

Primary care

Stigma, shame, and blame experienced by patients with lung cancer: qualitative study

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Abstract

Objectives To draw on narrative interviews with patients with lung cancer and to explore their perceptions and experience of stigma.

Design Qualitative study.

Setting United Kingdom.

Participants 45 patients with lung cancer recruited through several sources.

Results Participants experienced stigma commonly felt by patients with other types of cancer, but, whether they smoked or not, they felt particularly stigmatised because the disease is so strongly associated with smoking. Interaction with family, friends, and doctors was often affected as a result, and many patients, particularly those who had stopped smoking years ago or had never smoked, felt unjustly blamed for their illness. Those who resisted victim blaming maintained that the real culprits were tobacco companies with unscrupulous policies. Some patients concealed their illness, which sometimes had adverse financial consequences or made it hard for them to gain support from other people. Some indicated that newspaper and television reports may have added to the stigma: television advertisements aim to put young people off tobacco, but they usually portray a dreadful death, which may exacerbate fear and anxiety. A few patients were worried that diagnosis, access to care, and research into lung cancer might be adversely affected by the stigma attached to the disease and those who smoke.

Conclusion Patients with lung cancer report stigmatisation with far reaching consequences. Efforts to help people to quit smoking are important, but clinical and educational interventions should be presented with care so as not to add to the stigma experienced by patients with lung cancer and other smoking related diseases.

Introduction

Stigma occurs when society labels someone as tainted, less desirable, or handicapped.¹ This negative evaluation may be “felt” or “enacted.” A felt negative evaluation refers to the shame associated with having a condition and to the fear of being discriminated against on the grounds of imputed inferiority or social unacceptability.² An enacted negative evaluation refers to actual discrimination of this kind. Stigma can lead to feelings of guilt, shame, and spoiled identity.³ It may increase the stress associated with illness and contribute to psychological and social morbidity.³ Stigma may also threaten personal identity, social life, and economic opportunities and can profoundly affect families and significant others.⁴⁻⁶ The stigma associated with disease

depends on whether or not the patient is held responsible for the disease and whether the disease leads to serious disability, disfigurement, lack of control, or disruption of social interactions.⁷ Some research suggests that stigma ascribed to controllable factors elicits a greater negative reaction than stigma ascribed to uncontrollable factors.⁸

In the Western world any diagnosis of cancer can be associated with fear and stigma.⁹ This may be because the cause of cancer is not always understood and is often seen as a death sentence. According to Sontag, cancer is often “felt to be obscene—in the original meaning of that word: ill-omened, abominable, and repugnant to the senses.”¹⁰ Others have shown that cancer can attract stigma that has a huge effect on people’s lives.^{5 11} Patients may experience their bodies as “permeable, vulnerable, and out of control,” and some feel they have to protect others from embarrassment.^{12 13} Treatments often lead to hair loss, scars, or other bodily changes, which may add to the stigma.^{14 15}

Care and sensitivity is needed by healthcare professionals when treating patients with illnesses that are considered self-inflicted. Since 1950 evidence has shown that cigarette smoking is directly responsible for at least 90% of lung cancers.¹⁶ With notable exceptions,^{17 18} there have been few in-depth qualitative studies of patients with lung cancer and even fewer studies of their perceptions and experience of stigma. Comments by psychology students on vignettes indicates that young people with lung cancer are likely to experience more stigma and greater negative reactions than older people, but little is known about the stigma experienced or felt by patients themselves and how this may affect their lives.¹⁹ During our study of people’s experience of lung cancer, conducted partly to contribute to the DIPEx (personal experiences of health and illness) website (www.dipex.org), the subject of stigma was often raised spontaneously and emerged as an important theme. We analysed the perceptions and experiences of stigma in the accounts of patients with lung cancer and considered the possible consequences for clinical care and anti-smoking campaigns.

Methods

We interviewed 45 patients with lung cancer throughout the United Kingdom. To look at experience in all stages of lung cancer, our maximum variation sample included men and women, young and older, from various social backgrounds; people diagnosed as having small cell lung cancer, non-small cell lung cancer; and mesothelioma, and people who had been medically treated in different ways (table).²⁰ Originally we aimed to include about 40 patients, but we continued interviewing until we obtained the sample described. People were invited to participate

Characteristics of 45 patients interviewed about their lung cancer

Characteristic	No of people
Age at interview:	
40-50	9
51-60	20
61-70	11
71-80	4
80-90	1
Ethnicity:	
White British	44
Indian	1
Type of work*:	
Professional or higher managerial	14
Other non-manual	15
Skilled manual	9
Manual	7
Type of cancer:	
Non-small cell	14
Small cell	10
Mesothelioma	4
Not known to patients	17
Source of recruitment:	
Support group	24
Chest physician, oncologist, or nurse specialist	9
General practitioner	7
Other†	5

*Includes those retired for medical reasons.

†Includes patients who volunteered after reading about DIPEX.

through general practices, oncologists, chest physicians, and support groups.

With informed consent, one of the authors (AC, a medical sociologist), interviewed patients in their homes between October 2002 and August 2003. Patients were asked to tell their story from when they first suspected they had a problem. Among other things, we were interested in people's perception of the cause of their illness and how others reacted to the diagnosis. Many patients talked about stigma and expressed feelings of guilt or shame. The interviews lasted one to three hours and were audiotaped.

Transcribed transcripts were returned to each respondent for revision if necessary. From the transcripts we developed categories or themes.²¹ Sections of text were marked and linked to sections of text from other interviews that covered similar issues or experiences by using NUD*IST.²² Themes were considered in the context of all the interviews.^{23, 24} Inter-rater reliability scores were not developed as the interviews had little structure—such scores are not appropriate to data that have little or no predefined coding²⁵; AC and SZ regularly discussed the coding and interpretation of the data.

Results

Patient's experience and fear of stigma

Many of the patients recalled that during their illness people often crossed the road to avoid contact. They gave several explanations for this, such as others' desire to avoid those who have a disease associated with a horrible death—a disease with symptoms such as “gasping for air”; being embarrassed; and not knowing what to say:

When I first had it [cancer] certain people that I've known, I mean I've lived on this estate for nearly 40, well just over 40 years, and certain people will almost cross the road not to talk to you because I think they were frightened of what to say, didn't know how to treat you ... That makes you feel very uncomfortable. (LC28, retired fire fighter, aged 55, recruited through support group)

Some patients said that family or friends had not been in touch since they heard about the diagnosis. One patient with mesothelioma said that his daughter had not telephoned because she felt “dirtied” by contact with cancer:

Because we don't understand it, because there's no way of understanding cancer. Um, it's something that grows within certain people and there's something disgusting about it (laughs) ... because it's not nice, I suppose, you know, it's just something that's, um, it's cells that are some sort of “misformation.” I think there's an association, not dirtiness in terms of “I need to Hoover it up” or “I need to get the dishcloth out” but just dirty in the sense that “I need to keep away from it, I want to remove myself from it.” (LC38, managing director, aged 62, recruited through specialist nurse) This behaviour might be understood in the light of a general dislike of “matter out of place” (the need for clear classifications and boundaries),²⁶ and a fear of “courtesy stigma” (the common fear that stigma may affect other people).¹

People's experience of other diseases may make them wary. A woman who had had epilepsy explained why she feared stigma and its consequences and why she did not want to join a support group or tell others outside the family about her cancer:

When my children were quite young I had a major fit and I was diagnosed as having epilepsy. ... And when a particular friend of mine found out it was almost as though I had some terrible disease that was catching to everyone and stopped her children seeing my children very abruptly. ... It really made me feel very uncomfortable, took me quite a while to get over that and I wonder if that's at the back of it, people's reaction. ... I don't feel I'd take that chance. (LC25, housewife, aged 62, recruited through a consultant)

The experience of stigma in lung cancer is shaped by the association between the disease and smoking, the perception of the disease as a self-inflicted injury, its high death rate, and the type of death. Television advertisements about smoking cessation often conclude by saying that the patient shown has died. They upset one woman because they had made her fear a dreadful death through drowning:

I hate those adverts that come on the television when they finish it by saying two weeks after this she died. And one of them said when you've got lung cancer you drowned. And I said to the nurse, I was really offended by this, well by all of them. I know they're to stop people smoking but they're not pleasant to watch when you've got lung cancer. (LC39, retired clerk, aged 73, recruited through support group)

People with other cancers experience stigmatisation too.^{9, 11} One woman contrasted lung cancer with other cancers, in particular perceptions of the unpleasant symptoms and the belief that people are dirty and blameworthy because they smoke:

Respondent: I think they [others] are frightened. ... it's like when you get a death in the family, people will cross the road so as not to actually have to bring up the subject, and I think it's the same with cancer.

Interviewee: Do you think it's the same with all cancers or more so with lung cancer?

Respondent: I think more so with lung cancer because people think you're dirty because you smoked. But I don't think they really realise it's not only from smoking, there's other things that it's caused by. But also I think that they can't bear to think that they're going to see you suffer. With a lot of cancers you don't actually suffer, with lung cancer your breathing is very bad and you're gasping for breath and I think that is the bit they don't want to know. ... with lung cancer people automatically think you've brought it on yourself and it's a sort of stigma. (LC29, retired community support worker, aged 56, recruited through support group)

Even though mesothelioma is known to be caused by asbestos particles, patients share the stigma of a self-inflicted disease²⁷:

I think all people with lung cancer are stigmatised, especially if they're smokers, and those that aren't generally blame it on the smokers for their passive smoking. So everybody feels that lung cancer, I believe anyway, is self-inflicted. But you could say that about any illness. Every illness, or almost every illness is self-inflicted in some way or another so, but the stigma is definitely to do with smoking. (LC18, retired welder, aged 55, recruited through support group)

Doctors as well as friends and family seemed to assume that a patient's lung cancer was caused by smoking even if he or she had stopped smoking years ago or never smoked. One man, despite never smoking, recalled negative attitudes at the hospital when he had his operation:

I think cancer does have a stigma attached to it... I think all lung cancer patients are stigmatised because of smoking... When I went to see an oncologist for further treatments because I'd had an operation and I'd had half of my left lung removed, I asked them what he thought had caused it and he just laughed and said, "That's obvious, through smoking." And my wife who was with me at the time, and we've been together since we were 14, she just said, "Well he's never smoked." So right away what annoyed me as well as that, on my medical records I'm classed as a smoker and every time I ever went for review after that they would ask me, "Are you still smoking?" because that's down there. And no matter how I told them, I'd say, "Look I don't want that on there, I never smoked," it's only my word that can go against that. (LC15, retired joiner, aged 56, recruited through support group) Even though this patient had never smoked he felt responsible for his disease. He was sure that he must have done something wrong and felt deeply ashamed because he could no longer provide for his family. He imagined others looked at him as a "leper." This also had financial consequences because he refused to tell tribunal judges that he had had lung cancer and consequently failed to obtain tax relief.

We found a few "deviant cases" (those who denied feeling stigmatised or blamed for their illness), particularly among older patients.²⁸ One man with small cell lung cancer volunteered:

Nobody has actually come out to me and said "you see that's the penalties of being a smoker," nobody has ever said that to me, nobody. (LC13, retired electrician, aged 67, recruited through support group)

Older people are less likely to be blamed for having lung cancer than younger people. Perhaps it is remembered that older people became addicted to cigarettes when smoking was socially accepted and before the dangers were widely known. It is possible that others knew this patient had worked with asbestos in the boiler room of ships and saw this as a possible cause of his illness.

Resistance to blame and stigmatisation

Some patients accepted that smoking had caused their lung cancer. Many others, particularly those who had joined support groups, insisted that other factors could have played a part—for example, diesel fumes, carbon monoxide, spray paint, asbestos, pollution, diet, stress, and bereavement. Some smokers and ex-smokers resisted stigmatisation and blamed the tobacco industry:

Basically lung cancer patients find themselves in the position where they feel that they've caused it all themselves... They don't get funding like other cancers get and probably that's because we feel that it's our fault. But at the end of the day it's not our fault it's the tobacco manufacturers' fault for putting the carcinogens in in the first place. (LC09, retired accounts assistant, aged 55, recruited through support group)

One woman, who thought sure that her cancer had been caused by trauma at work, was angry that she was held responsible for her disease:

But it [smoking] was fashion in the sixties, it was fashion, you went along with it and once you're on it you can't get off it (laughs). But a lot of people, even now when you say, "Oh I had lung cancer," they look at you and say "Did you smoke?"... people automatically think you've brought it on yourself and it's a sort of a stigma. (LC29, retired community support worker, aged 56, recruited through support group)

An elderly woman commented that her consultant had resisted the tendency to blame her for her lung cancer:

Interviewee: Do you ever think what might have caused the lung cancer?

Respondent: Well I don't really know. I mean even the specialist said that, I said to him "What have I done?" I mean I know smoking doesn't help but I mean he said, "It's not only smoking," he said, "It could be other things like food or you know like in the air or like from exhaust from cars," and nobody can put their finger on it I don't think. (LC34, retired shop assistant, aged 68, recruited through support group)

Peto and coworkers showed that stopping smoking confers substantial benefit.¹⁶ They concluded that "even people who stop smoking at 50 or 60 years of age avoid most of their subsequent risk of developing lung cancer." Many of our participants had started smoking at a time when smoking was socially acceptable and when tobacco was even provided free during national service. Some had stopped smoking 20-30 years ago; others had never smoked. Thus they felt upset that that they were being blamed for their disease. One man said he had heard that if people gave up smoking for five years they were "clear," and that "your chances were much improved."

Some participants criticised the national press for suggesting that patients are to blame for having lung cancer:

When you see it reported in the press there's a blame to it, as if, "Well you've smoked, so it's your own fault that you got cancer." Which is rather stupid really, because we all do things right or wrong or whatever, but you're not going to blame other people for getting their illnesses. So I don't think it's a fair way of reporting this. (LC32, postman, aged 52, recruited through support group)

Fears about lack of access to medical care

Patients generally spoke highly of their doctors and nurses, but some were concerned about delays in diagnosis. One man with mesothelioma asserted that delays occur because doctors fail to take a "smoker's cough" seriously:

The first time you go to the doctor's with a bad cough and coughing up phlegm in the mornings the doctor will almost certainly say to you, "Do you smoke?" and once you've said yes, you're sent packing with a bottle of cough medicine. If you went to the doctor's with a small lump the size of a pea on your breast you'd be straight into the hospital but you can be coughing up phlegm for years and nobody will offer you a hospital appointment... you are just pushed to the back of the queue. And it's quite unfair really, people who go with problems with drink related or people who fall off a cliff through rock climbing are not stigmatised the same way that smokers are. (LC18, retired welder, aged 55, recruited through support group)

Another woman recalled her terror when she overheard that smokers might be refused treatment:

But at first I were terrified, really terrified that they wouldn't... They'd say, "That's it," you know. Or, they wouldn't say, "That's it," but they wouldn't offer me anything because they couldn't treat me... I'm sure it had been on television that, because of the state national health were in, and, you know, they needed that much

money, that people with diseases or who caused their own problems were going to stop getting treated. (LC35, retired clerk, aged 59, recruited through support group)

Others suggested that the government allocates less money for screening and research for lung cancer because of the link with smoking:

If you compare the amount of money that's allocated to breast cancer for research and screening programmes and so forth and compare that with those of lung cancer there is a huge difference, there is a massive difference to the point where one has to ask the question, "Why is there such a difference?", and you know I can only assume that it's because it's self-inflicted and it's because it's smoking related. (LC12, retired rigger, aged 43, recruited through support group)

Members of support groups were particularly passionate about felt and enacted stigma caused by the association of lung cancer with smoking. One of the benefits of support groups may be to help members resist stigmatisation and victim blaming. Although patients who had not joined support groups gave examples of stigma, these were related to social factors and not to clinical encounters.

Discussion

The stigma attached to lung cancer, both "felt" and "enacted," can have a serious effect on people's lives. Social interaction with friends and families may suffer, and fear of disclosure may affect people financially or prevent them from seeking support. Self-image may be seriously affected, particularly if patients have to stop work, and some fear that smokers will be denied treatment.

Almost all participants agreed to be video recorded for our website (www.dipex.org), although a few opted to remain anonymous through written or audio means. It might be expected that participants willing to be interviewed about their experiences would be less likely to feel stigma than most patients with lung cancer. We therefore suspect that the pattern of stigma we identified may be stronger in the wider population of patients with lung cancer.

Just over half the participants were recruited through support groups, and most of those who discussed stigma were members of these groups. Support groups discuss issues such as doctors' assumptions about smoking and the cause of lung cancer, and although members may be seen as biased it is likely that they also have a raised awareness of victim blaming. Opportunity to reflect on their experiences with others does not necessarily make their experiences atypical. Patients who do not join support groups may also experience stigma. They may make the decision not to disclose their illness to others because they have experienced stigma when talking to others about their cancer or another disease.

It is now recognised that people can become highly dependent on tobacco and that complete smoking cessation may be difficult,²⁹ but as one author noted "the tendency in medicine—especially in general practice and health education—is to implicate the sufferer in the generation of the disease or injury."³⁰ A few respondents were sure that asbestos had caused their cancer, and others believed that stress, trauma, pollution, or other chemicals were partly to blame. It is not surprising therefore that they felt angry and upset when they perceived that they were being blamed for their disease. The Roy Castle Lung Cancer Foundation is named after an entertainer who was a non-smoker and who was believed to have developed lung cancer from prolonged exposure to passive smoking in his work environment.

What is already known on this topic

Lung cancer is strongly associated with smoking, but little is known about the way in which patients respond to this association

What this study adds

Patients with lung cancer perceive that they are particularly stigmatised because others associate their disease with smoking and dirt and because patients die in an unpleasant way

This stigmatisation can have serious consequences such as deterring patients from seeking support

Media reports may have added to the stigma surrounding lung cancer

Some patients resist victim blaming, stress the culpability of the tobacco industry, and propose several causes of their disease, often related to pollutants at work

The rising cost of the NHS preoccupies government ministers. A recent Labour party national policy forum paper stated that overweight people and heavy smokers may one day have to sign contracts promising to diet or give up cigarettes in return for treatment.³¹ This has alarmed some patients who already perceive a disparity between the resources for lung cancer and those for conditions not considered self-inflicted. Some may need reassurance that they will not be abandoned by health professionals.

Studies that show the health benefits of giving up smoking by early middle age were not based on working class smokers, who may have been exposed to environmental pollutants as well as tobacco smoke.¹⁶ Those participants who had given up smoking many years ago often suspected that exposure to pollutants at work had at least contributed to their cancer.

Although policy documents acknowledge the role of social disadvantage in persisting health inequalities, campaigns still usually focus on individual responsibility for health.³² Policy measures such as free nicotine replacement therapy are intended to help low income groups to stop smoking, but government funded media campaigns routinely feature patients with lung cancer regretting their decision to smoke and facing a particularly unpleasant death.³³ This may contribute to a persisting image of not only personal responsibility for smoking related diseases but also victim blaming.

Efforts must be made to prevent young people from smoking, and smokers should be encouraged to stop as early as possible, but there is a dilemma for antismoking campaigns and for clinicians who take seriously their responsibility to deter people from smoking and to encourage smokers to stop. Those who produce images of "dirty lungs" rightly aim to put young people off tobacco, but such images may upset people with smoking related illness. In contrast, publicity about the Machiavellian role of the global tobacco industry may resonate with young people while avoiding further victim blaming of those with lung cancer and other smoking related diseases.

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