

Analysis of Patient Concerns Regarding Scalp Cooling Devices for Prevention of Chemotherapy Induced Alopecia in Breast Cancer

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Background

Most adjuvant chemotherapies for breast cancer cause hair loss in majority of patients. Although Chemo Induced Alopecia (CIA) is temporary, it is distressing for many patients and about 7% patients treated with docetaxel experience permanent hair loss. Scalp cooling devices (SCDs) have been shown to reduce hair loss in such patients receiving adjuvant chemo.

Objective

Many patients share their experiences in online forums that contain freely shared messages and can be used to analyze concerns regarding Chemotherapy induced Alopecia and Scalp cooling devices. We use our automated system, VoCP (www.voiceofcancerpatients.com), to analyze these messages and assess the utilization of Scalp Cooling devices, their efficacy, concerns and associated barriers.

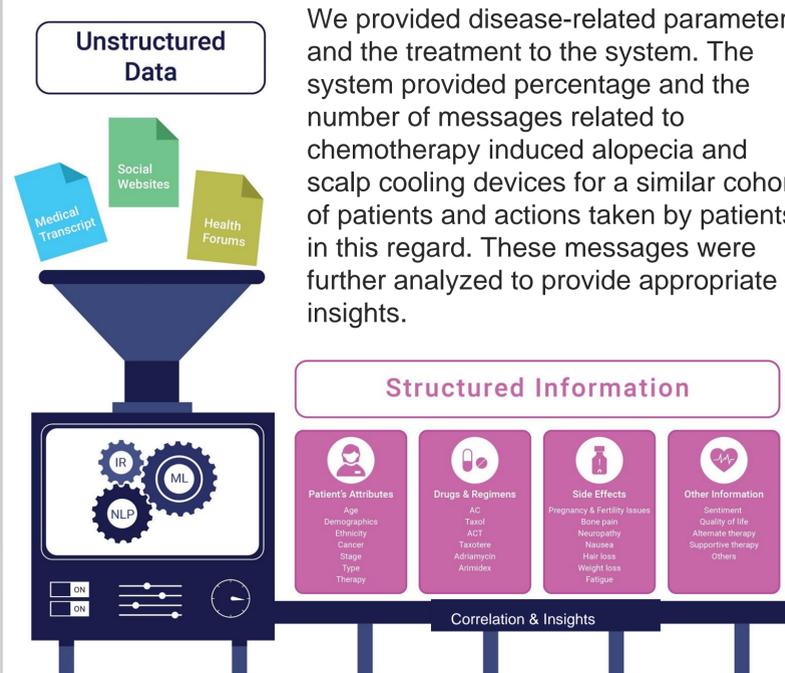
Methods

We collected 15.13 million unique messages (by 987,189 patients) from 37 cancer forums that provide clinically relevant information; we built custom ontologies for chemo drugs and regimens, hair loss, Scalp Cooling Devices, supportive therapy and efficacy. We then used VoCP (that uses techniques from Artificial Intelligence - deep learning, information retrieval and natural language processing) to extract relevant information.

The platform consists of the following techniques and modules:

❖ **Custom scrapers** and parsers extract data from online health forums, social sites and medical transcripts.

❖ **Analytics engine** uses natural language processing, machine learning, and rule based algorithms to process unstructured text and to extract various attributes of patients, drugs, regimens, and their side effects.



We provided disease-related parameters and the treatment to the system. The system provided percentage and the number of messages related to chemotherapy induced alopecia and scalp cooling devices for a similar cohort of patients and actions taken by patients in this regard. These messages were further analyzed to provide appropriate insights.

Results

Out of 15.13 million, 21,292 messages from 5,423 patients discussed the use of Scalp Cooling Devices during chemotherapy. 16,527 of these were inquiring and had concerns about SCDs, e.g., do SCDs work, what are their side effects, are they cumbersome to use, is there a risk of scalp and brain metastasis, what is the cost and insurance coverage, are they easy to obtain and brand manufacturers.

2,479 messages from 960 patients discussed SCDs with Taxotere, 2,137 from 1,011 patients discussed with FEC/AC, and 526 from 256 patients discussed with AC/Taxol.

The table given below illustrates the distribution of messages for patients discussing cold caps with various chemotherapeutic drugs or regimens:

	Chemotherapeutic Drug/Regimen	Message Count
Regimen	FEC	2,137
	FAC	16
	TAC	140
	AC-Taxol	526
	AC-Taxotere	168
	THP	69
	TCH	546
Drug	Taxotere	1,559
	Abraxane	60
	Eribulin/Halaven	20
	Cisplatin/Platamin/Cisaplat/Neoplatin/Platinol	41
	Carboplatin/Paraplatin	280
	Ixabepilone/Ixempra	5

In 2,167 messages, 874 distinct patients who used SCDs mentioned that by using them, they were able to **keep 50-75%** of their hair but experienced significant hair-thinning. Most users were satisfied with the use of SCDs and would prefer them over losing hair completely.

Specific comments regarding side effects, barriers and advice included:

- Headaches, shivering, frost-bite, heaviness, neck and shoulder discomfort, chills, brain freeze, scalp pain, migraine, drowsiness, dizziness and cold
- Use Lorazepam, Ibuprofen and Acetaminophen to mitigate the adverse effects

- Use mittens/hand-gloves, scarves, blankets and heating pads to keep body warm and avoid shivering
- Use cold caps during and 3-5 hours after chemo; change them every 15-30 minutes
- Cold caps with varying temperatures warmer in front and sides for ear and forehead protection may help
- Trim voluminous hair so that greater surface area of scalp gets subjected to cranial hypothermia

- For cold caps, either the facility needs to provide a freezer or patients need to bring their own
- Penguin** cold caps are most common (2,095 messages) but monthly rent is \$500-\$600
- Patients can buy **Elastogel** caps (955 messages) for about \$100
- Alternatives include icepacks and wrap-arounds provided by companies such as **ElastoGel**
- For single cap cooling devices such as **DigniCap** (369 messages) and **Paxman** (441), facility has to provide the underlying system
- Rapunzel Project** (172 messages) can help with scalp cooling gear, freezers and counseling; 79 SCD users mentioned getting their help

Discussion

Despite significant discomfort, cost and inconvenience, many patients are satisfied with the use of Scalp Cooling Devices for Chemotherapy induced alopecia.

More programs like Rapunzel project are needed to help patients. Such projects help manage chemotherapy induced hair loss.

By analyzing millions of messages, VoCP provides meaningful insights into patients' treatment and concerns and gives insight into their unmet needs for further research and resources.