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## **Lung cancer diagnosed following an emergency admission: Exploring patient and carer perspectives on delay in seeking help**

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## **Lung cancer diagnosed following an emergency admission: Exploring patient and carer perspectives on delay in seeking help**

### **Abstract**

**Purpose:** Compared to others, patients diagnosed with lung cancer following an emergency, unplanned admission to hospital (DFEA) have more advanced disease and poorer prognosis. Little is known about DFEA patients' beliefs about cancer and its symptoms, or about their help seeking behaviours prior to admission.

**Methods:** As part of a larger single centre, prospective mixed methods study conducted in one University hospital, we undertook qualitative interviews with patients DFEA and their carers to obtain their understanding of symptoms and experiences of trying to access health care services before admission to hospital. Interviews were recorded and transcribed. Framework analysis was employed.

**Results:** 13 patients and 10 carers, plus 3 bereaved carers took part in interviews. 3 patient/carer dyads were interviewed together. Participants spoke about their symptoms and why they did not seek help sooner. They described complex and nuanced experiences. Some (n=12) had what they recalled as the wrong symptoms for lung cancer and attributed them either to a pre-existing condition or to ageing. In other cases (n=9) patients or carers realised with hindsight that their symptoms were signs of lung cancer, but at the time had made other attributions to account for them. In some cases (n=3) a sudden onset of symptoms was reported. Some GPs (n=6) were also reported to have made incorrect attributions about cause.

**Conclusion:** Late diagnosis meant that patients DFEA needed palliative support sooner after diagnosis than patients not DFEA. Professionals and lay people interpret health and illness experiences differently.

Key words: delay in help seeking, diagnosed following emergency admission, late diagnosis, lay epidemiology, lung cancer.

## **Introduction**

Compared to other countries, fewer UK patients with lung cancer are diagnosed at an early stage [1]. Approximately 40% of UK patients are diagnosed following an emergency admission (DFEA) to hospital [2] through, for example, the accident and emergency department or urgent GP referral [3]. Patients DFEA are more likely to have advanced disease, and poor prognosis [4]. Patient related delay, defined as the period between patients becoming aware that something is wrong and the time when they seek medical advice [5], is identified as a key factor contributing to late diagnosis [6].

The reasons given by patients for their delay in seeking help may appear irrational to health professionals. Findings from previous research suggest that while patients understand scientific and clinical issues about risk in lung cancer, they also have beliefs and knowledge drawn from a wider cultural and social sphere, which influences their help-seeking behaviours [6, 7, 8, 9]. There is also a body of evidence from varied contexts which underlines the importance of lay beliefs and knowledge as determinants of help-seeking behaviour [10, 11, 12, 13, 14]. Understanding the context within which lay people make decisions about whether or not to seek help may enable health professionals to engage more effectively with patients with, or at risk of, lung cancer.

Patients who present late are likely to have many symptoms, which can have an adverse effect on their quality of life [15, 16, 17, 18]. Research studies in the context of lung cancer have identified a number of factors that may influence patients' decision-making processes [19, 20], including the belief that bodily changes are normal [7, 8], or that symptoms they experience are minor or do not require medical assistance [8, 9]. Worry about wasting doctors' time, fear of receiving a serious diagnosis or living in a social setting

where individuals make poor use of healthcare provision can all affect patients' decision-making processes with regard to help-seeking [9].

Campaigns targeted at individuals vulnerable to lung cancer can be effective. A project in Yorkshire, England, which implemented a public awareness campaign alongside intervention training for GPs, found that in the intervention area patients were 1.97 times more likely to go to their GP with a cough and 21% of the targeted population remembered the campaign [21].

In the East Midlands region of England during 2011 the Department of Health's *Be clear on cancer* campaign was piloted. This was a series of TV, radio and press advertisements which encouraged people to consult their GP if they had a cough for more than three weeks [22]. An evaluation of GP practices involved showed that the number of patient visits with a cough increased by 23% compared to the same period in the previous year [23]. In 2013 there was a follow up campaign on national TV, radio and press, encouraging individuals to seek help if they had a cough for three weeks or more [24].

## **Methods**

We report here on one aspect of a three phase, mixed methods study (Figure 1) which aimed to explore in detail the characteristics, needs, experiences and outcomes of a cohort of patients diagnosed with lung cancer following an emergency admission [25]. An overview of findings from the study, reporting both quantitative and qualitative findings, has been published elsewhere [26].

Figure 1: Three phase mixed methods study

The study aimed to explore the experiences and needs of patients DFEA and identify areas where care might be improved. It was carried out at Nottingham University Hospitals NHS Trust.

**Phase 1:** basic information from hospital records on all patients diagnosed with lung cancer in 12 month period (n=401)



**Phase 2:** all patients DFEA (n=154) and/or family carers invited to complete questionnaires covering performance status, needs, experiences, co-morbidities



43 questionnaires completed (37 patients and 6 carers)



**Phase 3:** qualitative interviews with patients and carers (13 patients and 10 carers)

This paper describes the perceptions of a subgroup of patients and carers who were recruited to qualitative interviews about early lung cancer symptoms, and their reported reasons for delay in seeking medical help. It focuses on what participants had to say about their experiences before diagnosis and how they made the decision to seek help as and when they did. Gaining perspectives from patients and their companions was seen as essential in informing understanding of areas where there may be potential to improve the care provided to them. It also provided an opportunity to discern respondents' views about the 'cough' campaign.

We follow the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines in reporting the qualitative aspect of this study [27].

Permission was sought from all phase two participants for the researcher (GC) to contact them to discuss the interviews further. Patients were excluded if they were experiencing extreme distress, were unaware of their diagnosis, lacked the capacity to consent or were unable to communicate in English. If patients were unable to participate an informal carer was asked to act as proxy.

Interviews were conducted at the time and place of the participant's choice, which was usually their home. Written informed consent was obtained and all interviews were, with participants' permission, audio recorded and transcribed. Thirteen patients and ten carers took part in interviews. Three patient and carer dyads chose to be interviewed together. Three interviews were carried out with bereaved carers, at least six weeks post-bereavement. Seven women and six men took part in interviews as patient participants; the men had a mean age of 79, and the women a mean age of 65 (see Table 1). Interviews were conducted between February 2013 and January 2014.

Semi-structured interviews were carried out by one researcher, using an aide-memoire based on patients' expected pathway through treatment. Participants were encouraged to talk about their experiences in their own words, to gain an understanding of patients' experiences prior to emergency admission. Additionally, narratives of the overall care they experienced since emergency admission were sought.

The study was approved by the National Research Ethics Service Committee East Midlands – Nottingham 1 (12/EM/0305) and adopted onto the UK National Institute of Health Research portfolio (12993).

Table 1: Characteristic of participants

Patients interviewed (n=13)

Male	6
Age range	64-91
Mean age	79
Female	7
Age range	49-82
Mean age	65

Carers interviewed (n=10)

Relationship to patient

Wife	2
Daughter	4
Widow	2
Daughter-in-law	1
Stepson (post-bereavement)	1

Location of interviews

Home	18
Quiet room in hospice	2
Chemotherapy unit	2
In-patient side-room	1



## *Analysis*

After transcription interviews were analysed using NVivo10 to manage the data. The analysis was carried out using the constant comparative method, with two researchers (JS and GC) working independently on transcripts to aid rigour [28].

## **Results**

Patients' experiences were complex and nuanced, and most did not have just one symptom which could be recognised as caused by a serious disease. Participants spoke about their early symptoms and the circumstances which meant they did not seek help from medical professionals sooner. Although some had symptoms which suggested that something was wrong, it was not necessarily the case that they could recognise those symptoms as indicative of lung cancer, even if they were aware of the public health campaigns which had run in the area. For example, being cough-free suggested to some individuals that the campaigns did not apply to them.

While the decisions patients made about whether or not to seek help were made in the context of their wider understandings of health and illness, pre-existing health conditions also influenced their perception of 'new' symptoms and health events.

In summary, we found three patterns, examined below:

- Patients attributed symptoms either to natural ageing or to a pre-existing illness
- Patients had symptoms which were appropriate for lung cancer, but which they did not recognise
- Patients experienced a sudden onset of symptoms

We begin by presenting a short case study which illustrates the complexity of patients' situations. Patients are identified by their study number, carers by the prefix 'C'.

Figure 2: Case study

Case study:

Patient 001 and his wife C001 were interviewed together. He had been diagnosed with atrial fibrillation (AF) some years before, and the earliest symptom of this had been breathlessness which became incapacitating. When 001 experienced breathlessness again he made what appeared to him to be the rational assumption that it was the AF causing it and for some reason the medication he was taking was no longer working efficiently. One of the medications that 001 took for his AF listed in its patient information sheet a cough as a known side effect. In addition, one of 001's young grandchildren had a cough to which he had been exposed. 001 was slow to seek help from his GP because he believed he knew what was causing his symptoms, and that cause was not lung cancer. 001 was a smoker at the time of diagnosis, but he considered himself to be fit and healthy because he went to the gym regularly, played cricket and had played non-contact rugby until fairly recently.

What 001 did was to fit the symptoms of cough and breathlessness into a lay script which made sense of what was going on in terms of his own life and experiences [30]. Although he was aware of possible scientific explanations for his symptoms he did not see himself as a likely candidate for cancer, even though he was a smoker, given his level of fitness and pre-existing controlled condition [31].

001's wife, C001, did not believe that his cough was a medication side effect, saying that his cough had endured for about a year, which he denied. C001 was aware of the advertising campaign about going to the doctor with a persistent cough, but although she pointed this out to her husband he refused to seek help and considered her to be nagging. His smoking worried her, and she was disappointed that no health professional at any time during the course of his progress through the system advised him to stop smoking. She did acknowledge, however, that her husband's lung function test showed excellent results for a man of his age. Like her husband, C001 was utilising her lay understanding of illness to make sense of what was happening with 001. However, her belief system was different to his, and included the knowledge that an aunt to whom she was close had died of lung cancer in the recent past, and her aunt had also had trouble breathing and a persistent cough.

In using their knowledge and beliefs, patient 001 and his wife were similar in approach to other patients and carers who participated in the study.

## **1) The wrong symptoms**

In some cases the patient or carer reported that they recognised the patient was ill, but did not recognise symptoms as indicating a serious illness. Such symptoms included swollen eyes, back ache, tiredness or pain. One patient (101) claimed that he had experienced no symptoms at all, but then revealed he had lost a lot of weight. A woman in her forties, interviewed with her daughter, said:

Well, I knew something was wrong when I, I realised my hands were, my hands were changing ...They went like my dad's. They went, they sort of went old and big (231).

In these situations patients and carers tended to develop alternative explanations for the symptoms (Table 2). Some reported that their GP also offered explanations not involving lung cancer so that GPs, at least in the early stages, sometimes reinforced patients' and carers' personal rationales.

### *Other attribution by patient*

A number of patients had pre-existing health problems, including diabetes, fibromyalgia and phlebitis. Symptoms experienced were often attributed to this pre-existing condition, even when the symptom was a new development. The widow of a patient who had a prior diagnosis of fibromyalgia said:

The other thing that was happening with him was he was getting very tired and he was in quite a lot of pain but that was because, well, we thought, it was because of other health problem that he had (C071).

Where patients had no pre-existing health problem their attribution of cause related to alternative factors, such as tiredness due to age or pain due to muscle strain:

She, my mum thought, because she'd got the flat where she lived, where she'd got a tray on a trolley and she used to have to pull

herself up with it so she thought she'd strained a, or pulled a muscle (C103).

In the following extract a wife describes her husband's increasing tiredness as he came closer to retiring from work:

You was a little bit tired, weren't you, but you kept saying Oh, I'm getting, getting on a bit, you know, feeling my age a bit... you'd come home and doze in the chair, wouldn't you, and then you'd have your dinner and then you'd have another doze (C273).

In this situation, patients and carers made common sense attributions of the new health events in their lives.

#### *Other attribution by GP*

In some cases patients went to see their GPs, and reported that the GP attributed their problem to a cause other than lung cancer. Such attributions included sciatica, tonsillitis, depression and pain. For example, the carer of a 78 year old man recalled how the GP attributed his signs of illness to pain from a knee replacement:

We said, you know, he's really finding it hard to mobilise and you know, loss of appetite and depression. And, (the GP) instead of looking for another reason, it was, oh well, he's in pain. You know, if you sort the pain out, we'll sort the other bits out (C164).

Table 2: The wrong symptoms

<p><b>The wrong symptoms</b></p> <p>Other attribution by patient:</p> <p>It didn't go on, I mean, sometimes, she was nasty to me, but I put it down to frustration because she'd also had, a year ago, a shoulder replacement of which she'd, some months back, she tore something and she was going, due to go in and have this looked at and repaired. So the, her odd behaviour now and again, I put down to pain (C362).</p> <p>I don't want to lose any more weight... I'm only nine stone four now. I was eleven stone two before I used to look after F., I looked after her for three and a half years at home and she just wore me out, wore me out (101).</p> <p>Other attribution by GP:</p> <p>So she came home that day from the doctor's really upset, thinking, like, I didn't realise I was depressed, and, she started acting depressed because the doctor told her she was depressed (C231).</p> <p>But what I don't like is that it's seeing a different doctor every time you go. And each doctor thinks one thing, that's why different things have been written on my, and in the end, I had say to them, 'Can you please put tonsillitis, you put tonsillitis on the last sick note, can you put tonsillitis on this?' (005).</p>
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### **The right symptoms**

Some patients had symptoms which they were able to recognise with the benefit of hindsight as being signs of lung cancer, but which they recalled not recognising at the time. These symptoms were mainly a cough and breathlessness, and, as shown in Table 3 patients, carers and GPs sometimes developed alternative attributions.

*Other attribution by patient*

In some instances a pre-existing health condition was thought responsible for the new symptoms so that a patient with atrial fibrillation (AF) thought his breathlessness was caused by the AF:

He had breathing problems and that was evident at Christmas, he was quite sluggish and any exertion, it was difficult to find his breath... And I did remember saying, 'Can you have a look at the heart?' ... he'd got (pre-existing) AF (C066).

Other patients with breathlessness thought this was caused by COPD or asthma, and in one case it was believed to be a side effect of medication taken for AF.

Not having a pre-existing medical condition to which a cause could be attributed did not necessarily mean that patients would consider lung cancer as a possible cause. For a 55 year old woman with a persistent cough, this made her like everyone else in her workplace:

I'd had a, well, everybody at work had had it, we'd all sort of persistent, I work for a GP's surgery, we'd all had persistent coughs... And I'd had a course of treatment with steroids and then the cough came back (104).

In some cases GPs were also reported as making a mistake as to cause of the symptoms with which patients presented.

#### *Other attribution by GP*

One daughter described how her mother was diagnosed with a urinary tract infection (UTI) by her GP:

And so she was given some antibiotics for the UTI which, first one didn't work, second one didn't work, and, she was phoning me up at three, four o'clock in the morning, she lives the other end of the village, stating she was feeling really, really poorly... I called the GP out a few times and then eventually, I got her in to hospital (C362).

An 82 year old woman described a complex health situation which included feeling generally unwell, having unexplained weight loss, and finally being admitted to hospital with pneumonia. She also suffered back pain which was ascribed to sciatica by her GP, although with the benefit of:

I'd (had) the doctor myself, she'd examined me, she said, I, I'd got pains in my back..., my own GP and she'd said I'd got sciatica in my back bone...and I reckon that's when the lung collapsed, I do. But, I'm not a doctor so I don't know. I just think it in my head, that's when it was (073).

### *Help sought from GP*

Patients who experienced recognisable lung cancer symptoms had differing perspectives on help-seeking. Four patients with a cough sought help from their GPs after three or four weeks. They were aware of the campaign about going to the doctor with a persistent cough and they followed the advice. In all four cases the GPs tried other remedies before referring the patient for investigations. One 81 year old woman went to her GP with a cough which she had unsuccessfully tried to treat herself:

It kept me awake at night, kept my husband awake and so you've got to do something about it when your, you try your own medication and things, don't you, buy things and try those. And it didn't work, so then I went to my GP... Took it from there and he tried lots of different things... Well, I read it in the surgery. If you have a cough for longer than three weeks, see your GP ... plus the fact that I didn't like the cough, I mean, I'm not, you know, I'm quite sensible, I've not lost my brain (249).

The only symptom one 91 year old man had was shortness of breath for about a week before he called his GP. He said:

I was suffering shortness of breath and she (GP) said I was short of oxygen and something else. Must go to hospital. Do I have to? Yes, you do... No pain, or anything... I was just short of breath (167).

### *Help not sought from GP*

Having an enduring cough or breathlessness was not necessarily enough to prompt patients to go to their GP, and three patients came into this category; they were aware of the advertising campaign, but did not apply it to themselves.

A 61 year old woman thought that the adverts were pointless. Prior to diagnosis she had a continually runny nose and a cough, but she had not sought advice because she did not believe her cough was caused by smoking. Receiving a diagnosis of lung cancer had prompted her to stop:

And since I've stopped smoking, well, I don't cough at all. Because my nose has stopped running. So it was my smoking that was causing my nose to run, what everybody kept telling me and I didn't believe them (179).



Table 3: The right symptoms

<p><b>The right symptoms</b></p> <p>Other attribution by patient:</p> <p>We'd both had a really bad sort of fluey type, I don't know, probably really bad colds, we thought. I recovered but R. got this cough... it was a sort of normal pattern for him, things to go to his chest, so we weren't thinking that it was something major (C071).</p> <p>Other attribution by GP:</p> <p>I couldn't get my breath very well, so I wasn't feeling too happy... Anyway, the next, oh that, we sent for the doctor, that was it, that day. And, he thought I was having a panic attack, so it was just left at that. The next morning, I was really ill... But by the time the medics came, I was quite ill. And they said I had to go into hospital (249).</p> <p>Severe back pain, at first... they thought it was a slipped disk or something like that... It gradually got worse, yes. Over, over that period, I would say, gradually got worse, didn't it (079).</p> <p>Well, it would be, last October, he had like a tickly cough... we had Christmas and he was fine, and after Christmas, we was more or less going every month to see Dr R., and but it took a long while to find out exactly. Because she did say It could be emphysema, it could be TB...(C154).</p>
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### **Sudden onset**

A small number of patients or carers reported a sudden onset of symptoms prompting them to seek medical advice. For two older men, one of whom experienced shortness of breath (109) and one who had worsening pain in his back (079), this was their only symptom. For other patients, however, who were prompted to seek help by the sudden appearance of one symptom, discussion during interview revealed a number of underlying symptoms. A 61

year old woman who had the sudden onset of pain and difficulty in breathing said:

And, sort of, when you wake up in the morning, I've got this little twingey thing, it'd been there quite a few month, and I just assumed it was because my bladder was full (179).

## **Discussion**

The symptoms and experiences which patients in this study reported, and the ways in which they viewed those symptoms, are consistent with the findings of other studies [6, 7, 8, 9, 15, 16, 17, 18, 19, 20]. Reporting patient experiences as has been done in this paper makes it appear that such experiences are linear and straightforward; as if each patient has one symptom about which they make one single attribution and one decision about help-seeking. This, however, is not the case. Each patient and carer who took part in an interview had a complex story to tell, in which the symptoms, attributions and decisions made about them were nuanced in sometimes subtle ways.

Health care professionals and patients perceive illness differently from each other, and use different explanatory models to explain experiences of health and illness [29, 30]. Lay people have access to a well-developed epidemiology which they use to make sense of their health-related experiences [31]. This epidemiology incorporates elements of scientific explanation, as well as elements from everyday experience and collective knowledge [32]. In terms of cancer, lay understandings may make use of an explanatory hierarchy in which smoking is identified as a prime cause, but in which cancer is also seen as unpredictable and random [32]. This unpredictability, alongside a lack of in-depth knowledge of lung cancer signs and symptoms, means that individuals may not recognise the significance of symptoms they experience.

Health professionals interpret the symptoms that patients bring to them from within their skill and knowledge set, developed through basic scientific training plus experience and ongoing professional development. Lay people also interpret their symptoms through their skill and knowledge set, but their

knowledge set is differently derived from that of professionals. Lay knowledge may owe something to science; it is well known, for example, that there is a causal link between smoking and lung cancer; but lay understandings of health and illness also incorporate ideas and beliefs garnered from other sources [32, 33]. These sources may be as diverse as personal experience and knowledge of how the individual's own body works; cultural beliefs about what constitutes health and illness; socially embedded ideas about the importance of stoicism in the face of adversity; inexperience of engaging with health services [8, 33] and beliefs acquired through inter-personal relationships [33].

Lay knowledge and beliefs will influence the decisions that individuals make with regard to their own health and illness, and how they interpret symptoms of disease. Patient 001 was a smoker, but because he exercised regularly he believed he was healthy despite the fact that he smoked. As a fit and healthy person he saw himself as an unlikely candidate for cancer, so the decisions he made vis-à-vis seeking assistance for his cough were influenced by his self-perceived immunity. Patient 179 was also a smoker who did not consider herself a candidate for lung cancer. Smoking was the norm in her family, and none of her relations had ever been diagnosed with lung cancer; from 179's perspective this made her an unlikely candidate for lung cancer [31, 32].

### **Strengths and limitations**

One limitation of the study is that we were reliant on participants' recall of events that had taken place during a stressful period in their lives. In addition, we were unable to achieve data saturation; some in the patient group became too ill or died before we had the opportunity to interview them. This also prevented us from engaging in the process of respondent validation. A particular strength of the study is that we were able to interview terminally ill patients and gain their perspectives; these are members of a group not routinely included as research participants.

## **Conclusion**

Late presentation for diagnosis and treatment remains a major problem in lung cancer care, with consequent poor prognosis and high mortality. This paper provides insights into patients' interpretations of their symptoms and what they recall about GP responses to their concerns when they visited the surgery. The complex stories that patients and their companions narrated suggests that patients and GPs sometimes interpret the significance of otherwise 'red flag' symptoms in the context of multiple morbidities and ageing, and may only recognise the significance of these in hindsight. Amongst patients and carers, we also saw an explanatory hierarchy in which smoking was identified as a prime cause, but in which cancer was seen as unpredictable and random. Our data highlight the challenges the cough campaign faces in trying to change knowledge and behaviour amongst both lay people and primary care professionals and suggests that there are limitations to focusing on one symptom in public health campaigns and professional education. An enduring cough is well known as a possible sign of lung cancer, but public and professional health education is needed about symptoms beyond a cough to help patients and their companions to access help more quickly. We recommend that patients who have received a lung cancer diagnosis on emergency admission are routinely referred for a specialist palliative care assessment, in order to provide them with the best possible supportive care while taking account of their multiple morbidities, age and frequently complex social contexts.

## **Disclosures:**

None

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