

## Diagnostic delay in lung cancer: a qualitative study

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Accepted for publication 27 July 2007

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TOD A.M., CRAVEN J. & ALLMARK P. (2008) Diagnostic delay in lung cancer: a qualitative study. *Journal of Advanced Nursing* 61(3), 336–343  
doi: 10.1111/j.1365-2648.2007.04542.x

### Abstract

**Title.** Diagnostic delay in lung cancer: a qualitative study

**Aim.** This paper is a report of a study to identify factors influencing delay in reporting symptoms of lung cancer.

**Background.** Lung cancer accounts for approximately 5% of deaths in the Western world. For up to 80% of patients, their disease is inoperable because it has been diagnosed too late. This suggests that reducing diagnostic delay could reduce mortality.

**Methods.** This qualitative study was conducted from July 2005 to May 2006 in community and hospital settings in the United Kingdom. A purposive sample of people diagnosed with lung cancer in the previous 6 months ( $n = 18$ ), and two 18-month survivors took part in individual interviews.

**Findings.** Participants reported a range of interrelating factors that influenced delay in reporting symptoms of lung cancer. Barriers to symptom reporting included symptom experience, lack of knowledge and fear. Blame and stigma because of smoking were also prevalent influences, as well as cultural factors, non-standard patterns of healthcare utilization and underlying stoical attitudes. The only factor to emerge as helpful in overcoming delay was the role families played.

**Conclusion.** Lack of knowledge and awareness about lung cancer could be addressed by better education of the public. Social marketing is a way of developing education messages which tackle cultural influences on treatment-seeking delay. Nurses have a potential role in developing and disseminating those messages.

**Keywords:** health education, interviews, lung cancer, nursing, qualitative research

### Introduction

#### Lung cancer incidence and mortality

Lung cancer is one of the main causes of cancer death in the Western world. For 80% of people with lung cancer, their disease is inoperable because it has been diagnosed too late. The UK lung cancer 5-year survival rates (7%) are lower than those in Europe (16%) (Cancer Research UK 2007a). This variation in mortality is attributed partly to differences in

patient delay in symptom reporting. Reported patient delay ranges from 7 days in Italy and 6 months in the USA (Jensen *et al.* 2002). In a striking comparison, Corner *et al.* (2005) revealed a delay of over a year in the UK. Poor UK lung cancer survival rates may be further compounded by lower rates of surgical resection (10% in the UK compared to 28% in the US) (Corner *et al.* 2006) and chest X ray (Rogers 2006).

In the UK, national inequalities in lung cancer incidence and survival are compounded by deprivation. Possible

explanations include higher smoking levels (Cancer Research UK 2007a) and barriers to accessing health services (Tod *et al.* 2001). There is now recognition of the need to address this unfavourable picture in the UK. One strategy is to address the delay that may occur between patients noticing symptoms and reporting them to a doctor:

If lung cancer could be detected sooner then survival could improve without advances in therapeutic armoury. (National Cancer Research Institute 2006, p. 21)

Initial work by Corner *et al.* (2005, 2006) indicates that interpretations of symptoms and broader social factors may delay diagnosis. One UK lung cancer study that suggests delay is explained by blame and stigma, but more evidence is required (Chapple *et al.* 2004). This study aims to further explore and explain delay, particular prediagnostic delay, in lung cancer and to consider the implications for public education and nursing.

## The study

### Aim

The aim of the study was to identify factors influencing delay in reporting symptoms of lung cancer.

### Design

A qualitative approach was adopted, using semi-structured individual interviews and framework analysis techniques to interpret the data (Ritchie & Spencer 1994, Ritchie *et al.* 2003).

### Participants

The study took place from July 2005 to May 2006 in a deprived health district in the north of the UK with high rates of lung cancer. Participants were recruited through a respiratory physician and lung cancer nurse specialists, who contacted interviewees on our behalf.

Purposive sampling was used to recruit 20 patients who varied in age, sex, geographical location, lung cancer history (e.g. type of cancer and symptoms) and smoking history (Table 1). Eighteen had had a diagnosis of lung cancer within the past 6 months and two were 18-month survivors. There were eight women and 12 men, ranging from 47 to 81 years of age. Nine patients were ex-smokers who had smoked for between 7 months and 33 years; three were lifelong non-smokers.

### Data collection

Interview schedules for the semi-structured individual interviews were developed with reference to previous qualitative literature on delay (Corner *et al.* 2005, Chapple *et al.* 2004). Patients were interviewed at home, lasted between 30 and 60 minutes, and interviews were audiotaped and transcribed. Field notes were taken during and after the interviews. Partners or a friend participated in the interview at the request of 12 participants.

### Ethical considerations

The study was approved by a health service research ethics committee. Written and oral information about the study was given to potential participants, with opportunities to ask questions before being interviewed. We informed participants that their interview data would be anonymized and that, although direct quotes might be used in reporting the data, any identifying details would be deleted. Consent forms were signed and the tapes were destroyed at the end of the study.

### Data analysis

Transcripts were anonymized and entered into QSR NVIVO, a computer software package for managing qualitative data. They were analysed using framework analysis techniques of familiarization, developing a thematic framework, indexing, charting, and mapping and interpretation (Ritchie & Spencer 1994, Ritchie *et al.* 2003). The interviews and analysis were conducted independently by two of the authors (AMT and JC), who during the analysis process to discuss the emerging findings and any differences in interpretation.

## Findings

### Symptom experience

There was wide variation in symptoms and therefore no clear symptom profile emerged (Table 1). Symptoms were often minor and unspecific:

But in the early days there was a very little cough. I coughed occasionally, but the cough didn't really give me a clue. (Patient 12)

He didn't seem as fit as he was and you couldn't have put your finger on anything, but just didn't seem as fit as he had been. (Wife of patient 16)

Some participants thought that lung cancer was different from other cancers which had clear symptoms detectable through physical self-examination:

Table 1 Individual interview participants

Participant	Age/gender	Marital status	Symptom profile	Symptom to reporting delay	Delay from symptom to diagnosis	Courses of antibiotics	Smoking status	Job
1	47/Female	Married	Breathless, loss of appetite, voice problems	2 weeks	1 month	3	Gave up on diagnosis	Shop worker
2	81/Male	Widowed	Shoulder pain, breathless	48 months	48 months	> 2	Ex-smoker 25 years	Miner
3*	63/Female	Married	Chest pain, arm pain, facial rash and swelling, palpitations	4 months	24 months	3	Non-smoker	Cleaner
4*	58/Male	Married	Cough, recurrent chest infections	48 months	60 months	5	Ex-smoker 21 years	Engineer, factory manager
5*	54/Female	Married	Slight breathlessness	None, CXR at diabetic check up	None	None	Current smoker	National Health Services (NHS) clerk
6	64/Female	Divorced	Haemoptysis	None	6 months	2	Ex-smoker 1 year	Shop assistant
7	57/Male	Divorced (living with partner)	Collapse	None, picked up on CXR at A&E	None	None	Ex-smoker 3 years	Publican (living above the pub)
8	77/Female	Widow	No related symptoms. Pain in left buttock	None, picked up on CXR at OPD	None	None	Non-smoker	Nursing Auxiliary
9*	81/Male	Married	Breathless (COPD) for 6 years	None. CXR in hospital for pneumonia	None	None (recently)	Ex-smoker 33 years	Miner
10*	59/Male	Married	Pains down right side of trunk, tiredness, breathless.	None	3 months	3 (1 for ear infection)	Ex-smoker 7 months	Senior Police Officer
11*	72/Female	Married	Cough, squeaky voice, difficulty swallowing	4 months	9 months	3	Gave up on reporting symptoms	Nursery nurse and shop assistant
12*	68/Male	Widowed	Discomfort in left hand side of body	None	3 months	2	Non-smoker	Fitter in a power station
13*	64/Male	Married	Irritable persistent cough, breathlessness, haemoptysis	2 months	4 months	3	Ex-smoker, 25 years	Decorator, then security guard

Table 1 (Continued)

Participant	Age/gender	Marital status	Symptom profile	Symptom to reporting delay	Delay from symptom to diagnosis	Courses of antibiotics	Smoking status	Job
14*	51/Male	Divorced (but living with fiancé)	Collapse	None, picked up on CXR through A&E	None	None	Stopped for 17yrs, started again 2yrs ago	Production manager
15*	68/Male	Married	Pins and needles in arm and chest. Loss of power in hand. Gruff voice for about 9 months	9 month delay in reporting voice disturbance	12 months	3	Current smoker	Railway vehicle builder
16*	67/Male	Married	Blackout, speech loss, right sided weakness, fits.	None-picked up on CXR through A&E	None	At least one	Ex-smoker, 25 years	RAF officer
17	63/Female	Married	Stomach pain, anaemic, diagnosed with bowel cancer	None. Routine chest x ray following bowel cancer surgery	None	None	Current smoker	Housewife
18*	69/Male	Married	Increasing cough	None	None (GP referred for CXR straight away)	None	Smoker for 55years	British rail
19	65/Female	Married	Irritable persistent cough	1 month	3 months	1	Gave up on diagnosis	NHS clerk
20	65/Male	Married	Fatigue, slight cough, reduced energy and activity	None	3 months	None	Ex-smoker 33 years	Television engineer

CXR, Chest X-Ray; COPD, Chronic Obstructive Pulmonary Disease; GP, general practitioner.

\*Denotes partner or friend present at the interview.

You do get more publicity for breast cancer and testicular cancer with men... but I've never heard anything about checking for lung cancer or that type of thing. (Patient 12)

There was a tendency to attribute symptoms to other acute and chronic conditions.

I'd got this irritating cough and... where I (was) working they'd just put air conditioning in and going and I put it down to that. (Patient 12)

It was just getting older, you know? (Patient 16)

This tendency was exaggerated in those who did not smoke.

So you just put it down to the weather, your age, physical exertion, nothing new. I mean, all of your friends said to me, "But he doesn't smoke". (Wife of Patient 16)

### Knowledge

Knowledge and awareness of lung cancer symptoms and treatments was poor, and available information focused on other cancers. Any lung cancer information was smoking-related.

There's an awful lot of publicity about breast cancer, about testicular cancer, about prostate cancer, but the only publicity around lung cancer is.... If you smoke, you get lung cancer. If you don't smoke you're going to be all right. (Patient 19)

Some had no idea what symptoms to expect, while others expected lung cancer symptoms to be severe and extreme. This expectation conflicted with experience.

I thought probably it was an infection. I didn't think it was anything very serious really because I didn't feel ill. (Patient 12)

I would have expected to start losing weight as a first symptom and expected a cough, but I haven't had a cough. (Patient 5)

Participants did not have accurate knowledge of lung cancer risk and saw themselves as more at risk of other cancers.

Well, I smoked, but I didn't think I'd be at risk, no. (Patient 11)

You're more likely to think of yourself getting breast cancer than lung cancer, even as a smoker. (Patient 1)

Two participants believed that after they gave up smoking their risk of lung cancer would be nil. This belief prompted them to ignore symptoms.

I mean, I gave up 25 years ago so you almost forgot that you ever were a smoker. (Patient 16)

If he'd been a smoker and he was getting breathless and he...his irritating cough had got worse It would be different.... We might well

have said, "Hang on, you'd better get this looked at." I think everybody associates lung cancer with smoking and if you don't smoke they assume you're not at risk. (Wife of Patient 16)

### Fear

Fear was fostered by a lack of knowledge of treatments and strong fatalistic beliefs. Fear of death and a cancer diagnosis delayed reporting of symptoms.

They are frightened, aren't they, you know, of the outcome. (Patient 6)

He admitted he (was) frightened. (Wife of Patient 15)

Current information campaigns were seen to contribute to fatalistic views as they focused on death rather than treatment.

Fear of a medical consultation and being seen as a time-waster further prompted delay, especially where people had previous bad experiences.

The way I was treated during the tests it was as if I was cheating, and I lost any confidence I had for doctors. (Patient 2)

Doctors are very busy people. We're always being told, "Don't waste the doctor's time". (Patient 16)

### Blame and stigma

The findings revealed a prevailing expectation that people with lung cancer would experience blame and stigma.

Whenever you see warnings about cancer, there's always a cigarette there. I don't think I've seen a warning where there hasn't been a cigarette, and I think that's wrong. (Patient 13)

Non- or ex-smokers delayed in reporting symptoms because of an expectation, based on previous experience, that they would be stigmatized as a smoker and blamed for their illness.

They keep asking have I smoked? Have I drunk? It's mainly have I smoked... anytime? I (said), "No." The only thing I have (performed) is gone into bingo, where there's been smoke. (Patient 3)

### Culture

A number of cultural issues were cited in relation to delay in lung cancer symptom reporting in local communities. For example, great value was placed on stoicism, not complaining and "putting on a brave face".

He was out with some friends and I picked him up and he said he'd blacked out and I said, "You did what?" He said, "I blacked

out.” I said, “Well, I think you ought to get checked out at the hospital.” (He replied) “Oh there’s nothing wrong with me. You fuss”. (Patient 16)

Stoicism was present in older, male participants and those who had worked in traditional industries such as coal mining and steel, and at the railway plant.

Men don’t like to know, generally. They don’t like to fuss. Going to the doctors is fussy. It’s a sign of weakness.... They don’t want to know. (Wife of Patient 16)

Lifelong patterns of poor healthcare utilization in these communities contributed to participants not using primary care services. For example, those who could remember pre-National Health Services (NHS) health care, where people had to pay to see a doctor, also reported reluctance to see a general practitioner (GP) unless symptoms were severe.

It had to be something really seriously wrong to make you go. The pair of us has very rarely been to the doctor, very rare all our working lives. (Patient 15)

There was also a tradition of accessing health care at work from the ‘pit doctor’ or ‘railway doctor’.

If you were sick.... We had a doctor come in and so we had all this first class health stuff.... Not your own doctor, but the railway doctor. (Patient 15)

Media messages interacted with cultural tendencies to reinforce the belief that people should not use primary care services unless a problem was extreme.

You don’t want to waste the doctor’s time because the message is you don’t need a doctor for 95% of things that are wrong with you. You

know, you phone NHS Direct (telephone health advice service), you talk to a pharmacist and you say, “I’ve got this niggling cough,” and he gives you cough medicine. (Patient 16)

Families were key facilitators in noticing symptoms and overcoming delay by picking up early signs. Family members also legitimized and encouraged reporting by, for example, making them an appointment with their GP. Relatives arbitrated for the patient if symptoms were not being investigated.

My daughter says, “You’re coughing a lot, aren’t you”? I says, “I am, lately”. She says “I’ve phoned the doctor up anyway and you’re booked in for Thursday, half-past nine”. (Patient 18)

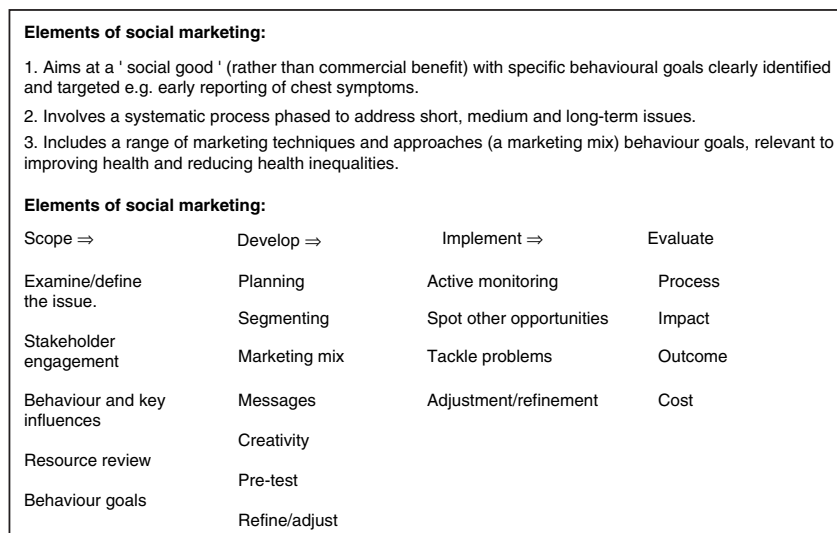
My daughter-in-law got on to him on the phone: “You’d better come and see my father-in-law, who’s pretty bad”. (Patient 2)

## Discussion

### Study limitations

As this was a small qualitative study, any claims of generalizability should be made with caution. However, the findings are a starting point from which to understand diagnostic delay, develop educational interventions for the public and healthcare professionals and support reflection on practice.

As the study was conducted in one locality, this limits the transferability of the findings further. However, it was conducted in an area of social deprivation with high levels of lung cancer, and the findings may be transferable to similar communities.



**Figure 1** Elements and stages of social marketing. Adapted from: National Social Marketing Centre 2006.

Adapted from: National Social Marketing Centre, 2006

### What is already known about this topic

- Lung cancer accounts for approximately 5% of deaths in the Western world.
- The high mortality rate is, in part, attributed to delay in reporting symptoms and obtaining a diagnosis.
- Rates of surgical intervention and survival in lung cancer are lower in the United Kingdom (UK) than other developed countries including Europe and the United States of America (USA).

### What this paper adds

- Lack of public knowledge of lung cancer risk and symptoms interacts with fear, blame and stigma as barriers to reporting lung cancer symptoms.
- Cultural influences may contribute to delay and families have a potential role to help overcome delay.
- New educational strategies are required for the public to overcome diagnostic delay, and nurses have the potential to have a key role in developing and implementing this education.

The sample was limited in terms of ethnicity. No patients from black and ethnic minority groups were recruited, but this reflects the demographics of the study location. Further research is required to explore the influences in other ethnic groups.

### Discussion of findings

Lung cancer presents a serious challenge in the UK in comparison to some other Western countries because of high mortality rates, late presentation and diagnostic delay. Our data illustrate how delays can occur before reporting symptoms to primary care practitioners. Issues that emerged as contributing to diagnostic delay include:

- The absence in lung cancer of a tangible symptom, like a lump, that would aid detection through self-examination.
- A belief that non- and ex-smokers would not get lung cancer. This created a lack of symptom vigilance and fostered the tendency to attribute symptoms to erroneous causes.
- A tendency to explain symptoms away because they were not as severe as expected, or because of environmental or other health issues.
- Cultural factors that contributed to delay in symptom reporting, most notably stoical attitudes and non-standard patterns of healthcare utilization.
- Family members are major facilitators to symptom referral.

The study was conducted in an area of high risk and incidence of lung cancer. However, these findings have international relevance as they indicate the value of critiquing public health campaigns used in populations experiencing social and healthcare inequalities. The study highlights issues influencing effective public education in such populations. Low knowledge levels were additionally compromised by the focus of public health campaigns on smoking and death, thereby affirming a fatalistic attitude. This confused people and limited their understanding of risk. Blame and stigma were also reinforced by the stress on smoking, and participants were not aware that advantage can be gained from early symptom reporting.

Our findings illustrate a point of wider application, that is, how social inquiry can help to understand health inequalities. The study supports other research indicating that people self-manage symptoms for many months before reporting them to their GP (Corner *et al.* 2005, 2006). This illustrates how cultural mores of strength and stoicism, bound up in the study area's industrial past, promote independence and self-management. This tendency adds to diagnostic delay and existing inequalities in healthcare utilization.

A recent UK survey revealed that up to 50% of smokers and 27% of adults generally consider cancer risk to be a matter of luck rather than lifestyle (Cancer Research UK 2007b). The survey, together with this study, strengthens the call to develop new educational interventions to address diagnostic delay. The contribution of family members in reducing delay also needs to be acknowledged and fostered in education of the public.

Our study highlights the need for those working in primary care to be vigilant for symptoms that might indicate lung cancer in high risk populations. Nurses involved in chronic disease and lifestyle management are in a prime position to play a role in this. Partnership working between GPs, practice nurses and pharmacists could be central in picking up these early symptoms.

### Social marketing

Social marketing is a potential approach to addressing public and professional awareness and education about lung cancer symptoms and symptom reporting. Social marketing uses concepts, techniques and theories used in commercial marketing to promote socially important behaviour change, for example smoking cessation and healthy eating (Figure 1). The goal in social marketing is social, not commercial, benefit (National Social Marketing Centre 2006). In the case of lung cancer, this approach can be used to generate messages that are acceptable and accessible to high risk

communities to promote early detection and reporting of lung cancer symptoms. Similar approaches can be used to develop educational resources for healthcare professionals, including nurses.

## Conclusion

Our findings reveal the complexity of factors influencing symptom-reporting in lung cancer in high risk populations and illustrates the need for public and professional educational strategies to address these factors. They also raise a number of points of broader international importance, for example that public education campaigns can worsen health inequalities if misinterpreted. Social marketing provides a potential vehicle for developing public messages that tackle the complex and cultural barriers to symptom reporting identified in this study.

## Acknowledgement

Lilly UK contributed to the funding of the research study and the following people gave crucial support, including recruitment, and commenting on the findings, Dr Trevor Rogers, Ms Nicky Godfrey, Ms Linda Pollard, Ms Pam Cooke, Dr Chris Bentley, Dr Rupert Suckling. The views expressed in this paper are those of the authors alone.

## Author contributions

AMT was responsible for the study conception and design and AMT, JC and PA were responsible for the drafting of the manuscript. AMT and JC performed the data collection and AMT, JC and PA performed the data analysis. AMT obtained funding and AMT, JC and PA provided administrative support. AMT, JC and PA made critical revisions to the paper.

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