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Eliciting symptoms interpreted as normal by patients with early stage lung cancer – could GP elicitation of normalised symptoms reduce delay in diagnosis?: Cross sectional interview study

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ABSTRACT

Objectives: To investigate why symptoms indicative of early-stage lung cancer (LC) were not presented to GPs and how early symptoms might be better elicited within primary care.

Design, setting and participants: A qualitative cross-sectional interview study about symptoms and help-seeking in 20 patients from 3 south England counties, awaiting resection of LC (suspected or histologically confirmed). Analysis drew on principles of discourse analysis and constant comparison to identify processes involved in interpretation and communication about symptoms, and explain non-presentation.

Results: Most participants experienced health changes possibly indicative of LC which had not been presented during GP consultations. Symptoms that were episodic, or potentially caused by ageing or lifestyle, were frequently not presented to GPs. In interviews, open questions about health changes/symptoms in general did not elicit these symptoms; they only emerged in response to closed questions detailing specific changes in health. Questions using disease-related labels, e.g. pain or breathlessness, were less likely to elicit symptoms than questions that used non-disease terminology, such as aches, discomfort or 'getting out of breath'. Most participants described themselves as feeling well and were reluctant to associate potentially explained, non-specific or episodic symptoms with LC, even after diagnosis.

Conclusion: Patients with early LC are unlikely to present symptoms possibly indicative of LC that they associate with normal processes, when attending primary care before diagnosis. Faced with patients at high LC risk, GPs will need to actively elicit potential LC symptoms not presented by the patient. Closed questions using non-disease terminology might better elicit normalised symptoms.

ARTICLE SUMMARY

Article focus:

• Why are symptoms potentially indicative of lung cancer not presented to GPs?
• How and why are some lung cancer symptoms normalised by lung cancer patients?
• What can a discourse analytic study of communication about symptoms tell us about cultural and communication factors involved in the non-presentation and normalisation of symptoms, and how symptoms might be better elicited in primary care?

Key messages:

• Non-specific, episodic and non-progressive symptoms were normalised by patients with operable lung cancer who felt well.
• Symptoms normalised by patients with operable lung cancer were not presented to GPs during consultations before diagnosis. GP elicitation of normalised symptoms would lead to better informed referral decisions.
• Closed questions using non-disease terminology were more effective at eliciting symptoms normalised by patients.

Strengths and limitations of this study:

• This study used interviews to identify interactional factors which influenced symptom presentation within a research study, and it may be that symptom presentation occurs differently within everyday GP consultations; nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms were elicited by GPs, referral decisions would be better informed.

• The majority of lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is necessarily unrepresentative of the whole population of lung cancer patients. However, research involving operable patients enables the investigation of communication about currently experienced early symptoms, rather than relying on retrospective accounts of early symptoms provided by patients with later stage disease. Furthermore, the reasons these patients with lung cancer give for non-presentation of symptoms concur with other studies of help-seeking for cancer symptoms,[19] supporting the transferability of our findings.

What is already known:

Despite visiting the GP more frequently than randomly selected controls in the year before diagnosis, most lung cancer patients are diagnosed too late (when potentially curative treatment is no longer possible).

Retrospective interview studies indicate that symptoms experienced months to years before diagnosis are often 'normalised' by those with lung cancer; symptoms are often interpreted as not serious, or as not requiring medical investigation.

What this study adds:

Patients being investigated for operable lung cancer who felt well normalised many non-specific and episodic symptoms potentially indicative of lung cancer; consulting patients were unlikely to present normalised symptoms to GPs.

Closed questions using non-disease related terminology elicited symptoms interpreted as normal by patients. More effective elicitation of non-specific and episodic symptoms in those at high risk of lung cancer might improve earlier diagnosis in this group.

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – can we use closed questions to reduce delay in diagnosis?

INTRODUCTION

Lung cancer is diagnosed too late in the UK and survival rates are lower than in most other Western European countries;[1-4] 86% are diagnosed at a stage when curative treatment is not possible and less than 25% survive one year following diagnosis.[5-6] Lung cancer kills approximately 30,000 people a year in the UK so even modest improvements in the time to diagnosis could dramatically improve health outcomes.[7] Despite successful national cancer screening programmes, most tumours are diagnosed following presentation with symptoms [8] so it is vital to identify patients with significant symptoms early. The UK National Institute of Clinical Excellence (NICE) recommends urgent chest x-ray for patients presenting with any 1 of 10 unexplained or persistent symptoms [9] but General Practitioners (GPs) have to balance risks associated with unnecessary x-ray against possible late diagnosis, and make judgements about the relative validity of alternative explanations for symptoms. This is further complicated by the fact that lung cancer is often preceded by chronic respiratory disease [10] making detection difficult.

Recent evidence [11] indicates that most newly diagnosed lung cancer patients do not recognise all of their cancer symptoms. Isolated single symptoms have low predictive value for lung cancer [12] but patients seldom present multiple symptoms to GPs. [13-14] Interview research has shown that lung cancer patients normalise symptoms and delay seeking help [15-16] and in the general population many symptoms are never presented to GPs [17-18]. However, patients diagnosed with lung cancer have been shown to report symptoms to their GP more frequently than controls 6-24 months before diagnosis [12] but it seems that a combination of cultural and communication processes combine, sometimes fatally, to prevent help-seeking [13,19-20] for the full range of symptoms experienced by patients at increased risk of lung cancer (LC).[11;21]

Previous studies have identified symptom normalisation - the association of symptoms with normal processes - as an important factor in delayed LC diagnosis. However, research has not yet addressed the reasons for normalisation of LC symptoms, or investigated how normalised symptoms that are not presented to health care professionals might be better elicited. Structured interviewing has been used in primary care to improve psychiatric diagnosis but it is not clear if it could help to elicit early lung cancer symptoms. Our study examined how symptoms were normalised by patients and compared structured and unstructured elicitation of symptoms. By using a discourse analytic approach we were able to suggest ways that health care professionals might better elicit normalised symptoms, and investigate why they are not presented to GPs.

METHODS

Design

Previous studies have focused on inoperable lung cancer, but we were interested in how patients communicated early symptoms so we conducted interviews with patients awaiting surgical resection of lung cancer (suspected or histologically confirmed). Previous interview studies with lung cancer patients have relied upon retrospective accounts of early symptoms experienced before diagnosis. In contrast, we were interested in how patients communicate about, and negotiate the relevance of current early symptoms. In retrospective accounts patients might normalise symptoms to justify delays in seeking help so we also investigated the normalisation of symptoms that started following LC investigation. We used unstructured

followed by structured interviewing to find out if this could elicit symptoms more effectively than open questions about changes in health, which have been found not to elicit all lung cancer symptoms (see Smith et al, 2009).

Participants

The interview sample for this study was drawn from 28 adult patients with a diagnosis of, or suspected of having, operable lung cancer (probable: >90% or histologically confirmed) recruited to a questionnaire development study. Patients were either approached by the researcher following their first consultation with participating thoracic surgeons at a South England Trust, or were sent a letter and information sheet by the surgical team. Seventeen out of twenty consecutive patients within 3 recruitment periods (07/2006-10/2007; 02/2008-05/2008; 02/2009-05/2009) approached by a researcher agreed to take part. An opportunistic sample of 11 participants was recruited by letter (within the three recruitment periods). Twenty eight patients in total were recruited and interviewed about their current and recent health and help-seeking behaviour.

This paper reports the analysis of 20 interviews with patients identified as having operable lung cancer at the end of the study period (data from seven interviewees who received a non-malignant diagnosis after the interview were analysed separately and are not reported here. One patient diagnosed with advanced disease was also excluded). Characteristics of these 20 patients are given in Table 1.

[Insert table 1 here]

Interviews

The unstructured (first) section of the interview used open questions to generate narrative accounts of participants' experiences and changes in health status (See Appendix 1 for the interview checklist). Participants were asked to describe anything at all that they had noticed about their health, even if they thought it not relevant to their investigation for lung cancer. The second part of the interview was semi-structured and focused on duration and characteristics of symptoms, and reasons for seeking or not seeking help. The third part of the interview used closed questions to explore symptoms and help-seeking using a list of potential lung cancer symptoms compiled from Cancer Research UK [6] information, NICE [9] guidelines, and a previous interview study with lung cancer patients.[15] Field notes were recorded after the interview. Interviews lasted between 1-2 hours, took place in the participants' home (18/20) or a hospital setting (2), some involved the participant's partner (2) or carer (1), all were audio-recorded, transcribed verbatim, checked for accuracy and anonymised. An adapted version of Jefferson's transcription conventions [22] were used (described in Box 1).

[Insert Box 1 here]

Analysis

The first stage of analysis involved an iterative coding process using elements of the constant comparative method to develop themes (initially identified by LB and checked by a second researcher, GL, who independently read a sample of transcripts and verified codes and themes). This iterative process continued until data saturation was achieved. All transcripts were revisited and deviant cases were sought.[23] Discourse analysis[24-25] which considers language use in context, was used to examine the interview accounts, and to explore how

health changes were presented in patient-interviewer interactions. We combined thematic analysis with discourse analysis to explain normalisation and non-presentation of symptoms.

The Results section presents key findings about symptom presentation, including reasons for non-presentation, and examines the impact of closed questions. Two types of symptom accounts were identified: 'symptoms as normal processes' and 'symptoms of disease/concern'. The first results section – 'Reasons for non-presentation' – describes the main features of 'symptoms as normal processes' accounts (episodic/non-progressive symptoms or ageing and lifestyle related explanations), and exceptions to the normalisation of symptoms. The distribution of the two types of symptom accounts (and non-presentation) by symptom, route to diagnosis and declining health/feeling unwell, are described in table 3. The second results section examines the use of closed questions to elicit normalised accounts and the implications of symptom terminology. Examples of the two types of symptom account and their elicitation are provided in table 4.

RESULTS

Most participants described themselves as having good health; only four presented accounts of declining health preceding diagnosis, characterised by multiple symptoms and feeling unwell (see table 2).

[Insert table 2 here]

Symptomatic diagnosis occurred for 13 participants and 7 participants claimed not to have any lung cancer symptoms, describing incidental diagnoses made during the investigation of unrelated health problems, traumatic injury or screening (Table 3).

[Insert link to table 3 here]

15 participants described further changes in health possibly indicative of lung cancer (according to NICE Guidelines/CRUK symptom list) that were not thought a reason for concern and had not been presented to their GP, despite the presentation of the trigger symptom or use of primary care services for other reasons (Table 3). They did not associate these un-investigated health changes with LC and they were elicited by closed questions about specific symptoms, but not by open questions about symptoms or changes in health.

Reasons for non-presentation

Normal processes such as lifestyle and ageing were commonly used as explanations for not presenting symptoms to GPs. For example, breathlessness was frequently associated with being unfit, getting older, over-activity or seasonal changes rather than lung cancer:

> P18: I just put it down to me being too unfit for that particular run or circuit or down to age…I didn't associate that with anything other than me being old or unfit, one of those.

In these 'symptoms as normal process' accounts patients portrayed symptoms as part of everyday life processes and avoided claiming cancer causation:

> LB: ...do you get any discomfort anywhere, do you have any aches or pains?
> P11: No (.) only round me neck but that's just recently it's come on. I don't know whether it's to do with this problem I've got ... I think it's a bit of arthritis there. And (.) you know (.) it's old age really I mean, because we do get these things I know, as you get older, (.) but just as I say this last couple of weeks it's got really really bad.

Some of those who described current 'good health' at odds with their diagnosis, also described episodic ill health, or long term symptoms which had led to lifestyle changes and adaptation. Symptoms like breathlessness or cough might be more severe during a chest infection, but were not commented on if they persisted. Here, P25 did not mention breathlessness on climbing the stairs to her GP:

> P25: It was getting the pains in my hands and my wrists… It was when it started here [in wrists], it started to hinder me with things…but I wasn't going [to the GP] through breathlessness …because that had finished when I got better…You know within the week I was back to being able to breathe again. Apart from when I you know whether you get out of breath carrying the hoover upstairs... [Husband] says "What have you been doing? [ ]?" and I just say "Nothing just those stairs".

The ability to improve did not appear to fit with the expected progressive pattern for a disease such as lung cancer:

> P25: [ ]...once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now... Why don't I feel really, really ill now to understand this? How can you have this and get better and feel better, get ill but then you get better, well how can you do that?

These normalised accounts, by simultaneously presenting alternative non-disease explanations, such as ageing, for health changes, also helped construct the participant as healthy. Exceptions to the use of normalised accounts for un-investigated symptoms were found in four interviews where patients had declining health (consisting of multiple symptoms and feeling unwell); two of these four patients also provided 'quest for diagnosis narratives' in which they had battled, or were still battling, for a diagnosis in the face of clinical ignorance or clinical delay. In the interviews they described most of their health changes in response to open questions (Table 3: Exceptions to the normalisation of symptoms), including symptoms not presented to GPs, and did not normalise these symptoms. Even symptoms presented in response to closed questions were most often not normalised:

> LB: So have you noticed any changes in breathing or breathlessness?
> P19: Yes I am definitely more breathless now... I am not normally that breathless!
> LB: ...and before that, how would you describe your breathlessness?
> P19: Well it's never been really too bad, as long as I've had my inhalers... So it's just recently that I am beginning to get a bit more breathless and I don't think that's associated with the asthma.

Participants who presented themselves as well, normalised non-specific, non-progressive and episodic symptoms. Examples of 'symptoms as normal processes' accounts and 'symptoms of disease/concern' accounts are provided in Table 4.

[Insert table 4 here]

Using closed questions to elicit symptoms not elicited by open questions

Symptoms interpreted as normal by participants tended not to be described in response to open interview questions (Tables 3 & 4) and were not presented to GPs. For example, P22, who had been investigated by his GP for a bowel disorder in the weeks before diagnosis, described an absence of symptoms he associated with lung cancer:

> P22: No as I say this was a complete shock to find out that it was on the lung. As I said, we would never have known anything about it if I hadn't fallen off that thing. I suppose it would eventually with

finding this I suppose I could have lost weight or gone awful thing one to the doctor "well we'll have to find out what's causing it" but no nothing.

However when asked specifically about long-term cough, he revealed he had experienced a cough for 4-5 months:

P22: Well I've got a cough now. Every now and again I cough and get a little phlegm up.
LB:… And is it something that you ever went to your doctor about?
P22: No.
LB: No.
P22: No I've never had to do that.

Accounts produced in response to closed interview questions about specific symptoms displayed two common structures for symptom reporting: 'Affirmation/Normalisation' and 'Delayed Affirmation/Normalisation'. The symptom referred to by the interviewer might either be affirmed but normalised ('Affirmation/Normalisation') or initially denied and then normalised ('Delayed Affirmation/Normalisation'). When closed questions phrased health changes in ways which did not necessarily indicate disease, the participant was more likely to answer affirmatively, or describe a health change, but then suggest the symptom was normal and not related to lung cancer (Affirmation/Normalisation). In contrast, questions using disease-related terms - e.g. 'pain' - produced an immediate denial or pause (non-response) followed by normalisation (Delayed Affirmation/Normalisation):

LB: ... have you had any chest pain at all that you can describe?
P12: No, not really. I mean as the cough's got shall we say more persistent and sort of shall we say worse yes (.) I can feel it a bit (.) but I mean I can't feel it now... if you look at the x-rays you think 'oh blimey!' but you wouldn't know it was there!

Reformulation of the question, involving a shift from disease to non-disease terminology, could elicit normalised accounts of symptoms – as in these examples where a change in terminology shifting from 'pain' to 'aches' and 'discomfort', and shifting from 'breathlessness' to 'not being able to get your breath' leads to elicitation of the symptoms:

LR: Have you had any pain anywhere?
P16: None at all. No
LR: …have you experienced any sort of aches or general sort of discomfort at all? ...
P16: No, not serious no. Well …sometimes I have a feeling that something's going on, but it's not there all the time, you know

LR: And have you experienced breathlessness? ((pause))
P18: ((intake of breath))
LR: Just feeling like you haven't been able to get your breath quite so easily?
P18: I would go up a couple of flights of stairs quite randomly, I would feel out of breath. I would never never usually be like that, so yes, for a fit guy I would go ooh I'm breathless ...but then you know I shouldn't have really bothered about it at all. But then again I have put on a slight bit of weight haven't I?

In contrast with disease-related terminology, terminology not strongly associated with disease such as 'aches' or 'discomfort' rather than 'pain', produced affirmation and then normalisation (affirmation/normalisation):

LB: And have you had any kind of aches or discomforts anywhere?
P12: Well I have been complaining about a stiff neck haven't I...and also this shoulder…but I mean I can play golf, so it's not that bad!

Similarly the use of terms that imply 'breathing changes' or 'getting out of breath more easily', rather than 'breathlessness', produced an affirmation/normalisation response structure:

> LB: ...what about breathing changes, or have you ever noticed at all that you can become more breathless than you would have done say a few years ago when you were doing something?
> P11: I do now. This past (.) oh couple of months I suppose. I get more breathless if I (.) if I hurry around too much you know…but normally you know, I don't run around! (LB: no no) If I remember my age... I don't sort of get out of (.) breathless or anything like that, it's only if I'm (.) ... overdo things really.

Even though closed questions using disease-related terminology might elicit previously unmentioned health changes, closed questions using non-disease terminology did so more effectively.

DISCUSSION

Eliciting 'hidden' symptoms

Most of our sample described themselves as feeling well, despite going on to have a diagnosis of operable lung cancer. Patients who felt well had experienced a range of health changes indicative of lung cancer but they did not tell their GPs about many of these, despite making use of primary care services. Instead they framed these symptoms as normal features of lifestyle and ageing processes.

Delay in lung cancer diagnosis in the UK has been blamed upon patients' failure to recognise early symptoms.[26] However, our research indicates that normalised symptoms can be elicited by closed questions. This runs counter to current educational and communication practice which encourages open and expansive questioning. Whereas open questioning is necessary to elicit symptoms perceived as abnormal by the patient, normalised symptoms will remain hidden. Once elicited by closed questions, normalised symptoms are often quickly obscured within accounts which provide every day explanations for health changes. This means that interviewers (or health professionals) have to probe normalised accounts to uncover hidden symptoms.

Questions using disease-related symptom terminology, such as 'chest pain', or 'breathlessness', appeared to have limited potential to elicit potential lung cancer symptoms experienced by those with operable lung cancer. Our analysis suggests that to get at these symptoms we need to ask closed questions without referencing disease-related symptom labels. Again this runs counter to some guidance such as the NICE referral criteria terminology which uses disease-related terms. Furthermore, contextual factors and framing of the patient's presentation are known to influence GPs' diagnostic reasoning;[27] patients who present themselves as well and without declining health might be less likely raise concern and be referred for investigation of potential cancer symptoms.

Recent survey research looking at public awareness of cancer symptoms in the UK, concluded that levels of knowledge are low for many potential cancer symptoms.[28] These findings have informed regional NAEDI (National Awareness and Early Diagnosis Initiatives) [29] materials designed to educate the public about cancer symptoms. Our work suggests that lists of symptoms alone are unlikely to prompt patients to reveal multiple non-specific and normalised symptoms, especially when they are asked to give unstructured accounts. Furthermore, our research indicates that lung cancer risk scores provided by

symptom based clinical decision support aids (e.g. RATS[30]), are likely to be influenced by how symptoms are elicited within the consultation.

Patient-centred medicine attempts to honour patients' experiences and concerns – presented in their own terms. It has been accompanied by more open consultation styles and a shift away from interactions directed by the health professional. For patients with potential lung cancer this may not be the best way to elicit symptoms. Instead routine medical consultations involving those at increased cancer risk [31] might better be restructured to enable the presentation of health changes which appear normal or unproblematic to the patient. This would require the clinician to be aware of the risk of lung cancer in all patients presenting to their service with symptoms seemingly unrelated to lung cancer. The elicitation of normalised symptoms in patients at increased lung cancer risk might then facilitate GPs' chest x-ray referral decisions.

Strengths and Limitations

This study used interviews to identify interactional factors which influenced symptom presentation within a research study. The systematic and in-depth study of language of the type reported in this article can lead to critical insights about conventions used in conversation that are transferable between settings.[32] However, it may be that symptom presentation occurs differently within everyday GP consultations; closed questions involving non-disease terminology might not be as effective at eliciting normalised symptoms within primary care practice. Further research involving GP consultations will be required to establish how effective these methods of symptom elicitation are within primary care. Nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms that are potentially indicative of LC were elicited by GPs, referral decisions would be better informed.

The participant group were patients with an established or probable lung cancer diagnosis. This may influence symptom presentation in the interview as a LC diagnosis is already suspected. However, the normalisation of symptoms that started after diagnosis within this study suggests that normalisation is not justifying delays in diagnosis; the association of episodic, non-specific symptoms with normal processes appears commonplace for those feeling well, even when lung cancer provides a potential explanation for symptoms.

NICE referrals guidelines are based upon a weak evidence base; therefore, we do not know the likelihood that the symptoms not presented to GPs were caused by LC. However, these guidelines represent the best evidence currently available to inform referral for lung cancer investigation. If these non-specific symptoms experienced by patients at increased lung cancer risk were elicited in primary care, GPs would be better able to operationalize NICE guidelines. A prospective study may eventually determine the utility of these symptoms in the early diagnosis of lung cancer and the efficacy of treatment (including surgery).

The majority of lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is necessarily unrepresentative of the whole population of lung cancer patients. It may be that our participants were more symptomatic in the early stages, or more likely to seek medical help, than those diagnosed with inoperable disease. However, this makes it all the more compelling that these participants still experienced a number of symptoms that they did not report. The reasons these patients with lung cancer give for non-presentation of symptoms concur with other studies of help-seeking

for cancer symptoms,[19] supporting the transferability of our findings. Furthermore, our finding that those who reported good health tended to normalise nonspecific, episodic and non-progressive symptoms might have implications for improving earlier detection of other cancers where patients describe good health in the early stages, and for patient-clinician communication more generally.

Conclusions

Even though lung cancer patients are more likely to attend their GP with potential symptoms in the year before diagnosis than healthy controls, our findings indicate that many non-specific symptoms are not presented within these consultations. The use of non-disease related symptom labels in combination with some closed questioning appears to improve symptom elicitation.

Eliciting and investigating normalised symptoms – to uncover the invisible part of the illness iceberg,[16-17] whilst not feasible for all patients attending primary care, would be possible for those identified as at increased lung cancer risk.[31]

Ethical approval: NHS ethical approval was gained from Southampton South Central Research Ethics Committee (05/Q1702/46).

Authorship: All authors have commented on the first and final draft of the paper, and contributed to interpretation of the data. LB designed the study, conducted interviews, provided the discourse analytic expertise that informed data analysis, analysed data, and produced all drafts. CP also commented on the penultimate draft of the paper and edited the final draft. GL contributed to coding of the interview transcripts. AB also contributed to data collection. LB is the guarantor for the study.

Access to data: All authors had access to the data and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interest declaration: "All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: LB had support from Research Councils UK for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work."

Contributions: Liz Roffe conducted some interviews. The structured section of the interview was based upon an interview schedule developed by Corner, Hopkinson, Fitzsimmons et al. (2005).

Data Sharing: Research participants have not given informed consent for data sharing; a complete qualitative data set cannot be anonymised adequately.

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Box 1

Transcription Notation (Simplified and adapted version of Jeffersonian transcribing conventions)

- The speaker is identified by a participant identifier (P1-P28) followed by a colon. The participant's partner is indicated by a P following the participant identifier e.g.:

  P24P: No I don't agree

- Round brackets indicate that the material in the brackets is either inaudible, e.g.:

  M: I ( ) that

Or there is doubt about its accuracy, e.g.:

  M: I (couldn't tell you) that

- A micropause (a noticeable pause of less than 0.2 seconds) is indicated by a dot enclosed in brackets:

  (.)

- Non-verbal activities and noticeable pauses of 0.2 seconds or more are indicated within double brackets:

  M: Yes ((laughter)) but ((pause)) I don't know

- Square brackets indicate that material has been removed, usually to protect the participant's identity, e.g.:

  [ ] or [town]

- Three consecutive dots indicates that a section of transcript has been removed:

  M: He ran up the hill…to the house at the top

- Square brackets between adjacent lines of speech mark the start and end of overlapping talk

  [ ]

Table 1	
Patient characteristics (n=20)	
Sex (male/female)	13/7
Age – years (median; range)	71.5; 41-86
40-49	1
50-59	1
60-69	6
70-79	10
>=80	2
Diagnosis	
Incidental	8
Symptomatic	12
Smoking status	
Current smoker	4
Ceased in the last 3 months	4
Former smoker (ceased >3 months ago)	11
Never smoker	1
Comorbidities:	
Symptomatic COPD (spirometry +ve or clinical diagnosis)	8
Primary/Secondary Care COPD diagnosis (primary care diagnosis preceding 2ndry care LC investigation/diagnosis during secondary care LC investigation)	3/5
Asthma	5
Ischaemic Heart Disease	1
Congestive cardiac failure	1
Other cardiac Problems	2
Socioeconomic status (Index of Multiple Deprivation)**:**	
Most deprived 50%	8
Least deprived 50%	12

Table 2: Accounts of general health

	Feeling well despite symptoms	
P7	LR: P7: P7P: P7:	But you have had these headaches. Um. Would you say you've been feeling generally unwell? Not really I don't know if you're feeling unwell No. Just odd now and again.
P10	P10:	I mean I've been quite healthy (.) I've got high blood pressure I mean I've had that ooh [>20 years]... so that's all fairly long going you know but I haven't had any actual illnesses or anything
P11	P11:	I didn't feel anything was wrong inside. I mean I had no inkling at all. Um. If I had had that x-ray, but I wouldn't have known because I (.) there was (.) I felt quite well really, it was only just you know this operation on my neck
P16	P16:	When I had the cough you know she said they'd picked up the shadow...I probably sat there for a few seconds you know trying to take it in but that wasn't, when she said that I didn't get the feeling then that there was something wrong (LR: No) because as far as I knew I hadn't got anything wrong with me, but it's so there you are.
P25	P25:	I was ill a lot last year but when I was taken into hospital and the antibiotics and the treatment I had and the months rest I had when I came home where I wasn't going to work (since then I've cut my hours down) I feel so well. But I honestly was not expecting anything like that to be said to me, because I feel so much better than I did last year… In fact I feel better now at the moment than I have done for a long time...you see once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now. So at the moment, I feel so much better that I think it's not making any sense to me.
	Exceptions to feeling well despite symptoms – declining health	
P17	P17:	About a year ago. "What's that? What's going wrong with me" you know and I was going like that. Everything goes tonta... feels as though I can't breathe you know and then I'd just (indicates short breaths) only for a second, and then it's gone and then I'd go back to breathing and everything like that, ... And that was about a year ago, that's when I noticed "[ ], there's something wrong with you".
P19:	LB: P19:	How would you describe how you feel now? Not perfect. No. I mean I'm tired now. This made me tired! That's shows you how and it wouldn't normally do that!
P20:	P20:	And it was afterwards I was thinking I shall be able to get back on me feet now but instead I seem to be going on a slow decline. And I started to lose weight and like I said, things started tasting funny and all this, and I'm saying "Ok". And then I'd have a cold and this cough that wouldn't go away and to be honest I used to be coughing nearly all the time and it was like having a cold 24 hours a day, seven days a week. I'd start to get really tired and as I say, I was quite busy on Tuesday and I was throwing out rubbish... and then I cleaned all me windows. And yesterday, I felt like I'd been run over by a ten ton truck! And I thought 'well this is not me' It's just not me...maybe it's mental, you know, your own brain saying 'your body's not very well, just slow down'
P26	P26P: P26: P26P: P26:	This last year she's deteriorated in many things. Well I think you can understand it though. That's geriatrics for you isn't it? No it isn't you can understand it, when you've had a cough for this long. I mean it really takes it out of you, it really does. You try explaining that to the doctor!

Table 3: Patient reported symptoms and triggers to diagnosis

Participant	**Triggers to diagnosis**	**Symptoms of concern/disease** (Elicited by open questions except where indicated)	**Symptoms as normal processes** (Elicited by closed questions except where indicated)
Symptomatic Diagnoses			
06	Severe cough > 3 weeks	Severe productive cough (3-4 times a year of 2 days duration, for 5 years.)	Increase in breathlessness, Fatigue
08	Weight loss	weight loss	[1]Weight loss – some weight now regained **(open question)**
12	Persistent cough; haemoptysis	Persistent, tickly, non-productive, mild cough; haemoptysis	Aches and discomfort: Stiff neck and left shoulders; weight loss; some discomfort with coughing as time went on
016	Cough; fatigue; feeling unwell; appetite loss; weight loss.	Appetite loss; weight loss - returned to normal; dry cough; feeling unwell	Increase in breathlessness; a feeling (not pain) "that something is going on' in the chest"; fingers go numb.
018	Chest infection; haemoptysis	Repeated cough; chest infections; regular sneezing and flu like symptoms; sore throat; fatigue; Sore testicles; flushing across stomach; ache across back	Increase in breathlessness; pain in centre of chest; occasional coughing with chest infection
023	Weight loss; anaemia	Flu and a scratchy dry cough; night sweats; weight loss; anaemia; tiredness; sensitive gums; soft hair; taste change **(closed question)**	Twinges in fingers and hands
024	Haemoptysis; Dyspnea	Haemoptysis; night sweats	Cough; breathlessness and wheezing.
025	Dyspnea	Pains in legs and joints; fatigue, breathlessness	Chest pain recently when lying down.
027	Dyspnea	Breathlessness on exertion	Occasional hot shooting pain in chest

Exceptions to the normalisation of symptoms not presented to GPs/elicited by closed questions: Decline narratives (D) and Quest for Diagnosis narratives (Q)			
017 **(D)**	Chest/abdominal pain	Aching pain from indigestion; cough; pain across shoulders; aches; having less energy; breathlessness on resting/panic attacks **Elicited by closed questions:** breathlessness on walking and when lying down	
019 **(D)**	Anaemia	Sickness if over eat; bleeding in throat and vomiting large amounts of blood (now stopped). **Elicited by closed questions**: Pain in stomach; loss of appetite; tiredness; increase in breathlessness; pain in chest when breathing in.	
020 **(D and Q)**	Persistent cough	Weight loss; fatigue; taste change; hot and cold sweats; reduction in appetite **(closed question)**	breathlessness on physical activity; weight loss - some weight now regained **(open question)**
026 **(D and Q)**	Persistent cough; recurrent chest infections for the last 10 years.	Regular chest infections and productive coughs; recent weight loss; cough triggered by eating, talking and cold air; dullish ache in back; coughing up occasional flecks of blood; fatigue and energy loss; night sweats – started at menopause but now every night **(closed question)**	

Incidental Diagnoses			
	Triggers to diagnosis	**Symptoms of concern/disease** (Elicited by open questions)	**Symptoms as normal processes** (Elicited by closed questions)
03	CXR following traumatic injury	Gradually increasing breathlessness not noticed until diagnosis.	Weight loss
07	Routine CXR on hospital admission		Fatigue
010	Routine CXR on hospital admission		Change in bowel movements, fatigue
011	CXR Investigation of increased		Breathlessness; aches and pain back of left shoulder

	heart rate following surgery		under arm and side of chest; fatigue
021	CXR investigation of weight loss and anaemia detected by health screen	Anaemia	Weight loss
022	CXR following traumatic injury		Cough; taste change; bowel changes
028	Imaging of kidney to investigate haematuria	Chest infection following investigation for LC	Breathlessness

[1]Occasionally participants would provide a symptom of concern/disease account when describing previous help-seeking, but would then reinterpret and normalise the symptom if it had improved since seeking help.

Table 4: Comparison of 'Symptoms of Concern' and 'Symptoms as Normal Processes' accounts

	Symptoms of Concern/Disease accounts	Symptoms as Normal Processes accounts
P6	LR: ...how [do] you think it all sort of started? P6: ... we went merrily on our holiday, and the cough just got worse and worse and worse. Coughing 24 hours a day the whole of the five days we were away...I went to see a doctor [who prescribed antibiotics] ...the antibiotics didn't touch it at all, so when we came back, I went to see one of my own doctors and he said 'you've probably got a chest infection. I'll give you some more antibiotics'...'if at the end of seven days it hasn't gone, then I think you'd better go and get an x-ray'.	LR: OK. So cough, we've done. Breathlessness? P6: …That [the pacemaker] cured it...so at the moment I'm just left with the cough or whatever... LR: So the only times you get breathless really are then when you're coughing? P6: Yeah. LR: Do you notice (.) is there any other time now P6: Occasionally I get breathless walking up hill, but that's to be expected. P6P: And you did a bit Friday which was stress I think. P6: Yeah, Friday…It does occasionally happen when I'm sitting down ... Up to recently I've been playing golf twice a week, so there can't be an awful lot wrong with me, but I do get occasionally short of breath…Just suddenly start breathing rather rapidly
P12	LB: Do you want to just tell me how you came to be in Mr [ ] clinic and what were the events that [P12: yes. I had a particularly persistent cough that wouldn't go away...although it was literally just a sort of a clearing the throat, that sort of thing... [then] I woke in the middle of the night with a cough, my mouth filled with what I thought was catarrh, went to the basin, spat it out (.) blood bright red and dark red. And it bled for about 10 or 15 minutes...and it hasn't bled since... Anyway, Monday ... went to see GP... immediately gave me the ticket to go to the walk in x-ray [ ].	LB: Have you lost any weight at all? P12: A bit, mm. I would say less than half a stone P12P: We have a very active cruise, we do a lot of walking and sightseeing... P12: And then you know, we go to [UK holiday destination] most years. And we walk a tremendous amount. And I swim a lot there, don't I? So that's a very active holiday.

P16	P16**:** I developed a cough and also that I didn't feel very well and I'd also lost some weight. I went to the doctors ... [s/he] sent me for a blood test and an x-ray. And several days later [s/he] rang and said I want to see you and by this time I'd got my appetite back and my weight had come back up again...	P16 : I think perhaps if it had just been a cough, perhaps I wouldn't have bothered … P16P: … after you were feeling better, you'd put weight back on and you'd still got this funny cough, I think you could have gone on for months with that funny cough [ ]... P16: LR: have you experienced any breathlessness at all? ((pause)) Or sort of thing like you [P16: I play golf and parts of the course are a bit steep and I must admit I get a bit puffed going up there but yeah it's not serious I just got to take it easy… as you get older so you can't do the things you did when you were a bit younger so ...quite often you put things down to change of your age and lifestyle and it wasn't that significant...I really wouldn't say I get breathless, I mean you [participant's wife] couldn't keep up with me.
P23	P23: and then we got to Christmas, and we were partying etc and to be quite honest, I should have put on more weight than I did. So I started to think 'well what's going on?' About [ ] months ago I had a colonoscopy and had a few polyps removed etc...I started to get night sweats, totally different from hot flushes...so I thought 'oooh this is a bit odd'.	LB: Have you suffered from any backache or shoulder ache? P23: No. LB: Anything that you thought might be something else wrong? P23: I've had perhaps the odd twinge [in fingers] that I would put down to arthritis while doing the garden or something but – this is the annoying fact, I am quite healthy; well I think I'm quite healthy, and so no I wouldn't say I've had aches and pains.
P24	P24: I started coughing up blood and I was already at Dr [ ]s clinic and when I told [her] I was coughing up blood, s/he referred me to the chest clinic which is next to Oncology, so that made me feel a bit suspicious... By that time I was admitted to hospital because I was coughing up what I thought was a lot of blood, and I had a lot of problem breathing... Dr [ ] came over to see ...and	LB:...when you were having breathing problems, did you ever have any wheezing with it? P24: Oh I do wheeze a bit in bed now. It's just you get used to the noises that your chest makes don't you really? I just think 'oh shut up'. I mean I do sleep very, very well unless I'm depressed...Sometimes just when I lie down I'll wheeze a bit and that's

	he changed my inhalers and took me off beta blockers and transformed my life!	obviously changing from upright position to lying down but and not to any extent.
	Incidental Diagnosis	
P3		LR: Er, so have you had any weight loss at all? P3: Yes. The lady [ ] that dances with me, she's been making off for months now that I'm losing weight. LR: Yeah? P3: Yeah. So I expect to lose weight in the summer months because you're more active over the allotments. .. plus the days are longer so you spend longer away from home so you don't eat so much, but I used to be [ ] stone, but when she weighed me yesterday with my clothes on, she said I was [1.5 stones less] LR: ...you think that's just over the summer or ? P3: I reckon that's over the last two years. LR: Yeah? RES: Yeah. I reckon about the last two years, because I always said [1.5 stone heavier than current weight] stones is too heavy for me. And then people would say it's a beer gut
P28		LB: Have you had any other types of cough that have lasted more than three weeks? P28: No. LB: No. Would you say you had a smokers cough... P28: No I wouldn't actually! Would you? No. P28P: Not really. P28: No, never hacking coughs or anything. P28P: not a dry cough like ( ) LB: Sorry you didn't have a dry cough? P28P: No. No. ((pause)) No more than a lot of people have got you know. In the day and you know

APPENDIX 1 (Web Only File)

Interview topic guide: IPCARD Chest Symptoms Study

I. +II. **Unstructured and Semi-structured interview**:

- Record patient's health and illness experiences
- Focussing on the period leading up to their referral for LC Investigation and all experiences of health and illness during the last 2 years, explore:
    - participants' interpretations of and explanations for symptoms
    - Impact of ill health/symptoms

III. **Structured interview**:

- Explore list of specific symptom presentations and health changes (attached).

IV. **Further semi-structured interview questions**: Help-seeking behaviour and use of health services (These questions are to follow accounts of symptoms elicited in sections I, II and III):

- What did you do about [symptom/health change]?
    - any health care, treatments, information or advice received
    - reasons for seeking or not seeking medical help.

Introduction

"Thank you for agreeing to this interview. It should take about 60-90 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. I would like to build up a detailed picture of your experiences of health and illness. I am interested in anything that you noticed about your health even if you thought it was minor or not connected to your recent visit to [hospital/clinic]. I will then be asking you to talk in more detail about your experiences of health from when you first noticed a change in your health up to the time when you were referred to the [clinic] and about all aspects of your health in the last 2 years."

Section I

The topic guide provides a number of questions which the interviewer might use to initiate discussion about a particular topic. However, the interviewer might revise the questions, or alter their order, in light of the interviewee's response to earlier questions.

Part 1: Exploration of health and illness

Purpose: To explore the participant's experiences of health and illness over their lifetime including any symptoms/problems/changes in health that they have noticed in the last 2 years.

- Please tell me about your health and any illnesses that you have experienced
- How has your health changed (are there any changes that you noticed)?

- [1] Could you tell me how you came to be in Dr [ ]'s clinic/ came to be seeing Dr X

Section II

- When did you first notice something was wrong, or a there had been a change in your health?

- Have you experienced any other changes in your health during the last 2 years?

Prompts: use following prompts to aid recall of dates:

- What year was this?
- What month was this?
- What season was this?
- What it close to an event in the year, such as Christmas or Easter?
- Was this at the same time as any other event in your life?
- Was this at the same time as any family/ social event?
- What else was going on in your life at the time?

- Has there been anything else that you have visited your doctor about during the last 2 years?

- Has there been anything else at all relating to your health that you have noticed during the last 2 years even if minor?

Probes: for all illnesses explore:

- Severity
- Duration
- Change over time/how/when (use same probes as for Part 1)
- Impact (social/lifestyle/ family/psychological/ what did the participant think about their symptom)
- Participant's explanations for illness/associated with?/causes

[1]This question was asked first in earlier interviews but was either omitted, or asked after questions about general health and health changes, in later interviews.

Section III

"I have a list of things that some people notice before they are told that they have a chest problem. I am going to ask you if you experienced each of these things. I will then ask you about each health change that you experienced in more detail."

01. Cough	YES NO (see structured guide - cough)
02. Coughing up blood	YES NO (see structured guide - haemoptysis)
03. Breathlessness or panic attacks	YES NO (see structured guide - breathlessness)
04. Changes in eating, appetite, taste or weight	YES NO (see structured guide – eating/weight)
05. Pain	YES NO (see structured guide - pain)
06. Discomfort or strange sensations	YES NO (see structured guide – discomfort)
07. Aches or pain in chest, back, shoulders or joints	

(if not mentioned in response to 5 and 6)	YES NO (see structured guide – specific aches)
08. Skin changes	YES NO (see structured guide – skin)
09. Lots of infections	YES NO (see structured guide - infections)
10. Tiredness	YES NO (see structured guide – tiredness)
11. Feeling generally unwell	YES NO (see structured guide – unwell)
12. Hot or cold sweats	YES NO (see structured guide – sweats)
13. Voice changes or hoarseness	YES NO (see structured guide – voice changes)
14. Other (DESCRIBE) ¬¬¬¬¬¬¬¬¬¬¬¬_____	YES NO (see generic guide – other)

Information: Turn to relevant problems identified by participant. Only sections relating to the problems/changes identified by the should be completed

Section IV

Semi-structured interview: Help-seeking behaviour and use of health services (These questions follow accounts of symptoms elicited in sections I, II and III, and do not necessarily come at the end of the interview):

- What did you do about the symptom?

  Prompts
  - Confided in close family member/friend– who did you talk to first?/who else did you speak to
  - Found information (Read health related article in magazine or book, Consulted a medical dictionary/encyclopaedia, watched a health related TV/Video, Undertook an internet search),
  - Sought advice (e.g .Sought advice from NHS direct/ walk-in centre, Spoke to practice nurse/other health professional, Spoke to your GP/made appointment to see GP)
  - Treatment (other than GP advised) Took over the counter medication (self-prescribed or pharmacist consulted), Took complementary medicine/ therapy

- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?

  - If further help was sought - what made you seek this help?

- Please describe any changes in the way you manage or live with the [symptom] since x

Relationship with GP and barriers to use of primary care services

- Have there been any circumstances in which you were unsure about whether to seek help from your GP?
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- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?

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- Have there been any other circumstances in which attending your GP would have been difficult?
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COREQ guidelines table

Domain 1: Research team and reflexivity			**Comment**
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview?	LB
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	BA PhD
3.	Occupation	What was their occupation at the time of the study?	Research Fellow
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	>15 years experience of conducting and leading qualitative research.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No – participants were recruited following contact with a clinician
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Participants were made aware of reasons for doing the research – to better understand their experiences of health and symptoms. And develop a symptom questionnaire
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research*	Research interests were reported

COREQ guidelines table

		topic	
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Discourse analysis, thematic analysis and Constant comparative method
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Two sampling methods were used, consecutive sampling of eligible patients attending surgeons and opportunistic sampling of patients by clinician letter.
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Consecutively sampled participants were approached face to face. Participants contacted by letter who expressed interest in the study were then approached by phone.
12.	Sample size	How many participants were in the study?	20
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	3
Setting			

COREQ guidelines table

14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Participants own homes (18). Hospital setting (2).
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	In 3 cases a partner (2) or carer (1) was present. If a partner was present this is indicated in the excerpts presented.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Route to diagnosis (symptomatic, incidental), age, comorbidities.
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The Interview guide was pilot tested.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recording
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made after the interview.
21.	Duration	What was the duration of the interviews or focus group?	1 - 1.5 hours.
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. Participants were awaiting lung resection and clinicians did not want participants to be contacted in the months following this procedure.
Domain 3: analysis and			

COREQ guidelines table

findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2. LB and GL
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No but a description of main themes was provided
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Identified from the data
27.	Software	What software, if applicable, was used to manage the data?	MS Word. Discourse analysis was used, so coded data was kept in context within the interview transcript.
28.	Participant checking	Did participants provide feedback on the findings?	No – for the reasons given above regarding the return of transcripts
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Yes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes – exceptions are discussed

BMJ open

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – could GP elicitation of normalised symptoms reduce delay in diagnosis?: Cross sectional interview study

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Complete List of Authors:	Brindle, Lucy; University of Southampton, Faculty of Health Sciences Pope, Catherine; University of Southampton, Health Sciences Corner, Jessica; University of Southampton, Health Sciences Leydon, Geraldine; University of Southampton, Faculty of Medicine Banerjee, Anindo; Southampton General Hospital, Respiratory Medicine
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Patient-centred medicine, General practice / Family practice, Communication, Respiratory medicine, Oncology
Keywords:	Symptoms, Early cancer diagnosis, Terminology as topic, Help seeking, Lung cancer, Discourse Analysis

COREQ guidelines table

Domain 1: Research team and reflexivity			**Comment**
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview?	LB
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	BA PhD
3.	Occupation	What was their occupation at the time of the study?	Research Fellow
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	>15 years experience of conducting and leading qualitative research.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No – participants were recruited following contact with a clinician
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Participants were made aware of reasons for doing the research – to better understand their experiences of health and symptoms. And develop a symptom questionnaire
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research*	Research interests were reported

COREQ guidelines table

		topic	
Domain 2: study design			
Theoretical framework			
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COREQ guidelines table

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16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Route to diagnosis (symptomatic, incidental), age, comorbidities.
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COREQ guidelines table

findings			
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32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes – exceptions are discussed

APPENDIX 1 (Web Only File)

Interview topic guide: IPCARD Symptoms Study

I. +II. **Unstructured and Semi-structured interview**:

- Record patient's health and illness experiences
- Focussing on the period leading up to their referral for LC Investigation and all experiences of health and illness during the last 2 years, explore:
  - participants' interpretations of and explanations for symptoms
  - Impact of ill health/symptoms

III. **Structured interview**:

- Explore list of specific symptom presentations and health changes (attached).

IV. **Further semi-structured interview questions**: Help-seeking behaviour and use of health services (These questions are to follow accounts of symptoms elicited in sections I, II and III):

- What did you do about [symptom/health change]?
  - any health care, treatments, information or advice received
  - reasons for seeking or not seeking medical help.

Introduction

"Thank you for agreeing to this interview. It should take about 60-90 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. I would like to build up a detailed picture of your experiences of health and illness. I am interested in anything that you noticed about your health even if you thought it was minor or not connected to your recent visit to [hospital/clinic]. I will then be asking you to talk in more detail about your experiences of health from when you first noticed a change in your health up to the time when you were referred to the [clinic] and about all aspects of your health in the last 2 years."

Section I

The topic guide provides a number of questions which the interviewer might use to initiate discussion about a particular topic. However, the interviewer might revise the questions, or alter their order, in light of the interviewee's response to earlier questions.

Part 1: Exploration of health and illness

Purpose: To explore the participant's experiences of health and illness over their lifetime including any symptoms/problems/changes in health that they have noticed in the last 2 years.

- Could you tell me how you came to be in Dr [ ]'s clinic/ came to be seeing Dr X

- Please tell me about your health and any illnesses that you have experienced
- How has your health changed (are there any changes that you noticed)?

Section II

- When did you first notice something was wrong, or a there had been a change in your health?

- Have you experienced any other changes in your health during the last 2 years?

Prompts: use following prompts to aid recall of dates:

- What year was this?
- What month was this?
- What season was this?
- What it close to an event in the year, such as Christmas or Easter?
- Was this at the same time as any other event in your life?
- Was this at the same time as any family/ social event?
- What else was going on in your life at the time?

- Has there been anything else that you have visited your doctor about during the last 2 years?

- Has there been anything else at all relating to your health that you have noticed during the last 2 years even if minor?

Probes: for all illnesses explore:

- Severity
- Duration
- Change over time/how/when (use same probes as for Part 1)
- Impact (social/lifestyle/ family/psychological/ what did the participant think about their symptom)
- Participant's explanations for illness/associated with?/causes

Section III

"I have a list of things that some people notice before they are told that they have a chest problem. I am going to ask you if you experienced each of these things. I will then ask you about each health change that you experienced in more detail."

01. Cough	YES NO (see structured guide - cough)
02. Coughing up blood	YES NO (see structured guide - haemoptysis)
03. Breathlessness or panic attacks	YES NO (see structured guide - breathlessness)
04. Changes in eating, appetite, taste or weight	YES NO (see structured guide – eating/weight)
05. Pain	YES NO (see structured guide - pain)
06. Discomfort or strange sensations	YES NO (see structured guide – discomfort)
07. Aches or pain in chest, back, shoulders or joints (if not mentioned in response to 5 and 6)	YES NO (see structured guide – specific aches)
08. Skin changes	YES NO (see structured guide – skin)

09. Lots of infections	YES NO (see structured guide - infections)
10. Tiredness	YES NO (see structured guide – tiredness)
11. Feeling generally unwell	YES NO (see structured guide – unwell)
12. Hot or cold sweats	YES NO (see structured guide – sweats)
13. Voice changes or hoarseness	YES NO (see structured guide – voice changes)
14. Other (DESCRIBE) _____	YES NO (see generic guide – other)

Information: Turn to relevant problems identified by participant. Only sections relating to the problems/changes identified by the should be completed

Section IV

Semi-structured interview: Help-seeking behaviour and use of health services (These questions follow accounts of symptoms elicited in sections I, II and III, and do not necessarily come at the end of the interview):

- What did you do about the symptom?

  Prompts
  - Confided in close family member/friend– who did you talk to first?/who else did you speak to
  - Found information (Read health related article in magazine or book, Consulted a medical dictionary/encyclopaedia, watched a health related TV/Video, Undertook an internet search),
  - Sought advice (e.g .Sought advice from NHS direct/ walk-in centre, Spoke to practice nurse/other health professional, Spoke to your GP/made appointment to see GP)
  - Treatment (other than GP advised) Took over the counter medication (self-prescribed or pharmacist consulted), Took complementary medicine/ therapy

- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?

  - If further help was sought - what made you seek this help?

- Please describe any changes in the way you manage or live with the [symptom] since x

Relationship with GP and barriers to use of primary care services

- Have there been any circumstances in which you were unsure about whether to seek help from your GP?
- What things have made you decide against visiting your GP/practice nurse?
- Have there been any other circumstances in which attending your GP would have been difficult?
    - What were these?

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – could GP elicitation of normalised symptoms reduce delay in diagnosis?: Cross sectional interview study

Lucy Brindle, Catherine Pope, Jessica Corner, Geraldine Leydon, Anindo Banerjee

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Faculty of Health Sciences, University of Southampton, Building 67, University Road, Southampton, SO17 1BJ. Catherine Pope, Professor of Medical Sociology.
Faculty of Health Sciences, University of Southampton, Building 67, University Road, Southampton, SO17 1BJ. Jessica Corner, Head of Faculty of Health Sciences.
Department of Primary Medical Care, University of Southampton, Aldermoor Health Centre, Aldermoor Close, Southampton, SO16 5ST. Geraldine Leydon, Principal Research Fellow.
Southampton General Hospital, Coxford Road, Southampton, SO16 6YD, Anindo Banerjee, Lead Chest Physician.

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Words

Abstract: 247

Article: 4030

ABSTRACT

Objectives: To investigate why symptoms indicative of early-stage lung cancer (LC) were not presented to GPs and how early symptoms might be better elicited within primary care.

Design, setting and participants: A qualitative cross-sectional interview study about symptoms and help-seeking in 20 patients from 3 south England counties, awaiting resection of LC (suspected or histologically confirmed). Analysis drew on principles of discourse analysis and constant comparison to identify processes involved in interpretation and communication about symptoms, and explain non-presentation.

Results: Most participants experienced health changes possibly indicative of LC which had not been presented during GP consultations. Symptoms that were episodic, or potentially caused by ageing or lifestyle, were frequently not presented to GPs. In interviews, open questions about health changes/symptoms in general did not elicit these symptoms; they only emerged in response to closed questions detailing specific changes in health. Questions using disease-related labels, e.g. pain or breathlessness, were less likely to elicit symptoms than questions that used non-disease terminology, such as aches, discomfort or 'getting out of breath'. Most participants described themselves as feeling well and were reluctant to associate potentially explained, non-specific or episodic symptoms with LC, even after diagnosis.

Conclusion: Patients with early LC are unlikely to present symptoms possibly indicative of LC that they associate with normal processes, when attending primary care before diagnosis. Faced with patients at high LC risk, GPs will need to actively elicit potential LC symptoms not presented by the patient. Closed questions using non-disease terminology might better elicit normalised symptoms.

Article Summary

Article Focus:

• Why symptoms potentially indicative of lung cancer are not presented to GPs

• Exploration of how and why some lung cancer symptoms are normalised by lung cancer patients

• Use of discourse analysis to investigate communication factors involved in the non-presentation and normalisation of symptoms, and how symptoms might be better elicited in primary care.

Key Messages:

• Non-specific, episodic and non-progressive symptoms were normalised by patients with operable lung cancer who felt well.

• Symptoms normalised by patients with operable lung cancer were not presented to GPs during consultations before diagnosis. GP elicitation of normalised symptoms would lead to better informed referral decisions.

• Closed questions using non-disease terminology were more effective at eliciting symptoms normalised by patients.

Strengths and limitations of this study:

• This study used interviews to identify interactional factors which influenced symptom presentation within a research study, and it may be that symptom presentation occurs differently within everyday GP consultations; nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms were elicited by GPs, referral decisions would be better informed.

• Most lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is unrepresentative of this patient population. However, research involving operable patients enables the investigation of communication about currently experienced early symptoms, rather than relying on retrospective accounts of early symptoms provided by patients with later stage disease. Furthermore, the reasons these patients gave for non-presentation of symptoms concur with other studies of help-seeking for cancer symptoms, supporting the transferability of our findings.

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – can we use closed questions to reduce delay in diagnosis?

INTRODUCTION

Lung cancer is diagnosed too late in the UK and survival rates are lower than in most other Western European countries;[1-4] 86% are diagnosed at a stage when curative treatment is not possible and less than 25% survive one year following diagnosis.[5-6] Lung cancer kills approximately 30,000 people a year in the UK so even modest improvements in the time to diagnosis could dramatically improve health outcomes.[7] Despite successful national cancer screening programmes, most tumours are diagnosed following presentation with symptoms [8] so it is vital to identify patients with significant symptoms early. The UK National Institute of Clinical Excellence (NICE) recommends urgent chest x-ray for patients presenting with any 1 of 10 unexplained or persistent symptoms [9] but General Practitioners (GPs) have to balance risks associated with unnecessary x-ray against possible late diagnosis, and make judgements about the relative validity of alternative explanations for symptoms. This is further complicated by the fact that lung cancer is often preceded by chronic respiratory disease [10] making detection difficult.

Recent evidence [11] indicates that most newly diagnosed lung cancer patients do not recognise all of their cancer symptoms. Isolated single symptoms have low predictive value for lung cancer [12] but patients seldom present multiple symptoms to GPs. [13-14] Interview research has shown that lung cancer patients normalise symptoms and delay seeking help [15-16] and in the general population many symptoms are never presented to GPs [17-18]. However, patients diagnosed with lung cancer have been shown to report symptoms to their GP more frequently than controls 6-24 months before diagnosis [12] but it seems that a combination of cultural and communication processes combine, sometimes fatally, to prevent help-seeking [13,19-20] for the full range of symptoms experienced by patients at increased risk of lung cancer (LC).[11;21]

Previous studies have identified symptom normalisation - the association of symptoms with normal processes - as an important factor in delayed LC diagnosis. However, research has not yet addressed the reasons for normalisation of LC symptoms, or investigated how normalised symptoms that are not presented to health care professionals might be better elicited. Structured interviewing has been used in primary care to improve psychiatric diagnosis but it is not clear if it could help to elicit early lung cancer symptoms. Our study examined how symptoms were normalised by patients and compared structured and unstructured elicitation of symptoms. By using a discourse analytic approach we were able to suggest ways that health care professionals might better elicit normalised symptoms, and investigate why they are not presented to GPs.

METHODS

Design

Previous studies have focused on inoperable lung cancer, but we were interested in how patients communicated early symptoms so we conducted interviews with patients awaiting surgical resection of lung cancer (suspected or histologically confirmed). Previous interview studies with lung cancer patients have relied upon retrospective accounts of early symptoms experienced before diagnosis. In contrast, we were interested in how patients communicate about, and negotiate the relevance of current early symptoms. In retrospective accounts patients might normalise symptoms to justify delays in seeking help so we also investigated the normalisation of symptoms that started following LC investigation. We used unstructured

followed by structured interviewing to find out if this could elicit symptoms more effectively than open questions about changes in health, which have been found not to elicit all lung cancer symptoms (see Smith et al, 2009).

Participants

The interview sample for this study was drawn from 28 adult patients with a diagnosis of, or suspected of having, operable lung cancer (probable: >90% or histologically confirmed) recruited to a questionnaire development study. Patients were either approached by the researcher following their first consultation with participating thoracic surgeons at a South England Trust, or were sent a letter and information sheet by the surgical team. Seventeen out of twenty consecutive patients within 3 recruitment periods (07/2006-10/2007; 02/2008-05/2008; 02/2009-05/2009) approached by a researcher agreed to take part. An opportunistic sample of 11 participants was recruited by letter (within the three recruitment periods). Twenty eight patients in total were recruited and interviewed about their current and recent health and help-seeking behaviour.

This paper reports the analysis of 20 interviews with patients identified as having operable lung cancer at the end of the study period (data from seven interviewees who received a non-malignant diagnosis after the interview were analysed separately and are not reported here. One patient diagnosed with advanced disease was also excluded). Characteristics of these 20 patients are given in Table 1.

[Insert table 1 here]

Interviews

The unstructured (first) section of the interview used open questions to generate narrative accounts of participants' experiences and changes in health status (See Appendix 1 for the interview checklist). Participants were asked to describe anything at all that they had noticed about their health, even if they thought it not relevant to their investigation for lung cancer. The second part of the interview was semi-structured and focused on duration and characteristics of symptoms, and reasons for seeking or not seeking help. The third part of the interview used closed questions to explore symptoms and help-seeking using a list of potential lung cancer symptoms compiled from Cancer Research UK [6] information, NICE [9] guidelines, and a previous interview study with lung cancer patients.[15] Field notes were recorded after the interview. Interviews lasted between 1-2 hours, took place in the participants' home (18/20) or a hospital setting (2), some involved the participant's partner (2) or carer (1), all were audio-recorded, transcribed verbatim, checked for accuracy and anonymised. An adapted version of Jefferson's transcription conventions [22] were used (described in Box 1).

[Insert Box 1 here]

Analysis

The first stage of analysis involved an iterative coding process using elements of the constant comparative method to develop themes (initially identified by LB and checked by a second researcher, GL, who independently read a sample of transcripts and verified codes and themes). This iterative process continued until data saturation was achieved. All transcripts were revisited and deviant cases were sought.[23] Thematic analyses identified symptoms not presented to GPs, characteristics of symptoms, and reasons given for non-presentation. Discourse analysis [24-25] which considers language use in context, was used to examine

how health changes were presented in patient-interviewer interactions; The discourse analysis was informed by ethnomethodology, an approach which focuses on how social action is accomplished within accounts. This enabled us to look at the implications of talk's sequential and micro-organisation for symptom presentation, and showed how normalised symptoms might be better elicited. We combined the thematic analysis and discourse analyses to explain normalisation and non-presentation of symptoms. The results section presents key findings about symptom presentation, including reasons for non-presentation, and the implications of question type and terminology.

RESULTS

Most participants described themselves as having good health; only four presented accounts of declining health preceding diagnosis, characterised by multiple symptoms and feeling unwell (see table 2).

[Insert table 2 here]

Symptomatic diagnosis occurred for 13 participants and 7 participants claimed not to have any lung cancer symptoms, describing incidental diagnoses made during the investigation of unrelated health problems, traumatic injury or screening (Table 3).

[Insert link to table 3 here]

15 participants described further changes in health possibly indicative of lung cancer (according to NICE Guidelines/CRUK symptom list) that were not thought a reason for concern and had not been presented to their GP during LC investigations, despite the presentation of the trigger symptom or use of primary care services for other reasons. They did not associate these un-investigated health changes with LC and they were elicited by closed questions about specific symptoms, but not by open questions about symptoms or changes in health (Table 3).

Two types of symptom accounts were identified: 'symptoms as normal processes' and 'symptoms of disease/concern'. Examples of these accounts and their elicitation are provided in table 4. Participants reported un-investigated symptoms, and produced normalised accounts of these, irrespective of patient socio-demographic characteristics, smoking status or route to diagnosis; there were no discernible differences in relation to table 1 characteristics. Exceptions appeared to arise only in the case of participants providing narratives of declining health. The association of symptom normalisation with narratives of good health is highlighted in table 3; those providing narratives of declining health tended not to normalise symptoms. Participants with incidental diagnoses also provided normalised accounts of un-investigated potential LC symptoms, but were less likely to produce symptom of concern accounts than those with symptomatic diagnoses (see table 3).

The first results section – 'Reasons for non-presentation' – describes the main features of 'symptoms as normal processes' accounts (episodic/non-progressive symptoms or ageing and lifestyle related explanations). 'Symptoms of concern' accounts are described in order to demonstrate exceptions to the normalisation of symptoms. The second results section

examines the use of closed questions to elicit (normalised) accounts of symptoms not elicited by open questions or presented to GPs, and the implications of symptom terminology.

Reasons for non-presentation

Normal processes such as lifestyle and ageing were commonly used as explanations for not presenting symptoms to GPs. For example, breathlessness was frequently associated with being unfit, getting older, over-activity or seasonal changes rather than lung cancer:

> P18: I just put it down to me being too unfit for that particular run or circuit or down to age…I didn't associate that with anything other than me being old or unfit, one of those.

In these 'symptoms as normal process' accounts patients portrayed symptoms as part of everyday life processes and avoided claiming cancer causation:

> LB: ...do you get any discomfort anywhere, do you have any aches or pains?
> P11: No (.) only round me neck but that's just recently it's come on. I don't know whether it's to do with this problem I've got ... I think it's a bit of arthritis there. And (.) you know (.) it's old age really I mean, because we do get these things I know, as you get older, (.) but just as I say this last couple of weeks it's got really really bad.

Some of those who described current 'good health' at odds with their diagnosis, also described episodic ill health, or long term symptoms which had led to lifestyle changes and adaptation. Symptoms like breathlessness or cough might be more severe during a chest infection, but were not commented on if they persisted. Here, P25 did not mention breathlessness on climbing the stairs to her GP:

> P25: It was getting the pains in my hands and my wrists… It was when it started here [in wrists], it started to hinder me with things…but I wasn't going [to the GP] through breathlessness …because that had finished when I got better…You know within the week I was back to being able to breathe again. Apart from when I you know whether you get out of breath carrying the hoover upstairs... [Husband] says "What have you been doing? [ ]?" and I just say "Nothing just those stairs".

The ability to improve did not appear to fit with the expected progressive pattern for a disease such as lung cancer:

> P25: [ ]...once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now... Why don't I feel really, really ill now to understand this? How can you have this and get better and feel better, get ill but then you get better, well how can you do that?

These normalised accounts, by simultaneously presenting alternative non-disease explanations, such as ageing, for health changes, also helped construct the participant as healthy. Exceptions to the use of normalised accounts for un-investigated symptoms were found in four interviews where patients had declining health (consisting of multiple symptoms and feeling unwell); two of these four patients also provided 'quest for diagnosis narratives' in which they had battled, or were still battling, for a diagnosis in the face of clinical ignorance or clinical delay. In the interviews they described most of their health changes in response to open questions (Table 3: Exceptions to the normalisation of symptoms), including symptoms not presented to GPs, and did not normalise these symptoms. Even symptoms presented in response to closed questions were most often not normalised:

> LB: So have you noticed any changes in breathing or breathlessness?

P19: Yes I am definitely more breathless now... I am not normally that breathless!
LB: ...and before that, how would you describe your breathlessness?
P19: Well it's never been really too bad, as long as I've had my inhalers... So it's just recently that I am beginning to get a bit more breathless and I don't think that's associated with the asthma.

Participants who presented themselves as well, normalised non-specific, non-progressive and episodic symptoms.

[Insert table 4 here]

Using closed questions to elicit symptoms not elicited by open questions

Symptoms interpreted as normal by participants tended not to be described in response to open interview questions (Tables 3 & 4) and were not presented to GPs. For example, P22, who had been investigated by his GP for a bowel disorder in the weeks before diagnosis, described an absence of symptoms he associated with lung cancer:

P22: No as I say this was a complete shock to find out that it was on the lung. As I said, we would never have known anything about it if I hadn't fallen off that thing. I suppose it would eventually with finding this I suppose I could have lost weight or gone awful thing one to the doctor "well we'll have to find out what's causing it" but no nothing.

However when asked specifically about long-term cough, he revealed he had experienced a cough for 4-5 months:

P22: Well I've got a cough now. Every now and again I cough and get a little phlegm up.
LB:… And is it something that you ever went to your doctor about?
P22: No.
LB: No.
P22: No I've never had to do that.

Accounts produced in response to closed interview questions about specific symptoms displayed two common structures for symptom reporting: 'Affirmation/Normalisation' and 'Delayed Affirmation/Normalisation'. The symptom referred to by the interviewer might either be affirmed but normalised ('Affirmation/Normalisation') or initially denied and then normalised ('Delayed Affirmation/Normalisation'). When closed questions phrased health changes in ways which did not necessarily indicate disease, the participant was more likely to answer affirmatively, or describe a health change, but then suggest the symptom was normal and not related to lung cancer (Affirmation/Normalisation). In contrast, questions using disease-related terms - e.g. 'pain' - produced an immediate denial or pause (non-response) followed by normalisation (Delayed Affirmation/Normalisation):

LB: ... have you had any chest pain at all that you can describe?
P12: No, not really. I mean as the cough's got shall we say more persistent and sort of shall we say worse yes (.) I can feel it a bit (.) but I mean I can't feel it now... if you look at the x-rays you think 'oh blimey!' but you wouldn't know it was there!

Reformulation of the question, involving a shift from disease to non-disease terminology, could elicit normalised accounts of symptoms – as in these examples where a change in terminology shifting from 'pain' to 'aches' and 'discomfort', and shifting from 'breathlessness' to 'not being able to get your breath' leads to elicitation of the symptoms:

LR: Have you had any pain anywhere?
P16: None at all. No
LR: …have you experienced any sort of aches or general sort of discomfort at all? ...

P16: No, not serious no. Well …sometimes I have a feeling that something's going on, but it's not there all the time, you know

LR: And have you experienced breathlessness? ((pause))
P18: ((intake of breath))
LR: Just feeling like you haven't been able to get your breath quite so easily?
P18: I would go up a couple of flights of stairs quite randomly, I would feel out of breath. I would never never usually be like that, so yes, for a fit guy I would go ooh I'm breathless ...but then you know I shouldn't have really bothered about it at all. But then again I have put on a slight bit of weight haven't I?

In contrast with disease-related terminology, terminology not strongly associated with disease such as 'aches' or 'discomfort' rather than 'pain', produced affirmation and then normalisation (affirmation/normalisation):

LB: And have you had any kind of aches or discomforts anywhere?
P12: Well I have been complaining about a stiff neck haven't I...and also this shoulder…but I mean I can play golf, so it's not that bad!

Similarly the use of terms that imply 'breathing changes' or 'getting out of breath more easily', rather than 'breathlessness', produced an affirmation/normalisation response structure:

LB: ...what about breathing changes, or have you ever noticed at all that you can become more breathless than you would have done say a few years ago when you were doing something?
P11: I do now. This past (.) oh couple of months I suppose. I get more breathless if I (.) if I hurry around too much you know…but normally you know, I don't run around! (LB: no no) If I remember my age... I don't sort of get out of (.) breathless or anything like that, it's only if I'm (.) ... overdo things really.

Even though closed questions using disease-related terminology might elicit previously unmentioned health changes, closed questions using non-disease terminology did so more effectively.

DISCUSSION

Eliciting 'hidden' symptoms

Most of our sample described themselves as feeling well, despite going on to have a diagnosis of operable lung cancer. Patients who felt well had experienced a range of health changes indicative of lung cancer but they did not tell their GPs about many of these, despite making use of primary care services. Instead they framed these symptoms as normal features of lifestyle and ageing processes.

Delay in lung cancer diagnosis in the UK has been blamed upon patients' failure to recognise early symptoms.[26] However, our research indicates that normalised symptoms can be elicited by closed questions. This runs counter to current educational and communication practice which encourages open and expansive questioning. Whereas open questioning is necessary to elicit symptoms perceived as abnormal by the patient, normalised symptoms will remain hidden. Once elicited by closed questions, normalised symptoms are often quickly obscured within accounts which provide every day explanations for health changes. This means that interviewers (or health professionals) have to probe normalised accounts to uncover hidden symptoms.

Questions using disease-related symptom terminology, such as 'chest pain', or 'breathlessness', appeared to have limited potential to elicit potential lung cancer symptoms experienced by those with operable lung cancer. Our analysis suggests that to get at these symptoms we need to ask closed questions without referencing disease-related symptom labels. Again this runs counter to some guidance such as the NICE referral criteria terminology which uses disease-related terms. Furthermore, contextual factors and framing of the patient's presentation are known to influence GPs' diagnostic reasoning;[27] patients who present themselves as well and without declining health might be less likely raise concern and be referred for investigation of potential cancer symptoms.

Recent survey research looking at public awareness of cancer symptoms in the UK, concluded that levels of knowledge are low for many potential cancer symptoms.[28] These findings have informed regional NAEDI (National Awareness and Early Diagnosis Initiatives) [29] materials designed to educate the public about cancer symptoms. It might be argued that participants in our study simply did not recognise the significance of symptoms such as breathlessness. However, participants did not report lack of knowledge as the reason for symptom normalisation and non-presentation. Furthermore, the accounts produced by participants avoided personal claims of lung cancer aetiology for changes in health, even if this was raised as a possibility in the interview. Alternative non-lung cancer explanations for symptoms were provided that had social legitimacy. Our work suggests that lists of symptoms alone are unlikely to prompt patients to reveal multiple non-specific and normalised symptoms, especially when they are asked to give unstructured accounts. Furthermore, our research indicates that lung cancer risk scores provided by symptom based clinical decision support aids (e.g. RATS[30]), are likely to be influenced by how symptoms are elicited within the consultation.

Patient-centred medicine attempts to honour patients' experiences and concerns – presented in their own terms. It has been accompanied by more open consultation styles and a shift away from interactions directed by the health professional. For patients with potential lung cancer this may not be the best way to elicit symptoms. Instead routine medical consultations involving those at increased cancer risk [31] might better be restructured to enable the presentation of health changes which appear normal or unproblematic to the patient. This would require the clinician to be aware of the risk of lung cancer in all patients presenting to their service with symptoms seemingly unrelated to lung cancer. The elicitation of normalised symptoms in patients at increased lung cancer risk might then facilitate GPs' chest x-ray referral decisions.

Strengths and Limitations

This study used interviews to identify interactional factors which influenced symptom presentation within a research study. The systematic and in-depth study of language of the type reported in this article can lead to critical insights about conventions used in conversation that are transferable between settings.[32] However, it may be that symptom presentation occurs differently within everyday GP consultations; closed questions involving non-disease terminology might not be as effective at eliciting normalised symptoms within primary care practice. Further research involving GP consultations will be required to establish how effective these methods of symptom elicitation are within primary care. Nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms that are potentially indicative of LC were elicited by GPs, referral decisions would be better informed.

The participant group were patients with an established or probable lung cancer diagnosis. This may influence symptom presentation in the interview as a LC diagnosis is already suspected. However, the normalisation of symptoms that started after diagnosis within this study suggests that normalisation is not justifying delays in diagnosis; the association of episodic, non-specific symptoms with normal processes appears commonplace for those feeling well, even when lung cancer provides a potential explanation for symptoms.

NICE referrals guidelines for suspected lung cancer are based upon a weak evidence base; therefore, we do not know the likelihood that the symptoms not presented to GPs were caused by LC. However, these guidelines represent the best evidence currently available to inform referral for lung cancer investigation. If these non-specific symptoms experienced by patients at increased lung cancer risk were elicited in primary care, GPs would be better able to operationalize NICE guidelines. A prospective study may eventually determine the utility of these symptoms in the early diagnosis of lung cancer and the efficacy of treatment (including surgery).

The majority of lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is necessarily unrepresentative of the whole population of lung cancer patients. It may be that our participants were more symptomatic in the early stages, or more likely to seek medical help, than those diagnosed with inoperable disease. However, this makes it all the more compelling that these participants still experienced a number of symptoms that they did not report. The reasons these patients with lung cancer give for non-presentation of symptoms concur with other studies of help-seeking for cancer symptoms,[19] supporting the transferability of our findings. Furthermore, our finding that those who reported good health tended to normalise nonspecific, episodic and non-progressive symptoms might have implications for improving earlier detection of other cancers where patients describe good health in the early stages, and for patient-clinician communication more generally.

Conclusions

Even though lung cancer patients are more likely to attend their GP with potential symptoms in the year before diagnosis than healthy controls, our findings indicate that many non-specific symptoms are not presented within these consultations. The use of non-disease related symptom labels in combination with some closed questioning appears to improve symptom elicitation.

Eliciting and investigating normalised symptoms – to uncover the invisible part of the illness iceberg,[16-17] whilst not feasible for all patients attending primary care, would be possible for those identified as at increased lung cancer risk.[31]

Ethical approval: NHS ethical approval was gained from Southampton South Central Research Ethics Committee (05/Q1702/46).

Authorship: All authors have commented on the first and final draft of the paper, and contributed to interpretation of the data. LB was the chief investigator; she had the original idea, designed the study, conducted interviews, analysed the data, and produced all drafts. CP also commented on the penultimate draft of the paper and edited the final draft. GL

contributed to coding of the interview transcripts. AB also contributed to data collection. LB is the guarantor for the study.

Access to data: All authors had access to the data and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interest declaration: "All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: LB had support from Research Councils UK for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work."

Contributions: Liz Roffe conducted some interviews. The structured section of the interview was based upon an interview schedule developed by Corner, Hopkinson, Fitzsimmons et al. (2005).

Data Sharing: Research participants have not given informed consent for data sharing; a complete qualitative data set cannot be anonymised adequately.

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Box 1

Transcription Notation (Simplified and adapted version of Jeffersonian transcribing conventions)

- The speaker is identified by a participant identifier (P1-P28) followed by a colon. The participant's partner is indicated by a P following the participant identifier e.g.:

  P24P: No I don't agree

- Round brackets indicate that the material in the brackets is either inaudible, e.g.:

  M: I ( ) that

Or there is doubt about its accuracy, e.g.:

  M: I (couldn't tell you) that

- A micropause (a noticeable pause of less than 0.2 seconds) is indicated by a dot enclosed in brackets:

  (.)

- Non-verbal activities and noticeable pauses of 0.2 seconds or more are indicated within double brackets:

  M: Yes ((laughter)) but ((pause)) I don't know

- Square brackets indicate that material has been removed, usually to protect the participant's identity, e.g.:

  [ ] or [town]

- Three consecutive dots indicates that a section of transcript has been removed:

  M: He ran up the hill…to the house at the top

- Square brackets between adjacent lines of speech mark the start and end of overlapping talk

  [ ]

Table 1	
Patient characteristics (n=20)	
Sex (male/female)	13/7
Age – years (median; range)	71.5; 41-86
40-49	1
50-59	1
60-69	6
70-79	10
>=80	2
Diagnosis	
Incidental	8
Symptomatic	12
Smoking status	
Current smoker	4
Ceased in the last 3 months	4
Former smoker (ceased >3 months ago)	11
Never smoker	1
Comorbidities:	
Symptomatic COPD (spirometry +ve or clinical diagnosis)	8
Primary/Secondary Care COPD diagnosis (primary care diagnosis preceding 2ndry care LC investigation/diagnosis during secondary care LC investigation)	3/5
Asthma	5
Ischaemic Heart Disease	1
Congestive cardiac failure	1
Other cardiac Problems	2
Socioeconomic status (Index of Multiple Deprivation)**:**	
Most deprived 50%	8
Least deprived 50%	12

Table 2: Accounts of general health

	Feeling well despite symptoms	
P7	LR: P7: P7P: P7:	But you have had these headaches. Um. Would you say you've been feeling generally unwell? Not really I don't know if you're feeling unwell No. Just odd now and again.
P10	P10:	I mean I've been quite healthy (.) I've got high blood pressure I mean I've had that ooh [>20 years]... so that's all fairly long going you know but I haven't had any actual illnesses or anything
P11	P11:	I didn't feel anything was wrong inside. I mean I had no inkling at all. Um. If I had had that x-ray, but I wouldn't have known because I (.) there was (.) I felt quite well really, it was only just you know this operation on my neck
P16	P16:	When I had the cough you know she said they'd picked up the shadow...I probably sat there for a few seconds you know trying to take it in but that wasn't, when she said that I didn't get the feeling then that there was something wrong (LR: No) because as far as I knew I hadn't got anything wrong with me, but it's so there you are.
P25	P25:	I was ill a lot last year but when I was taken into hospital and the antibiotics and the treatment I had and the months rest I had when I came home where I wasn't going to work (since then I've cut my hours down) I feel so well. But I honestly was not expecting anything like that to be said to me, because I feel so much better than I did last year… In fact I feel better now at the moment than I have done for a long time...you see once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now. So at the moment, I feel so much better that I think it's not making any sense to me.
	Exceptions to feeling well despite symptoms – declining health	
P17	P17:	About a year ago. "What's that? What's going wrong with me" you know and I was going like that. Everything goes tonta... feels as though I can't breathe you know and then I'd just (indicates short breaths) only for a second, and then it's gone and then I'd go back to breathing and everything like that, ... And that was about a year ago, that's when I noticed "[ ], there's something wrong with you".
P19:	LB: P19:	How would you describe how you feel now? Not perfect. No. I mean I'm tired now. This made me tired! That's shows you how and it wouldn't normally do that!
P20:	P20:	And it was afterwards I was thinking I shall be able to get back on me feet now but instead I seem to be going on a slow decline. And I started to lose weight and like I said, things started tasting funny and all this, and I'm saying "Ok". And then I'd have a cold and this cough that wouldn't go away and to be honest I used to be coughing nearly all the time and it was like having a cold 24 hours a day, seven days a week. I'd start to get really tired and as I say, I was quite busy on Tuesday and I was throwing out rubbish... and then I cleaned all me windows. And yesterday, I felt like I'd been run over by a ten ton truck! And I thought 'well this is not me' It's just not me...maybe it's mental, you know, your own brain saying 'your body's not very well, just slow down'
P26	P26P: P26: P26P: P26:	This last year she's deteriorated in many things. Well I think you can understand it though. That's geriatrics for you isn't it? No it isn't you can understand it, when you've had a cough for this long. I mean it really takes it out of you, it really does. You try explaining that to the doctor!

Table 3: Patient reported symptoms and triggers to diagnosis

Participant	**Triggers to diagnosis**	**Symptoms of concern/disease** (Elicited by open questions except where indicated)	**Symptoms as normal processes** (Elicited by closed questions except where indicated)
Symptomatic Diagnoses			
06	Severe cough > 3 weeks	Severe productive cough (3-4 times a year of 2 days duration, for 5 years.)	Increase in breathlessness, Fatigue
08	Weight loss	weight loss	[1]Weight loss – some weight now regained **(open question)**
12	Persistent cough; haemoptysis	Persistent, tickly, non-productive, mild cough; haemoptysis	Aches and discomfort: Stiff neck and left shoulders; weight loss; some discomfort with coughing as time went on
016	Cough; fatigue; feeling unwell; appetite loss; weight loss.	Appetite loss; weight loss - returned to normal; dry cough; feeling unwell	Increase in breathlessness; a feeling (not pain) "that something is going on' in the chest"; fingers go numb.
018	Chest infection; haemoptysis	Repeated cough; chest infections; regular sneezing and flu like symptoms; sore throat; fatigue; Sore testicles; flushing across stomach; ache across back	Increase in breathlessness; pain in centre of chest; occasional coughing with chest infection
023	Weight loss; anaemia	Flu and a scratchy dry cough; night sweats; weight loss; anaemia; tiredness; sensitive gums; soft hair; taste change **(closed question)**	Twinges in fingers and hands
024	Haemoptysis; Dyspnea	Haemoptysis; night sweats	Cough; breathlessness and wheezing.
025	Dyspnea	Pains in legs and joints; fatigue, breathlessness	Chest pain recently when lying down.
027	Dyspnea	Breathlessness on exertion	Occasional hot shooting pain in chest
Exceptions to the normalisation of symptoms not presented to GPs/elicited by closed questions: Decline narratives (D) and Quest for Diagnosis narratives (Q)			
017 **(D)**	Chest/abdominal pain	Aching pain from indigestion; cough; pain across shoulders; aches; having less energy; breathlessness on resting/panic attacks	

		Elicited by closed questions: breathlessness on walking and when lying down	
019 **(D)**	Anaemia	Sickness if over eat; bleeding in throat and vomiting large amounts of blood (now stopped). **Elicited by closed questions**: Pain in stomach; loss of appetite; tiredness; increase in breathlessness; pain in chest when breathing in.	
020 **(D and Q)**	Persistent cough	Weight loss; fatigue; taste change; hot and cold sweats; reduction in appetite **(closed question)**	breathlessness on physical activity; weight loss - some weight now regained **(open question)**
026 **(D and Q)**	Persistent cough; recurrent chest infections for the last 10 years.	Regular chest infections and productive coughs; recent weight loss; cough triggered by eating, talking and cold air; dullish ache in back; coughing up occasional flecks of blood; fatigue and energy loss; night sweats – started at menopause but now every night **(closed question)**	

Incidental Diagnoses

	Triggers to diagnosis	**Symptoms of concern/disease** (Elicited by open questions)	**Symptoms as normal processes** (Elicited by closed questions)
03	CXR following traumatic injury	Gradually increasing breathlessness not noticed until diagnosis.	Weight loss
07	Routine CXR on hospital admission		Fatigue
010	Routine CXR on hospital admission		Change in bowel movements, fatigue
011	CXR Investigation of increased heart rate following surgery		Breathlessness; aches and pain back of left shoulder under arm and side of chest; fatigue
021	CXR investigation of weight loss and anaemia detected by health screen	Anaemia	Weight loss
022	CXR following traumatic injury		Cough; taste change; bowel changes
028	Imaging of kidney to investigate haematuria	Chest infection following investigation for LC	Breathlessness

[1]Occasionally participants would provide a symptom of concern/disease account when describing previous help-seeking, but would then reinterpret and normalise the symptom if it had improved since seeking help.

Table 4: Comparison of 'Symptoms of Concern' and 'Symptoms as Normal Processes' accounts

	Symptoms of Concern/Disease accounts	Symptoms as Normal Processes accounts
P6	LR: ...how [do] you think it all sort of started? P6: ... we went merrily on our holiday, and the cough just got worse and worse and worse. Coughing 24 hours a day the whole of the five days we were away...I went to see a doctor [who prescribed antibiotics] ...the antibiotics didn't touch it at all, so when we came back, I went to see one of my own doctors and he said 'you've probably got a chest infection. I'll give you some more antibiotics'...'if at the end of seven days it hasn't gone, then I think you'd better go and get an x-ray'.	LR: OK. So cough, we've done. Breathlessness? P6: …That [the pacemaker] cured it...so at the moment I'm just left with the cough or whatever... LR: So the only times you get breathless really are then when you're coughing? P6: Yeah. LR: Do you notice (.) is there any other time now P6: Occasionally I get breathless walking up hill, but that's to be expected. P6P: And you did a bit Friday which was stress I think. P6: Yeah, Friday…It does occasionally happen when I'm sitting down ... Up to recently I've been playing golf twice a week, so there can't be an awful lot wrong with me, but I do get occasionally short of breath…Just suddenly start breathing rather rapidly
P12	LB: Do you want to just tell me how you came to be in Mr [ ] clinic and what were the events that [P12: yes. I had a particularly persistent cough that wouldn't go away...although it was literally just a sort of a clearing the throat, that sort of thing... [then] I woke in the middle of the night with a cough, my mouth filled with what I thought was catarrh, went to the basin, spat it out (.) blood bright red and dark red. And it bled for about 10 or 15 minutes...and it hasn't bled since... Anyway, Monday ... went to see GP... immediately gave me the ticket to go to the walk in x-ray [ ].	LB: Have you lost any weight at all? P12: A bit, mm. I would say less than half a stone P12P: We have a very active cruise, we do a lot of walking and sightseeing... P12: And then you know, we go to [UK holiday destination] most years. And we walk a tremendous amount. And I swim a lot there, don't I? So that's a very active holiday.
P16		

	P16**:** I developed a cough and also that I didn't feel very well and I'd also lost some weight. I went to the doctors ... [s/he] sent me for a blood test and an x-ray. And several days later [s/he] rang and said I want to see you and by this time I'd got my appetite back and my weight had come back up again...	P16 : I think perhaps if it had just been a cough, perhaps I wouldn't have bothered … P16P: … after you were feeling better, you'd put weight back on and you'd still got this funny cough, I think you could have gone on for months with that funny cough [ ]... P16: LR: have you experienced any breathlessness at all? ((pause)) Or sort of thing like you [P16: I play golf and parts of the course are a bit steep and I must admit I get a bit puffed going up there but yeah it's not serious I just got to take it easy… as you get older so you can't do the things you did when you were a bit younger so ...quite often you put things down to change of your age and lifestyle and it wasn't that significant...I really wouldn't say I get breathless, I mean you [participant's wife] couldn't keep up with me.
P23	P23: and then we got to Christmas, and we were partying etc and to be quite honest, I should have put on more weight than I did. So I started to think 'well what's going on?' About [ ] months ago I had a colonoscopy and had a few polyps removed etc...I started to get night sweats, totally different from hot flushes...so I thought 'oooh this is a bit odd'.	LB: Have you suffered from any backache or shoulder ache? P23: No. LB: Anything that you thought might be something else wrong? P23: I've had perhaps the odd twinge [in fingers] that I would put down to arthritis while doing the garden or something but – this is the annoying fact, I am quite healthy; well I think I'm quite healthy, and so no I wouldn't say I've had aches and pains.
P24	P24: I started coughing up blood and I was already at Dr [ ]s clinic and when I told [her] I was coughing up blood, s/he referred me to the chest clinic which is next to Oncology, so that made me feel a bit suspicious... By that time I was admitted to hospital because I was coughing up what I thought was a lot of blood, and I had a lot of problem breathing... Dr [ ] came over to see ...and he changed my inhalers and took me off	LB:...when you were having breathing problems, did you ever have any wheezing with it? P24: Oh I do wheeze a bit in bed now. It's just you get used to the noises that your chest makes don't you really? I just think 'oh shut up'. I mean I do sleep very, very well unless I'm depressed...Sometimes just when I lie down I'll wheeze a bit and that's obviously changing from upright

	beta blockers and transformed my life!	position to lying down but and not to any extent.
	Incidental Diagnosis	
P3		LR: Er, so have you had any weight loss at all? P3: Yes. The lady [ ] that dances with me, she's been making off for months now that I'm losing weight. LR: Yeah? P3: Yeah. So I expect to lose weight in the summer months because you're more active over the allotments. .. plus the days are longer so you spend longer away from home so you don't eat so much, but I used to be [ ] stone, but when she weighed me yesterday with my clothes on, she said I was [1.5 stones less] LR: ...you think that's just over the summer or ? P3: I reckon that's over the last two years. LR: Yeah? RES: Yeah. I reckon about the last two years, because I always said [1.5 stone heavier than current weight] stones is too heavy for me. And then people would say it's a beer gut
P28		LB: Have you had any other types of cough that have lasted more than three weeks? P28: No. LB: No. Would you say you had a smokers cough... P28: No I wouldn't actually! Would you? No. P28P: Not really. P28: No, never hacking coughs or anything. P28P: not a dry cough like ( ) LB: Sorry you didn't have a dry cough? P28P: No. No. ((pause)) No more than a lot of people have got you know. In the day and you know

APPENDIX 1 (Web Only File)

Interview topic guide: IPCARD Chest Symptoms Study

I. +II. **Unstructured and Semi-structured interview**:

- Record patient's health and illness experiences
- Focussing on the period leading up to their referral for LC Investigation and all experiences of health and illness during the last 2 years, explore:
    - participants' interpretations of and explanations for symptoms
    - Impact of ill health/symptoms

III. **Structured interview**:

- Explore list of specific symptom presentations and health changes (attached).

IV. **Further semi-structured interview questions**: Help-seeking behaviour and use of health services (These questions are to follow accounts of symptoms elicited in sections I, II and III):

- What did you do about [symptom/health change]?
    - any health care, treatments, information or advice received
    - reasons for seeking or not seeking medical help.

Introduction

"Thank you for agreeing to this interview. It should take about 60-90 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. I would like to build up a detailed picture of your experiences of health and illness. I am interested in anything that you noticed about your health even if you thought it was minor or not connected to your recent visit to [hospital/clinic]. I will then be asking you to talk in more detail about your experiences of health from when you first noticed a change in your health up to the time when you were referred to the [clinic] and about all aspects of your health in the last 2 years."

Section I

The topic guide provides a number of questions which the interviewer might use to initiate discussion about a particular topic. However, the interviewer might revise the questions, or alter their order, in light of the interviewee's response to earlier questions.

Part 1: Exploration of health and illness

Purpose: To explore the participant's experiences of health and illness over their lifetime including any symptoms/problems/changes in health that they have noticed in the last 2 years.

- Could you tell me how you came to be in Dr [ ]'s clinic/ came to be seeing Dr X
- Please tell me about your health and any illnesses that you have experienced

- How has your health changed (are there any changes that you noticed)?

Section II

- When did you first notice something was wrong, or a there had been a change in your health?

- Have you experienced any other changes in your health during the last 2 years?

Prompts: use following prompts to aid recall of dates:

- What year was this?
- What month was this?
- What season was this?
- What it close to an event in the year, such as Christmas or Easter?
- Was this at the same time as any other event in your life?
- Was this at the same time as any family/ social event?
- What else was going on in your life at the time?

- Has there been anything else that you have visited your doctor about during the last 2 years?

- Has there been anything else at all relating to your health that you have noticed during the last 2 years even if minor?

Probes: for all illnesses explore:

- Severity
- Duration
- Change over time/how/when (use same probes as for Part 1)
- Impact (social/lifestyle/ family/psychological/ what did the participant think about their symptom)
- Participant's explanations for illness/associated with?/causes

Section III

"I have a list of things that some people notice before they are told that they have a chest problem. I am going to ask you if you experienced each of these things. I will then ask you about each health change that you experienced in more detail."

01. Cough	YES NO (see structured guide - cough)
02. Coughing up blood	YES NO (see structured guide - haemoptysis)
03. Breathlessness or panic attacks	YES NO (see structured guide - breathlessness)
04. Changes in eating, appetite, taste or weight	YES NO (see structured guide – eating/weight)
05. Pain	YES NO (see structured guide - pain)
06. Discomfort or strange sensations	YES NO (see structured guide – discomfort)
07. Aches or pain in chest, back, shoulders or joints (if not mentioned in response to 5 and 6)	YES NO (see structured guide – specific aches)
08. Skin changes	YES NO (see structured guide – skin)
09. Lots of infections	YES NO (see structured guide - infections)

10. Tiredness	YES NO (see structured guide – tiredness)
11. Feeling generally unwell	YES NO (see structured guide – unwell)
12. Hot or cold sweats	YES NO (see structured guide – sweats)
13. Voice changes or hoarseness	YES NO (see structured guide – voice changes)
14. Other (DESCRIBE) ¬¬¬¬¬¬¬¬¬¬¬¬_____	YES NO (see generic guide – other)

Information: Turn to relevant problems identified by participant. Only sections relating to the problems/changes identified by the should be completed

Section IV

Semi-structured interview: Help-seeking behaviour and use of health services (These questions follow accounts of symptoms elicited in sections I, II and III, and do not necessarily come at the end of the interview):

- What did you do about the symptom?

  Prompts
  - Confided in close family member/friend– who did you talk to first?/who else did you speak to
  - Found information (Read health related article in magazine or book, Consulted a medical dictionary/encyclopaedia, watched a health related TV/Video, Undertook an internet search),
  - Sought advice (e.g .Sought advice from NHS direct/ walk-in centre, Spoke to practice nurse/other health professional, Spoke to your GP/made appointment to see GP)
  - Treatment (other than GP advised) Took over the counter medication (self-prescribed or pharmacist consulted), Took complementary medicine/ therapy

- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?

  - If further help was sought - what made you seek this help?

- Please describe any changes in the way you manage or live with the [symptom] since x

Relationship with GP and barriers to use of primary care services

- Have there been any circumstances in which you were unsure about whether to seek help from your GP?

- What things have made you decide against visiting your GP/practice nurse?
- Have there been any other circumstances in which attending your GP would have been difficult?
    - What were these?

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – could GP elicitation of normalised symptoms reduce delay in diagnosis?: Cross sectional interview study

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ABSTRACT

Objectives: To investigate why symptoms indicative of early-stage lung cancer (LC) were not presented to GPs and how early symptoms might be better elicited within primary care.

Design, setting and participants: A qualitative cross-sectional interview study about symptoms and help-seeking in 20 patients from 3 south England counties, awaiting resection of LC (suspected or histologically confirmed). Analysis drew on principles of discourse analysis and constant comparison to identify processes involved in interpretation and communication about symptoms, and explain non-presentation.

Results: Most participants experienced health changes possibly indicative of LC which had not been presented during GP consultations. Symptoms that were episodic, or potentially caused by ageing or lifestyle, were frequently not presented to GPs. In interviews, open questions about health changes/symptoms in general did not elicit these symptoms; they only emerged in response to closed questions detailing specific changes in health. Questions using disease-related labels, e.g. pain or breathlessness, were less likely to elicit symptoms than questions that used non-disease terminology, such as aches, discomfort or 'getting out of breath'. Most participants described themselves as feeling well and were reluctant to associate potentially explained, non-specific or episodic symptoms with LC, even after diagnosis.

Conclusion: Patients with early LC are unlikely to present symptoms possibly indicative of LC that they associate with normal processes, when attending primary care before diagnosis. Faced with patients at high LC risk, GPs will need to actively elicit potential LC symptoms not presented by the patient. Closed questions using non-disease terminology might better elicit normalised symptoms.

Article Summary

Article Focus:

• Why symptoms potentially indicative of lung cancer are not presented to GPs

• Exploration of how and why some lung cancer symptoms are normalised by lung cancer patients

• Use of discourse analysis to investigate communication factors involved in the non-presentation and normalisation of symptoms, and how symptoms might be better elicited in primary care.

Key Messages:

• Non-specific, episodic and non-progressive symptoms were normalised by patients with operable lung cancer who felt well.

• Symptoms normalised by patients with operable lung cancer were not presented to GPs during consultations before diagnosis. GP elicitation of normalised symptoms would lead to better informed referral decisions.

• Closed questions using non-disease terminology were more effective at eliciting symptoms normalised by patients.

Strengths and limitations of this study:

• This study used interviews to identify interactional factors which influenced symptom presentation within a research study, and it may be that symptom presentation occurs differently within everyday GP consultations; nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms were elicited by GPs, referral decisions would be better informed.

• Most lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is unrepresentative of this patient population. However, research involving operable patients enables the investigation of communication about currently experienced early symptoms, rather than relying on retrospective accounts of early symptoms provided by patients with later stage disease. Furthermore, the reasons these patients gave for non-presentation of symptoms concur with other studies of help-seeking for cancer symptoms, supporting the transferability of our findings.

Eliciting symptoms interpreted as normal by patients with early stage lung cancer – can we use closed questions to reduce delay in diagnosis?

INTRODUCTION

Lung cancer is diagnosed too late in the UK and survival rates are lower than in most other Western European countries;[1-4] 86% are diagnosed at a stage when curative treatment is not possible and less than 25% survive one year following diagnosis.[5-6] Lung cancer kills approximately 30,000 people a year in the UK so even modest improvements in the time to diagnosis could dramatically improve health outcomes.[7] Despite successful national cancer screening programmes, most tumours are diagnosed following presentation with symptoms [8] so it is vital to identify patients with significant symptoms early. The UK National Institute of Clinical Excellence (NICE) recommends urgent chest x-ray for patients presenting with any 1 of 10 unexplained or persistent symptoms [9] but General Practitioners (GPs) have to balance risks associated with unnecessary x-ray against possible late diagnosis, and make judgements about the relative validity of alternative explanations for symptoms. This is further complicated by the fact that lung cancer is often preceded by chronic respiratory disease [10] making detection difficult.

Recent evidence [11] indicates that most newly diagnosed lung cancer patients do not recognise all of their cancer symptoms. Isolated single symptoms have low predictive value for lung cancer [12] but patients seldom present multiple symptoms to GPs. [13-14] Interview research has shown that lung cancer patients normalise symptoms and delay seeking help [15-16] and in the general population many symptoms are never presented to GPs [17-18]. However, patients diagnosed with lung cancer have been shown to report symptoms to their GP more frequently than controls 6-24 months before diagnosis [12] but it seems that a combination of cultural and communication processes combine, sometimes fatally, to prevent help-seeking [13,19-20] for the full range of symptoms experienced by patients at increased risk of lung cancer (LC).[11;21]

Previous studies have identified symptom normalisation - the association of symptoms with normal processes - as an important factor in delayed LC diagnosis. However, research has not yet addressed the reasons for normalisation of LC symptoms, or investigated how normalised symptoms that are not presented to health care professionals might be better elicited. Structured interviewing has been used in primary care to improve psychiatric diagnosis but it is not clear if it could help to elicit early lung cancer symptoms. Our study examined how symptoms were normalised by patients and compared structured and unstructured elicitation of symptoms. By using a discourse analytic approach we were able to suggest ways that health care professionals might better elicit normalised symptoms, and investigate why they are not presented to GPs.

METHODS

Design

Previous studies have focused on inoperable lung cancer, but we were interested in how patients communicated early symptoms so we conducted interviews with patients awaiting surgical resection of lung cancer (suspected or histologically confirmed). Previous interview studies with lung cancer patients have relied upon retrospective accounts of early symptoms experienced before diagnosis. In contrast, we were interested in how patients communicate about, and negotiate the relevance of current early symptoms. In retrospective accounts patients might normalise symptoms to justify delays in seeking help so we also investigated the normalisation of symptoms that started following LC investigation. We used unstructured

followed by structured interviewing to find out if this could elicit symptoms more effectively than open questions about changes in health, which have been found not to elicit all lung cancer symptoms (see Smith et al, 2009).

Participants

The interview sample for this study was drawn from 28 adult patients with a diagnosis of, or suspected of having, operable lung cancer (probable: >90% or histologically confirmed) recruited to a questionnaire development study. Patients were either approached by the researcher following their first consultation with participating thoracic surgeons at a South England Trust, or were sent a letter and information sheet by the surgical team. Seventeen out of twenty consecutive patients within 3 recruitment periods (07/2006-10/2007; 02/2008-05/2008; 02/2009-05/2009) approached by a researcher agreed to take part. An opportunistic sample of 11 participants was recruited by letter (within the three recruitment periods). Twenty eight patients in total were recruited and interviewed about their current and recent health and help-seeking behaviour.

This paper reports the analysis of 20 interviews with patients identified as having operable lung cancer at the end of the study period (data from seven interviewees who received a non-malignant diagnosis after the interview were analysed separately and are not reported here. One patient diagnosed with advanced disease was also excluded). Characteristics of these 20 patients are given in Table 1.

[Insert table 1 here]

Interviews

The unstructured (first) section of the interview used open questions to generate narrative accounts of participants' experiences and changes in health status (See Appendix 1 for the interview checklist). Participants were asked to describe anything at all that they had noticed about their health, even if they thought it not relevant to their investigation for lung cancer. The second part of the interview was semi-structured and focused on duration and characteristics of symptoms, and reasons for seeking or not seeking help. The third part of the interview used closed questions to explore symptoms and help-seeking using a list of potential lung cancer symptoms compiled from Cancer Research UK [6] information, NICE [9] guidelines, and a previous interview study with lung cancer patients.[15] Field notes were recorded after the interview. Interviews lasted between 1-2 hours, took place in the participants' home (18/20) or a hospital setting (2), some involved the participant's partner (2) or carer (1), all were audio-recorded, transcribed verbatim, checked for accuracy and anonymised. An adapted version of Jefferson's transcription conventions [22] were used (described in Box 1).

[Insert Box 1 here]

Analysis

The first stage of analysis involved an iterative coding process using elements of the constant comparative method to develop themes (initially identified by LB and checked by a second researcher, GL, who independently read a sample of transcripts and verified codes and themes). This iterative process continued until data saturation was achieved. All transcripts were revisited and deviant cases were sought.[23] Thematic analyses identified symptoms not presented to GPs, characteristics of symptoms, and reasons given for non-presentation. Discourse analysis [24-25] which considers language use in context, was used to examine

how health changes were presented in patient-interviewer interactions; The discourse analysis was informed by ethnomethodology, an approach which focuses on how social action is accomplished within accounts. This enabled us to look at the implications of talk's sequential and micro-organisation for symptom presentation, and showed how normalised symptoms might be better elicited. We combined the thematic analysis and discourse analyses to explain normalisation and non-presentation of symptoms. The results section presents key findings about symptom presentation, including reasons for non-presentation, and the implications of question type and terminology.

RESULTS

Most participants described themselves as having good health; only four presented accounts of declining health preceding diagnosis, characterised by multiple symptoms and feeling unwell (see table 2).

[Insert table 2 here]

Symptomatic diagnosis occurred for 13 participants and 7 participants claimed not to have any lung cancer symptoms, describing incidental diagnoses made during the investigation of unrelated health problems, traumatic injury or screening (Table 3).

[Insert link to table 3 here]

15 participants described further changes in health possibly indicative of lung cancer (according to NICE Guidelines/CRUK symptom list) that were not thought a reason for concern and had not been presented to their GP during LC investigations, despite the presentation of the trigger symptom or use of primary care services for other reasons. They did not associate these un-investigated health changes with LC and they were elicited by closed questions about specific symptoms, but not by open questions about symptoms or changes in health (Table 3).

Two types of symptom accounts were identified: 'symptoms as normal processes' and 'symptoms of disease/concern'. Examples of these accounts and their elicitation are provided in table 4. Participants reported un-investigated symptoms, and produced normalised accounts of these, irrespective of patient socio-demographic characteristics, smoking status or route to diagnosis; there were no discernible differences in relation to table 1 characteristics. Exceptions appeared to arise only in the case of participants providing narratives of declining health. The association of symptom normalisation with narratives of good health is highlighted in table 3; those providing narratives of declining health tended not to normalise symptoms. Participants with incidental diagnoses also provided normalised accounts of un-investigated potential LC symptoms, but were less likely to produce symptom of concern accounts than those with symptomatic diagnoses (see table 3).

The first results section – 'Reasons for non-presentation' – describes the main features of 'symptoms as normal processes' accounts (episodic/non-progressive symptoms or ageing and lifestyle related explanations). 'Symptoms of concern' accounts are described in order to demonstrate exceptions to the normalisation of symptoms. The second results section

examines the use of closed questions to elicit (normalised) accounts of symptoms not elicited by open questions or presented to GPs, and the implications of symptom terminology.

Reasons for non-presentation

Normal processes such as lifestyle and ageing were commonly used as explanations for not presenting symptoms to GPs. For example, breathlessness was frequently associated with being unfit, getting older, over-activity or seasonal changes rather than lung cancer:

> P18: I just put it down to me being too unfit for that particular run or circuit or down to age…I didn't associate that with anything other than me being old or unfit, one of those.

In these 'symptoms as normal process' accounts patients portrayed symptoms as part of everyday life processes and avoided claiming cancer causation:

> LB: ...do you get any discomfort anywhere, do you have any aches or pains?
> P11: No (.) only round me neck but that's just recently it's come on. I don't know whether it's to do with this problem I've got ... I think it's a bit of arthritis there. And (.) you know (.) it's old age really I mean, because we do get these things I know, as you get older, (.) but just as I say this last couple of weeks it's got really really bad.

Some of those who described current 'good health' at odds with their diagnosis, also described episodic ill health, or long term symptoms which had led to lifestyle changes and adaptation. Symptoms like breathlessness or cough might be more severe during a chest infection, but were not commented on if they persisted. Here, P25 did not mention breathlessness on climbing the stairs to her GP:

> P25: It was getting the pains in my hands and my wrists… It was when it started here [in wrists], it started to hinder me with things…but I wasn't going [to the GP] through breathlessness …because that had finished when I got better…You know within the week I was back to being able to breathe again. Apart from when I you know whether you get out of breath carrying the hoover upstairs... [Husband] says "What have you been doing? [ ]?" and I just say "Nothing just those stairs".

The ability to improve did not appear to fit with the expected progressive pattern for a disease such as lung cancer:

> P25: [ ]...once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now... Why don't I feel really, really ill now to understand this? How can you have this and get better and feel better, get ill but then you get better, well how can you do that?

These normalised accounts, by simultaneously presenting alternative non-disease explanations, such as ageing, for health changes, also helped construct the participant as healthy. Exceptions to the use of normalised accounts for un-investigated symptoms were found in four interviews where patients had declining health (consisting of multiple symptoms and feeling unwell); two of these four patients also provided 'quest for diagnosis narratives' in which they had battled, or were still battling, for a diagnosis in the face of clinical ignorance or clinical delay. In the interviews they described most of their health changes in response to open questions (Table 3: Exceptions to the normalisation of symptoms), including symptoms not presented to GPs, and did not normalise these symptoms. Even symptoms presented in response to closed questions were most often not normalised:

> LB: So have you noticed any changes in breathing or breathlessness?

P19: Yes I am definitely more breathless now... I am not normally that breathless!
LB: ...and before that, how would you describe your breathlessness?
P19: Well it's never been really too bad, as long as I've had my inhalers... So it's just recently that I am beginning to get a bit more breathless and I don't think that's associated with the asthma.

Participants who presented themselves as well, normalised non-specific, non-progressive and episodic symptoms.

[Insert table 4 here]

Using closed questions to elicit symptoms not elicited by open questions

Symptoms interpreted as normal by participants tended not to be described in response to open interview questions (Tables 3 & 4) and were not presented to GPs. For example, P22, who had been investigated by his GP for a bowel disorder in the weeks before diagnosis, described an absence of symptoms he associated with lung cancer:

P22: No as I say this was a complete shock to find out that it was on the lung. As I said, we would never have known anything about it if I hadn't fallen off that thing. I suppose it would eventually with finding this I suppose I could have lost weight or gone awful thing one to the doctor "well we'll have to find out what's causing it" but no nothing.

However when asked specifically about long-term cough, he revealed he had experienced a cough for 4-5 months:

P22: Well I've got a cough now. Every now and again I cough and get a little phlegm up.
LB:… And is it something that you ever went to your doctor about?
P22: No.
LB: No.
P22: No I've never had to do that.

Accounts produced in response to closed interview questions about specific symptoms displayed two common structures for symptom reporting: 'Affirmation/Normalisation' and 'Delayed Affirmation/Normalisation'. The symptom referred to by the interviewer might either be affirmed but normalised ('Affirmation/Normalisation') or initially denied and then normalised ('Delayed Affirmation/Normalisation'). When closed questions phrased health changes in ways which did not necessarily indicate disease, the participant was more likely to answer affirmatively, or describe a health change, but then suggest the symptom was normal and not related to lung cancer (Affirmation/Normalisation). In contrast, questions using disease-related terms - e.g. 'pain' - produced an immediate denial or pause (non-response) followed by normalisation (Delayed Affirmation/Normalisation):

LB: ... have you had any chest pain at all that you can describe?
P12: No, not really. I mean as the cough's got shall we say more persistent and sort of shall we say worse yes (.) I can feel it a bit (.) but I mean I can't feel it now... if you look at the x-rays you think 'oh blimey!' but you wouldn't know it was there!

Reformulation of the question, involving a shift from disease to non-disease terminology, could elicit normalised accounts of symptoms – as in these examples where a change in terminology shifting from 'pain' to 'aches' and 'discomfort', and shifting from 'breathlessness' to 'not being able to get your breath' leads to elicitation of the symptoms:

LR: Have you had any pain anywhere?
P16: None at all. No
LR: …have you experienced any sort of aches or general sort of discomfort at all? ...

P16: No, not serious no. Well …sometimes I have a feeling that something's going on, but it's not there all the time, you know

LR: And have you experienced breathlessness? ((pause))
P18: ((intake of breath))
LR: Just feeling like you haven't been able to get your breath quite so easily?
P18: I would go up a couple of flights of stairs quite randomly, I would feel out of breath. I would never never usually be like that, so yes, for a fit guy I would go ooh I'm breathless ...but then you know I shouldn't have really bothered about it at all. But then again I have put on a slight bit of weight haven't I?

In contrast with disease-related terminology, terminology not strongly associated with disease such as 'aches' or 'discomfort' rather than 'pain', produced affirmation and then normalisation (affirmation/normalisation):

LB: And have you had any kind of aches or discomforts anywhere?
P12: Well I have been complaining about a stiff neck haven't I...and also this shoulder…but I mean I can play golf, so it's not that bad!

Similarly the use of terms that imply 'breathing changes' or 'getting out of breath more easily', rather than 'breathlessness', produced an affirmation/normalisation response structure:

LB: ...what about breathing changes, or have you ever noticed at all that you can become more breathless than you would have done say a few years ago when you were doing something?
P11: I do now. This past (.) oh couple of months I suppose. I get more breathless if I (.) if I hurry around too much you know…but normally you know, I don't run around! (LB: no no) If I remember my age... I don't sort of get out of (.) breathless or anything like that, it's only if I'm (.) ... overdo things really.

Even though closed questions using disease-related terminology might elicit previously unmentioned health changes, closed questions using non-disease terminology did so more effectively.

DISCUSSION

Eliciting 'hidden' symptoms

Most of our sample described themselves as feeling well, despite going on to have a diagnosis of operable lung cancer. Patients who felt well had experienced a range of health changes indicative of lung cancer but they did not tell their GPs about many of these, despite making use of primary care services. Instead they framed these symptoms as normal features of lifestyle and ageing processes.

Delay in lung cancer diagnosis in the UK has been blamed upon patients' failure to recognise early symptoms.[26] However, our research indicates that normalised symptoms can be elicited by closed questions. This runs counter to current educational and communication practice which encourages open and expansive questioning. Whereas open questioning is necessary to elicit symptoms perceived as abnormal by the patient, normalised symptoms will remain hidden. Once elicited by closed questions, normalised symptoms are often quickly obscured within accounts which provide every day explanations for health changes. This means that interviewers (or health professionals) have to probe normalised accounts to uncover hidden symptoms.

Questions using disease-related symptom terminology, such as 'chest pain', or 'breathlessness', appeared to have limited potential to elicit potential lung cancer symptoms experienced by those with operable lung cancer. Our analysis suggests that to get at these symptoms we need to ask closed questions without referencing disease-related symptom labels. Again this runs counter to some guidance such as the NICE referral criteria terminology which uses disease-related terms. Furthermore, contextual factors and framing of the patient's presentation are known to influence GPs' diagnostic reasoning;[27] patients who present themselves as well and without declining health might be less likely raise concern and be referred for investigation of potential cancer symptoms.

Recent survey research looking at public awareness of cancer symptoms in the UK, concluded that levels of knowledge are low for many potential cancer symptoms.[28] These findings have informed regional NAEDI (National Awareness and Early Diagnosis Initiatives) [29] materials designed to educate the public about cancer symptoms. It might be argued that participants in our study simply did not recognise the significance of symptoms such as breathlessness. However, participants did not report lack of knowledge as the reason for symptom normalisation and non-presentation. Furthermore, the accounts produced by participants avoided personal claims of lung cancer aetiology for changes in health, even if this was raised as a possibility in the interview. Alternative non-lung cancer explanations for symptoms were provided that had social legitimacy. Our work suggests that lists of symptoms alone are unlikely to prompt patients to reveal multiple non-specific and normalised symptoms, especially when they are asked to give unstructured accounts. Furthermore, our research indicates that lung cancer risk scores provided by symptom based clinical decision support aids (e.g. RATS[30]), are likely to be influenced by how symptoms are elicited within the consultation.

Patient-centred medicine attempts to honour patients' experiences and concerns – presented in their own terms. It has been accompanied by more open consultation styles and a shift away from interactions directed by the health professional. For patients with potential lung cancer this may not be the best way to elicit symptoms. Instead routine medical consultations involving those at increased cancer risk [31] might better be restructured to enable the presentation of health changes which appear normal or unproblematic to the patient. This would require the clinician to be aware of the risk of lung cancer in all patients presenting to their service with symptoms seemingly unrelated to lung cancer. The elicitation of normalised symptoms in patients at increased lung cancer risk might then facilitate GPs' chest x-ray referral decisions.

Strengths and Limitations

This study used interviews to identify interactional factors which influenced symptom presentation within a research study. The systematic and in-depth study of language of the type reported in this article can lead to critical insights about conventions used in conversation that are transferable between settings.[32] However, it may be that symptom presentation occurs differently within everyday GP consultations; closed questions involving non-disease terminology might not be as effective at eliciting normalised symptoms within primary care practice. Further research involving GP consultations will be required to establish how effective these methods of symptom elicitation are within primary care. Nonetheless our findings indicate that the symptoms normalised by patients within interviews were also the symptoms that consulting patients did not present to GPs. If these normalised symptoms that are potentially indicative of LC were elicited by GPs, referral decisions would be better informed.

The participant group were patients with an established or probable lung cancer diagnosis. This may influence symptom presentation in the interview as a LC diagnosis is already suspected. However, the normalisation of symptoms that started after diagnosis within this study suggests that normalisation is not justifying delays in diagnosis; the association of episodic, non-specific symptoms with normal processes appears commonplace for those feeling well, even when lung cancer provides a potential explanation for symptoms.

NICE referrals guidelines for suspected lung cancer are based upon a weak evidence base; therefore, we do not know the likelihood that the symptoms not presented to GPs were caused by LC. However, these guidelines represent the best evidence currently available to inform referral for lung cancer investigation. If these non-specific symptoms experienced by patients at increased lung cancer risk were elicited in primary care, GPs would be better able to operationalize NICE guidelines. A prospective study may eventually determine the utility of these symptoms in the early diagnosis of lung cancer and the efficacy of treatment (including surgery).

The majority of lung cancer patients are diagnosed with inoperable disease and so any sample of patients diagnosed with operable lung cancer is necessarily unrepresentative of the whole population of lung cancer patients. It may be that our participants were more symptomatic in the early stages, or more likely to seek medical help, than those diagnosed with inoperable disease. However, this makes it all the more compelling that these participants still experienced a number of symptoms that they did not report. The reasons these patients with lung cancer give for non-presentation of symptoms concur with other studies of help-seeking for cancer symptoms,[19] supporting the transferability of our findings. Furthermore, our finding that those who reported good health tended to normalise nonspecific, episodic and non-progressive symptoms might have implications for improving earlier detection of other cancers where patients describe good health in the early stages, and for patient-clinician communication more generally.

Conclusions

Even though lung cancer patients are more likely to attend their GP with potential symptoms in the year before diagnosis than healthy controls, our findings indicate that many non-specific symptoms are not presented within these consultations. The use of non-disease related symptom labels in combination with some closed questioning appears to improve symptom elicitation.

Eliciting and investigating normalised symptoms – to uncover the invisible part of the illness iceberg,[16-17] whilst not feasible for all patients attending primary care, would be possible for those identified as at increased lung cancer risk.[31]

Ethical approval: NHS ethical approval was gained from Southampton South Central Research Ethics Committee (05/Q1702/46).

Authorship: All authors have commented on the first and final draft of the paper, and contributed to interpretation of the data. LB was the chief investigator; she had the original idea, designed the study, conducted interviews, analysed the data, and produced all drafts. CP also commented on the penultimate draft of the paper and edited the final draft. GL

contributed to coding of the interview transcripts. AB also contributed to data collection. LB is the guarantor for the study.

Access to data: All authors had access to the data and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interest declaration: "All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: LB had support from Research Councils UK for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work."

Contributions: Liz Roffe conducted some interviews. The structured section of the interview was based upon an interview schedule developed by Corner, Hopkinson, Fitzsimmons et al. (2005).

Data Sharing: Research participants have not given informed consent for data sharing; a complete qualitative data set cannot be anonymised adequately.

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Box 1

Transcription Notation (Simplified and adapted version of Jeffersonian transcribing conventions)

- The speaker is identified by a participant identifier (P1-P28) followed by a colon. The participant's partner is indicated by a P following the participant identifier e.g.:

  P24P: No I don't agree

- Round brackets indicate that the material in the brackets is either inaudible, e.g.:

  M: I ( ) that

Or there is doubt about its accuracy, e.g.:

  M: I (couldn't tell you) that

- A micropause (a noticeable pause of less than 0.2 seconds) is indicated by a dot enclosed in brackets:

  (.)

- Non-verbal activities and noticeable pauses of 0.2 seconds or more are indicated within double brackets:

  M: Yes ((laughter)) but ((pause)) I don't know

- Square brackets indicate that material has been removed, usually to protect the participant's identity, e.g.:

  [ ] or [town]

- Three consecutive dots indicates that a section of transcript has been removed:

  M: He ran up the hill…to the house at the top

- Square brackets between adjacent lines of speech mark the start and end of overlapping talk

  [ ]

Table 1	
Patient characteristics (n=20)	
Sex (male/female)	13/7
Age – years (median; range)	71.5; 41-86
40-49	1
50-59	1
60-69	6
70-79	10
>=80	2
Diagnosis	
Incidental	8
Symptomatic	12
Smoking status	
Current smoker	4
Ceased in the last 3 months	4
Former smoker (ceased >3 months ago)	11
Never smoker	1
Comorbidities:	
Symptomatic COPD (spirometry +ve or clinical diagnosis)	8
Primary/Secondary Care COPD diagnosis (primary care diagnosis preceding 2ndry care LC investigation/diagnosis during secondary care LC investigation)	3/5
Asthma	5
Ischaemic Heart Disease	1
Congestive cardiac failure	1
Other cardiac Problems	2
Socioeconomic status (Index of Multiple Deprivation)**:**	
Most deprived 50%	8
Least deprived 50%	12

Table 2: Accounts of general health

	Feeling well despite symptoms	
P7	LR: P7: P7P: P7:	But you have had these headaches. Um. Would you say you've been feeling generally unwell? Not really I don't know if you're feeling unwell No. Just odd now and again.
P10	P10:	I mean I've been quite healthy (.) I've got high blood pressure I mean I've had that ooh [>20 years]... so that's all fairly long going you know but I haven't had any actual illnesses or anything
P11	P11:	I didn't feel anything was wrong inside. I mean I had no inkling at all. Um. If I had had that x-ray, but I wouldn't have known because I (.) there was (.) I felt quite well really, it was only just you know this operation on my neck
P16	P16:	When I had the cough you know she said they'd picked up the shadow...I probably sat there for a few seconds you know trying to take it in but that wasn't, when she said that I didn't get the feeling then that there was something wrong (LR: No) because as far as I knew I hadn't got anything wrong with me, but it's so there you are.
P25	P25:	I was ill a lot last year but when I was taken into hospital and the antibiotics and the treatment I had and the months rest I had when I came home where I wasn't going to work (since then I've cut my hours down) I feel so well. But I honestly was not expecting anything like that to be said to me, because I feel so much better than I did last year… In fact I feel better now at the moment than I have done for a long time...you see once I've had my antibiotics or a bit of an inhaler I'm fine again, like I am now. So at the moment, I feel so much better that I think it's not making any sense to me.
	Exceptions to feeling well despite symptoms – declining health	
P17	P17:	About a year ago. "What's that? What's going wrong with me" you know and I was going like that. Everything goes tonta... feels as though I can't breathe you know and then I'd just (indicates short breaths) only for a second, and then it's gone and then I'd go back to breathing and everything like that, ... And that was about a year ago, that's when I noticed "[ ], there's something wrong with you".
P19:	LB: P19:	How would you describe how you feel now? Not perfect. No. I mean I'm tired now. This made me tired! That's shows you how and it wouldn't normally do that!
P20:	P20:	And it was afterwards I was thinking I shall be able to get back on me feet now but instead I seem to be going on a slow decline. And I started to lose weight and like I said, things started tasting funny and all this, and I'm saying "Ok". And then I'd have a cold and this cough that wouldn't go away and to be honest I used to be coughing nearly all the time and it was like having a cold 24 hours a day, seven days a week. I'd start to get really tired and as I say, I was quite busy on Tuesday and I was throwing out rubbish... and then I cleaned all me windows. And yesterday, I felt like I'd been run over by a ten ton truck! And I thought 'well this is not me' It's just not me...maybe it's mental, you know, your own brain saying 'your body's not very well, just slow down'
P26	P26P: P26: P26P: P26:	This last year she's deteriorated in many things. Well I think you can understand it though. That's geriatrics for you isn't it? No it isn't you can understand it, when you've had a cough for this long. I mean it really takes it out of you, it really does. You try explaining that to the doctor!

Table 3: Patient reported symptoms and triggers to diagnosis

Participant	**Triggers to diagnosis**	**Symptoms of concern/disease** (Elicited by open questions except where indicated)	**Symptoms as normal processes** (Elicited by closed questions except where indicated)
Symptomatic Diagnoses			
06	Severe cough > 3 weeks	Severe productive cough (3-4 times a year of 2 days duration, for 5 years.)	Increase in breathlessness, Fatigue
08	Weight loss	weight loss	[1]Weight loss – some weight now regained **(open question)**
12	Persistent cough; haemoptysis	Persistent, tickly, non-productive, mild cough; haemoptysis	Aches and discomfort: Stiff neck and left shoulders; weight loss; some discomfort with coughing as time went on
016	Cough; fatigue; feeling unwell; appetite loss; weight loss.	Appetite loss; weight loss - returned to normal; dry cough; feeling unwell	Increase in breathlessness; a feeling (not pain) "that something is going on' in the chest"; fingers go numb.
018	Chest infection; haemoptysis	Repeated cough; chest infections; regular sneezing and flu like symptoms; sore throat; fatigue; Sore testicles; flushing across stomach; ache across back	Increase in breathlessness; pain in centre of chest; occasional coughing with chest infection
023	Weight loss; anaemia	Flu and a scratchy dry cough; night sweats; weight loss; anaemia; tiredness; sensitive gums; soft hair; taste change **(closed question)**	Twinges in fingers and hands
024	Haemoptysis; Dyspnea	Haemoptysis; night sweats	Cough; breathlessness and wheezing.
025	Dyspnea	Pains in legs and joints; fatigue, breathlessness	Chest pain recently when lying down.
027	Dyspnea	Breathlessness on exertion	Occasional hot shooting pain in chest

Exceptions to the normalisation of symptoms not presented to GPs/elicited by closed questions: Decline narratives (D) and Quest for Diagnosis narratives (Q)			
017 **(D)**	Chest/abdominal pain	Aching pain from indigestion; cough; pain across shoulders; aches; having less energy; breathlessness on resting/panic attacks **Elicited by closed questions:** breathlessness on walking and when lying down	
019 **(D)**	Anaemia	Sickness if over eat; bleeding in throat and vomiting large amounts of blood (now stopped). **Elicited by closed questions**: Pain in stomach; loss of appetite; tiredness; increase in breathlessness; pain in chest when breathing in.	
020 **(D and Q)**	Persistent cough	Weight loss; fatigue; taste change; hot and cold sweats; reduction in appetite **(closed question)**	breathlessness on physical activity; weight loss - some weight now regained **(open question)**
026 **(D and Q)**	Persistent cough; recurrent chest infections for the last 10 years.	Regular chest infections and productive coughs; recent weight loss; cough triggered by eating, talking and cold air; dullish ache in back; coughing up occasional flecks of blood; fatigue and energy loss; night sweats – started at menopause but now every night **(closed question)**	

Incidental Diagnoses			
	Triggers to diagnosis	**Symptoms of concern/disease** (Elicited by open questions)	**Symptoms as normal processes** (Elicited by closed questions)
03	CXR following traumatic injury	Gradually increasing breathlessness not noticed until diagnosis.	Weight loss
07	Routine CXR on hospital admission		Fatigue
010	Routine CXR on hospital admission		Change in bowel movements, fatigue
011	CXR Investigation of increased		Breathlessness; aches and pain back of left shoulder

	heart rate following surgery		under arm and side of chest; fatigue
021	CXR investigation of weight loss and anaemia detected by health screen	Anaemia	Weight loss
022	CXR following traumatic injury		Cough; taste change; bowel changes
028	Imaging of kidney to investigate haematuria	Chest infection following investigation for LC	Breathlessness

[1]Occasionally participants would provide a symptom of concern/disease account when describing previous help-seeking, but would then reinterpret and normalise the symptom if it had improved since seeking help.

Table 4: Comparison of 'Symptoms of Concern' and 'Symptoms as Normal Processes' accounts

	Symptoms of Concern/Disease accounts	Symptoms as Normal Processes accounts
P6	LR: ...how [do] you think it all sort of started? P6: ... we went merrily on our holiday, and the cough just got worse and worse and worse. Coughing 24 hours a day the whole of the five days we were away...I went to see a doctor [who prescribed antibiotics] ...the antibiotics didn't touch it at all, so when we came back, I went to see one of my own doctors and he said 'you've probably got a chest infection. I'll give you some more antibiotics'...'if at the end of seven days it hasn't gone, then I think you'd better go and get an x-ray'.	LR: OK. So cough, we've done. Breathlessness? P6: …That [the pacemaker] cured it...so at the moment I'm just left with the cough or whatever... LR: So the only times you get breathless really are then when you're coughing? P6: Yeah. LR: Do you notice (.) is there any other time now P6: Occasionally I get breathless walking up hill, but that's to be expected. P6P: And you did a bit Friday which was stress I think. P6: Yeah, Friday…It does occasionally happen when I'm sitting down ... Up to recently I've been playing golf twice a week, so there can't be an awful lot wrong with me, but I do get occasionally short of breath…Just suddenly start breathing rather rapidly
P12	LB: Do you want to just tell me how you came to be in Mr [ ] clinic and what were the events that [P12: yes. I had a particularly persistent cough that wouldn't go away...although it was literally just a sort of a clearing the throat, that sort of thing... [then] I woke in the middle of the night with a cough, my mouth filled with what I thought was catarrh, went to the basin, spat it out (.) blood bright red and dark red. And it bled for about 10 or 15 minutes...and it hasn't bled since... Anyway, Monday ... went to see GP... immediately gave me the ticket to go to the walk in x-ray [ ].	LB: Have you lost any weight at all? P12: A bit, mm. I would say less than half a stone P12P: We have a very active cruise, we do a lot of walking and sightseeing... P12: And then you know, we go to [UK holiday destination] most years. And we walk a tremendous amount. And I swim a lot there, don't I? So that's a very active holiday.

P16	P16**:** I developed a cough and also that I didn't feel very well and I'd also lost some weight. I went to the doctors ... [s/he] sent me for a blood test and an x-ray. And several days later [s/he] rang and said I want to see you and by this time I'd got my appetite back and my weight had come back up again...	P16 : I think perhaps if it had just been a cough, perhaps I wouldn't have bothered … P16P: … after you were feeling better, you'd put weight back on and you'd still got this funny cough, I think you could have gone on for months with that funny cough [ ]... P16: LR: have you experienced any breathlessness at all? ((pause)) Or sort of thing like you [P16: I play golf and parts of the course are a bit steep and I must admit I get a bit puffed going up there but yeah it's not serious I just got to take it easy… as you get older so you can't do the things you did when you were a bit younger so ...quite often you put things down to change of your age and lifestyle and it wasn't that significant...I really wouldn't say I get breathless, I mean you [participant's wife] couldn't keep up with me.
P23	P23: and then we got to Christmas, and we were partying etc and to be quite honest, I should have put on more weight than I did. So I started to think 'well what's going on?' About [ ] months ago I had a colonoscopy and had a few polyps removed etc...I started to get night sweats, totally different from hot flushes...so I thought 'oooh this is a bit odd'.	LB: Have you suffered from any backache or shoulder ache? P23: No. LB: Anything that you thought might be something else wrong? P23: I've had perhaps the odd twinge [in fingers] that I would put down to arthritis while doing the garden or something but – this is the annoying fact, I am quite healthy; well I think I'm quite healthy, and so no I wouldn't say I've had aches and pains.
P24	P24: I started coughing up blood and I was already at Dr [ ]s clinic and when I told [her] I was coughing up blood, s/he referred me to the chest clinic which is next to Oncology, so that made me feel a bit suspicious... By that time I was admitted to hospital because I was coughing up what I thought was a lot of blood, and I had a lot of problem breathing... Dr [ ] came over to see ...and	LB:...when you were having breathing problems, did you ever have any wheezing with it? P24: Oh I do wheeze a bit in bed now. It's just you get used to the noises that your chest makes don't you really? I just think 'oh shut up'. I mean I do sleep very, very well unless I'm depressed...Sometimes just when I lie down I'll wheeze a bit and that's

	he changed my inhalers and took me off beta blockers and transformed my life!	obviously changing from upright position to lying down but and not to any extent.
	Incidental Diagnosis	
P3		LR: Er, so have you had any weight loss at all? P3: Yes. The lady [ ] that dances with me, she's been making off for months now that I'm losing weight. LR: Yeah? P3: Yeah. So I expect to lose weight in the summer months because you're more active over the allotments. .. plus the days are longer so you spend longer away from home so you don't eat so much, but I used to be [ ] stone, but when she weighed me yesterday with my clothes on, she said I was [1.5 stones less] LR: ...you think that's just over the summer or ? P3: I reckon that's over the last two years. LR: Yeah? RES: Yeah. I reckon about the last two years, because I always said [1.5 stone heavier than current weight] stones is too heavy for me. And then people would say it's a beer gut
P28		LB: Have you had any other types of cough that have lasted more than three weeks? P28: No. LB: No. Would you say you had a smokers cough... P28: No I wouldn't actually! Would you? No. P28P: Not really. P28: No, never hacking coughs or anything. P28P: not a dry cough like ( ) LB: Sorry you didn't have a dry cough? P28P: No. No. ((pause)) No more than a lot of people have got you know. In the day and you know

APPENDIX 1 (Web Only File)

Interview topic guide: IPCARD Chest Symptoms Study

I. +II. **Unstructured and Semi-structured interview**:

- Record patient's health and illness experiences
- Focussing on the period leading up to their referral for LC Investigation and all experiences of health and illness during the last 2 years, explore:
    - participants' interpretations of and explanations for symptoms
    - Impact of ill health/symptoms

III. **Structured interview**:

- Explore list of specific symptom presentations and health changes (attached).

IV. **Further semi-structured interview questions**: Help-seeking behaviour and use of health services (These questions are to follow accounts of symptoms elicited in sections I, II and III):

- What did you do about [symptom/health change]?
    - any health care, treatments, information or advice received
    - reasons for seeking or not seeking medical help.

Introduction

"Thank you for agreeing to this interview. It should take about 60-90 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. I would like to build up a detailed picture of your experiences of health and illness. I am interested in anything that you noticed about your health even if you thought it was minor or not connected to your recent visit to [hospital/clinic]. I will then be asking you to talk in more detail about your experiences of health from when you first noticed a change in your health up to the time when you were referred to the [clinic] and about all aspects of your health in the last 2 years."

Section I

The topic guide provides a number of questions which the interviewer might use to initiate discussion about a particular topic. However, the interviewer might revise the questions, or alter their order, in light of the interviewee's response to earlier questions.

Part 1: Exploration of health and illness

Purpose: To explore the participant's experiences of health and illness over their lifetime including any symptoms/problems/changes in health that they have noticed in the last 2 years.

- Could you tell me how you came to be in Dr [ ]'s clinic/ came to be seeing Dr X
- Please tell me about your health and any illnesses that you have experienced

- How has your health changed (are there any changes that you noticed)?

Section II

- When did you first notice something was wrong, or a there had been a change in your health?

- Have you experienced any other changes in your health during the last 2 years?

Prompts: use following prompts to aid recall of dates:

- What year was this?
- What month was this?
- What season was this?
- What it close to an event in the year, such as Christmas or Easter?
- Was this at the same time as any other event in your life?
- Was this at the same time as any family/ social event?
- What else was going on in your life at the time?

- Has there been anything else that you have visited your doctor about during the last 2 years?

- Has there been anything else at all relating to your health that you have noticed during the last 2 years even if minor?

Probes: for all illnesses explore:

- Severity
- Duration
- Change over time/how/when (use same probes as for Part 1)
- Impact (social/lifestyle/ family/psychological/ what did the participant think about their symptom)
- Participant's explanations for illness/associated with?/causes

Section III

"I have a list of things that some people notice before they are told that they have a chest problem. I am going to ask you if you experienced each of these things. I will then ask you about each health change that you experienced in more detail."

01. Cough	YES NO (see structured guide - cough)
02. Coughing up blood	YES NO (see structured guide - haemoptysis)
03. Breathlessness or panic attacks	YES NO (see structured guide - breathlessness)
04. Changes in eating, appetite, taste or weight	YES NO (see structured guide – eating/weight)
05. Pain	YES NO (see structured guide - pain)
06. Discomfort or strange sensations	YES NO (see structured guide – discomfort)
07. Aches or pain in chest, back, shoulders or joints (if not mentioned in response to 5 and 6)	YES NO (see structured guide – specific aches)
08. Skin changes	YES NO (see structured guide – skin)
09. Lots of infections	YES NO (see structured guide - infections)

10. Tiredness	YES NO (see structured guide – tiredness)
11. Feeling generally unwell	YES NO (see structured guide – unwell)
12. Hot or cold sweats	YES NO (see structured guide – sweats)
13. Voice changes or hoarseness	YES NO (see structured guide – voice changes)
14. Other (DESCRIBE) ¬¬¬¬¬¬¬¬¬¬¬¬_____	YES NO (see generic guide – other)

Information: Turn to relevant problems identified by participant. Only sections relating to the problems/changes identified by the should be completed

Section IV

Semi-structured interview: Help-seeking behaviour and use of health services (These questions follow accounts of symptoms elicited in sections I, II and III, and do not necessarily come at the end of the interview):

- What did you do about the symptom?

  Prompts
  - Confided in close family member/friend– who did you talk to first?/who else did you speak to
  - Found information (Read health related article in magazine or book, Consulted a medical dictionary/encyclopaedia, watched a health related TV/Video, Undertook an internet search),
  - Sought advice (e.g .Sought advice from NHS direct/ walk-in centre, Spoke to practice nurse/other health professional, Spoke to your GP/made appointment to see GP)
  - Treatment (other than GP advised) Took over the counter medication (self-prescribed or pharmacist consulted), Took complementary medicine/ therapy

- Why was that, what was it about your [symptom] that made you do /see X/not seek help?

- What happened when you did X?

- Have you done anything further about/received any further medical care /help with [symptom] since X?

  - If further help was sought - what made you seek this help?

- Please describe any changes in the way you manage or live with the [symptom] since x

Relationship with GP and barriers to use of primary care services

- Have there been any circumstances in which you were unsure about whether to seek help from your GP?

- What things have made you decide against visiting your GP/practice nurse?
- Have there been any other circumstances in which attending your GP would have been difficult?
    - What were these?