Integration af specialiseret palliation og onkologi. Er det realististisk?

Per Sjøgren, Palliativ Forskningsgruppe, Onkologisk Klinik, Rigshospitalet

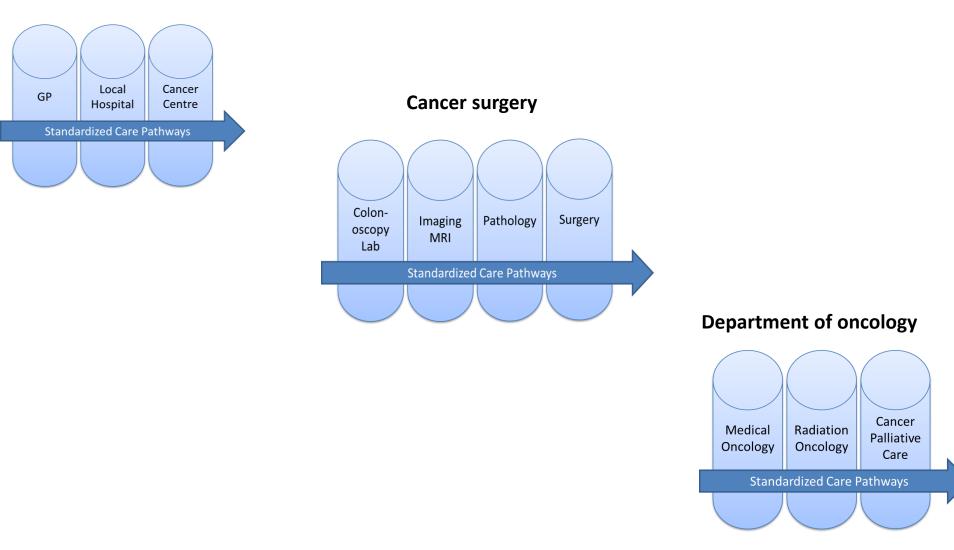
Integration

The World Health Organization (WHO) has defined the term integrated health services as: "the organization and management of health services, so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and promote value for money".

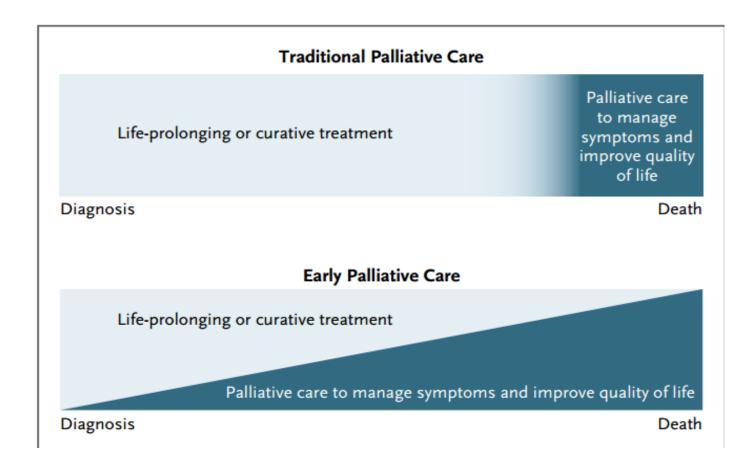
The European Pathway Association (EPA) defines Standardized Care Pathways as "a complex intervention of the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period".

Health care includes silos at different levels

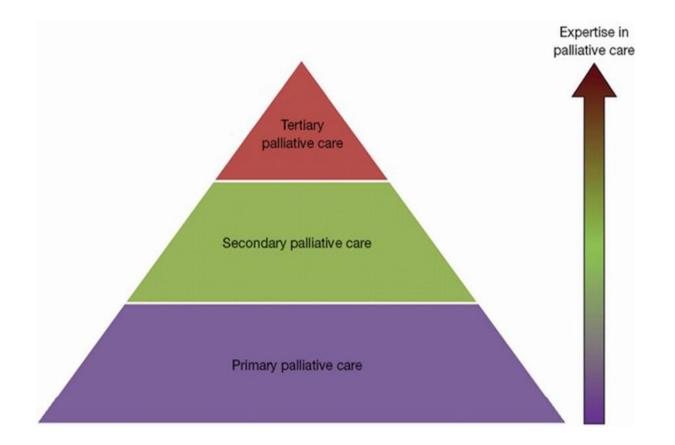
Health care system



Earl(ier) Palliative Care



Conceptual model of palliative cancer care delivery based on provider expertise



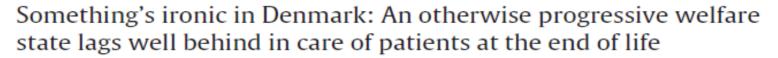




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ARTICLE INFO

Keywords; Palliative care Terminal care Hospice care

ABSTRACT

Tremendous strides have been made in the last two decades with regard to the quality of palliative care available to patients at the end of life. But progress has not been uniform, even among countries in the same region of the world. The objective of this study is to describe, in a comparative context, the current status of end-of-life palliative care in Denmark using quantitative research published in the past five years. This study's conclusions, based on a synthesis of the research, suggest that despite its well earned reputation as a generally progressive welfare state, Denmark tends to trail well behind its European neighbors when it comes to end-of-life care. Understanding the cultural forces that underlie this reality may help Danish health care professionals and policy makers overcome the barriers that stand in the way of providing state-of-the-art medical care to patients who suffer at the end of life.

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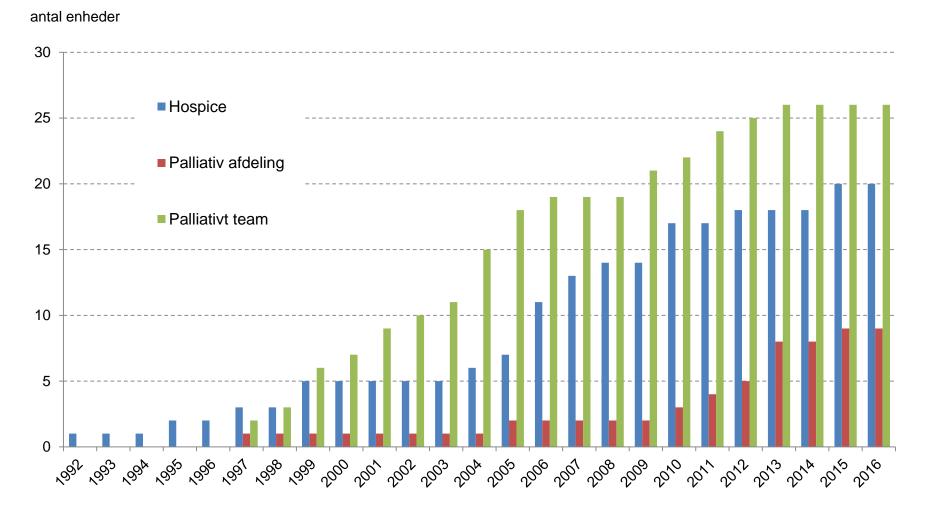
Udviklingen af specialiseret palliativ indsats i DK

Årstal	Milepæle
1992	Skt. Lukas Hospice, Hellerup (1. hospice)
1997	Palliativ Medicinsk Afdeling, Bispebjerg Hospital (1. afdeling) Palliativt Team, BBH (1. udgående team) Forskningsenheden v. Palliativ Medicinsk Afdeling, BBH
1999	Faglige retningslinier for den palliative indsats (SST)
2000	Hospicelov – offentligt betalt tilbud, omfattet retten til frit sygehusvalg
2001	Dansk Selskab for Palliativ Medicin, DSPaM, (lægefagligt selskab) Hospice Forum Danmark (national interesseorganisation)
2003	The Nordic Specialist Course in Palliative Medicine
2004	Hospicelov – driftsoverenskomst med hvert amt om minimum 12 pladser
2009-2010	PAVI, nationalt og tværfagligt videncenter DMCG-PAL, tværfaglig organisering indenfor DMCG strukturen, herunder Dansk Palliativ Database

Udviklingen af specialiseret palliativ indsats i DK

Årstal	Milepæle	
2011 – 2012	Kræftplan III REPHA Nye nationale anbefalinger for palliativ indsats (SST) Forløbsprogram for rehabilitering og palliation til kræftpatienter (SST) Palliativ indsats som en del af alle sundhedsaftaler Regionale implementeringsprogrammer	Sindhedsstyrelsen
2012 – 2013	Kompetencebeskrivelser (DMCG-PAL) Kliniske retningslinjer (DMCG-PAL) Ny vejledning om palliation (DSAM) Fagområde godkendelse af læger	
2014 -15	Regional implementering af forløbsprogrammer Sundhedsaftaler Behovs-screening og individuelle planer 24/7 vagtordninger? Uddannelse og kompetence Kvalitetssikring – ny kvalitetsmodel?	
2016 - 2017	Kræftplan IV Anbefalinger for den palliative indsats (SST)	

Udviklingen i antal enheder i den specialiseret palliativ indsats i DK, 1992-2016



I alt: 26 teams og ca 250 senge

EAPC White Paper 2009/10: Anbefalinger

palliativt team pr. 100.000 • 1 indbyggere = 56 teams i DK

• 80-100 palliative senge pr. 1 mio. indbyggere = $90 \times 5,6$ mio. = ca. 500 senge i DK

EAPC update

White Paper on standards and norms for hospice and palliative care in Europe: part 1

Recommendations from the European Association for Palliative Care

In this official position paper of the European Association for Palliative Care (EAPC), Lukas Radbruch, Sheila Payne and the Board of Directors of the EAPC outline and explain the association's recommendations for a common terminology and common quality norms

1. Background

The modern hospice movement was introduced by Cicely Saunders with the opening of St Christopher's Hospice in London in 1967. However, as early as 1975, Balfour Mount found are necessary not only for healthcare a confusion of terms when he looked for a designation for his new inpatient unit in Montreal, as in French-speaking Canada 'hospice' was already used in a different context, leading to the introduction of the term 'palliative care'

The struggle for a common language has been going on since then in hospice and palliative care throughout the world and has hampered the development of international standards and norms. Recently, the European Association for Palliative Care (EAPC) commissioned a survey on the development of palliative care in European countries. The Task Force on the Development of Palliative Care in Europe, led by Carlos Centeno and David Clark, has just published the results in the EAPC Atlas of Palliative Care in Europe, providing for the first time valid data for comparison of the state of palliative care across European countries.12 This evaluation showed some common structures, but also a wide variety in the structure of service development and care delivery. These differences are at least partly related to different understanding of the underlying concepts and the terms of palliative medicine. The development of a common terminology has been claimed as a prerequisite for meaningful comparisons. Following this lead, the EAPC is now putting forward suggestions for a common European

terminology following a consensus process with the national associations. Norms will be defined on the basis of this consensual terminology. Guidance on norms and standards professionals working in hospice and palliative care settings, but also for decision-makers in healthcare who are responsible for adequate access to palliative care for patients.

With the ongoing development of palliative care throughout Europe, decision-makers are challenged not only to decide where and when palliative care services should be developed, but also how they should be equipped and configured. Adequate structural quality is a prerequisite for high quality of care. Administrative and political decision-makers will aim for cost-effectiveness, and try to reduce costs by allocating a minimum of staff or reimbursement. Care providers will negotiate for adequate staff resources necessary for high quality of care. In this conflict, both sides will seek guidance on structural quality.

In this paper, the EAPC presents norms on structural quality for the provision of palliative care with in- and outpatient services in different settings. This White Paper takes into account the different concepts in the European countries and regions. This is acknowledged by the description of norms rather than the definition of standards. Whereas standards would imply an absolute limit below which quality palliative care is not possible (minimal standards), norms represent a consensus on quality goals that have to be aimed for (aspirational norms). If (or

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2009; 16(6)

278

Dansk Palliativ Database: Årsrapport 2016

Rapporten omfatter ca 10.000 patienter i SPI der døde i 2015 (96% er kræftpatienter):

- Stigning i henvisninger siden 2015 (3%)
- Sen henvisning (mediane overlevelse 39 dage fra henvisningstidspunkt)
- For lang ventetid
- Meget store forskelle regionalt og mellem institutioner

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.

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.

N Engl J Med 2010;363:733-42. Copyright © 2010 Massachusetts Medical Society.

Specialized palliative care in advanced cancer: What is the efficacy? A systematic review

Holmenlund et al, Palliat Support Care 2017

Author, journal, year	Country	Design	Time in disease trajectory	Intervention	Control	Primary aim	Effect	ary aim	Limitations	Quality of evidence
Grønvold et al., Palliat Med, 2017	Denmark	RCT	Stage IV cancer and need-based inclusion.	Early referral to a specialist palliative care team plus standard care	Standard care. SPC on request.	QoL: -	Physical symptoms: - Depression: - Anxiety: - Survival: -	ar à ann		-
Maltoni et al., EJC, 2016	Italy	RCT	≤8 weeks after diagnosis of metastatic pancreatic cancer.	Outpatient consultations with a PC specialist. Follow-up every 2nd-4th week, more often if necessary.	Standard care + On- demand early SPC.	QoLat 12±3 weeks: ↑	Physical symptoms: ↓ Depression: - Anxiety: - Overall survival: - Place of death: -		Power calculation not followed PC team not a full multidisciplinary team Only pancreatic cancer patients Lack of socio-demographic data Cross-over not described	Moderate
Temel et al., JCO, 2016	USA	RCT	≤8 weeks after diagnosis of metastatic cancer.	Outpatient consultations with a PC clinician. Follow-up at least monthly.	Standard care SPC on request.	QoL at 12 weeks: -	After 12 weeks: Depression: -	After 24 weeks: QoL: ↑ Depression: ↓	 No details about intention to treat Lack of diversity related to race and ethnic group Cross-over (34.3% of patients in control group had met with a PC member at least once at week 24 follow-up) 	High
Bakitas et al., JCO, 2015	USA	RCT	Diagnosed with advanced cancer within 30-60 days and prognosis of 6- 24 months.	The initial meeting was an outpatient PC consultation with PC specialist. Weekly telephone-based coaching sessions in 6 weeks. Monthly follow-up calls until death provided by a nurse.	Standard care + Nurse- led PC (3 months later).	QoL: - Physical symptoms: - Mood: - I-year survival: ↑ 15%	Overall survival: - Place of death: -		 Power not reached due to termination of study Cross-over (50% met with a PC member earlier than the prescribed 3 months) 	Low
Zimmermann et al., The Lancet, 2014	Canada	Cluster RCT	Advanced cancer and prognosis of 6- 24 months.	A PC physician and a nurse were present at the first consultation. Telephone call one week after initial consultation provided by a PC nurse. Thereafter telephone-based consultations were given when requested. Once a month there was outpatient follow-up in the PC clinic.	request.	QoL at 3 months: -	After 3 months: Physical symptoms: -	After 4 months: QoL: ↑ Physical symptoms: ↓	No details about intention to treat Recruitment bias in cluster RCT Sinall cross-over effect (8.6%)	High
Temel et al., NEJM, 2010	USA	RCT	≤8 weeks after diagnosis of metastatic lung cancer.	Outpatient consultations with a board-certified PC physician and advanced-practice PC nurses. Follow-up at least monthly, more often if necessary.	Standard care. SPC on request.	QoL at 12 weeks: ↑	Depression:↓ Survival:↑(post hoc ana)	lysis)	Only NSCLC patients Lack of diversity related to race and ethnic group Small cross-over effect (14%)	High
Bakitas et al., JAMA, 2009	USA	RCT	Diagnosed with advanced cancer within 8-12 weeks and prognosis of 12 months.	Telephone-based PC provided by PC nurse. Weekly follow-up calls the first four weeks. Monthly hereafter. Monthly group meetings, where PC physicians and nurses were present.	Standard care. SPC on request.	QoL over 13 months: ↑ Physical symptoms: -	Depression:↓ Overall survival: -		Power not reached due to termination of study Lack of information handling of missing data for follow-up Lack of diversity related to race and ethnic group Cross-over not described	Low
Jordhøy et al., Lancet 2000 and JCO 2001	Norway	Cluster RCT	Incurable cancer and prognosis of 2-9 months.	Patients were referred to the PC unit when enrolled. Meetings with general practitioner and community nurse were arranged when needed.	Standard care. SPC on request.	QoL: - Physical symptoms: - Mood: - Death at home: ↑			Randomization not clear Power calculation unclear Recruitment bias in cluster RCT Small cross-over effect (6%)	Low

Specialized palliative care in advanced cancer: What is the efficacy? A systematic review

Holmenlund et al, Palliat Support Care 2017

- The effect of SPC was varying between the studies:
 - 5/8 studies improved QoL (2 as secondary outcome)
 - 2/4 studies prolonged survival (1 as secondary outcome)
 - 3/7 studies relieved depression (secondary outcome)
 - 2/8 studies reduced symptom burden (secondary outcome)
- The heterogeneity in interventions, settings, target populations, and study outcomes make it difficult to compare trials.
- The evidence in this area is still incipient, but an emerging recommendation is in favor for using "early" SPC for adult patients with advanced cancer to improve QoL.
- One RCT focused on integration of community and SPI. More patients in the intervention group died at home (Jordhøy et al., 2001).





DOMUS

Systematic Fast-Track Transition from Oncological Treatment to Dyadic Specialized Palliative Home Care: DOMUS - A randomized clinical trial

Nordly M, Skov Benthien K, Soelberg Vadstrup E, Kurita GP, von Heymann-Horan AB, von der Maase H, Johansen C, Timm H, Kjellberg J, Sjøgren P.



Clinicaltrials.gov Identifier: NCT01885637





Preference for place-of-care and death

- Studies have shown that most patients with advanced cancer prefer to spend the last part of their lives at home (50-90%)
- In most western countries more than half of patients with advanced cancer die in a hospital
- Place of death for cancer patients in Denmark
 - 57% died in hospitals
 - 26% died at home

OECD 2010. Health at a Glance: Europe 2010 Higginson et al., J Palliat Med 2000 Neergaard et al., Scand J Carring Sci 2011 Gomes et al., BMC Palliat Care 2013 Skorstengaard et al., J Palliat Med 2017

Beccaro et al., J Epidemiol Community Health 2006 Bruera et al., JCO 2002 Burge et al., CMAJ 2003 Cohen et al., Palliat Med 2008 Cohen et al., Br J Cancer 2015

Dødsted og dødsårsager i Danmark 2007-2011



Introduction



The role of the GP in palliative home care (primary palliative care)

Substantial barriers the delivery of high quality PPP:

- GPs lose contact with their patients during cancer treatment
- Time is often a barrier to PPC provision; appointment times can be as short as ten minutes; especially out-of-hours support may be a problem
- Lack of training or expertise in managing physical or psychological symptoms
- Integration of PPP and SPC ?

Burt et al., Palliat Med 2006; Rhee et al., J Palliat Med 2008; Pivodic al., Palliat Med 2016

Wilson and Childs., Cochrane Database Syst Rev 2006

Mitchell., Palliat Med 2002

Caring for the informal caregivers

Family caregivers may experience:

- Distress, poor QoL, increased morbidity and healthcare utilization
- The prevalence of moderate to severe depression and complicated grief was 15% and 40%, respectively, at 6 months post-loss
- There is an increased awareness of the caregiver burden and interventions directed towards the patient-caregiver dyads

Psycho-Oncology Psycho-Oncology 22: 1688–1704 (2013) Published online 9 October 2012 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.3200

Review

A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer^{\dagger}

Hoda Badr¹* and Paul Krebs² ¹Oncological Sciences, Mount Sinai School of Medicine, New York, NY USA ²New York University, School of Medicine, New York, NY, USA

Regan et al. BMC Cancer 2012, 12:279 http://www.biomedcentral.com/1471-2407/12/279



RESEARCH ARTICLE

Open Access

Do Couple-Based Interventions Make a Difference for Couples Affected by Cancer?: A Systematic Review

Tim W Regan^{1*}, Sylvie D Lambert², Afaf Girgis², Brian Kelly¹, Karen Kayser³ and Jane Turner⁴







- The primary aim of the DOMUS study was to investigate whether a model of systematic fast-track transition from oncological treatment to specialized palliative care at home results in more patients reaching home as the preferred place of care and death.
- Secondary aims were to investigate effects on quality of life, symptoms and survival time.



Methods



Study Design	Randomized Controlled Trial Sample size: 340 in- and outpatients Balanced parallel-group randomization (1:1)
When and where	Cancer patients treated at the Department of Oncology, Rigshospitalet, Copenhagen University Hospital from June 2013 -> August 2016
Primary objective	To investigate whether an accelerated transition from oncological treatment to SPC enriched with a psychological intervention at home for patients with incurable cancer results in more time spent at home and death at home
Secondary objectives	To relieve the patients' symptoms To improve the patients' and the caregivers' quality of life To relieve the patients' as well as the caregivers' psychosocial problems To relieve the bereavement process among the closest relatives To prolong survival of patients To improve cooperation between professionals To analyze cost-effectiveness

Inclusion criteria

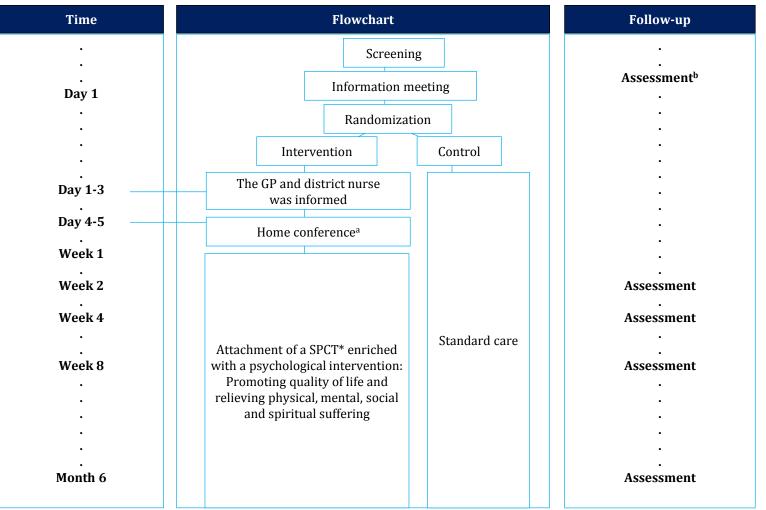
- Adult (at least 18 year old) cancer patients treated at the Department of Oncology, Copenhagen University Hospital
- Patients who wanted to spend as much time as possible in their own homes supported by a Specialized Palliative Care Team (SPCT)
- Patients with incurable cancer
- Patients with no or limited antineoplastic treatment options or patients who resigned antineoplastic treatment
- Patients living in the Capital Region, Denmark
- Written informed consent

Exclusion criteria

- Patients who have already been referred to an SPT
- Hospitalized patients who are judged incapable of being discharged home
- Patients who are admitted to other hospitals
- Patients who did not speak Danish well enough to answer the questionnaires
- Patients who were considered incapable of cooperating in the trial



Intervention and control group



a) The patient was referred to an SPCT operating in the local area. If the SPCT's capacity was depleted within the time limits of the protocol, another SPCT was involved according to an algorithm (unpublished).

b) Assessment with questionnaires at baseline, 2, 4 and 8 weeks, and 6 months.





Intervention- and control group

	Intervention	Control
Contact to Health Care service	Continued treatment in department of oncology clinic and other health care services	Continued treatment in department of oncology clinic and other health care services
Specialized palliative care	Starting within 5 days with a home care conference followed by contact when needed	Treatment referred SpC in to be arises the be
Basic palliative care	Contact with the GP and municipal home care/home nursing service within 5 days	ed Sption Usual but
Psychologist	Min. 2 conversations with patients and closest relative(s) and thereafter when needed	referred SpC in to be arises the need



Methods



Settings

- The health care system of the Capital Region of Denmark serves 1.77 million inhabitants.
- Nine SPCTs operate in the Capital Region of Denmark out of which four are hospice-based and five hospital-based.
- According to the EAPC White Paper, which recommends 1 team per. 100,000 inhabitants, the team capacity is approximately half of the recommended number.
- As, only 2/9 teams have appointed psychologists as a part of the multidisciplinary home care team a manualized psychologist intervention was added in order to support the patient and caregiver dyads in spending the most possible time at home.
- The Danish health system is funded through taxes and is free at the point of delivery for the patient and caregiver. In addition, closest relatives can be granted care leave from their workplace.

von Heymann-Horan et al., Palliat Support Care 2017







Intervention group

- The first contact with a SPCT was 7±5 weekdays after randomisation and 230±120 days before death
- 9 of 162 patients did not receive the planned home conference
- The GPs participated in only 14% of the home conferences

Control group

- The first contact with a SPCT was 117±115 weekdays after randomisation and 95+121 days before death
- 66% were in contact with a SPCT or hospice after randomisation





Time Spent at Home and Place of Death

				Sensitivity analysi	is		
	Control group	Intervention group	p-value	Estimated difference	p-value	95 % Confidence interval	Odds-ratio
Time spent at home, mean±SD	n = 159	n = 162		\frown			
% Days	83·3±21·7	85·7±18·5	0·491ª	4.8%	0·026 ^d		
Place of death, n (%)	n = 125	n =132					
Home Nursing home	22 (17·6) 4 (3·2)	30 (22·7) 3 (2·3)	0·460 ^{b,c}	9.9%	0.110 ^d	[0.88;3.22]	1.69
SPC units	63 (50·4)	66 (50·0)		\bigcirc			
Hospital (ex SPC units)	22 (17·6)	25 (18·9)					
Respite care facility	11 (8.8)	6 (4·6)					
Unknown	3 (2·4)	2 (1.5)					

a: Wilcoxon, b: Fisher's exact test, c: Home (including nursing home) vs. other places, d: Logistic regression

- Regarding number of deaths at home there was not statistically significant difference between groups.
- The patients in the intervention group spent 86% of the time after inclusion at home, compared to 83% in the control group, which was a statistically non-significant difference (p=0.491). Adjusting for significant differences in baseline data in clinical and sociodemographic variables the difference was 4.8% reaching statistical significance (p=0.026).







Symptoms and QoL

At 6 months statistically significantly positive effects were observed for emotional functioning (p=0.039), social functioning (p=0.001), and global health status/QoL (p=0.005).

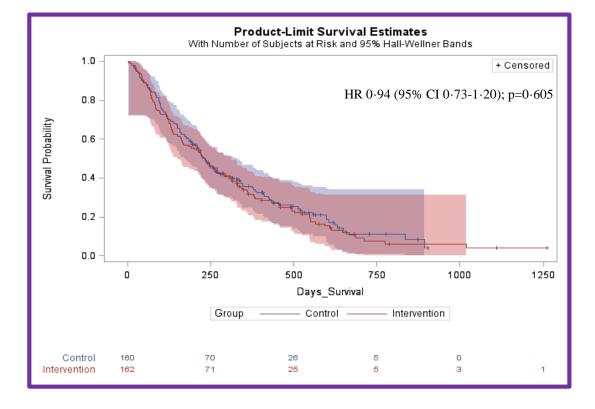
	Control group		Intervention group		Difference		Adjusted for	Multiple
	n	Mean observed change from baseline ± SD	n	Mean observed change from baseline ± SD	between change scores	Wilcoxon (p-value)	differences in clinical and sociodemographic variables (p-value)	imputations (p-value)
Physical Functioning								
4 weeks	112	0·2±15·3	132	2·1±12·8	-1·8±14·0	0.022	0.248	0.345
Emotional Functioning								
6 months	66	-4·3±22·9	79	4·9±19·6	-9·1±21·2	0.039	0.055	0.010
Social Functioning								
6 months	66	-12·9±35·5	79	3·0±27·5	-15·8±31·4	0.001	0.014	0.009
QoL/Global health								
status								
6 months	66	-11·5±27·9	79	0·1±23·2	-11·6±25·5	0.005	0.040	0.012
Nausea/Vomiting								
8 weeks	100	-0·3±21·8	116	-5·0±23·6	4·7±22·8	0.005	0.040	0.116
6 months	66	0·5±24·3	79	-6·1±21·0	6·6±22·6	0.023	0.079	0.148
Dyspnoea								
2 weeks	126	-2·4±26·1	134	3·7±24·4	-6·1±25·2	0.008	0.023	0.049
8 weeks	99	-5·4±26·0	114	4·4±27·5	-9·8±26·8	0.014	0.005	0.007
Appetite loss								
4 weeks	110	-0·6±25·9	133	-9·3±33·4	8·7±30·3	0.044	0.020	0.029
6 months	65	9·2±36·1	79	-2·5±40·6	11.8±38.6	0.010	0.226	0.137
Diarrhoea								
2 weeks	125	0·3±26·3	136	-6·1±25·7	6·4±26·0	0.020	0.028	0.067



Results

UNIVERSITY OF COPENHAGEN FACULTY OF HEALTH AND MEDICAL SCIENCES

Survival



Survival of the patients was assessed with a Kaplan-Maier plot with 95% confidence intervals.

- No difference where found between the two groups with the Log-rank test p=0.6054
- Sensitivity analysis did not change the result





The DOMUS intervention resulted in slightly more time spent at home in the adjusted analysis as well as clinically significantly positive effects on QoL, social-, and emotional functioning at 6 months.

There were indications of poor collaboration between health care sectors

The DOMUS model is realistic and can be implemented within a reasonable organizational and economical frame

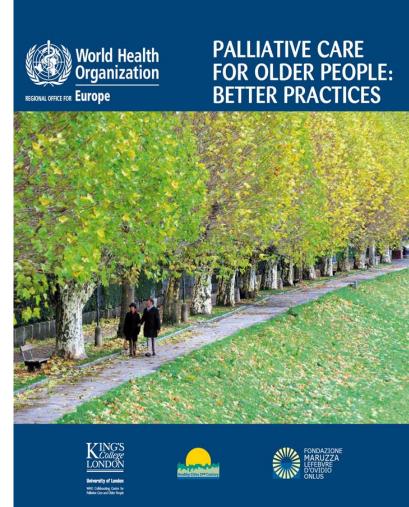
It may be adjusted and modified to the changing capacity of the health care system and needs of patients with incurable cancer and their informal caregivers

A post-hoc analysis will be carried out when all participating patients have died

We are awaiting assessment of the effects of the intervention on the informal caregivers, cost-benefit analyses and evaluation from health care staff in SPTs, Department of Oncology and from GPs and district nurses

Konklusioner og perspektiver vedrørende integration af SPI og onkologi

- Non-maligne palliativ indsats
- Hospice vs hospitalsbaseret indsats
- Medicinsk speciale i palliativ medicin
- Robusthed angående palliative enheders kapacitet
- og ledelse
- Integration med primær sektor: Hjemmebehandling
- Tidlig intervention
- Mind-set hos onkologer og palliative medicinere





24-26 May 2018, Bern, Switzerland

EAPC



Early bird registration deadline: 15 March 2018 www.eapcnet.eu/research2018