DANSKE KRÆFTFORSKNINGSDAGE 2022

Hvad kan vi opnå med rettidig palliativ indsats i de forskellige sektorer?

#DKD2022
#SamarbejdeOmKræft

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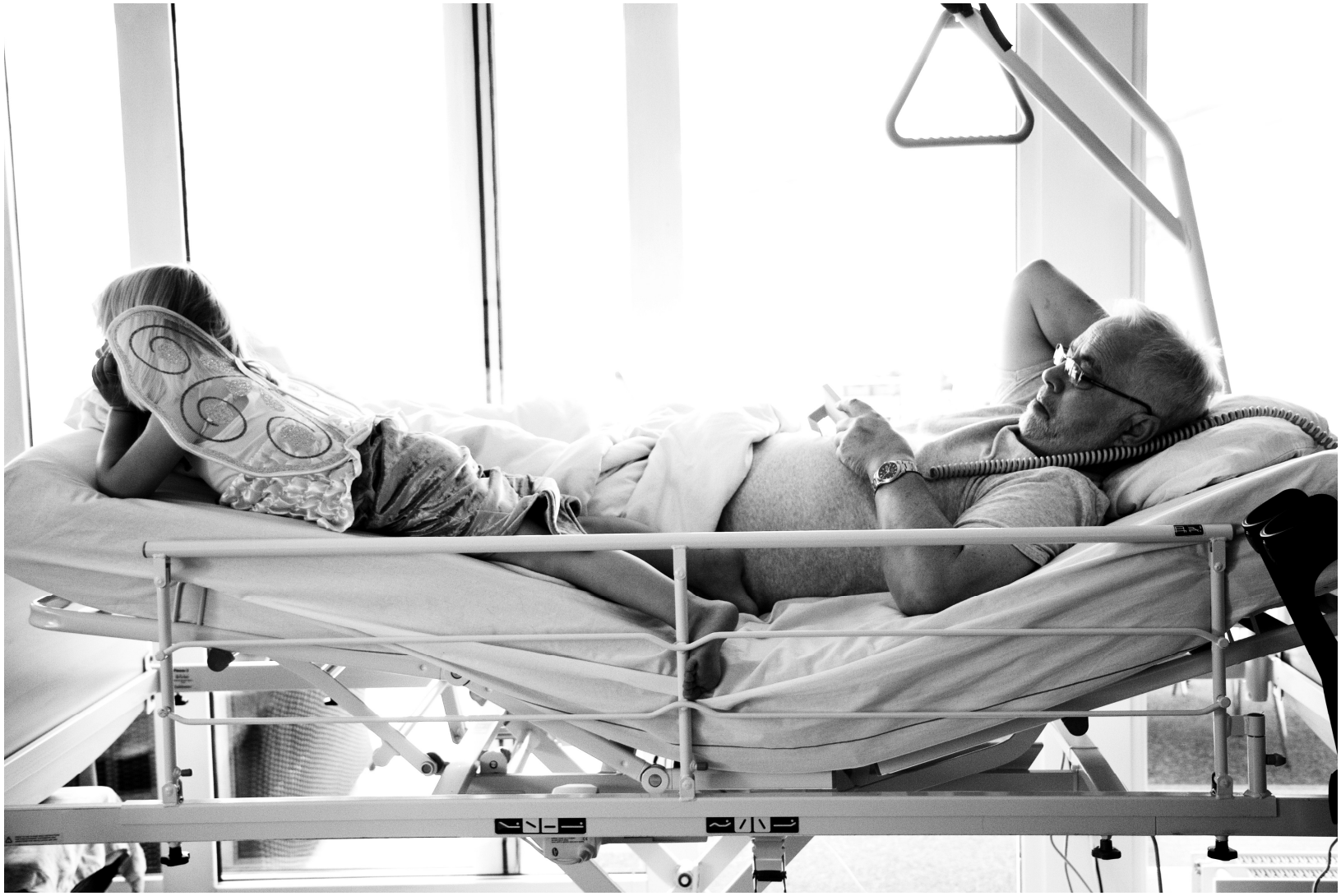
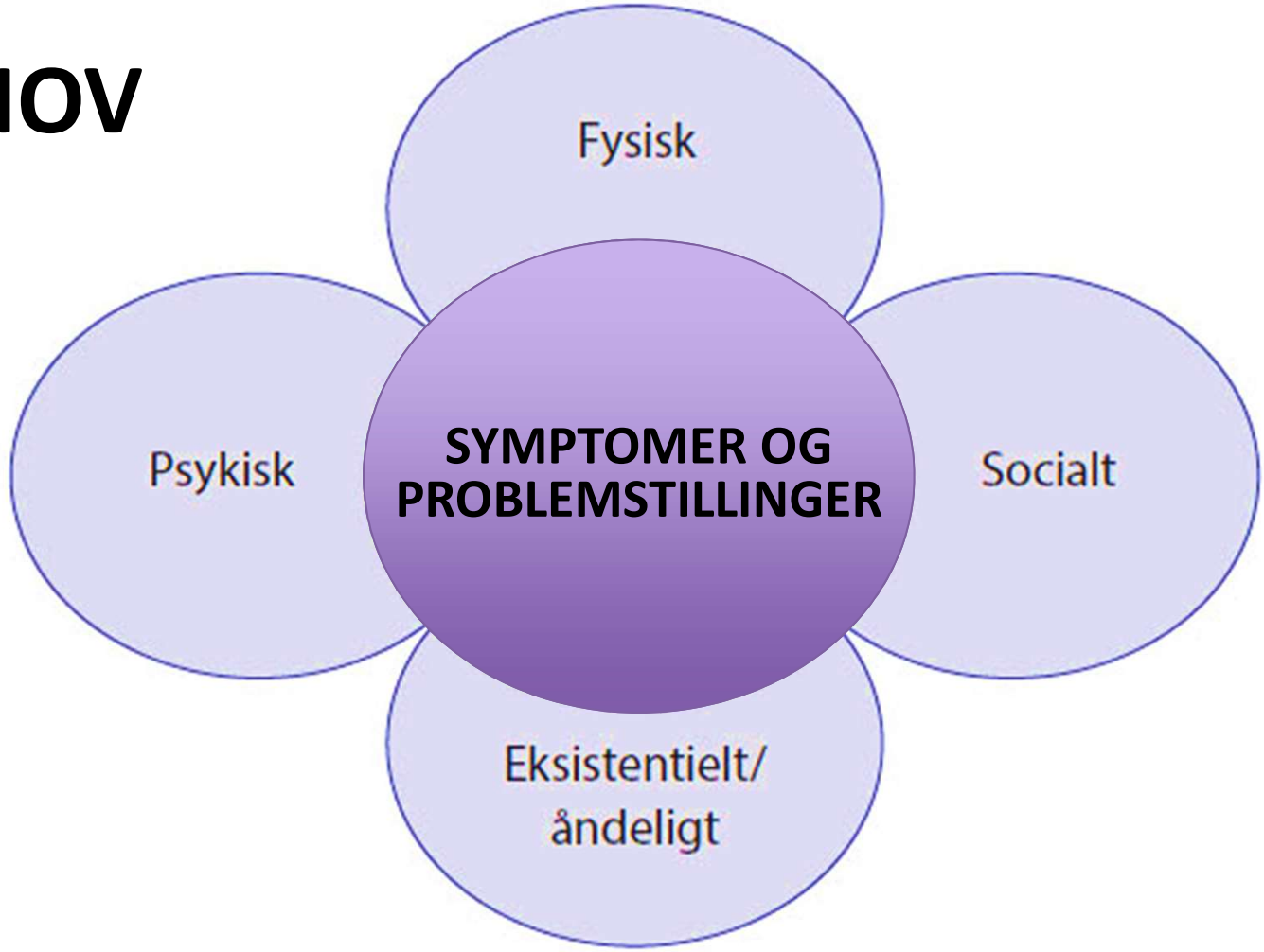


Hvordan får vi bedre forløb?

1. **Afdække patientens / familiens behov og ressourcer**
   – **Systematisk, tidligt og løbende**

BEHOV


Fysisk
Psykisk
SYMPTOMER OG PROBLEMSTILLINGER
Socialt
Eksistentielt/ åndeligt

SUNDHEDSSTYRELSEN

Anbefalinger for den palliative indsats

4 Det palliative forløb

Anbefalinger

- Alle med livstruende sygdom uanset diagnose og alder tilbydes en palliativ indsats med udgangspunkt i den enkeltes behov
- Det palliative forløb tilrettelægges og foregår individuelt og i samarbejde med patient og pårørende ud fra en faglig helhedstænkning og med størst mulig kontinuitet af tilknyttede fagpersoner
- Identifikation og vurdering af patientens behov for palliative indsatser tager udgangspunkt i en helhedstænkning og den enkelte patients forudsætninger; sker tidligst muligt - gerne på diagnosetidspunktet og systematisk ved brug af ens og validerede redskaber på tværs af sektorer og gentages ved behov
- De palliative indsatser omfatter efter behov indsatser over for lidelser, fysiske og psykiske symptomer samt sociale og eksistentielle/åndelige forhold. Endvidere indsatser til pårørende og efterladte
- Alle med livstruende sygdom tilbydes systematiske samtaleforløb om fremtidig behandling og pleje

Sundhedsstyrelsen

ANBEFALINGER FOR DEN PALLIATIVE INDSATS

2011

Anbefalinger:

- Regioner og kommuner bør sikre, at der hos patienter med livstruende sygdom foretages behovsvurdering. Behovsvurdering foretages når diagnosen stilles, ved forværring af sygdommen, ved sektorovergang samt ved andre væsentlige begivenheder (som fx ændringer i den sociale situation)
- Der bør udarbejdes redskaber til brug for behovsvurderingen – dette arbejde bør forankres nationalt
- Det bør tilstræbes, at der anvendes validerede redskaber til behovsvurdering og uddybende udredning
- De videnskabelige og faglige selskaber samt sammenslutninger, der beskæftiger sig med behandling af patienter med andre sygdomme end kræft, bør udarbejde retningslinjer for palliativ indsats – retningslinjerne bør om muligt være evidensbaserede

Klinisk vejledning for almen praksis

Dansk Selskab for Almen Medicin

Palliation

Dansk Selskab for Almen Medicin

2014

PALLIATION

1

Tjeklister i det palliative forløb

Start af et palliativt forløb	Det fortsatte palliative forløb	I terminalfasen
☐ Ansvarlig læge	☐ Fysiske/psykiske/sociale/eksistentielle problemer	☐ Fysiske/psykiske/sociale/eksistentielle problemer
☐ Markering i journalen	☐ EORTC QLQ-C15-PAL	☐ EORTC QLQ-C15-PAL
☐ Hvad ved patient og pårørende?	☐ Medicin – ny medicinliste	☐ Symptomer – reversible? Årsag?
☐ Det sociale netværk	☐ Forudse de kommende behov	☐ Estimer forventet restlevetid
☐ Misbrugsproblemer	☐ Terminaltilskud/terminalerklæring?	☐ Forudse akutte forværringer – forebyg
☐ Fysiske/psykiske/sociale/eksistentielle problemer	☐ Tryghedskasse – inkl. ordination	☐ Forbered patient, pårørende og hjemmesygeplejerske
☐ EORTC QLQ-C15-PAL	☐ Forbered patient og pårørende på fremtiden	☐ Terminaltilskud/terminalerklæring?
☐ Objektiv undersøgelse	☐ Lav handleplan	☐ Tryghedskasse – inkl. ordination
☐ Gennemgå medicin (medicinliste til pt.)	☐ Kommuniker med hjemmesygeplejen – koordinationsmøde	☐ Medicin – ny medicinliste
☐ Andre professionelle	☐ Aftal ny kontakt.	☐ Lav handleplan
☐ Rehabilitering		☐ Tilgængelighed? Direkte telefonnummer til klinikken og evt. privatnummer
☐ Hjælpemidler		☐ Ved egen læges fravær: Orienter vikar!
☐ Åben indlæggelse/hospitalskontakt		☐ Efter dødens indtræden – information
☐ Det palliative team		☐ Kommuniker med hjemmesygeplejen
☐ Aftal kontaktform – telefon, akut-telefon, e-mail, vagttid		☐ Aftal ny kontakt.
☐ Terminaltilskud?		
☐ Terminalerklæring?		
☐ Pjecen 'Når diagnosen er alvorlig'		
☐ Aftal ny kontakt		
☐ Notatkopi (inkl. medicinliste) til hjemmepleje (plus evt. andre aktører).		

EORTC-QLQ-C15-PAL

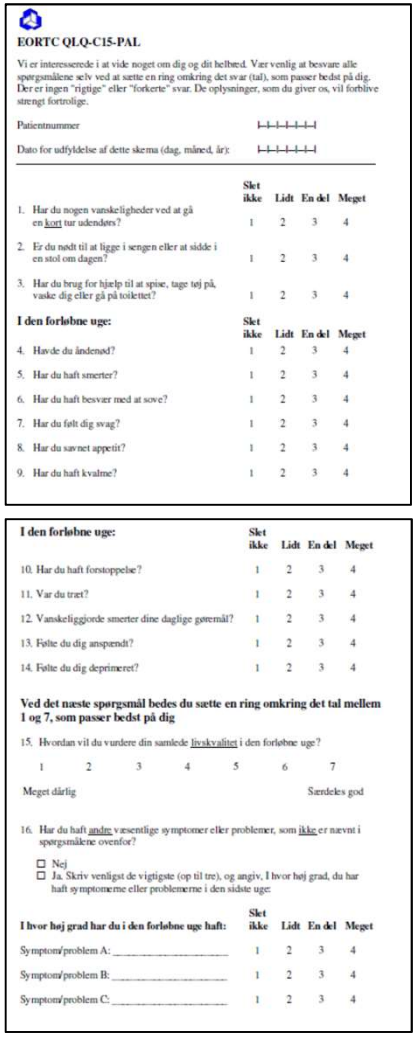
AUH:

- 1. halvdel af 2019: 60 skemaer

  10 skemaer / md

- 1. halvdel af 2022: 192 skemaer

  32 skemaer / md



EORTC QLQ-C15-PAL

Vi er interesserede i at vide noget om dig og dit helbred. Vær venlig at besvare alle spørgsmålene selv ved at sætte en ring omkring det svar (tal), som passer bedst på dig. Der er ingen "rigtige" eller "forkerte" svar. De oplysninger, som du giver os, vil forblive strengt fortrolige.

Patientnummer |-|-|-|-|-|-|

Dato for udfyldelse af dette skema (dag, måned, år): |-|-|-|-|-|-|

	Slet ikke	Lidt	En del	Meget
1. Har du nogen vanskeligheder ved at gå en kort tur udendørs?	1	2	3	4
2. Er du nødt til at ligge i sengen eller at sidde i en stol om dagen?	1	2	3	4
3. Har du brug for hjælp til at spise, tage tøj på, vaske dig eller gå på toilettet?	1	2	3	4

I den forløbne uge:	Slet ikke	Lidt	En del	Meget
4. Havde du åndenød?	1	2	3	4
5. Har du haft smerter?	1	2	3	4
6. Har du haft besvær med at sove?	1	2	3	4
7. Har du følt dig svag?	1	2	3	4
8. Har du savnet appetit?	1	2	3	4
9. Har du haft kvalme?	1	2	3	4

I den forløbne uge:	Slet ikke	Lidt	En del	Meget
10. Har du haft forstoppelse?	1	2	3	4
11. Var du træt?	1	2	3	4
12. Vanskeliggjorde smerter dine daglige gøremål?	1	2	3	4
13. Følte du dig anspændt?	1	2	3	4
14. Følte du dig deprimeret?	1	2	3	4

Ved det næste spørgsmål bedes du sætte en ring omkring det tal mellem 1 og 7, som passer bedst på dig

15. Hvordan vil du vurdere din samlede livskvalitet i den forløbne uge?

1 2 3 4 5 6 7

Meget dårlig Særdeles god

16. Har du haft andre væsentlige symptomer eller problemer, som ikke er nævnt i spørgsmålene ovenfor?

☐ Nej
☐ Ja. Skriv venligst de vigtigste (op til tre), og angiv, I hvor høj grad, du har haft symptomerne eller problemerne i den sidste uge:

I hvor høj grad har du i den forløbne uge haft:	Slet ikke	Lidt	En del	Meget
Symptom/problem A: _____	1	2	3	4
Symptom/problem B: _____	1	2	3	4
Symptom/problem C: _____	1	2	3	4

Hvordan får vi bedre forløb?

1. Afdække patientens / familiens behov og ressourcer
   – Systematisk, tidligt og løbende
2. **Uddanne alle sundhedsprofessionelle (Speciale)**
   – **Lindring af symptomer / problemstillinger**
   – **Have den palliative tankegang med tidligt i forløbet**

Integration of oncology and palliative care: a *Lancet Oncology* Commission

Stein Kaasa*, Jon H Loge*, Matti Aapro, Tit Albreht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S Grotmol, Breffni Hannon, Dagny F Haugen, Irene J Higginson, Marianne J Hjermstad, David Hui, Karin Jordan, Geana P Kurita, Philip J Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjøgren, Patrick Stone, Camilla Zimmermann, Tonje Lundeby

Full integration of oncology and palliative care relies on the specific knowledge and skills of two modes of care: the tumour-directed approach, the main focus of which is on treating the disease; and the host-directed approach, which focuses on the patient with the disease. This Commission addresses how to combine these two paradigms to achieve the best outcome of patient care. Randomised clinical trials on integration of oncology and palliative care point to health gains: improved survival and symptom control, less anxiety and depression, reduced use of futile chemotherapy at the end of life, improved family satisfaction and quality of life, and improved use of health-care resources. Early delivery of patient-directed care by specialist palliative care teams alongside tumour-directed treatment promotes patient-centred care. Systematic assessment and use of patient-reported outcomes and active patient involvement in the decisions about cancer care result in better symptom control, improved physical and mental health, and better use of health-care resources. The absence of international agreements on the content and standards of the organisation, education, and research of palliative care in oncology are major barriers to successful integration. Other barriers include the common misconception that palliative care is end-of-life care only, stigmatisation of death and dying, and insufficient infrastructure and funding. The absence of established priorities might also hinder integration more widely. This Commission proposes the use of standardised care pathways and multidisciplinary teams to promote integration of oncology and palliative care, and calls for changes at the system level to coordinate the activities of professionals, and for the development and implementation of new and improved education programmes, with the overall goal of improving patient care. Integration raises new research questions, all of which contribute to improved clinical care. When and how should palliative care be delivered? What is the optimal model for integrated care? What is the biological and clinical effect of living with advanced cancer for years after diagnosis? Successful integration must challenge the dualistic perspective of either the tumour or the host, and instead focus on a merged approach that places the patient's perspective at the centre. To succeed, integration must be anchored by management and policy makers at all levels of health care, followed by adequate resource allocation, a willingness to prioritise goals and needs, and sustained enthusiasm to help generate support for better integration. This integrated model must be reflected in international and national cancer plans, and be followed by developments of new care models, education and research programmes, all of which should be adapted to the specific cultural contexts within which they are situated. Patient-centred care should be an integrated part of oncology care independent of patient prognosis and treatment intention. To achieve this goal it must be based on changes in professional cultures and priorities in health care.

Introduction

The overall aim of this Commission is to show why and how palliative care can be integrated with oncology for adults with cancer, irrespective of treatment intention, in high-income and middle-income countries. This integration will combine two main paradigms, tumour directed and patient (host) directed, through the use of the most effective and optimal resources from oncology and palliative care in well-planned, patient-centred care pathways.

The two paradigms might be understood to be representing two different cultures. Oncology has roots in mainstream medicine (ie, internal medicine), and is primarily based on the acute care model. From the mid 1960s, hospice and palliative care were established outside the main health-care systems, often financed by charities. At the time, the primary focus of palliative care was end-of-life care, with care provided by multidisciplinary teams working with patients and their families. Now, for the most part, oncological and palliative care cultures are still separate.

Research on integrating oncology and palliative care is heterogeneous. Almost all studies have been done in high-income countries, but the variation across countries, systems, and settings often limits the generalisability of findings. The 2018 *Lancet* Commission report on palliative care focusing on low-income and middle-income countries stated, "Poor people in all parts of the world live and die with little or no palliative care or pain relief."[1] That Commission gave a series of recommendations, such as how to quantify serious health-related suffering, and proposes an Essential Package of palliative care, which might also be relevant to high-income countries as a basic benchmark of successful implementation at the patient level. Their previous Commission also recommended international and collective action to receive universal coverage of palliative care and pain relief, and better evidence and

Lancet Oncol 2018

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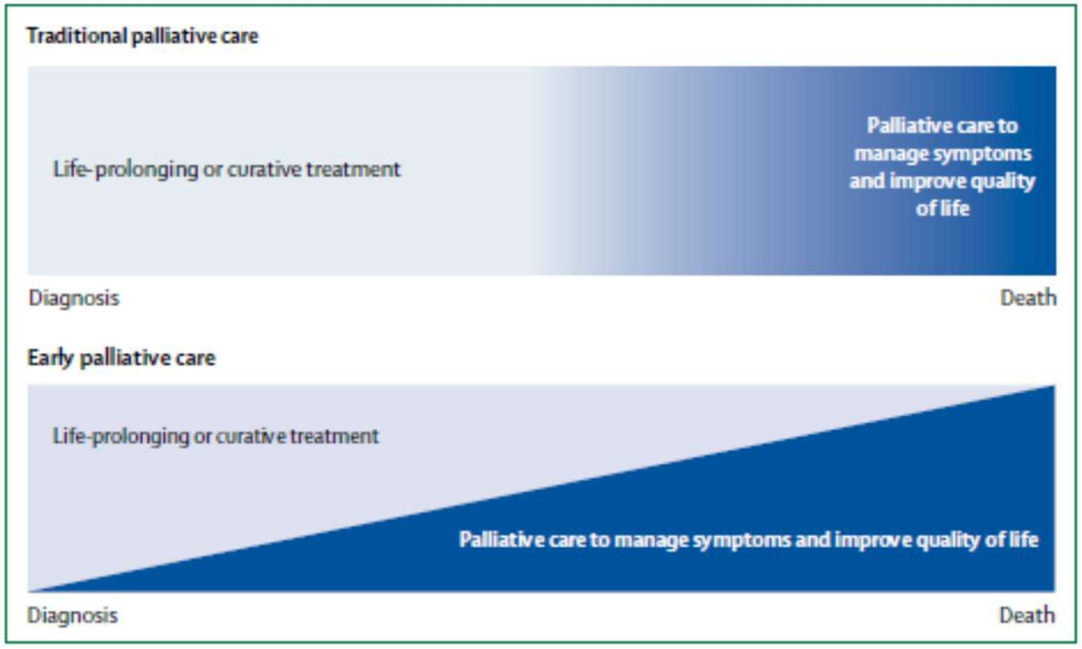

Statusartikel

Ugeskr Læger 2020;182:V06190343

Integration af specialiseret palliation og onkologi

Jonas Sørensen[1], Mette Asbjørn Neergaard[2], Mogens Grønvold[3], Anders Bonde Jensen[4], Per Sjøgren[5], Kristoffer Marsaa[6] & Geana Paula Kurita[5]

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Ugeskr Læger 2020;182:V06190343

HOVEDBUDSKABER

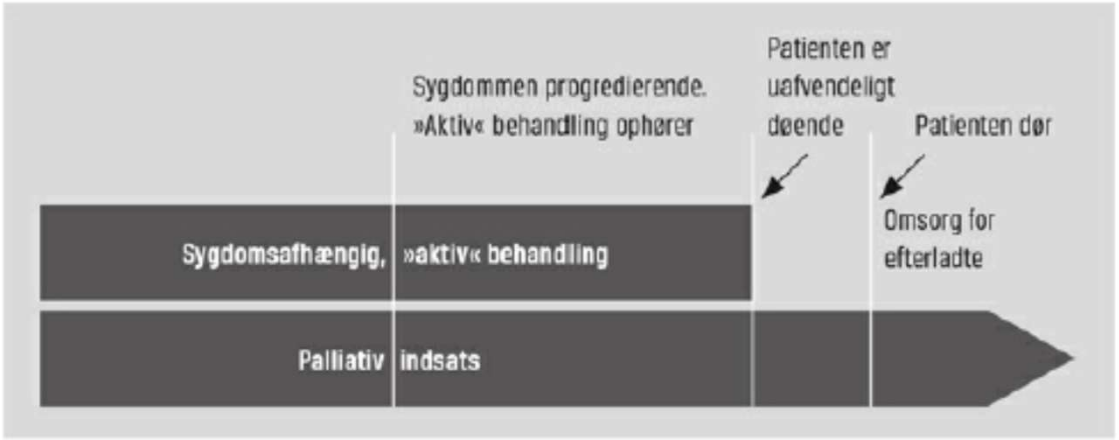
- Palliativ indsats opfattes fortsat af mange som ligestillet med terminal lindring og pleje.
- Integreret specialiseret palliativ indsats til onkologiske patienter har dokumenterede positive effekter.
- Integration kræver et styrket fokus på rekruttering, uddannelse og forskning inden for palliativ medicin.

Som reaktion på en tiltagende hospitalisering af døden og fokus på helbredende behandling udvikledes hospicetanken i 1960'erne, og fra 1980'erne udvikledes en mere systematisk tilgang til lindrende og understøttende behandling til kræftpatienter [1]. Grundlæggende for denne udvikling var et øget patientcentreret fokus og derved et fokus på patientens udækkede behov under og efter tumorrettet behandling.

»Den palliative indsats har til formål at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art« [2, 3].

Palliativ indsats tilbydes på enten specialiseret eller basalt niveau. Specialiseret palliativ indsats (SPI) ydes i både hospice- og hospitalsregi. I 2019 var der i Danmark 20 hospicer og 31 SPI-enheder med ambulatorie-/udefunktion, hvoraf 11 havde egne sengeafsnit [4]. Den basale palliative indsats forventes at blive ydet i alle dele af sundhedsvæsenet og indgå som led i anden pleje og behandling. Den dækkes bl.a. af kliniske hospitalsafdelinger, egen læge og hjemmesygeplejen og varetages af fagpersoner, der ikke har palliation som deres hovedopgave.

FIGUR 1 / Palliative indsatser i et sygdomsforløb [3, 7].



The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

RESULTS

Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (86% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; P=0.03). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, P=0.01). Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, P=0.05), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, P=0.02).

CONCLUSIONS

Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

From Massachusetts General Hospital, Boston (J.S.T., J.A.G., A.M., E.R.G., V.A.J., C.M.D., J.J., W.F.P., J.A.B.); the State University of New York, Buffalo (S.A.); Adult Palliative Medicine, Department of Anesthesiology, Columbia University Medical Center, New York (C.D.B.); and Yale University, New Haven, CT (T.J.L.). Address reprint requests to Dr. Temel at Massachusetts General Hospital, 55 Fruit St., Yawkey 7B, Boston, MA 02114, or at jtemel@partners.org.

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Original Article

PALLIATIVE MEDICINE

Palliative Medicine
1–11

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SAGE

Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: The Danish Palliative Care Trial

Mogens Groenvold[1,2], Morten Aagaard Petersen[1], Anette Damkier[3], Mette Asbjoern Neergaard[4], Jan Bjoern Nielsen[5], Lise Pedersen[1], Per Sjøgren[6], Annette Sand Strömgren[6], Tove Bahn Vejlgaard[7], Christian Gluud[8], Jane Lindschou[8], Peter Fayers[9,10], Irene J Higginson[11] and Anna Thit Johnsen[1,12]

Abstract

Background: Beneficial effects of early palliative care have been found in advanced cancer, but the evidence is not unequivocal.
Aim: To investigate the effect of early specialist palliative care among advanced cancer patients identified in oncology departments.
Setting/participants: The Danish Palliative Care Trial (DanPaCT) (ClinicalTrials.gov NCT01348048) is a multicentre randomised clinical trial comparing early referral to a specialist palliative care team plus standard care versus standard care alone. The planned sample size was 300. At five oncology departments, consecutive patients with advanced cancer were screened for palliative needs. Patients with scores exceeding a predefined threshold for problems with physical, emotional or role function, or nausea/vomiting, pain, dyspnoea or lack of appetite according to the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) were eligible. The primary outcome was the change in each patient's primary need (the most severe of the seven QLQ-C30 scales) at 3- and 8-week follow-up (0–100 scale). Five sensitivity analyses were conducted. Secondary outcomes were change in the seven QLQ-C30 scales and survival.
Results: Totally 145 patients were randomised to early specialist palliative care versus 152 to standard care. Early specialist palliative care showed no effect on the primary outcome of change in primary need (−4.9 points (95% confidence interval −11.3 to +1.5 points); $p = 0.14$). The sensitivity analyses showed similar results. Analyses of the secondary outcomes, including survival, also showed no differences, maybe with the exception of nausea/vomiting where early specialist palliative care might have had a beneficial effect.
Conclusion: We did not observe beneficial or harmful effects of early specialist palliative care, but important beneficial effects cannot be excluded.

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Hvordan får vi bedre forløb?

1. Afdække patientens / familiens behov og ressourcer
   - Systematisk, tidligt og løbende
2. Uddanne alle sundhedsprofessionelle (Speciale)
   - Lindring af symptomer / problemstillinger
   - Have den palliative tankegang med tidligt i forløbet
3. **Tale tidligt om patientens / familiens bekymringer og ønsker**

Advance Care Planning (ACP)

BMJ

RESEARCH

The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,[1] Andrew D Hancock, project officer,[1] Michael C Reade, physician,[2] William Silvester, intensive care physician and director[1]

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ABSTRACT

Objective To investigate the impact of advance care planning on end of life care in elderly patients.

Design Prospective randomised controlled trial.

Setting Single centre study in a university hospital in Melbourne, Australia.

Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

Interventions Participants were randomised to receive usual care or usual care plus facilitated advance care planning. Advance care planning aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes.

Main outcome measures The primary outcome was whether a patient's end of life wishes were known and respected. Other outcomes included patient and family satisfaction with hospital stay and levels of stress, anxiety, and depression in relatives of patients who died.

Results 154 of the 309 patients were randomised to advance care planning, 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%; P<0.001). In the intervention group, family members of patients who died had significantly less stress (intervention 5, control 15; P<0.001), anxiety (intervention 0, control 3; P=0.02), and depression (intervention 0, control 5; P=0.002) than those of the control patients. Patient and family satisfaction was higher in the intervention group.

Conclusions Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.

Trial registration Australian New Zealand clinical trials registry ACTRN12608000539336.

INTRODUCTION

Since the 1990s there has been an increasing awareness of the inadequacy of end of life care and of the poor knowledge of patients' wishes about their medical treatment at a time when they lose the capacity to make decisions,[1-6] resulting in patients being cared for in a way they would not have chosen.[7] This has continued to the present day.[8] Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical decisions."[9-11] The process of advance care planning informs and empowers patients to have a say about their current and future treatment. Advance care planning and the importance of improving end of life care are both supported by legislation in Australia,[9] the United Kingdom,[7] and the United States,[9-11] and are endorsed by professional bodies, including the Australian,[10] British,[7] and American[11] medical associations.

Elements of advance care planning include clarifying a patient's understanding of their illness and treatment options; understanding their values, beliefs, and goals of care; and identifying their wishes. If required a substitute decision maker (surrogate) is nominated.[12 13] The potential barriers to advance care planning include the availability of trained staff with the time, competence, and confidence to discuss advance care planning with patients; organisational commitment and policy to support advance care planning; and ensuring that doctors understand and support advance care planning.[14-16] Carrying out effective advance care planning in elderly patients is challenging, especially when they are acutely unwell and have a short length of stay in hospital before discharge.

Much of the focus on advance care planning has been on improving the completion rate of advance directives.[16 17] Such improvement does not necessarily improve medical care[17 18] or end of life care.[13 19] Models of advance care planning such as the Respecting Choices programme have shown that a coordinated, systematic, patient centred approach to advance care planning by trained non-medical facilitators can improve outcomes for patients.[13 20-22] Evidence also shows that advance care planning and end of life discussions reduce stress, anxiety, and depression in surviving relatives.[23-26]

Advance care planning and place of death, hospitalisation and actual place of death in lung, heart and cancer disease: a randomised controlled trial

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ABSTRACT

Objectives Advance care planning (ACP) can be a way to meet patients' end-of-life preferences and enhance awareness of end-of-life care. Thereby it may affect actual place of death (APOD) and decrease the rate of hospitalisations. The aim was to investigate if ACP among terminally ill patients with lung, heart and cancer diseases effects fulfilment of preferred place of death (PPOD), amount of time spent in hospital and APOD.

Methods The study was designed as a randomised controlled trial. Patients were assessed using general and disease-specific criteria and randomised into groups: one received usual care and one received usual care plus ACP. The intervention consisted of a discussion between a healthcare professional, the patient and their relatives about preferences for end-of-life care. The discussion was documented in the hospital file.

Results In total, 205 patients were randomised, of which 111 died during follow-up. No significant differences in fulfilment of PPOD (35% vs 52%, p=0.221) or in amount of time spent in hospital among deceased patients (49% vs 23%, p=0.074) were found between groups. A significant difference in APOD was found favouring home death in the intervention group (17% vs 40%, p=0.013).

Conclusion Concerning the primary outcome, fulfilment of PPOD, and the secondary outcome, time spent in hospital, no differences were found. A significant difference concerning APOD was found, as more patients in the intervention group died at home, compared with the usual care group.

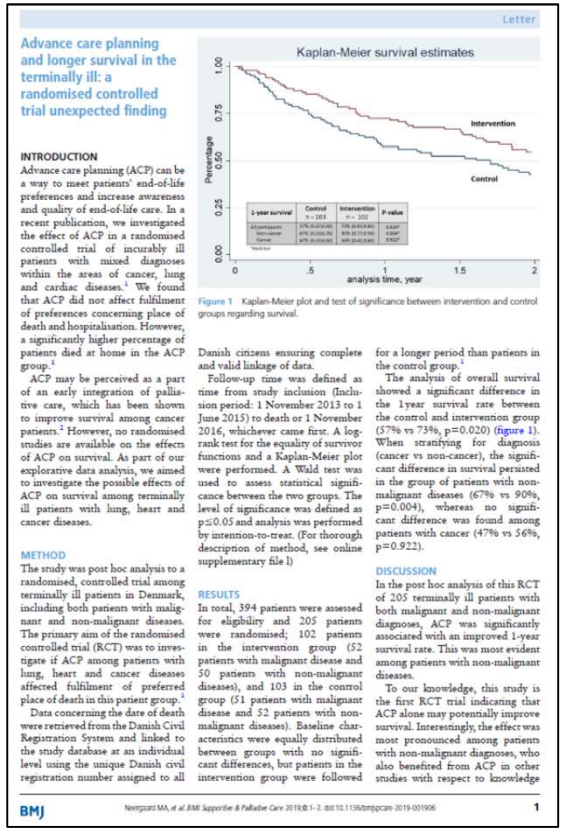
Trial registration number NCT01944813.

INTRODUCTION

Fulfilment of patients' preferred place of death (PPOD) is essential in palliative care. The potential inability of patients to participate in decision-making and voice their preferences could hinder optimal end-of-life care. Most patients prefer to spend the last part of their lives in their own home and not in hospital, and they also prefer to die at home; however, most patients still spend a lot of time in hospital and eventually die there.[1-3]

Advance care planning (ACP) is a way to extend the patient's autonomy to the terminal phase. ACP is a process "*whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions*".[4] Previously, ACP was often synonymous with the completion of advance directives.[4] Now, ACP is seen as a process clarifying how patients understand their illness and treatment options, thereby facilitating realistic views on their current situation and preferences.[5-7]

Advantages and disadvantages of ACP have been debated since the 1990s.[8-11] Previous research indicates that patients with different diagnoses who received ACP had an increased likelihood of achieving end-of-life care in line with their preferences compared with patients who did not receive ACP.[12-14] The effect of ACP may be through enhancing awareness of patients' preferences and creating a communicative room for patients,



Advance care planning and longer survival in the terminally ill: a randomised controlled trial unexpected finding

INTRODUCTION

Advance care planning (ACP) can be a way to meet patients' end-of-life preferences and increase awareness and quality of end-of-life care. In a recent publication, we investigated the effect of ACP in a randomised controlled trial of incurably ill patients with mixed diagnoses within the areas of cancer, lung and cardiac diseases.[1] We found that ACP did not affect fulfilment of preferences concerning place of death and hospitalisation. However, a significantly higher percentage of patients died at home in the ACP group.[1]

ACP may be perceived as a part of an early integration of palliative care, which has been shown to improve survival among cancer patients.[2] However, no randomised studies are available on the effects of ACP on survival. As part of our explorative data analysis, we aimed to investigate the possible effects of ACP on survival among terminally ill patients with lung, heart and cancer diseases.

METHOD

The study was post hoc analysis to a randomised, controlled trial among terminally ill patients in Denmark, including both patients with malignant and non-malignant diseases. The primary aim of the randomised controlled trial (RCT) was to investigate if ACP among patients with lung, heart and cancer diseases affected fulfilment of preferred place of death in this patient group.[1]

Data concerning the dare of death were retrieved from the Danish Civil Registration System and linked to the study database at an individual level using the unique Danish civil registration number assigned to all Danish citizens ensuring complete and valid linkage of data.

Follow-up time was defined as time from study inclusion (Inclusion period: 1 November 2013 to 1 June 2015) to death or 1 November 2016, whichever came first. A log-rank test for the equality of survivor functions and a Kaplan-Meier plot were performed. A Wald test was used to assess statistical significance between the two groups. The level of significance was defined as p≤0.05 and analysis was performed by intention-to-treat. (For thorough description of method, see online supplementary file 1)

RESULTS

In total, 394 patients were assessed for eligibility and 205 patients were randomised; 102 patients in the intervention group (52 patients with malignant disease and 50 patients with non-malignant diseases), and 103 in the control group (51 patients with malignant disease and 52 patients with non-malignant diseases). Baseline characteristics were equally distributed between groups with no significant differences, but patients in the intervention group were followed for a longer period than patients in the control group.[1]

The analysis of overall survival showed a significant difference in the 1year survival rate between the control and intervention group (57% vs 73%, p=0.020) (figure 1). When stranifying for diagnosis (cancer vs non-cancer), the significant difference in survival persisted in the group of patients with non-malignant diseases (67% vs 90%, p=0.004), whereas no significant difference was found among patients with cancer (47% vs 56%, p=0.922).

Kaplan-Meier survival estimates

1-year survival	Control n = 103	Intervention n = 102	P value
All participants	57% (0.47;0.66)	73% (0.63;0.83)	0.020*
Non-cancer	67% (0.53;0.78)	90% (0.77;0.95)	0.004*
Cancer	47% (0.33;0.60)	56% (0.42;0.68)	0.922*

*Wald test

Figure 1 Kaplan-Meier plot and test of significance between intervention and control groups regarding survival.

DISCUSSION

In the post hoc analysis of this RCT of 205 terminally ill patients with both malignant and non-malignant diagnoses, ACP was significantly associated with an improved 1-year survival rate. This was most evident among patients with non-malignant diseases.

To our knowledge, this study is the first RCT trial indicating that ACP alone may potentially improve survival. Interestingly, the effect was most pronounced among patients with non-malignant diagnoses, who also benefited from ACP in other studies with respect to knowledge

THE (BON VIVANT) ELEPHANT IN THE ROOM

”Skal jeg dø af min kræftsygdom?”

”Vil jeg få ulidelige symptomer?”

Hvordan får vi bedre forløb?

1. Afdække patientens / familiens behov og ressourcer
   - Systematisk, tidligt og løbende
2. Uddanne alle sundhedsprofessionelle (Speciale)
   - Lindring af symptomer / problemstillinger
   - Have den palliative tankegang med tidligt i forløbet
3. Tale tidligt om patientens / familiens bekymringer og ønsker

DANSKE KRÆFTFORSKNINGSDAGE 2022

Hvad kan vi opnå med rettidig palliativ indsats i de forskellige sektorer? Bedre forløb, bedre behandling! – også i den sidste tid

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