



EORTC

European Organization for Research
and Treatment of Cancer

Development of an EORTC quality of life module for cholangiocarcinoma: UPDATE

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AIMS

- To test the questions and issues of the LMC21 and the PAN26 in cholangiocarcinoma and gall bladder cancer patients and assess if either or both are adequate.
- If neither alone is thought to be adequate, then the EORTC protocol “guidelines for module development” will be adapted to develop a new module for cholangiocarcinoma patients.

Recruitment

101 patients recruited

- UK=76
- Germany =21
- Taiwan =4

6 Health care professionals interviewed

Debriefing questionnaire

- 47 issues

26 from PAN 26

21 from LMC21

3 extra questions from literature search and
HCP interviews

Modification of questionnaire

Based on scoring for each question and views from patients and HCP

- 5 from PAN 26
- 15 from LMC21
- 3 extra questions

Statistical Methods

- Mean and SD of likert scores
- Range of responses
- Valid %(number of patients who wanted to leave issue out divided by total number of patients who answered question)
- HCP relevance scoring (leave issue out)
- HCP top 5 questions
- Trends/ correlations in patients and HCP comments

Modified questionnaire

- **EATING**

- L31. Have you had trouble with eating?
- L32. Have you felt full up too quickly after beginning to eat?
- P36. Were you restricted in the types of food you can eat as a result of your disease or treatment?
- L34. Have you had problems with your sense of taste?

- **JAUNDICE**

- L41. Have your skin or eyes been yellow (jaundiced)?
- P44. Have you had itching?
- X. Have you been worried about your skin being yellow?

Modified questionnaire

- **TIREDNESS**
- L37. Have you been less active than you would like to be?
- L43. Have you felt “slowed down”?
- L44. Have you felt lacking in energy?
- **PAIN**
- L39. Have you had pain in your stomach area?
- L42. Have you had pain in your back?
- P34. Did you have pain during the night?
- P32. Did you have a bloated feeling in your abdomen?

Modified questionnaire

- **ANXIETY**
- L47. Have you felt stressed?
- L48. Have you felt less able to enjoy yourself?
- L49. Have you worried about your health in the future?
- L50. Were you worried about your family in the future?
- **OTHER**
- P50. To what extent have you been troubled with side-effects from your treatment?
- F1. Have you had any fevers?
F2. Have you had difficulties with drainage tubes/ bags?
- L46. Have you had trouble talking about your feelings to your family or friends?
- L33. Have you worried about losing weight?

Plans

- Module development report now completed
- Interview another 35 patients on remaining 23 questions and complete final data analysis