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Symptom perceptions and help-seeking behaviour prior to lung and colorectal cancer diagnoses: a qualitative study

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Abstract

Background. Lung and colorectal cancer are common and have high UK mortality rates. Early diagnosis is important in reducing cancer mortality, but the literature on lung and colorectal cancers suggests many people wait for a considerable time before presenting symptoms.
Objective. To gain in-depth understanding of patients' interpretations of symptoms of lung and colorectal cancer prior to diagnosis, and to explore processes leading to help-seeking.
Methods. Semi-structured interviews were conducted with patients diagnosed with lung ($N = 9$) or colorectal ($N = 20$) cancer within the previous 12 months. Patients were asked about symptoms experienced in the period preceding diagnosis, their interpretations of symptoms, and decision making for help-seeking. Thematic analysis was conducted and comparisons drawn within and across the patient groups.
Results. Patients were proactive and rational in addressing symptoms; many developed alternative, non-cancer explanations based on their knowledge and experience. Discussions with important others frequently provided the impetus to consult, but paradoxically others often initially reinforced alternative explanations. Fear and denial did not emerge as barriers to help-seeking, but help-seeking was triggered when patients' alternative explanations could no longer be maintained, for instance due to persistence or progression of symptoms.
Conclusion. Patients' reasoning, decision making and interpersonal interactions prior to diagnosis were complex. Prompting patients for additional detail on symptoms within consultations could elicit critical contextual information to aid referral decisions. Findings also have implications for the design of public health campaigns.

Key words. Diagnosis, neoplasms, primary health care, qualitative, referral and consultation.

Introduction

Lung and colorectal cancer are two of the most common cancers in the UK (1). Both have high mortality rates, with early diagnosis essential for reducing this mortality (2). Although there is a target of 2 weeks for the referral of all patients in England with suspected cancer from primary care for specialist assessment (3), poorer cancer survival rates have been reported in comparison with other countries (4). Various factors may explain international differences, but the

lower survival rates could indicate late disease stage at diagnosis, possibly due to longer time to presentation of symptoms (5).

The majority of cancers in the UK are diagnosed in symptomatic patients presenting in primary care (6). The UK national strategy for cancer (7) suggests that early diagnosis for some cancers will be increased if people are encouraged to recognize signs and symptoms and seek help from a doctor as quickly as possible. Two public health campaigns were launched nationally in 2012 with the aim of increasing awareness of key symptoms of lung (persistent cough) and colorectal (rectal bleeding or change in bowel habit) cancers. Despite this, intervals between detection of a symptom or bodily change and help-seeking are often lengthy.

The Aarhus statement for improving design and reporting of research on early cancer diagnosis (8) distinguishes between the appraisal interval, or the time taken by the patient to interpret bodily changes, and the help-seeking interval, which describes the time taken to consult a clinician. Substantial intervals between patients' detection of symptoms and presentation in primary care are widely documented in literature on lung and colorectal cancers (9,10). Lack of recognition of the seriousness of symptoms, fear and lack of knowledge of cancer (10,11) are among the factors associated with longer time to help-seeking. Furthermore, patients sometimes rationalize their symptoms through inferring everyday causes, rather than linking them to a serious health problem (9). This can reduce the likelihood of consulting a general practitioner (GP) (12). It is important to note that health care provider (HCP) and system factors can also impact on time to diagnosis of cancer (13), and a recent political initiative in England has called for 'naming and shaming' of GPs who miss signs of cancer and delay referrals (14).

Despite a substantial body of evidence on psychosocial factors associated with delay in help-seeking, there is a dearth of literature on behavioural and social factors triggering help-seeking for symptoms which may represent an underlying cancer (15). Andersen *et al.* (16) emphasized the importance of devoting research to processes of symptom interpretation. A recent study focused on symptom appraisal and help-seeking in patients with cancer in rural Australia (17), but it is important to explore these processes further in other groups of patients with cancer. This study examines symptom interpretation and decision making for help-seeking in patients with lung and colorectal cancer in England in the period preceding diagnosis.

Methods

Recruitment and sampling

Participants were recruited from a hospital in North West England. Oncology research nurses screened the notes of all patients attending routine clinic appointments to identify those who had been diagnosed with lung or colorectal cancer in the previous 12 months and were therefore eligible to participate in the study. Nurses were permitted to exercise clinical judgement in approaching patients about the study, if they were concerned about an adverse impact of participation. The nurses explained the study and obtained initial consent for further contact from the research team from those patients who were interested in taking part. A total of 37 patients were approached for the study, 8 of whom declined to participate, leaving a total of 29 to be interviewed. This sample provided sufficient numbers to ensure exploration of the themes, and theoretical data saturation was reached by the final interviews. Potential participants were contacted by the researcher via telephone at least 48 hours after providing initial consent, to agree a suitable time for the interviews. Informed consent was obtained prior to the commencement of each interview. Patients were provided with an information sheet about the study and invited to ask the researcher any questions. The researcher then reiterated the purpose of the study, described what participation would entail and explained that all data would be kept confidential. Patients were reminded that they were free to withdraw at any time, without providing a reason and without their care being affected. The researcher also asked for consent to audio-record the interviews and ensured that patients and, if present, family members understood that the data would be used for research purposes, including publication. When the researcher had established that patients were happy to proceed, the consent form was explained and patients were encouraged to ask any further questions. Written consent was then obtained from patients while family members provided verbal consent. The decision to allow family members to be present or not was given to patients so that they could decide for themselves if they wanted family support to participate.

Data generation

Data collection was carried out by three researchers between January and March 2013. Individual qualitative interviews were conducted with patients in their own homes using a semi-structured topic guide. The topic guide was used to initiate discussion and included questions on the patient's background (e.g. occupation, family history of cancer), detection and perceptions of symptom(s), discussion of symptoms with others and what led patients to consult a GP (see Appendix 1). Patients were also shown a list of symptoms generated from a linked Delphi study (18), in which primary health care professionals and researchers identified diagnostic indicators considered important to elicit in a GP consultation with a patient presenting with possible lung or colorectal cancer symptoms. These were discussed with patients and used as prompts for additional symptom-related information.

Interviews were audio-recorded and transcribed verbatim for 27 patients. Two patients requested that their interview was not recorded, and so detailed field notes were made by the interviewer.

Data analysis

Analysis firstly involved careful reading of each transcript to identify themes. Coding was carried out independently by five members of the research team (SM, GM, TS, SY and LB) and discussed at project meetings. NVivo™ software version 9 (QSR International) was used to organize and store the coded data. A thematic approach to analysis was adopted, using constant comparative methodology drawn from 'grounded theory' (19) within and across patient groups in search of patterns and associations within the data. Following discussion of overarching themes and subthemes, linkages between themes were established and used to develop the interpretative model presented in Fig. 1. SM and GM identified key representative quotes from the data to support each theme.

Results

A total of 29 patients were interviewed (colorectal cancer, $n = 20$; lung cancer, $n = 9$); 21 patients were male and 8 were female, and ages ranged from 33 to 84 years. The median interval between diagnosis and interview was 5 months. Interview duration ranged between 15 and 140 minutes, and the average duration was 52 minutes. Fifteen patients had family members present, who were fully informed about the study and contributed in a limited way to discussion, such as by confirming appointment or diagnosis dates.

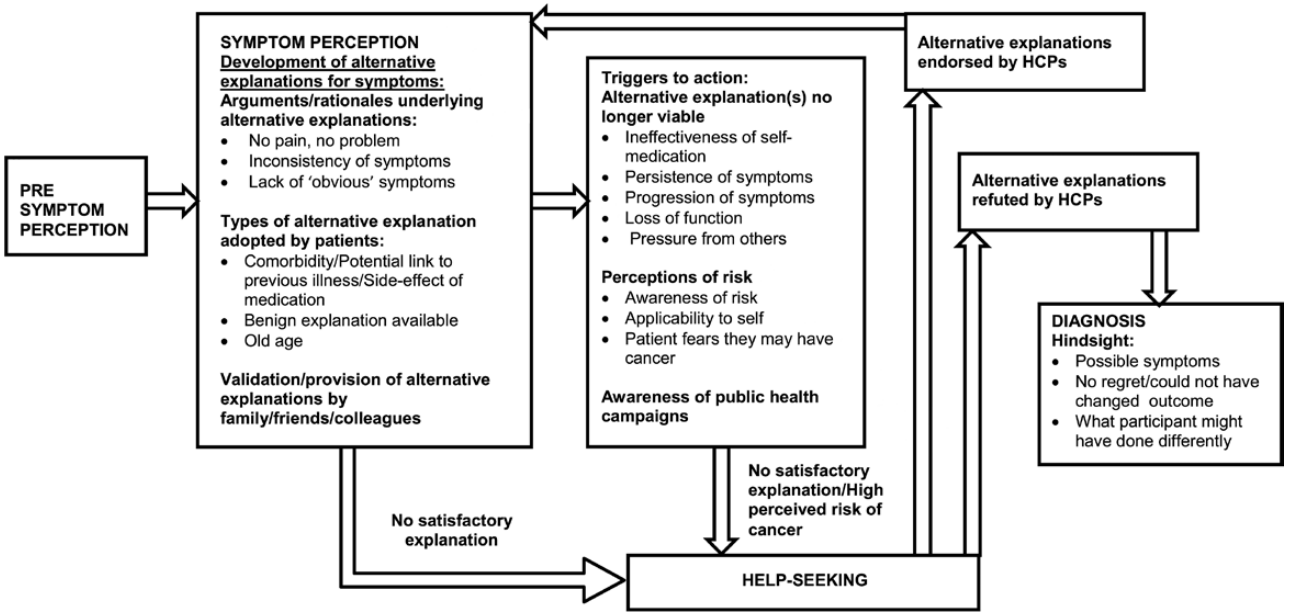

Figure 1. Model of symptom perceptions and help-seeking behaviour prior to cancer diagnoses, based on data from 29 patients with lung or colorectal cancer

Analysis resulted in a number of distinct themes arising from the data, which describe the thought processes and behaviours patients engaged in from first experiencing a symptom through to diagnosis and reflections with hindsight. Using a step-by-step approach, we present our findings as a model of decisions and behaviours adopted by patients, including interactions with health care professionals, which could help to inform clinicians' understanding of patients' symptom perceptions and decision making (see Fig. 1). Illustrative quotes to support each component of the model are presented in Table 1.

Pre-symptom perception

Patients suggested that they did not initially perceive their changes in health as indicating that they may have a serious illness. Although they had identified something different to normal, this had not triggered alarm or been considered worthy of the label of 'symptom' at the outset. Patients distinguished the presence of symptoms from being ill (Table 1, quotes 1–3).

Symptom perception

Following the identification of symptoms, many patients actively sought to form innocuous explanations. These tended to be well considered and based on logical arguments. In some cases, significant others (and later, professionals) also offered alternative explanations, which were accepted by patients.

Three main rationales were identified as underlying patients' alternative explanations for symptoms. The first related to a perception of 'no pain, no problem'. Some patients did not initially perceive their symptoms as serious because they had not experienced any pain. This finding is consistent with the public perception of cancer as a painful disease (20) (Table 1, quotes 4 and 5).

The second rationale related to the inconsistency of their symptoms. Many patients described infrequent or intermittent episodes, which led to the perception that symptoms were not serious. This association was particularly common for bowel symptoms, such as rectal bleeding and constipation (Table 1, quote 6).

The third rationale was a lack of 'obvious' or worrying symptoms, such as bleeding. A number of patients with colorectal cancer reported that they had not contemplated the possibility of cancer because, despite awareness of some physical changes, they had not experienced symptoms they thought could be cancer related (Table 1, quote 7).

Three key subtypes of alternative explanation emerged from the data: (i) association of symptoms with a comorbidity, previous illness or as a side effect of medication; (ii) availability of a benign explanation and (iii) old age.

Symptoms were often put down to previous or on-going illnesses and/or side effects of medications (Table 1, quotes 8 and 9). Patients with lung cancer also attributed chest symptoms to their smoking (Table 1, quote 10). Patients preferentially selected benign explanations for symptoms, for example linking them to lifestyle factors (Table 1, quote 11).

Several patients indicated that the adoption of benign explanations led them to dismiss symptoms, and consequently to delay seeking medical advice (Table 1, quotes 12 and 13). Some patients associated symptoms with growing older. This was used to account for a range of symptoms, including tiredness, breathlessness and yellowing of the eyes (Table 1, quotes 14 and 15).

Many patients indicated that their alternative explanations for symptoms had been validated or reinforced by the experiences or views of family members, friends and colleagues. Some patients mentioned particular individuals, whereas others referred to normative perceptions (Table 1, quotes 16 and 17).

Triggers to action

A common reason for seeking help was that the alternative explanations originally used by patients could not be maintained in light of changes in, or persistence of, symptom(s), or because attempts to self-medicate were ineffective (Table 1, quotes 18 and 19). Length of time a symptom was experienced for was often an important factor in patients' interpretation and decision making (Table 1, quotes 20 and 21). In some cases, it was the worsening of symptoms over time which prompted consultation (Table 1, quotes 22 and 23).

Loss of function also prompted patients to see a GP, as symptoms impaired their ability to perform day-to-day tasks (Table 1, quote 24). In several cases, patients reported that they had consulted a GP

Table 1. Summary of themes and supporting quotes from the data of 29 patients with lung or colorectal cancer

Overarching theme		Subtheme	Supporting quotes
Pre-symptom perception			1. I didn't really feel any different, so I didn't go to the GP. (CQ18, 69-year-old female with colorectal cancer); 2. I wasn't 'ill' ill to go to the doctors. (CQ17, 69-year-old female with colorectal cancer); 3. I didn't really think a great deal about it. I had a bit of a cough but nothing bad, you know. (CQ14, 58-year-old male with lung cancer)
Symptom perception	Arguments/rationales underlying alternative explanations	No pain, no problem	4. No pain, no chest pain, or anything, no pain anywhere, just this [fatigue], so I just attributed it to being tired, if you like. (CQ4, 56-year-old male with lung cancer); 5. No it wasn't a pain; I think if I'd have been in pain I would have gone to the doctors earlier. (CQ25, 73-year-old female with colorectal cancer)
		Inconsistency of symptoms	6. It [bowel movements] was every now and then, like, you know, so that's why I didn't put it down to anything serious, sort of, thing. (CQ1, 74-year-old male with colorectal cancer)
		Lack of 'obvious' symptoms	7. …there was nothing obvious, there was no blood or you know obvious blood in the toilet or anything that would make me… (CQ15, 67-year-old female with colorectal cancer)
	Types of alternative explanation adopted by patients	Comorbidity/link to previous illnesses/side effect of medication	8. Yeah, well, I'm asthmatic, see, anyway, because you have a tendency to cough a bit more, being asthmatic. (CQ19, 69-year-old male with lung cancer); 9. I suppose really, I'd hear so much from different people, that you get side effects with Statins and I know lots of people who just won't take them because of these side effects. I'd been on one, Atorvastatin … and then another GP, she changed me to Simvastatin and it was a while after when I got these sensations [bowel movements] you know, that; and I thought ooh, you know, is it because I'm taking these Statins, the different ones, and it went on from there, you know. (CQ25, 73-year-old female with colorectal cancer); 10. So I've been over 12 months now that I haven't smoked, but I smoked for a long time [yeah]. So, well, with the asthma and the smoking, I put that down to the shortwindedness. (CQ19, 69-year-old male with lung cancer)
		Benign explanation available	11. If I'd had a big meal like a Sunday dinner or something, …I always needed to go to the toilet not long after. And I did get a bit of a pain in my tummy then but I just thought it was down to eating too much. (CQ22, 59-year-old female with colorectal cancer); 12. Yeah, and it [rectal bleeding] stopped and it was probably a slight cut, maybe, an abrasion of some form for whatever reason, whether it was sport or anything. I played a lot of sport and stuff. So yeah, that's where you get to dismiss it a little more. (CQ8, 44-year-old male with colorectal cancer); 13. …to my wife, 'I think I've coughed some blood up'. Well, I said to them at work, 'I'm sure I've coughed some blood up'. There again, I said, 'I was drinking red wine last night, it could be that,' [okay] you know, you just passed it off. I did it a couple of times then it went away. (CQ19, 69-year-old male with lung cancer)
		Old age	14. I just put it down to being on the engine, just driving, just standing there pulling levers, and not doing what I'd done for 40 or 50 years. I was running up and down, you know, at the side of the trains, sort of, thing, doing the shunting. So I thought, 'I'm getting a bit old here [laughs]. I'm losing it a bit, like, with just being stuck in one position on the engine, just doing the levering'. So I just put it down to that. (CQ1, 74-year-old male with colorectal cancer); 15. When I asked the patient about the first indication that something was wrong, he told me that he had experienced breathlessness and a lack of energy while digging in the garden. However, the patient attributed this to ageing and did not discuss the symptom with anyone. (Notes from interview with CQ7, 72-year-old male with lung cancer)
	Validation/provision of alternative explanations by significant others		16. But everybody was saying at that time they'd got a cough, the people we were with at [place], he was cough, cough, cough, all the while. He's been going to the doctors ever since and they can't find anything wrong with him. (CQ5, 71-year-old male with lung cancer); 17. People say, 'Oh, it's just as you're getting older'. Everybody puts it down to age. (CQ17, 69-year-old female with colorectal cancer)

Table 1. *Continued*

Overarching theme		Subtheme	Supporting quotes
Triggers to action	Alternative explanation(s) no longer viable	Ineffectiveness of self-medication	18. I think it [constipation] was getting on for about 10 days. I was getting quite worried because I'd tried all over-the-counter medication from the chemist, but nothing seemed to help at all, that's why I went to the GP. (CQ27, 74-year-old female with colorectal cancer); 19. …because being a man, you don't go to the doctors [laughs]. You suffer it out, you know, which I did to a degree, and I was just taking cough medicines and things like that. But there was no relief. (CQ4, 56-year-old male with lung cancer)
		Persistence of symptoms	20. At first I thought because, you know, I'd had it a bit earlier in the year, and it had gone away, I thought, 'Maybe it's just some sort of tummy bug or something like that, but when it got to the 1st of June, and I thought, 'It's not gone away. I need to make a doctor's appointment,' and so that was when I went to see my GP. (CQ20, 33-year-old male with colorectal cancer); 21. This cough was different. I could not just stop coughing. And I couldn't sleep. I'd get down on my back, cough and cough and cough. So I thought, 'Right, I'll go see a doctor'. (CQ23, 63-year-old male with lung cancer)
		Progression of symptoms	22. As I said, when it become heavy blood, that was whoa, this is a totally different ball game now, this is something majorly wrong. (CQ3, 63-year-old male with colorectal cancer); 23. And I thought, 'I know there's something not right,' and it was getting worse, actually. This coughing got worse. The aches and pains got worse. (CQ23, 63-year-old male with lung cancer)
		Loss of function	24. I just couldn't breathe, and my job is plastering, which is all physical work. (CQ14, 58-year-old male with lung cancer)
		Pressure from others	25. Yes they [family] were concerned. They were ringing all the time. …When my sister came from [place], she came on 1st March and she said 'you have to get to a doctor, you need to go into hospital regardless of what the doctor says'. (CQ21, 84-year-old male with colorectal cancer); 26. She [patient's wife] was concerned, initially, because I was coughing, and it didn't seem to be getting any better, it would get worse. So that was what concerned her in the first place, which, in a sense, was a good thing, because me being a man [laughs], I would have left it until I was on death's door to go to the doctor. (CQ4, 56-year-old male with lung cancer)
	Perceptions of risk	Awareness of risk	27. P: I had to go and get it seen to because I knew I'd been a heavy smoker didn't I, so…? I: Right, so you had that sort of knowledge did you in your mind that…? P: Yeah, yeah. In your mind that you've asked for it in a way, haven't you? Although when we were younger it wasn't considered to be asking for it, was it? It was considered the thing to do. (CQ5, 71-year-old male with lung cancer)
		Patient fears they may have cancer	28. Yeah, I was quite convinced it was a tumour by the time I went to the doctors, I think the polyp theory had gone by then, the blood was too much, it was solid, it was congealed. (CQ3, 63-year-old male with colorectal cancer); 29. I knew myself it was more than—he did mention COPD first one. But I've got a friend with COPD and my symptoms didn't match hers. (CQ30, 63-year-old female with lung cancer)
	Awareness of public health campaigns		30. And there was an advert on the television at the time as well that kept coming on all the time that made me keep thinking about it as well. (CQ22, 59-year-old female with colorectal cancer); 31. And there was a big advertising campaign on about bowel cancer. Two weeks went by and the referral time is supposed to be two weeks, two weeks went by and I haven't heard anything and I phoned up and he got the receptionist to say he was sorry, he didn't think I thought it was important. (CQ3, 63-year-old male with colorectal cancer); 32. I didn't have, like, a cough like when you see the adverts, you know, a cough all the time. (CQ14, 58-year-old male with lung cancer)

Table 1. *Continued*

Overarching theme	Subtheme	Supporting quotes
Endorsement or refutation of alternative explanations by HCPs		33. I was getting breathless, I was getting breathless. But as I say again I was putting it all down to my asthma…The doctors were saying 'take your blue inhaler, your blue thing more often'. (CQ24, 61-year-old female with lung cancer); 34. …so I went to the doctors, and I didn't see my regular one; it was just a locum doctor that was there and his diagnosis was haemorrhoids, but he referred me to [name of hospital]. (CQ20, 33-year-old male with colorectal cancer); 35. Yeah I went along and she just said well you'd better go for an X-ray, and that was about it really. … And I think I went on the Friday, she'd got the results on the Tuesday I think. (CQ5, 71-year-old male with lung cancer)

because a significant other encouraged them to make the appointment (Table 1, quotes 25 and 26).

In the process of decision making for help-seeking, patients also considered risk factors and applicability to themselves. When alternative explanations became unviable, perceptions of risk and fear that symptoms may indicate cancer were sometimes influential in prompting help-seeking (Table 1, quotes 27–29).

A further trigger to action was awareness of public health campaigns for cancer. In 2012, national media campaigns to highlight key symptoms of lung and colorectal cancer were launched by the UK Department of Health. Some patients reported knowledge of these campaigns and mentioned that this had affected their decision making, or at least triggered the thought of cancer (Table 1, quote 30). In one instance, knowledge of the bowel cancer campaign prompted a patient to push the GP to take their symptoms more seriously (Table 1, quote 31). However, the campaigns did not consistently encourage help-seeking; in some instances, patients differentiated their symptoms from those described in the media (Table 1, quote 32).

Endorsement or refutation of alternative explanations by HCPs

Following the decision to seek medical help regarding symptoms, some patients' alternative explanations were reportedly endorsed by GPs (Table 1, quote 33). For several patients, this led to further delays on the path to diagnosis although in other cases specialist referrals were still made (Table 1, quote 34). However, HCPs also played an important role in refuting patients' alternative explanations for symptoms and moving them forward on the pathway to diagnosis (Table 1, quote 35).

Similarities and differences between patients with lung and colorectal cancer

There were striking similarities in symptom perceptions and decision-making processes reported by patients with lung cancer and those with colorectal cancer. The majority of themes were identified clearly in both patient groups and the processes illustrated by the model represent patients' responses to lung and colorectal symptoms. As the underlying principles and reasoning do not appear to be dependent on cancer type, the model may also be usefully transferred to exploring symptom perceptions and experiences in other cancer diagnoses. There were small differences between the groups in terms of subthemes, with inconsistency of symptoms and lack of obvious symptoms more commonly cited as rationales underlying alternative explanations for colorectal than lung symptoms. Further, loss of function and awareness of risk were more frequently reported as triggers to help-seeking for patients with lung than colorectal cancer. The former finding is likely to relate to the experience of severe breathlessness in lung cancer and the latter to an awareness of the association between lung cancer and smoking.

Conclusions

This study explored patients' perceptions and responses to symptoms of lung or colorectal cancer, and how this sense-making process led to consultation of a GP and subsequent diagnosis. The work adds to findings on symptom perception and help-seeking for cancer symptoms to provide an overview of patients' interpretive and decision-making processes and offers a model to assist HCPs in eliciting symptom-related information from patients.

The processes recounted by patients with lung and colorectal cancer, and of different gender and ages, were similar, which suggests that the model could be usefully applied to other patient groups. Identification of these common processes across the two different cancer types represents an important contribution made by this study. The model is based on rich data gathered through in-depth interviews and provides detailed insight into patients' symptom perception and decision making over time. Although the accounts provided by patients were retrospective and perceptions of key events may have been affected by hindsight, many patients contrasted their interpretation of symptoms at the time with more recent perceptions, thereby making the role of hindsight explicit. The research nurses who assisted with recruitment were free to exercise clinical judgement in approaching patients about the study, and it is possible that they approached patients who they felt would be able to discuss their experiences in more depth. This could have affected the composition of our final sample to some extent, such that findings do not account for the pre-diagnosis pathways of patients who were too ill to be interviewed. However, it is necessary to balance this potential limitation against the important role played by research nurses in facilitating access to patients.

Several findings are consistent with existing literature on symptom interpretation and help-seeking behaviour for possible cancer symptoms. The alternative explanations deployed by patients could be described as 'normalization', which has been reported previously. These included reference to symptoms that might be associated with ageing (12) or attributions to lifestyle and everyday causes such as over-eating (9,12,21). A recent study of symptom appraisal and help-seeking for cancer in Western Australia also found that benign explanations were often used to account for symptoms (17). The role of intermittent symptoms in delaying help-seeking has been reported in recent studies of patients diagnosed with pancreatic (21), lung, colorectal, breast and prostate cancer (17) suggesting that this finding is not limited to lung and colorectal cancers. Resonance between the current findings and those of Emery *et al*. (17) is important, as this suggests that processes of symptom interpretation and help-seeking are similar across two very different populations. Patients' explanations for symptoms are often developed through consideration of symptoms in relation to relevant events or circumstances, or features of familiar illnesses (22). This can be associated with an optimistic bias (22), whereby innocuous explanations are selected over more serious possibilities. In the context of primary care, where the symptom is more likely to be benign than malignant, this is not unreasonable from either the patient's or the GP's perspective. In contrast to previous research suggesting patients' passivity in response to symptoms of cancer (9), current findings indicate that patients engage in active reasoning and seek out information to make sense of symptoms. Further, although fear and denial have been associated with increased delay in symptomatic presentation (10,11), these factors did not emerge as barriers to help-seeking in the current study. Rather, concern that symptoms may indicate cancer was reported by some patients as a trigger for consultation when alternative explanations could not be maintained. Another important finding relates to the role of others in patients' interpretation of symptoms and decision making. Previous research has indicated that involvement of others is associated with less delay in symptomatic presentation for cancer (11) through sanctioning of help-seeking. Although this was evident to some extent in the current findings, discussion of symptoms with others also increased delay through validation or provision of alternative explanations.

Findings suggest that far from exhibiting denial or lack of understanding, many patients take an active and rational approach to addressing symptoms. The decision to monitor symptoms over time for exacerbations or persistence resembles the GP 'watch and wait' process, and interpretation of symptoms as benign, at least initially, is unlikely to differ from an initial clinical diagnosis within a primary care context. However, findings also suggest that prompting patients for further information within a consultation may elicit important details regarding the context of their symptoms, which could aid decision making for referral. The model presented could serve as a useful tool for assisting primary care practitioners in this process by encouraging them to probe into patients' explanatory accounts of symptoms and expedite the identification of those requiring further investigations. Findings also indicate that it may be beneficial to address the pervasive 'no pain, no problem' misconception in public health campaigns, as this was cited by a number of patients as an important factor in delaying symptomatic presentation. Further, it may be valuable to take a more inclusive approach to symptoms targeted within media campaigns, beyond classical presentations such as a persistent cough for lung cancer and rectal bleeding for colorectal cancer, to symptoms such as weight loss and fatigue. This should, however, be balanced against the problem of low specificity of symptoms and the risk of overwhelming GPs. With regard to the recent political announcement calling for naming and shaming of GPs who miss signs of cancer in their patients, current findings suggest that such an approach is over-simplistic and fails to account for the complexity and variability of reasoning, decision making and interpersonal interactions preceding diagnosis.

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Declarations

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Appendix 1. Topic guide for patient interviews

Research question

To explore patients' experiences of chest/bowel symptoms [as appropriate] prior to clinical presentation and diagnosis

Section 1: Introduction and background to study

'Thank you for your time today. We are interested in finding out more about patients' experiences of chest/bowel symptoms before seeking medical advice. This work is being carried out as part of a large nationwide study which will investigate what symptoms, risk factors etc. that a person goes to see their doctor about are most likely to mean that they might have cancer'.

Explain the study, confidentiality and consent.

Section 2: Main interview discussion

Topics

- General background/context
  - Job (or previous occupation)
  - Family context/history
  - First sign of symptoms
  - List the symptoms that you were experiencing and say a little about what each one meant to you?
    1.Symptoms 1, 2, 3 etc.
- Early symptoms
  1. When did you notice the first indication that something was not right?
  2. Did you perceive your symptoms were normal or unusual?
  3. Why did you feel that way?
  4. Did your symptoms gradually/quickly become worse/better?
  5. Did this affect your decision to seek medical advice?
  6. How long did it take from noticing your first symptoms and seeking medical advice/advice from friends or relatives?
  7. How many times did you consult medical advice before being referred to hospital?
     1. What was the reason why you sought medical advice × number of times?
- Lay evaluation and decision making
  - How did you perceive your symptoms when you first noticed something was not quite right?
    1. What made you perceive them in the way you describe?
    2. Who did you talk with about these signs/symptoms?
    3. What kinds of things did you discuss?
    4. What was the outcome of these discussions?
    5. Which people were important in helping you decide on what you should do next?
    6. How did they help in helping you reach a decision?
- Presentation at the GPs
  - What led you to consult your GP (or other medical services)?
    1. What was the immediate 'trigger' to presentation at medical services? For example discussion with spouse?
    2. What happened when you saw your GP (or other medical professional)?
    3. What did they say/do? What was your reaction to this?
    4. What was the management plan that was agreed?
    5. In hindsight, would you have done anything differently if you noticed similar symptoms (e.g. spoke to someone or seen the GP sooner)?
    6. Which symptoms were most important to recognise quickly?
    7. Please explain why you think that?
- Use of screening tool
  - Would a scientifically 'proven' screening tool for identifying people at higher risk of more serious health problems offer reassurance that the GP or health professional have made the right decision to:
    1. Refer a patient for further investigations, or
    2. Decide not to refer?
  - Can you elaborate on your answer?

Section 3: Summary

Feedback any key points from the interview for clarification and final discussion. Invite respondent to share any additional experiences.

Colorectal cancer: risk factors

Do you have a close relative who has had small growths in the lining of the gut or bowels (polyps) before the age of 50?

Do you have a close relative who has had bowel cancer before the age of 50?

Do you have a family history of abnormal small growths in the lining of the gut or bowels (polyp/familial polyposis coli)?

Do you suffer from a condition like Crohn's disease or ulcerative colitis, which results from inflammation in the gut, which flares up now and again? (inflammatory bowel disease)

Have you ever been diagnosed with non-cancerous small growths in the lining of the gut or bowels (polyps)?

Have you ever been told that you have >10 of these polyps?
Did you think your symptoms might indicate something serious?

Colorectal cancer: symptoms

Did you notice any blood in your bowel motions?

Did you notice whether this was dark blood?

Did you notice any change in your bowel habits, for example diarrhoea alternating with constipation?

Did you notice a strong feeling of the need to empty your bowels, without being able to do so or only passing minimal amounts of stool?

Did you have a sudden feeling of an urgent desire to empty your bowels?

Did you feel that you had not emptied your bowels completely?

Did you notice that you were passing frequent, very loose bowel motions (diarrhoea)?

Did you lose any weight unintentionally?

How long did you have your symptoms?

Did your symptoms progress quickly from when you first noticed them?

Did you notice any abnormal, yellowish discolouration in your eyes or skin (jaundice)?

Lung cancer: symptoms
Did you have a cough?
Did you cough up blood?
Did you have pain in your chest?
Did you feel short of breath?
Did you or other people notice any hoarseness in your voice?
Did you lose weight unintentionally?
How long did you have your symptoms (before seeing your GP)?

Lung cancer: risk factors
Does your work involve you using dangerous chemicals, such as asbestos?
Did your symptoms get better at the weekend?
Do you have a close relative who has been diagnosed with lung cancer?
Have you been exposed to smoking for prolonged periods by contact with a person who smokes?
Do you suffer from chronic obstructive pulmonary disease, a chronic condition where you have difficulty breathing?
Did you feel more easily exhausted engaging in physical activities than before?
Did you think your symptoms might indicate something serious?
When did you last see your GP?