

# Scalp Cooling: A Patient's Experience

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## CASE STUDY

Ms. X is a 23-year-old female who presented to clinic with stage 2A endometrial cancer of the ovary. At her first visit, Ms. X was prescribed paclitaxel and carboplatin on day 1 for 6 cycles. During the visit, the nurse noted Ms. X could not keep her hands out of her hair; she continually played with it. The nurse, judging by Ms. X's body language, suspected she valued her hair. Ms. X revealed she had been doing some research and wanted to use a cold cap to try and prevent alopecia during her treatment.

On the first day of chemotherapy, Ms. X came to the clinic with her mother. They brought a manual cap for scalp cooling and a cooler of dry ice. Her mother was to serve as a "capper" and change the cap at 20- to 30-minute intervals during treatment to keep her scalp cool. Ms. X was made comfortable in an infusion bed, and the cap was applied 30 minutes prior to the start of therapy. Ms. X's mother changed the dry ice caps every 20 minutes throughout the infusion. Ms. X then left it on for 90 minutes following her chemotherapy. After 6 cycles of chemotherapy, Ms. X still had all her hair. She appeared to have retained 100% of her hair, although she estimates that she lost about 5% of her hair. During therapy, she followed the instructions outlined in Table 1. Ms. X reported that she rented the cap for \$500 per month and paid \$45 per week for the dry ice. Her mother also had to miss work to be the "capper," and this added to the out-of-pocket costs of scalp cooling.

Chemotherapy-induced alopecia (CIA) is a frequent side effect of systemic antineoplastic therapy for cancer. It occurs when chemotherapy drugs such as taxanes, anthracyclines, and alkylating agents target rapidly dividing keratinocytes cells, damaging the hair follicle and resulting in CIA (Paus, Haslam, Sharov, & Botchkarev, 2013). Although it is not life-threatening and is often reversible, CIA is frequently described as the most distressing side effect of

chemotherapy (Jayde, Boughton, & Blomfield, 2013). McGarvey, Baum, Pinkerton, and Rogers (2001) found half of female cancer survivors considered CIA to be the most upsetting side effect of antineoplastic therapy. Chemotherapy-induced alopecia affects 65% of individuals receiving chemotherapy, with up to 8% refusing treatment due to fear of developing this side effect (Shah, 2018). Ms. X is an example of a patient whose identity was impacted by the potential body image change of alopecia.

For young adults with cancer, body image and how they look and feel about themselves can be particularly important given that they may be starting careers and looking for future partners.

Scalp cooling is reemerging in the United States due to the fact that health-care professionals are realizing the impact alopecia has on patients' psychosocial and emotional well-being (Roe, 2014). Scalp cooling works by causing vasoconstriction, therefore limiting the exposure of the hair follicles to chemotherapy (Ross & Fischer-Carlidge, 2017). Sensor-controlled, machine-based scalp cooling has been demonstrated to be effective in reducing CIA in the majority of patients receiving chemotherapy for breast cancer; however, it is not yet used routinely in the United States (Cigler et al., 2015; Friedrichs & Carstensen, 2014; Shin, Jo, Kim, Kwon, & Myung, 2015; van den Hurk et al., 2014). Manual scalp cooling systems are also available for use. Scalp cooling has only recently been approved by the US Food and Drug Administration (FDA) in the United States and is not yet widely reimbursed by third-party payers. However, scalp cooling has been available for more than a decade in Europe and is routinely used by clinicians in the United Kingdom and the Netherlands (Ross & Fischer-Carlidge, 2017). The purpose of this paper is to describe the options and logistics of scalp cooling using a case study approach.

## HISTORY OF SCALP COOLING

Scalp cooling dates back more than 30 years and has been studied with more frequency in recent years. Until recent trials were published, scalp cooling had not been as widely used in the United States as compared to Europe (Rugo, 2017). When first introduced in the United States, scalp cooling did not gain popularity, perhaps due to the disappointing efficacy in the older manual caps. Physicians and nurses were also concerned about the risk of scalp metastasis as a result of the decreased amount of chemotherapy delivered to the scalp (Rugo et al., 2017b).

In a trial of scalp cooling conducted at five medical centers in the United States by Rugo and colleagues (2017a), 122 women diagnosed with breast cancer were randomized to receive either adjuvant or neoadjuvant chemotherapy with or

without machine-based scalp cooling. Two years of follow-up indicated no evidence of scalp metastasis, and follow-up will continue for 5 years (Rugo et al., 2017b).

In a larger European retrospective study, Lemieux and colleagues (2015) studied 1,370 breast cancer patients receiving chemotherapy who used scalp cooling and compared them to women who were not using scalp cooling. They found no negative effect on long-term survival (Lemieux et al., 2015).

In an examination of a sample of women, van den Hurk and colleagues (2013) found an incidence of 1% or less of scalp metastasis in breast cancer patients receiving paclitaxel, doxorubicin, and cyclophosphamide, compared to a 3% incidence of scalp metastasis in women with breast cancer who did not use scalp cooling. The study by Lemieux and colleagues (2015) supported the hypothesis that there is no negative impact on overall survival for women who use scalp cooling.

Lemieux and colleagues (2015) followed women for a period of 5 to 6 years. Because the highest incidence of breast cancer recurrence occurs 5 years after treatment, this time point is often chosen as a study endpoint. These studies led to the FDA approving one machine-based scalp cooling mechanism in 2015 and 2017. Devices currently available in the United States are briefly described in Table 1. Scalp cooling is emerging as an option for patients in the United States who are concerned about reducing hair loss during their antineoplastic therapy (Ross & Fischer-Carlidge, 2017).

## PATIENT SELECTION

Research on the effects of scalp cooling has focused mainly on the breast cancer population. Scalp cooling is not appropriate for every patient undergoing antineoplastic therapy. Patients with hematologic cancers associated with high levels of circulating tumor cells, such as leukemias and lymphomas, are not eligible. Cold agglutinin disease, cold sensitivity, cryoglobulinemia, cryofibrinogenemia, and cold urticaria are also considered to be contraindications for scalp cooling. Those who have central nervous system or scalp metastases, head and neck cancer, squamous cell or small cell cancer of the lung, patients currently receiving or with

**Table 1. Examples of Scalp Cooling Methods Available in the United States**

<b>Comment</b>	<b>Penguin Cold Caps</b>	<b>Paxman Cooling System</b>	<b>Dignitana Cooling System</b>
Type	Manual system	Machine-based system	Machine-based system
Description	Gel cap that goes over a headband is secured by Velcro-fastening elastic straps	FDA-approved compact refrigeration system attached to 1 or 2 single-use cooling caps	FDA-approved silicone cooling cap connected to a cooling control unit
Logistics before therapy	Client contacts the company directly via website to arrange treatment	Cap fitting done at treatment facility and prescription is written for scalp cooling. Referral sent to company that includes information about the number of chemotherapy cycles planned. Company contacted by patient and payment is made by patient. Company provides telephone-based education and sends cap in proposed size to patient's home with written directions. Patient double-checks fit using video tutorial and contacts company if a different size is needed. The patient is responsible for bringing the cap to each treatment. The treatment facility has a refrigeration unit on site for patients.	Cap fitting done at treatment facility and prescription is written for scalp cooling. Referral sent to company that includes information about the number of chemotherapy cycles that are planned. Company contacted by patient and payment is made by patient. Company provides telephone-based education and sends cap in proposed size to patient's home with written directions. Patient double-checks fit using video tutorial and contacts company if a different size is needed. The patient is responsible for bringing the cap to each treatment. The treatment facility has a refrigeration unit on site for patients.
Fitting	Company coaches client through fitting herself at home before chemotherapy begins	Chemotherapy treatment center helps with fitting	Chemotherapy treatment center helps with fitting
Shipping	Sent by company to patient's home	Sent by company to patient's home	Sent by company to patient's home
Moving cap to treatment site	Caps are transported on dry ice in a cooler and changed at intervals during treatment. Assistance often needed to transport cooler to clinic.	Patient brings kit and ID card to appointment	Patient brings kit and ID card to appointment
Size	-	Small, medium, large	Small, medium, large
Cost	Varies by manufacturer and treatment setting; reimbursement may be available but no billing code is available at this time	Contact manufacturer; reimbursement may be available but no billing code is available at this time	Contact manufacturer; reimbursement may be available but no billing code is available at this time
Ability to move during therapy	Penguin Cold Caps are cooled using dry ice. Patients are able to ambulate as desired while wearing the Penguin cap.	The patient may disconnect for up to 10 minutes during therapy before needing to reconnect to reduce risk of the scalp warming up	The patient may disconnect for up to 8 minutes during therapy before needing to reconnect to reduce risk of the scalp warming up
Requirements during therapy	Patients are asked not to use any products on their hair during scalp cooling treatment	Patient may need assistance disconnecting scalp cooling tubing from the refrigeration machine in order to walk or go to the restroom during chemotherapy	Patient may need assistance disconnecting scalp cooling tubing from the refrigeration machine in order to walk or go to the restroom during chemotherapy
Requirements at home between treatments	Varies according to manufacturer; see tips for typical recommendations (Table 3)	Varies according to manufacturer; see tips for typical recommendations (Table 3)	Varies according to manufacturer; see tips for typical recommendations (Table 3)

**Table 1. Examples of Scalp Cooling Methods Available in the United States (cont.)**

Comment	Penguin Cold Caps	Paxman Cooling System	Dignitana Cooling System
Potential discomfort	Headache due to cold or dizziness during therapy	Headache due to cold or dizziness during therapy	Headache due to cold or dizziness during therapy
Physical room concerns	Treatment room should be large enough to keep a cooler	Treatment room must be large enough for machine	Treatment room must be large enough for machine. The cooling machine creates heat and a humming noise, similar to a refrigerator.
Website	<a href="http://penguincoldcaps.com/us">penguincoldcaps.com/us</a>	<a href="http://paxmanscalpcooling.com">paxmanscalpcooling.com</a>	<a href="http://dignitana.com">dignitana.com</a>

a history of radiation therapy to the brain, or who require treatment with bone marrow ablating chemotherapy, are also not candidates (Paxman, 2018; US Food and Drug Administration, 2018). Scalp cooling is less successful in older adults due to a diminished ability to vasoconstrict when exposed to cold (van den Hurk et al., 2012). Patients with a large volume of hair or very thick hair, menopausal status, nicotine use, of certain ethnicities, and other medication use are at risk for decreased efficacy (Schaffrin-Nabe, Schmitz, Josten-Nabe, von Hehn, & Voigtmann, 2015).

## CHEMOTHERAPY

The majority of published evidence to support scalp cooling focuses on regimens used for breast cancer. The chemotherapy regimens that have been closely studied in the United States in scalp cooling trials include regimens using taxanes and anthracyclines. Several studies revealed higher rates of hair preservation with weekly taxane vs. every-21-day paclitaxel (Fehr, Welter, Sell, Jung, & Felberbaum, 2016; Nangia et al., 2017).

In the Scalp Cooling Alopecia Prevention (SCALP) randomized trial of 142 women receiving a taxane, anthracycline, or both, investigators saw a 59% higher rate of hair retention with scalp cooling (Nangia et al., 2017). This hair retention rate was higher than that found in previous studies. Other studies that have been done in the United States using only taxane-containing regimens showed similar results, with a 66.3% rate of hair retention with scalp cooling (Nangia et al., 2017). Two randomized studies completed in the United States have shown that scalp cooling is effective in preventing CIA in primary breast cancer treated with taxane-based chemotherapy, whereas little effect has been found

in those also treated with doxorubicin (Nangia et al., 2017; Rugo, 2017). However, in a randomized trial that took place in Germany, patients exposed to anthracyclines did not compare unfavorably in terms of CIA, which may be attributable to the exclusive use of epirubicin instead of doxorubicin (Smetanay et al., 2017). Alopecia in triplet regimens is unavoidable and therefore scalp cooling should not be used. As scalp cooling becomes more popular in the United States, there is a potential for patients to make chemotherapy choices based on the ability to preserve their hair with scalp cooling (Nangia et al., 2017). Ms. X chose weekly paclitaxel treatments based on her own research that suggested that this treatment schedule is associated with less hair loss. With the recent FDA approval of the expanded use of cooling caps for all solid tumor cancers, more patients will have the option to attempt to avoid CIA with scalp cooling (US Food and Drug Administration, 2018).

## SIDE EFFECTS OF SCALP COOLING

There are several common side effects reported with scalp cooling, which include a feeling of intense cold (27%–39%), headache (12%–24%), dizziness (20%), and boredom (11%–27%; Betticher et al., 2013; Mols, van den Hurk, Vingerhoets, & Breed, 2009).

## LOGISTICS OF SCALP COOLING

Patients must be evaluated by a provider to determine whether they are eligible for scalp cooling. If eligible, the patient ideally should be offered the option of manual vs. machine-based scalp cooling if both scenarios are available. If reimbursement is available, the insurance company may dictate which approach may be covered, which

may affect patient decision-making. Appropriate education specific to each patient should be provided by treatment center staff as well as the cap provider/company. The responsibility for fitting the cap and preprocedure education may be shared by the treatment center and cap manufacturer. Often, the manufacturer carries the bulk of the responsibility as well as handling payment, and may refer to patient resources to assist with payment, some of which are outlined in Table 2. It is important for the patient and family to understand their role in scalp cooling and the possibility that scalp cooling may not lead to the retention of 100% of hair. Ms. X used a brand of manual cold cap that requires the use of dry ice to keep the scalp cool. With the particular brand of cap she chose, the cap must be changed every 20 to 30 minutes, thus requiring her caregiver to be present throughout the treatment to change the caps. In this instance, Ms. X's caregiver had to bring multiple caps in a cooler on dry ice to each treatment.

Unfortunately, scalp cooling is not routinely covered by insurance for patients in the United States (Dignicap, 2018; Paxman, 2018). Costs of scalp cooling vary. Patients make arrangements directly with the company, which assists with fitting, and patients may be eligible for financial support for scalp cooling. van den Hurk (2012) reported that in the Netherlands, the mean cost of scalp cooling was \$213.21 per patient per hospital visit, with \$109.52 in equipment cost and \$103.69 in nursing care costs. The cost of scalp cooling in the United States has not been reported but may range from \$1,500 to \$3,000 without

financial assistance, depending on the number of chemotherapy treatments and the brand of cap used (Dignicap, 2018; Paxman, 2018). Ms. X shared with us that she paid \$3,000 out of pocket for the rental of the Penguin cap for the 6 months of treatment and \$1,800 for the dry ice for the same length of time. This does not include the lost wages of her caregiver, who had to take off work each week to be at her treatments.

On treatment days, following the manufacturer's instructions, the patient's scalp is usually cooled for 30 minutes before infusion, during the infusion of chemotherapy, and for a period of time after chemotherapy, depending on the treatment regimen being given. The length of time required for scalp cooling after infusion is under investigation and varies by type of treatment given (Komen, Smorenburg, van den Hurk, & Nortier, 2013). The treatment center caring for the patient needs to consider how to accommodate the patient before and after treatment while cooling, when chemotherapy is not infusing. Chemotherapy administration time spent in the infusion chair or bed needs to be used as effectively as possible to promote throughput in the infusion clinic, while at the same time ensuring patient comfort. For this reason, some treatment centers choose to have a pre- and postchemotherapy treatment area for patients to cool their scalps. If a center or clinic opts to use a scalp cooling machine, more than one machine may need to be made available so the patient can detach from the treatment area machine, move to the post-treatment area, and reattach to a machine within a short period of time. Manufacturer guidelines

**Table 2. Resources for Patient Assistance With Scalp Cooling**

Resource	Website	Comment
HairToStay	HairToStay.org	<ul style="list-style-type: none"> <li>Provides education to patients about scalp cooling</li> <li>Offers need-based grants to help with cost</li> </ul>
The Rapunzel Project	Rapunzelproject.org	<ul style="list-style-type: none"> <li>Provides education to patients about scalp cooling</li> <li>Offers information about brands of scalp cooling</li> <li>Lists locations across the country that offer scalp cooling</li> <li>Has links to news about FDA approvals, and studies and funding for scalp cooling</li> <li>Offers need-based grants to help with cost</li> </ul>
Breastcancer.org	Breastcancer.org	<ul style="list-style-type: none"> <li>Patients can connect with other survivors to discuss their experiences with scalp cooling</li> </ul>
Manufacturers	See Table 1	<ul style="list-style-type: none"> <li>Some manufacturers offer financial assistance with scalp cooling</li> </ul>



**Table 3. Tips for the Patient Using Scalp Cooling**

- Use a neck pillow during scalp cooling, as the cap is heavy.
- Have warm blankets, an electric blanket, or heating pads on hand to use, especially during and right after each cap change.
- Consider wrapping ears, forehead, and bald spots to prevent frostbite.
- If using manual cold caps, you may need an assistant to help with cap wear time and switch them at the appropriate time.
- Wash hair gently using a gentle shampoo with a pH in the 4.5 to 5.5 range. Do NOT use products that are volumizing or opaque (rather than clear). Such products may coat the hair and keep oxygen from reaching the hair follicles.
- Use a detangling spray (spray-on conditioner) rather than a regular conditioner. Again, this helps keep the hair follicles from being coated.
- Make the transition to new hair care products as soon as possible before chemotherapy starts, as it may take 2 weeks or more to fully clean old product residue off the hair.
- Coloring hair is not recommended until 3 months after chemotherapy is finished because the follicles need time to recover from the trauma of chemotherapy.
- Style hair simply during chemotherapy. Do not bunch or pile hair on top of your head; wear it straight.
- Don't pull on the roots during hair care or combing. Hold hair when combing so as not to strain the roots, if possible.
- Sleeping on a satin pillow case may reduce tension on follicles.
- Do not use curling irons, electric rollers, or hot air hair dryers.

Note. Adapted from HairToStay (2018) and The Rapunzel Project (2015).

suggest the maximum time (e.g., 10 minutes) a patient may be detached from the machine before the cap starts to warm up and vasodilation can occur, which allows chemotherapy to reach the follicles and cause CIA.

Some centers may choose to charge a facility fee to cover the cost of a cap fitting visit if applicable (depending on the brand of cap used), and to provide care to the patients who need assistance changing caps and need to be monitored while cooling before or after therapy. Patients may also choose to privately hire a “capper,” a person trained to change manual caps at intervals during therapy.

### PATIENT RESOURCES

There are resources for patients who may seek to secure financial assistance to pay for scalp cooling. One of these is HairtoStay ([hairtostay.org](http://hairtostay.org)), a non-profit organization that offers need-based grants to help patients. Another organization is The Rapunzel Project ([rapunzelproject.org](http://rapunzelproject.org)), which has a website listing locations across the country offering scalp cooling. On [breastcancer.org](http://breastcancer.org), patients can connect with other survivors who are using scalp cooling to discuss their experiences. See Table 2 for more information about patient resources.

### HAIR CARE AND RESTRICTIONS DURING THERAPY

Patients need to make modifications to their hair care routines if they elect to scalp cool during chemotherapy treatments. Manufacturer instructions regarding hair care vary but often include recommendations regarding frequency and timing, hair product selection, limitations on hair styling, restrictions on using certain hair tools (e.g., hair dryers, curling irons, straightening irons, hot rollers), and brushing and combing. Patients are also usually told to avoid using rubber bands to tie back hair, using head bands, and dyeing their hair (Dignicap, 2018; Paxman, 2018).

### CONCLUSION

Ms. X received 16 treatments of weekly paclitaxel. An assessment on her final treatment day revealed that she had retained 95% of her hair. Ms. X explained to her providers that having a head of hair that appeared normal made her feel comfortable in social and business situations that are so key to “normal” life during cancer therapy. She felt that her scalp cooling experience was a success.

The process and logistics of scalp cooling should be considered before a program is set up. For some clinicians, interventions to decrease alo-

pecia may be of secondary importance to chemotherapy with curative intent. Health-care providers need to understand the evidence behind scalp cooling as well as the data in regards to safety and efficacy. As more patients are requesting its use, advanced practitioners will need to advocate and educate other clinicians and patients about the impact of decreasing the risk or extent of alopecia. The prevention of CIA may have a positive impact on patients' overall quality of life. The use of scalp cooling for patients with solid tumors other than breast cancer, in male patients, and the length of time required for cooling after various chemotherapy regimens needs further study. With more data, providers can offer scalp cooling to a wider selection of patients without reservations. ●

### Disclosure

The authors have no conflicts of interest to disclose.

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