Which outcomes are important to patients and surgeons?

Core disclosure prior to oesophageal cancer surgery

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Black box of surgical consultations
Too little

Too much

“I’m sorry. It appears Mr. Mitchell won’t be accepting any more information today.”
Why is this important?
Core disclosure

“The minimum information to be discussed with patients during preoperative consultations to improve shared decision-making and informed consent.”
Aim

• To develop a core disclosure set of information to use in surgical consultations prior to oesophagectomy
Methods

1. Identification of all possible individual outcomes and creation of ‘long list’
2. Creation of outcome domains from individual outcomes, & questionnaire items
3. Delphi survey of patients and clinicians
Delphi survey for consensus

Round 1

Round 2

Round 3

‘core disclosure set’
Identification of all potential outcomes

- Systematic review of clinical outcomes
- Systematic review of patient-reported outcomes
- Review of all patient information leaflets
- National Audit Data 2010 (AUGIS)
- Pre-operative consultations & interviews

‘Long list’ of all possible information
Categorisation into outcome domains
Categorisation into outcome domains

Death
In-hospital mortality
Operative mortality
90-day mortality
Mortality
30-day mortality
Overall mortality
Post-operative mortality
Intra-operative mortality

In-hospital death
**Creation of questionnaire items**

- Death
- In-hospital mortality
- Operative mortality
- 90-day mortality
- Mortality
- 30-day mortality
- Overall mortality
- Post-operative mortality
- Intra-operative mortality
- In-hospital death

**Dying in hospital after the operation**
(in-hospital mortality)
Check items with patients/experts
**SECTION C1  CLINICAL INFORMATION AND THE HOSPITAL STAY**

The following section lists some information regarding oesophagectomy, and problems that **may** occur during the hospital stay. Please note, these are only possibilities and do not occur in everyone. The words in brackets represent the medical terminology.

Please rate how **essential** you think it is that the following information is discussed with patients before surgery and circle the number that best represents your opinion.

<table>
<thead>
<tr>
<th>For example:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying in hospital after the operation (in-hospital mortality)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
Distribution of questionnaires

University of Bristol

The Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland

European Society of Esophagology
Groupe d’Etude Europeen des Maladies de l’Oesophage
Retaining items for Delphi round 2

- Rated between 7 and 9 by over 50%
- Rated between 1 and 3 by less than 15%
Results

- 701 individual outcomes
- 67 outcome domains
- 185 patients (76%) & 125 (54%) clinicians completed survey
Work to be completed

- Delphi round 2 (and 3?)
- Consensus meeting
Summary

- Patients and clinicians rate different outcomes as important
- Currently no standards of information provision
- Core disclosure may help with this
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