

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 who 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.

Conclusions Patients with lung cancer report stigmatisation with far reaching consequences. Efforts to help people 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”; when felt it refers to the shame associated with having a condition and the fear of being discriminated against on the grounds of imputed inferiority or social unacceptability²; when enacted it refers to actual discrimination of this kind. Stigma can lead to feelings of guilt, shame, and spoiled

identity and may increase the stress associated with illness (see bmj.com).³

Any diagnosis of cancer can be associated with fear and stigma. This may be because the cause is not always understood and it is often seen as a death sentence. Cancer can attract stigma that has a huge effect on people's lives.⁴⁻⁵ Patients may experience their bodies as “permeable, vulnerable, and out of control,” and some feel they have to protect others from embarrassment.⁶⁻⁷ Treatments often lead to hair loss, scars, or other bodily changes, which may add to the stigma.⁸⁻⁹

Care and sensitivity is needed by healthcare professionals when treating patients with illnesses that are considered self-inflicted. Cigarette smoking is directly responsible for at least 90% of lung cancers.¹⁰ With notable exceptions,¹¹⁻¹² there have been few in-depth qualitative studies of patients with lung cancer and even fewer studies of their perceptions and experience of stigma. Research suggests that young people with lung cancer are likely to experience more stigma than older people.¹³ Some research suggests that stigma ascribed to controllable factors elicits a greater negative reaction than stigma ascribed to uncontrollable factors.¹⁴ 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.

Methods

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). One of the authors conducted taped interviews with 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 prob-



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lem. 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.

Respondents revised the transcribed transcripts if necessary, and then from these we developed categories or themes. Sections of text were marked and linked to sections of text from other interviews that covered similar issues. Themes were considered in the context of all the interviews. We regularly discussed the coding and interpretation of the data (see bmj.com).

Results

Patients' 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 “dirty” by contact with cancer. This behaviour might be understood in the light of a general dislike of “matter out of place” (the need for clear classifications and

boundaries),¹⁵ 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.

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.^{5 16} 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. And even though mesothelioma is known to be caused by asbestos particles, patients share the stigma of a self-inflicted disease.

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:

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 and felt 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) particularly among older patients:

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)

Research suggests that older people are less likely to be blamed for having lung cancer than younger

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.

people. Perhaps it is remembered that older people became addicted to cigarettes when smoking was socially acceptable 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 felt 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.

Many participants had started smoking at a time when it 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 they were being blamed for their disease. 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 doctors 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 appoint-

ment... you are just pushed to the back of the queue. (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.

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.

Participants willing to be interviewed about their experiences might be less likely to feel stigma than most patients with lung cancer; we suspect that stigma 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. The opportunity to reflect on their experiences with others does not necessarily make these views 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.

It is now recognised that people can become highly dependent on tobacco and that complete smoking cessation may be difficult,¹⁷ 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."¹⁸ 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, and felt angry and upset when being blamed for their disease.

A Labour party national policy forum paper has suggested that overweight people and heavy smokers may have to sign contracts promising to diet or give up cigarettes in return for treatment.¹⁹ This has alarmed some patients who already perceive a disparity between the resources for lung cancer and those for

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

while avoiding further victim blaming of those with lung cancer and other smoking related diseases.

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- 1 Goffman E. *Stigma*. Englewood Cliffs, NJ: Prentice Hall, 1963.
- 2 Scambler G. Perceiving and coping with stigmatising illness. In: Fitzpatrick R, Hinton J, Newman S, Scambler G, Thompson J, eds. *The experience of illness*. London: Tavistock, 1984:203-26.
- 3 Williams S, Goffman, interactionism, and the management of stigma in everyday life. In: Scambler G, ed. *Sociological theory and medical sociology*. London: Tavistock, 1987.
- 4 Fife B, Wright E. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* 2000;41:51-67.
- 5 MacDonald L. The experience of stigma: living with rectal cancer. In: Anderson R, Bury M, eds. *Living with chronic illness: the experience of patients and their families*. London: Allen and Unwin, 1988.
- 6 Waskul D, van der Riet P. The abject embodiment of cancer patients: dignity, selfhood and the grotesque body. *Symbolic Interact* 2002;25:487-513.
- 7 Frank A. *The wounded storyteller: body, illness and ethics*. London: University of Chicago Press, 1995.
- 8 Rosman S. Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Educ Couns* 2004;52:333-9.
- 9 Frank AW. *At the will of the body: reflections on illness*. New York: Houghton Mifflin, 1991.
- 10 Peto R, Darby S, Deo H, Silcocks P, Whitley E, Doll R. Smoking, smoking cessation, and lung cancer in the UK since 1950: combination of national statistics with two case-control studies. *BMJ* 2000;321:323-9.
- 11 The A. *Palliative care and communication: experiences in the clinic*. Buckingham: Open University Press, 2002.
- 12 Murray E, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003;326:368-71.
- 13 Menec V, Perry R. Reactions to stigmas. *J Aging Health* 1995;7:365-83.
- 14 Weiner B, Perry R, Magnusson J. An attributional analysis of reactions to stigmas. *J Pers Soc Psychol* 1988;55:738-48.
- 15 Douglas M. *Purity and danger: an analysis of concepts of pollution and taboo*. London: Routledge and Kegan Paul, 1966.
- 16 Muzzin L, Anderson N, Figueredo A, Gudelis S. The experience of cancer. *Soc Sci Med* 1994;38:1201-8.
- 17 Fowler G. Proven strategies for smoking cessation. *Eur J Public Health* 2000;10(suppl 3):3-4.
- 18 Bellaby P. What is genuine sickness? The relation between work-discipline and the sick role in a pottery factory. *Sociol Health Illness* 1990;12:47-68.
- 19 Moore A. Shape up or ship out? *Health Serv J* 2003;12 Jun:12-3.
- 20 Department of Health. *Our healthier nation*. London: Stationery Office, 1998. (Cm 3852.)

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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.¹⁰ 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 usually focus on individual responsibility for health.²⁰ This may contribute to a persisting image of not only personal responsibility for smoking related diseases but also victim blaming.

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

An obstinate patient

Just as a runner passes on the baton to the next one in a relay race, so she gave birth to her daughter and died. In the antiseptic environment of an obstetric theatre, I witnessed this spectacle with the detachment of a duty conscious executioner. I had talked frankly with the patient in the weeks before, and had explained point blank the risks of continuing a pregnancy with Eisenmenger's syndrome.

She was a science graduate and had a clear understanding of the risks involved. To be sure, I had said, "Percentages apart, those who die, die fully." Her husband, parents, and in-laws had also counselled her but could not persuade her to terminate the pregnancy. I vacillated between hatred for her obstinacy and respect for her autonomy, but she was resolute in her decision to continue. It is difficult to be sure if she really believed that somehow I could save her, or perhaps the desire for motherhood over-rode everything else. She continued the pregnancy for eight

months with worsening cyanosis and decreasing effort tolerance. I watched her gradually moving towards death, but she seemed happy seeing the life inside her grow.

On that fateful night, several things went wrong despite our preparations. The epidural anaesthesia was tedious and suboptimal, the rigors were unwarranted, and the blood loss a little more than usual. She was awake at the birth and acknowledged the arrival of her "free spirit" by a feeble smile. I could not see her expression as her eyes were covered. Shortly afterwards she became hypotensive and hypoxic and then died.

She was waiting for a miracle that did not happen; or perhaps it had happened. While we were busy trying resuscitate her, the room was filled with the lusty cries of a newborn infant as if announcing the victory of life over death. "Death, be not proud."

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