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Clinical evaluation of quality of life: a survey among members of European Society of Thoracic Surgeons (ESTS)

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Abstract

OBJECTIVES: Quality of life (QoL) has been recognized as an important postoperative outcome. Despite the growing interest in this topic, there is almost no information about the daily use of QoL questionnaires within European Society of Thoracic Surgery (ESTS). The aim of this paper is to present the results of a survey launched to know the current practice of collecting and using QoL data within the Society.

METHODS: The survey was designed by the members of the QoL and Patient Safety ESTS committee and included 13 questions about different aspects of QoL assessment: time points of data collection, type and method of administration of questionnaires, dropouts, surgical-related symptoms and definition of the target population. An electronic link was sent to invite 1250 ESTS members to complete the survey by e-mail.

RESULTS: One hundred and fifty surgeons worldwide completed the survey. Of the total, 54.4% of the surgeons indicated that they never collect QoL data in their daily practice. Both SF-36 and EORTC C30 were the most commonly used questionnaires. They are considered as the most appropriate for thoracic surgery patients. Only 20% of the surgeons used the LC-13 module in addition. Most of the time (45.5%), questionnaires are completed through a face-to-face interview led by a physician. Only 21.2% of the responders collected data prior to surgery; 39.3% of the responders collect QoL data only from lung cancer patients and 16% add patients with oesophageal diseases. Postoperative complications, comorbidities, surgical and oncological baseline data and wound pain, healing disorders, arm mobility, oxygen dependency, return to work and postoperative medication were important items that responders suggested to include in future questionnaires.

CONCLUSIONS: The obtained data showed a broad area for improvement in QoL. The ESTS has to lead this effort collaborating to standardize the research in this field, endorsing specific questionnaires, incorporating patient-reported outcomes more and more into guidelines and facilitating multicentre studies.

Keywords: Quality of life • Thoracic surgery • Patient-reported outcomes

INTRODUCTION

Patients-reported outcomes, particularly quality of life (QoL), have been found by previous studies to correlate not only to surgical outcomes, but also to the long-term survival of lung cancer patients.

Furthermore, QoL has been introduced into government strategic frameworks to be implemented by hospitals in order to obtain financial bonus or research grants.

However, despite the growing interest in our speciality for the collection of these data, there is no evidence about the effective use and influence of these outcomes in clinical practice.

The aim of this survey is to obtain sufficient information about the current practice of collecting and using QoL data from the European Society of Thoracic Surgeons (ESTS) community. This knowledge should be a guide in the process of planning new multicentre studies about QoL and may highlight the need to incorporate patient-reported outcomes (PROs) in the perioperative guidelines.

MATERIALS AND METHODS

All ESTS members received an e-mail with information about the survey. They were invited to complete the questionnaire online in

a commercially available format (www.surveymonkey.com) from December 2012 to March 2013.

The survey was designed by the ESTS Quality of Life and Patients Safety Committee and is composed of 13 questions exploring different aspects of QoL assessment: time points of data collection, type of questionnaire, dropout management, surgical-related symptoms, method of administering the QoL questionnaires and population studied.

The present survey did not differentiate between the use of QoL tools in research studies and routine practice.

RESULTS

Question 1–3: Demographics

The survey was completed by 150 surgeon members of ESTS. Table 1 presents the worldwide distribution of participants. Of the total, 25 members skip the demographics identification. Only 0.5% of respondents were from the same institutions.

Question 4: Have you ever used a quality of life evaluation for your patients?

Of all the participants, 45.6% stated that the QoL data have been collected in their unit; 54.4% have never incorporated the use of this specific PRO into their routine practice (Fig. 1).

Question 5: Which type of quality-of-life questionnaire have you used?

Among those collecting QoL information, a higher percentage of respondents (50%) used the generic questionnaire SF-36, while 48.5% of respondents introduced the administration of the cancer-specific tool EORTC C30 (Fig. 2). A few respondents (20%) integrated in their EORTC questionnaire the lung-specific module (EORTC C30 + LC-13) whereas, in a minority of cases (10.61%), surgeons administered the Functional Assessment of Cancer Therapy-Lung (FACT-L).

Question 6: Which is, in your opinion, the most appropriate existing questionnaire for thoracic surgical patients?

Responses at this question are almost balanced. Twenty respondents (30%) indicated that they would consider the most appropriate instrument for lung surgical patients the EORTC C-30. Other twenty-two surgeons (33.3%) would add to that the Lung-Specific Module (LC13). About other 30% of respondents prefer the generic questionnaire (SF-36). Only a minority of respondents (6%) would rather use the FACT-L.

Question 7: How do you administer the quality-of-life questionnaire to patients?

The majority of respondents (45.5%) stated that they assessed QoL in patients through a face-to-face interview led by a physician, while 31.8% prefer a self-administration of the questionnaire in the

Table 1: Countries participating in the ESTS QoL survey and their relative contributions (expressed in percentage)

Country participating in the QoL survey	%
Greece	5.3
Italy	17
Serbia	0.7
Russia	2.7
France	2.7
Germany	1.3
Hungary	0.7
Spain	6
Netherlands	1.3
Belgium	2.7
UK	5.3
Denmark	2
Slovenia	0.7
Lithuania	1.3
Poland	2
Armenia	0.7
Czech Republic	0.7
Switzerland	0.7
USA	2.7
Japan	1.3
Sweden	1.3
Bulgaria	0.7
China	0.7
Republic of Ireland	0.7
Georgia	1.3
Brazil	1.3
Turkey	4.7
Romania	2
Ukraine	0.7
Saudi Arabia	0.7
India	0.7

ESTS: European Society of Thoracic Surgeon; QoL: quality of life.

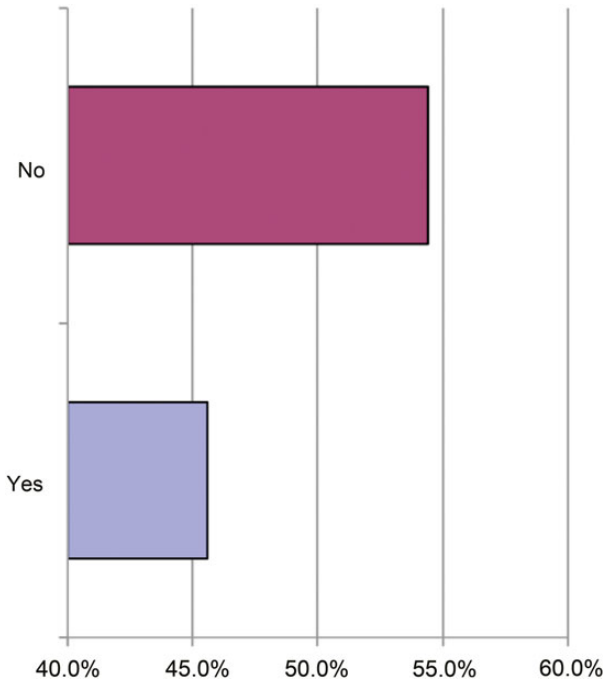

Figure 1: Results from the question: 'Have you ever used a quality of life evaluation for your patients?'

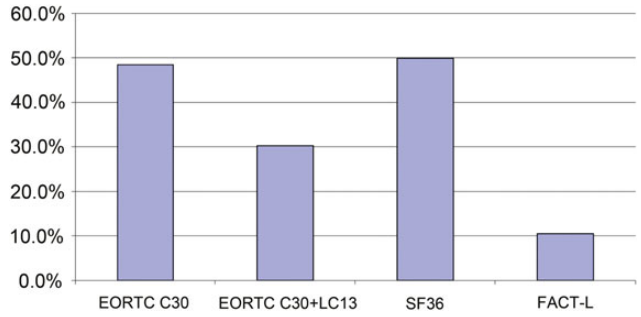

Figure 2: Results from the question: 'Which type of quality-of-life questionnaire have you used?'

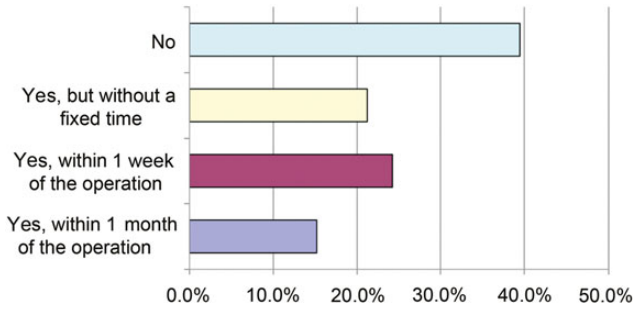

Figure 3: Results from the question: 'Do you collect QoL preoperatively?'

clinic without the presence of health-care personnel. Face-to-face interview led by a nurse was the choice in 16 other units (24.4%). However, a good proportion of respondents sent questionnaires by regular mail (27.7%) or e-mail (4.55%). Only 6% of our respondents confirmed use of self-administration of QoL tools at computer desks in their clinic.

Question 8: Do you collect quality of life preoperatively?

The time for collection of QoL data is crucial. Most of the respondents did not collect QoL data at all prior to surgery. Eighteen respondents (24.4%) gathered QoL information within 1 week of the operation, while another 10 (15.5%) did so within 1 month. Another 21.2% of this population of surgeons collected data before the surgery but without a fixed time (Fig. 3).

Question 9: About what percentage of your patients know their cancer diagnosis at the time of preoperative administration of the questionnaire?

The majority of respondents (39.4%) agreed that 60–90% of their patients already have been aware of their cancer diagnosis while filling in the preoperative questionnaire. Fourteen respondents (21.2%) have given the preoperative survey only to patients who know their cancer diagnosis. The percentages of patients with awareness of cancer fell down to 0–30 for 18.8% of respondents and to 30–60 for the remaining 21.2%.

Question 10: Do you collect postoperative quality-of-life data?

A majority of respondents (33.3%) collect postoperative data of QoL at three months after the operation. The distribution of other answers is the following: at discharge (6%), at less than 1 month (6%), at 1 month (22.7%), at 6 months (18.8%), at 12 months (25.7%), at 18 months (7.6%), at 24 months (10.6%) and at more than 24 months (13.6%) after the surgery. Of the total, 31.8% of respondents did not collect QoL data at all.

Question 11: Which surgical patients are included in your quality-of-life evaluation?

Of the total, 37.5% of respondents collected QoL information from all their surgical patients, while 39.29% limited this research only to lung cancer patients. More interestingly, 10.7% of the respondents administered a QoL survey only to early stages (I and II) of lung cancer patients and 12.5% to advanced stages (only Stage III). Moreover, patients submitted to oesophagostomy have been studied through a QoL questionnaire by 16% of respondents. Only minor percentages were described for metastasectomy procedures and lung transplantations (Fig. 4).

Question 12: Which of the following baseline and surgical variables do you think may influence quality-of-life analysis and are important to be recorded?

Most of the respondents (83.9%) agreed to indicate complications as the main surgical factor affecting QoL of thoracic surgical patients. Other variables considered to be recorded in these patients are functional variables (for 67.7%), comorbidities (for 75%), surgical (for 75%) and oncological (for 75%).

Demographics have been indicated by 42.9% of respondents, while social status, like education, work and marital status, was judged important by 57.1% of surgeons.

Only 8 respondents (10.7%) indicated genomic factors to be included between the influencing variables, while hospital stay was considered to impact QoL for 37.5% of respondents.

Question 13: Which of the following items do you think would be important to include in a quality-of-life questionnaire specific for thoracic surgical patients?

The majority of respondents (80.36%) identified wound pain as the most important post-surgical symptom. Associated to it are a group of related symptoms such as wound healing disorders (30.36%), sensibility disorders (39.29%) and fear of wound pain (14.29%).

Of the total, 41% of respondents indicated arm mobility disorders as an important surgical item to be included in a new questionnaire, while others put more physiological parameters deserving investigations after surgery: performance restrictions due to the extent of surgery (51.79%), oxygen dependency (51.79%), dyspnoea after surgery (67.9%), coughing after surgery (37.50%).

Other items considered to be of crucial importance by respondents are the following: fear of anaesthesia (10.7%), return to work (69.6%), fear of hospitalization (10.7%), loss of control (25%), long-term use of analgesics (69%) and smoking cessation (53.6%) (Fig. 5).

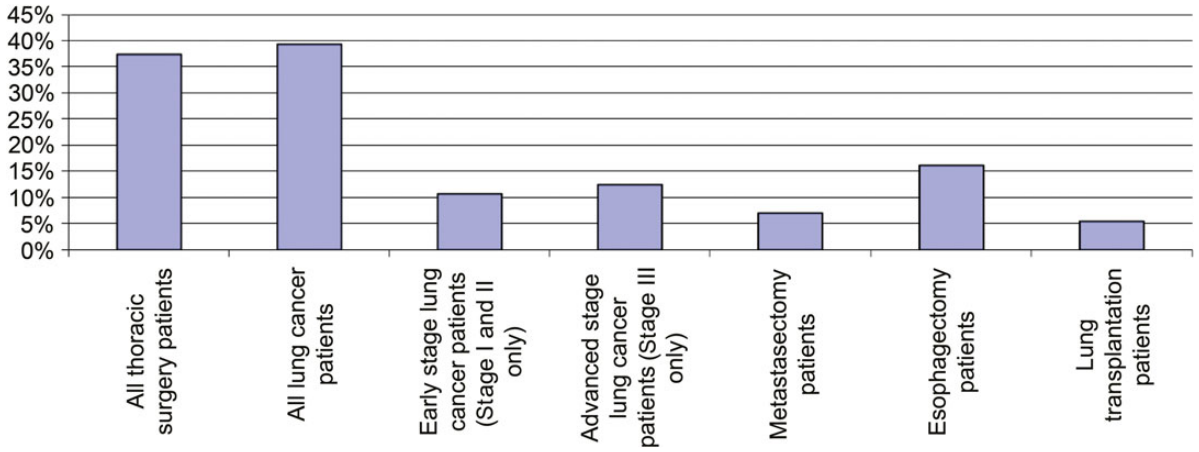

Figure 4: Results from the question: 'Which surgical patients are included in your quality-of-life evaluation?'

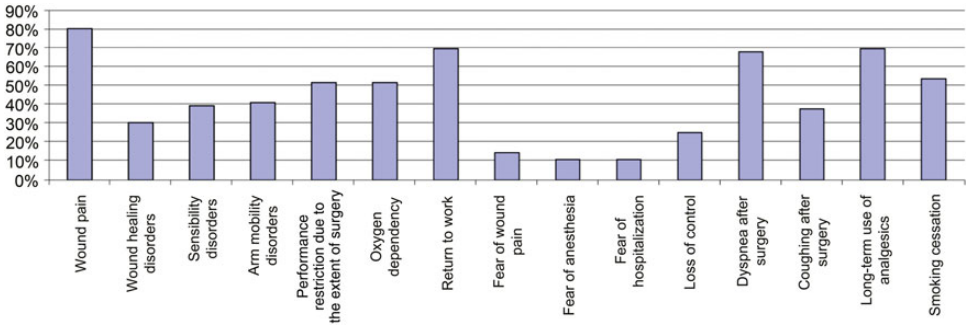

Figure 5: Results from the question: 'Which of the following items do you think would be important to include in a quality-of-life questionnaire specific for thoracic surgical patients?'

DISCUSSION

The response rate in this survey was 20.3%. This result is in line with recent surveys among ESTS members [1]. As presented in Table 1, our results are representative of thoracic surgeons across Europe.

This survey underlines the lack of a routine collection of PROs after thoracic surgery. In fact, about half of the centres among the ESTS community participating in this survey routinely collected QoL data. The growing interest of the societies and Public Health Commissions to evaluate Hospitals and Units through the PROs should persuade surgeons to increase these data collections. The lack of a standardized and specific instrument for evaluating patients after lung cancer surgery has to be considered the main open issue for QoL research in the field of thoracic surgery. A considerable portion of surgeons confirmed the use of a generic tool like SF-36 for studying QoL in lung cancer surgical patients. This should be useful for comparing general populations, but it will likely miss some specific symptoms following lung cancer surgery. Other papers have demonstrated the importance of cancer-specific questionnaires in lung cancer clinical trials incorporating QoL as a specific end-point [2–5].

Many surgeons suggested in this survey to include more symptoms related to the effect of surgery on the QoL. This has been one of the main purposes of an EORTC QoL workforce which is currently updating the lung cancer module LC-13 [6].

Unexpectedly, the majority of respondents preferred to administer the QoL questionnaire to all thoracic surgery patients. This is controversial, as surgical procedure and pathology may affect the daily lifestyle and symptom burden of thoracic patients differently. Furthermore, the predominant choice of a generic cancer questionnaire may confirm the paucity of specific tools for the investigation of this subjective end-point. So far few reports have been published about the residual QoL after less common procedures in thoracic surgery using validated surveys [7–11].

Still a minor percentage of units use e-mail to administer the questionnaires. This may probably become the method of choice in the future of QoL studies, even if some authors have demonstrated the importance of the caregivers to help fill up the QoL questionnaire [12, 13]. It is worth noting that almost half of our respondents do not evaluate QoL before the operation. The effect of surgery on the subjective symptoms of the patients has been considered to be of crucial importance for the acceptance of the surgical risk by the cancer patient [14]. Furthermore, the association between QoL and survival after major lung resections has been largely described [15, 16].

This survey represents a snapshot of the use of QoL questionnaires in clinical practice of 150 thoracic surgeons. It may not take into account all the real practice of thoracic surgeons in investigating one of the main patient-reported outcomes. Furthermore, as we investigated only the country of work of the respondents, we cannot rule out that certain surgeon demographics, like type of institutions or field of surgical interests, may have biased the results of the survey.

In conclusion, this survey has highlighted the shortcomings in the QoL research among the ESTS community. With this information, the Society may improve the standard of research in this field, endorsing specific questionnaires, incorporating patient-reported outcomes more and more into guidelines and facilitating multicentre studies.

Conflict of interest: none declared.

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eComment. Quality of life in thoracic surgery: often neglected but of vital importance!

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Quality of life (QOL) and in general, patient-reported outcomes, are becoming increasingly important when evaluating the short-term and long-term results of technically complex surgical interventions. This pertains particularly to bimodality and trimodality treatment combining different therapies which are known to have a profound impact on a patient's well-being and daily functioning. Is an aggressive treatment warranted when it reduces QOL to a great extent, even when it proves to be an effective therapeutic modality?

In thoracic surgery, QOL has been neglected for a long time with only a limited interest in its recording and evaluation to determine whether a change in therapeutic approach should be implemented. In the EORTC 08941 phase III trial randomizing patients with stage IIIA-N2 lung cancer between induction chemotherapy and surgery versus induction chemotherapy and radiotherapy, QOL forms were incompletely filled out with a lot of missing data, which did not allow for a valid QOL analysis [1]. In this way, a comparison of QOL between surgery and radiotherapy was not feasible. Moreover, the ideal validated questionnaire applicable to a wide range of thoracic surgical procedures is not available yet.

In the present report, the European Society of Thoracic Surgeons (ESTS) performed a timely survey amongst its members to determine current practice of QOL registration in the general thoracic surgical community [2]. Bram Balduyck, one of the co-authors, successfully defended a doctoral thesis at the Antwerp University in Belgium on QOL in thoracic surgery, which covered pneumothorax to pulmonary metastasectomy combined with isolated lung perfusion [3,4]. In total, 1250 members were invited to participate in the survey and 150 (12%) responded, mainly surgeons from Southern Europe. The most commonly used questionnaires were SF-36 and EORTC C30. Only 20% of surgeons used the additional EORTC LC13 module. Rather surprisingly, of the 150 responders, 54.4% never collected QOL data in their daily practice, something that should certainly be improved in the near future. Only 21.2% of the responders collected preoperative data on QOL. Several items were proposed for inclusion in future questionnaires as e.g. postoperative complications, comorbidities, surgical and oncological baseline data and wound pain, healing disorders, oxygen requirements, and return to work.

The ESTS recognizes QOL as an important topic to be incorporated in our surgical practice. Thoracic surgeons should be encouraged to pay adequate attention to its evaluation and recording in a broad range of thoracic surgical procedures. They should be prepared to provide QOL data when discussing results of surgical interventions. This is of vital importance as the minimally invasive and invasive surgical procedures are increasingly compared not only to one another, but also to less invasive treatment modalities as stereotactic radiotherapy and radiofrequency ablation. QOL cannot be neglected anymore!

Conflict of interest: none declared.

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