

Do healthcare professionals and relatives agree on dying patients quality of end of life care?

Martin Dreilich MD, PhD. Supervisor Staffan Lundström MD, PhD

Background. Specialized palliative care units in Sweden have a high response rate in the Swedish Register of Palliative Care (SRPC), which has provided good conditions for improvements of end of life care (Martinsson et al., 2012). Defining a good death has several perspectives and dimensions, which implicates that multiple data sources preferably should be used when evaluating end of life care (Bainbridge et al., 2010). The aim of the project was to compare answers from health care professional's registration in the SRPC (end-of-life questionnaire, ELQ) with answers from a corresponding SRPC survey (r-SRPC) sent to the closest relatives. Comparing data on quality of end of life care registered by HCP with quality of end of life care as perceived by relatives can give interesting perspectives and help improving the quality of care at our unit.

Method. We performed a retrospective descriptive study on all patients at Uppsala Hospice registered in the SRPC during 2017. The ELQ, answered by HCP, was registered online after the death of a patient, and information was based on the medical chart. The voluntary r-SRPC questionnaire have corresponding questions but is based on the relatives' experience of the end of life care. The questionnaire was sent to the relatives 6-8 weeks after the death of the patient. Answers from both surveys were matched and paired in cross tables to reveal consistent answers. In order to detect bias in the response group, patient characteristics were compared with characteristic of all patients' deaths. Wilcoxon-Mann-Whitney Test was used to compare the cohorts.

Results. In 2017, a total of 156 ELQs were registered in the SRPC by the HCP. Fifty-two r-SRPC questionnaires were registered and compared with the corresponding ELQ, which corresponds to 33% of all deaths at Uppsala Hospice during 2017. The majority of the included patients had a cancer diagnosis and there was an even distribution regarding gender. No correlation was found between length of stay and willingness to participate in the r-SRPC survey. According to the ELQ, 75% of the patients received oral information about transition to end-of-life care, but only 50% of the relatives acknowledged this conversation ($p < .05$ p-value). Agreement between HCP and relatives regarding occurrence of breakthrough pain during the last week of life was 57%, death rattle 63%, dyspnoea 65%, anxiety 50%, nausea 57% and for confusion the agreement on the occurrence was 44%. According to the ELQ, none of the patients received parental nutrition or fluids during the last 24 hours of life. However, in the r-SRPC, 6 divergent answers were found regarding nutrition and fluids. According to the ELQ, there was someone present at the time of death in 49 out of the 52 patients. HCP and relatives had almost a full agreement on this issue. Data from the ELQs stated that all relatives were offered a follow-up talk 1-2 month after the death, whereas 34/52 (65%) of the relatives perceived the offer of a follow-up talk.

Conclusion. In this study we found that conformity between answers from the ELQ and the r-SRPC was high regarding presence at the time of death and whether nutrition or fluids were distributed during the last 24 hours of life. We found discordance regarding communication about transition to end-of-life care. The results warrant further discussions about how we communicate around these transitions and whether we can use additional sources of information and measures to improve the quality of end-of-life care.