


Late decisions about treatment limitation in patients with cancer: empirical analysis of end-of-life practices in a haematology and oncology unit at a German university hospital



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ABSTRACT

Background Decisions to limit treatment (DLTs) are important to protect patients from overtreatment but constitute one of the most ethically challenging situations in oncology practice. In the Ethics Policy for Advance Care Planning and Limiting Treatment study (EPAL), we examined how often DLT preceded a patient's death and how early they were determined before (T1) and after (T2) the implementation of an intrainstitutional ethics policy on DLT.

Methods This prospective quantitative study recruited 1 134 patients with haematological/oncological neoplasia in a period of 2×6 months at the University Hospital of Munich, Germany. Information on admissions, discharges, diagnosis, age, DLT, date and place of death, and time span between the initial determination of a DLT and the death of a patient was recorded using a standardised form.

Results Overall, for 21% (n=236) of the 1 134 patients, a DLT was made. After implementation of the policy, the proportion decreased (26% T1/16% T2). However, the decisions were more comprehensive, including more often the combination of 'Do not resuscitate' and 'no intense care unit' (44% T1/64% T2). The median time between the determination of a DLT and the patient's death was similarly short with 6 days at a regular ward (each T1/T2) and 10.5/9 (T1/T2) days at a palliative care unit. For patients with solid tumours, the DLTs were made earlier at both regular and palliative care units than for the deceased with haematological neoplasia.

Conclusion Our results show that an ethics policy on DLT could sensitise for treatment limitations in terms of frequency and extension but had no significant impact on timing of DLT. Since patients with haematological malignancies tend to undergo intensive therapy more often during their last days than patients with solid tumours, special attention needs to be paid to this group. To support timely discussions, we recommend the concept of advance care planning.

BACKGROUND

Towards the end of a disease trajectory of patients with cancer, it is often necessary to weigh up the value of further tumour-specific therapy, as well as the use of life-prolonging

Key questions

What is already known about this subject?

► Towards the end of a cancer disease trajectory, oncologists and their patients often have to decide when to shift therapy from tumour-specific to standard palliative care. Decisions to limit treatment (DLTs) are important in order to protect the patient from burdensome treatment at the end of life (EOL) but constitute one of the most ethically challenging situations for oncologists. While the practice of DLT with respect to frequency and timing has been researched in the USA and some European countries, robust data for Germany are still lacking.

What does this study add?

► We recruited 1134 patients with haematological/oncological neoplasia in a prospective study and examined how often DLT preceded a patient's death, how early they were determined, and if there were any differences between patients with solid tumours and those with haematological neoplasia before and after the implementation of an intrainstitutional ethics policy on DLT. We found that the ethics policy could sensitise for treatment limitations in terms of frequency (decreased) and extension (broadened), but had no significant impact on the timing (few days before death). Remarkably, patients with haematological malignancies tend to undergo intensive therapy more often during their last days than patients with solid tumours. Since this could be associated with a poorer quality of EOL care, special attention needs to be paid to this patient group.

treatments such as cardiopulmonary resuscitation (CPU) and transfer to the intensive care unit (ICU). Addressing end-of-life (EOL) issues early has been shown to secure many beneficial effects: avoiding overtreatment and unnecessary side effects near death, allowing for better coping and preparation of patients and family for EOL decisions

Key questions**How might this impact on clinical practice?**

► Based on the results, an organisational change in clinical practice is required to support timely discussions on DLT. Hence, we recommend promoting the concept of advance care planning (ACP), which goes well beyond DLT as a structured communication process of enabling individuals to define goals and preferences for future medical treatment, to discuss these goals and preferences with the family and healthcare providers, as well as record and review them if appropriate. Our results can be seen as a contribution to the development of cross-sectoral and cross-institutional guidelines for improving DLT and fostering ACP.

and better allowing for eliciting and respecting patient preferences.¹⁻⁴ However, physicians, caregivers, patients and family perceive decisions to limit treatment (DLT) as demanding as they require confrontation with prognosis and decreasing chances for gaining lifetime as well as a consideration which measures benefit the patient regarding the remaining time.⁵⁻⁷ Systematic literature reviews recommend starting EOL conversations and eliciting patients' treatment preferences early on,^{8,9} and efforts have been made to improve EOL decision-making in patients with cancer like the European Society for Medical Oncology Clinical Practice Guidelines on palliative care advance care planning (ACP)¹⁰ or the updated Clinical Practice Guideline of the American Society of Clinical Oncology (ASCO) on early integration of palliative care into standard oncology care.¹¹

Hence, data on the clinical practice of DLT show that patients with cancer frequently undergo tumour-specific treatment in the very last phase of life, which is associated with more aggressive EOL care: studies report on up to 24% of patients undergoing chemotherapy in the last month of life.^{12,13} Such treatment can prolong survival, but it can also cause side effects, prevent patients from making meaningful life assessments and preparing for death, and prevent entry into hospices.¹⁴ Studies also indicate that oncologists avoid communicating treatment limitations¹⁵ and do not involve patients in such decisions in more than 50% of cases.¹⁶

While the practice of DLT has been researched in the USA^{17,18} and many European countries,^{19,20} robust data for Germany are lacking. Apart from studies without a special focus on oncology,²¹⁻²³ to our knowledge, there is only one German cancer-related empirical investigation that has collected documented information on EOL care in a retrospective cross-sectional study for 532 cases²⁴ and which found that intensive treatments are still reality for many patients with cancer, especially for haematological malignancies.

The aim of this paper was to present comprehensive data from a prospective longitudinal observation on frequencies and timing of DLT in patients with cancer collected in the Ethics Policy for Advance Care Planning and Limiting Treatment (EPAL) project before and after

the implementation of an intrainstitutional ethics policy on treatment limitation. By providing insight regarding the current state of practice in a German university hospital at two different points in time, long-term challenges in EOL decision-making can be identified. The empirical analysis presented in this paper focuses on the following questions:

- How many patients die in a haematology and oncology inpatient unit with a documented DLT?
- How long before the patient's death are decisions against CPR, transferal to ICU and tumour-specific treatment made by the respective physicians?
- How many patients are referred to a palliative care setting (either hospice or palliative care unit)?
- What are the differences between patients with solid tumours and those with haematological neoplasia with regard to treatment limitations?

METHODS**Study design**

This observational study with longitudinal design is based on hospital data for all inpatient admissions with advanced haematological/oncological neoplasia at the Medical Clinic and Polyclinic III of Munich University Hospital, Germany, during two periods: baseline measurement period 1 (T1) lasted 6 months and was followed by another 6-month measurement period 2 (T2) after the implementation of an ethics policy on treatment limitation to collect and compare data before and after the intervention (predesign–postdesign). This is an intrainstitutional ethics guideline which contains a framework for early and repeated discussions about treatment limitation and 20 corresponding recommendations for action.²⁵ At both measurement periods, we recorded information on admissions, discharges, diagnosis, age, DLT, date and place of death and time span between the initial determination of a DLT and the death of a patient using a standardised form. Patient characteristics and outcomes of treatment were prospectively registered. We retrospectively reviewed the medical records for information on limitations in treatment. The study is part of the EPAL project. A detailed description of the entire project, including the development of the ethics policy, can be found in the study protocol.²⁶

Data source

Anonymised patient data from the hospital information system were analysed using a self-developed documentation form. It was deductively developed in a multistage process: scoping literature review and analysis of existing documentation forms regarding treatment limitation, discussions with experts (haematology/oncology ICU, psycho-oncology, palliative medicine, legal medicine and medical ethics), pretests for comprehensibility and feasibility in an inpatient setting.

Study population

The study population consists of all inpatient admissions with advanced cancer (full census) at the Medical Clinic

and Polyclinic III of Munich University Hospital, Hospital of Ludwig Maximilian University, Germany, at the defined measurement periods T1 and T2 (n=1134). Patients with cancer were divided into two subgroups for a differentiated consideration with regard to the practice of DLT: (1) patients with a solid tumour and (2) patients with haematological neoplasia.

Statistical analyses

Frequencies of patient characteristics, DLTs and deaths are presented in absolute and percentage figures. Timing of DLT is presented in median days before death. Calculations were carried out for the complete group of all patients with cancer, for patients with DLT and for those who died. Differences between the subgroups of solid tumours versus haematological neoplasia and patients with DLT at T1 versus T2 were tested with the t-test at a significance level of $p < 0.05$. Statistical analysis was carried out with IBM SPSS Statistics V.25.

RESULTS

Sample

A total of 1134 patients have been included in the study, in each case 567 at T1 and T2. Fifty-four per cent of the respondents were male. Of all patients, 622 (54.9%) had a solid tumour (54.7% at T1, 55.0% at T2) and 512 (45.1%) had haematological neoplasia (45.3% at T1, 45.0% at T2). The most frequent solid tumours were sarcoma (27.5%), pancreatic carcinomas (8.8%) and breast cancer (8.2%). The most frequent haematological neoplasia was acute myeloid leukaemia (18.8%), multiple myeloma (16.4%) and diffuse large cell B-cell lymphomas (16.4%) (see table 1).

For 236/1134 (20.8%) patients, a DLT was made (25.9% at T1, 15.7% at T2). One hundred seventy-two (72.9%) of these patients with DLT had a solid tumour (72.8% at T1, 73.0% at T2) and 64 (27.1%) had haematological neoplasia (27.2% at T1, 27.0% at T2). Of the 1134 patients, 167 (14.7%) died during the measurement periods. One hundred twenty patients (71.9%) died

Table 1 Patient characteristics

	All patients (n=1134)		Patients with DLT (n=236)		Deceased patients (n=167)	
	T1 (567)	T2 (567)	T1 (147)	T2 (89)	T1 (76)	T2 (91)
Age (years)						
<35	7.9% (45)	9.5% (54)	1.4% (2)	1.1% (1)	2.6% (2)	3.3% (3)
35–49	13.1% (74)	12.3% (70)	7.5% (11)	6.7% (6)	7.9% (6)	6.6% (6)
50–64	28.9% (164)	29.1% (165)	24.5% (36)	20.2 (18)	26.3% (20)	23.1% (21)
65–80	43.0% (244)	43.7% (248)	53.1% (78)	62.9% (56)	51.3% (39)	58.2% (53)
>80	7.1% (40)	5.3% (30)	13.6% (20)	9.0% (8)	11.8% (9)	8.8% (8)
Cancer						
Solid tumour	54.7% (310)	55.0% (312)	72.8% (107)	73.0% (65)	73.7% (56)	70.3% (64)
Sarcoma	25.8% (80)	29.2% (91)	10.3% (11)	10.8% (7)	16.1% (9)	12.5% (8)
Pancreatic Ca	9.4% (29)	8.3% (26)	10.3% (11)	12.3% (8)	7.1% (4)	9.4% (6)
Colorectal Ca	3.2% (10)	4.2% (13)	2.8% (3)	4.6% (3)	1.8% (1)	3.1% (2)
Bronchial Ca	1.9% (6)	7.7% (24)	2.8% (3)	4.6% (3)	1.8% (1)	3.1% (2)
Breast cancer	7.4% (23)	9.0% (28)	9.3% (10)	9.2% (6)	8.9% (5)	9.4% (6)
Prostate Ca	2.9% (9)	5.1% (16)	4.7% (5)	9.2% (6)	8.9% (5)	9.4% (6)
Oesophagus Ca	2.3% (7)	1.9% (6)	3.7% (4)	4.6% (3)	3.6% (2)	4.7% (3)
Other	47.1% (146)	34.6% (108)	56.1% (60)	44.6% (29)	51.8% (29)	48.4% (31)
Haematological neoplasia	45.3% (257)	45.0% (255)	27.2% (40)	27.0% (24)	26.3% (20)	29.7% (27)
Multiple myeloma	16.7% (43)	16.1% (41)	20.0% (8)	8.3% (2)	5.0% (1)	7.4% (2)
Acute myeloid leukaemia	17.1% (44)	20.4% (52)	20.0% (8)	29.2% (7)	40.0% (8)	37.0% (10)
Acute lymphoblastic leukaemia	6.2% (16)	5.9% (15)	5.0% (2)	12.5% (3)	10.0% (2)	11.1% (3)
Diffuse large B-cell lymphoma	14.4% (37)	18.4% (47)	17.5% (7)	20.8% (5)	15.0% (3)	14.8% (4)
Chronic lymphocytic leukaemia	7.0% (18)	3.5% (9)	7.5% (3)	4.2% (1)	5.0% (1)	3.7% (1)
Mantle cell lymphoma	6.2% (16)	5.5% (14)	7.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Hodgkin's lymphoma	6.6% (17)	3.9% (10)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Other	25.7% (66)	26.3% (67)	22.5% (9)	25.0% (6)	25.0% (5)	25.9% (7)

Ca, carcinoma; CRC, colorectal carcinoma; DLT, decision to limit treatment.

Table 2 Frequency of DLT

	All patients (n=1134)	Deceased patients (n=167)	Deceased at regular ward (n=52)	Deceased at palliative care unit (n=39)	Deceased at hospice (n=12)	Deceased at ICU (n=13)
Termination of DLT	20.8% (236)	79.0% (132)	90.4% (47)	82.1% (32)	91.7% (11)	23.1% (3)

DLT, decision to limit treatment; ICU, intensive care unit.

with a solid tumour (73.7% at T1, 70.3% at T2) and 47 (28.1%) died with haematological neoplasia (26.3% at T1, 29.7% at T2).

The sample composition does not differ significantly between the two measurement periods with regard to the considered characteristics in age and cancer type.

Frequency and content of DLT

While overall for a total of 236/1134 (20.8%) patients a DLT was made, the percentage of deceased patients with DLT is substantially higher: 132/167 (79.0%) (see [table 2](#)). For even 47/52 (90.4%) patients who died at a regular ward, a DLT was made. For 82.1% of the patients who died at a palliative care unit and for 91.7% of those who died in hospice, a DLT was made. At ICU, the percentage of patients who died under DLT was 23.1%. The intensity of therapy of the deceased without DLT was not documented.

DLTs were more frequent during measurement period T1 (147/567, 25.9%) than T2 (89/567, 15.7%) and for patients with solid tumours (172/236, 72.9%) compared with those suffering from haematological neoplasia (64/236, 27.1%) (see [table 1](#)).

For all patients with DLT, the decision against resuscitation ('Do not resuscitate' (DNR)) and ICU ('no transferal to ICU') was the most frequent DLT (133/236, 56.4%) followed by decisions against resuscitation retaining the option ICU ('DNR') 95/236 (40.3%) (see [table 3](#)). Comparing patients with solid tumours and haematological neoplasia, the distribution is nearly the same (57.0% vs 56.3% no resuscitation/ICU, 39.5% vs 40.6% no resuscitation). Differences appeared with regard to the two measurement periods: much more patients during T2 had the combined DLT 'DNR/no transferal to ICU' than during T1 (43.7% vs 64.0%).

Timing of DLT

Median time of primal determination of a DLT for the patients who died at a regular ward was 6 days before death. For those who died at palliative care unit the median

time of DLT before death was 10 days (see [table 4](#)). These differences are significant ($p=0.003$). For patients with solid tumours the DLT were made earlier at both regular (7 vs 4 days) and palliative care unit (10 vs 8 days) than for the deceased with haematological neoplasia (differences are not significant). There were no differences between the two measurement periods with regard to DLT at a regular ward. Considering DLT at the palliative care unit, the decisions were made slightly earlier at T1 (10.5 vs 9.0 days before death; differences are not significant).

Place of death

Of the 167 deceased patients, 108 (64.1%) died in clinical wards (53 in a normal ward, 13 in the ICU, 3 on a transplantation unit, 39 in a palliative care unit); 47 (28.1%) patients died at home after discharge; and 12 (7.2%) died in a hospice (see [table 5](#)). More patients with haematological neoplasia died in clinical wards (83.0%) than patients with a solid tumour (57.5%), especially with regard to death in the ICU (17.0% vs 4.2%). Of the patients with solid tumours, 65.8% and only 40.4% of those with haematological neoplasia died in a palliative setting (palliative care unit, at home mostly with outpatient palliative care and hospice). Comparing the two measurement periods, we found that more patients died in a palliative setting during T2 (61.6%) than during T1 (55.3%).

DISCUSSION

Considering the lack of robust data on medical decision practice near death in patients with advanced cancer in Germany and the importance of such empirical information for the scientific and social discussion on EOL decisions, we conducted a documentation study about DLTs. This is the first prospective study capturing longitudinal data on frequencies and timing of DLT in patients with cancer at a German university hospital.

Our main results show that DLT

- ▶ Precede the death of most terminally ill patients with cancer.

Table 3 Content of DLT at primal determination

	Patients with DLT (n=236)	Patients with solid tumour and DLT (n=172)	Patients with haematological neoplasia and DLT (n=64)	Patients with DLT T1 (n=174)	Patients with DLT T2 (n=9)
DNR/no transferal to ICU	56.4% (133)	57.0% (98)	56.3% (36)	43.7% (76)	64.0% (57)
DNR	40.3% (95)	39.5% (68)	40.6% (26)	39.1% (68)	30.3% (27)
Other	3.4% (8)	3.5% (6)	3.1% (2)	1.7% (3)	5.6% (5)

DLT, decision to limit treatment; DNR, do-not-resuscitate; ICU, intensive care unit.

Table 4 Timing of DLT (median days before death)

	Deceased under DLT (n=132)	Deceased under DLT with solid tumour (n=90)	Deceased under DLT with haematological neoplasia (n=42)	Deceased under DLT T1 (n=62)	Deceased under DLT T2 (n=70)
Regular ward	6	7	4	6	6
Palliative care unit	10	10	8	10.5	9

DLT, decision to limit treatment.

- ▶ Are made only a few days before many patients' deaths.
- ▶ Are determined for patients with solid tumours earlier and more frequently than for those with haematological neoplasia.
- ▶ Are made rarer but more comprehensive after the sensitisation through an ethics policy.

Frequency of DLT

Overall, for 236 of the 1134 included patients with cancer (21%), a DLT was determined and 132/167 (79%) died under DLT. This finding indicates that treatment limitations at the EOL are frequently made in oncology and are part of everyday practice in a German university hospital. The proportion of patients who died under DLT in our study is comparable to data reported by the the Ethicus ICU Study (73%), a large multicentre observation of EOL practices in ICUs in several European countries.²⁷ Compared with non-ICU studies conducted in Europe,^{19,20} limitations of life-prolonging treatment (23%–51%) were practised more frequently in our sample. Two other German investigations found rates between 65%²⁸ and 69%²¹ of treatment limitation prior to death. However, none of the other studies focused on patients with cancer. As many cancer deaths are non-sudden, this is an explanation for the relatively high rate of DLT. Another reason may be an increased awareness due to changes in the German legislation on advance directives (enacted in 2009) and a law on assisted suicide (enacted in 2015).

Timing of DLT

The median time of the first determination of a DLT was 6 days before death at the regular wards and 10 days at the palliative care unit. A possible reason for the significant time difference is that the admission to the palliative care

unit presupposes that certain DLTs have already been made and therefore have been addressed earlier. DLTs often take place late in the disease process.²⁹ In the literature, DNR orders were placed on a median of 2–3 days before the patient's death^{28,30,31} and are thus made even later than in our study. Information on whether the decision was communicated to the patient was not collected in our investigation, but we know from a preceding study that less than half of the patients were involved in DLT.¹⁵ Prognostic uncertainty, lack of communication skills, fear of consternating the patient and/or his family, lack of time and fear of taking away the patient's hope are reported by physicians as factors for the delay of decision-making.^{15,32} Hence, delayed decision-making is one reason for over-treatment, even though a therapy that is not indicated may neither be offered nor administered. Another reason is disagreement among physicians and between doctors and patients on the likelihood of futile treatments.³³ Late DLT could, for example, be the result of complying with the patients' wish to extend lifetime whatever it takes.

Differences between oncological and haematological patients

Our study shows that DLT at normal wards took place earlier in patients with oncological illnesses than with haematological diseases, although these differences did not turn out to be significant. Additionally, oncological patients were more likely to be transferred to palliative treatment settings than haematological patients. A possible explanation for this could be the assessment of haematological treatment as being potentially curative and that haematological patients need an intensive treatment even if the chances of survival are dismal. In contrast to patients with metastatic tumour diseases, haematological patients often have a chance for a curative success,

Table 5 Place of death

	All deceased (n=167)	Deceased with solid tumour (n=120)	Deceased with haematological neoplasia (n=47)	Deceased T1 (n=76)	Deceased T2 (n=91)
Normal ward	31.7% (53)	30.0% (36)	36.2% (17)	36.8% (28)	27.4% (25)
ICU	7.8% (13)	4.2% (5)	17.0% (8)	5.3% (4)	9.9% (9)
Transplantation unit	1.8% (3)	0.0% (0)	6.4% (3)	2.6% (2)	1.1% (1)
Palliative care unit	23.4% (39)	23.3% (28)	23.4% (11)	26.3% (20)	20.9% (19)
At home	28.1% (47)	34.2% (41)	14.9% (7)	21.1% (16)	34.1% (31)
Hospice	7.2% (12)	8.3% (10)	2.1% (1)	7.9% (6)	6.6% (6)

ICU, intensive care unit.



even if the probability may be low. Another reason for haematological patients being less frequently transferred to domestic care or hospices may be that they are more likely to need acute inpatient care due to higher treatment risk and their need for blood substitution. Our results are consistent with another German study which found that, in comparison to patients with solid tumours, patients with haematological malignancies underwent intensive therapy during their last days more frequently and were more likely to die in an intensive care setting like the ICU or transplantation ward.²⁴ Since further studies from various countries demonstrate that haematological patients tend to receive poorer quality of EOL care,^{34 35} this patient group needs to be given special attention.

Differences between measurement periods

Between the two measurement periods, an ethics policy to structure the decision-making process on treatment limitations was implemented in the Department of Medicine III, LMU University Hospital.²⁶ The frequency of DLT has decreased from measurement period 1 to 2 (26%–16%). Moreover, much more patients received the combined DLT DNR/no transferal to ICU than a single order (44% vs 64%) after the implementation of the ethics policy. In terms of timing of DLT, there were no great differences between the two measurement periods. Regarding the place of death, more patients died in a palliative setting after implementation of the policy (62%) than before (55%). Especially the proportion of patients who were discharged and died at home increased (21% vs 34%), which is a positive development, considering that home environment is the preferred place of care and death for many patients.^{36–38} We assume that the differences between T1 and T2 can at least partially be attributed to the ethics policy. It sensitised for these crucial decisions, which seem to be made more comprehensively and led to transferal to appropriate care settings for patients near the EOL more frequently. A possible reason for the reduction in frequency of DLT could be the policy's demand for patient involvement. Maybe the discussions about treatment limitations (in team and with the patient) are starting earlier, but the decisions themselves are actually made as late as before the policy. Another factor hindering early decisions could be the general length of hospital stay. As the median residence time in German hospitals is under 10 days, it is nearly impossible to undercut the time measured in our study without starting discussions on treatment limitations already in outpatient care. Earlier investigations have revealed that institutional EOL policies have only a limited impact on the documented provision of care.³⁹ However, an Australian study demonstrated that significant progress in the timing of the EOL decision is possible in patients with advanced cancer.⁴⁰

Ethical considerations

In most cases, patients' preferences for or against intensive therapy are the results of a more or less realistic evaluation of their situation. However, a realistic evaluation

will only be possible if the patient is sufficiently and early informed about his or her prognosis, considering the best-case as well as worst-case scenario. In a preceding qualitative study, oncologists reported patients with unrealistic expectations to be a challenge for EOL communication that is especially prominent in comprehensive cancer centres.⁴¹ In another study, the majority of interviewed professionals stated that discussions about foregoing cancer-specific therapy occur too late in the trajectory of disease and should be initiated much earlier.⁴² However, in their daily practice, oncologists often wait until the patient himself/herself starts the discussion about foregoing cancer-specific treatment or until all tumour-specific therapeutic options are exhausted, because they are uncertain about the right timing for EOL discussions and because of the complex balancing of medical evidence against their own subjective, emotional involvement and the patient's wishes.⁴¹

Therefore, apart from sensitising and training physicians for timely discussions and treatment decisions at the EOL (eg, by policies), patients should also be supported in considering and communicating their preferences and values toward the EOL early in the course of their incurable disease. A concept that promotes patients having timely conversations with their physicians about their preferences for future medical treatment is ACP.⁴³

Advance care planning

The concept of ACP is broader and goes well beyond the single decision to terminate life-prolonging treatment. ACP is defined as the process that 'enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate'.⁴³ In this context, ACP is a decidedly procedural event. Arriving at DLT presupposes continuous timely communication among all parties concerned and hence is a result of a good ACP process. Studies document that patients want their doctor to open the conversation about their advance care plans and to have them at an early stage.⁴⁴ In addition, ACP has a number of positive effects: patients were referred earlier to hospices and underwent less aggressive treatment near death, and had less anxiety and depression and even a gain in lifetime.^{1–3 45} In the end, palliative care can lower total healthcare cost in certain care settings.^{46 47} Yet, despite evidence and the fact that most physicians think that patients ideally should have a realistic understanding of their prognosis,⁴⁸ the majority avoids prognosticating in the last phase of life, and communication of treatment limitation does not happen in many cases.¹⁶ A helpful model for facilitation of serious illness conversations is, for example, the recently published medical situation, values and plan model.⁴⁹ After clinical studies have shown that for some oncological patient groups early palliative care improves quality and quantity of life,² ASCO updated the guideline on the integration of palliative care into standard oncology care as the most effective way to care

for patients with advanced cancer.¹¹ The term early integration is widely used and normally seen as months to years before death without a clear time frame. In Germany, the German Palliative Care Guideline defines quality criteria for EOL care in terminally ill patients with cancer and suggests involving palliative care at the diagnoses of the incurability of an oncological disease.⁵⁰ Furthermore, it requests the offer of ACP conversations but does not specify when these discussions should take place. From our point of view, more concrete guidance on when to initiate EOL communication is necessary to improve the quality of decision-making for patients with advanced cancer. Concerning the optimal timing of EOL decision-making with patients with cancer, we developed a structured framework including time and trigger points for these discussions in patient care⁴² and would additionally very much welcome the initiation of such ACP conversations in the outpatient care setting.

Limitations

The data of this study were derived from chart review, and therefore were reliant on the quality and completeness of notes. An investigation using only medical records may not fully reflect clinical practice. As the study is based on anonymised patient data, there was no information available on factors that might have influenced the DLT like patients' treatment preferences or physicians' reasons for DLT. Another limitation concerns the prestudy–poststudy design: as such studies assume that any difference in measurement in 'prestudy' compared with 'poststudy' is due to the intervention, they do not account for other elements that are also changing at the same time as the intervention is taking place. Therefore, it is not certain whether the policy itself impacted the observed EOL practices.

CONCLUSION

This prospective study collected longitudinal data on frequency and timing of DLT in patients with cancer at a German university hospital to evaluate the impact of an intrainstitutional ethics policy on treatment limitations. Although there was no effect with regard to timing of DLT, the presented results indicate that the policy could sensitise for these crucial decisions, which decreased in frequency, became more comprehensive and led to transferal to appropriate care settings for patients near the EOL more often. Our findings confirm that oncologists and haematologists are frequently confronted with decisions about treatment limitation and associated clinical and ethical challenges. The DLT process differs between haematological and oncological patients, and the decisions themselves are made still quite late. Early integration of palliative care in the course of treatment thus hardly takes place. We suggest that discussions about future medical treatment like the provision of anticancer treatment and involvement of palliative care near death should be already initiated in the outpatient setting.

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