

Patients reported outcomes in thoracic surgery

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Patient reported outcomes (PROs) in lung cancer surgery

Recent advances in early detection and targeted therapies of lung cancer have contributed to improve prognosis. In this context, the importance of preserving quality of life (QOL) of lung cancer survivors is compounded.

For this reason, during last decades there has been a shift towards utilising PROs in this field, championing the preservation of health-related quality of life (HRQOL) as a new important outcome to look at in addition to cancer survival.

Unfortunately, lung cancer is often linked to significant medical comorbidity with high symptom burden and thus associated with a poor QOL. The majority of these PROs studies are predominantly reported by oncologists or palliative care teams (1). Surgical treatment remains the gold standard of care for early stage non-small cell lung cancer (NSCLC) patients and the importance of collecting PROs among the lung cancer surgical population has become even more important as new surgical options have been introduced and with the increase in early stage lung cancer patients that are anticipated with more widespread lung cancer screening. Advances in minimally invasive techniques [video-assisted thoracoscopic surgery (VATS) and robotic surgery] and use of non-surgical treatment options [stereotactic ablative radiotherapy (SABR)] have also moved clinicians closer towards a position of equipoise regarding the ideal treatment for small peripheral tumors. While waiting for long-term survival results on these treatment, many authors have sought to compare these options from the patient perspective for guidance regarding best treatment (2,3).

It would seem, then that improving patient QOL

should be a goal of good oncology practice and a quality performance indicator of thoracic surgery care. Yet, a published survey among European thoracic surgeons, revealed a lack of standardized PROs collection among this community with 88% of all surgeons currently not incorporating these outcomes into their clinical practices (4).

In surgery, with the fast pace of technology progress and the increasing acceptance of patient empowerment, the value-based health care model is expected to gradually replace the existing transaction-based model (5,6). Patients will have an increased freedom to choose where, how and by whom they are treated. Hospitals and providers need to be more transparent in demonstrating the impact and expected outcomes of different treatment options to the patient for a shared decision care model. Furthermore, as new cancer treatments or devices are developed, the medical industry needs to demonstrate improvement in outcomes that are meaningful to the patient. PROs and HRQOL are important components that the thoracic surgery community cannot ignore anymore.

Challenges in thoracic surgery PROs collection

Instruments

What clearly needs to be defined is the difference between symptoms and HRQOL as the surgical literature often uses these concepts interchangeably in outcomes analysis and reporting. "Symptom" is a one-dimensional property while "HRQOL" is multidimensional.

This is particularly important when we are choosing the instrument to use in both clinical practice and research. The patient reported outcome measure (PROM) most suitable to the aim of our study may be composed by

multiple questions and may generate a multi-items scale which make results interpretation more difficult. Published clinical trials often use different measures to assess the same concepts, limiting the ability of decision makers to compare results across studies. One example in our field is pain assessment, which has been investigated in conjunction with the standardized HRQOL questionnaire as in a recent randomized controlled trial between VATS and open lung resections for NSCLC, leading to debatable conclusions (7).

This may explain why in the past many surgical trialists didn't use standardized, validated instruments, but preferred to use self-made simplified questionnaires. Many clinicians in fact, still declare that increasing brevity would help make PROs assessments more widely adopted in clinical research although this would mean sacrificing validity (8).

In surgical practice, where all the preoperative assessments are now streamlined in few appointments, it would be advisable to have a simple, unique measure to evaluate patients' QOL, but it should come from a validated instrument, regardless of the burden in completing it.

This would also be helpful for implementing PROs into multi-institutional databases and guidelines in a standardized fashion for broader reporting. In the US a first attempt has been recently done demonstrating the feasibility of integrating PROs into the Society of Thoracic Surgeons (STS) Database for patients undergoing lung cancer operations (9). The move is meaningful since the STS General Thoracic Surgery Database represents more than 506,000 general thoracic surgery procedure records and currently has more than 950 participating surgeons.

There is no doubt that PROMs collection has been demonstrated to enhance communication between patients and care providers (10,11) and improve patient involvement in care planning and decision making. However, in thoracic surgery we still need to standardize the preoperative evaluation of PROs. In the postoperative period, the lack of a standardized surveillance programme has made this implementation even more difficult (12). Post-resection surveillance presents additional challenges regarding type and frequency of surveillance which in and of itself may contribute to adverse patient experiences.

Electronic patient reported outcome measures (ePROMs) and lung cancer demographic

Good evidence indicates that PROMs administered on paper are quantitatively comparable with measures administered on an electronic device and this has increased

the used of ePROMs in oncology (13). Specific challenges have been identified and include resources available for system implementation; planning and designing the system infrastructure adequately; training and engagement of clinical staff. However, lung cancer patients are often underrepresented in these trials, and more difficulties in patient engagement are usually reported for electronic PROMs. In our experience, a greater proportion of lung cancer patients may have lower levels of computer and health literacy which may be related to age or socioeconomic background, but certainly has potential to impact the ability collect PROs via electronic platforms.

We definitively need to educate lung cancer patient about PROMs, how they will help other people in making informed decisions and also how the electronic systems may give additional support in a near future, like automated feedback or self-care instructions without the need of hospital appointments. A recent randomized trial in oncology setting, has in fact shown that computer-inexperienced patients had the greater benefit from a structured symptoms on-line self-reporting system in terms of HRQOL, emergency room (ER) visits, hospitalizations, and survival (11).

PROMS Initiatives from different settings

There are selected initiatives, which are pioneering the integration of PROMs into routine practice also in the surgical lung cancer field.

As without a comprehensive outcome measurement, it is hard to know which change can makes the difference, the International Consortium for Health Outcomes Measurement (ICHOM) has identified a core set of outcomes and related case-mix variables that can be collected for lung cancer patients in routine clinical practice internationally (14). These recommendations reflect the opinion of a selected group of experts and patient representatives around the world and will help our speciality in implementing PROMs in clinical practice. Both clinicians and patient advocates considered EORTC QLQ-C30 and EORTC QLQ-LC13 essential instruments in the process of clinical care.

The Patient Reported Outcomes Measurement Information System (PROMIS[®]) was funded by the US National Institutes of Health to completely change the assessment of PROs by establishing a national online platform for the measurement of patient-reported symptoms and other health outcomes. It has already been

piloted in our speciality with good results, for the first time incorporating PRO data into a large clinical registry as the STS database (9).

The importance of PROMs in healthcare has been championed by the creation of a government-sponsored organization charged with investigating the relative effectiveness of various medical treatments. Important lung cancer projects have been funded by the Patient-Centered Outcomes Research Institute (PCORI) (15), which remit is also improving methods of patient-centered clinical effectiveness comparative trials.

The EORTC Quality of Life Group has just announced launch of its new item library, which is an interactive online platform comprised of more than 900 items developed and validated for use in EORTC core questionnaires and modules (16). It will also provide users with tools to create custom-made ad hoc item lists, to be used in conjunction with the standard core questionnaires and modules. This will increase the responsiveness to change issues claimed to many PROMs in the past and would make clinicians more flexible in designing their studies.

In conclusion, although we acknowledge some difficulties in clinical practice, thoracic surgeons are now provided with many instruments to include patient voice during all aspects of the journey of early stage NSCLC treatment which should be one of the hallmarks of good clinical thoracic surgical care.

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Footnote

Conflicts of Interest: G Velikova and C Pompili are members of the EORTC Quality of Life Group. The other authors have no conflicts of interest to declare.

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