Re: Enhancing Cancer Registry Data to Promote Rational Health System Design

In her recent editorial in the Journal, Schrag (1) underlined the importance of including comorbidity and performance status when comparing survival outcomes between generalized and specialized centers. The characteristics of patients who seek care at or are referred to specialized hospitals probably differ from those in general hospitals. We totally agree. In a study in the southeastern part of The Netherlands, surgically treated pancreatic cancer patients who were referred to university hospitals were younger, more often male, more often diagnosed with stage 3, exhibited less comorbidity, and had a higher socioeconomic status than patients surgically treated in general hospitals (2). Furthermore, in a previous study (3) with data on all patients diagnosed with International Federation of Gynecology and Obstetrics (FIGO) stage 2 or 3 ovarian cancer in the region of the population-based Eindhoven Cancer Registry, we found that age, FIGO stage, presence of comorbidity, and year of diagnosis were independent predictors of receiving the advised treatment (combination of surgery and chemotherapy). Furthermore, both age and the treatment with surgery and chemotherapy independently affected overall survival, even after adjustment for comorbidity. Because the prognostic effect of age remained after adjustment for comorbidity, age in itself or other factors related to increasing age must be responsible for the age effect. Performance status is one of the most important factors (independent of comorbidity), as Extermann et al. (4) have, indeed, found. Although comorbidity is routinely recorded from the medical records for all patients diagnosed with cancer in the Eindhoven Cancer Registry (5), performance status could often not be extracted from the medical record. In an in-depth retrospective study, we have attempted to register performance status for cancer patients, but this status remained unknown for approximately half of all patients.

We agree with Schrag that by working across international boundaries to develop consensus on data collection strategies, metrics, timing rules, and even systems for engaging patients in data collection more
directly, we can optimize the value of cancer registry data to provide information not only about cancer incidence and mortality but also about the optimal design of cancer care delivery. This goal is among those of Eurocourse project funded in the Seventh Framework Programme (FP7) of the European Union, which is starting soon.

In addition, feedback to the medical specialists about the importance of performance status is also necessary. In the regional Dutch comprehensive cancer centers, we can accomplish this objective by giving feedback in the meetings of the regional tumor working groups, which are attended by medical specialists.

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Dr Schrag declined our invitation to respond to this correspondence.
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