Short communication

Service evaluation of patients’ views on the Patients’ Concerns Inventory (at diagnosis)

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Abstract

The amount of information wanted by patients after the diagnosis of cancer of the head and neck varies, and valid consent is not possible without information. The Patients’ Concerns Inventory (diagnosis) (PCI-D) is a list intended to prompt patients to ask about aspects of their diagnosis and its potential treatments and outcomes. It has not previously been evaluated in clinical practice. Our aim was to assess how often patients recall using it and their satisfaction with both it and the information they received. New patients with oral cancer who attended one consultant’s clinic between 2014 and 2015 were evaluated and the response rate was 20/48. A total of 16/18 reported that they were very satisfied or satisfied with it. The Satisfaction with Cancer Information Profile Part B (SCIP-B) showed that the inventory seemed to improve patients’ satisfaction with the information that they were given. Further evaluation is required.

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Keywords: Patient Concerns Inventory; Head and neck cancer; Information; Audit

Introduction

The information given to patients about cancer must be of a high quality and specific to each one.1,2 There is a legal requirement for a doctor to ensure that all the “material risks” that may be considered important by a “reasonable patient” must be explored for consent to be valid.3 There are considerable immediate and long-term side effects of head and neck cancer,4 and patients may find it difficult to express what is important to them.

The PCI-D is a prompt list designed to help the patient gather information from the surgeon.5 Our aim was to assess the patients’ experience and their satisfaction with the information that they were given.

Patients and methods

New patients with oral cancer who attended one consultant’s clinic (SNR) between 2014 and 2015 were evaluated. Date of diagnosis, decision to treat, TNM stage, site, age, and sex were recorded and 48 patients were identified.

The PCI-D checklist asks the patient to indicate aspects of diagnosis, treatment, and recovery about which they would like further information (which was provided during the consultation during which the diagnosis was given).

A questionnaire elicited patients’ views and satisfaction with the inventory. The Satisfaction with Cancer Information Profile Part B (SCIP-B) (Table 1) was used to rate the usefulness of information on a 5-point scale (very satisfied = 5 to very unsatisfied = 1).6 The investigation was approved by the Audit Department at University Hospital Aintree. Questionnaires were posted to patients and reminders for non-responders were sent out six weeks later.

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Table 1
Responses to Satisfaction with Cancer Information Profile Part B (SCIP-B) questionnaire.

<table>
<thead>
<tr>
<th>Perception</th>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>The usefulness of the information to you</td>
<td>6</td>
<td>13</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The usefulness of the information to your partner/family</td>
<td>4</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The amount of written information supplied</td>
<td>5</td>
<td>11</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>The amount of verbal information supplied</td>
<td>11</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The timing at which you received information</td>
<td>8</td>
<td>11</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>The detail of the information given to you</td>
<td>8</td>
<td>10</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>How understandable the information was to you</td>
<td>4</td>
<td>15</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2
Comparison of the satisfaction with the information they asked for between those who used the Patients’ Concerns Inventory (diagnosis) and those who did not.

<table>
<thead>
<tr>
<th>Perception</th>
<th>Mean (SD) satisfaction of respondents who used PCI</th>
<th>Mean (SD) satisfaction of respondents who did not use the PCI</th>
<th>Total mean (SD) satisfaction of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>The usefulness of the information to you</td>
<td>4.60 (0.55)</td>
<td>4.13 (0.52)</td>
<td>4.25 (0.55)</td>
</tr>
<tr>
<td>The usefulness of the information to your partner/family</td>
<td>4.25 (0.50)</td>
<td>4.13 (0.52)</td>
<td>4.16 (0.50)</td>
</tr>
<tr>
<td>The amount of written information supplied</td>
<td>4.4 (0.55)</td>
<td>3.87 (0.83)</td>
<td>4.0 (0.80)</td>
</tr>
<tr>
<td>The amount of verbal information supplied</td>
<td>4.8 (0.45)</td>
<td>4.33 (0.72)</td>
<td>4.45 (0.69)</td>
</tr>
<tr>
<td>The timing at which you received information</td>
<td>4.6 (0.55)</td>
<td>4.2 (0.77)</td>
<td>4.30 (0.73)</td>
</tr>
<tr>
<td>The detail of the information given to you</td>
<td>4.6 (0.55)</td>
<td>4.13 (0.83)</td>
<td>4.26 (0.81)</td>
</tr>
<tr>
<td>How understandable the information was to you</td>
<td>4.2 (0.45)</td>
<td>4.13 (0.42)</td>
<td>4.05 (0.69)</td>
</tr>
</tbody>
</table>

The Satisfaction with Cancer Information Profile Part B questions were scored on a level 5-point scale, where 5 was very satisfied, and 1 was very unsatisfied. A higher score means greater satisfaction.

Results

Of the 48 patients who met the inclusion criteria (30 men, 18 women), 20 responded (12 men, 8 women, mean (SD) age 66 (11) years). Of those who responded, 16 had early stage primary disease (TX-T2) and four had advanced lesions (T3-4). Half had N1/N2 involvement.

The tongue was the most common site in responders (n = 6), followed by floor of mouth (n = 5). Ten patients had laser resections and 10 had neck dissections. Four had major excisions with free flap reconstruction.

Of the responders, 5/20 recalled using the survey at the time of diagnosis, and all 5 found it useful (very useful n = 1, useful n = 4). None of them thought changes should be made to the PCI-D. Of those who stated that they did not use it at diagnosis 13/15 responded: (very useful n = 3, useful n = 8, neither n = 1 and not very useful n = 1).

The SCIP-B part of the questionnaire (Table 2) shows that overall, satisfaction with information provided was high, and was higher across each measure of the SCIP-B for those who completed the PCI-D than for those who did not.

Discussion

To the best of our knowledge this is the first report of the use of the PCI-D in practice. The findings are limited by the low response and retrospective design. Relatively few patients reported using the PCI-D, which could be because they used other sources of information or had poor recollection of being given it in clinic.

It is encouraging that most responders thought that the PCI-D was, or could be, useful in gathering information. Although numbers were small, the PCI-D seems to improve the satisfaction with the information they were given across each measure of the SCIP-B.

Comparison between the PCI-D and other information gathering tools must be considered before we can draw conclusions about its relative efficacy. This is beyond the scope of this initial audit and a prospective study is planned.

Conflict of interest

We have no conflicts of interest.

Ethics statement/confirmation of patients’ permission

Ethics approval not required. Patients’ permission obtained.

References


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