The POSTCARD Study: a mixed methods exploration of the Pathway to Oesophageal and STomach CAncer Diagnosis

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BACKGROUND

- >15,000 new cases of oesophageal and gastric (stomach) cancer diagnosed, and >12,000 deaths in the UK in 2014.
- DoH national ‘Be Clear on Cancer’ campaign in 2015 aimed to raise symptom awareness, with the key message focused on recurrent heartburn.
- However, previous research identified limited understanding of the term ‘heartburn’.
- A patient’s ability to access, understand, appraise and apply health information, and navigate health systems is described as their ‘health literacy’1,2.
- Increasing symptom awareness and understanding, encouraging prompt help-seeking and facilitating timely referral are priorities for improving outcomes.

AIM

To explore how health literacy and other patient factors influence symptom understanding and appraisal, self-treatment decisions, and help-seeking behaviour in the timely diagnosis of oesophageal and gastric cancer.

METHODS

- Mixed methods underpinned by the Model of Pathways to Treatment (Figure 1)3
- 12 month recruitment (from May 2016), 2 hospitals: East and North East of England

Eligible Patients

All patients aged 18 and over and recently diagnosed with oesophageal or gastric cancer. Identified at weekly upper GI MDT meetings.

Recruitment

Patients approached by hospital team (in person or by post) within 2-4 weeks of diagnosis. Asked to return a consent form and the POSTCARD questionnaire to the research team.

Quantitative Study Participants

Questionnaire to explore socio-demographics, symptom experience, help-seeking, and aspects of health literacy (two domains, Health Literacy Questionnaire)4.

Case note review for referral date, diagnosis date, cancer type, histology, disease stage.

Qualitative Study Participants

Purposive sampling by location, age, gender and cancer for semi-structured, face-to-face in-depth interviews conducted within 10 weeks of diagnosis.

- Interim analyses used simple descriptive statistics and thematic analysis assisted by NVivo 11.

RESULTS

Table 1: Participant characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Quantitative (n=63)</th>
<th>Qualitative (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>70 (52-96)</td>
<td>70 (55-83)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>63</td>
<td>15</td>
</tr>
<tr>
<td>Cancer</td>
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<td></td>
</tr>
<tr>
<td>Oesophageal (OC)</td>
<td>54</td>
<td>12</td>
</tr>
<tr>
<td>Gastric (GC)</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I-IIIA</td>
<td>51</td>
<td>10</td>
</tr>
<tr>
<td>IIIB-IV</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Pre-referral GP visits</td>
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<td></td>
</tr>
<tr>
<td>≤1</td>
<td>34</td>
<td>9</td>
</tr>
<tr>
<td>≥2</td>
<td>28</td>
<td>6</td>
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<tr>
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</table>

* Based on quantitative data to 17th February 2017
† 43% response rate

Figure 1: Model of The Pathways to Treatment

Qualitative Data

Appraisal Interval

- Most participants did not access health information in relation to their symptoms.
- Some participants were concerned about cancer, usually due to a close family history.
- Most participants did not appraise symptoms in relation to a defined illness and felt ‘too well’ for their symptoms to be that of cancer.
- Many participants experienced difficulty swallowing and often made significant changes to their eating habits such as eating smaller meals, excluding certain foods, and eating soft food in order to accommodate their symptoms.

Help-seeking Interval

- Help-seeking was generally prompted by new symptoms such as pain or sickness, or when coping behaviours were no longer effective.

Diagnostic Interval

- Participants attending the GP more than once were initially either reassured or given an alternative diagnosis.
- Where the participant subsequently felt unsure in navigating the healthcare system, re-appraisal and help-seeking was often prolonged.

DISCUSSION

- Our interim analyses suggest that participants are aware of their symptoms but do not seek information in relation to them, instead trying to accommodate them with lifestyle and dietary changes.
- The findings may provide important insights into the timely diagnosis of these cancers, which could underpin the development of targeted awareness campaigns and strategies enhancing GP/patient communication.

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