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# Benefits of Structured Advance Care Plan in end-of-Life Care Planning among Older Oncology Patients: A Retrospective Pilot Study

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## Abstract

**Objectives:** Studies suggest that advance care planning (ACP) results in improved quality of life and reduced healthcare consumption. We assessed how the use of a structured advance care planning tool (ACPT) in oncology patients relates to their healthcare consumption before death, and to the match between preferred and actual place of death. **Methods:** We performed a pilot study at a teaching hospital in the Netherlands. Endpoints were 1) healthcare consumption at three and one month(s) before death, and 2) the match between preferred and actual place of death. **Results:** The study included 75 patients without an ACPT (group 1) and 59 patients with an ACPT (group 2) of whom the preferred place of care or death were documented at least three months before death in 15 patients (subgroup 2b). Compared to group 1, patients in group 2 had significantly more healthcare consumption. However, compared to group 1, patients in subgroup 2b underwent significantly less diagnostic (33.3% (n = 5) versus 69.3% (n = 52),  $p < 0.05$ ) and laboratory tests (33.3% (n = 5) versus 62.7% (n = 47),  $p < 0.05$ ) one month before death. Patients in subgroup 2b died at their preferred place more often (76.9%, n = 10) compared to patients in group 1 (58.3%, n = 7) (NS), which meant more deaths at home and less in-hospital-deaths. **Conclusions:** The results suggest that timely documentation of the preferred place of care or death in a structured ACPT may result in less healthcare consumption and a better match between the preferred and actual place of death.

## Keywords

advance care planning, palliative care, end-of-life care, oncology, place of death, healthcare consumption

## Introduction

Advance care planning (ACP) aims to respect individual patient autonomy, improve quality of care, strengthen care relationships, prepare for end-of-life care and reduce overtreatment.<sup>1</sup> In addition, several studies showed that ACP may result in improved perceived quality of life<sup>2-5</sup> and reduced healthcare consumption among patients with chronic progressive diseases.<sup>2,4,6-9</sup> Although ACP can be initiated in any phase of life, it becomes more relevant with deteriorating health or with ageing in general.<sup>10,11</sup> To apply effective ACP, it is important to document the outcomes of ACP conversations into the electronic patient record (EPR) in a structured way,<sup>9,10</sup> at a specific and visible location. This may improve the quality of care and access to information<sup>12</sup> and facilitate regular review of documented preferences.<sup>10</sup> However, in current practice, preferences and needs of (older) patients are often not documented in care plans.<sup>11,13-16</sup>

Ideally, both the patient and the healthcare provider should be familiar with the process of ACP before it starts. Moreover, the initiation of ACP conversations requires patients' readiness to have these conversations,<sup>17,18</sup> after being informed about the goals of ACP by the healthcare

provider. Previous research found that most people over 75 years of age had thought about end-of-life care, yet only a few discussed this with their healthcare provider.<sup>10,17,19</sup> Several studies indicated that oncology patients wanted to talk about the end of life,<sup>14,16,19-21</sup> while they expected healthcare providers to take the initiative.<sup>14,19,20,22</sup> However, healthcare providers often find it difficult to speak about the end of life<sup>19,23-29</sup> and to mark the palliative

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phase.<sup>23,25,27,28</sup> Hence, finding the right time to initiate ACP is a challenge for healthcare providers.

End-of-life care often does not match the preferences of patients.<sup>8</sup> Most people prefer to die at home (56%-78%),<sup>8,30-32</sup> yet a large part of patients still dies in the hospital (40%).<sup>8</sup> In the Netherlands, 22% of the people with non-acute deaths died in a hospital despite their wish to die elsewhere and only 36% died in their own home.<sup>33</sup> Because of the difficulties of marking the palliative phase, ACP conversations are often initiated too late or not at all. Similarly, palliative care provision often starts relatively late,<sup>4,34-37</sup> which results in possible over-treatment in the last months of life.<sup>33,37</sup> This can lead to more hospital admissions for emergency treatment or symptom management,<sup>8</sup> which increases the risk of in-hospital-death.

We hypothesize that the documentation of ACP discussions in a structured advance care planning tool (ACPT) at a visible location in the EPR, relates to less healthcare consumption and a better match between the preferred and actual place of death. As a first step to explore the effects of using a structured ACPT this study assessed 1) healthcare consumption at three and one month(s) before death and 2) preferred versus actual place of death in deceased oncology patients aged 80 years or above. We compared patients with a structured complete or incomplete ACPT and patients without an ACPT.

## Methods

### Study Design

This is a retrospective pilot study among deceased oncology patients aged 80 years and above, who were treated in a Dutch teaching hospital (Jeroen Bosch Hospital) with 640 clinical beds and a catchment area of 360.000 people, located in 's-Hertogenbosch. We specifically focused on older patients, as the involved hospital started the implementation of the ACPT with this patient group. The main reason for this was that healthcare providers in the hospital mentioned that they felt more comfortable to speak with older patients about ACP compared to a younger population. Therefore, we expected that the largest number of patients with an ACPT could be included by focusing on older patients.

### Advance Care Planning Tool

In January 2019, the Jeroen Bosch Hospital started the implementation of an ACPT (See Supplemental Appendix) into the EPR. Our ACPT is developed by field experts from 15 Dutch hospitals and important network partners, based on the National Guidance for ACP<sup>38</sup> and is included as standard format into the EPR in many Dutch hospitals. The ACPT will be regularly reviewed and updated according to the latest insights from field and the involved experts. The ACPT covers the four dimensions of palliative care,<sup>38</sup> ie, it poses questions with respect to physical, psychological, social and spiritual needs. Moreover, it contains information on the preferred manner of communication (eg, how the patient prefers to be approached), decision-making

(eg, whether the patient wants to be readmitted to hospital) and life expectancy. In addition to the national ACPT, in our ACPT the social context (ie, living situation, marital status) is included and more extensive attention is given to meaning (ie, what is important to the patient) and organization of care (ie, patients' preferred place of care and death). The availability of this additional information provides better insight in "who this person is" and what is needed to comply with the person's preferences, which can lead to more appropriate end-of-life care. Preferences concerning care are documented by the (hemato-)oncologist or nurse (specialist). The full ACPT does not need to be completed at once; ideally, it is discussed during several ACP conversations<sup>10</sup> and enables its adjustments to present the actual situation. Every healthcare provider can access the information via a button at the front page of the EPR and can be shared with healthcare professionals outside the hospital.

### Setting and Participants

Patients were included if they met the following criteria: 1) diagnosed with cancer, 2) aged 80 years and above, 3) treated by a (hemato-)oncologist, and 4) died between 1-1-2019 and 31-5-2020. Patients were excluded if they had registered an objection for using their data for research purposes. The study population was selected from the EPR, using a query based on abovementioned criteria.

The included patients were divided based on the absence (group 1) or presence (group 2) of an ACPT with at least one completed item, regardless of the moment of initiation or the type and amount of completed items. For example, if the social domain question "Are you married?" was answered, the patient was included in group 2. The aim was to include as many patients as possible in the available time frame. Based on the groups that were initially formed (group 1 and 2), we calculated that 49 participants per group were needed to demonstrate a 25% reduction in the primary outcome (40% vs 15%) with 80% power and alpha 0.05.

### Data Collection

Retrospective data were collected from January 2019 through May 2020. Patient who died outside the hospital were not automatically registered as deceased in the EPR. Therefore, as a check, municipality data were used if the oncology patients were not registered as deceased in the EPR. All outcome variables were retrieved from the EPR by hand and using queries and were checked for consistency. We collected relevant patient characteristics (ie, gender, type of cancer, presence of informal care). Data were stored encrypted to ensure patients' privacy.

### Measures

Healthcare consumption was operationalized based on relevant literature.<sup>37,39-41</sup> The primary endpoint was the use of systemic oncological treatments (chemo-, immune-, endocrine therapy

and/or combination), which could be either curative or palliative in nature. This variable was coded as “yes” or “no”. When coded as “yes”, the type of treatment was specified. Secondary endpoints were the number of radiotherapy sessions, surgery requiring anesthesia, number of contacts within the hospital (emergency room (ER), outpatients’ clinic, day-care, other disciplines, admission to hospital (ward, intensive care unit (ICU)), number of diagnostic tests (laboratory analysis, invasive and radiological diagnostics tests), palliative interventions

(blood transfusions, ascites or pleural puncture, stent placement) and the match between preferred and actual place of death. Most of these variables were first coded as “yes” or “no” and when coded as “yes”, specified with frequencies, length of stay, type of diagnostic tests and palliative interventions.

Initial exploration of the data showed that the ACPT was initiated late in the disease trajectory mostly during the patients’ hospital admission. For patients in group 2, relevant items regarding organization of care were not always completed or

**Table 1.** Patient Characteristics.

Variables	Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b	
Age	83 (80–99) <sup>1</sup>	84 (80–99) <sup>1</sup>	83 (80–91) <sup>1</sup>	82 (80–86) <sup>1</sup>	0.090 <sup>2</sup>	0.022 <sup>2</sup>	
Gender	Male	71 (53.0)	35 (46.7)	36 (61.0)	8 (53.3)	0.118 <sup>3</sup>	0.779 <sup>3</sup>
	Female	63 (47.0)	40 (53.3)	23 (39.0)	7 (46.7)		
Comorbidity*	Yes	108 (80.6)	65 (86.7)	43 (72.9)	11 (73.3)	0.051 <sup>3</sup>	0.240 <sup>3</sup>
	Unknown	26 (19.4)	10 (13.3)	16 (27.1)	4 (26.7)		
Marital status	Married/living together	58 (56.3)	31 (67.4)	27 (47.4)*	8 (53.3)	0.098 <sup>4</sup>	0.338 <sup>4</sup>
	Widowed/alone	40 (38.8)	13 (28.3)	28 (49.1)*	7 (46.7)		
	Living alone, but partner	5 (4.9)	2 (4.3)	2 (3.5)	-		
	Unknown	31	29	2	-		
Residence	At home	97 (80.8)	48 (78.7)	49 (83.1)	10 (66.7)	0.210 <sup>4</sup>	0.044 <sup>4</sup>
	Family/friends	4 (3.3)	1 (1.6)	3 (5.1)	1 (6.7)		
	Nursing home	17 (14.2)	12 (19.7)	5 (8.5)	2 (13.3)		
	Hospice	1 (0.8)	-	1 (1.7)	1 (6.7)**		
	Other	1 (0.8)	-	1 (1.7)	1 (6.7)**		
	Unknown	14	14	-	-		
Living	Alone	48 (46.2)	23 (47.9)	25 (44.6)	5 (33.3)	0.844 <sup>3</sup>	0.383 <sup>3</sup>
	With adult	56 (53.8)	25 (52.1)	31 (55.4)	10 (66.7)		
	Unknown	30	27	3			
Caregiver	Yes	54 (40.3)	20 (26.7)	34 (57.6)	9 (60.0)	<0.001 <sup>3</sup>	0.017 <sup>3</sup>
	Unknown	80 (59.7)	55 (73.3)	25 (42.4)	6 (40.0)		
Tumour	Breast	18 (13.4)	9 (12)	9 (15.3)	4 (26.7)	0.012 <sup>4</sup>	0.154 <sup>4</sup>
	Gynaecological	7 (5.2)	4 (5.3)	3 (5.1)	-		
	Gastro-intestinal	22 (16.4)	14 (18.7)	8 (13.6)	3 (20.0)		
	Lung	2 (1.5)	2 (2.7)	-	-		
	Urological	18 (13.4)	3 (4.0)	15 (25.4)**	3 (20.0)**		
	Haematological	49 (36.6)	30 (40)	19 (32.2)	4 (26.7)		
	Other	18 (13.4)	13 (17.3)	5 (8.5)	1 (6.7)		
Treatment	Curation	1 (1.1)	1 (2.0)	-	-	0.159 <sup>4</sup>	0.574 <sup>4</sup>
	Disease management	3 (3.2)	3 (6.0)	-	-		
	Symptom management	90 (95.7)	46 (92.0)	44 (100)	13 (100)		
	Unknown	40	25	15	2		
WHO-PS	WHO-PS 0	3 (5.4)	1 (4.0)	2 (6.5)	-	0.233 <sup>4</sup>	0.425 <sup>4</sup>
	WHO PS 1-2	37 (66.1)	14 (56.0)	23 (74.2)	3 (75.0)		
	WHO-PS 3-4	16 (28.6)	10 (40.0)	6 (19.4)	1 (25.0)		
	Unknown	78	50	28	11		

Note: <sup>1</sup> median (min-max); <sup>2</sup>Mann Whitney U test; <sup>3</sup>Fisher Exact test; <sup>4</sup>Chi-square test, \* comorbidity defined as the use of  $\geq 3$  medicines, \*\* categories whose column proportions do differ significantly from each other at the, 05 level.

(Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items; subgroup 2b: patients with a timely initiated structured ACPT including preferred place of care or death). (WHO-PS = world health organization-performance status, ACPT = advance care planning tool).

not in a timely manner (eg, only weeks before death). Timely completing these specific items may be relevant for future healthcare decisions and enables timely initiation of interventions that are necessary to meet a person's preferences. Therefore, we formed a subgroup (2b) within group 2. In this subgroup, patients had a) completed the organization of care items and b) these items were documented in a timely manner. This meant that the questions "What is the preferred place of care" or "What is the preferred place of death" had been completed at least three months before death.<sup>42</sup> Because subgroup 2b was analyzed post-hoc, the sample size of this subgroup did not meet the calculated power of 49 patients.

### Statistical Analysis

The results were described using frequency tables, percentages and medians. Differences between group 1 and 2, and subsequently group 1 and 2b, were tested for numerical variables with the Mann-Whitney U test and for categorical variables with the Chi-square test or Fisher exact test. We checked if patient characteristics were comparable between groups. After the initial exploration of the data for groups 1 and 2, we used the data of groups 1 and 2b in further analyses. Remaining patients in group 2, ie, without their preferred place of care or death documented at least three months before death, were excluded after the initial analyses. A p-value < 0.05 was

**Table 2.** Treatment and Contact with Hospital, Three Months Before Death.

Variables		Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b
Treatment	Yes	58 (43.3)	28 (37.3)	30 (50.8)	6 (40.0)	0.160 <sup>1</sup>	1.000 <sup>1</sup>
	Systemic therapy	51 (38.1)	24 (32.0)	27 (45.8)	6 (40.0)	0.111 <sup>1</sup>	0.564 <sup>1</sup>
	Chemotherapy	18 (13.4)	11 (14.7)	7 (11.9)	2 (13.3)		
	Immunotherapy	9 (6.7)	3 (4.0)	6 (10.2)	2 (13.3)		
	Endocrine therapy	23 (17.2)	10 (13.3)	13 (22.0)	2 (13.3)		
	Combination <sup>^</sup>	2 (1.5)	1 (1.3)	1 (1.7)	0		
	Radiotherapy	5 (3.7)	3 (4.0)	2 (3.4)	0	1.000 <sup>1</sup>	1.000 <sup>1</sup>
	Surgery	5 (3.7)	2 (2.7)	3 (5.1)	0	0.665 <sup>1</sup>	1.000 <sup>1</sup>
Hospital admission	Yes	83 (61.9)	38 (50.7)	45 (76.3)	8 (53.3)	0.004 <sup>1</sup>	1.000 <sup>1</sup>
	1x	67 (50.0)	33 (44.0)	34 (57.6)	8 (53.3)	0.004 <sup>2</sup>	0.533 <sup>2</sup>
	2-4x	16 (11.9)	5 (6.7)	11 (18.6)*	0		
Duration of admission	1-7 days	37 (27.6)	19 (25.3)	18 (30.5)	7 (46.7)	0.014 <sup>2</sup>	0.247 <sup>2</sup>
	8-14 days	20 (14.9)	7 (9.3)	13 (22.0)*	0		
	≥15 days	26 (19.4)	12 (16.0)	14 (23.7)	1 (6.7)		
ICU admission	Yes	5 (3.7)	3 (4.0)	2 (3.4)	0	1.000 <sup>1</sup>	1.000 <sup>1</sup>
ER visits	Yes	75 (56.0)	38 (50.7)	37 (62.7)	5 (33.3)	0.220 <sup>1</sup>	0.266 <sup>1</sup>
	1x	58 (43.3)	30 (40.0)	28 (47.5)	5 (33.3)	0.377 <sup>2</sup>	0.482 <sup>2</sup>
	2x	13 (9.7)	7 (9.3)	6 (10.2)	0		
	≥ 3x	4 (3.0)	1 (1.3)	3 (5.1)	0		
Outpatients' clinic visit	Yes	113 (84.3)	63 (84.0)	50 (84.7)	10 (66.7)	1.000 <sup>1</sup>	0.149 <sup>1</sup>
	1-2x	42 (31.3)	25 (33.3)	17 (28.8)	4 (26.7)	0.022 <sup>2</sup>	0.428 <sup>2</sup>
	3-4x	33 (24.6)	24 (32.0)	9 (15.3)*	3 (20.0)		
	≥5x	38 (28.4)	14 (18.7)	24 (40.7)*	3 (20.0)		
Outpatients clinic oncology	Yes	104 (77.6)	57 (76.0)	47 (79.7)	9 (60.0)	0.680 <sup>1</sup>	0.214 <sup>1</sup>
Outpatients clinic other than oncology	Yes	68 (50.7)	36 (48.0)	32 (54.2)	5 (33.3)	0.492 <sup>1</sup>	0.398 <sup>1</sup>
Day care visit	Yes	47 (35.1)	22 (29.3)	25 (42.4)	7 (46.7)	0.145 <sup>1</sup>	0.230 <sup>1</sup>
	1x	20 (14.9)	9 (12.0)	11 (18.6)	3 (20.0)	0.201 <sup>2</sup>	0.374 <sup>2</sup>
	2-4x	17 (12.7)	10 (13.3)	7 (11.9)*	2 (13.3)		
	≥ 5x	10 (7.5)	3 (4.0)	7 (11.9)	2 (13.3)		
Contact with other disciplines	Yes	77 (57.5)	35 (46.7)	42 (71.2)	6 (40.0)	0.005 <sup>1</sup>	0.779 <sup>1</sup>

Note: <sup>1</sup> Fisher Exact Test <sup>2</sup> Chi-square test, \*categories whose column proportions do differ significantly from each other at the, 05 level, <sup>^</sup>a combination of different systemic treatment.

(Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items; subgroup 2b: patients with a timely initiated structured ACPT including preferred place of care or death). (ICU = intensive care unit, ER = emergency room, ACPT = advance care planning tool).

considered statistically significant. The analyses were conducted in SPSS version 25.

### Ethical Considerations

This study was submitted for approval to the Medical Research Committee Brabant, which confirmed that the Medical Research Involving Human Subjects Act did not apply. The data were collected in accordance with the most recent version (version 7, October 2013) of the Declaration of Helsinki and the Guidelines for Good Clinical Practice. This study was approved by the local research committee of the Jeroen Bosch Hospital (2020.04.22.02).

## Results

### Participants

Of all patients who were not registered as “deceased” in the EPR, an additional 13 patients (9.7%) were identified as

deceased by checking municipality data and were therefore included. In total, the analyses included 134 patients: 75 patients without an ACPT (group 1) and 59 patients with an ACPT (group 2) of whom the preferred place of care or death was documented at least three months before death in 15 patients (subgroup 2b). Table 1 presents patient characteristics.

### Healthcare Consumption

For patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items (group 2), healthcare consumption was higher than for patients without an ACPT (group 1). They had significantly more hospital admissions, more prolonged hospital stays, more visits to the outpatients’ clinic, more contacts with other disciplines (Tables 2 and 4) and more palliative interventions (Tables 3 and 5). Also, one month before death, patients in group 2 underwent significantly more radiological diagnostic tests than patients without an ACPT (group 1)

**Table 3.** Diagnostics and Palliative Interventions, Three Months Before Death.

Variables		Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b
Diagnostic tests	Yes	127 (94.8)	71 (94.7)	56 (94.9)	12 (80.0)	1.000 <sup>1</sup>	0.088 <sup>1</sup>
Laboratory analyses	Yes	126 (94.0)	70 (93.3)	56 (94.9)	12 (80.0)	1.000 <sup>1</sup>	0.126 <sup>1</sup>
	1x	12 (9.0)	9 (12.0)	3 (5.1)	3 (20.0)	0.332 <sup>2</sup>	0.424 <sup>2</sup>
	2–4x	44 (32.8)	25 (33.3)	19 (32.2)	4 (26.7)		
	5–9x	35 (26.1)	21 (28.0)	14 (23.7)	3 (20.0)		
	≥10x	35 (26.1)	15 (20.0)	20 (33.9)	2 (13.3)		
Invasive diagnostics	Yes	37 (27.6)	21 (28.0)	16 (27.1)	1 (6.7)	1.000 <sup>1</sup>	0.105 <sup>1</sup>
	PA	24 (17.9)	12 (16.0)	12 (20.3)	1 (6.7)	0.734 <sup>2</sup>	0.653 <sup>2</sup>
	Scope	2 (1.5)	2 (2.7)	0	0		
	ERCP	1 (0.7)	1 (1.3)	0	0		
	Bone marrow puncture	5 (3.7)	3 (4.0)	2 (3.4)	0		
	Other	5 (3.7)	3 (4.0)	2 (3.4)	0		
Frequency invasive tests	1x	29 (21.6)	16 (21.3)	13 (22.0)	1 (6.7)	0.928 <sup>2</sup>	0.204 <sup>2</sup>
	≥2x	8 (6.0)	5 (6.7)	3 (5.1)	0		
Radiological diagnostics	Yes	99 (73.9)	52 (69.3)	47 (79.7)	7 (46.7)	0.235 <sup>1</sup>	0.135 <sup>1</sup>
	1x	23 (17.2)	16 (21.3)	7 (11.9)	3 (20.0)	0.121 <sup>2</sup>	0.249 <sup>2</sup>
	2–4x	52 (38.8)	26 (34.7)	26 (44.1)	4 (26.7)		
	≥5x	24 (17.9)	10 (13.3)	14 (23.7)	0		
Palliative interventions	Yes**	42 (31.3)	17 (22.7)	25 (42.4)	5 (33.3)	0.024 <sup>1</sup>	0.510 <sup>1</sup>
	Blood transfusion	33 (24.6)	14 (18.7)	19 (32.2)	4 (26.7)	0.105 <sup>1</sup>	0.489 <sup>1</sup>
	Ascites puncture	5 (3.7)	1 (1.3)	4 (6.8)	1 (6.7)		
	Pleural puncture	5 (3.7)	1 (1.3)	4 (6.8)	0		
	Stent placement	2 (1.5)	1 (1.3)	1 (1.7)	0		
Frequency blood transfusion	1–2x	24 (17.9)	12 (16.0)	12 (20.3)	3 (20.0)	0.080 <sup>2</sup>	0.664 <sup>2</sup>
	3–4x	4 (3.0)	0	4 (6.8)*	0		
	≥5x	5 (3.7)	2 (2.7)	3 (5.1)	1 (6.7)		

Note: <sup>1</sup> Fisher Exact Test <sup>2</sup> Chi-square test, \*categories whose column proportions do differ significantly from each other at the, 05 level, \*\*some patients received multiple palliative interventions, ^a combination of different palliative interventions.

(Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items; subgroup 2b: patients with a timely initiated structured ACPT including preferred place of care or death).

(ACPT = advance care planning tool, PA = pathology, ERCP = endoscopic retrograde cholangiopancreatography).

**Table 4.** Treatment and Contact with Hospital, one Month Before Death.

Variables		Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b
Treatment	Yes	35 (26.1)	16 (21.3)	19 (32.2)	2 (13.3)	0.170 <sup>1</sup>	0.726 <sup>1</sup>
	Systemic therapy	34 (25.4)	15 (20.0)	19 (32.2)	2 (13.3)	0.115 <sup>1</sup>	0.727 <sup>1</sup>
	Chemotherapy	11 (8.2)	5 (6.7)	6 (10.2)	0		
	Immunotherapy	3 (2.2)	1 (1.3)	2 (3.4)	1 (6.7)		
	Endocrine therapy	1 (0.7)	1 (1.3)	0	0		
	Combination <sup>^</sup>	19 (14.2)	8 (10.7)	11 (18.6)	1 (6.7)		
	Radiotherapy	1 (0.7)	0	1 (1.7)	0	0.440 <sup>1</sup>	
	Surgery	2 (1.5)	1 (1.3)	1 (1.7)	0	1.000 <sup>1</sup>	1.000 <sup>1</sup>
Hospital admission	Yes	55 (41.0)	22 (29.3)	33 (55.9)	2 (13.3)	0.003 <sup>1</sup>	0.337 <sup>1</sup>
	1x	51 (38.1)	(28.0)	30 (50.8)*	2 (13.3)	0.007 <sup>2</sup>	0.430 <sup>2</sup>
	≥2x	4 (3.0)	1 (1.3)	3 (5.1)	0		
Duration of admission	1–7 days	27 (20.1)	15 (20.0)	12 (20.3)	2 (13.3)	<0.001 <sup>2</sup>	0.546 <sup>2</sup>
	8–14 days	17 (12.7)	2 (2.7)	15 (25.4)*	0		
	>15 days	11 (8.2)	5 (6.7)	6 (10.2)	0		
ICU admission	Yes	5 (3.7)	3 (4.0)	2 (3.4)	0	1.000 <sup>1</sup>	1.000 <sup>1</sup>
ER visit	Yes	51 (38.1)	23 (30.7)	28 (47.5)	2 (13.3)	0.051 <sup>1</sup>	0.219 <sup>1</sup>
	1x	(37.3)	22 (29.3)	28 (47.5)*	2 (13.3)	0.074 <sup>2</sup>	0.383 <sup>2</sup>
	2x	1 (0.7)	1 (1.3)	0	0		
Outpatients' clinic visit	Yes	72 (53.7)	33 (44.0)	39 (66.1)	4 (26.7)	0.014 <sup>1</sup>	0.260 <sup>1</sup>
	1–2x	55 (41.0)	27 (36.0)	28 (47.5)	4 (26.7)	0.010 <sup>2</sup>	0.541 <sup>2</sup>
	3–4x	15 (11.2)	4 (5.3)	11 (18.6)*	0		
	≥5x	2 (1.5)	2 (2.7)	0	0		
Outpatients' clinic visit oncology	Yes	62 (46.3)	29 (38.7)	33 (55.9)	4 (26.7)	0.056 <sup>1</sup>	0.559 <sup>1</sup>
Outpatients' clinic visit other than oncology	Yes	33 (24.6)	12 (16.0)	21 (35.6)	1 (6.7)	0.015 <sup>1</sup>	0.687 <sup>1</sup>
Day care visit	Yes	20 (14.9)	9 (12.0)	11 (18.6)	2 (13.3)	0.333 <sup>1</sup>	1.000 <sup>1</sup>
	1x	9 (6.7)	4 (5.3)	5 (8.5)	1 (6.7)	0.558 <sup>2</sup>	0.979 <sup>2</sup>
	2–4x	10 (7.5)	5 (6.7)	5 (8.5)	1 (6.7)		
	≥5x	1 (0.7)	0	1 (1.7)	0		
Contact with other disciplines	Yes	52 (38.8)	19 (25.3)	33 (55.9)	2 (13.3)	<0.001 <sup>1</sup>	0.506 <sup>1</sup>

Note: <sup>1</sup> Fisher Exact Test <sup>2</sup> Chi-square test, \* categories whose column proportions do differ significantly from each other at the .05 level, <sup>^</sup>a combination of different systemic treatment.

(Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items; subgroup 2b: patients with a timely initiated structured ACPT including preferred place of care or death).

(ICU = intensive care unit, ER = emergency room, ACPT = advance care planning tool).

(Table 5). In contrast, one month before death, diagnostic tests and laboratory tests (Table 5) was significantly lower in patients with a timely initiated ACPT (subgroup 2b) compared to patients without an ACPT (group 1). A similar trend was seen for other endpoints of healthcare consumption, although not statistically different (Tables 2–5). Three months before death, patients in subgroup 2b had more day-care visits than patients without an ACPT, however, this was not statistically different (Table 2).

### Place of Death

In patients with an ACPT (group 2 and 2b), the preferred place of death was significantly known more often than for those without an ACPT (Table 6). In group 1, if the preferred place

of death was known, it was not structured documented in the EPR and therefore difficult to find. Patients with a timely initiated ACPT (subgroup 2b) died in the hospital less often than patients in group 1 and 2 (Table 6) and more often died at their preferred place compared to patients in group 1. However, these differences were not statistically significant (Table 6).

### Discussion

This pilot study showed the potential value of timely initiated ACP conversations by means of a structured ACPT among older oncology patients. We explored documentation in the ACPT in relation to healthcare consumption in the last months of life, and the match between the preferred and

**Table 5.** Diagnostics and Palliative Interventions, one Month Before Death.

Variables		Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b
Diagnostic tests	Yes	96 (71.6)	52 (69.3)	44 (74.6)	5 (33.3)	0.565 <sup>1</sup>	0.016 <sup>1</sup>
Laboratory analyses	Yes	88 (65.7)	47 (62.7)	41 (69.5)	5 (33.3)	0.466 <sup>1</sup>	0.047 <sup>1</sup>
	1x	26 (19.4)	16 (21.3)	10 (16.9)	2 (13.3)	0.489 <sup>2</sup>	0.298 <sup>2</sup>
	2–4x	27 (20.1)	15 (20.0)	12 (20.3)	2 (13.3)		
	5–9x	25 (18.7)	10 (13.3)	15 (25.4)	1 (6.7)		
	≥10x	10 (7.5)	6 (8.0)	4 (6.8)	0		
Invasive diagnostics	Yes	11 (8.2)	7 (9.3)	4 (6.8)	0	0.755 <sup>1</sup>	0.596 <sup>1</sup>
	PA	5 (3.7)	1 (1.3)	4 (6.8)	0	0.195 <sup>2</sup>	0.911 <sup>2</sup>
	Scope	1 (0.7)	1 (1.3)	0	0		
	ERCP	1 (0.7)	1 (1.3)	0	0		
	Bone marrow puncture	1 (0.7)	1 (1.3)	0	0		
	Other	3 (2.2)	3 (4.0)	0	0		
Frequency invasive diagnostics	1x	9 (6.7)	6 (8.0)	3 (5.1)	0	0.790 <sup>2</sup>	0.468 <sup>2</sup>
	2x	2 (1.5)	1 (1.3)	1 (1.7)	0		
Radiological diagnostics	Yes	57 (42.5)	24 (32.0)	33 (55.9)	3 (20.0)	0.008 <sup>1</sup>	0.539 <sup>1</sup>
	1x	24 (17.9)	8 (10.7)	16 (27.1)*	3 (20.0)	0.028 <sup>2</sup>	0.226 <sup>2</sup>
	2–4x	24 (17.9)	12 (16.0)	12 (20.4)	0		
	≥5x	9 (6.7)	4 (5.3)	5 (8.5)	0		
Palliative interventions	Yes**	27 (20.1)	10 (13.3)	17 (28.8)	2 (13.3)	0.031 <sup>1</sup>	1.000 <sup>1</sup>
	Blood transfusion	22 (16.4)	8 (10.7)	14 (23.7)*	2 (13.3)	0.071 <sup>1</sup>	0.671 <sup>1</sup>
	Ascites puncture	2 (1.5)	1 (1.3)	1 (1.7)	0		
	Pleural puncture	5 (3.7)	1 (1.3)	4 (6.8)	0		
Frequency blood transfusion	1–2x	20 (14.9)	8 (10.7)	12 (20.3)	2 (13.3)	0.071 <sup>2</sup>	0.671 <sup>1</sup>
	3–4x	2 (1.5)	0	2 (3.4)	0		

Note: <sup>1</sup> Fisher Exact Test <sup>2</sup> Chi-square test, \*categories whose column proportions do differ significantly from each other at the, 05 level, ^a combination of different palliative interventions.

(Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type and amount of completed items; subgroup 2b: Patients with a timely initiated structured ACPT including preferred place of care or death).

(ACPT = advance care planning tool, PA = pathology, ERCP = endoscopic retrograde cholangiopancreatography).

actual place of death. In patients with a timely initiated ACPT (ie, at least three months before death) including preferred place of care or death, we found a trend towards less healthcare consumption and more prevalent death at the preferred place. In contrast, when disregarding the moment of initiation or the type of completed items, patients with an ACPT had *more* healthcare consumption than those without an ACPT. This finding may be explained by the fact that at the time of this study, documenting results in an ACPT had not been fully implemented into practice. Thus, when patients with advanced cancer were admitted to the hospital, the ACP conversations were initiated *during* hospitalization and at the end of life, which implies that their healthcare consumption was already relatively high.

In the timely initiated ACPT-subgroup, we observed a trend towards fewer hospital admissions. Also, in this subgroup the number of re-admissions, prolonged hospital stays and admissions to ICU were lower than the national percentages among older oncology patients in earlier studies.<sup>30,43</sup> Corresponding to our findings, more day-care visits have been observed among oncology patients in the Netherlands, when ACP

conversations took place in a timely manner.<sup>44</sup> Moreover, a previous study found that early initiated ACP conversations may lead to more conscious decision-making about whether to start a (toxic) systemic treatment, to conduct (diagnostic) examinations at the end of life or to admit a patient to the hospital.<sup>45</sup> In line with this, our results showed significantly less diagnostic and laboratory tests in the timely initiated ACPT-subgroup.

Overall, the results implicate that early initiated ACP conversations with specific attention to organization of care may lead to more appropriate end-of-life care. Patients may also benefit on other important outcomes, such as quality of life. ACP conversations initiated in, preferably, an outpatient setting, enables timely application of interventions that are needed to meet the patient's preferences.<sup>46</sup> This could contribute to patients spending more time at home at the end of life near their loved ones. More research is needed into the effects of early discussions about the organization of care on patients' perceived quality of care and life. In addition to the quality of life benefits, less overtreatment due a timely initiated ACPT may also contribute to reallocation of health care costs.<sup>46,47</sup>

**Table 6.** Characteristics of the Advance Care Planning Tool.

Variables		Total group n = 134 n (%)	Group 1 n = 75 n (%)	Group 2 n = 59 n (%)	Subgroup 2b n = 15 n (%)	P value group 1 versus 2	P value group 1 versus 2b
Meaning of life documented	Yes	42 (31.3)	0	42 (71.2)	14 (93.3)		
Organisation of care documented	Yes	41 (30.6)	0	41 (69.5)	15 (100)		
Preferred place of death documented	Yes	61 (45.5)	16 (21.3)	45 (76.3)	14 (93.3)	<0.001 <sup>1</sup>	<0.001 <sup>1</sup>
	At home	39 (29.1)	9 (12.0)	30 (50.8)	9 (60.0)	0.145 <sup>2</sup>	0.274 <sup>2</sup>
	Hospice	13 (9.7)	2 (2.7)	11 (18.6)	4(26.7)		
	Hospital	1 (0.7)	0	1 (1.7)	0		
	Nursing home	3 (2.2)	2 (2.7)	1 (1.7)	1 (6.7)		
	Other	5 (3.7)	3 (4.0)	2 (3.4)	0		
	Unknown/no	73	59	14	1		
Actual place of death	In hospital	24 (17.9)	12 (16.0)	12 (20.3)	1 (6.7)	0.651 <sup>1</sup>	0.687 <sup>1</sup>
	Outside hospital	110 (82.1)	63 (84.0)	47(79.7)	14 (93.3)	0.016 <sup>2</sup>	0.252 <sup>2</sup>
	At home	51 (38.1)	25 (33.3)	26 (44.1)	9 (60.0)		
	Hospice	24 (17.9)	9 (12.0)	15 (25.4)	3 (20.0)		
	Nursing home	16 (11.9)	14 (18.7)	2 (3.6)*	1 (6.7)		
	Unknown	19	15	4	1		
Match preferred place and actual place of death	Yes	34 (64.2)	7 (58.3)	27 (65.9)	10 (76.9)	0.736 <sup>1</sup>	0.411 <sup>1</sup>
	No	19 (35.8)	5 (41.7)	14 (34.1)	3 (23.1)		
	Unknown	81	63	18	2		

Note: <sup>1</sup>Fisher Exact test; <sup>2</sup>Chi-square test (Group 1: patients without ACPT; group 2: patients with a structured ACPT, regardless of the moment of initiation or the type of completed items; subgroup 2b: patients with a timely initiated ACPT including preferred place of care or death) (ACPT = advance care planning tool).

In line with earlier studies,<sup>6,31,35,48,49</sup> our results suggest that timely initiated ACP conversations may improve the match between the preferred and actual place of death. In contrast, one recent study among patients with heart, lung and cancer diseases in Denmark, the initiation of an ACP conversation did not significantly relate to death at the preferred place.<sup>50</sup> As in our study, the lack of a statistically significant result may be due to a low sample size and thus insufficient statistical power to detect differences. Even though current and previous findings are inconclusive, preliminary evidence suggests that the initiation of a timely ACPT including organization of care may result in a better match between preferred and actual place of death.

Our results suggests that ACP only contributes to better end-of-life care when the conditions “timely” and “explicit attention to organization of care” are met. This approach may help healthcare professionals to get to know the “person behind the disease” and to learn about the context surrounding a person. In turn, this may help them to create more realistic expectations and to undertake the right interventions to meet the patients’ preferences.<sup>46</sup> Hence, the initiation and continuation of ACP conversations requires a holistic approach to allow tailoring of end-of-life care to the individual situation. This goes beyond the mere documentation of treatment agreements such as resuscitation policy and ideally involves communication about psychosocial and spiritual needs as well.<sup>38</sup>

### Limitations

The study population involved a small age-based sample from only one hospital. Also, only a small number of patients with an ACPT had a well-timed ACPT that also included preferred place of care or death. Therefore, the sample size was insufficient for this specific subgroup and conclusions cannot be generalized. Further research is needed with a larger sample size to investigate the value of timely and structured ACPT. Also, we focused on patients of 80 years and above, yet advance care planning is not restricted to age. Therefore, as a follow-up to this pilot study, we recently initiated a study with an adequately powered number of oncology patients  $\geq 18$  of age in which one group of patients does not have an ACPT and the other group has an ACPT in which timely attention has been paid to discussing at least organization of care. At last, we marked organization of care and the timeframe in which this item was documented as important. We did not study other items of the ACPT that can be meaningful to meet the preferences of the patient. Items within the domain of “decision-making” in which preferences are documented, such as whether a patient wishes to be readmitted to hospital, might also be important. However, these items are often not completed until the preferred place of care or preferred place of death has been discussed.

## Practical Implications

With the ACPT, healthcare providers can document and retrieve patients' advance care preferences at a visible location in the EPR, which has been shown to be relevant for better end-of-life care.<sup>6,13</sup> The content of the ACPT can be used as a starting point at any time when discussing treatment options and during decision-making, to ensure appropriate care provision in relation to patients' preferences in the last years of life.<sup>46</sup> This information needs to be available to all involved healthcare providers, because fragmented documentation and poor communication between professionals are well known barriers to good end-of-life-care.<sup>51,52</sup> Advance care planning may be initiated at any time regardless of age or stage of illness.<sup>53</sup> Therefore, it is important to conduct follow-up research into the value of an ACPT also in younger patients. Different skills may be required by the healthcare provider and other barriers or facilitators may be experienced both by patients and health care providers. More research is needed on the distinct challenges in ACP with younger patients to inform further and broader implementation of the ACPT. The optimal time to start ACP seems to be at least three or four months before death,<sup>4,42,54</sup> but preferably at a much earlier phase.<sup>55</sup> This also applies to initiating the ACPT, including the questions about one's preferred place of care and death. To be able to provide better end-of-life care, the timely initiation of ACP with specific attention to the organization of care are important preconditions which must be taken into account in future research.

## Conclusions

Timely documentation of the preferred place of care or death in a structured ACPT within the EPR may result in less healthcare consumption and a better match between the preferred and actual place of death among older oncology patients aged 80 years and above.

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