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 worldwide
- 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 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

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