

Trends in end-of-life decisions among patients dying in a university hospital oncology ward after implantation of a palliative outpatient clinic

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ABSTRACT

Background: The need for high quality palliative care at end-of-life has been increasingly recognized while regional differences exist in its quality and availability. Basic palliative care is given by oncologists at any stage of the disease, but this does not cover the high need for specialized palliative care. The aim of this study was to assess the trends in end-of-life decisions among patients dying in a university hospital oncology ward before and after the implementation of a palliative outpatient clinic.

Material and Methods: The study population consists of all patients who died in the Kuopio University Hospital oncology ward between 1.1.2010–31.10.2011 and 1.1.2012–31.12.2018. The palliative outpatient clinic was established and set up in November - December 2011. Data on inpatient stays, cancer treatments, treatment decisions, and some background factors were retrieved from electronic records.

Results: The study population totaled 644 patients dying in the oncology ward at KUH (57.8% males; 42.2% females). The deaths comprise 17.2% (191/1108) of all cancer deaths in 2010–2011 and 11.1% (461/4049) in 2012–2018 in the KUH catchment area (North-Savo Health Care District). In years 2012–2018, 14.1% of patients treated at KUH oncology clinic visited the palliative outpatient clinic. The percentage of DNR (do-not-resuscitate), palliative care, and end-of-life (EOL) care decisions increased significantly in the later period. The decisions were mainly made during the last week of life. The proportion of patients receiving chemotherapy during the last two weeks of life remained stable.

Conclusion: The proportion of patients receiving DNR, palliative care and EOL care decisions increased after the implementation of the palliative outpatient clinic, but the decisions were still made rather late, mainly during the last days of life.

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Background


According to the World Health Organization (WHO), palliative care is a crucial part of integrated, people-centered health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility [1]. It is estimated that globally only 14% of patients who need palliative care receive it. Countries must strengthen palliative care services to achieve the goals set by the WHO. Utilization of hospital-based and in-home hospice, palliative care services and palliative consultant teams reduce the cost of care [2–4]. At the same time, they provide equal, if not better, quality of care [5]. The transition from active oncological treatment to palliative care at the right time can offer the patient better quality of life (QoL) and lower the burden in health care service systems [6]. Basic palliative care should be given by oncologists at any stage of the

disease. The integration of oncology and specialized palliative care brings many advantages; improves symptom control, reduces use of chemotherapy at the end of life, lessens depression and anxiety, improves quality of life etc. [7]. There is now a general agreement that palliative care must be recognized as a population health need and should be viewed as an integral part of universal health coverage [5].

Annually, approximately 30 000 patients in Finland need palliative care and the need is increasing [8]. The WHO gave recommendations for palliative care in 2002, which the European Commission enforced a year later [9]. The Finnish National Advisory Board on Social Welfare and Health Care Ethics published the recommendations for end-of-life care in 2003. Additionally, in 2017 the Ministry of Social Affairs and Health in Finland demanded the establishment of palliative care units in all university hospitals and in the largest central hospitals to ensure high quality palliative care and

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consultation facilities and to improve the development of palliative medicine. The quality and availability of palliative care in Finland is still known to vary across the country [8].

Integration with palliative care should be part of the early treatment in diseases with a poor prognosis, a relatively long survival and multiple treatments, and when there are only few treatment options [10]. A study from Germany [11] showed that almost half of deaths occurred in hospitals, but with palliative patients the number was significantly lower, 23.2%. Further analysis revealed that with a specialist home palliative care service only 13.3% of patients died in hospitals.

Studies show that there is an increasing trend for aggressive end-of-life (EOL) care [12,13]. Cancer care is considered overly aggressive when chemotherapy is administered within the last two weeks of life, and the proposed benchmark includes < 10% of patients having chemotherapy within that period [12,13]. Oncologists tend to continue chemotherapy longer if there is no high-quality palliative care service [13]. Anticancer agents in incurable diseases can improve QoL, relieve symptoms, help maintain function, and even prolong survival [14,15]. However, the survival benefit is often limited, and the treatments have many adverse effects. Chemotherapy given within the last weeks of life may even shorten life expectancy. Patients who receive palliative chemotherapy require more administrations at the hospital, have a lower chance of dying at home, and may have a shortened survival [16]. A minority of patients, who have a prognosis of less than a year, have discussed end-of-life care with their oncologist. Many discussions occur during acute hospital care and late in the course of illness [17].

Kuopio University Hospital (KUH) is one of the five university hospitals in Finland. The number of deaths in the oncology ward has been high compared to oncology wards in other university hospitals in Finland (unpublished data). A specialized palliative outpatient clinic at KUH was established in 2011, with the aim to improve palliative and end-of-life care in the region. Palliative outpatient clinic is part of the Department of Oncology and at the study period all the patients who were referred to the clinic were cancer patients.

This study was performed to evaluate the effects of the implementation of the palliative outpatient clinic on end-of-life care of cancer patients by assessing trends in end-of-life decisions among patients dying in the university hospital oncology ward.

Material and methods

This study was designed as a retrospective registry-based study.

Study setting and cohort selection

The Finnish health care system is tax-financed and provides cancer care for all residents with minimal cost to the patients. KUH is the main hospital in the Health Care District of North-Savo in Eastern Finland. KUH is responsible for

cancer care of some 247 000 residents in its catchment area. The KUH Oncology ward had a capacity of 38 beds until the years 2011–2012, when it was reduced to 18 beds. Most of the patients are referred to the ward from the Emergency Department, some from oncology or palliative outpatient clinics, and some come for scheduled treatment.

The population of this study consists of all patients who died in the KUH oncology ward during two time periods, before (1.1.2010–31.10.2011) and after (1.1.2012–31.12.2018) the establishment of the palliative outpatient clinic. The two months during which the clinic was established (1.11.2011–31.12.2011) were left out of the main data, but they were included in the analysis of total cancer deaths in the area ($n=8$). There were 644 patients included in the study, of which 183 died in the earlier study period and 461 in the latter study period. Most patients in the study period had a solid tumor, since at that time almost all lymphomas were treated at the Hematology unit.

There is no separate palliative ward in KUH, and thus many palliative cancer patients are admitted to the oncology ward when they need hospital in-patient care. Since 2011, there is one hospice run by the city of Kuopio, and the other municipal primary health care wards provide basic level palliative and end-of-life care.

Methods

All crucial patient data in KUH is electronic and includes ICD-10 codes, laboratory values, intravenously given medications, etc. that are systematically recorded. The information about inpatient visits, cancer treatments, treatment decisions, and background factors (including age and cancer diagnosis) were retrieved from electronic records. The researchers (authors AT, KTK) reviewed all medical records. If a patient had more than one cancer diagnosis, only the diagnosis the patient was being treated for was included in the final analysis. The patients were categorized based on the treatment decisions made before death: I) there were no treatment decisions made (anticancer agent ongoing or plans to start it), II) a decision for palliative treatment was made and III) an EOL care decision was made. A palliative decision means that either anticancer agents (e.g., chemotherapy) had been ended or the decision made not to plan to start it, and the focus was on symptom management. One exception was prostate cancer patients; their endocrine treatment LHRH analog could continue. Palliative radiotherapy (e.g., for pain relief) was allowed. The EOL care decision is not considered as an EOL quality indicator in the literature, but it is widely used in Finland to state the dying phase of the illness, usually defining the last few days or weeks of life. Customarily, during that time antibiotics aren't used, no blood tests are taken, no scans are made etc.; i.e., the focus is only to treat symptoms and relieve suffering. We also determined whether the DNR decision was made, and the ICD-10 code Z51.5 for palliative treatment was registered. The exact date was recorded.

The patients were also categorized based on what oncological treatment they had within 6 months before death.

Active oncological treatment was divided into chemotherapy (oral and intravenous) or other treatment, which included tyrosine kinase inhibitors (TKI), hormone therapy and antibody treatments. Check-point inhibitors were categorized as other treatment, since at the study period they were not widely used. The last day of radiotherapy within 6 months was also recorded.

Statistical analysis

All statistical analyses were performed with IBM SPSS 27 software. The Chi-square test was used to determine the difference between categorical variables, and the non-parametric Mann-Whitney U-test was used to investigate the differences between the continuous variables.

This retrospective registry-based study was permitted by the KUH administration authority. The North-Savo Health Care District Ethics Committee performed an ethical evaluation and approved the study.

Results

The key characteristics of the population are presented in Table 1.

The most common cancer types were lung, breast, colorectal, and pancreatic cancer. The proportion of lymphomas was only 1.7% (Supplementary table). The proportion of biopsy-based and pathologically verified diagnosis of cancer was 88.2%, while the rest of the patients had clinical diagnosis of cancer based e.g. on radiology findings. In about 15% the diagnosis was done within a month before death. A second malignancy had been diagnosed for 6.7% ($n = 43$) of the patients, most often colorectal and prostate cancer. Death occurred during active oncological treatment in 33.4% of the patients ($n = 215$).

In 2010–2011, of all cancer deaths in the North-Savo Health Care District, 17.2% (191/1108) took place in the KUH Oncology ward. This declined to 11.1% (461/4049) in 2012–2018 ($p < .001$).

After the implementation of the palliative outpatient clinic in, 14.1% of the patients treated at KUH in 2012–2018 had

an appointment at the unit, while the visit was planned for 22.8% of the patients. Most visited only one time, 10.2% having more than one appointment.

The percentage of patients who had a DNR, palliative care, or EOL care decision increased significantly between the time periods (Table 2). The DNR decision was made in the earlier years to only 15.3% of the patients, in the latter study period significantly more often in 81.8% ($p < .001$). Palliative care decision was made for one third of the patients in the earlier years and two thirds in the later years ($p = 0.005$). End-of-life decision was also made more often during the later years. The median inpatient days was also significantly lower in years 2012–2018 (16 vs 22 days, $p < .001$). The ICD-10 code Z51.5 for palliative care was used more often in the last year (Figures 1 and 2).

The majority (83.5%) of patients received some active oncological treatment after the cancer diagnosis. The percentage of patients who received chemotherapy at any time was 64.8%, radiotherapy 52.8%, and other cancer treatment, including endocrine treatment, antibody treatment, and TKIs, was 34.8%. In 2010–2011 chemotherapy was given to 7.1% of the patients within 14 days before death and in 2012–2018 for 10%, whereas radiation therapy was given to 9.3% in the earlier period and 14.1% in the latter period (Table 2).

The percentages of chemotherapy at EOL in different cancer types, as well as the median times from palliative and EOL decisions, are presented in Table 3.

Discussion

The proportion of patients dying in the oncology ward with DNR, palliative care, and EOL care decisions clearly increased after the implementation of the palliative outpatient clinic. However, the median time between the decisions and death remained similar. Most of the patients had only a single appointment. This implies that the need for palliative care was not recognized early enough. It may be speculated that this is based on treatment culture.

The palliative outpatient clinic was established in November – December 2011. At first, the clinic only

Table 1. Baseline characteristics of patients in 2010–2011 and 2012–2018 cohorts.

	Years 2010–2011 ($n = 183$)		Years 2012–2018 ($n = 461$)		p-value for difference
	n/median	%/range	n/median	%/range	
Gender					0.086
Female	87	47.5%	185	40.1%	
Male	96	52.5%	276	59.9%	
Age	63	23–96	65	19–94	
Cancer type					0.37
Breast cancer	32	17.5%	61	13.2%	
Lung cancer	38	20.8%	120	26.0%	
Colorectal cancer	17	9.3%	52	11.3%	
Pancreatic cancer	22	12.0%	45	9.8%	
Other cancer	74	40.4%	183	39.7%	
Time from diagnosis to death					0.13
<30 days	32	17.5%	73	15.8%	
30 days–1 year	61	33.3%	193	41.9%	
>1 year	90	49.2%	195	42.3%	
Palliative outpatient clinic visit planned	0	0%	105	22.8%	
Palliative outpatient clinic visits before death	0	0%	65	14.1%	

Table 2. Treatment decisions, inpatient days, and oncological treatments before death between the study periods.

	Years 2010–2011 (n = 183)		Years 2012–2018 (n = 461)		p Value for difference
	n/median	%/range	n/median	%/range	
DNAR decision made	28	15.3 %	377	81.8 %	<.001
Days from DNAR decision to death	6.5	0–515	6	0–1264	.9
Palliative care decision made before death	122	66.7 %	246	53.4 %	.002
Days from palliative care decision to death	7	0–382	8	0–1761	.8
End-of-life care decision made before death	100	54.6 %	307	66.6 %	.007
Days from end-of-life care decision to death	2	0–128	2	0–31	.07
Total inpatient care days in last 6 months	22	1–108	16	1–138	<.001
Chemotherapy in the last 6 months	89	48.6 %	249	54.0 %	.22
Last 30 days	30	16.4 %	94	20.4 %	.25
Last 14 days	13	7.1 %	46	10.0 %	.25
Radiation therapy in the last 6 months	59	32.2 %	163	35.4 %	.45
Last 30 days	26	14.2 %	88	19.1 %	.14
Last 14 days	17	9.3 %	65	14.1 %	.10
Other treatment in the last 6 months	16	8.7 %	57	12.4 %	.2
Last 30 days	19	10.4 %	61	13.2 %	.4
Last 14 days	17	9.3 %	40	8.7 %	.9

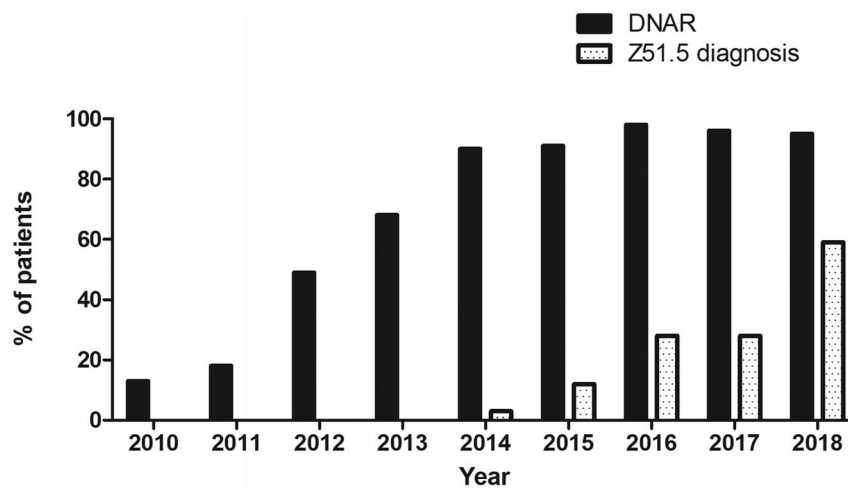


Figure 1. Percentage of DNR decisions and the use of ICD-10 code Z51.5 for palliative care by study year.

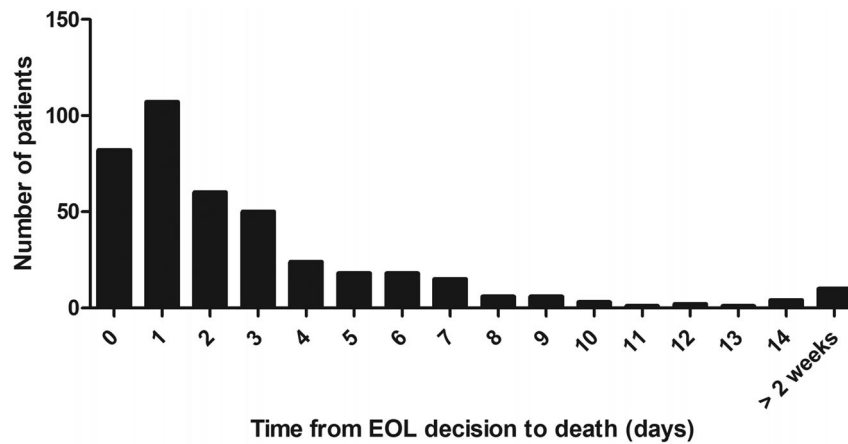


Figure 2. Time from the end-of-life care decision to death in days.

Table 3. Chemotherapy in the last 14 and 30 days before death and time from treatment decisions to death in different cancer types.

Cancer type	Chemotherapy last 14 days		Chemotherapy last 30 days		Time from palliative care decision to death (days)		Time from end-of-life care decision to death (days)	
	n	%	n	%	Median	Range	Median	Range
Breast cancer	8	8.6	23	24.7	5	0–228	1	0–10
Lung cancer	16	10.1	28	17.7	6	0–301	1.5	0–14
Colorectal cancer	6	8.7	16	23.2	15	0–278	2	0–20
Pancreatic cancer	10	14.9	19	28.4	12	0–175	2	0–31
Other cancer	19	7.4	38	14.8	8	0–1761	2	0–128

consisted of a part-time nurse and a part-time physician specialized in palliative medicine, but since November 2015 it has operated with a fulltime staff, with 2 nurses and 2 physicians with palliative specialty and one specializing physician. In-house consultations to wards in the hospital have also been provided since 2016. During the study period the palliative clinic mainly served patients with advanced cancer. Patients are referred to the clinic when the palliative care decision is already made, or some patients have so-called early palliative appointments during cancer treatments. The focus is on symptom management and advanced care planning. In the clinic there is also a possibility to meet a social worker or a hospital chaplain, to have psychological support, nutrition guidance, etc.

The activity of the palliative outpatient unit increased during the study period and has continued to increase since, with plans to include a palliative ward as part of the unit. The palliative unit has provided systematic education for the doctors and nurses in the area about palliative care, and about how to integrate palliative care in all cancer care. Moreover, in the nationwide level, the importance of palliative care has been increasingly recognized in Finland during the last decade. For example, since 2017 there has been a government led project to improve palliative care nationally [6] and 2018–2021 also a government led project to develop palliative nursing and medical education [18]. In recent studies, the percentages of DNR decisions have varied from 18 to 41% [19–22]. In a Finnish study on the emergency visits of cancer patients [23], the DNR was significantly more common for those who had visited the palliative outpatient clinic (88% vs 42%). Also, in our study the percentage of patients with DNR increased significantly between the periods.

In another study from Finland, the decision for palliative care was recorded in 82% of patients who had been treated in an oncology department. The decision was made at least a month before death for half of the patients. In our study the number of palliative and EOL care decisions increased significantly between the periods. When compared to different cancer types, there was a slight trend of colorectal and pancreatic cancer patients having a palliative decision made earlier. However, the decisions were mainly made during the last week of life, which did not change during the periods. Other studies [17] show that many EOL discussions occur during acute hospital care and late in the course of illness, which is in line with our data.

Although the number of Palliative outpatient clinic appointments was relatively low in the latter study period (14.1%), the number of DNR, palliative care and EOL care decisions increased. We assume that the trends to improve palliative care nationwide and the increased education is reflected in these results.

The use of ICD-10 code Z51.5 for palliative care is recommended by authorities in Finland [24]. Administrative data is increasingly used to report on healthcare practices. It provides data with low cost [25]. The use of Z51.5 data could potentially indicate all in-hospital palliative care, but currently substantially underreports. Palliative care specialist involvement and a diagnosis of cancer increases the odds for

the code to be assigned [26]. In this study, before 2013 there was no use of the code but by 2018 it was in routine use reflecting the nationwide improvement in palliative care, we assume.

The prevalence of anti-cancer treatments during the last month before death has varied from 12% to 52% in previous studies [13,14,16,27–32]. The likelihood of receiving chemotherapy during the last month of life had an increasing trend from 2000 to 2010 [30]. In our study, the proportion of active oncological treatments remained stable, although there was a slight trend of more active treatment in the latter period. In a recent Finnish study [33], 20% of patients received systemic, including both oral chemotherapy and biological agents, cancer treatment during the last month of life and 18% during the last two weeks before death. In a study by Rautakorpi et al. [34], 18% of patients received intravenous chemotherapy during the last month and 7% during the last two weeks of life. In our study the benchmark for less aggressive cancer care was met, since patients receiving chemotherapy during the 14 days prior to death was 10.0% in the years 2012–2018 and 7.1% in the years 2010–2011. In our study chemotherapy included both intravenous and oral regimens, while TKIs, hormone therapy, and antibody therapies were included in other treatments. Of those patients who did not receive chemotherapy, 9.3% and 8.7% (2010–2011 and 2012–2018, respectively) received some other treatment 14 days prior to death. Altogether, 16.4% and 18.7% had some anticancer agents, so the number of active medical treatment was somewhat higher during the last days. Previous studies do not usually contain all anti-cancer agents, so the comparison to our results is difficult.

In the study by Hirvonen et al. [33], 14% of the patients who died of cancer in 2014 received radiotherapy during the last two weeks. In our study, the proportions were 9.3% in 2010–2011 and 14.1% in 2012–2018, which are quite similar. In a study by Rautakorpi et al. [35], nearly half of the radiotherapy treatments during the last two weeks of life were discontinued due to the patient's worsened general condition. In addition, patients receiving radiotherapy during the last weeks of life were more likely to die in a tertiary care unit. Only 30% of radiotherapy within the last two weeks of life was given to alleviate pain. After irradiation of painful bone metastases, the time to pain relief is typically a few weeks [36,37]. It has been suggested that radiotherapy administered during the last 14 to 30 days of life might be a useful quality indicator because there often isn't enough time to reach a response [38]. On the other hand, a single fraction to, for example, a painful bone lesion, seldom wears out the patient and may provide sufficient pain relief.

Limitations and strengths

There are some limitations to the study. Our data may have selection bias because all the patients died at a university hospital oncology ward, and we excluded patients who died elsewhere. Hence, the patients may have had more intense symptoms that demanded in-patient care in a specialist care clinic. This may have especially been the case during the

later years with an existing palliative outpatient unit. In the earlier years the bed capacity of the ward was higher (38 beds in the years 2011–2012 and after that reduced to 18 beds), which could have affected the number of patients dying at the ward, especially when the palliative care in primary care wards was not yet properly organized. Also, the establishment of a hospice in the city of Kuopio may have affected the numbers. Overall, palliative care is more and more recognized as an integral part of the treatment of cancer patients, and our results are likely to reflect this trend. The strengths of this real-life study are its relatively large size and that it provides unique information about the trends in palliative care of cancer patients.

Conclusion

The proportion of patients receiving DNR, palliative care, and EOL care decisions increased after the implementation of the palliative outpatient clinic, but the decisions were still made rather late, during the last days of life.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

The data that support the findings of this study are available from the corresponding author (A-MT) upon reasonable request.

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