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Communication of Diagnosis in Elderly Lung Cancer Patients: Who is Informed, What Information is Given and What Patients Know and Want to Know

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Abstract

Objectives: Lung cancer chemotherapy decisions in patients >70 years old are complex. To assess the modes of communication with older lung cancer patients, we prospectively collected data. We assessed patients' level of knowledge about diagnosis and prognosis.

Materials and Methods: 83 patients diagnosed with lung cancer from January 2006 to February 2008 were recruited from a single center. Logistic regression and multiple imputation methods were used to assess associations between patient information and independent variables.

Results: Families received the diagnosis of lung cancer (92.8%). Family was more protective when the patients were elderly (p:0,036), depressed (p: 0,054), had dementia (p:0,03), had poor performance status (p:0,03) or complied with frailty criteria (p: 0,014). Physicians who gave cancer diagnoses were not oncologists and they usually gave cancer diagnosis preferably to family members. Only 27,7% of patients were informed that they had tumors. 73,5% of patients actively solicited information, however elderly and frail patients tended to do so less.

Conclusions: A large proportion of elderly lung cancer patients do not receive adequate information about their disease prior to contact with oncologists. However they do actively ask for information and speak about cancer with oncologists.

Keywords: Information; Geriatrics; lung cancer

Introduction

Patients with advanced, non-curable cancers face difficult decisions regarding further treatment, in which a small increase in survival time must be balanced against the toxicity of treatment. If patients want to be involved in these decisions, in keeping with current notions of autonomy and empowerment, they also need to be adequately informed about the treatments proposed and about their own disease status and prognosis. Almost all patients express a desire for full information [1].

An important aspect of caring for cancer patients is breaking bad news. Only a few publications on this issue have adopted the patients' perspective, and some of these have studied fewer than 15 patients [2]. Studies focused on elderly patients are scarce. It seems that elderly people prefer to be well informed [3], nonetheless, only a minority of them wish to play an active role in decision-making [3]. Informing patients about bad news is difficult, and the process is subject to bias and misconceptions. This process also depends on cultural and social aspects, and physicians occasionally believe that their patients are not strong enough to be informed. Therefore, family members are usually informed first. Protective attitudes toward elderly patients are common, and a lack of studies in the elderly population could be a reason for these attitudes.

Working with older cancer patients requires a greater inversion in terms of time spent providing information and discussing treatment [4].

To evaluate modes of communication with older lung cancer patients, we prospectively collected data about information in a cohort of elderly patients. This study provides an overview of elderly patient preferences for receiving information about their diagnosis from the lung cancer-affected population of a single center. The study aimed to document elderly patients' views on the delivery of lung cancer diagnoses, what these patients know, and their attitudes toward being informed. We collected attitudes with respect to information from those who participate in this process: family members, physicians and patients.

Methods

At our center we developed a prospective study that studied the association between Comprehensive Geriatric Assessment (CGA) variables with tumor parameters and survival in elderly lung cancer patients. The study was conducted between January 2006 and February 2008. The patients completed a geriatric assessment tool to measure functional status, comorbidity, cognitive function, psychological state, social support and nutritional status. The Geriatric Assessment tool included validated measures.

The study included a section in order to investigate communication of cancer information in elderly lung patients. The study design also contained a section with respect to the preferences for treatment of lung cancer in the elderly. The patients that fulfilled the criteria for the CGA study also completed the information section and patient preferences section. CGA results and preferences for treatment have already been published [5,6].

Patients

The eligibility criteria for the entire study were; elderly patients

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(aged ≥70 years) with a diagnosis of lung cancer at any stage and who were referred to the outpatient oncology unit of the Hospital Lluis Alcanyis between January 2006 and February 2008.

Information data collection: During the first visit, data on information was recorded.

The same oncologist, Dra. Gironés, performed the Geriatric Assessment and the study on information and treatment preferences.

Case by case we structured history of patient communication and information before coming to the following conclusions with respect to the oncologists:

Doctors' communicative behavior: Patients that were admitted to our oncology unit usually are not usually diagnosed and informed by oncologists. We reviewed clinical history in order to identify who diagnosed the cancer. We asked the patient and family about the kind of information given, the words used, and if the family and/or the patient was informed.

Family's communicative behavior: we asked the family members about diagnosis disclosure between the physician and their relative. We explored the satisfaction of the family with the information, asking about the family's attitude toward informing the patient. An indirect attitude about patient-information-family is the option about being informed without the patient. We reported whether the family asked for an appointment separate to the oncology visit without the presence of the patient.

Patients' communicative behavior: Inside the clinic, with family members, we asked if the patient had been informed, what kind of information was given, and, in case of the patients had not been informed, if she/he wanted to be informed. Research questions are represented in Table 1.

Other parameters and correlations with information: Correlations between patients' attitudes toward information, their clinical characteristics and geriatric variables were identified.

Statistical analysis

This was a descriptive and prospective study designed to identify the attitudes of physicians, family and patients toward information. SPSS (Statistical Package for the Social Sciences) version 11.5 was used for all of the analyses. For quantitative variables, measurements of central tendency (mean and median) and measures of spread (standard deviation and interquartile range) were used. For qualitative variables, absolute and relative frequency tables were employed. Graphical representation of the data obtained was used wherever possible. We evaluated the associations between the information given and the study variables using t-tests and $\chi 2$ tests. The Mann-Whitney U-test and Fisher's exact test were used to assess the significance of the findings. Differences with a p value less than 0.05 were considered significant.

Ethical considerations

The institution's ethical review board approved this study. All of the patients provided written informed consent and provided their permission prior to the initiation of the study to collect their clinical data for scientific purposes and for publication.

Results

Characteristics of the subjects

From January 2006 to February 2008, 83 consecutive patients with lung cancer aged 70 years old or older were enrolled in the study.

The mean age of the patients was 77 years of age, and almost all of them (97.6%) were male.

Non-small cell lung cancer was the most prevalent histological type identified (76%).

Table 2 summarizes the characteristics of these patients and the results of geriatric assessment were shown on Table 3.

Findings

Doctor's communicative behavior: The majority of physicians that visited the patient before the appointment with the oncologist were interns (in 56 cases; 68%), pulmonologists (28%), thoracic surgeons in 2 cases (2%) and others in the last two cases (2%).

Physicians usually did not give information to the patient (56% of physicians did not give any kind of diagnosis). In 37 of the cases some type of communication occurred (family and/or patient).

Those who most informed were pulmonologists (62% of the 37 who informed).

The kind of information given varies notably; of the 37 cases where the physician gave information, 4 were told they had pneumonia; 4 inflammation, in 6 cases a lung spot and 23 were told they had a tumor.

Pulmonologists were the most likely to tell the patient they had a tumor.

In most of the cases (74%), physicians did not inform the patients.

Almost all the physicians (92%) were rated higher when medical

Doctors' communicative behavior: What kind of physician diagnosed the patient? What kind of information was given? Had the physician informed the patient? Had the physician informed the family?
Family's communicative behavior? Was the family informed? Had the family agreed that the patient be informed? Had the family asked for a separate interview prior to the oncologists visit, without the patient?
Patients' communicative behavior: Was the patient informed? What kind of information was given? If the patient wasn't informed, did the patient want to be informed?

Table 1: Research questions

Characteristics	N (%)
Mean age (years)	77 ± 5.1
≥ 80	28.9%
Sex	
Male	81 (97.6%)
Female	2 (2.4%)
Histological type	
Non-small cell	63 (76%)
Small cell	12 (14.4%)
No histological diagnosis	8 (9.6%)
Performance status	
0	25 (30.1%)
1	33 (39.8%)
2	19 (23%)
3	6 (7.2%)
4	0
Stage at diagnosis:	
I	9 (10.8%)
II	10 (12.1%)
III	34 (41%)
IV	30 (36.1%)

Table 2: Characteristics of elderly patients with lung cancer (n=83).

Areas investigated	N(%)
Autonomy (ADL) Independent Dependent	 43 (51.8%) 40 (48.2%)
Autonomy (IADL) Independent Dependent	 25 (30.1%) 58 (69.9%)
Comorbidities Mean Charlson (range) 0 1 2 ≥3	 3 (0-9) 4 (5%) 10 (12%) 2 (2,7%) 64 (80.3%)
Comorbidities Mean SCS (range) ≤9 >9	 9 (4-19) 44 (53%) 39 (47%)
Cognitive function (MMSE) >21/30 ≤21/30	 61 (73.6%) 22 (26.4%)
State of mind (GDS) <3 ≥3	 57 (68.7%) 26 (31.3%)
Nutritional status: weight loss No Yes Mean % weight loss (range) Mean time (range)	 37 (44.6%) 46 (55.4%) 8.2% (1-21%) 3 months (1-8)
Nutritional status: albuminemia (g/l) Mean (range) ≤35	 26 (20-59) 29 (34.9%)
Social situation Place of residence: Home Institution Person in charge: Spouse Children Others Transport: Own car Children's car Public transport Ambulance	 79 (95.2%) 4 (4.8%) 51 (61.5%) 29 (34.9%) 3 (3.6%) 14 (16.9%) 56 (67.5%) 2 (2.4%) 11 (13.3%)
Geriatric syndromes Yes No	 40 (48.2%) 43 (51.8%)

Table 3: Results of geriatric assessment (Gironés JGO5)

explanations were given to family members.

Although not significantly, physicians were less likely to inform patients with dementia, depression or those who were frail. Table 4 shows correlations.

Family's communicative behavior: The families were informed in almost all of the cases (92.8%).

More than half of the families accepted that the patients would also be informed (67.5%).

Only 33.7% of the families asked for an interview prior to the oncologist visit, without the patient. The remaining families were present with the patient in the same appointment.

The families had more protective attitudes in cases in which the patient was aged, depressed, had dementia, had poor performance status or met frailty criteria (Table 5).

Patient attitudes: Although the physicians did not inform the patients, almost all of the patients wanted to be informed about their diagnosis (73.5%).

The attitudes of the patients differed from those of the physicians, as the characteristics that physicians considered significant enough to not inform the patient (age, dementia, depression, frailty) were in fact factors which were correlated to a stronger desire to be informed on the part of the patient (Table 6).

Discussion

At our institution we found that physicians who were not specialists in oncology usually did not inform elderly lung cancer patients about their diagnosis. Some clinical and geriatric characteristics such as dementia, depression, frailty, were correlated with less information being provided. In our work, it appears that pulmonologists and thoracic surgeons were those who most informed their patients.

Family members were usually the first to receive the diagnoses.

The results from the elderly lung cancer patients were surprising due to the fact that, while the majority did not directly receive information on their cancer, when asked, almost all wanted to be informed. Characteristics that could lead us to believe that the patients would be more reluctant to know the diagnosis (in the cases of aged patients, those with dementia, depression, frailty…) were, conversely, related with a desire for information.

	Patients with dementia (19)	p
Who was the one who diagnosed the tumour? No Internist Pneumologist Thoracic Surgeon Others	 14 (74%) 1 (5%) 3 (16%) 1 (5%) 0	0,15
What kind of diagnosis was given Nothing Pneumonia Inflammation Tumour Lung Stain	 14 (74%) 0 0 4 (22%) 1(4%)	0,3
	Patients with depression (n:27)	
Who was the one who diagnosed the tumour? No Internist Pulmonologist Thoracic Surgeon Others	 19 (41,3%) 1 (10%) 5 (21,7%) 1 (50%) 1 (50%)	0,22
What kind of diagnosis was given Nothing Pneumonia Inflammation Tumour Lung Stain		0
	Frail patients (n:60)	
Who was the one who diagnosed the tumour? No Internist Pneumologist Thoracic Surgeon Others	 38 (63,3%) 3 (5%) 3 (5%) 13 (21,7%) 3 (5%)	0,14
What kind of diagnosis was given Nothing Pneumonia Inflammation Tumour Lung Stain	 38 (63,3%) 3 (5%) 3 (5%) 13 (21,7%) 3 (5%)	0,39

Table 4: Physician attitudes in patients with dementia, had depression and fulfilled frail criteria

Communicating bad news effectively is difficult, particularly when the patient is elderly. We lack specific studies on the patterns of clinical communication in elderly patients and on the involvement of their physicians and the roles of their families [7].

Physicians' attitudes

One of the most difficult ethical dilemmas facing health care professionals working in oncology is how to inform cancer patients about their diagnosis and prognosis [8]. A 2006 American Medical Association Foundation and American Medical Association report specifies various health literacy barriers to effective communication; one is the lack of clinician training on effective communication strategies [8]. Older adults with cancer are the population group who are considered to be at most risk for poor communication with health professionals.

Research shows that health care providers of various specialties beyond oncology are often the first to discover the cancer and have to cope with communicating the bad news to the anxious patient and family members [9].

The dilemma could be greater if the first specialist in contact with the patient is not an oncologist, as well as in elderly patients. This is the case in our hospital. The preference of physicians to inform family members or caregivers instead of the patient can most likely be explained by a belief that older adults may be at a distinct disadvantage with respect to coping with cancer diagnosis due to age-related physiological, cognitive, psychological and communicative factors

	Patients with dementia (19)	p
Was the family informed? No Yes	 0 19	0,22
Had the family agreed that the patient be informed? No Yes	 9 10	0,03
Had the family asked for an interview before the oncologist visit, without the patient? No Yes	 7 19	< 0,001
	Patients with depression (n:27)	
Was the family informed? No Yes	 10 17	0,54
Had the family agreed that the patient be informed? No Yes	 10 17	0,54
Had the family asked for an interview before the oncologist visit, without the patient? No Yes	 4 23	<0,054
	Frail patients (n:60)	
Was the family informed? No Yes	 5 55	0,069
Had the family agreed that the patient be informed? No Yes	 22 38	0,42
Had the family asked for an interview before the oncologist visit, without the patient? No Yes	 20 40	0,047

Table 5: Family attitudes

Patients communicative behaviour	All patients (n:83)	Age (years)	Dementia (n:19)	Depression (n:27)	Frail (n:60)
Was the patient informed? No Yes	 61 22	77,4 76,1 p: 0,33	15 4 p: 0,045	23 4 p: 0,009	48 12 P: 0,009
If the patient was not informed, did the patient want to be informed? No Yes	 22 61	 80 75 P: <0,001	 8 11 P: 0,008	 8 19 P: 0,065	 20 40 P: 0,059

Table 6: Patient's attitudes

[10]. While a majority of physicians are now more often honest with their patients than in the past [8], the assumption that truth-telling is always beneficial for patients is sometimes still questioned, and more so in the case of the elderly. In our Department, few patients were given full disclosure.

Paternalistic patterns at our institution were adopted when the patients were older or frail. An explanation for this attitude from physicians could be cultural [3,11,12]. Protectionism is a deeply-rooted custom in our area of Spain, where the degree of patient autonomy typical in other healthcare systems in Europe [13] is lacking.

Elderly patients were exposed to a paternalistic model of health care.

There are differing views as to how much to disclose to patients about their diagnosis. Cultural factors may influence health-related behaviors [14]. Some medical communities in other cultures consider it good medical practice to lie to patients about their true condition as well as enlisting the family to perpetuate the prevarication. This was found to be the case in our work. Few articles can be found which that report Spanish cultural aspects on informing cancer patients. We know that Spanish approach is paternalistic [15]. Centeno-cortes et al. demonstrated that in Spanish patients 68% were not informed about their terminal cancer; however this was not shown to be specific to the elderly [15]. We know that in Spain, it is usual to inform the family members about cancer diagnosis; in all likelihood our paper is the first to document this attitude. Another Spanish paper, not specific to the elderly, also highlighted that few patients (15%) were correctly informed of their cancer diagnosis [16]. This information model is based on taboos with respect to cancer and is repeated with our elderly patients.

Paternalistic attitudes to cancer patients exist, and this is exaggerated in the elderly as our document reports. This could be in conflict with patient autonomy.

There are many differences between different countries with respect to practices on disclosure of health information [8]. Society and healthcare providers continue to view the older population through a skewed "ageist" prism, acting on assumptions of frailty, treatment intolerance, and cognitive impairment [12].

Although treatment for metastatic lung cancer have demonstrated years ago benefit in terms on survival and quality of life, incorporation these advances to all specialties, and specially in elderly people, has been made in a lower manner that for other histologies.

Medical oncology is a relative younger discipline and treatments, specially, chemotherapy, is not usually well understood by all others fields. Assumptions, mainly in elder, that treatment is toxic, could be a reason to this paternalist attitude.

We think that pneumologist and other disciplines directly related to lung cancer (thoracic (surgeons, radiotherapists..) are more brought up to date about benefits and harms of treatment on lung cancer. A way to improve this attitude for other physicians could be their participation in committees, incorporation in decisions in a more active manner, giving specially training on lung cancer, etc.

Family attitudes

Family members at our center were the first and sometimes the only to receive poor news. Almost all of them agreed with the oncologist on whether to inform the patient. It seems that the paternalistic attitude was stronger in physicians than in the caregivers. Even in cases where the patients were frail, aged, or had dementia…caregivers also agreed with the oncologist to inform the patient, therefore respecting patient autonomy.

To illustrate this situation, we found a paper which inquired healthy Spanish individuals on communicating cancer diagnoses to patients [17]. This study covered 2493 persons over the age of 18, not specifically the elderly. In the case of their own potential cancer diagnosis, 69% wanted to be informed. However if cancer was diagnosed in a very near relative, only 42% wanted their relative to be informed [17]. We did not find papers illustrating the caregivers role with elderly lung cancer Spanish patients.

We have not enough information about family education or attitude to know if would have been differences toward information.

Patients 'attitudes

Elderly lung cancer patients, admitted to our outpatient unit, wanted to be informed about their cancer diagnosis, independent of factors such as frailty, dementia or depression. Only age was correlated to lower demands for active information.

Older adults have different communicative needs and desires to other age groups [9]. We did not ask for the type of information preferred by the patient.

Patient preferences and needs should be the gold standard in the process of providing information. Older patients receive less information about diagnosis and prognosis than younger patients, as reported by several authors. It is known that cancer patients require information about their diagnosis [18-20], and this need is similar when the patient is elderly [3,11,21]. Our patients wanted to be informed. It is known that cancer patients request more information than doctors believe [22-25]. There is little concordance between patients' preferences and doctors' perceptions regarding preferences [8,9,26,27]. In some cases, the physician feels that the patient is not strong enough to be informed. In our study, we found that this phenomenon occurred repeatedly.

Receiving little or inadequate information about disease status and the plan of care can substantially affect the individual patient's ability to respond properly and to adapt to the disease and to treatment-related stress [28].

Study limitations

Due to the nature of our research questions, we realized that this work has some limitations.

The primary limitations of our analysis are the small sample size and restriction to the population of a single institution.

Information about cancer is difficult to provide, particularly in elderly patients. Aging is a process that implicates sociocultural factors. As a result of this association, we do not know whether a different elderly population would have similar feelings. It is possible that extrapolation of our data will prove us to be incorrect.

We only asked patients referred to oncology consults, and as such we only included outpatients. Selection bias could not be excluded in this project.

At our study, we included all stages. We asked about which kind of information had patients and families and about if they wanted to be informed. This was not a decision-making interview, only an exploratory study about feelings and perceptions of patients related to information. This interview was made at first visit, before giving information and prognostic/therapeutic decision. It's sure that information is different depending on stages. In the setting of advanced cancer that is rarely curable, informed treatment decisions required clear, detailed communication between patients and their oncologists. The physicians must accurately perceive their patient's wishes. Our work doesn't reflect the kind of information for each stage; it's only an approximation about what patients know. Our results suggest that explicit elicitation of information it's the preferable options for patients and family. We have not reported information by stages. We notice that patients and family felt more self-confidence and satisfied with physicians when these asked about feelings and desires, and it's established a best relation-ship.

We have an "excess" on male rate patients, not only for elderly, but also for global patients. We hypothesize that smoking habits are behind of the high proportion of men, as we have published yet [29].

However, the fact that the same oncologist performed all the interviews allows us to exclude inter-evaluator differences.

Conclusions

Our results demonstrated that a large proportion of elderly lung cancer patients do not receive adequate information about their disease prior to contact with oncologists. While most elderly patients were not informed, they actively requested information and discussed cancer with the oncologist. Advanced age and frailty in patients generated protective attitudes.

This study provides an overview of elderly patient preferences for receiving information about their diagnosis from a single center's lung cancer population. To our knowledge, this is the first Spanish study exploring these items on geriatric oncology.

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