

Development of a standardised patient reported outcome measure for chemotherapy-induced alopecia (CIA) and scalp cooling efficacy

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Background

- Increasing use of scalp cooling techniques world wide
- No reliable estimations about severity of chemotherapy-induced alopecia (CIA):
 - Scarce data on incidence of CIA
 - Wide range of incidence rates of CIA
 - Scarce data on efficacy of scalp cooling
- Research to further increase efficacy of scalp cooling requires an international standard patient-reported outcome measure (PROM) incorporating quality of life (QoL) & efficacy

Methods

- Literature search on scoring methods to measure scalp cooling efficacy
- Develop optimal evaluation methods: focus groups & patient interviews in the Netherlands (n=19) & Australia (n=17):

A. QoL:

- Following EORTC guidelines for developing questionnaires
- Patients shared their experiences & opinions about CIA

B. Efficacy of scalp cooling:

- Examples of the most frequently used methods were assessed
- Patients rated methods in terms of ease of understanding & use

Results

Literature search

- 85 papers & abstracts since 1970 about the effectiveness of scalp cooling
- 34 different Likert scales, in addition to Visual Analogue Scales & pictorial assessments (figure 1)

Evaluation methods

A. QoL:

- Reported issues categorized in: overall QoL issues affected by CIA, information about CIA, expectations, importance of hair, concerns of sudden CIA, management of CIA & regrowth of hair
- Next phase: testing relevance of the issues, defining & testing item list

B. Efficacy:

- Preferences for scoring varied substantially between patients: numerical, categorical in words or in sentences, or drawings of CIA grades
- The pictorial scale was quite well ranked but the pictures were felt to be stark

Discussion/ Conclusion

Measurement of CIA should be improved & standardized, resulting in

- meaningful comparisons for efficacy of scalp cooling
- reliable estimations about additional value of scalp cooling for our patients
- interventions to reduce the impact of QoL associated with this burdensome side effect of cancer treatment

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Figure 1:
Example of pictorial tool:
Ludwig's classification for female alopecia

