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Symptom evolution in the dying

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ABSTRACT

Objective Provide insight in the prevalence of symptoms in patients who are in the last days of life.

Methods A retrospective descriptive analysis of data on patients who died between 2012 and 2019 at the age of 18 or older in 1 of 20 Dutch healthcare facilities, including hospitals, inpatient hospices and long-term care facilities. We analysed data from 4 hourly registrations in the Care Programme for the Dying Person, to assess for how many patients symptom-related goals of care were not achieved. We looked at the first 4 hours episode after the start of the Care Programme and the last 4 hours episode prior to death.

Results We analysed records of 2786 patients. In the first 4 hours episode, at least one symptom-related care goal was not achieved for 28.5%–42.8% of patients, depending on the care setting. In the last 4 hours episode, these percentages were 17.5%–26.9%. Care goals concerning pain and restlessness were most often not achieved: percentages varied from 7.3% to 20.9% for pain and from 9.3% to 21.9% for restlessness.

Conclusions Symptom control at the end of life is not optimal in a substantial minority of patients. Systematic assessment and attention as well as further research on symptom management are of the essence.

INTRODUCTION

Many patients experience symptoms in the last phase of their life. Pain, dyspnoea, fatigue, restlessness and discomfort are among the most common symptoms.^{1–3} Little is known about how these symptoms evolve in the last days to hours of life.^{4–6}

Since 2001, the Care Programme for the Dying (CPD) is used in a number of healthcare organisations in the Netherlands. The CPD is started when the multidisciplinary care team expects the death of a patient to occur within hours to days and supports healthcare providers in systematically assessing goals of care in the physical, psychosocial and

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ At the end of life, people may experience symptoms like pain, dyspnoea, fatigue, restlessness and discomfort.

WHAT THIS STUDY ADDS

⇒ Symptoms are not controlled in a significant proportion of patients in the hours preceding death.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Systematic assessment and attention for symptoms in the last phase of life as well as further research on optimal symptom management are of the essence.

spiritual domains. The CPD consists of three parts: the first part includes items on the patient's background and goals of care at the start of the dying phase; in the second part, goals of care are evaluated by the healthcare provider every 4 hours until the patient dies and the third part includes goals of care after death, such as care for the relatives.⁷

The aim of this paper is to provide insight in the evolution of symptoms in patients who are in the last hours to days of life by analysing to what extent symptom-related goals of care are achieved, and to provide insight in differences in the occurrence of symptoms between different healthcare settings.

METHODS**Study design and data collection**

We performed a retrospective descriptive analysis of data from adult patients who died between 2012 and 2019. Data were provided by 20 Dutch healthcare facilities, including hospitals, long-term care facilities (LTC) and inpatient hospices. Participating hospital wards were internal medicine wards, oncology and haematology wards, pulmonology wards, neurology wards, geriatric wards and surgical wards. Records of all patients who were registered on the CPD were included after death. As these data were



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obtained after patients' death, consent was not required and obtained. The number of included patients varied from 20 to 800 per facility.

Symptom related goals of care

We analysed for how many patients symptom-related goals of care were not reported as having been achieved during the first 4 hours episode after the start of the CPD and during the last 4 hours episode prior to death. We looked at goals concerning pain, restlessness, respiratory tract secretions, nausea, vomiting and shortness of breath. Goals of care for these symptoms are formulated as follows:

Pain: the patient has no pain, as indicated by the patient, or, in case the patient is unconsciousness, by absence of pain during transfers or movements.

Restlessness: the patient is not restless, that is, there are no signs of confusion, picking behaviour or muscular contractions.

Respiratory tract secretions: the patient has no obstruction of breath by respiratory tract secretions, that is, there are no signs of shortness of breath, also not when there is death rattle.

Nausea: the patient has no nausea, as indicated by the patient.

Vomiting: the patient is not vomiting.

Shortness of breath: the patient is not short of breath, as indicated by the patient.

Statistical analysis

We compared how often symptom-related goals were reported as having been achieved in the first and last episode, overall and per symptom, in the different settings, and tested the statistical significance of differences using McNemar tests.

RESULTS

We analysed CPD records of 2786 patients. Table 1 shows the number of patients for whom goals of care were not reported as having been achieved in the first 4 hours episode after the start of the CPD and in the last 4 hours episode prior to patients' death, per setting. Sex and cause of death were known for a proportion of the patients (for 27.7 and for 40.5%, respectively): 48.6% were male and 51.4% were female, 58.0% died of cancer and 42.0% died of other underlying diseases.

In the first 4 hours episode, care goals were most often not achieved for patients dying in the hospital setting: at least one care goal was not achieved for 42.8% of hospitalised patients, 30.5% of LTC patients and 28.5% of hospice patients. The goal concerning pain was not achieved for 20.9% of hospitalised patients, 14.9% of LTC patients and 13.2% of hospice patients. For restlessness, these percentages were 21.9%, 14.7% and 17.2%, respectively. Care goals concerning shortness of breath and respiratory tract secretions were not achieved for 18.9% and 8.2% of hospitalised patients, respectively; not achieving these care goals was less common for LTC patients (5.3% and 4.7%, respectively) and hospice patients (5.4% and 4.9%, respectively). Goals concerning nausea and vomiting were rarely not achieved in the first 4 hours episode in all settings.

In the last 4 hours episode prior to death, the percentage of patients for whom care goals were not achieved was generally lower than in the first 4 hours episode. However, the percentage of patients for whom at least one care goal was not achieved was still 26.9% for the hospital setting, 24.9% for the LTC setting and 17.5% for the hospice setting. The decrease in the percentage of patients for whom care goals were not achieved between the first and the last 4 hours episode

Table 1 Goals of care that were not achieved during first 4 hours episode after the start of the CPD and the last 4 hours episode prior to death, per setting

Symptom	Hospital N=1252		LTC N=449		Hospice N=1086	
	First 4 hours episode after start CPD	Last 4 hours episode prior death	First 4 hours episode after start CPD	Last 4 hours episode prior death	First 4 hours episode after start CPD	Last 4 hours episode prior death
Patient has no pain	262 (20.9)	140 (11.2) p<0.001	67 (14.9)	42 (9.4) p<0.001	143 (13.2)	79 (7.3) p=0.005
Patient is not restless	274 (21.9)	179 (14.3) p<0.001	66 (14.7)	53 (11.8) p=0.198	187 (17.2)	101 (9.3) p<0.001
Patient has no obstruction of breath by respiratory tract secretions	103 (8.2)	97 (7.8) p=0.679	21 (4.7)	44 (9.8) p<0.001	53 (4.9)	56 (5.2) p=0.826
Patient has no nausea	49 (3.9)	14 (1.1) p<0.001	15 (3.3)	6 (1.3) p=0.049	14 (1.3)	5 (0.5) p=0.022
Patient is not vomiting	31 (2.5)	16 (1.3) p=0.014	8 (1.8)	4 (0.9) p=0.344	13 (1.2)	10 (0.9) p=0.629
Patient is not short of breath	236 (18.9)	134 (10.7) p<0.001	24 (5.3)	14 (3.1) p=0.064	59 (5.4)	26 (2.4) p<0.001
At least one of these goals was not achieved	536 (42.8)	337 (26.9) p<0.001	137 (30.5)	112 (24.9) p=0.040	310 (28.5)	190 (17.5) p<0.001

All p values are derived from McNemar test to assess the statistical significance of differences between the first and last 4 hours episode. Differences between settings were considered statistically significant with p≤0.005.
CPD, Care Programme for the Dying.

was largest for the hospital setting, especially for pain, restlessness and shortness of breath. The percentage of patients for whom care goals were not achieved in LTC and hospice settings also decreased in comparison to the first hour episode, but the differences were smaller than in the hospital setting. In those two settings, the percentage of patients with obstruction of breath by respiratory tract secretions increased, from 4.7% to 7.8% in the LTC setting, and from 4.9% to 5.2% in the hospice setting.

DISCUSSION

Control of pain and other symptoms is considered important for a 'good death'.⁸ Our study shows that at the start of the dying phase and in the last 4 hours prior death, for a substantial minority of patients at least one symptom could not be controlled. Symptom-related goals of care that were most frequently not achieved concerned pain, restlessness and for hospitalised patients also shortness of breath. In contrast to previous studies, not achieving goals concerning nausea and vomiting was rare in all settings in our study.^{9 10}

We found that symptom-related goals of care were more often not achieved in hospitals than in other settings. This finding could be the result of patient selection, as complex symptom management during the dying phase may have been a common reason for admitting patients to the hospital.¹¹ Percentages of patients with uncontrolled symptoms in the dying phase in our study were lower than what has been found in other studies. Reported percentages vary between 22.2% and 52.6% for pain; between 22.1% and 41.2% for dyspnoea and between 3.9% and 25% for nausea and vomiting.^{12–14}

It is unlikely that the lower percentages in our study are due to under-reporting in the medical file, because the CPD is aimed at preventing under-reporting of symptoms by facilitating structured observation and reporting. Use of the CPD to structure care in the dying phase may have resulted in better observation and as a consequence better treatment of symptoms, as has been suggested in a previous study.¹² However, pain and other symptoms still compromise the final hours of life of many dying patients, which may be due to suboptimal treatment or to the complex, often multifactorial origin of these symptoms. When terminally ill patients suffer severely from refractory symptoms, continuous deep sedation can be used, which is the lowering of the consciousness level of the patient by the use of sedatives. In the Netherlands, the use of continuous deep sedation has increased from 8% in 2005 up to 18% in 2015. Our finding that symptoms remain uncontrolled in the dying phase in a significant proportion of dying patients, may be part of the explanation of the frequent use of continuous deep sedation in the Netherlands.

Strengths and limitations

After a study of Ellershaw *et al*, this is one of the few studies that provides insight in symptoms in patients in the last hours of life over time.⁵ The use of clinical practice data of a high number of patients can be considered a strength of our study. We have limited insight in patients' characteristics, such as their underlying disease. Another limitation of our study is that we have no information about the severity of symptoms. Furthermore, we only report about patients for whom it was acknowledged that they were dying and for whom the CPD was used to monitor goals of care.

CONCLUSION

For a substantial minority of patients, one or more symptom-related goals of care in the dying phase were not achieved. Goals of care that were often not achieved concerned pain, restlessness and for hospitalised patients also shortness of breath. The results of this study show that symptom management in the dying phase requires ongoing attention in clinical practice and research.

Contributors All authors were involved in specifying the research question in advance. MH and AvdH analysed the data in the light of this research question. MH wrote the initial manuscript. All authors gave feedback and contributed to the final manuscript.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval All identifying information was removed from the database before it was analysed. Under the Dutch law, this research is exempt from ethics review by a medical research ethics committee.¹⁵

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