WHAT ARE THE QUALITY OF LIFE ISSUES FOR PATIENTS WITH CHEMOTHERAPY-INDUCED ALOPECIA?

DEVELOPMENT OF THE HAIR-QOL MEASURE

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INTRODUCTION

- Chemotherapy-induced alopecia (CIA) is one of the most common and distressing side effects related to cancer treatment.
- Although CIA is not life-threatening, it can cause a daily burden for many people with cancer and it may affect their health-related quality of life (HRQoL).
- The impact of CIA is described by patients is related to domains of psychological, social and role functioning, besides physical complaints.
- Most of the available instruments which measure patients’ HRQoL do not include items related to alopecia.
- Several EORTC cancer specific modules and some symptom questionnaires for people with cancer which contain an item about alopecia are not validated for gender or cancers other than breast.[6]
- We aimed to identify patient-reported HRQoL issues as a first step in the development of an internationally validated CIA instrument for all people with cancer. It is important that this is a patient-reported measure as symptom experiences are highly personal and subjective.

METHODS

This project was designed following an adapted methodology of the EORTC Quality of Life Group module development guidelines as follows:

1. Generation of a HRQoL issue list through literature review, focus groups, and semi-structured interviews with patients, and quantitative research with health care providers (HCPs);
2. Testing and adapting the issue list and transforming the identified issues into questionnaire items.

RESULTS

- Even though many studies and clinical practice have shown a high personal impact of CIA, little attention is afforded in the clinical setting.

    - The relevance of each issue was assessed by 57 patients with many cancer types and treatments:
      - White Caucasian/European (n=49, 86%); 35 (61%) were patients with breast cancer
      - For most patients (72%) the time since their last chemotherapy was less than one year, 20 (35%) patients were in early-stage disease and had received adjuvant treatment, 18 (31%) had advanced stage disease
      - Mean age was 55.0 (SD=11.2) years
      - No difference in relevance scores could be detected between language groups or age groups.
      - Wearing of a wig/head cover - more relevant for female patients than males (p between 0.001 and 0.004).
      - Additional remarks made by the patients did not raise any extra issues and no issue had been marked as being upsetting.
      - Eleven HCPs tested and adapted the list (4 oncologists, 5 nurses, 1 psychotherapist and 1 unknown profession. The calculated scores led to selection of 43 issues

    - The Step 3 translation from a list of 43 issues into questionnaire items was completed.

CONCLUSION and NEXT STEPS

- This study has shown that patients with cancer with CIA experience important HRQoL issues, not adequately measured by existing HRQoL measures
- The newly developed questionnaire on the impact of CIA on HRQoL adds breadth to the knowledge from existing PRO measures in cancer care and to supportive care research.
- This item list is ready for future international testing in larger groups of people with cancer and HCPs to finalize the HAIR-QoL measure.
- The provisional HAIR-QoL questionnaire is now being tested in hospitals in 5 continents (publication forthcoming).

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