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

Liane Lewis¹, Afrodita Marcu², Katriina Whitaker², Roma Maguire¹*

¹Department of Computing and Information Sciences, University of Strathclyde, 26 Richmond Street, Glasgow, G1 1XQ, United Kingdom
²School of Health Sciences, University of Surrey, Guildford, GU2 7XH, United Kingdom

*Corresponding author: Roma Maguire, Department of Computing and Information Sciences, University of Strathclyde, Livingston Tower, 26 Richmond Street, Glasgow, G1 1XQ, United Kingdom
t: +44 (0)141 548 3589, e: roma.maguire@strath.ac.uk

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ABSTRACT

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

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

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

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

Low cancer awareness is particularly relevant to EC because difficulty swallowing is one of the lesser known ‘alarm’ symptoms of cancer (Niksic et al., 2015). For example, 10-17% of the general population...
know of ‘difficulty swallowing’ as a potential alarm symptom of cancer, compared to 68-80% recognising lumps (Niksic et al., 2015; Robb et al., 2009). These studies also showed that low symptom awareness is associated with prolonged anticipated help-seeking intervals. Previous studies with EC patients indicate that vague symptoms may delay help-seeking (Missel & Birkeland, 2011), as people appraise symptoms as non-serious or ‘normal’.

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

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

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

METHOD

Participants and recruitment

Participants were recruited to a qualitative interview study to explore the supportive needs of recently diagnosed people with EC. As part of this exploration, we investigated the experience of EC symptoms,
help-seeking strategies, and adjustment after the EC diagnosis. Participants were approached by Gastrointestinal (GI) clinical nurse specialists (CNS) if they had a diagnosis of localised EC confirmed with a CT scan, were least 18 years of age, be able to read and write English, be able to provide written informed consent, and to be deemed by a member of the health care team to be physically and psychologically fit to participate in the study. Only participants within 9 months of being diagnosed with oesophageal cancer were recruited, because the diagnosis/staging process itself can be lengthy, and we were interested in observing recent accounts of people’s experiences to reduce recall bias.

Participants were purposively sampled according to gender and time since diagnosis. A maximum of four participants (2 females, 2 males) were recruited to each time-point (time since diagnosis: 0-1, 2-3, 4-5, 6-7, 8-9 months). In total, 14 participant (mean age = 71 years, females n=6, males n=8) contact details were provided to the researchers by the CNS, and all 14 took part in an interview.

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

Ethical considerations

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

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

[Insert Box 1 here]

Analytic approach

Demographic and clinical information were analysed using Microsoft Excel. Interviews were recorded and transcribed verbatim, with the transcription reflecting the idiosyncratic Scottish pronunciation. The analysis of the interviews drew on thematic analysis (Braun & Clarke, 2006), as well as on the principles of phenomenology and Interpretative Phenomenological Analysis (Smith, 1996) to gain an in-depth understanding of people’s lived experience of EC symptoms and diagnosis. This entailed: reading and re-reading of the interview transcripts; initial coding of the data, with codes representing units of meaning in the data; development of emerging themes; searching for connections amongst emergent themes; moving to the next case; and looking for patterns across cases. The software analysis package QSR Nvivo version 8 was used to aid the organisation of the data. Finally, tables in Microsoft Office were created to index the emerging themes. Superordinate themes were identified and subordinate themes were developed to describe these in more detail. This process involved close checks of the original transcripts, which also facilitated further identification of exemplar quotes. The first author led the data analysis, and the emerging themes were refined after consultation with the second and third
authors. Although we used the Model of Pathways to Treatment (Scott et al., 2013) as a framework for indexing the processes of sense-making and decision-making during the patient interval, our analysis was primarily inductive.

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

RESULTS

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

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

[Insert Table 1 here]

[Insert Box 2 here]

Interpreting symptoms

Normalising symptoms

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

When I first took the experience of not getting the food down I thought mmm, I didn’t chew that properly ... I didn’t ... I had gulped in air, you know, they’re the things that come in. (P10, 66, female)
It appeared that any ‘unusual’ behaviour that had some connection to the location of where the symptom was experienced was drawn upon to find an explanation for their symptoms and normalise it.

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

Experience or knowledge of other diseases

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

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

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

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

[The appointment] was the 19th of November and I mentioned it to him [the GP], but only with the respect that he would say to me “well, this is just one o’ the things you might have to put up with because o’ the hernias. (P10, 66, female)
In contrast to the participants who formulated explanations for their symptoms, one participant, although alerted by the severity of their symptoms, did not seem to make any comparisons to potential illnesses, possibly because of the intermittent nature of the symptoms, as he explained:

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

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

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

**Triggers to seeking help**

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

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

In contrast, another participant experienced mild dysphagia only once, yet immediately visited his GP:
I was struggling wi’ the pork and I was really having tae work tae get it [...] so I’d take a drink and wash it doon ... and I went tae the GP that week. (P6, 68, male)

Changing or unexpected symptoms

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

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

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

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

Symptoms interfering with daily life

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

Ah [I] just couldnae walk like Ah used to walk. I mean I could have walked for miles and miles and miles and neither been up, up nor down, but Ah could only do so much and that, really annoyed me. And Ah think that’s why when August came, this was in July, I says “oh, Ah’ll need tae do something ’cause Ah cannae stand the pains in ma legs and this... tiredness. (P1, 73, female)
She goes on to describe how this change in physical functioning negatively affected her daily life because she was unable to undertake her usual responsibilities:

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

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

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

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

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

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

Lack of knowledge of oesophageal cancer

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

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

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

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

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

Emotional responses to diagnosis

Virtually all participants experienced being diagnosed with EC as a great surprise or shock. Expressions such as ‘shocked’, ‘never in my wildest dreams’, and ‘never heard of anyone with this cancer’ testify to the participants’ consternation at the diagnosis. Being unfamiliar with EC as a type of cancer led to an inability to make sense of their diagnosis. When asked what EC means to them, participants often
used the word ‘nothing’ to describe their sense of bewilderment. Some even struggled to pronounce the medical terms of their diagnosis and felt unsure about the location of the disease in their body:

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

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

Interviewer: Oesophageal… [pause]… cancer.

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

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

"It's hard when, and I've always been a person that put health first, you know, eating well [...], it's hard to sort o' say 'well, I've done all the right things and I'm still going to be unwell’, I
mean I don’t drink tea or coffee, or fizzy drinks, eh I only drink water, I only drink water and lemon and now eh I see that we don’t eat processed food and, all these things”

Interviewer: How does that make you feel?

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

DISCUSSION

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

This is consistent with the Model of Pathways to Treatment (MPT) which states that bodily changes are normalised if they do not exceed a threshold of interference (Scott et al., 2013). Previous research with different types of cancers also highlight that participants report a tipping point for when their bodily sensations would trigger seeking help (Evans et al., 2014; Macleod et al., 2009). In particular, we found that several heuristics envisaged by the MPT were evident in our participants’ strategies when appraising their symptoms and deciding to seek help: the severity rule (symptoms that are severe and disrupt functioning), the duration rule (persistent symptoms), the rate of change rule (symptoms that
are worsening, increasing in number or have sudden onset), the age-illness rule (symptoms are due to old age), and the location rule (appraising symptoms as other health conditions based on the area of the body). These findings add to the evidence that heuristics play an important role in symptom appraisal and help-seeking behaviour when people experience the symptoms of a rare and unfamiliar cancer like EC.

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

In our sample, EC symptoms were not appraised as serious, and even after being sent for investigations, participants did not report being particularly concerned, reflecting the lack of knowledge and low perceived seriousness of symptoms associated with EC. Higher knowledge of symptoms has been found to be related to appraising symptoms as potential cancer symptoms (Simon et al., 2010). Despite some evidence that more symptom awareness leads to shorter delay (Quaife et al., 2014; Robb et al., 2009) the opposite has also been found (Simon et al., 2010), probably because, in some cases, higher knowledge of cancer symptoms may lead to higher fear of cancer diagnosis or/and of treatment (Vrinten et al., 2016). Thus, while there is a need to improve knowledge and awareness of EC, other factors that influence symptom appraisal and help-seeking behaviour should not be disregarded, for example,
emotional responses to symptoms, and wider socio-cultural influences (e.g. social sanctioning, competing priorities) (Von Wagner et al., 2011; Whitaker, Cromme, Winstanley, Renzi, & Wardle, 2015).

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

Implications of Findings

Survival rates of EC are poor with only 15% of those diagnosed to survive 5 years (Cancer Research UK, 2016) likely due to advanced stage at diagnosis (Abel, Shelton, Johnson, Elliss-Brookes, & Lyrratzopoulos, 2015). The time for early gastric cancer to double in size is between 1.5 and 10 years, but for advanced cancer 2 months to 1 year (Haruma et al., 1988; Kohli, Kawai, & Fujita, 1981). In this study participants reported delays of up to 2 years, and considering that nearly a quarter of participants presented with stage 3 disease, these participants could have been diagnosed at an earlier stage had they
presented sooner. Increasing public awareness of EC symptoms, and thus promoting early symptom
presentation and diagnosis are a priority to the Department of Health, and campaigns to facilitate early
diagnosis have been implemented. In this sense, the ‘Be Clear on Cancer’ awareness campaign, led by
Public Health England in partnership with the Department of Health and NHS England, has shown
promising results with regard to not only raising awareness, but also increasing the number of urgent
GP referrals (Cancer Research UK, 2014). Particularly for EC, the 4-months campaign to increase
awareness of the symptom ‘difficulty swallowing’ increased spontaneous symptom awareness by 7%,
the number of GP visits by 17%, and number of urgent referrals by 26% in the pilot areas (Cancer
Research UK, 2014). These findings are encouraging, and highlight the importance of raising
knowledge about cancer symptoms, especially those cancers for which symptoms are vague or easily
attributable to other causes, such as EC. As our study has found, lack of familiarity with EC influenced
not only symptom appraisal, but may have led to distress in the sense-making process after diagnosis.
Therefore, the benefits of increasing public knowledge about EC can be two-fold: reducing patient delay
and reducing psychological distress post diagnosis.

Study Strengths and Limitations

Our study was conducted retrospectively, and recall bias could be viewed as a limitation. However, the
findings reported were evident in quotes from participants across different stages of the care pathway
(1-9 months post-diagnosis), and participants’ experiences are inevitably constructed through the lens
of their current EC diagnosis. People diagnosed with cancer often remember intricate details of events
in the past that are related to their diagnosis (Khatri et al., 2012). Besides recall bias, potential bias could
have been introduced as the majority of participants were men. We did not have any data for women at
4-5 months and 8-9 months post-diagnosis. However, the findings were consistent in both genders.
Lastly, Furthermore, we did not collect reasons for why participants declined to participate, nor how
many potential participants the nurses approached. Because of the lack of detailed records from the
nurses who recruited the participants, we were unable to assess how the nurses’ judgement may have
influenced the selection of potential participants for the study. Therefore, we cannot rule out selection
bias. A lack of a control group of patients with similar symptoms but non-cancer diagnoses could be
viewed as a limitation, because a control group could help the selection of symptoms to be used in education campaigns about cancer symptoms. However, as this study was designed to investigate patients’ experiences and supportive care needs post-diagnosis, a control group was not considered necessary. Lastly, another potential limitation could be the fact that the interviews were conducted by two different researchers, who may have had different interviewing styles. However, both researchers had a background in cancer care and were experienced in qualitative research, and worked closely in the design of the interview schedule, thus ensuring consistency.

Conclusion

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

Acknowledgements

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

<table>
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<th>Variable</th>
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<td>Gender</td>
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<tr>
<td>Female</td>
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<td>Time since diagnosis</td>
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<td>2 (14)</td>
</tr>
<tr>
<td>Tumour type</td>
<td></td>
</tr>
<tr>
<td>Adenocarcinoma</td>
<td>8 (57)</td>
</tr>
<tr>
<td>Squamous cell carcinoma</td>
<td>6 (43)</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>4 (28.5)</td>
</tr>
<tr>
<td>Stage 2</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Stage 4</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Not staged</td>
<td>4 (28.5)</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
</tr>
<tr>
<td>Pre-treatment</td>
<td>6 (43)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>7 (50)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Surgery</td>
<td>3 (21)</td>
</tr>
</tbody>
</table>
**Box 1. Interview schedule**

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

**Box 2. Symptoms reported**

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