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1 ***Patient factors influencing symptom appraisal in oesophageal cancer: a qualitative interview study***

2

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12

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15 **ABSTRACT**

16

17 Oesophageal cancer (EC) is characterized by vague symptoms and is often diagnosed at an advanced  
18 stage, leading to poor outcomes. Therefore, we aimed to investigate whether there might be any patient  
19 factors contributing to delay in EC diagnosis, and focused on the symptom appraisal and help-seeking  
20 strategies of people diagnosed with EC in the UK. Semi-structured interviews were conducted with 14  
21 patients aged >18 years with localised EC at point of diagnosis. Purposive sampling was used to include  
22 patients from one to nine months post-diagnosis. Analysis of the interviews identified three main  
23 themes: Interpreting symptoms, Triggers to seeking help, and Making sense of an unfamiliar cancer.  
24 Findings suggested that participants normalised symptoms or used previous health experiences as a  
25 means to interpret their symptoms. The majority of participants were not alarmed by their symptoms,  
26 mainly because they had very little knowledge of EC specific symptoms. Lack of knowledge also  
27 influenced participants' sense-making of their diagnosis. The findings highlight that the process of  
28 symptom appraisal in EC is likely to be inaccurate, which may hinder early presentation and thus  
29 diagnosis. Public health campaigns communicating EC specific symptoms, however, could shorten the  
30 appraisal period and lead to earlier diagnosis.

31

32 **KEYWORDS:** oesophageal cancer, patient delay, symptom appraisal, knowledge, sense-making

33

34 **INTRODUCTION**

35 With one of the poorest survival rates among all malignant tumours, oesophageal cancer (EC) is an  
36 increasingly common disease, the 13<sup>th</sup> most common cancer in the UK and the eighth most common  
37 cancer worldwide (Cancer Research UK, 2013). Annually, about 8,800 people are diagnosed with EC  
38 in the UK (Cancer Research UK, 2016), and despite improvements in diagnosis, surgical treatment and  
39 adjuvant therapy, more than 50% of EC patients present at the advanced stage of the disease (Enzinger  
40 & Mayer, 2003). Prognosis also remains poor; only 15% of those diagnosed with EC survive 5 years  
41 (Cancer Research UK, 2016).

42 One of the potential reasons for late diagnosis and poor prognosis of EC is late symptom presentation  
43 (Bergquist, Ruth, & Hammerlid, 2007; Rothwell, Feehan, Reid, Walsh, & Hennessy, 1997; Wang et  
44 al., 2008), where patients wait for prolonged periods before contacting a doctor for help about relevant  
45 symptoms (Macdonald, Macleod, Campbell, Weller, & Mitchell, 2006; Martin, Young, Sue-Ling, &  
46 Johnston, 1997). The patient interval (time from detecting a bodily change to first consultation with a  
47 healthcare professional) is divided into appraisal (time from detecting bodily change to perceiving a  
48 reason to discuss symptom with HCP) and help-seeking parts (time from perceiving a reason to seek  
49 help to first consultation with HCP) (Scott, Walter, Webster, Sutton, & Emery, 2013; Weller et al.,  
50 2012). Potential factors related to prolonged patient intervals include low cancer symptom awareness  
51 (Quaife et al., 2014; Robb et al., 2009); non-recognition of symptom seriousness, particularly of vague  
52 or intermittent symptoms (Evans, Chapple, Salisbury, Corrie, & Ziebland, 2014; Macleod, Mitchell,  
53 Burgess, Macdonald, & Ramirez, 2009); situational constraints and competing priorities (Facione,  
54 1993; Marcu, Black, Vedsted, Lyratzopoulos, & Whitaker, 2017; Von Wagner, Good, Whitaker, &  
55 Wardle, 2011). Conversely, factors promoting help-seeking for cancer symptoms are consulting with  
56 others (de Nooijer, Lechner, & de Vries, 2001), and having confidence in navigating the healthcare  
57 system (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2011). These factors have yet to be explored  
58 in EC patients.

59 Low cancer awareness is particularly relevant to EC because difficulty swallowing is one of the lesser  
60 known ‘alarm’ symptoms of cancer (Niksic et al., 2015). For example, 10-17% of the general population

61 know of 'difficulty swallowing' as a potential alarm symptom of cancer, compared to 68-80%  
62 recognising lumps (Niksic et al., 2015; Robb et al., 2009). These studies also showed that low symptom  
63 awareness is associated with prolonged anticipated help-seeking intervals. Previous studies with EC  
64 patients indicate that vague symptoms may delay help-seeking (Missel & Birkelund, 2011), as people  
65 appraise symptoms as non-serious or 'normal'.

66 Unawareness of the symptoms of EC, and even a lack of knowledge of the disease itself may not only  
67 influence help-seeking behaviour, but also how patients attach meaning to their diagnosis (Andreassen,  
68 Randers, Ternulf Nyhlin, & Mattiasson, 2007). Information needs of cancer patients are particularly  
69 prominent at diagnosis (Rutten, Arora, Bakos, Aziz, & Rowland, 2005), a time when anxiety can  
70 seriously compromise the quality of life of cancer patients (Visser et al., 2006). Therefore, we were also  
71 interested in whether knowledge of EC influenced the way that participants made sense of their  
72 diagnosis and adjusted to it.

73 At present, the majority of studies with EC patients have focused on the psychological and physiological  
74 burden of living with EC post-surgery (Khatri, Whiteley, Gullick, & Wildbore, 2012; Malmström,  
75 Ivarsson, Johansson, & Klefsgård, 2013; Wainwright, Donovan, Kavadas, Cramer, & Blazeby, 2007)  
76 but there is little evidence on how EC patients experience and interpret their symptoms prior to  
77 diagnosis. Focusing on the latter can help us understand why EC is diagnosed at advanced stage and  
78 what can be done to promote earlier diagnosis.

79 We conducted a qualitative interview study to investigate symptom appraisal and help-seeking  
80 strategies of people diagnosed with EC in Scotland.

81

## 82 **METHOD**

### 83 **Participants and recruitment**

84 Participants were recruited to a qualitative interview study to explore the supportive needs of recently  
85 diagnosed people with EC. As part of this exploration, we investigated the experience of EC symptoms,

86 help-seeking strategies, and adjustment after the EC diagnosis. Participants were approached by  
87 Gastrointestinal (GI) clinical nurse specialists (CNS) if they had a diagnosis of localised EC confirmed  
88 with a CT scan, were least 18 years of age, be able to read and write English, be able to provide written  
89 informed consent, and to be deemed by a member of the health care team to be physically and  
90 psychologically fit to participate in the study. Only participants within 9 months of being diagnosed  
91 with oesophageal cancer were recruited, because the diagnosis/staging process itself can be lengthy,  
92 and we were interested in observing recent accounts of people's experiences to reduce recall bias.  
93 Participants were purposively sampled according to gender and time since diagnosis. A maximum of  
94 four participants (2 females, 2 males) were recruited to each time-point (time since diagnosis: 0-1, 2-3,  
95 4-5, 6-7, 8-9 months). In total, 14 participant (mean age = 71 years, females n=6, males n=8) contact  
96 details were provided to the researchers by the CNS, and all 14 took part in an interview.

97 The CNS briefly outlined the purposes of the study, provided potential participants with a patient  
98 information sheet, and took consent to allow a researcher to contact the potential participant with further  
99 information and to schedule an interview. Final written consent to take part in the interview was taken  
100 on the day of the interview.

101

## 102 **Ethical considerations**

103 Approval for the study was obtained from the East of Scotland Research Ethics Service (REC reference:  
104 12/ES/0055) and the local NHS Ethics committees. Participants were informed that they could withdraw  
105 from the study at any time without giving any reason. They were assured that data would be kept  
106 confidential and contact details for psychological support (local cancer charities, cancer specialist  
107 nurses) were provided. Identifiable information was removed from the transcripts and each transcript  
108 was given an ID to ensure anonymity. We chose to use participant ID numbers instead of pseudonyms  
109 because we found this more helpful in indexing the data and locating relevant quotes.

## 110 **Interviews**

111 Semi-structured interviews were conducted between 2012 and 2015 by two experienced qualitative  
112 researchers (LL and RM) with a background in cancer care. Interviews took place in participants' homes  
113 (n=11) or in a quiet room in one of the participating hospitals (n=3). Nine interviews were conducted  
114 by the first author and five by the last author. Questions were designed to encourage the participants to  
115 talk freely to establish a rich description of the meanings attached to their lived experience. Semi-  
116 structured questions facilitated this approach by allowing issues of specific interest to the participant to  
117 be explored further. The opening question asked '*Can you tell me what oesophageal cancer means to*  
118 *you?*' to assess the participants' experience of living with EC post-diagnosis. To get a deeper narrative  
119 the second interview question was '*Can you take me back to the beginning of your illness and tell me*  
120 *what has happened since then?*' Prompts were used to initiate responses to symptoms, and diagnosis if  
121 not covered in the participants' initial response (See Box 1 for full interview schedule). Interviews  
122 lasted on average 47 minutes (range: 22-101 minutes).

123 **[Insert Box 1 here]**

#### 124 **Analytic approach**

125 Demographic and clinical information were analysed using Microsoft Excel. Interviews were recorded  
126 and transcribed verbatim, with the transcription reflecting the idiosyncratic Scottish pronunciation. The  
127 analysis of the interviews drew on thematic analysis (Braun & Clarke, 2006), as well as on the principles  
128 of phenomenology and Interpretative Phenomenological Analysis (Smith, 1996) to gain an in-depth  
129 understanding of people's lived experience of EC symptoms and diagnosis. This entailed: reading and  
130 re-reading of the interview transcripts; initial coding of the data, with codes representing units of  
131 meaning in the data; development of emerging themes; searching for connections amongst emergent  
132 themes; moving to the next case; and looking for patterns across cases. The software analysis package  
133 QSR Nvivo version 8 was used to aid the organisation of the data. Finally, tables in Microsoft Office  
134 were created to index the emerging themes. Superordinate themes were identified and subordinate  
135 themes were developed to describe these in more detail. This process involved close checks of the  
136 original transcripts, which also facilitated further identification of exemplar quotes. The first author led  
137 the data analysis, and the emerging themes were refined after consultation with the second and third

138 authors. Although we used the Model of Pathways to Treatment (Scott et al., 2013) as a framework for  
139 indexing the processes of sense-making and decision-making during the patient interval, our analysis  
140 was primarily inductive.

141 In the results below, we report participants' ID, age, and gender next to their quotes.

142

## 143 **RESULTS**

144 Participants' demographic and clinical details are shown in Table 1. The range of symptoms that  
145 participants reported as experiencing before diagnosis are shown in Box 2.

146 Three main themes reflected participants' symptom appraisal and help-seeking experiences:  
147 *Interpreting Symptoms*, *Triggers to seeking help*; and *Making sense of an unfamiliar cancer*.

148 [Insert Table 1 here]

149

150 [Insert Box 2 here]

151

### 152 ***Interpreting symptoms***

#### 153 *Normalising symptoms*

154 Most participants interpreted their symptoms optimistically at first by drawing on a range of familiar  
155 symptom representations. Some participants located explanations in the context of familiar  
156 consequences for usual bodily reactions, e.g. interpreting the typical EC symptom of dysphagia as  
157 having 'swallowed food the wrong way' or 'not having chewed the food properly':

158 *When I first took the experience of not getting the food down I thought mmm, I didn't chew that*  
159 *properly ... I didn't ... I had gulped in air, you know, they're the things that come in. (P10, 66,*  
160 *female)*



161 It appeared that any ‘unusual’ behaviour that had some connection to the location of where the symptom  
162 was experienced was drawn upon to find an explanation for their symptoms and normalise it.

163 *I just thought, I had just been at a football match, a stupid wee team that plays like away in the*  
164 *middle o' naewhere (nowhere), I thought maybe I've done too much shouting ... and I've maybe*  
165 *kinda affected the gullet or the throat, I thought it was actually my throat ... (P6, 68, male)*

166

167 *Experience or knowledge of other diseases*

168 When attempting to make sense of their symptoms, participants drew upon previous knowledge about  
169 diseases and compared their symptoms to familiar illnesses to find an explanation. Common symptom  
170 attributions were ulcers or reflux. More diffuse symptoms (e.g. fatigue, general feelings of being  
171 unwell) were interpreted by some as a result of old age. Based on these interpretations, participants did  
172 not seem to be worried about their symptoms, even up to the point of seeing the consultant after initial  
173 medical tests:

174 *I got a phone call from the Consultant asking me to go up to [hospital] and I thought, “och,*  
175 *it's the results of the scope, it's maybe an ulcer or something”, you know. (P4, 66, male)*

176 *And then, Ah say, Ah forget the age Ah am as well. You know, and my friends have said that,*  
177 *one friend in particular, because I mean I really don't tell people, eh, but she says “you've got*  
178 *tae remember, you're 70 now, you'll be 71 this year, it catches up wi ye. (P1, 73, female)*

179

180 Some participants appraised their symptoms in the context of previously diagnosed health problems  
181 which they were already self-managing and were thus not concerned:

182 *[The appointment] was the 19th of November and I mentioned it to him [the GP], but only with*  
183 *the respect that he would say to me “well, this is just one o' the things you might have to put up*  
184 *with because o' the hernias. (P10, 66, female)*

185

186 In contrast to the participants who formulated explanations for their symptoms, one participant,  
187 although alerted by the severity of their symptoms, did not seem to make any comparisons to potential  
188 illnesses, possibly because of the intermittent nature of the symptoms, as he explained:

189 *I took a bad fit of it again [dysphagia], eh and it happened two or three times, eh, within a*  
190 *period of about a month and then it, and then it went away again and I never thought anything*  
191 *of it again. [...] I left it, I thought “ach, I don’t know what that was (P3, 50, male)*

192

193 When reflecting back on their symptoms and diagnosis, participants indicated limited knowledge of  
194 cancer symptoms in general, and less so of EC. Upon diagnosis of EC they experienced a mismatch  
195 between their knowledge of cancer symptoms and their symptom experiences, as this participant  
196 explained:

197 *I didn’t feel ill ... the only indication I had at all that there was something wrong was wi’*  
198 *continually being sick ... eh I had nae pain, I ... I thought for some reason or other eh that there*  
199 *would be a, a pain factor in ... having cancer, eh. (P12, 59, male)*

200

### 201 ***Triggers to seeking help***

202 This theme reflects what eventually prompted the participants to seek help. Of note was that some  
203 participants reported their symptoms to their GP soon after they first occurred (within one week to three  
204 months), while others experienced symptoms for prolonged intervals (3 month up to two years) before  
205 visiting their GP. The experienced severity of the symptom did not always prompt early help-seeking:

206 *I would say, about 18 months to two years ago, eh, I used to wake up as though I was choking,*  
207 *I thought I was gonnae die, you know, I was just like this choking. (P3, 50, male)*

208 In contrast, another participant experienced mild dysphagia only once, yet immediately visited his GP:

209 *I was struggling wi' the pork and I was really having tae work tae get it [...] so I'd take a drink*  
210 *and wash it doon ... and I went tae the GP that week. (P6, 68, male)*

211

212 *Changing or unexpected symptoms*

213 Changing symptoms (e.g. becoming more severe) prompted participants to contact their GP. Family  
214 could also play an important role in the process of symptom interpretation and prompting a visit to the  
215 GP when symptoms changed:

216 *And, eh, then I got this tickle in my throat which wasn't, didn't annoy me, but then it started*  
217 *sore every time I was swallowing. And... I didn't bother about it at first because... it was only*  
218 *when I swallow and, eh... then it got sorer and my wife says "you'd better go to the doctor's".*  
219 *(P4, 66, male)*

220 A symptom that was unfamiliar or unexpected, was also a motivator to seek help:

221 *I was burping, which, I have never ever done in my life, it's always been wind, go in a, different*  
222 *direction, but I've never brought it up ... em and I knew something wasn't right... didn't know*  
223 *what, but I mean I knew I wasn't right. (P8, 62, female)*

224

225 *Symptoms interfering with daily life*

226 Similarly, when the symptoms were persistent or reached a threshold of interference with usual life,  
227 advice was sought from a GP:

228 *Ah [I] just couldnae walk like Ah used to walk. I mean I could have walked for miles and miles*  
229 *and miles and neither been up, up nor down, but Ah could only do so much and that, really*  
230 *annoyed me. And Ah think that's why when August came, this was in July, I says "oh, Ah'll*  
231 *need tae do something 'cause Ah cannae stand the pains in ma legs and this... tiredness. (P1,*  
232 *73, female)*

233 She goes on to describe how this change in physical functioning negatively affected her daily life  
234 because she was unable to undertake her usual responsibilities:

235 *“I was so slow, it took me the whole day to do what I normally did in a few hours. And Ah kept*  
236 *sitting down for a rest. I even started watching Telly through the day, now Ah’ve no time for*  
237 *telly through the day.” (P1, 73, female)*

238

239 Another patient described how worsening symptoms affected his daily life because he could not keep  
240 any food or drink down.

241 *It developed from being sick, tae being perpetually and continually sick ... and being unable to*  
242 *hold down anything, eh that was including fluids, Coca-Cola, anything that I drunk just*  
243 *immediately came back up so eh obviously I had some kinda indication there was, there was*  
244 *..... there was a serious blockage there, so that's, that's how I got tae [go to the GP]. (P12, 59,*  
245 *male)*

246 In some cases, there was a mismatch between symptom seriousness and participants’ perceived  
247 seriousness for that symptom, which impacted on timely help-seeking. Some participants reporting  
248 serious symptoms carried on with their lives, only reporting them opportunistically when appointments  
249 for a ‘legitimate’ concern was scheduled with the GP:

250 *I got a, a really bad virus, the norovirus... eh, well, it was just, I was off for a week just really*  
251 *bad and stuff like that, straight after that wee period of time you know, and it wasn’t until, and*  
252 *I thought “this has gone on too long, you know...” not, not the symptoms I was talking about*  
253 *[dysphagia], but the, the virus. So I went, I just went to my local GP [...] and at that point I*  
254 *then mentioned, “listen, I want to mention this as well to you...” (P3, 50, male)*

255

256 ***Making sense of an unfamiliar cancer***

257 This theme summarizes how the participants made sense of the diagnosis of EC, and how they reflected  
258 retrospectively on their help-seeking prior to receiving the diagnosis.

259 *Lack of knowledge of oesophageal cancer*

260 Participants acknowledged their lack of knowledge about EC, as the frequent use of “don’t know” and  
261 “didn’t know” illustrates. Participants’ knowledge was limited to cancer as a general disease with  
262 predominantly negative outcomes:

263 *Em well before em I had this, I didn’t know much about it at all... and I had never heard of*  
264 *anyone having this em cancer. (P11, 76, female)*

265

266 Participants also expressed uncertainty about how to deal with their disease and the prognosis based on  
267 their limited knowledge about it:

268 *I’ve got a bit more knowledge but not the knowledge of the enormity of this surgery. Eh, I mean*  
269 *I don’t know about other, I’m sure lung cancer, or brain tumour, or anything like that carry the*  
270 *same risks and the enormity as well, I don’t doubt that, but this oesophageal cancer is just*  
271 *something I didn’t, I didn’t know about. (P10, 66, female)*

272 *And I don’t know how aggressive it is, oesophageal cancer. It is apparently quite a slow-*  
273 *growing cancer, maybe you can help me, I don’t know? (P2, 74, female)*

274

275 *Emotional responses to diagnosis*

276 Virtually all participants experienced being diagnosed with EC as a great surprise or shock. Expressions  
277 such as ‘shocked’, ‘never in my wildest dreams’, and ‘never heard of anyone with this cancer’ testify  
278 to the participants’ consternation at the diagnosis. Being unfamiliar with EC as a type of cancer led to  
279 an inability to make sense of their diagnosis. When asked what EC means to them, participants often

280 used the word ‘*nothing*’ to describe their sense of bewilderment. Some even struggled to pronounce the  
281 medical terms of their diagnosis and felt unsure about the location of the disease in their body:

282 This participant was asked what ‘Oesophageal cancer means to him’:

283 *“I couldnae answer that, pal. [Pause]. Eh... I just don’t know. See when you, [pause] when you*  
284 *caw [call]... what would you caw that there?”*

285 Interviewer: Oesophageal... [pause]... cancer.

286 *“See, I don’t even know where that is. Aw [all] I know, aw I know is... it’s here somewhere, is*  
287 *it?”* (P5, 75, male)

288

289 Not only did the participants struggle to make sense of an unknown disease, they also struggled to  
290 understand why they got this particular type of cancer. Participants reflected on their past lifestyle  
291 behaviours in an effort to find causes for their disease, with the inability to find a cause leading to anger  
292 and self-blame. Participants viewed the diagnosis of EC as a random occurrence or an instance of bad  
293 luck, and expressed feeling ‘betrayed’ because their efforts to live a healthy lifestyle had not yielded  
294 the expected health benefits. As a result, the participants were struggling to accept their diagnosis, which  
295 they saw as undeserved:

296 *Em I think [it’s] been a difficulty to try and get your head round the fact that I knew there was*  
297 *a problem, but I didn’t think it was this ...em and if you look at the statistics for it, you know*  
298 *it’s, it happens to people that are a lot older, em and it, you know you’re going back again to*  
299 *two random cancers... you know, I don’t drink, I don’t smoke, eat fairly, or I’d eat fairly well,*  
300 *[...] it seems like just, just bad luck* (P9, 43, male)

301

302 *“It’s hard when, and I’ve always been a person that put health first, you know, eating well [...],*  
303 *it’s hard to sort o’ say ‘well, I’ve done all the right things and I’m still going to be unwell’, I*

304           *mean I don't drink tea or coffee, or fizzy drinks, eh I only drink water, I only drink water and*  
305           *lemon and now eh I see that we don't eat processed food and, all these things"*

306           Interviewer: How does that make you feel?

307           *"And then you feel angry [I] still got it, I still, and I did, I can't remember, I think I said to [the*  
308           *specialist nurse] and she's... or, in fact one o' the doctors who was giving me the scans, and he*  
309           *said, "this is it," he says "sometimes these things happen and, and we don't even know the*  
310           *reasons". (P10, 66, female)*

311

## 312   **DISCUSSION**

313   This study investigated symptom appraisal and help-seeking strategies of people diagnosed with  
314   oesophageal cancer (EC) in Scotland. Key findings were that participants reported low awareness of  
315   the potential significance of EC symptoms (e.g. ~~dysphasia~~ dysphagia), and low knowledge of EC more  
316   generally, which contributed to prolonged patient intervals. This low symptom awareness and  
317   knowledge of EC impacted negatively on patient's sense-making process when diagnosed with EC as  
318   it was often shocking and unexpected, heightening feelings of distress at an already difficult time.  
319   Symptom seriousness alone (e.g. being unable to swallow) was not enough to trigger help-seeking as  
320   the participants attributed these to more mundane causes. However, symptoms worsening over time or  
321   symptoms interfering with daily life legitimised the decision to seek help.

322   This is consistent with the *Model of Pathways to Treatment* (MPT) which states that bodily changes are  
323   normalised if they do not exceed a threshold of interference (Scott et al., 2013). Previous research with  
324   different types of cancers also highlight that participants report a tipping point for when their bodily  
325   sensations would trigger seeking help (Evans et al., 2014; Macleod et al., 2009). In particular, we found  
326   that several heuristics envisaged by the MPT were evident in our participants' strategies when  
327   appraising their symptoms and deciding to seek help: the severity rule (symptoms that are severe and  
328   disrupt functioning), the duration rule (persistent symptoms), the rate of change rule (symptoms that

329 are worsening, increasing in number or have sudden onset), the age-illness rule (symptoms are due to  
330 old age), and the location rule (appraising symptoms as other health conditions based on the area of the  
331 body). These findings add to the evidence that heuristics play an important role in symptom appraisal  
332 and help-seeking behaviour when people experience the symptoms of a rare and unfamiliar cancer like  
333 EC.

334 It is noteworthy that some participants reported symptoms opportunistically, when seeing the GP about  
335 other health issues. This may be due to beliefs that symptoms for more common or familiar health  
336 conditions are more legitimate of medical attention (Andersen, Tørring, & Vedsted, 2015; Simon,  
337 Waller, Robb, & Wardle, 2010). Thus, appointments for these concurrent non-cancer health conditions  
338 may have been used to report the EC symptoms which were troubling the patients but were too vague  
339 to legitimise a medical appointment. While delay in help-seeking for EC symptoms may be reduced if  
340 patients have other co-morbidities that prompt them to seek help, these co-morbidities (e.g. recurrent  
341 ulcers, reflux) may also mask the importance of new or changing symptoms and their appraisal  
342 (Macdonald et al., 2006; Smith, Pope, & Botha, 2005). The findings from this study suggest that  
343 some symptoms (e.g. reflux) develop over many months, or even years. However, it is difficult to assess  
344 whether reflux was a symptoms or a risk factor that contributed to the development of EC and it is of  
345 concern that people may prefer to self-manage such persistent symptoms, which inevitably can cause  
346 further delay in diagnosis.

347 In our sample, EC symptoms were not appraised as serious, and even after being sent for investigations,  
348 participants did not report being particularly concerned, reflecting the lack of knowledge and low  
349 perceived seriousness of symptoms associated with EC. Higher knowledge of symptoms has been found  
350 to be related to appraising symptoms as potential cancer symptoms (Simon et al., 2010). Despite some  
351 evidence that more symptom awareness leads to shorter delay (Quaife et al., 2014; Robb et al., 2009)  
352 the opposite has also been found (Simon et al., 2010), probably because, in some cases, higher  
353 knowledge of cancer symptoms may lead to higher fear of cancer diagnosis or/and of treatment (Vrinten  
354 et al., 2016). Thus, while there is a need to improve knowledge and awareness of EC, other factors that  
355 influence symptom appraisal and help-seeking behaviour should not be disregarded, for example,



356 emotional responses to symptoms, and wider socio-cultural influences (e.g. social sanctioning,  
357 competing priorities) (Von Wagner et al., 2011; Whitaker, Cromme, Winstanley, Renzi, & Wardle,  
358 2015).

359 Another key finding of the present study was that low symptom awareness and lack of knowledge about  
360 EC shaped participants' sense-making of their diagnosis and their ways of coping post-diagnosis.  
361 Participants' stories demonstrated that lack of knowledge meant they were unprepared for the diagnosis,  
362 responding with shock and emotional distress to an unexpected diagnosis of an unfamiliar disease.  
363 Other qualitative studies with EC patients have also reported shock at diagnosis due to patients  
364 anticipating a less serious condition rather than cancer (Andreassen et al., 2007; Rothwell et al., 1997;  
365 Watt & Whyte, 2003). The feeling of consternation was also expressed by family members (Andreassen  
366 et al., 2007), demonstrating the general unfamiliarity with EC. The literature shows evidence of high  
367 prevalence for anxiety at diagnosis of EC (Bergquist et al., 2007; Jacobs et al., 2016) and the present  
368 study adds to the evidence by highlighting potential contributors to psychological morbidity at  
369 diagnosis. Providing sufficient disease-specific information at diagnosis may reduce feelings of distress  
370 (Husson, Mols, & Van de Poll-Franse, 2011), and subsequently improve patient outcomes in the long-  
371 term (Montazeri, 2009). Empowering people to recognise potential symptoms of EC cancer prior to  
372 diagnosis therefore not only has the potential to prompt timely help-seeking, but also to reduce the  
373 emotional distress at diagnosis and improve patient experience.

374

### 375 **Implications of Findings**

376 Survival rates of EC are poor with only 15% of those diagnosed to survive 5 years (Cancer Research  
377 UK, 2016) likely due to advanced stage at diagnosis (Abel, Shelton, Johnson, Elliss-Brookes, &  
378 Lyratzopoulos, 2015). The time for early gastric cancer to double in size is between 1.5 and 10 years,  
379 but for advanced cancer 2 months to 1 year (Haruma et al., 1988; Kohli, Kawai, & Fujita, 1981). In this  
380 study participants reported delays of up to 2 years, and considering that nearly a quarter of participants  
381 presented with stage 3 disease, these participants could have been diagnosed at an earlier stage had they

382 presented sooner. Increasing public awareness of EC symptoms, and thus promoting, early symptom  
383 presentation and diagnosis are a priority to the Department of Health, and campaigns to facilitate early  
384 diagnosis have been implemented. In this sense, the ‘Be Clear on Cancer’ awareness campaign, led by  
385 Public Health England in partnership with the Department of Health and NHS England, has shown  
386 promising results with regard to not only raising awareness, but also increasing the number of urgent  
387 GP referrals (Cancer Research UK, 2014). Particularly for EC, the 4-months campaign to increase  
388 awareness of the symptom ‘difficulty swallowing’ increased spontaneous symptom awareness by 7%,  
389 the number of GP visits by 17%, and number of urgent referrals by 26% in the pilot areas (Cancer  
390 Research UK, 2014). These findings are encouraging, and highlight the importance of raising  
391 knowledge about cancer symptoms, especially those cancers for which symptoms are vague or easily  
392 attributable to other causes, such as EC. As our study has found, lack of familiarity with EC influenced  
393 not only symptom appraisal, but may have led to distress in the sense-making process after diagnosis.  
394 Therefore, the benefits of increasing public knowledge about EC can be two-fold: reducing patient delay  
395 and reducing psychological distress post diagnosis.

#### 396 **Study Strengths and Limitations**

397 Our study was conducted retrospectively, and recall bias could be viewed as a limitation. However, the  
398 findings reported were evident in quotes from participants across different stages of the care pathway  
399 (1-9 months post-diagnosis), and participants’ experiences are inevitably constructed through the lens  
400 of their current EC diagnosis. People diagnosed with cancer often remember intricate details of events  
401 in the past that are related to their diagnosis (Khatri et al., 2012). Besides recall bias, potential bias could  
402 have been introduced as the majority of participants were men. We did not have any data for women at  
403 4-5 months and 8-9 months post-diagnosis. However, the findings were consistent in both genders.  
404 ~~Lastly~~ Furthermore, we did not collect reasons for why participants declined to participate, nor how  
405 many potential participants the nurses approached. Because of the lack of detailed records from the  
406 nurses who recruited the participants, we were unable to assess how the nurses’ judgement may have  
407 influenced the selection of potential participants for the study. Therefore, we cannot rule out selection  
408 bias. A lack of a control group of patients with similar symptoms but non-cancer diagnoses could be

409 viewed as a limitation, because a control group could help the selection of symptoms to be used in  
410 education campaigns about cancer symptoms. However, as this study was designed to investigate  
411 patients' experiences and supportive care needs post-diagnosis, a control group was not considered  
412 necessary. Lastly, another potential limitation could be the fact that the interviews were conducted by  
413 two different researchers, who may have had different interviewing styles. However, both researchers  
414 had a background in cancer care and were experienced in qualitative research, and worked closely in  
415 the design of the interview schedule, thus ensuring consistency.

416

## 417 **Conclusion**

418 The processes of symptom appraisal and help-seeking in oesophageal cancer are very complex and  
419 prone to misinterpretation. The present findings suggest that in the absence of familiarity with EC  
420 symptoms people are unlikely to interpret their symptoms as signs of cancer and to seek help promptly.  
421 Given the relatively rare incidence of EC compared to other cancers, it is unlikely that the public can  
422 learn about EC through lay sources of knowledge, such as family, friends, or the media. Instead, efforts  
423 should be made to increase public awareness through formal health education campaigns. This would  
424 lead to earlier diagnosis and more patients being diagnosed with a cancer stage that is operable, thus  
425 increasing survival. Having knowledge about EC prior being diagnosed could also reduce distress of  
426 patients at diagnosis, because patients would be more prepared and more able to make sense of their  
427 diagnosis.

428

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433

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553

554

555 **List of Tables/Figures/Boxes:**

556 **Table 1. Participant demographic and clinical details**

<b>Variable</b>	<b>Number of participants n=14 (%)</b>
<b>Gender</b>	
<b>Male</b>	8 (62)
<b>Female</b>	6 (38)
<b>Age in years -Mean (range)</b>	71 (43-76)
<b>Time since diagnosis</b>	
<b>0-1 months</b>	4 (29)
<b>2-3 months</b>	3 (21)
<b>4-5 months</b>	2 (14)
<b>6-7 months</b>	3 (21)
<b>8-9 months</b>	2 (14)
<b>Tumour type</b>	
<b>Adenocarcinoma</b>	8 (57)
<b>Squamous cell carcinoma</b>	6 (43)
<b>Stage</b>	
<b>Stage 1</b>	4 (28.5)
<b>Stage 2</b>	2 (14.3)
<b>Stage 3</b>	3 (21.4)
<b>Stage 4</b>	1 (7.1)
<b>Not staged</b>	4 (28.5)
<b>Treatment</b>	
<b>Pre-treatment</b>	6 (43)
<b>Chemotherapy</b>	7 (50)
<b>Radiotherapy</b>	2 (14)
<b>Surgery</b>	3 (21)

557

558

559 **Box 1. Interview schedule**

<b>Can you tell me a little bit about yourself?</b>
<b>Can you tell me what oesophageal cancer means to you?</b>
<i>When you heard the word cancer, what did you think?</i>
<i>How did it make you feel?</i>
<b>Can you take me back to the beginning of your illness tell me what has happened since then?</b>
<b>If not initially covered by the participant prompts within the interview will include:</b>
<i>Diagnosis</i>
<i>Staging</i>
<i>Treatment</i>
<i>Prognosis</i>
<i>Support (physical, psychological, emotional)</i>

560

561 **Box 2. Symptoms reported**

Symptom	N (%)
<b>Dysphagia</b>	8 (57)
<b>Chest pain</b>	2 (14)
<b>Acid reflux</b>	2 (14)
<b>Sore throat</b>	2 (14)
<b>Tickle sensation in throat</b>	1 (7)
<b>Painful legs</b>	1 (7)
<b>Cough</b>	1 (7)
<b>Fatigue</b>	1 (7)
<b>Heartburn</b>	1 (7)
<b>Burping</b>	1 (7)
<b>Vomiting</b>	1 (7)
<b>Loss of appetite</b>	1 (7)
<b>Weight loss</b>	1 (7)

562