Article

Does Lung cancer attract greater stigma than other cancer types?

Laura A.V Marlow, Jo Waller, Jane Wardle

Cancer Research UK Health Behaviour Research Centre,
Department of Epidemiology and Public Health, University College London

Abstract

Objectives: Cancer stigma can have widespread effects, influencing the behaviour and wellbeing of patients as well as the community and even research funding. Patients with lung cancer report feeling particularly stigmatised because of the association with a behaviour (smoking) that is perceived to be personally controllable. However there are other dimensions of cancer stigma, that might be more severe for other cancers. The present study therefore examined differences in attitudes towards lung cancer and four other cancer types, using a multidimensional measure of cancer stigma, to extend findings beyond personal responsibility attributions.

Materials and methods: Participants were a non-patient sample (n=1205) who were randomised to complete a survey online relating to one of five cancer types (lung, colorectal, skin, breast and cervical). Stigma was assessed using the Cancer Stigma Scale (CASS).

Results: There were significant differences across the five cancer types on all CASS subscales: *awkwardness* ($F_{(4, 1009)}=5.16$, $p<.001$), *severity* ($F_{(4, 984)}=26.24$, $p<.001$), *avoidance* ($F_{(4, 1008)}=5.38$, $p<.001$), *policy opposition* ($F_{(4, 1009)}=8.38$, $p<.001$), *personal responsibility* ($F_{(4, 995)}=31.67$, $p<.001$) and *financial discrimination* ($F_{(4, 957)}=9.45$, $p<.001$). Lung cancer attracted higher stigma scores than breast and cervical cancer on all subscales. Lung cancer was similar to skin cancer on *personal responsibility*, *avoidance,* and *policy opposition,* but attracted higher stigma in the domains of *awkwardness*, *severity* and *financial discrimination*. Lung cancer was similar to colorectal cancer for a*wkwardness,* but significantly higher on all other subscales.

Conclusion: Lung cancer stigma extends beyond personal responsibility attributions to other dimensions, particularly perceived severity of the disease and tolerance of financial discrimination against patients with the disease. Future work is needed to develop and evaluate interventions designed to limit cancer stigma for patients, health professionals and the community. Health policies should acknowledge the existence of lung cancer stigma and make a commitment to minimising this.

Introduction

Research into public perceptions of cancer suggests that it is often appraised more negatively than other serious illnesses such as heart disease [1;2]; attracting a particular sense of dread. In a large representative sample of the US population, 61% of adults agreed that when they think of cancer they automatically think of death [3], and a quarter thought 5-year cancer survival rates were 25% or less [4], despite the overall 5-year figure being 68% [5]. Studies with cancer patients and health professionals suggest that lung cancer in particular attracts stigma because of its poor prognosis and established link with smoking [6;7]. Recent decades have seen an increase in tobacco control policy initiatives, which aim to de-normalise smoking [8]. Initiatives include bans on smoking in public places and mass media campaigns persuading smokers to stop, often by using graphic images and emotional appeals. These have successfully shifted public perceptions, with smoking now widely seen as undesirable. In qualitative work non-smokers described smoking as 'dirty', 'anti-social' and 'unacceptable' [9], and just under two-thirds of non-smokers say they would mind if someone smoked near them [10]. This shift in perceptions has resulted in dramatic decreases in smoking prevalence in most high-income countries. With most lung cancers caused by smoking, and high public awareness of this, lung cancer is often seen as a self-inflicted illness and negative attitudes to smoking, as a result of health policy and promotion over the last twenty years, have arguably contributed to the stigmatisation of lung cancer patients [7].

Goffman's classic definition of stigma defined it as an attribute that makes a person different from others and results in them being discredited [11]. Link and Phelan agree that stigma occurs when a difference that is considered salient is labelled, this labelled difference is associated with negative attributes, those with the label are seen as a separate group ('them versus us') and the label results in loss of status or discrimination [12]. In line with these definitions, lung cancer patients may be seen as distinct from other cancer patients because they are assumed to be smokers with smoking seen as a negative attribute. In a vignette study, participants were randomised to read about a lung cancer patient with a genetic, smoking or combined cause [13]; patients in the genetic condition were attributed less personal responsibility, less anger and more pity than those with a smoking-related or combined cause. Similar findings have been shown with other cancers that have controllable causes, for example in another vignette study, participants were randomised to read about a patient with cervical cancer (caused by a sexually transmitted infection) or ovarian cancer (caused by family history) [14]; the patient with cervical cancer was judged more negatively (considered more dirty, dishonest and unwise), and attracted more moral disgust.

Else-Quest *et al* [15] compared perceived stigma scores (agreement with the statement: 'People judge me for my cancer type') in patients with lung, breast and prostate cancer. Scores were highest for lung cancer, lowest for breast cancer and in between for prostate cancer, although group differences were not significant. In a general population survey, a large sample of women were asked to indicate how much they would blame someone with lung, colorectal, breast, cervical cancer or leukaemia [16]. Consistent with previous work, lung cancer attracted the highest blame scores (mean rank: 4.9), while breast cancer and leukaemia attracted the lowest scores (mean ranks: 2.7 and 2.5).

Stigma of cancer can influence engagement with prevention behaviours [17-19], help-seeking behaviours in the presence of symptoms [20;21], disclosure of the disease [6;22], and wellbeing following a diagnosis [23;24]. For lung cancer in particular, recent work has shown that higher stigma is associated with greater depression and lower quality of life and this is the case among smokers and non-smokers [25]. Stigma could also affect community-wide responses to people who have cancer [26] and charitable donations to support research funding [27]. Previous studies have focused on personal responsibility judgements as a means of operationalizing lung cancer stigma. The aim of the present study was to take a

broader perspective using a multidimensional scale to explore stigma between lung cancer and four other cancer types.

Materials and methods

Participants

Participants were recruited through an online survey panel. The panel was supplied by Survey Sampling International, who hold a panel of participants willing to complete online questionnaires in exchange for small incentives (e.g. air miles). At the time of recruitment, their panel size was almost 250,000, of whom 57% were female, 66% were between 18 and 44 years old, and 23% had a university degree. The sample directed to our questionnaire was representative of the UK population in terms of gender, age and locality. The study was approved by the UCL Research Ethics Committee.

Procedure

Participants were randomised to respond for one of five cancer types: lung, cervical, breast, skin or colorectal cancer (referred to as bowel cancer). We estimated that 200 participants in each group would give us approximately 80% power to detect a significant difference of 0.5 (SD 1.2) between the least and most stigmatised cancer type (effect size f=0.105). We commissioned data collection from 1200 panel participants (240 per cancer type) using quota stops to ensure a good gender and education balance in the sample.

Measures

Participants reported their age, gender, ethnicity and education level. All completed the 25-item Cancer Stigma Scale (CASS) for their randomised cancer type [28]. The CASS assesses multiple aspects of cancer stigma including: *awkwardness* (5-items, e.g. I would find it hard to talk to someone with cancer), *severity* (5-items, e.g. Getting cancer means having to mentally prepare oneself for death), *avoidance* (5-items, e.g. If a colleague had cancer I would try to avoid them), *policy opposition* (4-items, e.g. The needs of people with cancer should be given top priority), *personal responsibility* (4-items, e.g. If a person has cancer it's probably their fault) and *financial discrimination* (3-items, e.g. It is acceptable for insurance companies to reconsider a policy if someone has cancer). Responses for each item are made on a 6-point scale; 'agree strongly' to 'disagree strongly' or 'yes, definitely' to 'definitely not' and reverse scored as needed. Cronbach's alpha scores in the present sample were >.7 for most of the subscales for each cancer type (*awkwardness*: 0.74-0.83; *severity*: 0.74-0.89; *avoidance*: 0.91-0.94; *policy opposition*: 0.61-0.77; *personal responsibility*: 0.91-0.95; *financial discrimination*: 0.76-0.82).

Analyses

Scores for each subscale were calculated by taking the mean of the items (potential range 1-6). Data were analysed in SPSS version 15.0. Two-way between-groups ANOVAs were used to compare the mean scores for each cancer type. Post-hoc tests (Tukey) were used to explore these differences in more detail; identifying whether lung and breast cancer differed from the other cancers.

Results

Sample characteristics

Overall 1205 participants completed the questionnaire. Cases with >20% missing data on the CASS were excluded (16%). After exclusions, 1014 cases were available for further analyses: cervical cancer (n=187), lung cancer (n=204), breast cancer (n=213), colorectal cancer (n=195) and skin cancer (n=215). Half the participants were female (49%) and the mean age was 37.8 years (range 16-80). Sample characteristics are shown in Table 1. There were no significant differences in gender, age, ethnicity or educational attainment

across the five cancer types. In general, stigma scores were at the lower end of the scale, with most mean scores for each subscale less than 3 on the 1-6 scales, see figure 1.

Variation in stigma by cancer type
There were significant differences in mean scores across the five cancer types for each of the six subscales: *awkwardness* $(F(4, 1009)=5.16, p<.001)$, *severity* $(F(4, 984)=26.24, p<.001)$, *avoidance* $(F(4, 1008)=5.38, p<.001)$, *policy opposition* $(F(4, 1009)=8.38, p<.001)$, *personal responsibility* $(F(4, 995)=31.67, p<.001)$ and *financial discrimination* $(F(4, 957)=9.45, p<.001)$. Lung cancer stigma was significantly greater than cervical and breast cancer stigma across all six subscales $(p<.01)$, greater than colorectal cancer on all subscales except *awkwardness* $(p<.05)$, and greater than skin cancer on *awkwardness*, *severity* and *discrimination* $(p<.01)$.

Breast cancer attracted lower stigma than most of the other cancer types. Scores were significantly lower than lung cancer on all six subscales $(p<.01)$, lower than skin cancer on three subscales (*avoidance*, $p<.05$; *policy opposition*, $p<.05$; *personal responsibility*, $p<.001$) and colorectal cancer on two subscales (*severity*, $p<.05$; *personal responsibility*, $p<.01$). Breast and cervical cancer were not significantly different on any of the subscales $(p>.05)$.

Discussion

This study used a multidimensional measure of stigma to explore differences between lung cancer and four other cancer types. As others have reported [6;15;16], the study participants saw lung cancer as more severe than other cancers, and were more likely to feel awkward around, and avoid, someone with lung cancer. Lung cancer was attributed more personal responsibility than the other cancers (except for skin cancer). In addition, there was less support for policy initiatives to protect lung cancer patients and more acceptance of financial discrimination. Breast cancer attracted the least stigma across all six of the subscales, although it was not significantly different from cervical cancer and not always significantly lower than skin and colorectal cancer. The remaining three cancer types (colorectal, skin and cervical cancer) mostly fell in between lung and breast cancer, but their patterning varied across the six subscales.

Previous studies have suggested lung cancer stigma is driven by the perception that all lung cancer patients are smokers, meaning their illness is self-inflicted [7]. Health policy and media campaigns have successfully de-normalised smoking, and while this has had the desired effect on smoking prevalence, the step from stigmatising smoking to stigmatising lung cancer patients is often considered unjust. Lung cancer stigma does not appear to be restricted to personal responsibility attributions and attempts to alleviate lung cancer stigma could help to improve the lung cancer patient experience. Studies suggest that lung cancer patients feel 'dirty' and like 'lepers' [6] as well as suffering higher levels of distress [29] and suicide compared to other cancer patients [30]. Chambers et al. [31] recently published the first study aimed at decreasing health-related stigma in lung cancer patients through telephone sessions delivering acceptance-focused cognitive behavioural therapy (CBT). The intervention appeared to successfully reduce felt-stigma as well as distress and depression.

A multi-level approach to interventions, aiming to change perceptions among the general public, family members and health professionals as well as patients might be beneficial, but research is needed to explore the best ways of doing this. Studies of drug addiction stigma suggest that communicating positive stories about patients may be an effective way to influence social stigma, while contact-based training appears to be the best way to address stigma among health professionals [32]. Health policies should acknowledge the existence of lung cancer stigma and the multilevel consequences this has. Acknowledgement of cancer stigma alongside commitment to minimising this will help encourage research

establishing the best ways to reduce lung cancer stigma and ultimately improve patient experience.

There are limitations to the present study. Admitting to cancer stigma is likely to be considered socially undesirable, and respondents may have adjusted their responses to portray a less negative attitude; but we believe that anonymity and use of online questionnaires should have limited social desirability effects [33]. Although the panel sample was demographically representative of the population, generalisations to the wider population about the level of cancer stigma may be limited. However, we would expect that the differences between the cancers would be at least as great in a population representative sample.

Variation in scores on the stigma subscales was within a small range; in most cases the difference in mean scores between the most and the least stigmatised cancers was less than 1 (on a 6-point scale). Without further exploration of these findings, it is difficult to determine their social/behavioural significance. Research exploring the association between responses on these scales and support for self-disclosure of cancer patients would be valuable. In general stigma of cancer was low in the present sample; respondents did not think they would avoid or feel awkward around someone with cancer, they did not think someone with cancer was responsible for their illness or that the consequences of cancer were always severe, they did not endorse financial discrimination against people with cancer, and they supported funding and policies to help people with cancer. These findings were not unexpected; our interest lay more in the variation between cancer types.

Conclusion

Most stigma theorists suggest that stigma varies across time and between cultures [34], but rarely consider how it varies across different subtypes of a disease. As public awareness about the causes and consequences of cancer increases, stigma may become a more important issue for some cancers. There is a risk that increasing public awareness of 'lifestyle' causes could increase stigma [26], but at the same time, if outcomes improve and the dread associated with cancer recedes, some aspects of cancer stigma may be reduced.

Acknowledgements

Conflict of interest statement

None declared

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Table 1: Sample characteristics

	Total (n=1205)	Cervical (n=227)	Lung (n=247)	Breast (n=242)	Colorectal (n=241)	Skin (n=248)
Age (mean)	37.8	39.2	36.7	37.1	38.9	37.0
Gender (%)						
Female	49.3	50.7	46.2	47.9	53.9	48.0
Male	50.7	49.3	53.8	52.1	46.1	52.0
Ethnicity (%)						
White	87.0	91.8	88.4	87.2	89.1	84.6
Non-white	11.7	8.2	11.6	12.8	10.9	15.4
Education (%)						
GCSE or vocational	32.9	33.0	31.6	31.8	34.4	33.9
A-level or higher qualification < degree	34.4	37.0	38.9	28.9	35.3	31.9
Degree	28.2	24.2	25.1	35.5	25.7	30.2
Other	4.5	5.7	4.5	3.7	4.6	4.0

Figure 1: Mean scores (and 95% Confidence Intervals) for each subscale by cancer type