



EORTC

European Organization for Research
and Treatment of Cancer

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

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Centres:

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- **Kings College Hospital, London**
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Ms J Blazeby, Consultant Surgeon and Senior Lecturer

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Mr C Johnson, Consultant Surgeon and Reader in Surgery

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Dr Orhan Sezer, Dr. Claudia Fleissner

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Clare Byrne, Louise Broadfoot

- National Taiwan University

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Pending

- University College London

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- Paris, France

Dr T Conroy

AIMS

- To test the questions and issues of the LMC21 and the PAN26 in cholangiocarcinoma 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.

New Methodology

Phase 1: Generation of additional issues

Database search

Use of alternative questionnaires:

- FACT-Hep (The Functional Assessment of Cancer Therapy – Hepatobiliary Questionnaire)
- WHOQOL (WHO Quality of Life Questionnaire)
- Short Form 36 (Medical Outcome Health Survey Short Form)
- GI QLI (Gastrointestinal Quality of Life Index)

Keywords

- Cholangiocarcinoma
- Bile duct cancer/neoplasm
- Hepato/biliary duct cancer/neoplasm
- Periampullary cancer/neoplasm
- Gall Bladder cancer/neoplasm
- Gastrointestinal Cancer
- Quality of life

Phase 1: References

- Cholangiocarcinoma + QOL (43)
 - 2 used psychometrically tested disease specific questionnaires
- Bile duct cancer/neoplasm + QOL (34)
 - 1 used psychometrically tested disease specific questionnaires
- Hepato/biliary duct cancer/neoplasm + QOL (0)

Phase 1: References

- Periampullary cancer/neoplasm + QOL (7)
 - 2 used psychometrically tested disease specific questionnaires
- Gastrointestinal cancer + QOL (34)
- Hepatobiliary cancer + QOL (0)
- Gall Bladder Cancer (incomplete)

A search for additional issues not covered by the LMC21, PAN26 and EORTC QLQ-C30 was conducted.

Phase 2: Formation of additional issues

- Did you have fevers?
- Have you had any difficulties with drainage tube/bags?
- Have you been worried by jaundice?

Combined issues

- LMC21 – 21 issues
- PAN26 – 26 issues
 - 3 replicates (dry mouth/back pain/health worries)
- 3 additional questions
- TOTAL 47 questions

Scales

- EATING (7)
- BOWELS (2)
- OTHER (9)
- JAUNDICE (4)
- TIREDNESS (3)
- PAIN (6)
- RELATIONSHIPS (6)
- BODY IMAGE (4)
- ANXIETY (4)
- HEALTHCARE SATISFACTION (2)

Phase 3 (In-progress)

- Target 100 patients
- Basingstoke - (3)
- Kings - (11 and 8 pending)
- Germany -
- Taiwan -
- Southampton/Bristol/Liverpool starting now
- Patient group will encompass the full range of disease in terms of stage and performance status.

Study Observations:

- Interview time approx 40 minutes
- One patient declined participation – distressed/ not wanting to confront
- Difficulty with recall in frail patients
- Home visits obtain more detailed responses

Study Observations:

- Patients are not regular hospital attendees – difficulty in obtaining accurate information on current health status
- Cholangiocarcinoma and Gallbladder Cancer are often inaccurately coded on hospital databases

Initial trends

- Repetitive issues from the QLQ-C30 are being discarded
 - tiredness/bowel habit/social activity
- In favour of physical and emotional scales

Healthcare Satisfaction Issues:

- Always retained
- Most patients have experienced multiple treatment modalities under the care of numerous health care professionals
- Significant number already requesting questions to reflect their experience of local/specialist care.
- Communication breakdown = Impact on QOL
- Linkert Scale inadequate for some patients