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POSTER ABSTRACT

Lung cancer registry to promote person-centered care.

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Introduction: Lung cancer is a leading cause of death and major burden on healthcare systems. Patient-centered outcome measurements allow the optimization of care organization and quality improvement. The aim of this project was to outline a set of variables and outcomes to evaluate the quality of care provided to lung cancer patients.

Methods: This project took place at Hospital Italiano de Buenos Aires, a community-based tertiary care hospital in Argentina; which provides thoracic surgery, pneumology, oncology, pathology, radiology and radiotherapy services. It also has a Lung Cancer Multidisciplinary Board. All patient information is stored in a Data Repository fed by the electronic health record (EHR).

We established a team of experts in management, IT, thoracic surgery, pneumology, oncology, and internal medicine. We reviewed care processes and patient trajectory along the usual pathway, through a retrospective EHR analysis of a consecutive sample of lung cancer patients.

We performed a literature review to outline possible variables and health outcomes to be collected, instruments, and frequency of measurement. We determined needs, usefulness, and feasibility of collecting variables and outcomes in group meetings.

Results: We reviewed 15 cases of lung cancer, 53% male, median age 68 years old (range: 29-85). We detected heterogeneity in the time elapsed between critical points of management (eg first visit to diagnosis 21 to 642 days; biopsy report to chemotherapy 19 to 163). The proportion of use of the healthcare system was also variable (eg: 87% consulted pneumonolory or oncology, only 13% had pain management visits and 7% received respiratory kinesic therapy). Patient-reported outcomes were not systematically evaluated.

The selected baseline variables were: age, sex, weight loss, smoking status, comorbidities, patient-reported health status (EORTC European Organization for Research and treatment of cancer, QLC-LC30 Core quality of life questionnaire, QLC-LC13 Lung cancer-specific quality of life questionnaire), performance status (ECOG Eastern Cooperative Oncology Group), pulmonary function (VEF1), histology, clinical and pathological stage (AJCC-TNM 8th Ed), molecular tests and treatment intent. The outcomes (collected annually): clinical staging performed before treatment, time from diagnosis to treatment, performance status, patient-reported health status, major surgical complications, major chemotherapy/radiotherapy complications, time from

diagnosis to treatment, completed treatment, overall survival, cause of death, treatment-related mortality, place of death, time spent in hospital at the end of life (last 30 days).

Discussion: Cancer registries comprise a set of systematically and prospectively collected data. Quality measurements performed in the context of cancer registries could assist in monitoring and evaluating quality of care.

Conclusions: The project determined essential variables and outcomes to be measured, considering their relevance and feasibility.

Lessons learnt: Teamwork is essential when developing a registry, as different stakeholders' opinions are reflected. Integrated care is a useful solution to overcome fragmentation.

Limitations: Patients did not participate directly in this development.

Suggestions for future research: These results will assist in outlining a care pathway for patients with lung cancer, which is currently under development. Evaluation before and after the implementation of care pathways may evidence quality improvement.