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ORIGINAL REPORT

Receiving the Diagnosis of Lung Cancer: Patient Recall of Information and Satisfaction With Physician Communication

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A B S T R A C T

Purpose
Little is known about the information newly diagnosed patients with lung cancer recall and how satisfied they are with physicians' communication.

Patients and Methods
Seventy-one consecutive patients with newly diagnosed lung cancer were surveyed 1 to 3 days after the disclosure of diagnosis. Patients' recall of the given information was assessed, as well as their satisfaction with physicians' communication of diagnosis, treatment procedure, and goal of treatment as curative or palliative. Physicians who provided diagnosis were asked to complete a questionnaire concerning what information they had given to the patient. Congruence between physician information and patient recall of that information was then evaluated.

Results
Ninety percent (62 of 69 patients) correctly recalled their physician's information about the diagnosis, 83% (55 of 66 patients) knew what treatment procedure their physicians proposed, and 49% (32 of 65 patients) accurately recalled information about the goal of treatment. Seventy-six and 73% of patients were highly satisfied with their physician's communication of diagnosis and treatment procedure, respectively. Only 39% were highly satisfied with communication of the treatment goal. Patients who correctly recalled information regarding the treatment procedure were significantly more satisfied with its communication.

Conclusion
Recall of information about the intent of treatment is poor, and satisfaction with communication of the intent of treatment is lacking among newly diagnosed patients with lung cancer. Future studies should address whether specific interventions can improve these deficiencies.

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INTRODUCTION

Most cancer patients wish to be carefully informed about their diagnosis, treatment procedures, and the goal of treatment.[1-4] Physicians' behavior in disclosing the diagnosis of cancer to patients has changed dramatically in the last half-century. In 1961, 90% of physicians in the United States reported they would not inform their patients of a diagnosis of cancer, whereas in 1979, 97% of physicians said they would.[5,6] Much emphasis has been made in recent years to improve communication skills of physicians delivering bad news, in order to enhance patients' coping with this difficult situation, as well as to increase their sense of satisfaction regarding physician communication.[7] Still, little is known about what constitutes adequate and satisfying physician-patient exchanges within this challenging context.

When patients are told that they have lung cancer, they are confronted with a huge amount of information given to them under stressful circumstances. Also, the long-term prospects are extremely sobering: Despite recent advances in therapy, the prognosis for patients with lung cancer remains dismal, with a 5-year survival rate of around 14%.[8] In the past, physicians tended to propose only one therapy to their patients. Today, more treatment options are available, and patients want to be informed and to share decisions about treatment with their physicians. To make an informed decision about a proposed treatment, patients need to know the goal of treatment: Is the intent to cure cancer, or is it to improve symptoms and prolong life? Furthermore, legal rules emphasize the responsibility of physicians to provide all necessary information.

Having performed a systematic review, we could find only one investigation on communication of treatment goals among patients with lung cancer.[9] In that study, patients who already were receiving treatment were questioned. Although most clearly realized they had lung cancer, many mistakenly believed they were being treated with curative intent, when in fact, they were undergoing palliative therapies. Additionally, oncologists were solely employed in this study to provide diagnosis and information regarding aim and modality of treatment. As oncologists are often not the specialists who primarily perform these roles in many countries, we chose to examine these issues using a more typical and ecologically valid group of pulmonary physicians and internal medicine specialists to provide medical information.

Other studies about patient recall of diagnosis, treatment procedures, and goals have been performed in patients with mixed types of cancer. These studies typically assessed patient recall not after the initial disclosure but after initiation of treatment.[10-12]

To the best of our knowledge, no study has investigated whether there is a relationship between patients' recall of information given by their physicians at disclosure of cancer and their satisfaction with communication. Examination of this potential relation may be significant, since patient satisfaction might serve as a measure of quality of care.

To our knowledge, this study is the first to examine the extent to which patients acquire and recall accurate information regarding diagnosis, therapy procedure, and goal of treatment after initial disclosure of lung cancer. We also extend previous research by assessing not only patients' recall, but also their satisfaction with information regarding diagnosis, treatment procedure, and goal of treatment. Specifically, the aims of the study have been to explore the following aspects: (1) Lung cancer patients' recall of information received versus physicians' reports of information provided, with respect to a) diagnosis, b) treatment procedure, and c) goal of treatment after initial disclosure of cancer; (2) Lung cancer patients' satisfaction with their physicians' communication regarding diagnosis, treatment procedure and goal of treatment; (3) The association between patients' recall of information and satisfaction with communication.

PATIENTS AND METHODS

Sample

All newly diagnosed patients with lung cancer from February 2005 to February 2006 were consecutively identified at a weekly multidisciplinary case conference. Patients fulfilling the inclusion criteria (fluency in German and not critically ill) were approached 1 to 3 days after the diagnosis had been delivered by their physician. Written informed consent was obtained after full disclosure of the study purpose. The study was approved by the Ethics Commission of Both Basels, Switzerland.

Eighty-one patients met the eligibility criteria, five declined, three died before they were approached, two could not be reached, and 71 patients consented to participate.

All 27 physicians who had communicated diagnoses, therapy options, and goal of treatment were approached and agreed to participate. Nine were pulmonary specialists, five were internists, and 13 were residents in internal medicine. Residents treated only a total of 17 patients.

Measures

Patient information recall and satisfaction with communication were elicited with a structured interview. One interviewer performed all interviews and did not have prior knowledge of physician-patient communication. Patient recall was defined according to the degree of congruence between physician reports and patient recall about diagnosis, treatment procedure, and goal of treatment. Patients' and physicians' answers were compared, and three categories were defined: fully congruent, partially congruent, and incongruent.

Patient Recall Regarding Diagnosis

Patients were asked, "What did your physician tell you about your diagnosis?" Responses were rated fully congruent if patients could say that they had lung cancer with or without metastasis; partially congruent if patients answered with correct, but only partial description (eg, that they had cancer but were unclear about what kind), and incongruent if patients did not mention cancer (eg, said they had lung problems).

Patient Recall Regarding Treatment Procedure

Patients were asked, "What did your physician tell you about the treatment procedure?" To be scored as fully congruent, patients had to describe exactly the proposed treatment procedure; to be scored partially congruent, they had to accurately include part of the proposed treatment procedure; and they were scored incongruent if they answered incorrectly.

Patient Recall Regarding Treatment Goal

Patients were asked, "Did the physician tell you what the goal of treatment is?"

Additional probes and clarifications were made by the interviewer whenever patients appeared uncertain about what was being asked with respect to treatment goal.

Answers were rated fully congruent if patients could correctly say, in accord with the physician's report, whether the primary intent was to cure the cancer or not, or whether it had not yet been discussed; they were rated incongruent when patients incorrectly recalled this information completely (eg, they recalled a curative goal when the physician reported a palliative goal). All answers not classified as fully congruent or incongruent were rated as partially congruent (eg, patients stated that the treatment goal was improvement of health, but expressed uncertainty whether the aim was curative or not).

Patient Satisfaction With Communication

In order to assess satisfaction with communication, patients were asked the following questions, proposed by Schofield et al,[13] employing five choices of responses (excellent, good, satisfactory, inadequate or poor): (1) "How would you rate the way the diagnosis of cancer was discussed with you? " (2) "How would you rate the way the treatment procedure for your cancer was discussed with you?" (3) "How would you rate the way the aims of treatment were discussed with you?"

In addition, patients were administered the German versions[14,15] of the validated European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire QLQ-C30 (EORTC QLQ-C30),[16] the Lung Cancer Module (QLQ-LC13),[17] and the Hospital Anxiety and Depression Scale (HADS).[18]

Physicians who met with patients were asked to complete, within 1 to 3 days after the disclosure of diagnosis, a written report of information regarding diagnosis, treatment procedure, and goal of treatment. The contents of the physicians' structured questionnaire were carefully matched to those questions regarding recall contained in the interview conducted with patients.

Statistical Analyses

The EORTC QLQ-C30/QLQ-LC13 and HADS were scored according to established guidelines.[18,19] A *t* test for independent samples, with adjusted *df* based on the Welch test, was performed to compare EORTC QLQ-patient scores with those of the normal German population. Regarding satisfaction measures, response options were categorized a priori into two groups: high (excellent/good) and mid-low satisfaction (satisfactory/inadequate/poor). Records were excluded from analyses if patient or physician responses were missing.

Scores and quantitative variables were summarized as means and standard deviations. For comparisons of categoric variables between groups, χ^2 or Fisher's exact tests were used. Recall rates were compared using McNemar's test and Bonferroni corrected for multiple comparisons.

Table 1. Patients' Sociodemographic and Disease-Related Characteristics

Characteristics	Patients (%) No.	%
Total No. of patients	71	
Age, years		
Median	68	
Range	43-84	
Sex, female	29	41
Diagnosis and staging		
NSCLC	62	87
I	12	19
II	3	5
III	20	32
IV	27	44
SCLC	9	13
Limited disease	2	22
Extended disease	7	78
Treatment approach		
Curative approach	27	38
Palliative approach	37	52
Approach not yet determined	7	10

Abbreviations: NSCLC, non–small-cell lung cancer; SCLC, small-cell lung cancer.

Logistic regression analyses were performed to examine the extent to which patients' recall of information was predictive of patients' satisfaction with communication. Multivariate logistic regressions with backward selection were used to examine the extent to which patient characteristics (sex, therapeutic approach, psychometric, and quality of life scores) and physician characteristics (sex, specialty, and years of practice) could predict patients' recall and satisfaction. Due to small sample size, scores of the HADS, EORTC QLQ-C30, and EORTC QLQ-LC13 scales were added individually to the model, and their effect significance level was adjusted for multiple comparisons using the Bonferroni correction.

The significance level for all tests was set to $\alpha = .05$, and all analyses were performed with SAS 9.1 (SAS Institute Inc, Cary, NC).

RESULTS

Description of the Sample

Patient characteristics are summarized in Table 1. Quality of life of our sample versus the normal German population is shown in Figure 1[20]; specific symptom scores are shown in Figure 2. The prevalence of HADS scores indicative of anxiety disorder and depression were 7% and 12.7%, respectively.

Physician characteristics are presented in Table 2. Median age was 35 years, 21 of 27 physicians were male, and nine were trained as pulmonary physicians. Physicians were involved in patient care for a median of 8 years.

Patient Recall of Diagnosis, Treatment Procedure, and Goal of Treatment

As presented in Table 3, patient recall of information regarding diagnosis was fully or partially congruent in 62 of 69 patient cases (90%). In 55 (83%) of 66 patient cases, patient recall was fully or partially congruent with the information reported to have been given about treatment procedure. However, patient recall of treatment goal was fully or partially congruent only in 32 of 65 patients (49%). Recall of goal of treatment was significantly worse than recall of diagnosis or of treatment procedure ($P < .001$).

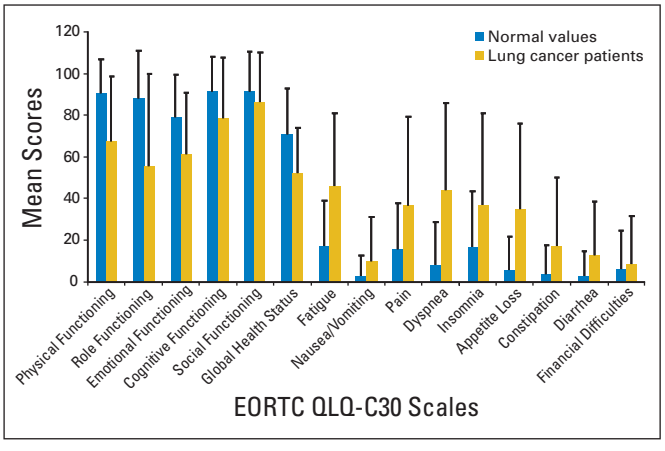

Fig 1. Mean scores for the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC) QLQ-C30 for patients compared with scores from the normal German population.[20] Whiskers indicate standard deviations. With the exception of social functioning ($P = .11$) and financial difficulties ($P = .36$), the differences are statistically significant ($P < .01$).

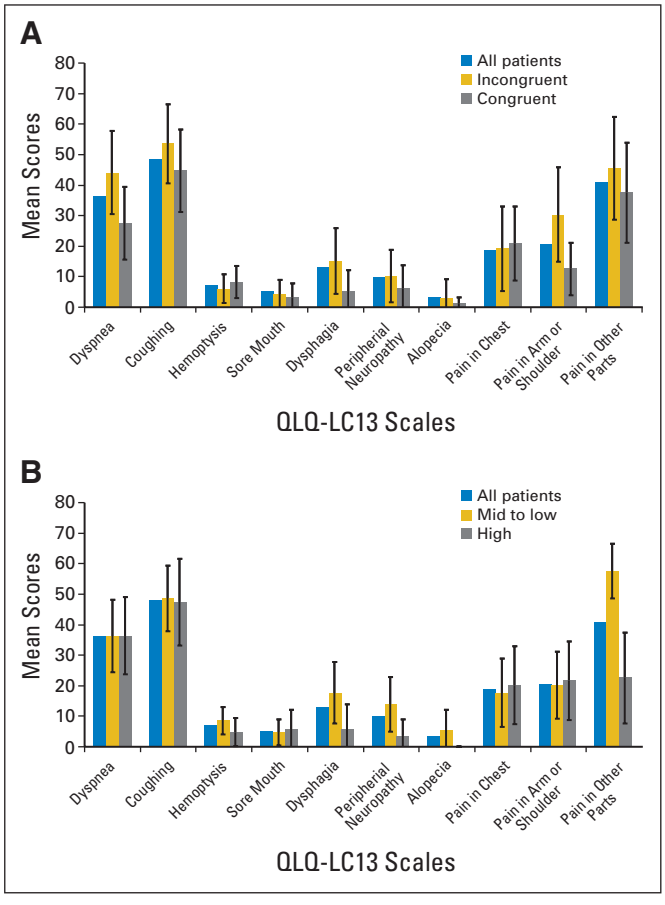

Fig 2. Mean scores for the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC) QLQ-LC13 stratified (A) by recall of treatment goal and (B) by satisfaction of communication of treatment goal. Whiskers indicate 95% CIs. All comparisons were Bonferroni adjusted for multiple comparisons and statistically nonsignificant.

Table 2. Sociodemographic Characteristics of Physicians

Characteristic	Physicians No.	Physicians %	Years of Practice Median	Years of Practice Range
Total No. of physicians	27			
Age, years				
Median	35			
Range	28-63			
Sex				
Female	6	22	6	2-17
Male	21	78	10	1-35
Specialty				
Pulmonary specialists	9	33.3	10	7-35
Internists	5	18.5	17	10-32
Residents in internal medicine	13	48.2	4	1-6

Among 26 patients informed that the therapeutic approach was to be curative, 15 patients (58%) recalled this information fully or partially compared with 14 of 32 patients (44%) in the palliative care group ($P = .29$). Of seven patients for whom the therapeutic approach had not yet been discussed, three patients (43%) fully or partially recalled the information reported by physicians.

Patient Satisfaction With Communication Regarding Diagnosis, Treatment Procedure, and Goal of Treatment

The majority of patients were highly satisfied with communication of diagnosis (76%) and treatment procedure (73%; $P = .53$). Satisfaction with communication of goal of treatment was only 39% and significantly lower compared with satisfaction with communication of treatment procedures ($P < .001$; Table 4). There was no significant difference between patients with curative (41%) versus palliative goal (30%) regarding satisfaction with communication of goal of treatment ($P = .40$).

Association Between Patient Recall and Patient Satisfaction

The relationship between recall of information about diagnosis, treatment goal, and satisfaction with communication in these areas were nonsignificant. Only better recall of information about treatment procedures was significantly associated with higher satisfaction of communication regarding this domain ($P = .02$).

Table 4. Patient Satisfaction With Communication About Diagnosis, Treatment Procedures, and Goal of Treatment

	Patient Satisfaction With Communication (N = 71)				
		High		Mid to Low	
	No.	No.	%	No.	%
Diagnosis		54	76	17	24
Treatment procedure		52	73	19	27
Treatment goal		28	39	43	61
Curative	27	11	41	16	59
Palliative	37	11	30	26	70
Not yet discussed	7	6	86	1	14

No patient characteristic (sex, therapeutic approach, psychometric, or quality of life scores) was related to recall or satisfaction. Of physician characteristics (sex, specialty, and years of practice), only physician specialty revealed a significant association: patients were significantly more satisfied with communication of diagnosis when provided by a pulmonary physician ($P < .01$).

Sensitivity analyses comparing residents to more experienced specialists revealed no significant differences in any domain of recall or satisfaction.

DISCUSSION

Half of the patients in this investigation did not recall the goal of treatment as reported by their physicians. Even when the aim of treatment was curative, 42% did not recall the treatment goal. Also many patients were dissatisfied with their physicians' communication of the treatment goal. In constrast, patient recall of and satisfaction with information regarding diagnosis and treatment procedures were generally good. In a sample of 100 patients with lung cancer, Quirt et al[9] reported that the majority of patients knew that they had lung cancer. In their study 72% of patients, compared with 50% in ours, reported information consistent with their physician's communication about the intent of treatment. Differences between results may be due to timing of assessment of information recall. In our study, it was done 1 to 3 days after the initial disclosure of lung cancer, whereas in Quirt et al study, assessment took place after therapy initiation.

Table 3. Congruence Between Physicians' Information and Patients' Recall Regarding Diagnosis, the Treatment Procedure, and the Goal of Treatment

Physician's Information	Congruence of Patient and Physician: N_{total}*	Fully Congruent No.	Fully Congruent %	Partially Congruent No.	Partially Congruent %	Incongruent No.	Incongruent %
Diagnosis	69	39	57	23	33	7	10
Treatment procedure	66	49	74	6	9	11	17
Treatment goal	65	22	34	10	15	33	51
Curative	26	7	27	8	31	11	42
Palliative	32	13	41	1	3	18	56
Not yet discussed	7	2	29	1	14	4	57

*Due to missing data, N_{total} differs from 71. Percentages were calculated using indicated totals.

Additionally, in our study, 27 physicians (pulmonary physicians, internists and residents) delivered the diagnosis of lung cancer, whereas in Quirt et al, nine physicians participated—three medical and six radiation oncologists. The fact that we engaged physicians from different subspecialties may also explain why recall of treatment goal is poorer in our investigation. Nevertheless, this situation may more closely reflect Western medical practice, in which pulmonary physicians or internists are most likely to provide an initial diagnosis of lung cancer, as opposed to oncologists whom patients are more likely to see at a later point.

There are also other explanations for our findings of low congruence between physicians' information and patients' recall: We cannot be sure that physicians always provided the information they claimed to have given. It would have been preferable to videotape the consultation, but we deemed it best to avoid such an intrusive intervention in this difficult situation. On the other hand, it is quite likely that physicians did provide complete and accurate information about the aims of treatment at initial disclosure of diagnosis, as it is strongly recommended in our hospital. Since 73% of patients reached a treatment decision at the time of assessment, it would seem that patients were, in fact, well informed.

Physicians, on the other hand, may have provided accurate explanations to patients, but in a manner not well tailored to the individual patient's momentary needs. Still, another possibility is that physicians informed patients thoroughly about the goal of treatment, but patients were unable to fully process the information, due to the extremely stressful circumstances. In fact, this may have possibly resulted in some kind of psychological denial, an explanation supported by a study of patients with varied cancer diagnoses.[10] In that study, patients were most likely to agree with physicians' estimates of likelihood of cure if they manifested relatively low levels of denial.

Our results underline the need to help patients improve their understanding of information given by physicians about their treatment goal. This may include improved training of physicians in ways to facilitate, encourage, and empower patients to participate more fully in treatment decision making, which hopefully would lead to improved patient recall of information.[11,21-24]

Patients, in general, were highly satisfied with how clinicians discussed diagnosis and treatment procedures. However, only 39% of patients were highly satisfied with the way physicians discussed the treatment goal. In a study by Schofield et al,[13] 64% of 131 patients with newly diagnosed melanoma were satisfied with communication regarding diagnosis, 79% with communication of treatment procedure, and 57% with communication of prognosis.

That patient satisfaction with communication of treatment goals was so low in our study might be due to the fact we investigated patients soon after disclosure of the diagnosis, whereas in the study by Schofield et al, they were investigated several months after diagnosis, leaving time for adjustment of the patient to the situation.

The greater satisfaction among patients who discussed diagnostic issues with pulmonary physicians might be due to the fact that these specialists are better versed than internists regarding diagnostic information and procedures related to lung cancer.

Only the association between satisfaction and accuracy of recall regarding treatment procedures was statistically significant. Accurate knowledge about treatment procedure would seem important to satisfy patients, under these circumstances, that a realistic and hopeful plan for the immediate future is available to them.

It is, nevertheless, unclear why patient recall of information is not associated with satisfaction in areas of communication about diagnosis or treatment goal. Other factors, besides accurate information about the treatment procedure, may additionally contribute to patient satisfaction regarding how physicians communicate diagnosis and treatment goal. Further investigation is needed.

Our study has several strengths. Compared with other investigations, fewer patients declined to participate.[9,25] All physicians who planned to disclose a lung cancer diagnosis to patients during the study period agreed to participate, and the physician sample size was substantially higher than in other studies.[9,12] Also, assessment of patients took place only 1 to 3 days after the cancer diagnosis, in contrast to other studies in which much more time had elapsed.[9,13]

Several important limitations also require mention despite our generally consistent findings. The study was based on retrospective self-reports by both patients and physicians, and physician-patient interaction was not documented (videotapes, audiotapes) as in several other studies.[11,12,25,26] Without such documentation, it is impossible to tell precisely what information was provided by the physician and which physician behaviors may have served to enhance or impair patient recall. Educational status and income were also not recorded, nor whether the patient was alone or accompanied by a significant other at the time of disclosure of diagnosis. These and other factors may influence recall of information and satisfaction with physician communication. Additionally, the sample size was relatively small, and the study took place in a single center. On the other hand, because no patient selection took place, the sample would seem to be broadly representative of newly diagnosed lung cancer patients.

In summary, the most significant findings are that newly diagnosed lung cancer patients' recall of information regarding the goal of treatment may, in general, be poor, and patients may often feel dissatisfied with physicians' communication within this existentially fundamental context. More research is needed to evaluate the pervasiveness of serious problems in physician-patient communication related to the issue of disclosure of cancer diagnosis, therapy modalities, and goals of treatment. Uncovering the causes of such communication breakdown may lead to the development of useful strategies to improve medical consultations.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Sabine Gabrijel, Alexander Kiss
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Final approval of manuscript: Sabine Gabrijel, Leticia Grize, Erich Helfenstein, Martin Brutsche, Michael Tamm, Paul Grossman, Alexander Kiss

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