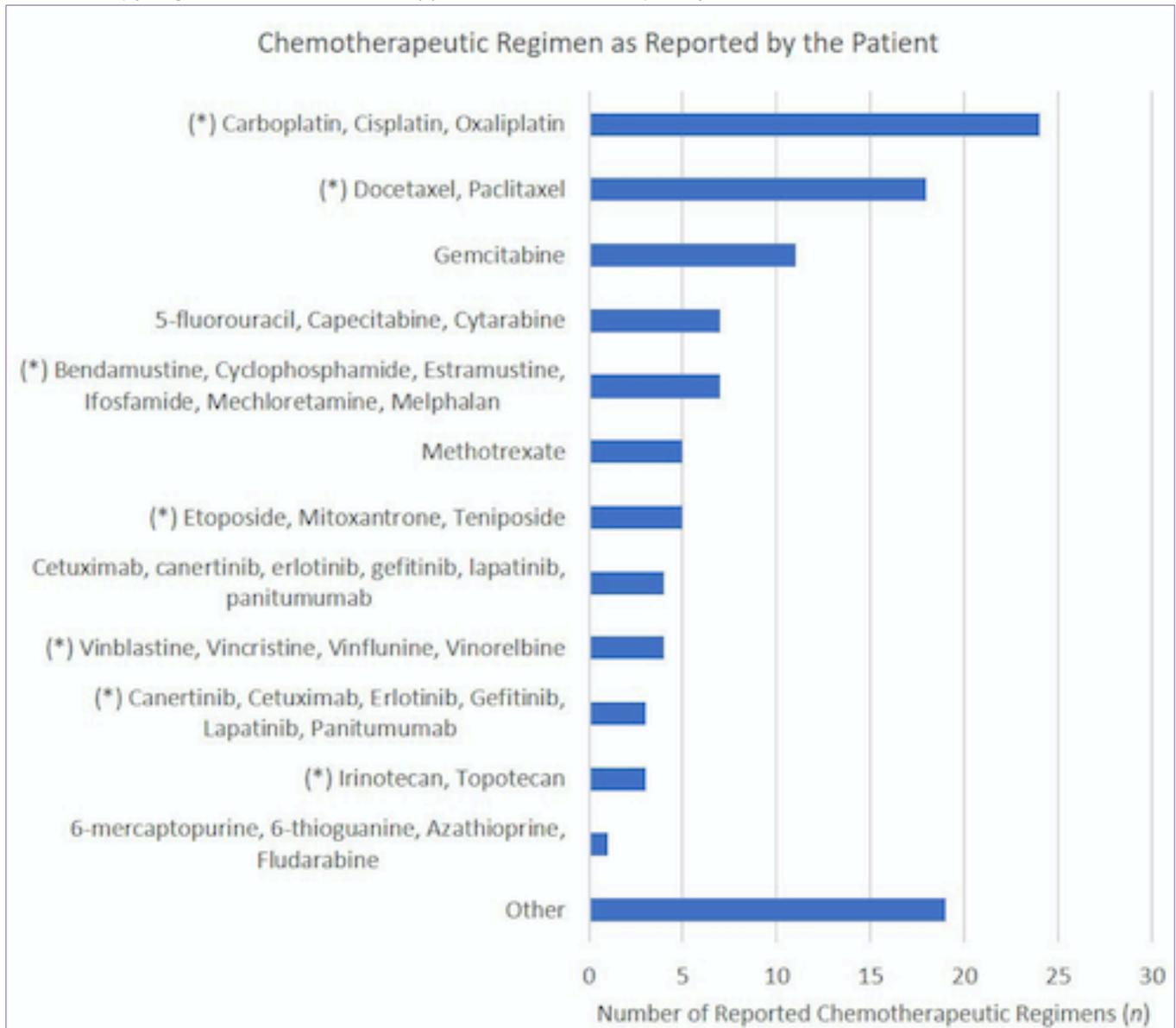


Figure 3. The CADS demonstrates that the majority of patients participating in this survey were “not at all” distressed by their CIA.

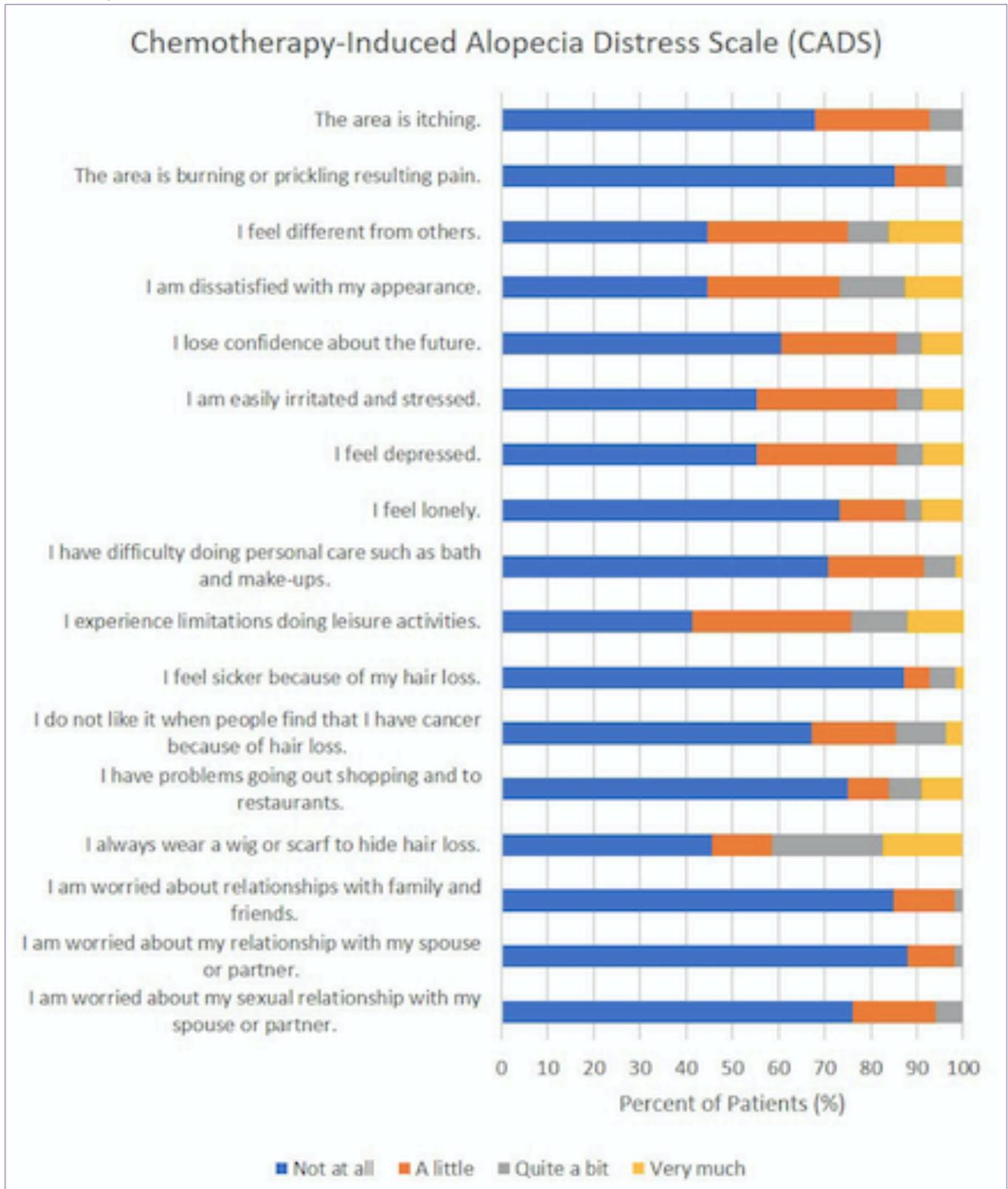


Figure 4. Although the majority of patients report prior counselling regarding CIA-risk, knowledge of CIA prevention/treatment is lacking. Patients are not interested in undergoing further prevention/treatment of CIA except using either head coverings or topical/over-the-counter products.

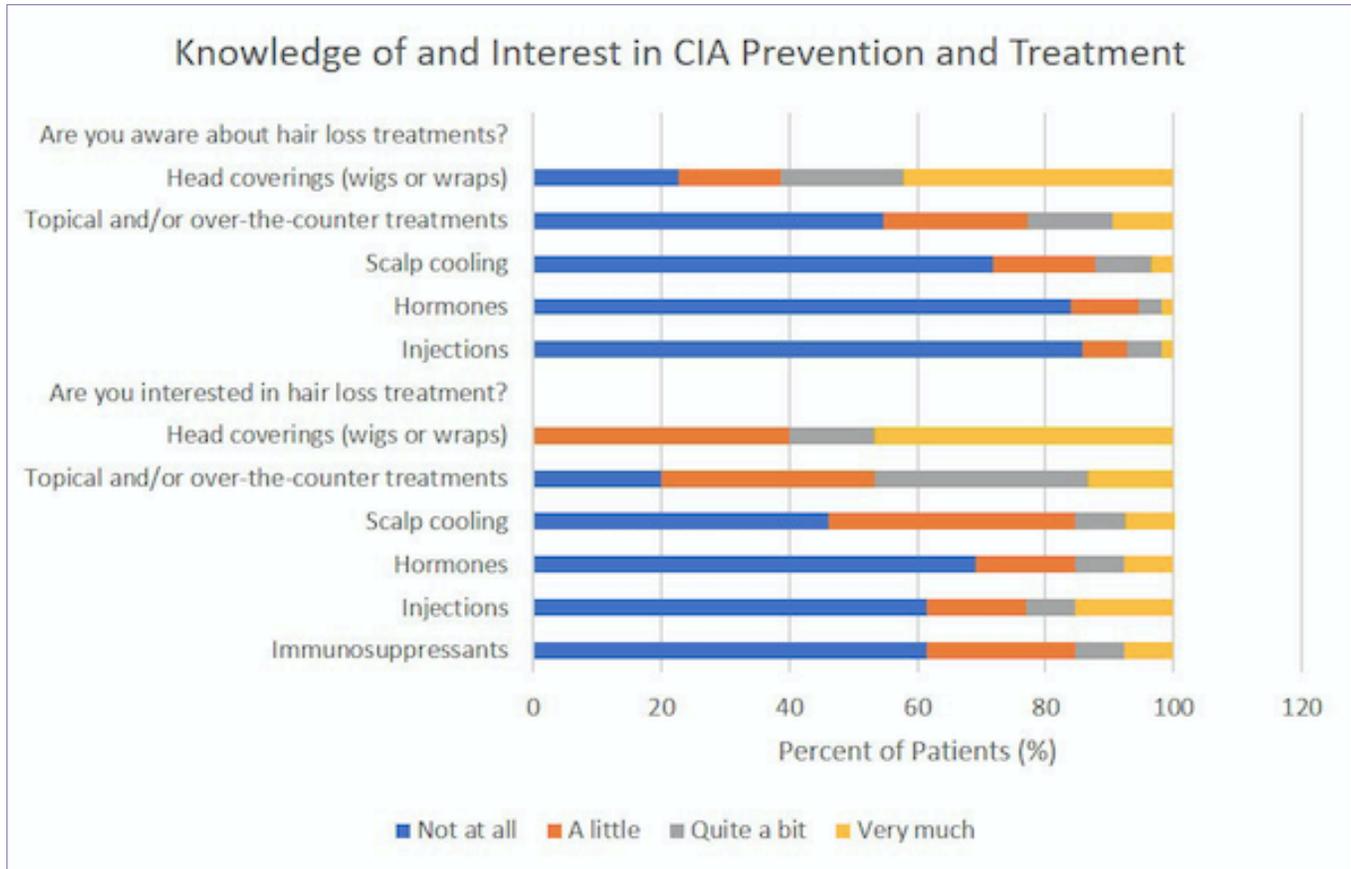


Table 1. Although this population of patients is not well-educated regarding CIA prevention/treatment, these results indicate that they are not interested or motivated to spend money or time on these modalities.

	No. of patients (n)	Percent (%)
Would you have declined chemotherapy if you had known about the risk of hair loss? (n=56)		
No	56	100%
What is the highest chance of cancer recurrence you would be willing to risk for at least 50% reduction in hair loss? (n=56)		
Not willing to risk cancer recurrence	53	94.6
1%-10% or 11%-20% or >75%	1 each	1.8 each
21%-30% or 31%-50% or 51%-75%	0	0
If there was an acceptable treatment to reduce you hair loss by at least 50%, what side effects would you be willing to endure? (n=47)		
None	38	80.9
Change in appetite	4	8.5
Change in weight	3	6.4
Increased body or facial hair	3	6.4
Skin rash or Nausea, vomiting or diarrhea or Headache or Anxiety, depression or confusion	1 each	2.1 each
Sleep changes or Increased risk of infection	0	0
If there was an acceptable treatment that could reduce your hair loss by at least 50% but was not covered by insurance, how much would you be willing to pay out-of-pocket per month? (n=48)		
Nothing	23	47.9
<\$20	7	14.6
\$20-49.99	6	12.5
\$50-99.99	2	4.2
\$100-199.99	5	10.4
\$200-499.99	3	6.3
\$500-999.99	1	2.1
\$1000-1,999.99	0	0
\$2000 +	1	2.1
If at least 50% reduction in hair loss is not acceptable for an out-of-pocket cost, what percentage of reduction would be acceptable? (n=23)		
50-60%	12	52.2
61-70%	4	17.4
71-80%	2	8.7
81-90%	3	13.0
91-100%	2	8.7
How much time would you dedicate to reducing hair loss by at least 50%? (n=47)		
None	18	38.8
During chemotherapy infusions	8	17.0
Temporary once daily application or ingestion	8	17.0
Temporary twice daily application or ingestion	9	19.1
Monthly office visits	7	14.9
Lifelong twice daily application of ingestion	4	8.5
Lifelong once daily application or ingestion	3	6.4
Weekly office visits	2	4.3

DISCUSSION

While multiple studies have attempted to quantify CIA's impact on cancer patients' QOL, few assess the "value" of hair to individuals undergoing chemotherapy in terms of adverse events, time and monetary worth. According to the current literature, although 58% of patients expect CIA to be the worst adverse event of chemotherapy, only 21.7% rate CIA the worst after completing cancer treatment;²⁶ however, up to 8% of patients would decline chemotherapy had they known about CIA.⁷ The findings from this study did not support the previous claim as all participants reported they would not have turned down treatment due to CIA risk. Possible factors contributing to these contradictory data include our unique study population in which all patients were covered by medical insurance, currently undergoing chemotherapy infusion, and did not report distress from CIA.

Our study location was a tertiary, academic medical center located in Southern California which predisposed our patient population to be one diagnosed with a large proportion of high morbidity-mortality cancers, including but not limited to ovarian, lung, and pancreatic. The patients' prognosis may have influenced their decision to receive chemotherapy regardless of adverse events including CIA. Another factor that may have significantly contributed to our participants lack of desire for CIA prevention/treatment or associated risks is the relatively minimal distress caused by CIA as measured by CADS. Patient answers may have been biased because only those feeling energetic and healthy participated in the survey. Patients too tired or sick during infusion turned down participation, thus skewing CADS results. Given that our patients were minimally distressed by CIA, it is

understandable that they were not willing to undergo further side effects, or monetary/time investments to prevent alopecia or promote regrowth.

Of patients willing to pay out-of-pocket, 60% would pay < \$100 USD/month, which is consistent with a previous willingness-to-pay study of non-small cell lung cancer patients undergoing chemotherapy in which women were willing to pay as much as 2.1% of their annual income to reduce CIA.²⁵ Given an average \$30,000 USD annual income, 2% would be \$50 USD/month. Unsurprisingly, given their active malignant disease burden, the majority of our patients did not want CIA prevention/treatment to be accompanied by additional adverse effects. The side effects that a small number of patients were willing to endure included change in weight or appetite and increased facial or body hair.

Additionally, our patients were not interested in spending extra time for CIA-prevention. For instance, scalp-cooling requires 30 minutes prior to, the entire time during, and 90 to 120 minutes post-infusion;^{15,16} based on our patient preferences this seems undesirable. There is an existing knowledge gap in potential CIA prevention/treatment amongst medical providers and patients which needs to be addressed. Our data correlates with other studies assessing CIA therapy knowledge, in which 73% of patients never heard of scalp-cooling, the most recent breakthrough in CIA-prevention, and oncologists reported insufficient knowledge regarding alopecia treatments including scalp-cooling.²³ Patients' lack of knowledge regarding CIA prevention/treatment may have significantly contributed to our findings.

Subgroup analysis did not demonstrate any differences in CIA views based on presumed cancer prognosis. We also compared our results from patients actively receiving

cancer treatment to a small cohort of patients ($n=5$), from the same tertiary medical center, who were currently in remission from breast cancer, multiple myeloma and/or leukemia/lymphoma. Universally, patients in remission reported they would have not turned down chemotherapy because of CIA-risk and were also not willing to endure extra monetary cost, time or effort for CIA prevention/treatment.

Limitations of this study include difficulty in standardizing results as not all questions were answered by all patients, recall bias and selection bias. The average participant response rate was 60.5%, with the hypothesis that more emotionally taxing or sensitive areas of the survey resulted in lower response rate. The sections of the survey with lowest response were in the middle which does not correlate with respondent fatigue. The survey was initially meant to be completed electronically with sections being skipped had the patient answered “no” to the first question. Unfortunately, given infection control within the infusion unit, it was only possible to administer the survey in paper format, thus negatively impacting our response rate. Only English-speaking participants were enrolled to complete this English-only survey. Because many patients reported experiencing some hair loss, a significant control group to compare CIA-distress as measured by CADS is lacking.

CONCLUSION

CIA undeniably affects QOL and should not be ignored. However, in patient populations with high morbidity-mortality cancers currently receiving chemotherapy, concerns for CIA may not be as impactful as previously thought. Poor prognosis may influence the decision to receive treatment despite adverse events such as CIA, contributes to a lack of

distress despite losing hair, and explains the hesitance to obtain CIA prevention/treatment with possible further adverse effects. Future studies to obtain information from patients who completed chemotherapy, are awaiting chemotherapy initiation, and/or are using CIA-preventive measures, such as scalp-cooling, need to be completed to see if the results will differ from our patient cohort.

Keywords: chemotherapy-induced alopecia, chemotherapy, hair loss, quality of life, prevention, cost-effectiveness

ABBREVIATION and ACRONYM LIST:

CADS = Chemotherapy-induced alopecia distress scale

CIA = Chemotherapy-induced alopecia

EGFRi = Epidermal growth factor receptor inhibitor

FDA = Food and drug administration

QOL = Quality of life

REDCap = Research electronic data capture

US = United States

USD = United States dollar

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Appendix 1a: Demographic and health information.

What is your age?	<input type="checkbox"/> 18-24 years old <input type="checkbox"/> 25-34 years old <input type="checkbox"/> 35-44 years old <input type="checkbox"/> 45-54 years old <input type="checkbox"/> 55-64 years old <input type="checkbox"/> 65-74 years old <input type="checkbox"/> 75 years or older
Biological sex	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Intersex
Gender identity	<input type="checkbox"/> Female <input type="checkbox"/> Male
Sexual orientation	<input type="checkbox"/> Asexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Heterosexual <input type="checkbox"/> Homosexual <input type="checkbox"/> Other
Marital status	<input type="checkbox"/> Divorced <input type="checkbox"/> Living together <input type="checkbox"/> Married <input type="checkbox"/> Separate <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Unknown/decline to state
Race	<input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Middle Eastern <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> Unknown
Ethnicity	<input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Not Hispanic or Latino <input type="checkbox"/> Unknown/not reported
Religious preferences	<input type="checkbox"/> Buddhism <input type="checkbox"/> Christianity <input type="checkbox"/> Hinduism <input type="checkbox"/> Irreligion (Atheist or Agnostic) <input type="checkbox"/> Islam <input type="checkbox"/> Judaism <input type="checkbox"/> Non-affiliated <input type="checkbox"/> Other
What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.	<input type="checkbox"/> 8 th grade or less <input type="checkbox"/> 9-11 th grade <input type="checkbox"/> High school graduate/GED <input type="checkbox"/> Vocational/technical school <input type="checkbox"/> Associate degree/some college <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Advanced degree (MD, PhD, Master's) <input type="checkbox"/> Unknown/declined to state
Employment status	<input type="checkbox"/> Employed for wages <input type="checkbox"/> Self-employed <input type="checkbox"/> Unemployed

	<input type="checkbox"/> Homemaker <input type="checkbox"/> Disabled <input type="checkbox"/> Retired <input type="checkbox"/> Unknown/declined to state
What is your total household income?	<input type="checkbox"/> Less than \$25,000 <input type="checkbox"/> \$25,000 to \$49,999 <input type="checkbox"/> \$50,000 to \$74,999 <input type="checkbox"/> \$75,000 to \$99,999 <input type="checkbox"/> \$100,000 to \$149,999 <input type="checkbox"/> \$150,000 to \$199,999 <input type="checkbox"/> \$200,000 or more
Do you have health insurance?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have children?	<input type="checkbox"/> Yes <input type="checkbox"/> No
What age are your children?	<input type="checkbox"/> Less than 5 years old <input type="checkbox"/> 5 to 10 years old <input type="checkbox"/> 11 to 17 years old <input type="checkbox"/> 18 years or older
Frequency of exercise	<input type="checkbox"/> Once a week <input type="checkbox"/> 2-3 times a week <input type="checkbox"/> 4-6 times a week <input type="checkbox"/> Daily <input type="checkbox"/> Rarely <input type="checkbox"/> Other
Details:	
Dietary restrictions	<input type="checkbox"/> Vegetarian <input type="checkbox"/> Vegan <input type="checkbox"/> Gluten free <input type="checkbox"/> Other <input type="checkbox"/> None
Details:	
Medical history	
What type of cancer were you diagnosed with? You may check multiple boxes.	<input type="checkbox"/> Bladder cancer <input type="checkbox"/> Breast cancer <input type="checkbox"/> Colon and rectal cancer <input type="checkbox"/> Endometrial cancer <input type="checkbox"/> Kidney cancer <input type="checkbox"/> Leukemia/lymphoma <input type="checkbox"/> Liver cancer <input type="checkbox"/> Lung cancer <input type="checkbox"/> Melanoma <input type="checkbox"/> Non-Hodgkin lymphoma <input type="checkbox"/> Pancreatic cancer <input type="checkbox"/> Prostate cancer <input type="checkbox"/> Thyroid cancer <input type="checkbox"/> Other
If you indicated other type, what is the type of cancer you were diagnosed with?	_____
Was your most recent cancer diagnosis an initial diagnosis, recurrent diagnosis, or second type of cancer diagnosis?	<input type="checkbox"/> Initial diagnosis <input type="checkbox"/> Recurrent diagnosis <input type="checkbox"/> Second type of cancer
What is the status of your cancer?	<input type="checkbox"/> Active <input type="checkbox"/> Stable <input type="checkbox"/> In remission

	<input type="checkbox"/> Recurrence
Are you currently receiving treatment for cancer?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Please indicate which chemotherapies you are (or were) treated with for your cancer. You may check multiple boxes.	<input type="checkbox"/> None <input type="checkbox"/> Cetuximab, canertinib, erlotinib, gefitinib, lapatinib, or panitumumab <input type="checkbox"/> Methotrexate <input type="checkbox"/> Bendamustine, cyclophosphamide, estramustine, ifosfamide, mechlorethamine, or melphalan <input type="checkbox"/> Carboplatin, cisplatin, or oxaliplatin <input type="checkbox"/> 6-mercaptopurine, 6-thioguanine, azathioprine, or fludarabine <input type="checkbox"/> 5-fluorouracil, capecitabine, or cytarabine <input type="checkbox"/> Vemurafenib or dabrafenib <input type="checkbox"/> Paclitaxel or docetaxel <input type="checkbox"/> Topotecan or irinotecan <input type="checkbox"/> Etoposide, teniposide, or mitoxantrone <input type="checkbox"/> Dacarbazine, procarbazine, or temozolomide <input type="checkbox"/> Sorafenib or sunitib <input type="checkbox"/> Vincristine, cinblastine, vinorelbine, vinflunine <input type="checkbox"/> Other
What other chemotherapy agents were part of your treatment regimen?	_____
Why are you not currently receiving treatment?	<input type="checkbox"/> I am waiting for my treatments to start <input type="checkbox"/> I completed my treatment regimen <input type="checkbox"/> I declined treatment
Other medical problems? You may check multiple boxes.	<input type="checkbox"/> Alopecia (hair loss) <input type="checkbox"/> High blood pressure <input type="checkbox"/> Celiac's disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Eczema <input type="checkbox"/> Endometriosis <input type="checkbox"/> Lupus <input type="checkbox"/> Obstructive sleep apnea <input type="checkbox"/> Ovarian cyst <input type="checkbox"/> Psoriasis <input type="checkbox"/> Rheumatoid arthritis <input type="checkbox"/> Thyroid disease
Have you been on hormone replacement therapy?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Menstrual status	<input type="checkbox"/> Pre-menopausal <input type="checkbox"/> Peri-menopausal <input type="checkbox"/> Post-menopausal
Age at start of menopause (give best estimate).	_____
Please check the boxes for known family history.	<input type="checkbox"/> Alopecia (hair loss) <input type="checkbox"/> Cancer <input type="checkbox"/> Thyroid disease

Appendix 1b: Hair information.

Natural hair details Please choose the options that best describe your hair prior to any chemotherapy treatments or hair loss.	
What is your natural hair color?	<input type="checkbox"/> Blonde <input type="checkbox"/> Brown <input type="checkbox"/> Red <input type="checkbox"/> Black <input type="checkbox"/> Gray <input type="checkbox"/> White <input type="checkbox"/> No hair
How much hair did you have prior to your cancer treatment (hair density)?	<input type="checkbox"/> Thick <input type="checkbox"/> Medium <input type="checkbox"/> Thin
How thick was each strand of hair prior to your cancer treatment (hair diameter)? Medium is approximately the diameter of a piece of thread.	<input type="checkbox"/> Coarse <input type="checkbox"/> Medium <input type="checkbox"/> Fine
What is your natural hair texture?	<input type="checkbox"/> Straight <input type="checkbox"/> Curly <input type="checkbox"/> Wavy <input type="checkbox"/> Other
How long was your hair prior to chemotherapy and/or hair loss?	<input type="checkbox"/> Hair ended above chin <input type="checkbox"/> Hair ended above shoulders <input type="checkbox"/> Hair ended above armpits <input type="checkbox"/> Hair ended above belly button <input type="checkbox"/> Hair ended at or below belly button
How satisfied were you with your hair prior to receiving cancer treatment?	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
History of alopecia (hair loss)	
Were you diagnosed with alopecia (hair loss) before cancer treatment started?	<input type="checkbox"/> Yes <input type="checkbox"/> No
What type of alopecia were you diagnosed with? You may check multiple boxes.	<input type="checkbox"/> Alopecia areata <input type="checkbox"/> Central centrifugal cicatricial alopecia <input type="checkbox"/> Frontal fibrosing alopecia <input type="checkbox"/> Lichen planopilaris <input type="checkbox"/> Patterned hair loss (androgenic, androgenetic, male patterned, female patterned) <input type="checkbox"/> Telogen effluvium <input type="checkbox"/> Traction alopecia <input type="checkbox"/> Other
What type of other alopecia were you diagnosed with?	_____
Does anyone else in your family have a history of alopecia (hair loss)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
If so, who? You may check multiple boxes.	<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Sister <input type="checkbox"/> Brother <input type="checkbox"/> Son <input type="checkbox"/> Daughter

What type of alopecia is in your family history? You may check multiple boxes.	<input type="checkbox"/> Alopecia areata <input type="checkbox"/> Central centrifugal cicatricial alopecia <input type="checkbox"/> Frontal fibrosing alopecia <input type="checkbox"/> Lichen planopilaris <input type="checkbox"/> Patterned hair loss (androgenic, androgenetic, male patterned, female patterned) <input type="checkbox"/> Telogen effluvium <input type="checkbox"/> Traction alopecia <input type="checkbox"/> Other
Do you have any surgical scars on scalp?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Chemotherapy-induced alopecia	
Have you experienced hair loss after cancer treatment started?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you experienced any of these types of hair loss after chemotherapy started? You may check multiple boxes.	<input type="checkbox"/> None <input type="checkbox"/> Shedding <input type="checkbox"/> Thinning <input type="checkbox"/> Breakage <input type="checkbox"/> Not growing <input type="checkbox"/> Unknown
Location of most hair loss on scalp after chemotherapy started? You may check multiple boxes.	<input type="checkbox"/> Front scalp <input type="checkbox"/> Bald patches <input type="checkbox"/> Top of head <input type="checkbox"/> Entire scalp <input type="checkbox"/> Other <input type="checkbox"/> Unknown
What percentage of hair did you lose?	<input type="checkbox"/> No hair loss <input type="checkbox"/> Less than 25% hair loss <input type="checkbox"/> 25% to 50% hair loss <input type="checkbox"/> 51% to 75% hair loss <input type="checkbox"/> More than 75% hair loss
Have you experienced hair loss in places other than your scalp?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Where have you experienced hair loss other than your scalp? You may check multiple boxes.	<input type="checkbox"/> Arms or legs <input type="checkbox"/> Chest, back or abdomen <input type="checkbox"/> Eyebrows <input type="checkbox"/> Eyelashes <input type="checkbox"/> Nose hair <input type="checkbox"/> Pubic area <input type="checkbox"/> Underarms
Have you experienced any associated scalp symptoms? You may check multiple boxes.	<input type="checkbox"/> Itching <input type="checkbox"/> Burning <input type="checkbox"/> Pain <input type="checkbox"/> Redness <input type="checkbox"/> Flaking <input type="checkbox"/> Bumps <input type="checkbox"/> Pimples <input type="checkbox"/> None <input type="checkbox"/> Other
Itching	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Burning	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate

	<input type="checkbox"/> Severe
Pain	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Redness	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Flaking	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Bumps	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Pimples	<input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Have you experienced hair regrowth on your scalp?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Hair color after regrowth?	<input type="checkbox"/> Blonde <input type="checkbox"/> Brown <input type="checkbox"/> Red <input type="checkbox"/> Black <input type="checkbox"/> Gray <input type="checkbox"/> Other
Hair density after regrowth?	<input type="checkbox"/> Thicker <input type="checkbox"/> Thinner <input type="checkbox"/> Same
Hair diameter after regrowth?	<input type="checkbox"/> More coarse <input type="checkbox"/> More fine <input type="checkbox"/> Same
Hair texture after regrowth?	<input type="checkbox"/> More curly <input type="checkbox"/> More wavy <input type="checkbox"/> More straight <input type="checkbox"/> Same
After you completed your chemotherapy regimen, when did regrowth start?	<input type="checkbox"/> Still receiving chemotherapy <input type="checkbox"/> Less than 1 month <input type="checkbox"/> 1 month to 3 months <input type="checkbox"/> 3 months to 6 months <input type="checkbox"/> 6 months to 1 year <input type="checkbox"/> 1 year to 2 years <input type="checkbox"/> More than 2 years
How much of your hair has regrown as compared to your hair before cancer treatment?	<input type="checkbox"/> Less than 25% <input type="checkbox"/> 25% to 50% <input type="checkbox"/> 51% to 50% <input type="checkbox"/> More than 75%
How satisfied are you with your hair after it has regrown?	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very Much
Hair care practices	
Previous hair care? You may check multiple boxes.	<input type="checkbox"/> Curly perm <input type="checkbox"/> Relaxer <input type="checkbox"/> Coloring <input type="checkbox"/> Blow dryer

SKIN

	<input type="checkbox"/> Hot iron/curling iron/flat iron <input type="checkbox"/> Hot comb <input type="checkbox"/> Hot rollers <input type="checkbox"/> Braids <input type="checkbox"/> Weave <input type="checkbox"/> Other <input type="checkbox"/> Unknown
Other previous hair care treatments?	
Did you shave your head or do you plan to?	<input type="checkbox"/> Yes <input type="checkbox"/> No
When did you shave your head or when are you planning on shaving your head?	<input type="checkbox"/> Before chemotherapy starts <input type="checkbox"/> Before hair loss starts <input type="checkbox"/> Once hair loss starts <input type="checkbox"/> After a significant amount of hair is lost
Do you or did you wear anything that covers your head? You may check multiple boxes.	<input type="checkbox"/> None <input type="checkbox"/> Wrap <input type="checkbox"/> Hat <input type="checkbox"/> Wig <input type="checkbox"/> Extensions <input type="checkbox"/> Other
Details:	

Appendix 1c: Hair loss treatment options.

Did someone talk to you about the risk of hair loss due to chemotherapy?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Who discussed the risk of hair loss with you? You may check multiple boxes.	<input type="checkbox"/> Primary care physician <input type="checkbox"/> Oncologist <input type="checkbox"/> Patient educators <input type="checkbox"/> Nurse <input type="checkbox"/> Support groups <input type="checkbox"/> Family and/or friends <input type="checkbox"/> Research on your own
Did you feel well-informed about hair loss?	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
How much do you agree with the statements below?	
My hair will regrow the same as it was before cancer treatment.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
My hair will regrow, but it will regrow different than it was before cancer treatment.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
My hair will not regrow.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Are you aware about hair loss treatments?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Are you aware about these hair loss treatments, including the procedure and cost?	
Scalp cooling	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Hormones	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Injections	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Immunosuppressants	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Topical and/or over-the-counter treatments	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Head coverings (wigs or wraps)	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much

Are you interested in hair loss treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Are you interested in these hair loss treatments?	
Scalp cooling	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Hormones	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Injections	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Immunosuppressants	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Topical and/or over-the-counter treatments	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Head coverings (wigs or wraps)	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
If there was an acceptable treatment to reduce your hair loss by at least 50%, what side effects would you be willing to endure? You may check multiple boxes.	<input type="checkbox"/> None <input type="checkbox"/> Increased body or facial hair <input type="checkbox"/> Anxiety, depression, or confusion <input type="checkbox"/> Change in appetite <input type="checkbox"/> Change in weight <input type="checkbox"/> Nausea, vomiting, or diarrhea <input type="checkbox"/> Headaches <input type="checkbox"/> Skin rash <input type="checkbox"/> Changes in sleep <input type="checkbox"/> Increased risk of infection
If you have insurance, does your insurance cover the cost of hair loss treatments?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know <input type="checkbox"/> I do not have insurance
If there was an acceptable treatment that could reduce your hair loss by at least 50% but was not covered by insurance, how much would you be willing to pay out of pocket per month?	<input type="checkbox"/> Nothing <input type="checkbox"/> Less than \$20 <input type="checkbox"/> \$20 to \$49.99 <input type="checkbox"/> \$50 to \$99.99 <input type="checkbox"/> \$100 to \$199.99 <input type="checkbox"/> \$200 to \$499.99 <input type="checkbox"/> \$500 to \$999.99 <input type="checkbox"/> \$1000 to \$1999.99 <input type="checkbox"/> \$2000 or more
If at least 50% reduction in hair loss is not acceptable for an out of pocket cost, what percentage would be acceptable?	<input type="checkbox"/> 50% to 60% <input type="checkbox"/> 61% to 70% <input type="checkbox"/> 71% to 80% <input type="checkbox"/> 81% to 90% <input type="checkbox"/> 91% to 100%

<p>How much time would you dedicate to reducing hair loss by at least 50%? You may check multiple boxes.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> None <input type="checkbox"/> During chemotherapy infusions <input type="checkbox"/> Temporary once daily application or ingestion <input type="checkbox"/> Temporary twice daily application or ingestion <input type="checkbox"/> Lifelong once daily application or ingestion <input type="checkbox"/> Lifelong twice daily application or ingestion <input type="checkbox"/> Weekly office visits <input type="checkbox"/> Biweekly office visits <input type="checkbox"/> Monthly office visits
<p>What is the highest change of cancer recurrence you would be willing to risk for at least 50% reduction in hair loss?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Not willing to risk cancer recurrence <input type="checkbox"/> 1% to 10% <input type="checkbox"/> 11% to 20% <input type="checkbox"/> 21% to 30% <input type="checkbox"/> 30% to 50% <input type="checkbox"/> 50% to 75% <input type="checkbox"/> More than 75% risk of recurrence
<p>Would you have declined chemotherapy if you have known about the risk of hair loss?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No

Appendix 2: Chemotherapy-induced alopecia distress scale (CADS).²²

Physical	
The area is itching.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
The area is burning or prickling or resulting in pain.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Emotional	
I feel different from others.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I am dissatisfied with my appearance.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I lose confidence about the future.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I am easily irritated and stressed.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I feel depressed.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I feel lonely.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Activity	
I have difficulty doing personal care such as bath and make-up.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I experience limitations doing leisure activities.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I feel sicker because of my hair loss.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I do not like it when people find that I have cancer because of my hair loss.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I have problems going out shopping and to restaurants.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little

	<input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I always wear a wig or scarf to hide hair loss.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Relationship	
I am worried about relationships with family and friends.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I am worried about my relationship with my spouse or partner.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
I am worried about my sexual relationship with my spouse or partner.	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much