Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints

Suzanne K. Chambers[1,2,3,4]*, Peter Baade[1,2,5], Philippa Youl[1,2,5], Joanne Aitken[2], Stefano Occhipinti[1], Shalini Vinod[6,7,8,9], Patricia C. Valery[10], Gail Garvey[10], Kwun M. Fong[11,12], David Ball[13,14], Helen Zorbas[15], Jeff Dunn[1,2,16] and Dianne L. O'Connell[17,18,19,20]

[1]Menzies Health Institute of Queensland, Griffith University, Brisbane, Australia

[2]Cancer Council Queensland, Brisbane, Australia

[3]Health and Wellness Institute, Edith Cowan University, Perth, Australia

[4]Centre for Clinical Research, University of Queensland, Brisbane, Australia

[5]School of Public Health and Social Work, Queensland University of Technology, Brisbane, Australia

[6]Liverpool Cancer Therapy Centre, Sydney, Australia

[7]Macarthur Cancer Therapy Centre, Sydney, Australia

[8]University of NSW, Sydney, Australia

[9]University of Western Sydney, Sydney, Australia

[10]Menzies School of Health Research, Charles Darwin University, Darwin, Australia

[11]Department of Thoracic Medicine, The Prince Charles Hospital, Brisbane, Australia

[12]Thoracic Research Centre, University of Queensland, Brisbane, Australia

[13]Division of Radiation Oncology and Cancer Imaging, Peter MacCallum Cancer Centre, East Melbourne, Australia

[14]The Sir Peter MacCallum Department of Oncology, University of Melbourne, Melbourne, Australia

[15]Cancer Australia, Sydney, Australia

[16]School of Social Science, University of Queensland, Brisbane, Australia

[17]Cancer Council New South Wales, Sydney, Australia

[18]School of Population Health and Community Medicine, University of NSW, Sydney, Australia

[19]School of Medicine and Public Health, University of Newcastle, Newcastle, Australia

[20]Sydney Medical School – Public Health, University of Sydney, Sydney, Australia

*Correspondence to:
Menzies Health Institute of
Queensland, Griffith University,
Building G05 2.44, Gold Coast
Campus, Brisbane QLD 4222,
Australia. E-mail: suzanne.
chambers@griffith.edu.au

Abstract

Objective: Health-related stigma is associated with negative psychological and quality of life outcomes in lung cancer patients. This study describes the impact of stigma on lung cancer patients' psychological distress and quality of life and explores the role of social constraints and illness appraisal as mediators of effect.

Methods: A self-administered cross-sectional survey examined psychological distress and quality of life in 151 people (59% response rate) diagnosed with lung cancer from Queensland and New South Wales. Health-related stigma, social constraints and illness appraisals were assessed as predictors of adjustment outcomes.

Results: Forty-nine percent of patients reported elevated anxiety; 41% were depressed; and 51% had high global distress. Health-related stigma was significantly related to global psychological distress and quality of life with greater stigma and shame related to poorer outcomes. These effects were mediated by illness appraisals and social constraints.

Conclusions: Health-related stigma appears to contribute to poorer adjustment by constraining interpersonal discussions about cancer and heightening feelings of threat. There is a need for the development and evaluation of interventions to ameliorate the negative effects of health-related stigma among lung cancer patients.

© 2015 The Authors. *Psycho-Oncology* Published by John Wiley & Sons Ltd.

Introduction

Lung cancer patients, more so than patients with other cancers, feel stigmatized by their disease; and this increases their subjective distress and may negatively influence help-seeking behaviours and overall patient outcomes [1]. Stigma occurs when society labels someone as tainted on the basis of an attribute that marks them out as different [2]. In lung cancer, health-related stigma results from the association between the disease and smoking and perception

of the disease as self-inflicted, high mortality and perceptions about the type of death that may be experienced [1]. Stigma is relationship and context-specific where a specific attribute is associated with a negative evaluation that can lead to negative discrimination and self-fulfilling prophecies, stereotype activation and identity threat [3]. When internalized, these negative evaluations lead to shame or guilt and fear of discrimination. Stigma negatively influences social interactions and threatens an individual's identity. Increased stress and poor coping leading to negative mental and physical health outcomes and the amplification of psychosocial morbidity may result from stigma [4].

A recent systematic review found that lung cancer patients consistently reported health-related stigma and that this was related to poorer psychological and quality of life outcomes as well as fears that medical treatment may be futile or even denied [1]. For example, perceived stigma is positively associated with depression in lung cancer patients and accounts for unique variance above background demographic, clinical and psychosocial factors [5] and also predicts poorer quality of life, again even when significant covariates are accounted for [6]. Importantly, this relationship persists regardless of whether the patient has ever smoked [7].

Problematically, the mechanism by which stigma influences quality of life and psychosocial outcomes is not yet clear. Lebel *et al.* found in head and neck and lung cancer patients that the extent to which the illness was perceived as having disrupted valued activities and interests partially mediated the relationship between stigma and psychological distress and subjective well-being [8]. Cataldo reported that stigma was associated with lower social support and higher social conflict, suggesting that social interactions are implicated in the stigma–distress relationship [9]. On this view, stigma about lung cancer may lead to social isolation [10–12] and limit the patient's ability to discuss their cancer within their social network [13], exacerbating distress. A social cognitive processing model of adjustment to cancer proposes that social constraints on the ability to disclose trauma-related thoughts (such as fears or concerns) have an adverse effect on patient adjustment outcomes [14]. Social constraints are shaped by social environments, and this includes norms, laws and the media [15], which also in turn shape stigma [3]. As well, stigma in lung cancer has been linked in qualitative research to perceptions about treatment being futile and death inevitable [10–12,16,17]. Thus, stigma may heighten lung cancer patients' negative appraisals of cancer threat. Specifically, if a person appraises their cancer primarily in a positive way, that is, as a challenge they can meet, they would be expected to experience less distress than a person who views their cancer predominantly as a threat [18]. To date, researchers have not quantitatively assessed how health-related stigma may influence these illness appraisals.

This study describes health-related stigma, psychological distress and quality of life in lung cancer patients and explores social constraints, and challenge and threat appraisals as potential influencing factors. We hypothesized that health-related stigma would be related to higher psychological distress and poorer quality of life and that the effect of stigma on these adjustment outcomes would be mediated by social constraints and challenge and threat appraisals.

Methods

Participants

This study was conducted in Queensland (QLD) and New South Wales (NSW), Australia (August 2012 to March 2013), with individuals newly diagnosed with lung cancer. Participants were recruited from respiratory clinicians, surgeons and medical and radiation oncologists at 11 public hospitals (six in QLD and five in NSW), and from the Queensland Cancer Registry (QCR; a population-based register of incident cancers). Eligible participants were aged 18 years or over, newly diagnosed with primary invasive lung cancer and able to understand English.

Recruitment procedures

Potential participants identified through direct referral from the medical or clinical care team were provided with a pamphlet by their clinician or a research officer that explained the study purpose. Individuals who were interested signed a 'permission to contact' form and were subsequently contacted by the research team to assess eligibility and obtain consent. Recruitment through the QCR was in two steps: first, details of the diagnosing clinician were obtained from the pathology reports in the QCR, and the clinicians were approached for permission to contact the patient. Second, when the doctor gave signed consent for contact, patients were mailed detailed information about the study and consent forms inviting them to participate. Following guidelines established by the QCR and governed by the Public Health Act 2005, non-responders were re-contacted if no response was received after a further 2 weeks.

Study integrity

Ethical approval was obtained from Griffith University Human, Gold Coast Health Service District Human and New South Wales Population and Health Services Research Ethics Committees. All participants provided written consent.

Materials

Assessment included a brief 10- to 15-min computer-assisted telephone interview (CATI) that assessed background

sociodemographic characteristics. CATI uses a software application that allows the interviewer to conduct a structured telephone interview with responses keyed directly into a database at interview. Interview questions were developed by the study team including a lung cancer clinician in consultation with a lung cancer support group. On completion of the interview, participants were mailed a self-report questionnaire that included a series of reliable and validated measures. The assessments were pilot tested with 10 participants.

Outcome variables

Psychological distress was measured using the Hospital Anxiety and Depression Scale (HADS) [19] that measures generalized anxiety and depression experienced during the past week with two subscales: anxiety (HADS-A) and depression (HADS-D) [19,20]. A cut-off of ≥ 8 was used to indicate at least mild distress on each subscale, as well as a total HADS score (HADS-T) ≥ 15, to indicate clinically significant distress. Scale reliability was very good ($\alpha = 0.86, 0.74, 0.86$). HADS has been widely used in cancer patients [21].

Quality of life was measured using the Functional Assessment of Cancer Therapy-Lung (FACT-L) Scale (version 4). The FACT-L assesses physical well-being, social/family well-being, emotional well-being, functional well-being and lung-cancer-specific concerns. Higher scores indicate better quality of life [22]. Scale reliability was excellent ($\alpha = 0.92$).

Predictor variables

The Cataldo Lung Cancer Stigma Scale (CLCSS) assessed lung cancer stigma [9]. The CLCSS has four subscales (stigma and shame, social isolation, discrimination and smoking). Higher scores indicate greater stigma. Scale reliability was very good: stigma and shame $\alpha = 0.88$, social isolation $\alpha = 0.92$, discrimination $\alpha = 0.85$ and smoking $\alpha = 0.75$.

The Social Constraints Scale measured social constraints on disclosure about cancer with family and friends [15] and has been used widely in cancer populations [23,24]. This scale assesses the degree of negative social interactions experienced in the last 2 weeks with a partner, close friend or relative with higher scores indicating more constraints. Scale reliability was excellent ($\alpha = 0.92$)

A stress appraisal scale measured threat and challenge appraisal as described by Roesch and Rowley [18]. These two appraisals are considered to be primary appraisals [25] and are most relevant to a diagnosis of cancer. A higher score for threat appraisal indicates more threat; higher challenge score indicates the participant feels challenged by the diagnosis of lung cancer in a positive way. Scale reliability was very good ($\alpha = 0.82–0.84$).

Statistical analysis

Multiple linear regression models applied a hierarchical variable selection method using an *a priori* approach in which the explanatory variables are entered in blocks specified by the researcher according to logical or theoretical considerations and presumed substantive priority [26]. In this approach, background sociodemographic variables were entered first, followed by the four lung cancer stigma subscales (shame, discrimination, social isolation and smoking) as individual psychological variables proposed to influence adjustment then appraisal and finally social variables that might act as mechanisms by which stigma influences outcomes. For each of the final regression models, we examined the assumption of homoscedasticity of the residuals (i.e. when there is no pattern of the residuals against the fitted values) and the normality of the residuals.

Given the number of sociodemographic variables in this study, an iterative backward stepwise variable selection method was first conducted for this group of variables only. First, the sociodemographic variables of gender, age group, recruitment method, education, private health insurance, marital status, country of birth and lifetime history of smoking were added to the null model. Variables were then successively excluded from the model based on the likelihood ratio test ($p \geq 0.2$). Excluded variables were then given the opportunity to re-enter the model at each step ($p < 0.1$). Once the final group of statistically significant sociodemographic variables was determined for each outcome measure, this group was used in the subsequent hierarchical model development. Cases with any missing values for the analysis variables were removed from the study dataset. The amount of variance explained by the modelled variables was estimated by the model R^2. The significance of individual variables in the final model was assessed by the likelihood ratio test, with model coefficients and their standard errors being used to generate 95% confidence intervals.

To test each of the mediation scenarios, a macro (*sgmediation.do*) within the STATA software package (Version 12.1, StataCorp LP, TX, USA) was used. This method of quantifying the mediation pathway [27] estimated the following three regression equations: (1) regress the mediator (appraisal or social constraints) against the independent variable (separate models for four subscales of lung cancer stigma); (2) regress the dependent variable (separate models for HADS-A, HADS-D and HADS-T) on the independent variable (four subscales of stigma); and (3) regress the dependent variable (distress) on the mediator and the independent variable. Mediation exists when the association is significant in regressions (1) and (2), and when the mediator is associated with the outcome in (3) but the effect of the independent variable is less (i.e. the coefficient is closer to zero) in equation (3) than in equation (2).

This four-step approach does not test the significance of the indirect pathway and has been shown to miss some real mediation effects [28], so the indirect effect was examined using the method of Sobel [29]. The regression coefficient for the indirect effect represents the change in the outcome variable (Y) for every unit change in the independent variable (X) that is mediated by the mediating variable (M). Mediation was only examined for those associations where the total effect involving one of the stigma variables was statistically significant.

Because of the highly skewed distribution of the indirect effects, standard statistical tests were not considered valid. Therefore, resampling bootstrapping was used, in which 2500 multiple random subsamples were drawn from the study cohort. Standard errors for the indirect effect were calculated using the results from the 2500 replications.

Results

Participants

Of the 295 patients who were approached, 199 were contacted through the QCR and 96 through the hospital-based clinics. Of these, 26 were deceased (15 from QCR and 11 from clinic recruitment); 43 did not respond to the invitation to participate (33 from QCR and 10 from the clinics); 54 refused participation (39 from QCR and 15 from clinic recruitment); and 172 individuals consented to participate in the study (112 from QCR and 60 from the clinics). The majority of consented participants were diagnosed with non-small-cell lung cancer (89%), with approximately 11% diagnosed with small-cell lung cancer. Of those who refused participation ($n = 54$), 49% were male, and the mean age was 69 years with no significant differences observed by method of recruitment. Of the 172 consented patients, six died prior to the telephone interview (all recruited through the QCR), six withdrew as they were too unwell at the time of the interview (five from QCR and one from the clinics) and two were deemed ineligible (both from QCR) as they spoke little English. Of the remaining 158 participants, three participants recruited through the QCR and one clinic-recruited participant did not complete either the telephone interview or the self-report questionnaire, while records for three (one QCR recruitment and two clinic-recruited participants) were excluded because of incomplete responses. Thus, the final cohort completing this cross-sectional study consisted of 151 participants (95 through QCR recruitment and 56 through clinic recruitment; 59% response from those actually eligible), with 114 (76%) from QLD and 37 (24%) from NSW. Participant characteristics are described in Table 1. Among all 151 participants, the median time since diagnosis was 25.6 weeks, and the mean was 29.1 weeks (standard deviation = 17.5). Half the participants (50%) had some form of private

health insurance. About 83% of participants reported that they had smoked at least 100 cigarettes in their life ('lifetime history of smoking'). There were no significant differences in sociodemographic variables between participants recruited through the QCR and the clinics with the exception that those recruited through the clinics were significantly less likely to have private health insurance ($p < 0.002$).

Overall, 49.0% of participants were anxious (HADS-A score ≥ 8), and 41.1% were depressed (HADS-D score ≥ 8). Overall, 51.0% of participants were distressed (HADS-T score ≥ 15). While female participants had a higher mean score for levels of anxiety (female participants = 8.1 and male participants = 7.2), this was not significant ($p = 0.063$). Mean scores for depression and total distress were similar for male and female participants (Table 2). Mean scores for measures of distress were significantly lower for older participants. Levels of distress were not significantly different across categories of the other sociodemographic variables. Overall, mean score for quality of life as measured by FACT-L was 99.6 (standard deviation = 21.6) with higher mean scores for older people but similar scores across other sociodemographic groups.

Effect of stigma on anxiety

Sociodemographic variables that were significantly ($p < 0.20$) associated with anxiety were age at diagnosis and gender, with women having slightly higher levels of anxiety than men and older people reporting lower levels of anxiety than younger people (likelihood ratio (LR) test $\chi^2 = 16.53$, df = 3, $p < 0.001$). Combined, these variables accounted for approximately 10% of the variance. Next, the lung cancer stigma variables were included, and these were statistically significant (LR test $\chi^2 = 32.72$, df = 4, $p < 0.001$), with the model now accounting for 28% of the variance. The impact of the stigma subscales on anxiety was limited to stigma and shame ($p = 0.029$) and discrimination ($p = 0.018$), with higher scores in these measures associated with higher anxiety. The challenge and threat appraisal variables were also statistically significant (LR test $\chi^2 = 16.56$, df = 2, $p < 0.001$) when added to the model, and the model now explained 35% of the variance. With these variables added in, the association between anxiety and the lung cancer stigma subscales became statistically non-significant ($p = 0.156$). Finally, the social constraints variable was added (LR test $\chi^2 = 8.13$, df = 1, $p = 0.004$), with the final model explaining 39% of the variance in the HADS-A (Table 3). In this final model, the only significant associations were between anxiety and threat appraisal (positive association) and social constraints (positive association).

Effect of stigma on depression

Sociodemographic variables that were associated with depression were age at diagnosis and recruitment method

Table 1. Mean scores for stigma, stress appraised and social constraints across sociodemographic and smoking variables ($n = 151$)

	Stigma shame mean (SD)[a]	Discrimination mean (SD)[a]	Social isolation mean (SD)[a]	Smoking mean (SD)[a]	Challenge appraisal mean (SD)	Threat appraisal mean (SD)	Social constraints mean (SD)
Sex							
Male ($n = 78$)	15.9 (4.6)	9.3 (2.9)	12.7 (4.1)	11.0 (3.4)	3.5 (1.0)	2.6 (1.0)	1.5 (0.5)
Female ($n = 73$)	18.0 (6.2)	10.5 (3.6)	13.8 (4.8)	12.3 (3.5)	3.7 (0.9)	3.1 (1.0)	1.7 (0.7)
Age at diagnosis							
<60 years ($n = 40$)	19.0 (6.2)	11.2 (3.6)	14.8 (4.3)	12.3 (3.7)	3.6 (0.9)	3.2 (1.1)	1.9 (0.7)
60–69 years ($n = 69$)	16.6 (5.1)	9.6 (3.2)	13.2 (4.6)	11.7 (3.3)	3.7 (1.0)	2.8 (1.0)	1.6 (0.6)
70 years and over ($n = 42$)	15.4 (4.9)	9.1 (2.8)	11.8 (3.8)	10.8 (3.7)	3.5 (1.0)	2.6 (0.9)	1.4 (0.5)
Highest education							
University/college ($n = 26$)	18.2 (6.5)	10.1 (3.4)	13.7 (5.1)	11.7 (3.0)	3.6 (0.9)	3.0 (1.1)	1.7 (0.7)
Trade/tech/diploma ($n = 68$)	17.4 (5.4)	10.3 (3.4)	13.5 (4.6)	11.5 (3.4)	3.6 (1.0)	2.9 (1.1)	1.6 (0.6)
No higher education ($n = 57$)	15.8 (5.0)	9.4 (3.2)	12.6 (3.9)	11.7 (3.8)	3.7 (0.9)	2.8 (1.0)	1.6 (0.6)
Private health insurance							
No ($n = 76$)	16.6 (5.5)	9.8 (3.6)	13.2 (4.9)	11.3 (3.7)	3.7 (1.0)	2.7 (1.1)	1.6 (0.6)
Yes ($n = 75$)	17.2 (5.5)	10.0 (3.1)	13.3 (4.0)	11.9 (3.3)	3.6 (1.0)	2.9 (1.0)	1.6 (0.6)
Marital status							
Not married ($n = 42$)	16.8 (5.5)	10.4 (3.6)	14.0 (4.7)	11.6 (3.6)	3.5 (0.9)	2.9 (1.0)	1.6 (0.7)
Married/living as married ($n = 109$)	17.0 (5.5)	9.7 (3.2)	12.9 (4.3)	11.6 (3.5)	3.7 (1.0)	2.8 (1.0)	1.6 (0.6)
Country of birth							
Australia ($n = 109$)	17.1 (5.6)	10.0 (3.4)	13.3 (4.2)	11.9 (3.5)	3.7 (1.0)	2.8 (1.0)	1.6 (0.6)
Overseas ($n = 42$)	16.5 (5.1)	9.7 (3.2)	13.1 (5.1)	10.9 (3.4)	3.4 (0.8)	2.8 (1.0)	1.6 (0.6)
Lifetime history of smoking							
Yes ($n = 125$)	16.9 (5.3)	9.8 (3.1)	13.2 (4.3)	11.9 (3.4)	3.6 (1.0)	2.8 (1.1)	1.6 (0.6)
No ($n = 26$)	17.2 (6.3)	10.4 (4.3)	13.5 (5.1)	10.2 (3.8)	3.6 (1.0)	2.8 (0.8)	1.9 (0.7)
Recruitment							
Queensland Cancer Registry ($n = 95$)	17.0 (5.3)	9.7 (3.1)	12.9 (4.0)	11.7 (3.4)	3.7 (1.0)	2.7 (1.0)	1.6 (0.6)
Clinic-based ($n = 56$)	16.8 (5.9)	10.2 (3.7)	13.7 (5.1)	11.5 (3.7)	3.5 (0.9)	3.0 (1.0)	1.7 (0.6)

SD, standard deviation.
[a]Higher mean scores indicate more stigma.

(LR Test $\chi^2 = 15.35$, df $= 3$, $p = 0.002$). Older people reported lower levels of depression, while those recruited through the clinics had slightly higher depression. This accounted for approximately 10% of the variance. Next, the lung cancer stigma variables were included, and model fit improved (LR Test $\chi^2 = 17.25$, df $= 4$, $p = 0.002$), with the model now accounting for 19% of the variance. However, in this model, only shame was significantly associated with depression ($p = 0.011$), along with age group. When the challenge and threat appraisal variables were added, they were statistically significantly related to depression (LR test $\chi^2 = 17.82$, df $= 2$, $p < 0.001$), with the model now explaining 28% of the variance. In this model, the association between shame and depression was borderline significant ($p = 0.051$). Finally, the social constraints variable was added; however, the addition of this variable provided no evidence of improved fit (LR test $\chi^2 = 0.21$, df $= 1$, $p = 0.647$). Therefore, the final model explained 28% of the variation in depression (Table 3). In this final model, the only significant associations were between depression and age at diagnosis (older people had lower depression), threat appraisal (positive association) and challenge appraisal (negative association).

Effect of stigma on total distress

The only sociodemographic variable that was significantly associated with total distress was age at diagnosis (LR test $\chi^2 = 19.22$, df $= 2$, $p < 0.001$), with older people reporting lower distress. This accounted for approximately 12% of the variance. Next, the lung cancer stigma variables were included, and the model fit significantly improved (LR test $\chi^2 = 34.79$, df $= 4$, $p < 0.001$) accounting for 30% of the variance. In this model, the only subscale that had an association with total distress was stigma and shame ($p = 0.004$). The addition of the challenge and threat appraisal variables further improved model fit (LR test $\chi^2 = 26.73$, df $= 2$, $p < 0.001$), with the model now explaining 41% of the variance. The association between stigma and shame and distress was still statistically significant ($p = 0.040$). Finally, the social constraints variable was added, but was not statistically significant (LR test $\chi^2 = 2.41$, df $= 1$, $p = 0.121$), so the final model explained 41% of the variation in total distress (Table 3). In this final model, the only significant associations were between total distress and age at diagnosis (older people had lower distress), stigma and shame (people with higher stigma

Table 2. Mean scores for distress, quality of life by sociodemographic and smoking variables (*n* = 151)

	HADS – anxiety		HADS – depression		HADS – total		Quality of life mean (SD)
	(% cases)[a]	Mean (SD)	(% cases)[b]	Mean (SD)	(% cases)[c]	Mean (SD)	
Sex							
Male	42	7.2 (2.9)	40	7.1 (2.9)	46	14.3 (5.2)	101 (24)
Female	56	8.1 (3.1)	42	7.2 (2.6)	56	15.3 (4.5)	98 (19)
Age at diagnosis							
<60 years	68	9.0 (3.0)	60	8.2 (2.6)	78	17.1 (4.6)	91 (22)
60–69 years	46	7.5 (3.1)	42	7.3 (2.9)	54	14.8 (4.9)	101 (21)
70 years and over	36	6.6 (2.5)	21	6.0 (2.3)	21	12.6 (3.9)	105 (21)
Highest education							
University/college	46	7.8 (3.3)	54	7.7 (3.3)	50	15.5 (5.6)	100 (21)
Trade/tech/diploma	50	7.8 (3.1)	37	6.9 (2.5)	50	14.6 (4.7)	98 (23)
No higher education	49	7.4 (2.8)	40	7.3 (2.8)	53	14.6 (4.8)	101 (20)
Private health insurance							
No	47	7.6 (2.7)	43	7.2 (2.8)	54	14.8 (4.6)	98 (22)
Yes	51	7.7 (3.3)	39	7.1 (2.7)	48	14.8 (5.1)	101 (21)
Marital status							
Not married	55	7.8 (3.1)	40	7.3 (2.8)	52	15.1 (4.8)	98 (22)
Married/living as married	47	7.5 (3.0)	41	7.1 (2.7)	50	14.7 (4.9)	100 (22)
Country of birth							
Australia	46	7.5 (3.0)	40	7.2 (2.8)	50	14.6 (4.9)	99 (21)
Overseas	57	8.0 (3.2)	43	7.1 (2.6)	52	15.1 (4.8)	100 (22)
Lifetime history of smoking							
Yes	47	7.5 (3.0)	41	7.2 (2.8)	52	14.7 (4.8)	99 (22)
No	58	8.2 (3.4)	42	7.0 (2.4)	46	15.2 (5.0)	102 (20)
Recruitment							
Queensland Cancer Registry (*n* = 95)	55	7.6 (3.2)	65	6.9 (2.7)	56	14.4 (5.1)	103.8 (21)
Clinic-based (*n* = 56)	45	7.7 (2.8)	48	7.7 (2.7)	38	15.4 (4.4)	92.4 (21)

SD, standard deviation.
[a]Case defined as score of ≥8 for the subscale of anxiety.
[b]Case defined as a score of ≥8 for the subscale of depression.
[c]Case defined as a total score of ≥15 for the total of anxiety and depression.

and shame had higher distress), threat appraisal (positive association) and challenge appraisal (negative association).

There was a statistically significant mediating effect for threat appraisal and for social constraints (separately) on the association between total distress and stigma and shame (Table 4).

Effect of stigma on quality of life

The only sociodemographic variables that were significantly associated with quality of life were age group at diagnosis and recruitment method (LR test $\chi^2 = 19.24$, df = 3, $p < 0.001$), with older people and those recruited through the QCR reporting higher quality of life. This accounted for approximately 12% of the variance. Next, the four lung cancer stigma variables were included (LR test $\chi^2 = 29.76$, df = 4, $p < 0.001$), with the model now accounting for 28% of the variance. However, of the individual subscales, in this model, only stigma and shame had a significant association with quality of life ($p = 0.010$). Adding in the challenge and threat appraisal variables significantly improved the model fit (LR test $\chi^2 = 50.75$, df = 2, $p < 0.001$), which now explained 48% of the variance. Finally, the social constraints variable was added (LR test $\chi^2 = 12.44$, df = 1, $p < 0.001$), with the final model now

explaining 52% of the variance in quality of life (Table 3). In this final model, the only significant associations were between quality of life and recruitment method (higher in QCR group), stigma and shame (negative association), challenge appraisal (positive association), threat appraisal (negative association) and social constraints (negative association).

There was a statistically significant mediating effect for threat appraisal and for social constraints (separately) on the association between quality of life and stigma and shame (Table 4).

Discussion

As in previous research [30–33], patients reported high levels of psychological distress, again demonstrating that lung cancer patients are highly vulnerable to psychosocial morbidity after diagnosis. Importantly, study hypotheses about the relationship between health-related stigma and the outcomes of psychological distress and quality of life were confirmed for the stigma and shame component of lung cancer stigma. By contrast, no significant associations were found for the social isolation, discrimination and smoking components. In brief, greater stigma and shame was associated with higher global distress and poorer

Table 3. Multivariate linear regression estimates (beta coefficients and 95% confidence intervals) for factors associated with psychological distress and quality of life (n = 151)

	Anxiety	Depression	Total distress	Quality of life
		Demographics		
Clinic group	N/a	0.541 (−0.28,1.36)	N/a	−8.500 (−13.80, −3.20) **
Female	−0.044 [−0.88, 0.80]	N/a	N/a	N/a
Age group (60–69 years)	−0.454 [−1.45, 0.55]	−0.403 [−1.37, 0.56]	−0.905 [−2.45, 0.64]	2.299 [−3.798 8.58]
Age group (70 years and over)	−0.926 [−2.08, 0.22]	−1.428 [−2.54, −0.32] **	−2.445 [−4.22, −0.67] **	3.243 [−4.00, 10.49]
Incremental group significance	LR test χ^2 = 16.53, df = 3, p < 0.001	LR test χ^2 = 16.53, df = 3, p < 0.001	LR test χ^2 = 19.22, df = 2, p < 0.001	LR test χ^2 = 19.24, df = 3, p < 0.001
		Lung cancer stigma variables		
Stigma and shame	0.113 [−0.01, 0.23]	0.118 [−0.00, 0.24]	0.214 [0.03, 0.40] *	−0.792 [−1.56, −0.02] *
Social isolation	−0.065 [−0.22, 0.09]	0.037 [−0.12, 0.24]	−0.010 [−0.26, 0.24]	0.267 [−0.75, 1.28]
Discrimination	0.167 [−0.06, 0.39]	−0.142 [−0.36, 0.8]	0.041 [−0.31, 0.40]	0.202 [−1.24, 1.65]
Smoking scale	−0.044 [−0.18, 0.09]	0.075 [−0.06, 0.21]	0.022 [−0.19, 0.23]	−0.274 [−1.14, 0.60]
Incremental group significance	LR test χ^2 = 32.72, df = 4, p < 0.001	LR test χ^2 = 16.23, df = 4, p = 0.003	LR test χ^2 = 34.79, df = 4, p < 0.001	LR test χ^2 = 29.76, df = 4, p < 0.001
		Stress appraisal		
Challenge appraisal	−0.131 [−0.57, 0.31]	−0.679 [−1.10, −0.26] **	−0.841 [−1.51, −0.17] *	5.610 [2.89, 8.32] ***
Threat appraisal	0.733 [0.28, 1.19] **	0.531 [0.10, 0.97] *	1.326 [0.62, 2.03] ***	−7.036 [−9.92, −4.15] ***
Incremental group significance	LR test χ^2 = 16.56, df = 2, p < 0.001	LR test χ^2 = 17.82, df = 2, p < 0.001	LR test χ^2 = 26.73, df = 2, p < 0.001	LR test χ^2 = 50.75, df = 2, p < 0.001
		Social constraints		
Social constraints	1.106 [0.32, 1.89] **	N/a	0.918 [−0.29, 2.12]	−8.603 [−13.51, −3.70] ***
Incremental group significance	LR test χ^2 = 8.13, df = 1, p = 0.004	LR test χ^2 = 0.21, df = 1, p = 0.647	LR test χ^2 = 2.41, df = 1, p = 0.121	LR test χ^2 = 12.44, df = 1, p < 0.001
Variation explained by model	39%	28%	42%	49%

Beta coefficients are from the final model. Incremental group significance is the results of the likelihood ratio test comparing the previous model (of null model for the initial model) with the updated model containing the grouped variables.
N/a, not included in final model; LR, likelihood ratio.
***<0.001.
**<0.01.
*<0.05.

Table 4. Mediating effect of threat appraisal and social constraints on global distress and quality of life

Independent variable	Mediating variable	% of total effect mediated	Indirect effect (CI)[a]	Sobel test statistics (coefficient, standard error, *p*-value)
Total Distress				
Shame	Threat Appraisal	30.0%	0.13 (0.07–0.21) *	$S = 0.129$ (0.035), $p < 0.001$
Shame	Social Constraints	17.3%	0.07 (0.03–0.15) *	$S = 0.074$ (0.027), $p = 0.007$
Quality of life				
Shame	Threat Appraisal	45.0%	−0.74 (−1.13 to −0.45) *	$S = -0.745$ (0.179), $p < 0.001$
Shame	Social Constraints	29.9%	−0.49 (−0.96 to −0.19) *	$S = -0.494$ (0.150), $p = 0.001$

[a]Coefficient for the indirect effect, along with the bias-corrected 95% confidence interval, was calculated using bootstrapping (2500 iterations) in brackets. The indirect effect is the product of the path (regression) coefficients between the independent variables and the mediator, and the mediator and the dependent variable.
*Bias-corrected 95% confidence interval does not include zero.

quality of life. We propose that this aspect of lung-cancer-related stigma may reflect internalized negative evaluations [3]. There are a number of proposed pathways by which stigma may harm health, for example, actual discrimination and marginalization [34] as well as internalization where the person feels devalued as a result of the stigmatized condition. A systematic review of stigma and mental illness reported a robust negative relationship between internalized stigma and a range of psychosocial variables [35]. Specifically, if a person internalizes stigma such that it becomes part of their world view, they may experience shame, low self-esteem, contracted social networks and come to expect fear and rejection, leading to a compromised quality of life and poorer mental well-being [36]. The present findings connecting stigma and shame to poorer outcomes are consistent with this pathway.

Also consistent are the identified mediating pathways of threat appraisal and social constraints for the effects of stigma and shame on distress and quality of life. First, how a person appraises their cancer in terms of being a threat or a challenge was found to mediate the effect of stigma and shame on psychological well-being and quality of life. Thus, stigma may work, at least in part, by raising the sense of threat that the cancer represents and lowering the person's appraisal that their cancer is a challenge that they can successfully cope with. This finding supports our earlier proposal that threat appraisal is a likely mechanism by which stigma effects outcomes [1]. Consistent with the social cognitive processing model [14] and with stigma theory [36], stigma and shame appeared to also constrain a person's perception that they are able to talk about their lung cancer. From this, it would be argued that these constraints limit that person's ability to obtain support as well as their opportunity to process their cancer experience towards a sense of acceptance.

The present study did not assess what factors underpinned the development of health-related stigma in these patients. Previous researchers have described anti-tobacco campaigns and negative portrayals about lung cancer as influencing stigmatization in these patients [10,11]. Hence, efforts to overcome health-related stigma in lung cancer may need to be multi-level and take into account current social drivers of stigma. Adopting a patient-centred approach, we have piloted

an acceptance-focussed psychological intervention for lung cancer patients with acceptance strategies targeted to specific situational cues to lung cancer stigma as well as perceptions of self-blame about the cancer [37]. This intervention led to meaningful improvements in psychological outcomes and decreases in stigma in the face of declining quality of life; however, larger efficacy trials are needed. To our knowledge, to date, there are no other published clinical interventions addressing stigma in lung cancer patients [1,38].

Limitations of this study include the cross-sectional design such that causality cannot be inferred. However, the link between stigma and poorer psychological and quality of life outcomes is consistent with previous research, and so we suggest that our findings are robust. We note also that the measurement of actual enacted discrimination was beyond the scope of this study where we applied self-reported patient outcome measurements. This is an interesting area for future research where a mixed-methods approach may prove informative. As well, only 59% of those approached and eligible participated. Finally, data on disease stage were not available, and so we were not able to include this potential effect modifier. Strengths include the testing of possible mechanisms of effect and from these new insights to inform future intervention.

These findings likely have relevance for other cancers and chronic diseases where lifestyle factors (e.g. diet, exercise and other drug or alcohol use) are implicated and stigma may result. Obesity is one area where it is argued that weight stigma threatens health, generates health disparities and interferes with effective intervention [39]. This is a future question for psycho-oncology and behavioural and public health researchers seeking to mitigate harm both for the well community and those who present with or are at risk of lifestyle-related illnesses.

Acknowledgements

References

1. Chambers SK, Dunn J, Occhipinti S, *et al*. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer* 2012;**12**(1):184.

2. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*, Simon & Shuster: New York, United States, 1963.

3. Major B, O'Brien LT. The social psychology of stigma. *Annual Review of Psychology* 2005;**56**(1):393–421.

4. Heijnders M, Van Der Meij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health and Medicine* 2006;**11**(3):353–363.

5. Gonzalez BD, Jacobsen PB. Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology* 2012;**21**(3):239–246.

6. Brown Johnson CG, Brodsky JL, Cataldo JK. Lung cancer stigma, anxiety, depression, and quality of life. *Journal of Psychosocial Oncology* 2014;**32**(1):59–73.

7. Cataldo JK, Jahan TM, Pongquan VL. Lung cancer stigma, depression, and quality of life among ever and never smokers. *European Journal of Oncology Nursing* 2012;**16**(3): 264–269.

8. Lebel S, Castonguay M, Mackness G, Irish J, Bezjak A, Devins GM. The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-Oncology* 2013;**22**(1): 140–152.

9. Cataldo JK, Slaughter R, Jahan TM, Pongquan VL , Hwang WJ. Measuring stigma in people with lung cancer: psychometric testing of the Cataldo Lung Cancer Stigma Scale. *Oncology Nursing Forum* 2011;**38**(1): 46–54.

10. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *BMJ* 2004;**328**(7454):1470.

11. Chapple A, Ziebland S, McPherson A, Summerton N . Lung cancer patients' perceptions of access to financial benefits: a qualitative study. *The British Journal of General Practice* 2004;**54**(505):589.

12. Conlon A, Gilbert D, Jones B, Aldredge P. Stacked stigma: oncology social workers' perceptions of the lung cancer experience. *Journal of Psychosocial Oncology* 2010;**28**(1):98.

13. Badr H, Taylor CLC. Social constraints and spousal communication in lung cancer. *Psycho-Oncology* 2006;**15**(8):673–683.

14. Lepore SJ. A social–cognitive processing model of emotional adjustment to cancer. In *Psychosocial Interventions for Cancer*, Baum A, Andersen B (eds.), American Psychological Association: Washington DC, 2001;99–116.

15. Lepore SJ, Revenson TA. Social constraints on disclosure and adjustment to cancer. *Social and Personality Psychology Compass* 2007;**1**(1):313–333.

16. Leydon G, Bynoe-Sutherland J, Coleman M. The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of Cancer Care* 2003;**12**(4):317–326.

17. Sharf BF, Stelljes LA, Gordon HS. 'A little bitty spot and I'm a big man': patients' perspectives on refusing diagnosis or treatment for lung cancer. *Psycho-Oncology* 2005;**14**(8):636–646.

18. Roesch SC, Rowley AA. Evaluating and developing a multidimensional, dispositional measure of appraisal. *Journal of Personality Assessment* 2005;**85**(2):188–196.

19. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 1983;**67**(6):361–370.

20. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale – a review of validation data and clinical results. *Journal of Psychosomatic Research* 1997;**42**(1):17–41.

21. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale – an updated literature review. *Journal of Psychosomatic Research* 2002;**52**(2):69–78.

22. Cella DF, Bonomi AE, Lloyd SR, Tulsky DS, Kaplan E, Bonomi P. Reliability and validity of the Functional Assessment of Cancer Therapy-Lung (FACT-L) quality of life instrument. *Lung Cancer* 1995;**12**(3):199–220.

23. Lepore SJ, Ituarte PHG. Optimism about cancer enhances mood by reducing negative social interactions. *Cancer Research, Therapy and Control* 1999;**8**:165–174.

24. xMosher CE, Lepore SJ, Wu L, et al. Social correlates of distress following hematopoietic stem cell transplantation: exploring the role of loneliness and cognitive processing. *Journal of Health Psychology* 2012; 1359105311432490.

25. Peacock EJ, Wong PTP. The stress appraisal measure (SAM): a multidimensional approach to cognitive appraisal. *Stress Medicine* 1990;**6**(3):227–236.

26. Tabachnick B, Fidell L. *Using Multivariate Statistics* (4th ed.), Allyn and Bacon: Northbridge, 2001.

27. Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology* 1986;**51**(6):1173–1182.

28. MacKinnon DP, Fairchild AJ, Fritz MS. Mediation analysis. *Annual Review of Psychology* 2007;**58**:593.

29. Sobel ME. Asymptotic confidence intervals for indirect effects in structural equation models. In *Sociological Methodology*, Leinhardt S (ed.), American Sociological Association: Washington DC, 1982;290–312.

30. Akechi T, Okuyama T, Akizuki N, et al. Course of psychological distress and its predictors in advanced non-small cell lung cancer patients. *Psycho-Oncology* 2006;**15**(6): 463–473.

31. Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer* 2004;**90**(12):2297–2304.

32. Graves KD, Arnold SM, Love CL, Kirsh KL, Moore PG, Passik SD . Distress screening in a multidisciplinary lung cancer clinic: prevalence and predictors of clinically significant distress. *Lung Cancer* 2007;**55**(2): 215–224.

33. Hopwood P, Stephens RJ, for the British Medical Research Council Lung Cancer Working Party. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *Journal of Clinical Oncology* 2000;**18**(4):893.

34. Stuber J, Galea S, Link BG. Smoking and the emergence of a stigmatized social status. *Social Science & Medicine* 2008;**67**(3):420–430.

35. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Social Science & Medicine* 2010;**71**(12):2150–2161.

36. Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology* 2001, 27 (ArticleType: research-article / Full publication date: 2001 / Copyright © 2001 Annual Reviews):363–385.

37. Chambers S, Morris B, Clutton S, et al. Psychological wellness and health-related stigma: a pilot study of an acceptance-focussed cognitive behavioural intervention for people with lung cancer. *European Journal of Cancer Care* 2014.

38. Rueda J-R, Solà I, Pascual A, Subirana CM. Non-invasive interventions for improving well-being and quality of life in patients with lung cancer (review). In *Cochrane Database of Systematic Reviews*, John Wiley & Sons, Ltd: Chichester, UK, 2011.

39. Puhl RM, Heuer CA. Obesity stigma: important considerations for public health. *American Journal of Public Health* 2010; **100**(6):1019–1028.