



University of Southern Denmark

## Early specialised palliative care interventions, symptoms, problems

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1 **Early specialized palliative care in the Danish Palliative Care Trial**  
2 **(DanPaCT): description of which interventions were initiated and for**  
3 **which symptoms and problems**

4  
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## **Abstract**

**Background:** Few studies have investigated the content of interventions provided in early specialized palliative care.

**Objectives:** To characterize the content of interventions delivered in early specialized palliative care in the Danish Palliative Care Trial (DanPaCT), a multicentre trial with six participating sites.

**Methods:** A retrospective qualitative and quantitative study coding all new interventions initiated by the palliative teams and documented in the medical records during the eight-week study period of DanPaCT. Interventions were categorized according to a) symptom/problem prompting the intervention, b) type of intervention, and c) professional(s) providing the intervention (NCT01348048).

**Results:** In total, 145 patients were randomized to the specialized palliative care teams. According to the medical records, patients received a median of 3.5 (range 0-22) new interventions in the eight-week intervention-period from the palliative teams. For 24 (18%) of the patients there was no documented interventions in the medical records. The most frequent symptom/problems treated were pain, (100 interventions; 20% of interventions given) and impaired physical function (62; 13% of interventions given). The most frequent type of interventions was pharmacological (232; 42% of interventions given).

**Conclusions:** This is one of the first studies to meticulously investigate the content of interventions documented in the medical records for patients receiving early specialized palliative care. Diverse symptoms were treated with many different interventions. However, a relatively low number of interventions were documented. This may explain the lack of effect in DanPaCT but also questions whether all interventions were adequately documented

## **Keywords**

Specialized palliative care  
Advanced cancer  
Interventions  
Pain management  
Multicentre  
Randomized clinical trial

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## **Introduction**

A primary goal of palliative care is to prevent and relieve suffering through early identification and treatment of pain and other symptoms and problems [1]. Despite specialized palliative care (SPC) being recommended early in the disease trajectory it still tends to be offered mainly to patients late in their disease trajectory in many countries, including Denmark [2].

Studies have indicated beneficial effects of referring patients to SPC earlier in their disease trajectory [3-7] and early palliative care is receiving increasing attention and is recommended in guidelines [8]. To explore the effect of early SPC in Denmark, we conducted the Danish Palliative Care Trial (DanPaCT) to investigate whether patients with metastatic cancer, who reported palliative needs in a screening, would benefit from an earlier referral to SPC [9-10]. The results of DanPaCT showed no significant effect of early SPC on the primary and secondary outcomes (symptoms, problems and survival) over the eight-week study period [11].

In DanPaCT, early SPC was practiced as conventional SPC. However, it was offered to patients earlier in the disease trajectory than what is normally the case in Denmark, which makes it an ‘early’ SPC intervention [7]: the patient group in DanPaCT had a median survival of 11 months [11], which is close to the 12 and 14 months median survival of the patients in the studies of early SPC conducted by Temel et al. in 2010 [3] and Bakitas et al. in 2009 [12]. The interventions in DanPaCT were not defined in advance but reflected a need-based intervention approach following the European Association for Palliative Care White Paper [13,14], the World Health Organizations’ guidelines [1] and national and local guidelines.

Few previous studies have investigated the content of early SPC [15-17]. In one study the content of the first palliative consultation was registered by using a template in the medical records [15]. In another study, clinicians rated the content of the consultation in a post-visit questionnaire containing categories of symptoms, coping, rapport, illness understanding, treatment decisions and advance care planning [16]. In a third study patients were interviewed about what they believed to be intervention benefits [17].

1 To understand in more detail what early palliative care may include, we decided to explore and  
2 meticulously describe the content of early SPC as it was documented in the medical records in the  
3 trial. One other study has done the same, however, only in a subset of 20 patients [18]. Our aim was  
4 to characterize the content and goals of interventions delivered in early SPC care in DanPaCT with a  
5 secondary aim that the results might shed light on the lack of effect found in DanPaCT.

## 8 **Methods**

### 9 Study design

10 DanPaCT was a randomized, multicentre, parallel-group, superiority clinical trial with 1:1  
11 randomisation conducted at six centres in Denmark [9,10]. Primary and secondary outcomes were  
12 measured using the EORTC QLQ-C30 [19,20] cancer specific questionnaire. The protocol was  
13 approved by the Ethics Committee for the Capital Region, Denmark (journal number H-3-2010-144),  
14 the Danish Data protection agency (journal number BBH-2011-05), and registered at  
15 [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

16  
17 The present study was a combined qualitative and quantitative study developing a coding system that  
18 could describe all new interventions registered in the medical records of patients included in the  
19 intervention arm of DanPaCT in the eight-week study period.

### 21 Patients

22 Eligibility criteria were age 18 years or older; cancer stage IV (according to the Tumor, Node and  
23 Metastasis classification [21]) or cancer in the central nervous system grade III or IV with no  
24 possibility of curative treatment; residency in the catchment area of the participating centres; and no  
25 contact with SPC within the previous year.

26  
27 Additionally, participants should have at least one ‘palliative need’. The assessment of whether the  
28 patients had a ‘palliative need’ was based on the EORTC QLQ-C30 questionnaire that was used as a  
29 screening tool to be filled in by all patients. If patients did not fill in the questionnaire or did not have  
30 a palliative need according to their answers in the questionnaire, they were not included – even if they  
31 expressed a need verbally or non-verbally. A palliative need was defined as an EORTC QLQ-C30  
32 scale score of at least 50% of the score equivalent to maximal symptomatology or maximal functional

1 impairment (e.g. they had to score quite a lot or very much on single-item scales). In addition, they  
2 had to have four additional symptoms where they had answered at least “a little” in the EORTC QLQ-  
3 C30 questionnaire. All participants gave written consent including permission to review their medical  
4 records.

#### 5 6 The DanPaCT intervention

7 Patients in the intervention group were referred to a specialized palliative care team in addition to  
8 standard care. The teams were instructed to receive the DanPaCT patients and treat these patients  
9 according to usual procedures and guidelines. Specialized palliative care is a complex,  
10 multidisciplinary, and personalized intervention tailored to each patient. All six teams had at least  
11 four different disciplines working in the team, always including doctors and nurses [9].  
12 Furthermore, all teams had a psychologist, most had a physiotherapist and some teams had a  
13 chaplain and a social worker [9]. It is a nationally defined target that patients should be discussed at  
14 a multi-disciplinary meeting [4]. No additional guidelines were developed for the intervention, and  
15 the teams providing the intervention were expected to use the guidelines and expertise they already  
16 had. As such, the intervention was not manualized.

#### 17 18 Material and coding

19 The study material consisted of the medical records from the SPC team of each patient in the  
20 intervention arm from randomization to end of the trial eight weeks later (the eight-week  
21 intervention period of DanPaCT). Patients were included in the trial from May 2011 to December  
22 2013, and the last follow-up questionnaire was sent out in March 2014.

23  
24 In Denmark, all patients have a medical record containing all notes from the secondary health  
25 sector/public hospitals in the region where they live. It can also be accessed by the patients  
26 themselves via a secure site on the internet. In this medical record the multi-disciplinary staff  
27 documents treatment and care provided.

28 The medical record of each patient was coded by the first author of the manuscript. For each  
29 intervention documented in the medical record by the SPC team, the following characteristics were  
30 described: 1) the symptom/problem prompting the intervention, 2) the type of intervention, and 3)  
31 the professional(s) providing the intervention.

32

1 An intervention was defined as an action taken to help the patient or his/her relative. This could be  
2 medication, making referrals to relevant specialists, or engaging in a supportive conversation with  
3 help and advice. Sometimes the documentation was limited to e.g. “phone call with xx”. In such  
4 cases, we did not know the content of the conversation and it was not registered as an intervention.  
5

#### 6 Symptom/problem prompting the intervention

7 Each intervention was encoded in terms of which symptom/problem the intervention was initiated  
8 for. First, if appropriate, the symptom or problem was encoded as one of the 14 symptoms and  
9 problems from the EORTC QLQ-C30 questionnaire: physical function, role function, emotional  
10 function, cognitive function, social function, fatigue, nausea and vomiting, pain, dyspnoea, insomnia,  
11 appetite loss, constipation, diarrhoea and financial difficulties. Secondly, symptoms/problems not  
12 represented in the EORTC QLQ-C30 were added to the symptom/problem list.  
13

14 We encoded the targeted symptom if it was masked by another symptom. For instance, we used the  
15 code ‘pain’ if a patient had insomnia arising from pain and accordingly received analgesic treatment.  
16

#### 17 Type of intervention

18 The type of documented intervention was encoded in three hierarchical categories: main, sub- and  
19 specific category. For example, morphine treatment was encoded as main category  
20 ‘pharmacological’, subcategory ‘opioid’ and specific category ‘morphine’.  
21

22 For the main category ‘pharmacological’, the subcategories were extracted from two Danish online  
23 pharmacological registers for health care professionals [22] and the European Medicines Agency  
24 [23]. At the end of the encoding, all specific categories under ‘pharmacological’ were re-encoded  
25 under their generic name using two other Danish online registers [24]  
26

27 Interventions that started before inclusion were excluded, because they were not a result of the  
28 DanPaCT. The same was true for interventions that started after the eight weeks study period. Thus,  
29 the study does not show all interventions given to the patients. It shows what was added to the  
30 patients’ care by the SPC team during the first eight weeks after referral.  
31



1 Fluid and electrolyte therapies were not included mainly because most patients were in active  
2 oncologic treatment and were therefore regularly receiving fluid and/or electrolyte therapy.  
3 Likewise, supplementary oxygen given on the ward was not encoded. Further, when working with  
4 the data, it became clear that fluid and oxygen treatment were not systematically recorded.  
5  
6 To simplify the system, we did not include pharmacological titrations or discontinuations but  
7 registered only new prescriptions. However, for opioids in pain management we made an exception  
8 and registered titrations and discontinuations.  
9  
10 We did not encode new prescriptions if they consisted of the same active substance, for example,  
11 when the prescribed drug was unavailable and was substituted. Likewise, if the patient was  
12 discharged, resulting in a change in pharmacological route e.g. from intravenous to oral  
13 administration, we encoded only the drug first prescribed. This approach prevented double coding of  
14 interventions.  
15  
16 A main category, referral, was used if patients were referred to someone outside the team, for example  
17 a psychologist not affiliated with the team. Interventions targeting caregivers were encoded in a  
18 separate system, using the same types of interventions as for patients.  
19  
20 For most interventions, coding was relatively straight forward. However, the category ‘supportive  
21 conversations’ was difficult to define. This category was used when there was notes describing longer  
22 substantial conversations between patient and health care personnel during which the health care  
23 professional was clearly supporting the patients. Thus, if it was just noted that the patient seemed  
24 psychologically well adjusted, this was not recorded as a supportive conversation. The supportive  
25 conversations could be about coping, financial difficulties, advance care planning or other important  
26 subjects. These conversations were coded together with the symptom/problem in focus, e.g. financial  
27 or emotional problems).  
28  
29 Professional(s) providing the intervention  
30 In total, seven types of professionals were involved in the interventions given to patients and relatives  
31 in the intervention arm of DanPaCT; physician/nurse, physiotherapist, occupational therapist,  
32 psychologist, social worker and dietician. Physicians and nurses were coded as in the same category

1 ('physician/nurse'). The reason was that in the medical record it was often not possible to identify  
2 who had written the note and whether they had contributed separately or together: in practice, the  
3 nurses and doctors work in teams, share the work and write notes in the medical records based on  
4 mutual agreement.

## 5 6 Statistical analysis

7 Descriptive statistics (frequencies, means, and percentages) were made using SAS statistical  
8 software.

## 9 10 11 **Results**

### 12 Patients

13 In total, 145 patients were randomized to the SPC teams in DanPaCT. Seven were not referred to SPC  
14 (due to death or administrative failure), leaving 138 patients and their medical records for the current  
15 study. In 24 (18%) of the 138 medical records, there were no recorded interventions according to our  
16 guidelines in the medical record and one medical record contained only interventions directed towards  
17 informal caregivers (Figure 1).

18  
19 The 138 participants had a mean age of 65 years, 55% were women, and most were receiving  
20 chemotherapy (83%). The most frequent diagnoses represented were lung cancer (39%) and breast  
21 cancer (22%) (Table 1).

22  
23 (Table 1 here)

### 24 25 Symptom/problem prompting the intervention

26 Documented interventions were given for a total of 37 different symptoms of which 12 were covered  
27 by the symptom and function scales of the EORTC QLQ-C30 questionnaire (Table 2).

28  
29 (Table 2 here)

### 30 31 Interventions

1 In total, 482 new interventions were documented by the SPC teams in the medical records during the  
2 eight-week study period, i.e. a median of 3.5 (range 0-22) interventions provided to the 138 patients.  
3 Most frequently, interventions were directed towards pain (100; 20% of all interventions given),  
4 problems with physical function (62; 13%) and emotional distress (60; 12%) (see Table 3, which also  
5 illustrates the structure of the coding system).

6  
7 (Table 3 here)

8  
9 The most frequent main categories of interventions were pharmacological (232 interventions; 42%  
10 of all interventions), supportive conversations (85; 16%), referrals (34; 6%), physiotherapy (33; 6%),  
11 instructions and guidance (33; 6%), activities of daily living equipment (34; 6%) and applications  
12 (29; 5%) (Table 3).

13  
14 For pain, most interventions were pharmacological with 37 involving opioids and 17 involving  
15 other analgesics (Tables 3 and 4), followed by physiotherapy, activities of daily living equipment  
16 and instructions and guidance (Table 4). Morphine was the most frequently used drug.

17  
18 (Table 4 here)

19  
20 In addition to the 482 (new) interventions towards patients and informal caregivers in DanPaCT there  
21 were 68 titrations and discontinuations of opioids in pain management in 36 patients (Table 5).  
22 Of these, the SPC teams had initiated the opioid therapy in 10 patients, and in 26 patients the opioid  
23 treatment was initiated before the referral to the teams. The most frequent titration was dose increase  
24 accounting for a total of 46 titrations, whereas there were 10 reductions and 12 discontinuations. The  
25 most frequently adjusted medicine was morphine followed by fentanyl and oxycodone.

26  
27 (Table 5 here)

28  
29 Interventions to informal caregivers

30 Of the 31 interventions towards informal caregivers of 21 patients, 22 were supportive conversations,  
31 seven were referrals (e.g., to psychologists and social workers), and 2 were instructions and guidance.

32

1 The professional(s) providing the interventions to patients

2 Interventions to patients were mainly given by a physician/nurse (73%), followed by physiotherapist  
3 (21%), psychologist (7%), social worker (4%) and occupational therapist and dietician (1%).  
4

5 **Discussion**

6 *Main findings*

7 This study describes the new interventions registered in the medical records in the intervention arm  
8 during the eight-week trial period of DanPaCT. This is one of the first studies to retrospectively  
9 describe all interventions documented in the medical records in an early SPC intervention. The study  
10 shows that according to the medical records, the most frequently treated symptom was pain and the  
11 most frequently used drug used to treat pain was opioids. Treating pain is one of the cornerstones of  
12 palliative care [25], however, as it is stated in the definition by The World Health Organisation [1];  
13 palliative care is much more than pain management and our study also showed a large variety of other  
14 symptoms and problems managed by the SPC teams. In total, 37 different types of  
15 symptoms/problems were registered, and a vast number of different interventions provided. Thus,  
16 this study contributes to the knowledge base of early SPC by showing in detail a) the many different  
17 types of pharmacological treatments used in SPC, b) the many different symptoms treated, and c) the  
18 link between intervention and symptom. Hereby, the study documents the complexity of SPC.  
19

20 However, an important finding of this study is the relatively few interventions registered in the  
21 medical records. Especially when considering the fact that all patients included in the trial had at  
22 least one palliative need defined as a score on the EORTC questionnaire above 50% of maximum.  
23 For a fifth of the referred patients there were no documented interventions at all, and for the  
24 remaining participants, the median number of documented interventions during the eight-week trial  
25 was 3.5. A direct comparison of the findings to other studies of early SPC is not possible, because  
26 the content of early SPC has been coded differently. For example, in the study by Yoong et al. [18],  
27 120 notes addressing symptoms was registered for the 20 patients at the initial SPC visit. This is an  
28 average of six notes concerning physical symptoms at the initial visit, compared to the 3.5  
29 interventions given during eight weeks in our study. However, we do not know the proportion of  
30 the notes in Yoong et al's [18] study that involved an intervention. In this study, notes were only  
31 coded when they concerned an intervention.  
32

1 Especially, the registered number of interventions targeted emotional function (EF) and illness  
2 understanding was low in our study (60 interventions targeted EF and 13 targeted illness  
3 understanding in a sample of 138 patients over 8 weeks), and only few supportive conversations was  
4 made (85 to 138 patients, e.g. less than one conversation per patient). This contrasts with other studies  
5 that have found that e.g. 64% of the palliative care consultations were addressing patients' coping  
6 [16]. Very few interventions were also targeted caregivers in this study, which contrasts with the  
7 study by Yoong et al. [18].

8  
9 The relatively low number of documented interventions raises a number of questions. First, we must  
10 ask if the documentation was complete. Even though all relevant information regarding treatment and  
11 care should be included in the medical records, some information was probably missing. We believe  
12 that the medical record was fairly complete regarding prescriptions of medications.

13  
14  
15 The relatively low number of medical interventions may be partially explained by the fact that the  
16 patients were still in contact with their oncological departments, and these departments may have  
17 prescribed the patients' primary interventions, e.g. against chemotherapy induced nausea and  
18 constipation. Another reason may be that the patients in this study due to the early referral had a better  
19 performance status and fewer symptoms and problems than what is normally the case in SPC. This  
20 may have led the SPC teams to give the DanPaCT patients less attention than the regular SPC patient  
21 with more severe and acute needs.

22  
23 Regarding psychosocial interventions, our best guess is that these interventions were underreported  
24 in the medical records. Psychosocial interventions may not always be documented, because it can be  
25 difficult to describe psychosocial problems in a few words or because it can be difficult to describe  
26 them in a way that is relevant to both patients and different types of health care providers. This  
27 potential lack of documentation is unfortunate as it undermines multidisciplinary collaboration and  
28 integration. However, we may also have developed a too strict definition of supportive conversations,  
29 and maybe we should have been more inclusive when trying to document psychosocial interventions.

30  
31

1 The low number of psychosocial interventions may also suggest that few of these interventions were  
2 actually made. If this is true, we have missed some potential important components of early SPC,  
3 such as the psychosocial, educational and advance care planning components of SPC [17]. Should  
4 we do such a trial again, we would have requested that all patients were offered such components.  
5

6 The low number of psychosocial interventions calls for serious considerations of the way early SPC  
7 was provided in DanPaCT. The SPC teams were familiar with handling a somewhat different patient  
8 group with more severe and acute needs than those included in DanPaCT. It may require effort and  
9 training to develop and implement the optimal content of early SPC in order to gain better outcomes  
10 of SPC.

11  
12 Regardless of the reasons for what we believe to be a relatively low number of interventions, this  
13 study may explain the lack of effect in the DanPaCT trial. Even though we had not defined the  
14 minimum dose for the SPC intervention in advance (which we probably should have done), it is likely  
15 that the level of interventions provided in DanPaCT, was not enough to constitute a change.  
16

17 The strengths of this study are the comprehensive data material consisting of all notes in the medical  
18 records documented by the SPC teams during the eight-week study period of DanPaCT. Another  
19 important strength is the size and the composition of the study population: 138 patients with various  
20 cancer diagnoses, which provides a broad perspective on interventions directed towards patients  
21 receiving early SPC. Further, the multicentre approach (six different teams) strengthens the  
22 possibility for generalisation of the results. It is also a strength of the study that it shows what happens  
23 if patients are referred to a specialized palliative care in addition to their regular contact with the  
24 oncology department. In the future it would be relevant supplement these results with a similar  
25 mapping of the interventions prescribed by the oncological departments during the same period.  
26 Further, it could also have been interesting to analyse the palliative interventions that were already  
27 taking place when the patients were randomized to DanPaCT and to have followed the patients  
28 beyond the eight-week study period. However, this is beyond the scope of this paper.  
29

30 Today, there is much focus on how to integrate SPC with oncology and a discussion of the role and  
31 content of SPC [26]. We have systematically coded all interventions given, and we hope our coding  
32 system may be used in future prospective studies to develop, describe and compare SPC models.

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**Conclusions**

We described all new interventions provided by the SPC teams and registered in the medical records during the eight-week study period of the DanPaCT trial. The process revealed a diversity of treatments given for many different symptoms/problems. However, importantly according to the medical record most patients received what we believe to be a relatively low number of interventions. Most interventions were pharmacological, and most often directed towards pain. There was a lack of documented interventions concerning psychosocial care and advance care planning, which are important components of SPC. This may be due to a low level of psychosocial interventions being offered or it may be due to a lack of documentation. This call for considerations concerning how psychosocial care can be better documented in the medical records to ensure quality development and systematic assessment.

The low number of documented interventions may explain the lack of effect in DanPaCT. Based on the notes in the medical journal, it was difficult to assess if the interventions provided were substantial enough to be expected to make a change. We hope that this study will prompt important discussions of the appropriate content of early SPC and how it is documented in medical records. We hope that our coding system will aid future studies in describing the content of early or regular (specialized) palliative care, thus allowing comparison between countries and programs and in relation to patient characteristics.

**Author contribution**

ATJ, PS, MAN, AD, CG, JL, PF, IH, AS and MG took part in designing DanPaCT. ATJ was postdoc on DanPaCT, project coordinator and data manager. MG was coordinating investigator and the funding beneficiary. MG and NS developed the system for coding of the medical records. NS was the primary coder of the medical records. NS and ATJ did the analyses. NS and ATJ drafted the paper and all authors read, amended, and approved the final manuscript.

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7

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11

## 12 **Compliance with ethical standards**

13 The protocol was approved by the Ethics Committee for the Capital Region, Denmark (journal  
14 number H-3-2010-144), and the Danish Data Protection Agency (journal number BBH-2011-05),  
15 and registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (NCT01348048;  
16 <https://clinicaltrials.gov/ct2/show/NCT01348048?term=01348048&rank=1>; registered May 2011).

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## 18 **Conflict of interest**

19 The authors declare that they have no competing interests.

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## 21 **Disclaimer**

22 The funding bodies had no role in the design, conduct, analysis, or reporting of the trial.

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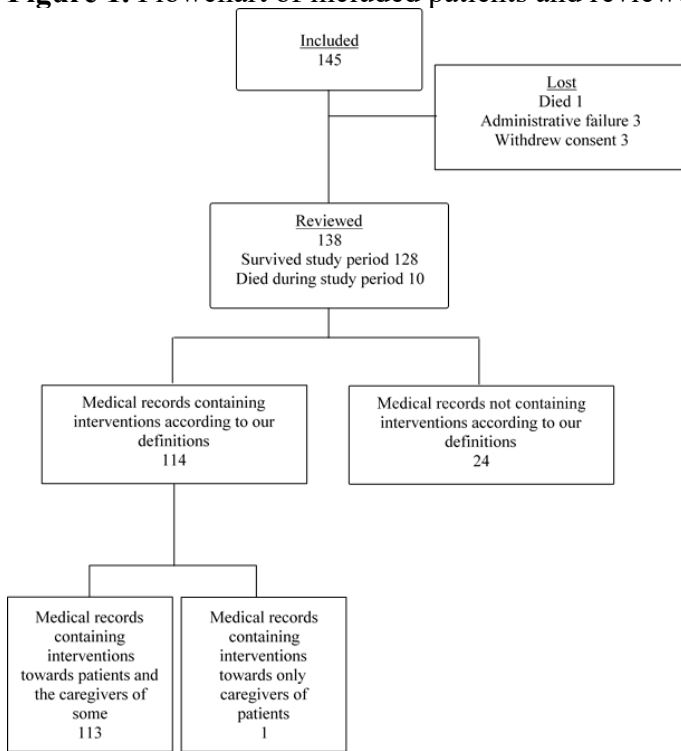
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1 **Figure 1.** Flowchart of included patients and reviewed medical records



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1 **Table 1. Patient characteristics of the intervention group in DanPaCT (N=145) and those who**  
 2 **received at least one intervention documented in the medical record (N=113)**

		Intervention group (N=145) N (%)	Patients who received at least one intervention (N=113) N (%)
Age (mean)		65	64
Sex	Men	63 (43)	50 (44)
	Women	82 (57)	63 (56)
Cancer	Lung	57 (39)	45 (40)
	Digestive system	20 (14)	16 (14)
	Breast	31 (21)	26 (23)
	Other	37 (26)	26 (23)
Time since diagnosed with stage IV	<12 months	83 (57)	50 (44)
	12-24 months	27 (19)	21 (19)
	>24 months	32 (22)	42 (37)
Receiving chemotherapy	Yes	120 (83)	104 (92)
	No	25 (17)	9 (8)
WHO performance score <sup>a</sup>	0	23 (18)	20 (19)
	1	78 (60)	60 (58)
	2	27 (21)	23 (22)
	3	1 (1)	0 (0)
Education	None	26 (19)	20 (18)
	Semi-skilled worker/short education (< 1 year)	19 (14)	18 (17)
	Skilled worker	23 (17)	18 (17)
	Short theoretical (1-3 years)	21 (15)	17 (16)
	Long theoretical (>3 years)	39 (28)	28 (26)
	Academic	9 (7)	8 (7)
Centre	Bispebjerg University Hospital	25 (17)	21 (19)
	Copenhagen University Hospital Rigshospitalet <sup>b</sup>	28 (19)	23 (20)
	Odense University Hospital	20 (14)	15 (13)
	Vejle Hospital	29 (20)	27 (24)
	Aarhus University Hospital	19 (13)	9 (8)
	Herning Hospital	24 (17)	18 (16)

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1 **Table 2. Number of interventions registered for different symptoms and problems in the**  
 2 **intervention arm of DanPaCT.**

Symptoms and problems	Number of interventions towards symptom/problem (%)
Symptoms and problems included in the EORTC QLQ-C30 questionnaire.	
Physical functioning	62 (13)
Role functioning	0 (0)
Emotional functioning	60 (12)
Cognitive functioning	0 (0)
Social functioning	2 (0)
Fatigue	12 (3)
Nausea and vomiting	10 (10)
Pain	100 (21)
Dyspnoea	47 (10)
Insomnia	9 (2)
Appetite loss	8 (2)
Constipation	37 (8)
Diarrhoea	2 (0)
Financial difficulties	39 (8)
Additional symptoms and problems (not included in the EORTC QLQ-C30)	
General condition <sup>a</sup>	2 (0)
Anaemia	2 (0)
Treatment <sup>b</sup>	7 (2)
Blood pressure	1 (0)
Dyspepsia	7 (2)
Delirium	2 (0)
Dehydration or over-hydration	2 (0)
Nutrition	1 (0)
Course and prognosis <sup>c</sup>	13 (3)
Cough and expectoration	16 (3)
Skin discomfort <sup>e</sup>	1 (0)
Infection	4 (1)
Convulsions/cramps	2 (0)
Pneumonia	2 (0)
Stomatitis	11 (2)
Sweats	2 (0)
Vertigo or dizziness	1 (0)
Comfort and safety <sup>d</sup>	2 (0)
Urinary tract infection	2 (0)
Motor agitation	3 (1)
Urination discomfort <sup>e</sup>	2 (0)
Oedema	5 (1)
Ocular discomfort <sup>e</sup>	1 (0)
Gastrointestinal discomfort <sup>e</sup>	2 (0)
Unknown indication <sup>f</sup>	1 (0)

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**Total number of interventions****482 (100)**

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<sup>a</sup>Cases where patients were generally affected; e.g. if patients suffered from both fatigue and appetite loss or nausea

<sup>b</sup>Supportive conversations about current treatment or referrals to other departments and specialists

<sup>c</sup>Supportive conversations about future treatment plans and the patients' disease and prognosis.

<sup>d</sup>Also included prescription of the so-called "safety medical box" to be used at home for the final hours of life.

<sup>e</sup>We used "discomfort" when it was not a specific disease or condition per se but more of an uneasiness or minor distress, e.g., an infection in the eye needs antibiotics and was encoded as infection, whereas slightly dry eyes treated with neutral eye drops would be encoded as an ocular discomfort.

<sup>f</sup>An intervention was made without any records revealing the indication

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**Table 3.** The most frequently used interventions (rows) and the most frequently treated symptoms and problems (columns) in the intervention arm of DanPaCT.<sup>a</sup>

	Pain	Physical function	Emotional function	Dyspnoea	Financial difficulties	Constipation	Cough and expectoration	Course and prognosis	Fatigue	Stomatitis	Nausea and vomitus	Insomnia	Appetite loss	Other symptoms <sup>d</sup>	Total in study (%)
<b>Pharmacologic</b>															
Opioids	37			15			7								59
Laxatives						36									36
Other analgesics	17														17
Antidepressants	11		5												16
Antifungals										11				3	14
Glucocorticoids	1			1					4		1		2	2	11
Hypnotics			3									5		1	9
Antiemetic											6		2		8
Antacids	1												1	6	8
Antiepileptics	6		1									1			8
Antipsychotics			1								3			2	6
Stimulants									6						6
Antibiotics														5	5
Diuretics														4	4
Combination drugs				1										3	4
NSAID*	4														4
Antihistamine												1		2	3
Other	1		2	1		1							1	8	14
<b>Total</b>	<b>78</b>		<b>12</b>	<b>18</b>		<b>37</b>	<b>7</b>		<b>10</b>	<b>11</b>	<b>10</b>	<b>7</b>	<b>6</b>	<b>36</b>	<b>232 (42%)</b>
<b>Supportive conversation</b>															
Support	2	7	39	3	10			13	2				2	7	85
<b>Total</b>	<b>2</b>	<b>7</b>	<b>39</b>	<b>3</b>	<b>10</b>			<b>13</b>	<b>2</b>				<b>2</b>	<b>7</b>	<b>85 (16%)</b>
<b>Referrals</b>															
Psychologist			2												8
Rehabilitation centres		3	3											1	8
Physiotherapist	1	4		2											7
Referral centre		2												2	4
Priest			3												3
Other		3		1	1							2		4	11
<b>Total</b>	<b>1</b>	<b>12</b>	<b>8</b>	<b>3</b>	<b>1</b>							<b>2</b>		<b>7</b>	<b>34 (6%)</b>
<b>Instructions and guidance</b>															
Motor exercises	3	9													12



Respiratory exercises				10											10
PEP*-whistle				2			3								5
<i>Other</i>		3	1												8
<b>Total</b>	3	12	1	12			5								<b>33</b> <b>(6%)</b>
<b>Physiotherapy</b>															
Lymphatic drainage	2	5												2	9
Massage	7													1	8
Motor exercises	1	4													5
Respiratory exercises				4											4
Compression equipment	1													2	3
<i>Other</i>	1	1		2											4
<b>Total</b>	12	10		6			1							5	<b>33</b> <b>(6%)</b>
<b>ADL*</b>															
<b>equipment</b>															
Walker		8													8
PEP*-whistle				3			4								7
Compression equipment		3													3
Wheelchair		2													2
<i>Other</i>	4	8		2											14
<b>Total</b>	4	21		5			3								<b>34</b> <b>(6%)</b>
<b>Applications</b>															
Financial support					19									1	20
Foundations					4										4
Other					5										5
<b>Total</b>					28									1	<b>29</b> <b>(5%)</b>
<i>Other</i>														2	2
<b>Total</b>														2	2
<b>Total in study</b>	<b>100</b>	<b>62</b>	<b>60</b>	<b>47</b>	<b>39</b>	<b>37</b>	<b>16</b>	<b>13</b>	<b>12</b>	<b>11</b>	<b>10</b>	<b>9</b>	<b>8</b>	<b>51</b>	<b>482</b> <b>(100%)</b>

<sup>a</sup>If a subcategory occurred only twice or less in the study it is included in the category “others”

\*Abbreviations: NSAID, nonsteroidal anti-inflammatory drugs. PEP, Positive Expiratory Pressure. ADL, activities of daily living.

**Table 4.** Pain interventions registered for the patients in the intervention arm of DanPaCT.

	Total specifics	Total sub- category	Total main category
<b>Pharmacological</b>			
Opioids <sup>a</sup>			
Morphine	23		
Fentanyl	5		
Oxycodone	2		
Methadone	4		
Tramadol	2		
Oxycodone combinations	1		
Total		37	
Other analgesics			
Acetaminophen	15		
Lidocaine	2		
Total		17	
Antidepressants			
Amitriptyline	9		
Nortriptyline	2		
Total		11	
Antiepileptic drugs			
Pregabalin	5		
Gabapentin	1		
Total		6	
NSAIDs			
Ibuprofen	4		
Total		4	
Anaesthetics			
Ketamine	1		
Total		1	
Glucocorticoids			
Prednisolone	1		
Total		1	
Antacids			
Pantoprazole	1		
Total		1	
<b>Total</b>			<b>78</b>
<b>Physiotherapy</b>			
Massage		7	
Lymphatic drainage		2	
Compression equipment		1	
Motor exercises		1	
(No subcategory)		1	

<b>Total</b>		<b>12</b>
ADL* equipment		
(No subcategory)	4	
<b>Total</b>		<b>4</b>
Instructions and guidance		
Motor exercises	3	
<b>Total</b>		<b>3</b>
Supportive conversation		
Motor exercises	1	
(No subcategory)	1	
<b>Total</b>		<b>2</b>
Referrals		
Physiotherapist 1	1	
<b>Total</b>		<b>1</b>

<sup>a</sup>Only new opioid interventions. Titrations and discontinuations are not included in this table.  
Abbreviations: NSAID, nonsteroidal anti-inflammatory drugs. ADL, activities of daily living.

**Table 5. Adjustments and discontinuations of opioids for pain registered for the patients in the intervention arm of DanPaCT.**

Opioid	Dose increase	Dose reduction	Discontinuation	Total
Morphine	26	7	3	36
Fentanyl	10	2	0	12
Oxycodone	5	1	3	9
Methadone	3	0	1	4
Tramadol	1	0	3	4
Oxycodone combinations	1	0	0	1
Codeine	0	0	2	2
Total	46	10	12	68