

Carers' satisfaction with care in an integrated oncology and palliative care intervention trial involving hospital and community care

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Background

There is increasing evidence that early access to palliative care improves cancer care. Evaluation of quality of care is important, but patients' self-report is often not possible. Family caregivers ('carers') play a significant role in care of cancer patients, especially late in the disease trajectory. Satisfaction with care after the patients' death may be a proxy outcome for the quality of patient care and as an outcome for the carers.

Aim

The aim of this study was to explore satisfaction with care among carers of patients with advanced cancer. Research question was if carers of patients receiving early integrated oncology and palliative care were more satisfied with care than carers of patients receiving palliative care as an "add-on" service.

Methods

Data from the Orkdal Model Study (ClinicalTrials.gov Identifier NCT02170168), a prospective controlled intervention trial, was analyzed. The Orkdal Model aims to improve cancer and palliative care by establishing an integrated oncology and palliative care outpatient clinic at a local hospital and by implementing a complex intervention in the region consisting of a standardized care pathway, an educational program for health care workers and an information strategy. The Romsdal region was control region. Patients with advanced cancer receiving non-curative treatment living in the Orkdal and Romsdal regions and their carers were included after informed consent. Carers' satisfaction with care was measured by the FAMCARE-19 questionnaire one month after patients' death. FAMCARE-19 is answered using a 5-point Likert scale (1 very satisfied, 5 is very dissatisfied). Sociodemographic data and medical characteristics were collected at inclusion. Mann Whitney U Test was used for statistical analysis.

Results

207 patients and 100 carers were included. Sixty-four carers of patients who passed away before February 15th 2018 received FAMCARE, 40 responded (62,5%), 28 in the intervention group and 12 in the control group. Median age of the carers was 69 years and 24 (60 %) were females. Thirty (75 %) were spouses. Carers in both groups were generally satisfied with care. The mean total FAMCARE score in the intervention group (32,25, range 19-45) was significantly better than in the control group (42,75, range 24-80, $p=0,03$). The intervention group scored significantly better mean FAMCARE score in availability of the doctor for the patient (1,57 vs 2,42, $p=0,003$) and the family (1,64 vs 2,67, $p=0,004$), coordination of care (1,5 vs 2,25, $p=0,016$), information (1,64 vs 2,56, $p=0,001$) and follow-up of the patient's test (1,55 vs 2,58, $p=0,001$), and how thorough the patient's symptoms were assessed (1,6 vs 2,50, $p=0,004$).

Discussion

Carers in both groups were generally satisfied with care showing that general cancer care in Orkdal and Molde regions were of good quality. In the Orkdal Model, one team of oncologists and oncology nurses provides oncology and palliative care, and the model also includes close collaboration with community care. This may explain why carers in the intervention group were more satisfied with availability of the doctor, coordination of care, information and follow-up of the patients' tests and symptom assessment. There were only 40 carers in the study population so the results should be interpreted with caution. However, the response rate was high compared to similar studies and at least to some extent representative. The results were consistent with our hypothesis.

Conclusion

This study indicates that early integration of palliative care into cancer care, continuity of care and close collaboration and coordination between the levels of care contribute to improved satisfaction with care among carers after patients' death.