

EORTC QoL module for Oral Health

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Background, scientific 1

- Adequate symptom treatment is an inherent part of follow-up care;
 - QoL assessment
 - patients' self-reported health are central issues
- Poor symptom assessment is the most important barrier for adequate symptom management
- 40-70% of cancer patients will experience oral side effects due to treatment and medication
- Physicians and nurses show less attention to the mouth than to other parts of the body

Background, scientific 2

- All normal cells with high turn over, ie. the epithelial tissue of the oral mucosa, are influenced by chemo-therapy and / or radiotherapy
 - damages the protective function of the mucosa
 - more vulnerable, more susceptible to infections (also systemic)
 - mucositis, mucosal infections, oral pain, dry mouth (xerostomia), taste changes, caries and soreness
 - treatment with bisphosphonates associated with osteonecrosis of the jaws
 - increasing incidence rates
- Negative impact on general health and well-being, nutritional status, social interaction and QoL

Background, scientific 3

- Poor oral status has negative consequences on most aspects of QoL
 - proper assessment should be conducted regularly;
 - before, under and after treatment
 - no brief, well-suited instrument for assessment of cancer related oral health and mouth problems
 - particularly not one that is feasible for clinical use!
 - none of the frequently used QoL questionnaires encompass specific questions on oral health
 - some H&N modules or tools do
 - specific tools for oral health/morbidity, often too long, eg. the 49 item Oral Health Impact Profile

Current status of the Oral Health module

- Close to terminating phase 1
- Phase 1A, completed
 - with extensive literature reviews
 - generation of a list of issues
 - interviews with 18 professionals
 - several specialties (oncologists, oral surgeons, dental hygienists, oncology nurses, dentists)
 - Norway, Greece, UK
 - Provisional list of items, 84, for patient interviews in 5 areas;
 - Pain / oral and dental related problems
 - Dental and oral care, incl. self-care
 - Functional aspects, (chewing, opening the mouth etc)
 - Social aspects
 - Information

Current status, 2

- Phase 1B patient interviews
 - Completed; 133 interviews from Norway, France, Germany, Netherlands, Greece, UK
- All data analysed
 - 70 % had received multimodal treatment
 - 3 phases of treatment;
 - In active
 - 2-6 months beyond
 - > 6 months beyond
- Discussions regarding item reduction of the initial 84 items has been undertaken by e-mail and continued here in Pamplona

Discussions regarding item reduction

- Initially 84; at present 35 items
 - pain/oral and dental problems: 37, now 18
 - dental/oral care: 12, now 6
 - functional aspects: 16, now 6
 - social aspects: 11, now 1
 - Information: 8, now 4
- H&N cancer, specific problems, higher ratings, as anticipated
- Dentists regard the items a little different than medical doctors
- Primarily a screening tool
 - capturing the most relevant aspects for professional follow-up
 - clinical use
- What about own teeth vs prosthesis / dentures, two parts of the questionnaire?

Timeline

- Phase 2, wording/formatting has started, prior to entering the translation procedures
- Hopefully Phase 3 will start in the late fall, 2009
- Publications:
 - Conference abstract about the background and the work in Phase 1, submitted to the NCRI conference in the UK, Oct. 2009
 - Submission of a manuscript is scheduled after the results from Phase 3 are ready, summer/fall 2010

Financial situation

- Oslo University Hospital, Ullevål
 - develops patient forms for scanning
 - performs the scanning free of charge
- The project was allocated an EORTC grant for module development
 - duration 18 months, running from Oct 2008

