Research article

Does knowledge of cancer diagnosis affect quality of life? A methodological challenge

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Abstract

Background: As part of an assessment of quality of life in lung cancer patients an investigation was carried out to examine whether the knowledge of their diagnosis affected their quality of life.

Methods: Every patient in a defined geographical area with a potential diagnosis of lung cancer was interviewed at first consultation and after a definitive treatment has been given. Quality of life was assessed using three standard measures: the Nottingham Health Profile (NHP), the EORTC quality of life questionnaire (QLQ-C30) and its lung cancer supplementary questionnaire (QLQ-LC13). Comparison was made in quality of life scores between patients who knew their cancer diagnosis and those who did not.

Results: In all, 129 lung cancer patients were interviewed. Of these, 30 patients (23%) knew and 99 (78%) did not know their cancer diagnosis at the time of baseline assessment. The patient groups were similar in their characteristics except for age (P = 0.04) and cell type (P < 0.0001). Overall, there were no significant differences between these two groups with regard to their scores on the three instruments used. A major finding was that both group scored almost the same on emotional reactions (P = 0.8) and social isolation (P = 1.0) as measured by the NHP, and emotional (P = 0.7) and social functioning (P = 1.0) as measured by the EORTC QLQ-C30. In addition there were no significant differences in patients' symptom scores between those who knew their diagnosis and those who did not, nor did any consistent pattern emerge. The only significant difference was for sleep difficulties (P = 0.02).

Conclusion: The findings suggest that the knowledge of cancer diagnosis does not affect the way in which patients respond to quality of life questionnaires.

Background

There is no doubt that the diagnosis of a life threatening disease such as cancer is devastating and has an enormous effect on one's quality of life. It is argued that cancer is not just a single event with a certain end but a permanent con- dition characterized by ongoing ambiguity, potentially delayed or late effects of the disease or treatment, and concurrent psychological issues [1]. For example, studies have shown that severe depressive illness is significantly associated with lung cancer diagnosis [2]. Thus historically there

was a belief that a patient should not be told about his or her cancer diagnosis. However, at present this has changed and physicians are taught how to break 'bad news' to patients and their family [3]. In recent years there has been considerable attention on how to break 'bad news' from a patient's perspective [4,5].

As far as studies of quality of life in cancer patients are concerned, the issue of 'truth-telling' can be viewed from a different perspective. In almost all studies, patients' quality of life was first assessed after the diagnosis and after or during each course of treatment. Therefore, the question remains as to what extent does the knowledge of diagnosis affect the results. If a patient has recently received 'bad news' indicating that he or she has developed cancer, any assessment especially on psychological aspects such as emotional functioning may be biased. Those who are skeptical in assessing quality of life in cancer patients usually raise questions about the validity of information collected. There appears to be no previous research on this challenging methodological issue in the English language literature. The only study that addressed the topic dealt with the relationship between 'truth-telling' and quality of life. It concluded that honest disclosure of the truth does not worsen any dimension of quality of life in general or emotional functioning in particular [6].

This paper investigates whether the knowledge of cancer diagnosis affects quality of life. It also investigates concerns about whether systematic biases associated with quality of life measures exist in cancer patients who knew their diagnosis.

Methods
Study design
This was a prospective population based study of quality of life in lung cancer patients carried out in Glasgow, Scotland. The study design and method of data collection are explained in detail elsewhere [7,8]. In summary the design of the study allowed every patient in a defined geographical area with a potential diagnosis of lung cancer attending a large general and teaching hospital to be interviewed from first outpatient consultation until after a definitive treatment has been given. Thus, both patients and the interviewer were blind to the final diagnosis at the time of the pre-diagnosis interview. However, in some instances because of quick referrals and logistic problems the assessments were made after the diagnosis and before the start of the treatment. Therefore, these patients were interviewed while they knew their diagnosis. In other words at baseline assessment there were two groups of lung cancer patients: those who were interviewed before diagnosis (not knowing group) and those who were interviewed after formal disease disclosure by the chest clinic team or their general practitioners (knowing group). Fol-

low-up assessments within three months of diagnosis were carried out for those with a confirmed diagnosis of lung cancer, but for the purpose of this study analysis was restricted to the baseline (pre-diagnosis) assessments.

Instruments
Quality of life was assessed using three standard measures: (i) the Nottingham Health Profile (NHP), a general health measure including profiles on energy, pain, emotional reactions, social isolation, sleep, and physical mobility [9], (ii) the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), a core cancer-specific questionnaire containing 30 items on patients' functioning, global quality of life, disease- and treatment related symptoms [10], and (iii) the EORTC Lung Cancer Questionnaire (EORTC QLQ-LC13), a site-specific questionnaire consisting of 13 items on lung cancer symptoms and its treatment related side-effects [11].

Data on the social and demographic characteristics of the patients and clinical information including performance status, weight loss, histology, extent of disease, and treatment were extracted from case records.

Analysis
Since most measures were not normally distributed, the Mann-Whitney U-test was performed to compare quality of life scores between the two patient groups at baseline (those who knew their cancer diagnosis versus those who did not). For categorical data comparison was made using the chi-square test.

Results
Patients' characteristics
In all, 238 patients were interviewed. Of these, 129 patients had a confirmed diagnosis of lung cancer and 109 were patients with chronic respiratory disease. There were no significant differences between lung cancer patients and patients with respiratory disease except for age (patients with respiratory disease were younger). In addition with regards to quality of life scores at baseline there were no significant differences between lung cancer patients and patients with respiratory disease except for pain and appetite loss (lung cancer patients had a greater degree of symptoms. Data are not shown but is available form the corresponding author). However, among lung cancer patients, 30 patients (23%) were interviewed while they knew their cancer diagnosis and 99 patients (77%) were interviewed while they did not their cancer diagnosis. In general there were no significant differences between the characteristics of patient groups except for age and cell type; patients who knew their diagnosis were younger (P = 0.04) and were more likely to have small cell

Table 1: Lung cancer patients' characteristics

	Study sample (n = 129) No. (%)	Did not know (n = 99) No. (%)	Knew (n = 30) No. (%)	P*
Gender				
Male	77 (60)	58 (59)	19 (63)	
Female	52 (40)	41 (41)	11 (37)	0.64
Age (year)				
Mean (SD)	67.5 (9.1)	68.4 (9.0)	64.5 (8.7)	0.04
Marital status				
Married	77 (60)	55 (56)	22 (73)	
Widowed/single	52 (40)	44 (44)	8 (27)	0.08
Extent of disease				
Limited	101 (78)	80 (80)	21 (70)	
Extensive	28 (22)	19 (20)	9 (30))	0.21
Cell type				
Non-small cell	67 (52)	57 (58)	10 (33)	
Small cell	27 (21)	12 (12)	15 (50)	
Unspecified	35 (27)	30 (30)	5 (17)	< 0.0001
Performance status (score)				
Normal activity (0)	29 (23)	23 (23)	6 (20)	
Symptoms (1)	60 (47)	47 (48)	13 (43)	
Sometimes in bed (2)	25 (19)	20 (20)	5 (17)	
Need to be in bed (3)	15 (11)	9 (9)	6 (20)	
Confined to bed (4)	0 (00)	0 (00)	0 (00)	0.44
Weight loss				
Significant weight loss	51 (40)	39 (39)	12 (40)	
Weight steady	40 (31)	30 (31)	10 (36)	
Possible weight loss/no comment on case records	38 (29)	30 (31)	8 (30)	0.53

* χ^2 test for categorical data and Mann-Whitney U-test for continuous variables.

lung cancer (P < 0.0001). The characteristics of the patients are shown in Table 1.

General health and functioning
Patient' general health as measured by the NHP and functioning and global quality of life scores as measured by the EORC QLQ-C30 are presented in Tables 2 and 3 respectively. There were no significant differences between the two groups' scores. Even patients' scores on emotional reactions and social isolation or emotional and social functioning were almost the same. However, patients who knew their diagnosis had more perceived health problems in terms of physical mobility, energy and a poor level of functioning in terms of physical and role functioning.

Symptoms
Patients' main symptom scores as measured by the EORTC QLQ-C30 and QLQ-LC13 are listed in Table 4. Again there were no significant differences between the two groups indicating that those who knew their diagnosis and those who did not perceived their symptoms in a similar way. However those who did not know their can-

cer diagnosis reported significant sleep difficulties compared to those patients who knew their diagnosis (P = 0.02).

Discussion
This study provides evidence to suggest that the knowledge of cancer diagnosis does not affect the way in which patients respond to a quality of life questionnaire. However, this does not mean that cancer diagnosis does not affect people's life. Looking at the scores for the two groups clearly indicate that these patients even at the pre-diagnosis stage had several health problems as well as symptoms related to lung cancer.

The intention here is to show that knowing or not knowing one's cancer diagnosis does not make any significant difference to the patients' responses to a quality of life questionnaire; either a general health questionnaire (the NHP), one that is cancer-specific (the EORTC QLQ-C30) or one that is site-specific (the EORTC QLQ-LC13). It is important to realize that the NHP and the EORTC quality of life questionnaires are very well developed instruments in nature [12,13] and provided a valid means for examin-

Table 2: Patients' scores on the NHP (the higher values indicate more perceived health problems, min.: 0, max.: 100)

	Did not know (n = 99)	Knew (n = 30)	P*
	Mean (SD)	Mean (SD)	
Physical mobility	27.7 (27.2)	38.5 (29.5)	0.07
Energy	40.8 (42.0)	49.1 (40.3)	0.3
Emotional reactions	25.6 (24.6)	26.2 (23.0)	0.8
Social isolation	12.9 (22.8)	11.9 (19.5)	1.0
Pain	26.3 (30.2)	18.6 (25.4)	0.2
Sleep	39.7 (32.9)	33.7 931.0)	0.5

* Mann-Whitney U-test.

Table 3: Patients' functioning and global quality of life scores as measured by the EORTC QLQ-C30 (the higher values indicate a higher level of functioning and quality of life, min.: 0, max.: 100)

	Did not know (n = 99)	Knew (n = 30)	P*
	Mean (SD)	Mean (SD)	
Physical functioning	64.2 (26.8)	54.0 (28.8)	0.1
Role functioning	62.1 (36.5)	48.3 (38.2)	0.08
Emotional functioning	78.1 (21.8)	79.4 (21.0)	0.7
Social Functioning	87.5 (22.0)	85.0 (27.5)	1.0
Cognitive functioning	85.0 (21.0)	87.2 (20.8)	0.4
Global quality of life	49.2 (22.5)	51.7 (25.2)	0.9

* Mann-Whitney U-test.

Table 4: Patients' symptom scores on the EORTC QLQ-C30 and QLQ-LC13 (the higher values indicate a greater degree of symptoms, min.: 0, Max.: 100)

	Did not know (n = 99)	Knew (n = 30)	P*
	Mean (SD)	Mean (SD)	
Cough	46.8 (33.0)	46.7 (32.3)	1.0
Haemoptysis	10.1 (23.5)	10.0 (23.4)	1.0
Dyspnoae	37.0 (27.1)	39.7 (28.8)	0.7
Pain (overall)	29.1 (29.2)	20.6 (26.5)	0.2
Pain in chest	22.2 (29.4)	20.0 (27.1)	0.8
Pain in arm and shoulder	30.0 (35.2)	18.9 (32.4)	0.1
Pain elsewhere	22.9 (32.2)	31.1 (37.1)	0.2
Sleep difficulties	34.7 (37.8)	17.8 (32.4)	0.02
Fatigue	37.4 (30.5)	37.0 (25.2)	0.8
Appetite loss	32.3 (34.8)	41.1 (32.4)	0.1

* Mann-Whitney U-test.

ing the study question. None of these instrument contain the word 'cancer' or other related terminology that would alert patients.

The striking findings in this study were that patients' scores on emotional reactions and social isolation (on the NHP) or emotional and social functioning (on the EORTC QLQ-C30) were very similar in the two groups. If

diagnosis had any effect on patients' responses then one might expect to see, if not significant, at least much higher differences between these two groups' scores on such measures. Yet, patients who knew their cancer diagnosis showed a slightly better global quality of life score (Table 3).

The findings indicated that there were slight differences between patient's scores for some measures. For example, patients who knew their diagnosis reported more problems with physical mobility, and energy, and had lower physical and role functioning. Certainly this was not due to their age differences since those who knew their cancer diagnosis were significantly younger than the other group.

With regards to patients' symptom scores, again there were no significant differences between the two groups, indicating that the knowledge of their cancer diagnosis did not lead to an overestimation of symptoms by patients who knew they had developed lung cancer. The only significant difference observed was for sleep difficulties showing that those who did not know their diagnosis had more problems. However it not clear why such a difference emerged but one explanation is that this group of patients was older than the other group and this may have contributed to the problem.

In summary, the findings from the present study indicate that knowledge of a diagnosis of cancer does not affect the way in which patients respond to a quality of life questionnaire. This was based on the fact that patients who knew their cancer diagnosis and those who did not, responded similarly to most measures studied especially the psychosocial ones. The findings confirm that baseline assessment of quality of life in a cancer patient with knowledge of their diagnosis can be considered valid providing that other methodological prerequisites are appropriately dealt with.

List of abbreviations
NHP: the Nottingham Health Profile; EORTC QLQ-C30: the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; EORTC QLQ-LC13: the European Organization for Research and Treatment of Cancer Lung Cancer Questionnaire; SD = Standard deviation.

Competing interests
None declared.

Authors' contribution
AM was the main investigator, collected and analyzed the data, and wrote the paper. DJH contributed to analysis of the data and final draft of the paper. RM contributed to the study design, patient recruitment and data collection.

JM and CRG contributed to study design and supervised the project.

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Pre-publication history
The pre-publication history for this paper can be accessed here:

http://www.biomedcentral.com/1471-2407/4/21/prepub