

Improving Information Provision on Chemotherapy-Induced Alopecia and Scalp Cooling: A Comprehensive Approach Including A Website and Web-Based Decision Tool

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ABSTRACT

Objective: Alopecia is a frequently occurring side effect of chemotherapy and has high impact on many patients. Currently, scalp cooling is the only method to prevent this chemotherapy-induced alopecia (CIA) and it is effective in about half of the patients. Since determinants of the success are largely unknown, all patients should be prepared for potential hair loss. The objective was to provide up-to-date online information about CIA and scalp cooling to support patients in coping with CIA and in their choice regarding scalp cooling.

Methods: Essential aspects of delivering information and lack of information were identified during focus groups, interviews, and a questionnaire survey among cancer patients, and in discussions with nurses. **Results:** The obtained information was used to develop a website (www.scalpcooling.org) and a

web-based tool. It combines scientific evidence and practical advice about CIA and regrowth of hair, scalp-cooling tolerance, efficacy and safety, as well as an overview of possible advantages and disadvantages. The web-based tool provides tailored information about the probability of CIA with and without scalp cooling in particular chemotherapy regimens. Besides, the tool offers patients' support in decision-making by allowing them to reflect and consider their values and opinions about scalp cooling. **Conclusions:** This comprehensive information is useful during nursing consultations.

Key words: Chemotherapy-induced alopecia, decision aid, hair loss, informed treatment decision, patient-tailored information, scalp cooling

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Introduction

Cancer patients' most urgent need for information during diagnosis and cancer treatment is about disease stage, treatment options, and side effects of treatment. The goals of information provision are to assist cancer patients in making treatment decisions, prepare them for their treatment, increase treatment adherence and abilities to cope with the illness, as well as promote recovery.^[1]

One common and most visible side effect of cancer treatment is chemotherapy-induced alopecia (CIA). Patients frequently rank alopecia among the most troublesome side effects of chemotherapy,^[2,3] but part of the oncological healthcare providers still tends to underestimate its impact.^[4] Alopecia is associated with loss of privacy, a possible negative effect on social activities and quality of life, and apprehension about returning to work.^[3]

Until now, scalp cooling has proven to be the only method to prevent CIA.^[5] Its effectiveness has again been shown in a recent randomized trial^[6] and a prospective study^[7] – which both led to Food and Drug Administration (FDA) clearance of scalp cooling in the USA and systematic reviews.^[8,9] About half of the patients are satisfied with the result of scalp cooling, varying from 8% satisfaction when exposed to the combination of docetaxel, adriamycin, and cyclophosphamide to 94% after docetaxel monotherapy.^[10] Until we know whether scalp cooling will be effective for an individual patient, they all should to be prepared for potential hair loss. Medical doctors and nurses play an important role in preparing for and coping with CIA and patients highly prefer to receive verbal information from their healthcare professionals along with written information.^[11]

During scalp cooling, a cool cap is applied to the head 20–30 min before the beginning of chemotherapy and left in place until 90 min after infusion. This decreases the temperature of the scalp skin to a mean of 19°C.^[12] Scalp cooling is generally well tolerated; moderate or severe headaches are reported by patients in <10% of the chemotherapy courses and can mostly be prevented by a prophylactic analgeticum.^[13] Other side effects of scalp cooling include sensations of cold, pain or dizziness, or complaints about the heavy weight of the cap. In the literature, <5% of the patients cease scalp cooling because of intolerance.^[14] Concerns are often expressed regarding the possible increased risk of developing scalp skin metastases. However, recent research showed no increase in incidence of these metastases, nor difference in survival when comparing scalp cooled and nonscalp cooled breast cancer patients after >5-year follow-up.^[15,16]

Information regarding the success of scalp cooling while receiving current chemotherapy regimens, as well as the

added value of scalp cooling for hair preservation, is not accessible for patients and healthcare providers in one place. Besides, medical doctors and oncology nurses perceive their knowledge about efficacy and safety on this topic insufficient to inform patients satisfactorily.^[17] Moreover, in addition, time constraints during counseling before starting chemotherapy make it difficult to address all side effects in depth. Therefore, online information regarding CIA, the scalp cooling process, and its advantages and disadvantages would be helpful for patients who require additional information and further support in decision-making. This is important since informed decisions and tailored information lead to less regret after treatment and higher patient satisfaction.^[18] When patients use decision aids, they improve their knowledge of the options, feel more informed and more confident about what matters most to them, have more realistic expectations of benefits and disadvantages of the options, and feel more satisfied with their decisions.^[19]

The objective of the current project was to design an up-to-date, compact, yet comprehensive online resource about CIA and scalp cooling to support patients in coping with CIA and in their choice regarding whether or not to undergo scalp cooling.

Methods

Finding gaps in the current information provision regarding chemotherapy-induced alopecia and scalp cooling

In the Netherlands, a guidance document was developed, summarizing the state of the art about CIA and scalp cooling for healthcare professionals.^[20] It was no official guideline, as the scientific evidence was considered to be insufficient. However, when using this document, nurses reported gaps in the information provision regarding CIA and scalp cooling. A working group was created to come up with a solution for this problem. This group consisted of researchers with backgrounds in psychology (FM) and epidemiology (CH), a nurse practitioner with many years of experience with and patient counseling about scalp cooling (PK), an advisor in patient participation (KH), and an expert in shared decision-making (IR).

To obtain more information on possible gaps and solutions, two focus groups were organized. One with 9 Dutch breast cancer patients who experienced CIA, and the other with 6 breast cancer patients who had received scalp cooling. During these focus groups, essential aspects of delivering information and lacks of information were identified in a semi-structured way. Central questions during these focus groups were “What information about CIA was provided to you?” and “What pieces of information or

support did you miss, in reflection after your treatment?" The moderator was looking for positive and negative experiences, possible solutions, and the importance of this information for patients.

In addition, a semi-structured interview was conducted among 11 Dutch breast cancer patients who underwent chemotherapy and who were eligible for scalp cooling. The main research question was "How do breast cancer patients make a choice regarding scalp cooling during chemotherapy treatment?" The interviews were audiotaped and transcribed verbatim. Data analysis was performed using the methods of open, axial, and selective coding with the application Kwalitan 6.0 (Nijmegen, Gelderland, the Netherlands).

As the focus groups and interviews did hardly reveal information on coping with hair loss, a panel of cancer patients was contacted through the website <https://www.kanker.nl/doneerjeervaring> (i.e., "donate your experience") of the Kanker.nl Foundation. Eighteen panel members experienced CIA and 10 completed our questionnaire. Respondents were breast cancer patients ($n = 8$) and prostate cancer patients ($n = 2$) between the ages of 37 and 56 years.

The data collections involving patients were not subjected to the Dutch Medical Research Involving Human Subjects Act (WMO), and therefore, no informed consent was required. All procedures were conducted in accordance with the 1964 Helsinki declaration and its later amendments.

In addition to the information that was obtained from patients, multiple discussions with Dutch-specialized oncology nurses took place. These nurses were all familiar with scalp cooling while they offered the possibility of scalp cooling to their patients in daily practice. These discussions were performed to obtain information on what they thought were the gaps in the current information provision regarding CIA and scalp cooling.

Development of a website and web-based tool

The information that was gathered as described above was used to develop a Dutch and English website (www.hoofdhuidkoeling.nl and www.scalpcooling.org) and a web-based tool which can be helpful for both patients and healthcare professionals to support shared decision-making on whether or not to undergo scalp cooling. Texts for the website were written by the working group. The web-based tool provides decision support by means of a probability calculator and a value clarification exercise, according to the International Patient Decision Aid Standards.^[21,22]

In the web-based tool, the calculator is based on the former Dutch scalp cooling registry in which the result is registered per type and dose of chemotherapy ($n > 7000$ as of December 2018).^[10] The multidisciplinary members of the Cancer related Hair loss; International Leadership

and Linkage (CHILL) group have continued the registry which will supply the tool with international data from the US, the UK, and Australia too. Seventy-five percent of the participants in this registry are breast cancer patients and the second largest group are prostate cancer patients (7%). Since new data are added to this registry daily, the information underlying the web-based tool is updated regularly as well. Reliable information on the risk of severe CIA without scalp cooling is scarce.^[23] Therefore, in the tool, these risks are mainly estimated by experienced oncology nurses. However, the recent version of the scalp cooling registry also includes patients without scalp cooling; so, this information will become available in the forthcoming years.

The value clarification exercise consists of statements which are based on patients' perceptions and experiences with CIA and scalp cooling that were identified during the focus groups and interviews with patients and nurses.

To inform patients about the availability of the website and web-based tool, a flyer was developed and made available in all Dutch hospitals. The English (pdf) version is available for each interested user. Patients can ask oncology nurses details about their chemotherapy regimen and write it down on the flyer; so, they can access tailored information from the website at home.

The preliminary version of the website and the tool was evaluated by 14 (ex) patients, 7 laymen, 8 nurses, 2 doctors, and 1 hairdresser.

Results

Gaps in information

The patients in the focus groups ($n = 15$) reported a need for information about why and how hair loss occurs, impact of hair loss, possibilities for camouflage, regrowth, and the possibility for scalp cooling. Patients who are about to decide about scalp cooling would like to be informed about the process of scalp cooling, possible hair loss and treatment of hair during scalp cooling, camouflage when the result is insufficient and they prefer an overview of advantages and disadvantages of the treatment. Patients also preferred to receive support regarding hair loss before, during and after treatment.

In the semi-structured interviews, respondents ($n = 11$) described hair loss as shocking. However, some respondents placed the meaning of hair loss into perspective since hair loss is temporary and they considered it part of the curing treatment of cancer. Patients mainly chose scalp cooling to try to keep their hair the way it was. An important reason not to choose for scalp cooling was the fact that scalp cooling does not guarantee they will keep their hair. Furthermore, having to spend more time in the hospital was an important consideration not to choose for scalp cooling.

The questionnaire about coping with CIA ($n = 10$) revealed diverse reactions on whether to camouflage baldness. Some never used a wig or head cover, others always used them, including indoors. Furthermore, the reactions of other people on the patients' baldness differed enormously. Patients mentioned both understanding and caring reactions but also had to deal with people that absolutely did not want to be confronted with their baldness. The regrowth of hair was too slow in the eyes of most patients. Regrowth started 3–5 months after chemotherapy, and it took 2 months before the scalp was covered with hair.

The discussions with nurses yielded several problems in delivering information including the extensiveness of information about the potential risk of scalp skin metastases, whether to thin the hair beforehand or to color or bleach it during scalp cooling, and when to advise the patient to cease scalp cooling.

All the aspects brought up by patients and nurses have been incorporated in the information on the website.

Website and web-based tool

The website contains both scientific information and practical advice about CIA and scalp cooling [Box 1]. Furthermore, it includes an overview of advantages and disadvantages of scalp cooling [Box 2] and a web-based tool. Finally, the website contains a section for healthcare professionals with additional information, for example, about the fitting of the cool cap and patient leaflets. The information is provided to patients and healthcare professionals by means of text and videos.

In the web-based tool, the calculator presents tailored information about the probability of severe CIA with and without scalp cooling for the most common chemotherapy regimens for which scalp cooling would be indicated. The probability calculation is presented as simple frequencies in diagrams as well as described in words, to facilitate understanding [Figure 1].^[24] The same denominator is used for comparison of the probabilities.

The web-based tool also includes a value clarification exercise. Patients can fill out a few statements, for example, on how they value their hair and the prospect of being bald, how they perceive their personal probability of hair loss and the safety of scalp cooling [Table 1]. For each statement, they first indicate whether they “agree” or “disagree.” Thereafter, patients are asked to rate the importance of the statement for their personal situation at this moment.^[25] This process takes about 10 min, and given privacy considerations, the answers are not stored on our website. Patients then receive an overview with their personal reasons whether to choose scalp cooling or not [Table 1]. Although this overview does not provide an actual advice, it can help patients in making a treatment choice. A handout can be printed to discuss the

Box 1: Information on the website

Hair loss

Alopecia (e.g., cause and course of CIA, hair pain, eyelashes and eyebrows and hair loss caused by other cancer-related treatments)

My chance for CIA

CIA: now what? (e.g., influence of CIA, preparing for CIA, coping with reactions to CIA, wigs and head covering)

Growth of hair

Scalp cooling

What is scalp cooling?

For whom?

Practical aspects (e.g., using toilet during scalp cooling, hair thinning, ceasing scalp cooling, hair growth and hair care)

Tolerance

Safety

Chance of hair preservation due to scalp cooling

Advantages and disadvantages [Text box 2]

Patient leaflets

Web-based tool

Contact and sources

For healthcare providers

Registration of hair loss

Standard for CIA

Cooling times

Results of scalp cooling

Instructions for scalp cooling

Publications

Patient leaflets

CIA: Chemotherapy-induced alopecia

Box 2: Advantages and disadvantages of scalp cooling as presented to patients on the website

Scalp cooling

Advantages

You have a greater chance of hair preservation

You may not need to wear a wig or head covering

You have the possibility to do something against the baldness

Your hair that is lost despite scalp cooling will regrow faster

Disadvantages

You are present in the hospital for a longer period of time

You have no warranty on hair preservation; there is uncertainty about the result

You may experience uncertainty about the safety of the treatment

The quality of your hair might become less

You will probably experience prolonged minimal hair loss

Scalp cooling is cold, especially the first 15 min

Scalp cooling might cause a headache or dizziness

You might experience extra disappointment if scalp cooling fails

No scalp cooling

Advantages

There is less uncertainty about hair loss, you will probably become bald

You will probably experience hair loss shortly, the hair usually falls out within several weeks

Disadvantages

It is highly likely that you will become bald

You will be bald for several months and then have a period with very short hair

You will bear additional costs if you buy a wig and/or head covering

tailored probability and personal values with health care professionals or family members.

The evaluation by patients, laymen, nurses, doctors, and hairdresser led to several suggestions for improvement before they were launched.

Discussion

The website that originated from this project supports cancer patients in preparing for CIA and enhancing expectations of its impact on daily life and provides insight into the advantages and disadvantages of scalp cooling. As scalp cooling is not always actively offered to all eligible patients,^[17,26-28] the website might also be beneficial for patients who are searching for additional information before starting chemotherapy. The web-based tool also offers patients support in decision-making by allowing them to reflect and consider their values and opinions with regard to scalp cooling.

When patients use decision aids, they have more accurate expectations of the possible benefits and harms of their options and are more likely to reach decisions that are consistent with their values.^[19] Potential decisional regret and treatment-related anxiety are mainly related to the expectations that patients have. Those expectations are most often based on counseling by the medical doctor

or oncology nurse before chemotherapy.^[17] In a recent Australian study, patients recalled from the conversation with their medical doctor about the decision for scalp cooling, that they received information about efficacy, the fact that they might experience some additional hair loss despite scalp cooling, and the possibility of faster regrowth of hair.^[27] Patients indicated that they would have preferred more information about the process of scalp cooling, tolerability issues and hair care, and also information to give to their hairdresser. This information is incorporated in videos for patients and hairdressers at the Mater Hospital in Sydney (<https://mns.org.au/home/our-services/list-of-services/cancer-care/scalp-cooling-system>) which are also used on the website.

Decisional regret is not common after scalp cooling. Many patients report that they would make the same choice if they might need chemotherapy in the future and would recommend scalp cooling to other cancer patients, independently whether they kept or lost their hair.^[17,27] At the other hand, there are also some patients with regret, mainly due to the level of discomfort, additional time spent in the hospital, and their poor outcomes regarding CIA (e.g., needing a wig or head cover).^[27]

Treatment-related anxiety, which mainly manifests by constantly checking the hair, is caused by the uncertainty of hair preservation during scalp cooling.^[17,27] Patients describe severe hair loss despite scalp cooling as an extra disappointment,^[29] a stressor, or a feeling of failing, whether or not on their part.^[27] However, nurses also report that the uncertainty of the outcome of scalp cooling influences their self-confidence and makes them feel responsible for the result. Determinants for successful scalp cooling are largely unidentified,^[7,10,30] gentle hair care will in no case be detrimental, and proper fitting of the cold cap is very important.^[12] Therefore, patients should be advised to check the fitting of the cap throughout treatment. Furthermore, nurses are advised to support patients in the process of – potential or inevitable – CIA before, during, and after it occurs, regardless whether or not they chose scalp cooling.^[17]

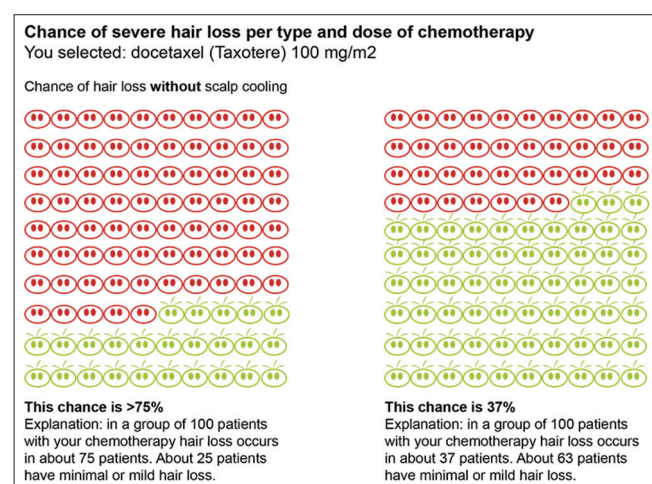


Figure 1: Overview on hair loss and scalp cooling for the patient

Table 1: Overview of value clarification exercise

Your value	Reasons NOT TO choose scalp cooling	Reasons TO choose scalp cooling
★ ★ ★		My hair is important to me I think my chance of hair loss without scalp cooling is high I think that scalp cooling makes my chance of hair loss (much) smaller I would be bothered if people can see that I am sick because of my baldness I think that scalp cooling is a safe treatment
★ ★	I cannot handle the uncertainty about the final result of scalp cooling I think that I cannot tolerate scalp cooling well	I would be upset by becoming bald
★	I do not have a problem with wearing a wig or head covering at home and outside my home	I do have a problem with showing my bald head outside my home I am willing to spend more time at the hospital for scalp cooling

Overall, patients are satisfied with healthcare professionals' information on hair loss and scalp cooling, which is sufficient for general understanding.^[17] There is however room for improvement, especially for patients categorized as "information seekers." As the use of scalp cooling is increasing worldwide, and especially after the FDA approval in the USA, many healthcare organizations independently develop their own patient leaflets, web information, videos, and nursing protocols. However, forces should be joined and knowledge shared, which is the aim of the recently founded CHILL group which functions under the umbrella of the Skin Toxicity Working Group of the Multinational Association of Supportive Care in Cancer.

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Conflicts of interest

C. van den Hurk: IKNL has received a grant from Paxman Ltd. and Dignitana A. B. to set up an international registry on scalp cooling. She has received reimbursement for travel costs to conferences from both manufacturers. No other conflicts of interest to be reported.

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