

Patient reported outcome in palliative head and neck cancer care: what can we learn to strengthen patient centered care?

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Background

Improving the quality of care is challenging as palliative head and neck cancer patients are a underexposed and vulnerable patient group

Objective

Obtaining long-term insight in clinical and patient reported outcomes in palliative head and neck cancer in order to earmark vulnerable subgroups and strengthen patient centered care.

Methods

- Longitudinal study, 331 patients
- Patient reported outcome measure: EORTC-QLQ-C15-PAL
 - Baseline, 2, 4 and 6 months
- Statistical analysis: linear mixed models

Institutional routine and ePRO's

- Within our expert centre, palliative care is provided by a specialized oncology nurse
- Individual palliative (remote) care is guided by a electronic Patient Reported Outcome Measure (ePRO)
- Outcomes are used on population level for continuous quality improvement



ePRO is filled in by the patient



Individual dashboard for (remote) counseling



Real-time quality improvement dashboard

Results

- Median survival 5.1 months (range: 1 – 40)
- Place of death: Home (66.4%), Hospital (7.4%), Nursing Home (7.0%), Hospice (16.7%)
- Cause of death: Natural death (75.9%), Blow-out (3.9%), Euthanasia (12.8%)
- 62 patients (18.7%) refrained from curative treatment
 - Associated with female gender and euthanasia as cause of death
- Quality of life
 - Global health, physical functioning, fatigue, dyspnea, appetite loss and constipation
 - Emotional functioning
- Vulnerable patient characteristics:
 - WHO performance status ≥ 3 , Comorbidity score ≥ 2 , recurrent disease, weight loss, gastric tube, patients with inadequate social network or living alone.
- A higher reported global health status is associated with longer survival (HR 0.988, $p < 0.001$)

Conclusion

- ePRO individual data gives guidance during 1:1 patient contacts
- Obtained data provides long-term insight in symptoms and quality of life
- Early identification of vulnerable patients enable more patient centered counseling and care

Take Home Message

During the palliative phase, our unique ePRO structure enables adequate symptom management and (end-of-life) counselling on an individual level and identification of vulnerable patient groups on a population level.