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Quality improvement in palliative care – the role of a national quality register and perceptions of information during palliative chemotherapy

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Abstract
There is a need in palliative care for development of structured methods to assess quality and support improvement. Honest information from physicians is regarded as an important part of palliative care. The Swedish Register of Palliative Care (SRPC) is a Swedish national quality register that collects data with an end-of-life questionnaire (ELQ).

The aim of this thesis was to examine the validity of the ELQ, to examine whether participation in the SRPC increases the quality of palliative care over a three-year period regarding eight items in the ELQ, to examine whether an educational intervention for physicians and nurses in nursing homes and hospitals increases the proportion of patients who receives information from physicians about the transition to end-of-life care (ITEOL) and to describe how patients with cancer perceive the information they receive from physicians during palliative chemotherapy.

Data from 100 medical records were compared with data reported to the SRPC to examine the validity of the ELQ. Data from eight items in the ELQ reported to the SRPC from all healthcare units that had reported patients continuously during a three-year period were compared year-by-year with logistic regression. Two municipalities and two hospitals were randomised to receive an interactive half-day course about ITEOL for physicians and nurses. Four hospitals and four municipalities were assigned matched controls. The proportion of patients who received ITEOL before and after the intervention was analysed with a multivariable logistic regression model. Fifteen semi-structured interviews with patients with incurable cancer were conducted, transcribed verbatim and analysed with qualitative content analysis.

The questions in the ELQ showed a congruity of 22% to 100% when comparing data from medical records with data reported to the SRPC. During the three-year period, the prevalence of six symptoms decreased, the prescription of four types of 'as needed' medications increased, a higher proportion of patients died in their place of preference and the patient's next of kin were more often offered a follow-up appointment. The proportion of patients in the intervention group who received ITEOL increased from 35% to 42% (p=0.005). Three categories were disclosed during the analytical process: 'living with a death sentence', 'depending on chemotherapy', and 'living with uncertainty'.

Keywords
Cancer, chemotherapy, communication, end-of-life care, oncology, palliative care, palliative medicine, quality in healthcare, quality register

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