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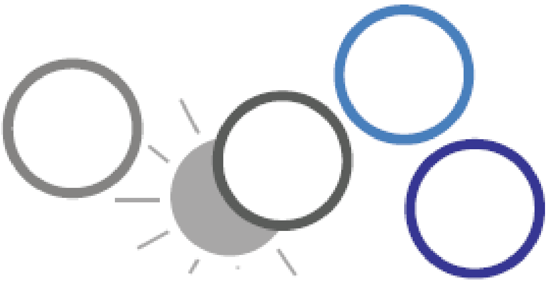
FACULTY OF HEALTH AND MEDICAL SCIENCES

Which cancer patients are admitted to specialised palliative care?



PhD Thesis

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Preface

‘Specialised palliative care’ (SPC) has been a part of my professional life since I graduated from the university in 2010. It was the topic for my master thesis and now it has been the topic for my PhD thesis. This project started five years ago and has been a journey I will never forget.

A great thank to my supervisor professor Mogens Grønvold for giving me the opportunity to do this thesis, for your support and for sharing your great experience in the process, for always believing in me, and for always having just a ‘few’ comments to my work. It has been a pleasure to work with you in the last seven years, with your positive attitude and great commitment to this research field.

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Original Papers

This thesis is based upon the following four papers:

1. Adsersen M, Thygesen LC, Jensen AB, Neergaard MA, Sjogren P, Groenvold M. Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD). *BMC Palliative Care* 2017 Mar 23;16(1):21
2. Adsersen M, Thygesen LC, Neergaard MA, Jensen AB, Sjogren P, Damkier A, Clausen LM, Groenvold M. Cohabitation status and admittance to specialised palliative care (SPC) for cancer patients - A nationwide study from the Danish Palliative Care Database. (*Draft*)
3. Adsersen M, Thygesen LC, Sjogren P, Neergaard MA, Mondrup L, Nissen JS, Clausen LM, Groenvold M. Social inequality in admittance to specialised palliative care (SPC) for patients with cancer. A nationwide study from the Danish Palliative Care Database. (*Draft*)
4. Adsersen M, Thygesen LC, Neergaard MA, Bonde JA, Sjogren P, Damkier A, et al. Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD). *Acta Oncologica* 2017 Sep;56(9):1210-17

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Original Papers

Introduction

Background

In Denmark 52,824 individuals died in 2016 (1) and cancer is the cause of death for around one third of the individuals (2). It is recommended by the Danish Health Authority that palliative care is available for cancer patients and all other patients with a life-threatening illness (3). Palliative care is defined by World Health Organization (WHO) as: *"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"(4)*. This definition is internationally accepted and is the definition used in Denmark. Palliative care is often divided into basic palliative care, given in the health care system where health professionals have palliative care as a part of their job function e.g. as general practitioner, employee of hospital departments (other than palliative) or municipalities; and specialised palliative care (SPC), provided by institutions where health professionals have palliative care as their main job function. The focus in this thesis will entirely be at SPC (3).

Previous studies have shown that SPC is valuable for both the patient and caregiver (e.g. a spouse/cohabitant) and from a societal economic perspective. A systematic review from 2010 concluded that patients admitted to SPC had better pain and symptom control and, less anxiety; and the number of hospital admissions was reduced (5). A systematic review and meta-analysis (2016) including 43 Randomised controlled trials (RCT) investigated the association between palliative care and people living with life limiting illness and their caregivers. They found for the patient: reduction in symptom burden; improvement in quality of life and; patient satisfaction; but no association with survival (6). Further, there has recently been published a systematic review investigating the effect of SPC in adult patients with advanced cancer. In line with the review from 2016, they concluded increasing support in the studies to higher quality of life for patients in SPC, moderate support to a reduction in symptom burden and few studies found even longer survival for patients in SPC (7).

SPC has been found to be helpful in relation to bereaved caregivers to move on with their lives and fewer caregivers had unmet needs if SPC was involved in the disease trajectory (8;9). A study from USA found higher survival for caregivers (wives) if their deceased husband used hospice. The association was not statistically significant in relation to bereaved husbands (10). The caregivers were more satisfied with the quality of care for patients (6;9), and it was found that the patient was more often treated respectfully in

SPC institutions (11). Further, a systematic review found that caregivers obtained better quality of life, and had reduced risk of depression and complicated grief symptoms (9).

In relation to economy, a systematic review and meta-analysis found that patients admitted to palliative care were less likely to attend emergency department in the last month of life than patients not receiving SPC (12). Two additional reviews of economic analyses of SPC indicated that the health care costs of patients receiving SPC were lower (13;14).

In line with other countries (15-23), the majority of Danish patients admitted to SPC had cancer (96%) (24;25) and an increase in admittance to SPC was found for this group of patients, - in 2016 it was around 50% (25). The number of cancer patients with a need of SPC is unknown, but data from Danish Palliative Care Database document that 20% of the patients referred to SPC – with a judge need of SPC in relation to the referring physician and the SPC institution receiving the referral – are not admitted to SPC (25). A limited capacity of SPC and waiting time for this patient group means that patients might die on the waiting list before admittance to SPC is possible. It may be problematic if patients, who have accepted a referral to a SPC institution, are not admitted. Patients referred to SPC have a life-threatening disease and often limited physiological and psychological resources. These patients may be afraid of not receiving the best possible treatment, and that the non-SPC institutions cannot handle their problems. This may be stressful for the patient.

Admittance to SPC demands a referral from a physician (with a few exceptions); and difference in attention, knowledge or the perception of the patient's situation by the health care professionals, and by patients and caregivers who should accept the referral to SPC, may affect the admittance. The types of SPC institutions and the integration with the rest of the health care system may be another factor related to admittance to SPC. In a large health care system with many different practices it takes time to change and develop new procedures. It takes time to establish new cooperation between the SPC institutions and the relevant non-SPC departments, and for SPC to be an integrated and accepted part of the health care system. A geographic variation in what is offered and to whom can complicate the situation further.

Table 1 shows an overview of the literature investigating admittance to SPC, including studies with main focus on admittance to SPC comparing patients admitted to SPC with patients not admitted to SPC.

Table 1 Overview of studies about admittance to specialised palliative care (SPC)

First author, country, year	Study design, N, study population	Data collection method	Type of SPC	Admittance measurement	Results in relation to sex, age, diagnosis, geography, cohabitation status and SEP	Comments
Addington-Hall, United Kingdom, 1998 (26)	Retrospective cohort study, N=2,915, Patients with cancer	Interview with family or other who knew about the last year of life	In-patient care in hospices and other SPC care in-patient units	Admitted to hospice in-patient care: yes/no	0 Sex 0 Marital status 0 Social class* + Younger + Patients with breast & colorectal cancer - Patients with haematological cancer	SEP: social class measured by occupation
Addington-Hall, United Kingdom, 2000 (27)	Retrospective cohort study, N=2915, Patients with cancer	Interview with family or other who knew about the last year of life	Community specialist palliative care nurses	Receiving community specialist palliative nurses: Yes/no	+ Patients under 75 years old +Patients with breast cancer + Married 0 Sex 0 Social class* - Patients with leukaemia, lymphoma, myeloma or brain cancer	SEP: social class measured by occupation
Beccaro, Italy, 2007 (28)	Retrospective cohort study, N=2,000, Patients with cancer	Interview with closest caregiver and best informed person	Domiciliary palliative care team	Admitted to domiciliary palliative care team: yes/no	+ Geographic: North 0 Marital status 0 Higher education* - Geographic: South	+ higher education for the caregiver
Bossuyt, Belgium, 2011 (29)	Retrospective cohort study, N=2,445, patients with cancer and non-cancer	SENTI-MELC study (patient-based data from the national Belgian Sentinel Network of General Practitioners)	SPC (multidisciplinary palliative home care, palliative support team in a home care/hospital, inpatient palliative care unit, palliative day care centre)	Admitted to multidisciplinary specialist palliative services: yes/no	+ Higher education*	
Burge, Canada, 2002 (30)	Retrospective cohort study , N=4376, Patients with cancer	administrative health care data	Palliative Care Programme (in-patient palliative care unit and palliative care teams)	Registered in a palliative care programme: Yes/no	+ Younger	

Burge, Canada, 2008 (31)	Retrospective population-based study, N= 7511, Patients with cancer	6 Administrative health databases and contextual data from provincial and census information	Palliative Care Programme (in-patient palliative care unit and palliative care teams)	Registered in a palliative care programme: yes/no	+ Younger +Women + Higher income + Living in urban areas + Higher education (for patients <65 years old) - patients with haematological, breast, prostate cancer	
Burt, United Kingdom, 2010 (32)	Prospective cohort study, N=252 (patients) Patients with lung cancer	Semi-structured questionnaire including QLQ-C30 and LC-13, medical records	Specialised palliative care team (community palliative care provider, palliative care outpatient clinics)	Admitted to SPC: yes/no	0 Age 0 sex, 0 'deprivation Index' 0 living alone	Area-level deprivation (IMD 2004) Need assessment: QLQ-C30 and LC-13
Chen, USA, 2003 (18)	Cohort study N=234 Patients with lung, breast, prostate and colon cancer	Structured interview using standardised questionnaire	Specialised palliative care (Hospice)	Admitted to Hospice care: yes/no	+ older 0 married 0 cancer diagnose - Highest educated*	
Cohen, Canada, 2012 (15)	Retrospective cohort study, N=495 Patients with cancer and non-cancer	Hospital charts	Palliative services (palliative care unit and in-house palliative care team)	Admitted to palliative care yes/no	+ Younger + Patients with cancer	
Costantini, Italy, 1993 (33)	Population-based cohort study N= 12,343 Patients with cancer	Data from the original death certificates (from the city's department of statistics)	Palliative home care team	Receiving palliative home car: Yes/no	+Younger + married + Higher education* + patients with lung, breast, prostate cancer	Descriptive analyse of admittance
Currow, Australia, 2004 (19)	The South Australian Health Omnibus survey (annual random face to face cross-sectional survey of 4,400 people) N=4,400 patients with cancer and non-cancer	Interview	Specialised palliative care services (nursing and medical specialist or consultants in palliative care working in an interdisciplinary team)	Use a palliative care services: Yes/no	+ Higher income* (respondent) + patients with cancer 0 geographic region (respondent)	Data about SEP is from respondents and not the patient Descriptive analyse of admittance
Currow, Australia, 2008 (20)	The South Australian Health Omnibus survey (annual random face to face cross-sectional survey of 4,400 people)	Interview	Specialist multidisciplinary palliative care services (hospice, acute care, outpatient clinics , home visits	Using a palliative care service: Yeas/no	+ Patients with cancer + Higher income* (respondent) 0 Age (respondent)	Data about SEP is from respondents and not the patient Descriptive analyse of

	N= 7,105 patients with cancer and non-cancer					admittance
Currow, Australia, 2012 (34)	Cohort study, N=10,064, patients with cancer and non-cancer	Palliative Care Outcome Collaboration – 'database' (national quality initiative, 91/179 services deliver data (80% of the patients)	Specialist palliative care service (inpatient, home visits and outpatient)	Using a palliative care service: Yeas/no	+ Cancer patient - Women - Highest SEIFA (most advantaged),	SEP: SEIFA group: socio-Economic Index for Areas – Index of disadvantage Descriptive analyse of admittance
Fadul, USA, 2007 (35)	Cohort study N=1,453, patients with cancer	Medical records from the computerised database	Palliative care service (palliative care consultation + follow up or palliative care unit)	Admitted to palliative care services: yes/no	0 Age - Patients with haematological cancer	
Fairfield, USA, 2012 (36)	Cohort study, N=8,211, women with ovarian cancer	Medicare database and Economic Research Service	Specialised palliative care (Hospice)	Admittance to Hospice care yes/no	+ Higher income + Higher education + Younger 0 Marital status	Descriptive analyse of admittance in relation to education Women only
Gagnong, Canada, 2004 (37)	Cohort study N=2291 women with breast cancer	Administrative health data	Palliative Care-orientated Profile Score (Including place of death and the last six months of live)	Admittance to palliative care: yes/no	- Younger	Women only
Grande United Kingdom, 2002 (38)	Case Control study, N=327, Patients with cancer	Register data	Hospital at Home for palliative care (HAH)	Admitted to hospital at home: yes/no	+ Younger + Genitourinary cancers 0 Sex, 0 Social class* 0 Jarman deprivation index - Patients with breast cancer	SEP: Jarman deprivation index & Social class
Grande, United Kingdom, 2006 (21)	Cohort study N=123 Patients with cancer and non-cancer	Interview and register data	Specialised palliative care (MacMillian specialist advice, Marie Curie home nursing and hospice inpatient care)	Admitted to specialised palliative care: yes/no	+ Younger (patient and caregiver) + Patients with cancer 0 Occupational class* 0 Jarman deprivation index	SEP: Jarman deprivation index Occupational class
Gray, United Kingdom, 1997 (39)	Retrospective cohort study, N=521, patients with cancer	Register data (death register)and questionnaire	specialist palliative care services (day hospice, home care, team of Marie Curie nurses, in-patient hospice)	Admittance to SPC: Yes/no	+ Younger 0 Social class* 0 Sex 0 Diagnosis	SEP: Social class (OPCS classification system – based on occupation) Descriptive analyses
Greiner,	Cohort Study (National	Death certificates and	SPC (home or inpatient	Admittance to hospice:	+ Never married	Age and sex results are from

USA, 2003 (40)	Mortality Followback Survey) N= 11,291	interview with relatives	hospice service)	yes/no	+ Higher education* + Higher income* +Younger - Women	descriptive analyses
Hui, USA, 2012 (16)	Retrospective cohort study, N=816, patients with Cancer	Medical records	Palliative care (active palliative care program: three mobile teams, an acute PC unit and a supportive care clinic)	Admittance to palliative care consultation: yes/no	+ Younger + Women + Married + Patients with gynaecological, breast or gastrointestinal cancer 0 Education* - Patients with haematological cancers	
Hunt, Australia, 1998 (41)	Cohort study N= 5673 Patients with cancer	Register data (Central Cancer Registry)	Specialised palliative care (Hospice)	Admittance to hospice: yes/no	+ Younger 0 Sex 0 Socioeconomic status* - Haematological cancer	SEP: Socioeconomic status for patients in metropolitan areas
Hunt, Australia, 2002 (42)	Cohort study, N=3,086 Patients with cancer	Register data	Specialised palliative care (hospice and palliative care team)	Admittance to a palliative care program: yes/no	+Younger 0 Sex 0 SEP (residential area) - Country residents - Patients with prostate, breast and haematological cancer	SEP: socioeconomic status of residential area
Iwashyna, USA, 2002 (43)	Cohort study N=1,221,153 Patients with cancer and non-cancer	Dataset from 'Care after the Onset of serious Illness (COSI)' – based on Medicare claims	Specialised palliative care (Hospice)	Admittance to hospice: yes/no	- Patients with haematological cancer	Descriptive analyses
Johnston, Canada, 1998 (44)	Retrospective cohort study N= 14,949	Register data (administrative health data)	Specialised palliative care (Halifax-based palliative Care Programme: inpatient, in-hospital consultations, ambulatory patients, home service, bereavement support)	Admittance to a Palliative Care Program: yes/no	+ Younger + Head and neck cancer 0 Sex - Hematopoietic cancer - Lymph nodes	
Keating, USA, 2006 (45)	Cohort study N= 3,805 Patients died of breast, colorectal, lung and prostate cancer	Register data (clinical and administrative from Kaiser Permanente of Northern Carolina)	Specialised palliative care (Hospice)	Admittance to hospice: yes/no	+ Women, +Older + Higher income 0 Cohabitation status 0 Education	SEP: high school graduates in patient's census block group of residence
Lackan, USA,	Retrospective cohort study,	Medical database (SEER-Midicare database)	Specialised palliative care (Hospice)	Admittance to hospice: yes/no	+ Younger + Married,	

2004 (46)	N=170,136, patients with breast, colorectal, lung and prostate cancer				+ Living in urban areas + Patients with lung cancer + Higher income	
Lackan, USA, 2005 (47)	Cohort study, N= 71,948, patients with breast, colorectal, lung and prostate cancer	Medical database (SEER-Midicare database)	Specialised palliative care (Hospice)	Admittance to hospice: Yes/no	+ Women + Married individuals	
Lammi, Finland, 2000 (48)	Case-control study, N=72 patients, cancer patients	Questionnaire	Specialised palliative care (Hospice)	Admittance to hospice: Yes/no	+ Younger + Higher socioeconomic status* 0 Sex 0 Marital status	SEP: Occupation status classified into socioeconomic status Descriptive analyses
Locher, USA, 2006 (22)	Cohort study N= Patients with cancer	Medical database (SEER-Midicare database)	Specialised palliative care (Hospice)	Admittance to hospice: Yes/no	+ Patients with cancer + Pancreas, lung, liver cancer + Married - Haematological cancer	Descriptive analyses (diagnosis)
Maddison, Canada, 2012 (17)	Cohort study, N =1,201 Patients with colorectal cancer	Administrative data	Palliative care program	Access to a palliative care program: yes/no	+ Younger + Higher income 0 sex	
Nayar, USA, 2014 (49)	Cohort study, N= 91,039, Patients with lung cancer	Administrative data	Specialised palliative care (Hospice)	Admittance to hospice: yes/no	+women + Higher SES - younger - residents of rural areas	SEP: socioeconomic status (median income – ZIP code of residence)
Neergaard, Denmark, 2013 (50)	Register-based cohort study, N= 599, Patient with cancer	Register data	Outreach specialist palliative care teams	Access to an outreach specialist palliative care team: yes/no	+ Younger + Married 0 Income* 0 urbanity - Patients with breast cancer Sex specific analysis: Women: + Married Men: +Patients with colorectal and prostate cancer	Education* was not included in the analysis – missing values
Rosenwax, Australia,	Retrospective cohort study,	Administrative databases	Specialised palliative care (Hospital-based and	Access to Specialised palliative care: yes/no	+ Younger + Married	SEP: index of Socio-Economic Disadvantage

2006 (23)	N=27,971, Patient with cancer and non-cancer		community-based specialised palliative care)		+ Patients with cancer + Living in major cities 0 Sex 0 Social class 0 Urbanity (non-cancer)	
Rosenwax, Australia, 2016 (51)	Retrospective cohort study, N=12,817, Patient with cancer and non-cancer	Administrative databases	Specialised palliative care (Hospital-based and community-based palliative care)	Access to Specialised palliative care: yes/no	+Younger + Women - Living alone - Rural areas, 0 Social class	SEP: index of Relative Social Disadvantages
Tang, USA, 2003 (52)	Prospective Cohort study N=127 Cancer patients	Interview	Specialised palliative care (Hospice home care)	Admittance to hospice home care: yes/no	+ Women	
Tang, Taiwan, 2010 (53)	Retrospective cohort study N= 204,850 Patients with cancer	Administrative data	SPC (hospice)	Admittance to hospice: yes/no	+ Women + Patients with lung and breast cancer - Younger - Married - Patients with haematological cancer	
Virnig, USA, 2002 (54)	Cohort study N=388,511, Patients with cancer	Administrative data	Hospice	Admittance to hospice: yes/no	+ Younger + Women 0 Cancer diagnosis	The age trend was not found in relation to patients with lung cancer

+ : higher admittance to SPC, - : lower admittance to SPC, 0 : no association, *data at patient level, SEP: socioeconomic position

Previous studies found conflicting results in relation to sex (16;17;23;26;27;31;32;34;38-42;44;45;47-49;51-54), cohabitation status (16;18;22;23;26-28;31;32;36;38;40;45-48;50;51;53) and socioeconomic position (SEP) (16-19;19;20;20;21;23;26-29;31-34;36;38-40;40-42;45;46;48-51), whereas most studies found that younger (15-17;21;23;26;27;30;31;33;36;38-42;44;46;48;50;51;54), and persons living in urban areas were more likely to be admitted to SPC (23;31;42;46;49;51). In relation to diagnosis the clearest pattern was for patients with haematological cancer diagnoses where low admittance to SPC was found (16;22;26;27;35;41-43;53).

In Denmark the scientific knowledge about admittance to SPC is sparse. Studies investigating admittance to SPC are mainly from USA, Canada, Australia and United Kingdom (see table 1), i.e., countries that may be different from Denmark which is a Nordic welfare state with a mainly tax-payed health care system. Only two studies from Nordic European countries (Denmark (50) and Finland (48)) were found. It is therefore unknown to which degree the results can be generalised to Denmark. Furthermore, the quality of the studies varies. Marked differences between the studies were found in relation to: the size of study population; cancer diagnoses included; the collection of data; the level of the data; type of SPC institution; which and how many variables were included; and in relation to the analyses some studies included descriptive analyses only.

Given the possible positive effects of SPC for the patient, caregiver and the society, and the conflicting results in the literature of varying quality, conducted in countries not quite comparable with Denmark, more research on admittance to SPC in Denmark is needed. The development of Danish Palliative Care Database (DPD) made it possible to investigate which cancer patients are admitted to SPC in Denmark.

Aim and research questions

Given that some cancer patients are admitted to SPC and others are not, this thesis elucidates which cancer patients are admitted to SPC in Denmark. Admittance was investigated as ‘overall admittance’ to SPC (including the two institution types in Denmark, hospital-based palliative care team/unit and hospice) and ‘institution type specific admittance’ addressing the two types of SPC separately.

Among patients who died from cancer in Denmark in 2010-12, the following research questions will be investigated.

- Are overall and institution type specific admittance to SPC associated with sex, age or diagnosis? (Paper 1)

- Are overall and institution type specific admittance to SPC associated with cohabitation status? (Paper 2)
- Are overall and institution type specific admittance to SPC associated with education or income? (Paper 3)
- Is overall admittance to SPC - among those referred to SPC – associated with sex, age, geographic region, diagnosis or referral unit? (Paper 4)

Setting

Denmark is a social welfare state with 5.7 million inhabitants. The health care system is tax-funded with free access to the main part of the health care system e.g., general practitioners, hospital departments and – of specific relevance for this study - SPC institutions. In Denmark the patient group comprises is patients having a life limiting disease and complex symptoms and problems both in relation to severity and frequency (3).

In Denmark the first SPC units were established in the early nineties in the Capital Region of Denmark and since several units have been established throughout the country (55;56). In the study period (2010-12), 37% of the individuals dying from cancer were admitted to SPC (57) and an increase in the number of SPC units was seen from 36 to 44 institutions (58). There are two kinds of SPC institutions; hospital-based palliative care teams/units, and hospices. Five out of 26 hospital-based palliative care teams/units have an in-patient function integrated in their palliative institution. Hospices are divided from the rest of the health care system, mostly having inpatients, however four out of 18 hospices had a home care function included in addition to their in-patient facility.

In Denmark national criteria for referring patients to SPC are now under development, but in the study period (2010-12) no national criteria existed (55). This might have complicated the communication with the physicians at non-SPC departments and possibly it could have affected which patients were referred, if e.g. the majority of the institutions accepted cancer patients only, it might have been this group of patients who were referred, even though this was not the criteria in all SPC institutions. Even though it was possible that the referral criteria differed between institutions the central and common criterium was that a physician judged that the patient had complex problems that could not be adequately treated elsewhere.

The SPC units are expected to consist of multidisciplinary teams and to have multidisciplinary meetings once a week to discuss their patients. About 80% of the patients admitted to SPC had contact to one hospice or hospital-based palliative care teams/units only whereas 20% had contact to more than one SPC institution, often contact to a hospital-based palliative care teams/units followed by a hospice. The survival time from the first contact with SPC was: for hospice median 27 days and mean 55 days; for hospital-based palliative care teams/units median 50 days and mean 90 days (58).

The SPC capacity (2012) varied between the five Danish geographic regions, with North Denmark Region having the highest capacity (59). EAPC recommended 80-100 SPC beds per one million inhabitants and 1 SPC team per 100.000 inhabitants (60). A comparison of the EAPC recommendations, with regard to the number of beds and teams with the number in Denmark in 2012, is presented in Table 2. The SPC capacity in Denmark was approximately half the size recommended (55;59), most insufficient in Capital Region of Denmark (90 beds and 8 teams) and Central Denmark Region (50 beds and 6 teams) (59).

Table 2 Comparison of EAPC recommendations with regard to the number of SPC beds and teams versus the number in Denmark (2012)

Regions in Denmark	**Inhabitants**	**SPC beds, EAPC recommendation vs Denmark**			**Hospital-based palliative care teams, EAPC recommendation vs Denmark**		
	N	EAPC; 80-100 beds per one million inhabitants (60) N	Denmark; SPC beds (hospices and SPC units) N	"Deficiency" N	EAPC; 1 team for 100.000 inhabitants (60) N	Denmark; Hospital-based Palliative Care team/unit N	"Deficiency" N
Capital Region of Denmark	1,729,952	138-173	90	48-63	17	8	9
Region Zealand	816,670	65-82	36	29-46	8	4	4
Region of Southern Denmark	1,201,547	96-120	60	36-60	12	4	8
Central Denmark Region	1,271,223	102-127	50	52-77	13	6	7
North Denmark Region	580,273	46-58	35	11-23	6	4	2
Total	5,599,665	448-560	271	177-289	56	26	30

Main concepts

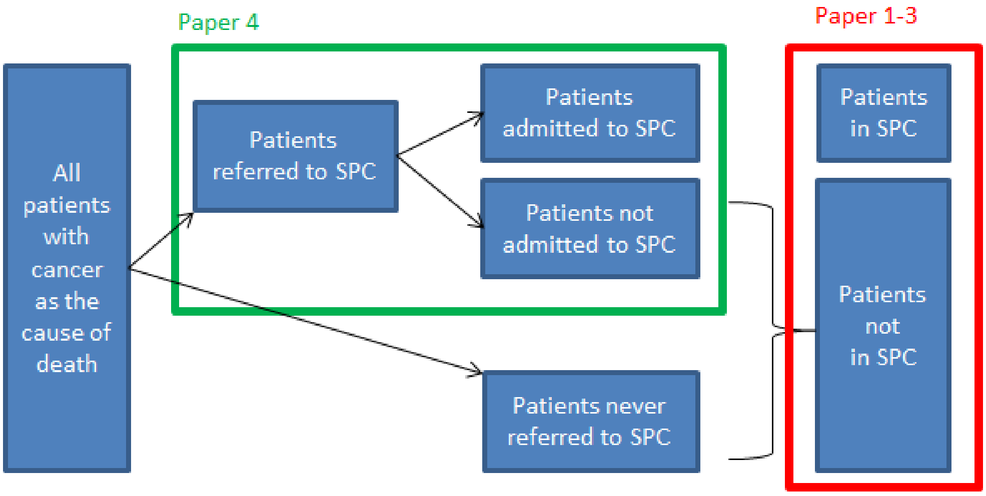
In this thesis the main concepts are: SPC, admittance, inequality and socioeconomic position (SEP). SPC has been defined in the background, and will therefore not be further described here. The other main concepts will be explained in the following section.

Admittance

The concepts ‘admittance’, ‘access’ and ‘admission’ are used synonymously throughout this thesis in relation to whether the patient had contact with SPC. Access to the health care system has been defined by Pechansky and Thomas as: *’A concept representing the degree of “fit” between the clients and the system’(61)*. They further argue that access can be seen as the general concept and define specific dimensions included in this concept *(61)*. In this thesis the concept will be included in the general form described by Pechansky and Thomas (61) in the meaning of both entry to and use of SPC.

Admittance to SPC can be investigated in different study designs and those included in this thesis are illustrated in Figure 1. Admittance to SPC can be investigated in relation to the entire group of patients dying from cancer, where the referral of the patient, indicating a need for SPC, is unknown (Paper 1-3). This study design is similar to previous research designs. Further, admittance can be investigated in relation to the patients who are referred to SPC, where all patients (when the SPC unit has confirmed that the patients fulfill inclusion criteria) have a need for SPC (Paper 4).

Figure 1 Study design in the paper 1-4



It was chosen to use ‘admittance’ to underline the selection process towards having SPC: a patient must have a need for SPC, must be referred to SPC by a physician and must be accepted by the SPC unit. Through this process there is a selection. First there is a selection in the patients who are being referred to SPC and second there is a selection in the patients who are being judged eligible and admitted to SPC by the SPC unit.

Inequality

The Danish health care system is based on universal admittance (62) and it is stated in the Law of Health Care (in Danish: Sundhedsloven) that admittance should be *equal* for patients with similar needs (63). In English it is possible to distinguish between inequality, which is used to describe differences and inequity which means more than just a difference, it is an unfair difference (64).

The contemporary philosopher John Rawls whose normative ethical position is deontological (duty ethics) has been focusing on the organisation of the society and argue that it is possible to define general moral principles. He has developed a theory about ‘justice’ with ‘social justice’ as one of the its components (65). According to Rawls the rules that individuals can agree about without knowing their own position in the society (e.g. rich, poor, intelligent) may be considered as fair and could be written in a ‘social contract’, which everybody needs to follow. He further argues that other elements in the social contract are that everybody has the same rights and freedom, a freedom compatible with similar freedom for others. Rawls states that differences in relation to social and economic factors can be accepted only if those who benefit are the most disadvantaged. These principles of justice are about freedom and equity (65).

Rawls has not been working with justice directly in relation to admittance to the health care system but this has been done by Aday et al. (66). They define equity as *“maximizing the fairness in the distribution of services across groups (micro level)”* (66) and *“minimizing the disparities in the distribution of health across groups (population level)”* (66). In line with Rawls, Aday et al. describe different paradigms of justice, and hereby different ways to evaluate equity: ‘distributive justice’ and ‘social justice’ (66). According to Aday et al., ‘distributive justice’ is based on liberalism, and the focus is on the individual, individual well-being and the individuals rights. Equity in this perspective is, *“what can I justly claim” (66)*. They further define 'Social justice’, where the focus is on the community and the norms are common good and social solidarity. The question of equity from this point of view is, *“what is good for us?” (66)*. The paradigms ‘distributive justice’ promotes the freedom of the individual, reduces the social aspect, and the criterium for equity is the freedom of choice, whereas the ‘social justice’ promotes social responsibility, decreases the focus on the individual, and the equity criteria is “*similar treatment, common good, and need across population*” (66).

Taking these terms and theoretical arguments into account, the paradigm of justice in this thesis is in line with 'social justice' (as described by Aday et al.), where admittance is seen more in a community perspective, in relation to other patients and their need, than in relation to the rights of the individual. With inspiration from Rawls and Aday et al., I distinguish in this thesis between fair and unfair differences in admittance. A difference that may reflect differences in the needs of the patients e.g., in relation to diagnosis, is seen as a fair difference and the term inequality will be used. On the other hand a difference that is unlikely to reflect a difference in need, e.g. in relation to SEP, and that does not benefit the most disadvantaged (see Rawls), is view as an unfair difference, and the term inequity will be used.

Socioeconomic position

One of the research questions is to investigate the association between SEP (measured by income and education) and SPC. SEP can be defined as "*the social and economic factors that influence what positions individuals or groups hold within the structure of a society" (67).* This definition is used in this thesis. Several other terms are used for this concept, for example socioeconomic status, social class and social position. In this thesis SEP is used as suggested by Krieger et al, who argue that the concept includes two dimensions, described as *"actual resources",* related to the resources of material and social character*, and "prestige- or rank related characteristics"* related to the position in the social hierarchy (68).

Similar to many other concepts used in research SEP can be viewed as a construction that only exists because we categorise it in a certain way. SEP can be measured in different ways and the choice of how to categorise it affects what it is possible to see, which differences can be found, how large they appear and which reasons for such differences it is possible to identify (69). A categorization seeing the society as a hierarchy based on factors as *"materials, resources, authority and prestige* (translated from Danish (69))" have their origins in theories of sociologist Max Weber. Income and education, which is included in this study, are examples of this hierarchically thinking (67;69).

The different measurements of SEP vary in how stable they are over time. Education, for instance, is stable for most individuals over 40 years old, where most individuals have finished their education, whereas income and occupation may be less stable and may change over time, e.g. if the person for a period is without a job, or has a new job. For diseases occurring later in life education is a more stable measure, as income and occupation will be affected by the possibility for a person to work (67;69). The different SEP measures are not independent, for example is education often important for occupation and income later in the life.

Materials and methods

Data sources

In Denmark it is possible to link data from several different nation-wide registers by the unique personal identification number. The following six registers were the data sources for this thesis.

- **Danish Palliative Care Database (DPD):** DPD is a national clinical and quality of care database and since 1 January 2010, it has been mandatory for all SPC units (institutions where the staff is working full time with SPC) in Denmark to register all patients referred to and/or admitted to SPC in the DPD. In appendix A the SPC institutions which are included in DPD are listed. The admittance data were validated by comparing the patients included in DPD with the Danish National Patient Register in a collaboration with the SPC units to clarify differences (58;70). The patient completeness is very high, and increased from 2010-12 (95.7% -100%) (58)
- **Danish Register of Causes of Death (RCD):** RCD includes all who die in Denmark and registered information on date of death, cause of death (diagnosis) and place of death. RCD has a very high completeness, less than one percent has incomplete data. The validity of the Danish Register of Causes of Death is uncertain and relies on the physician’s knowledge about the patient (71)
- **Danish Cancer Registry (CR):** CR was established in 1943 and it has been mandatory to document every new cancer diagnosis to CR since 1987 (72). The register has a high completeness. A study comparing the CR with medical records for breast cancer in one county in Denmark found 100 % completeness in relation to data about incidence (73). In addition, a report comparing CR with national clinical databases (2012) indicated an identically high completeness for breast cancer (99%) and a slightly lower completeness for lung cancer (96.%)(74). The register has furthermore a high validity (tumours morphically validated: 89%) (72)
- **Danish Civil Registration System (CRS):** The register was established in 1968 and includes all persons, who were alive and were living in Denmark at that time, and since then it has included all persons with permanent residence in Denmark, all new born and new inhabitants. The register was established for administrative use. All persons registered in CRS are assigned a unique person identification number (CPR-number) which includes information about data of birth and sex and the CPR-number is used in all registers in Denmark. It is believed that the data are of high validity and further the completeness is very high (75)
- **The Population’s Education Register (PER)**: The register is based on administrative data, but for persons who have completed their education before 1974 and immigrants with no Danish education most information is collected by self-reported data. PER has a high completeness and

validity. For 1945-1990 birth cohorts of ethnic Danish individuals the completeness was reported to be 97%, lower for immigrants (76)

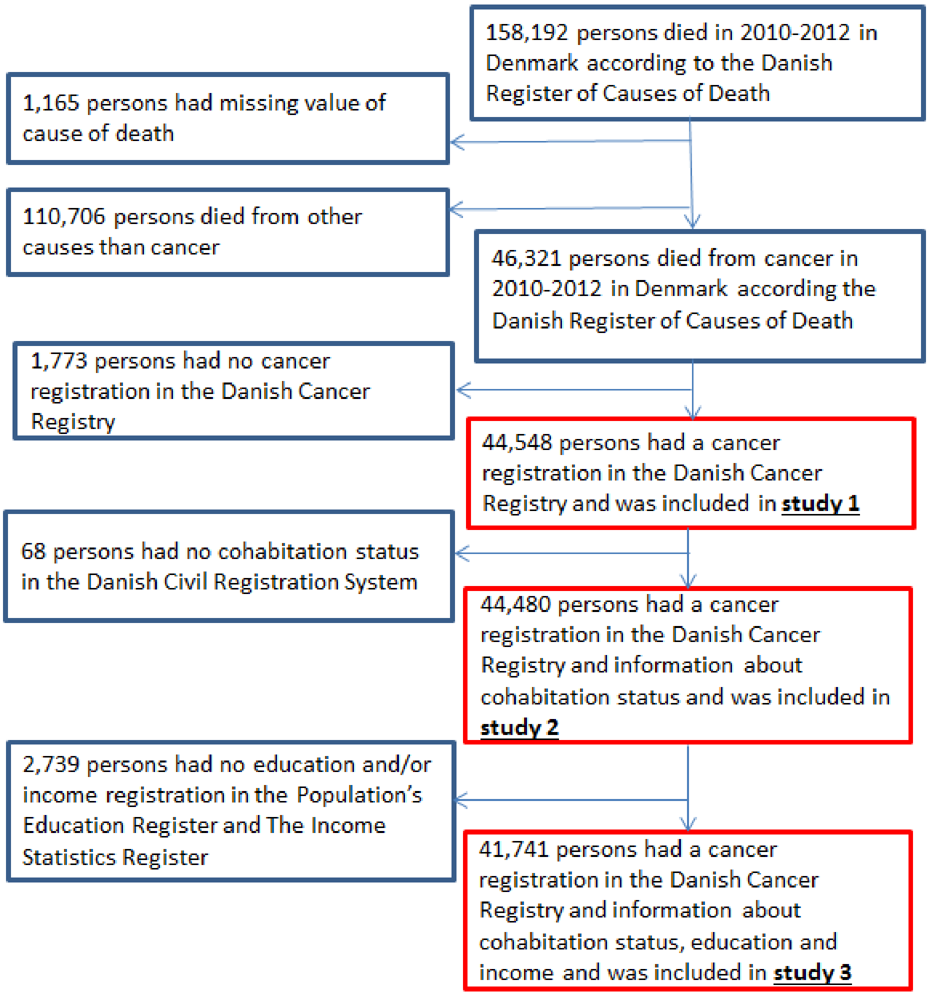
- **The Income Statistics Register (IR)**: The register started in 1970 with information on all economically active persons in Denmark. The register includes information about different types of income, e.g., salary, public transfer payment, pension (both public or private) (77)

Study population, papers 1-3

In 2010-12, 158,192 adults (18+years old) died in Denmark according to RCD (71). In paper 1-3 we included individuals who died of cancer in this period. The validity of the RCD is uncertain, partly because the information is given by a physician, who writes the death certificate, maybe without any prior contact to the patient (71). For that reason the cancer diagnosis was compared with the cancer diagnoses registered in CR (72). The comparison showed that 4% (N=1,773) had no registration in CR and was excluded from the study. Eighty-seven percent (N=38,848) of the cause of death (cancer diagnoses) found in DRC had the same diagnosis in CR. In relation to the 13% (N=5,700) with a disagreement between the registers, 75% (N=4,289) only had one cancer diagnosis in CR. This diagnosis was included as the cause of death in these studies. For the remaining 25% (N=1,411) persons with more than one cancer registration in CR the latest registration was used as the cause of death in this study.

Figure 2 shows the flowchart for the study population for papers 1-3. Paper 1 consisted of 44,548 persons, paper 2 excluded persons without information about cohabitation status (N=68) resulting in a population of 44,480 persons. In paper 3 we further excluded persons without an education and income registration (N=2,739) resulting in a population of 41,741 persons.

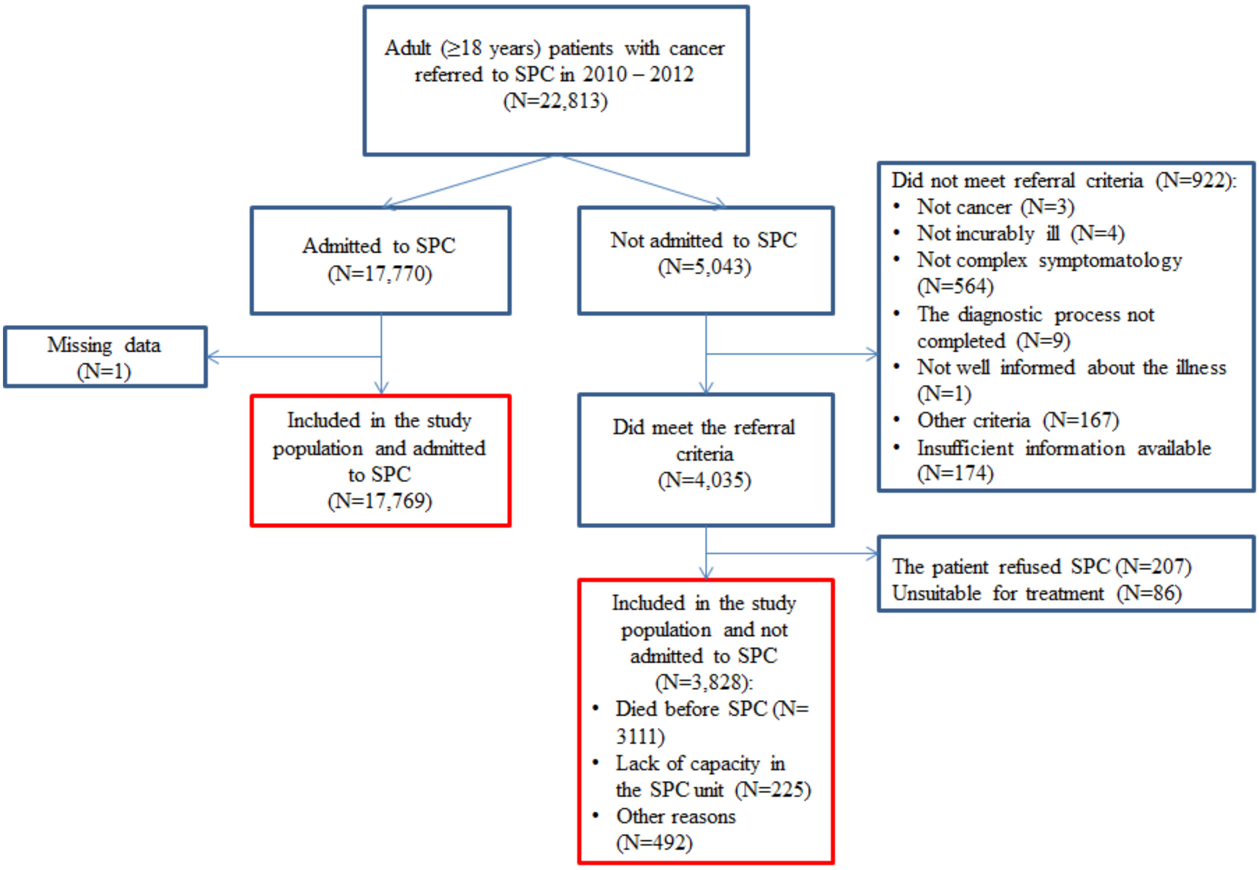
Figure 2 Flow-chart for sampling the study population, study 1-3



Study population, paper 4

In 2010-12, 21,813 patients (18+years old) with a cancer diagnosis and living in Denmark were referred to SPC and died in 2010-12. For patients who were only referred to SPC but never admitted we excluded patients who did not meet the referral criteria. In addition patients who met the referral criteria, but who refused admittance to SPC were excluded. Finally patients where treatment were unsuitable (for example because of late referral or not accommodated in the SPC institution) were also excluded. Included in the study were 21,597 patients (see Figure 3).

Figure 3 Flow chart of the patients referred to specialised palliative care and included in the study population, study 4



Variables

Outcome:

- Overall admittance to SPC: Admittance to SPC (yes/no) defined as being an inpatient in a SPC unit (hospice or hospital-based unit), being an inpatient in a non-SPC unit having a visit from SPC team, being an outpatient having a home visit from a SPC team or being an outpatient visiting a SPC unit.
- Institution type specific admittance was divided into:
  - Admittance to hospital-based palliative care team/unit
  - Admittance to hospice
  - Admittance to both types of institutions (paper 1)

Exposure:

- Sex
- Age at the time of death (18-39, 40-49, 50-59, 60-69, 70-79, 80+years old)

- Cancer diagnosis (ICD-10 Codes) (78)
- Cohabiting status was defined as a combination of two variables: marital status (married, divorced, widow/widower, never married) and living status (married, a couple (man and woman) living together with a child/children, a couple (man and woman, not in close family) living together without children and an age difference under 15 years, single:
    - Married/ cohabiting (married, living together with or without children)
    - Married, but not living together (married and single)
    - Divorced (divorced and single)
    - Widow/widower (widow/widower and single)
    - Never married (never married and single)
- Education: the individual highest attained education the year before death
    - Primary school
    - Skilled worker
    - Short theoretical education (1-3 years)
    - Long theoretical education (including persons with a bachelor or high school as these groups had similar SPC attendance) (>3 years)
    - Academic (5+ years).
- Income: Family equalised disposable income is the household disposable income divided by the number of members of the household converted into equalised adults. Income was measured two years before death and was divided into quartiles:
    - Q1: <19,352 EUR/year (lowest quartile)
    - Q2: 19,352-22,942 EUR/year
    - Q3: 22,943-30,643 EUR/year
    - Q4: >30,643 EUR/year (highest quartile)
- Geographic region (Capital Region of Denmark, Region Zealand, North Denmark region, Central Denmark Region, Region of Southern Denmark)
- Referral unit (general practitioner, hospital department, other)

Other variables

- Type of the first contact to SPC (inpatient, outpatient)
- Date of referral to SPC
- Date of death
- Fulfilment of eligibility criteria (yes, no, insufficient information available)

- Days from referral to death

The connection between the registers, variables and the four papers are shown in Table 3.

Table 3 Data sources and variables for the four papers

Registry	Paper 1	Paper 2	Paper 3	Paper 4
Danish Palliative Care Database				
Admittance to SPC	X	X	X	X
Admittance to institution type specific SPC	X	X	X	
Sex				X
Age				X
Cancer Diagnosis				X
Referral unit				X
Fulfilment of eligibility criteria				X
Reason for non-admittance				X
Days from referral to death				X
Type of the first contact to SPC		X		
Danish Register of Causes of Death				
Cause of death	X	X	X	
Danish Cancer Registry				
Cancer diagnosis	X	X	X	X
Danish Civil Registration System				
Sex	X	X	X	
Age	X	X	X	
Geographic region		X	X	
Cohabitation status		X	X	
The Population's Education Register				
Highest formal education			X	
The Income Statistics Register				
Family equalised disposable income			X	

X = Data source for the study

Statistical analyses

In the four papers logistic regression analyses were used to investigate the association between the dichotomous outcome, overall admittance to SPC, and the different exposures both unadjusted and in an adjusted model. Further, institution type specific admittance to hospital-based palliative care team/unit, hospice or both types of institution, respectively, was investigated. Interactions were included in some of the studies. Table 4 gives an overview of the statistical analyses in paper 1-4. In the logistic regression analyses the average of admittance for all diagnoses was used as the reference level.

In paper 2, I further used the method, standardised absolute prevalences. The standardisation was done in relation to the following four variables; sex, age, diagnosis and geographic region. For each combination of these four variables the number of patients was calculated and weights were estimated in relation to a standard population, which in this study was all cancer patients included in paper 2. Standardised prevalences of admittance to SPC for each cohabitation group were then generated on behalf of these weights and the patient combination in each cohabitation subgroup.

For further descriptions of the statistical analyses see the original papers (57;59;79;80).

The results from the logistic regression analyses were reported as odds ratios (ORs) and 95% confidence intervals (CIs). Statistical significance level was p<0.05. The results from the standardised absolute prevalences were reported as percentages (%) and 95% confidence intervals (81). The analyses were carried out in the statistical software SAS 9.3(82) and SAS 9.4 (83).

Table 4 The four papers in relation to exposure, outcome, variables controlled for and statistical methods

	Paper 1 (N=44,548)	Paper 2 (N=44,480)	Paper 3 (N=41,741)	Paper 4 (N=21,597)
Exposure	Sex, age, cancer diagnosis	Cohabitation status	Education, income	Sex, age, cancer diagnosis, geographic region, referral unit
Outcome	Overall admittance to SPC, hospital-based palliative care team, hospice, both types of institution	Overall admittance to SPC, hospital-based palliative care team, hospice	Overall admittance to SPC, hospital-based palliative care team, hospice	Overall admittance to SPC
Variables controlled for	Sex, age, cancer diagnosis	Sex, age, cancer diagnosis, geographic region	Sex, age, cancer diagnosis, geographic region, cohabitation status	Sex, age, cancer diagnosis, geographic region, referral unit
Statistical methods	Logistic regression analyses	Logistic regression analyses, including interaction analyses: Sex*cohabitation status, age* cohabitation status, diagnosis* cohabitation status, and region* cohabitation status. Prevalences	Logistic regression analyses, including interaction analyses: age*education	Logistic regression analyses

Results

In this section I briefly present the results from the four studies included in this thesis on how sex, age, cancer diagnosis, cohabitation status, SEP, referral unit and geographic region, are related to admittance to SPC.

Sex, age and cancer diagnosis (paper 1)

'Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD)'

In study 1 I found that 37.4% of the patients with cancer who died in 2010-12 (N= 44,548) were admitted to SPC (overall), 26.8% were admitted to hospital-based palliative care team/unit, 17.3% to hospice and 6.8% of the patients were admitted to both types of institutions.

A higher admittance proportion was seen among women compared to men (39.5% vs 35.5%). Overall admittance to SPC was higher for women compared with men (OR= 1.23; 95%CI: 1.17-1.28). In relation to hospital-based palliative care team/unit (OR= 1.06; 95%CI: 1.00-1.11) and hospice (OR= 1.45; 95%CI: 1.37-1.54), the sex difference was most pronounced in relation to hospice.

Tabel 5 Overall and institution type specific odds of admittance to SPC for Danish cancer patients, mutually adjusted.

	Overall admittance to SPC OR (95 % CI)	Admittance to hospital-based palliative care team/unit OR (95 % CI)	Admittance to hospice OR (95 % CI)	Admittance to both hospital-based palliative care team/unit and hospice OR (95 % CI)
Sex	(P<0.001)	(P<0.033)	(P<0.001)	(P<0.001)
Women	1.23 (1.17-1.28)	1.06 (1.00-1.11)	1.45 (1.37-1.54)	1.34 (1.23-1.47)
Men	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Age (years)	(P<0.001)	(P<0.001)	(P<0.001)	(P<0.001)
18-39	6.44 (5.19-7.99)	6.81 (5.53-8.38)	3.17 (2.54-3.97)	6.73 (5.08-8.93)
40-49	4.60 (4.09-5.18)	4.80 (4.26-5.41)	2.90 (2.54-3.31)	5.64 (4.72-6.74)
50-59	3.22 (3.00-3.47)	3.48 (3.22-3.76)	2.13 (1.94-2.32)	3.63 (3.16-4.17)
60-69	2.46 (2.32-2.60)	2.56 (2.41-2.73)	1.89 (1.76-2.03)	2.80 (2.49-3.16)
70-79	1.80 (1.70-1.89)	1.86 (1.75-1.97)	1.52 (1.42-1.64)	1.97 (1.74-2.22)
80+	1 (ref)	1 (ref)	1 (ref)	1 (ref)

OR: odds ratio, CI: Confidence interval

The study population mainly included older patients, 85% were 60+years old and less than 1% was 18-39 years old. The highest admittance proportion was found for the 18-39 years old, 65%, decreasing with age to 24.3% for patients 80+ years old. The association between age and admittance to SPC was strong. Compared with the patients 80+ years old, the OR for admittance to SPC for the youngest (18-39 years old) was OR= 6.44 (95%CI: 5.19-7.99). Divided into institution type specific admittance the age difference was more pronounce in relation to hospital-based palliative care team/unit.

The three most common diagnoses were; lung (23.3%), colorectal (12.7%) and breast cancer (8.1%). Overall admittance to SPC was lowest in relation to patients with haematological diseases: odds ratios between OR=0.33 (95%CI: 0.17-0.63) and OR=0.50 (0.42-0.61). Patients with sarcoma, pancreatic and stomach cancer had the highest odds of admittance to SPC, Odds ratios; 1.90 (95%CI: 1.52-2.38), 1.77 (95%CI: 1.61-1.94) and 1.69 (95%CI: 1.50-1.90), respectively. The institution type specific admittance in relation to hospital-based palliative care team/unit showed a pattern similar to overall admittance. For hospice the highest admittance was found for patients with ovarian cancer (OR=1.56; 95%CI: 1.35-1.80). In relation to both types of institutions the lowest admittance was found for patients with haematological malignancies. For patients with brain and prostate cancer a different pattern in relation to institution type was found: Patients with brain cancer had admittance above the average in relation to hospice and below average in relation to hospital-based palliative care team/unit. Patients with prostate cancer had admittance above the average in relation to hospital-based palliative care team/unit and below in relation to hospice. A more detailed description can be found in paper 1 (57).

Cohabitation status (paper 2)

'Cohabitation status and admittance to specialised palliative care (SPC) for cancer patients - A nationwide study from the Danish Palliative Care Database.'

In study 2 fifty percent of the study population was found to be cohabiting, 25% was widows/widowers, 12% divorced, 7% never married and 3% were married, but lived alone.

Overall admittance to SPC was found to be lower for patients living alone compared with patients living in a relation, apart from patients divorced. For example had never married individuals OR=0.74 (95% CI; 0.68-0.80) for overall admittance to SPC compared with cohabiting persons (Table 6).

Admittance to hospital-based palliative care team/unit showed results similar to overall admittance, while admittance to hospice was less likely for patients cohabiting: the odds ratio of admittance to hospice for individuals divorced was OR=1.41, 95% CI; 1.31-1.52 and for widows/widowers OR=1.20, 95% CI; 1.11-1.28 (Table 6).

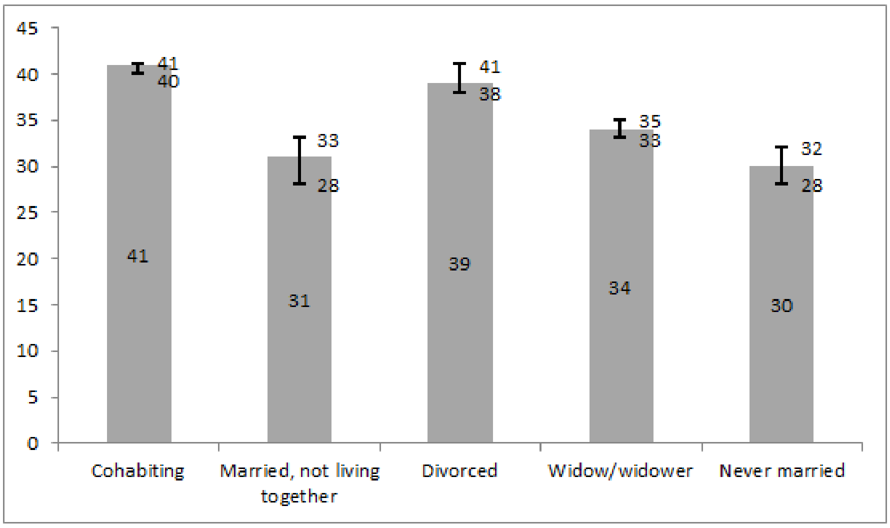
Table 6 The odds ratio (OR) of overall and institution type specific admittance to SPC for Danish cancer patients in relation to cohabitation status: unadjusted and adjusted for sex, age, diagnosis and geographic region.

	Cohabitation status OR (95 % CI)				
	Living together	Living alone			
	Cohabiting (reference) (N=23,531)	Married but not living together (N=1,244)	Divorced (N=5,300)	Widow/ widower (N=11,129)	Never married (N=3,276)
Overall admittance:					
Unadjusted	1	**0.79** (0.70-0.88)	0.99 (0.93-1.05)	**0.62** (0.59-0.65)	**0.84** (0.78-0.91)
Adjusted*	1	**0.82** (0.75-0.93)	0.96 (0.90-1.02)	**0.86** (0.81-0.91)	**0.74** (0.68-0.80)
Institution type specific admittance					
Admittance to hospital-based palliative care team/unit					
Unadjusted	1	**0.74** (0.65-0.85)	**0.79** (0.74-0.84)	**0.51** (0.48-0.54)	**0.72** (0.66-0.78)
Adjusted*	1	**0.80** (0.70-0.92)	**0.81** (0.75-0.87)	**0.74** (0.69-0.78)	**0.64** (0.59-0.70)
Admittance to hospice					
Unadjusted	1	1.07 (0.92-1.24)	**1.52** (1.41-1.63)	0.96 (0.91-1.02)	**1.23 (1.12-1.35)**
Adjusted*	1	1.09 (0.94-1.27)	**1.41** (1.31-1.52)	**1.20** (1.11-1.28)	1.10 (1.00-1.21)

In the type specific admittance analyses including the exposure dichotomised (living together/living alone) and interactions (sex, age, diagnosis and region) we found that, men living in a relation were more often admitted to hospital-based palliative care team/unit than men living alone (OR=0.67: 95% CI; 0.63-0.72), similar but weaker association was found for women (OR=0.80 95% CI; 0.75-0.86). A statistically significant interaction was also found in relation to diagnosis. The strongest difference was found for patients with prostate cancer: Patients living alone had lower odds ratio of admittance to hospital-based palliative care team (OR =0.64, 95% CI; 0.53-0.76) than patients with same diagnosis living in a relation. For admittance to hospice the strongest difference was found in relation to patients with lymphoid and haematopoietic cancer: Patients living alone had higher odds ratio of admittance (OR= 1.42, 95% CI; 1.07-1.87). In relation to region, the strongest difference between living together and living alone was found in the Central Region of Denmark (hospital-based palliative care team/unit OR=0.64 (95% CI; 0.58-0.70) and hospice OR= 1.49 (95% CI; 1.33-1.66)).

The standardised prevalence of overall admittance to SPC confirm the results from the logistic regression: Admittance was found to be highest in relation to patients cohabiting (41%) and lowest for never married individuals (30%).

Figure 4 Prevalence (%) of admittance to overall admittance to SPC among Danish patients who died from cancer in 2010-12 in relation to cohabitation status. Standardised by sex, age group, diagnosis and region (N=44,480).



More details about cohabitation status and admittance to SPC can be found in paper 2 (79).

Education and income (paper 3)

'Social inequality in admittance to specialised palliative care (SPC) for patients with cancer. A nationwide study from the Danish Palliative Care Database'

Data about education was missing for 6% of the patients and they were excluded from the study. In the study population (N=41,741) 45% had primary school as highest attain education, 33% was skilled worker, 2% had a short theoretical education, 10% had a long theoretical education and 6% had an academic education.

Overall and institution type specific admittance to SPC was found to increase with increasing education level. For example compared with persons with primary school only, skilled workers (OR= 1.18; 95% CI: 1.13-1.24) and persons with an academic education (OR=1.69; 95%CI: 1.51-1.89) had higher odds of overall admittance to SPC.

Table 7 The odds of overall and institution type specific admittance to SPC for Danish cancer patients in relation to formal education: unadjusted and adjusted for sex, age, diagnosis and geographic region and cohabiting status.

	Formal education OR (95 % CI)				
N = 41,741	Primary school	Skilled worker	Short theoretical	Long theoretical	Academic
Overall admittance:					
Unadjusted	1	1.23 (1.17-1.28)	1.41 (1.25-1.59)	1.65 (1.54-1.76)	1.55 (1.40-1.73)
Adjusted*	1	1.18 (1.13-1.24)	1.34 (1.18-1.53)	1.49 (1.39-1.60)	1.69 (1.51-1.89)
Institution type specific admittance					
Admittance to hospital-based palliative care team/unit					
Unadjusted	1	1.14 (1.09-1.20)	1.26 (1.11-1.44)	1.38 (1.29-1.48)	1.27 (1.13-1.43)
Adjusted*	1	1.09 (1.03-1.15)	1.20 (1.04-1.38)	1.29 (1.20-1.39)	1.49 (1.31-1.68)
Admittance to hospice					
Unadjusted	1	1.28 (1.21-1.35)	1.61 (1.39-1.86)	1.85 (1.72-2.00)	1.64 (1.45-1.87)
Adjusted*	1	1.29 (1.22-1.37)	1.63 (1.40-1.89)	1.70 (1.57-1.84)	1.73 (1.51-1.97)

We found similar to education, that admittance to SPC (overall and type specific) increased with increasing income, e.g., compared with persons in the lowest income quartile the odds ratio of overall admittance to SPC for patients with the highest income was OR=1.46 (1.37-1.56). For hospital-based palliative care team/unit the relation was only statistically significant in relation to the highest income.

A combination of education and income showed, with a few exceptions (short theoretical education and academics with lowest income) that for each education level, higher admittance to SPC with higher income was found. Individuals with the lowest income having primary school only, the odds of admittance for the highest educated with the highest income was 1.96 (95%CI: 1.71-2.25). For further details see paper 3 (80).

Admittance among referred patients (paper 4)

'Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD)'

In the study population (N=21,597) of patients referred to SPC 50% were men, the mean age was 70 years and lung, colorectal and breast cancer were the most frequent diagnoses. The most common referral unit was a hospital department and one fifth of the patients survived less than eight days from referral.

Similar to the results in paper 1 it was also for patients referred to SPC found decreasing admittance with increasing age, older patients (40-49 years old OR= 3.13; 95%CI: 2.48-3.95 vs 80+ years old) and patients with haematological malignancies (e.g. leukaemia OR=0.55; 95%CI: 0.42-0.73 compared with the average of all diagnoses) were less often admitted to SPC. Geographic difference in admittance was found between the geographic regions, the lowest odds ratio of admittance to SPC was found in the Capital Region of Denmark.

Time from referral to death explained the sex and referral unit differences; men and patients referred from hospital departments were referred late (see table 8). A more detailed description can be found in paper 4 (59).

Table 8 Mean and median time from referral to specialised palliative care to death based on sex and referral unit (N=21,597).

		Time from referral to death (days)	
		Mean (SD)	Median (IQR)
Sex			
	Women	67 (101)	31 (10-73)
	Men	62 (94)	28 (11-78)
Referral unit			
	General practitioner	68 (95)	34 (12-82)
	Hospital department	63 (98)	27 (10-73)
	Other	65 (101)	30 (11-72)

SD: Standard deviation, IQR: Interquartile range

Discussion

Sex, age and cancer diagnosis (paper 1)

The main findings in paper 1 were that 37.4% of the patients with cancer who died were admitted to SPC (overall), 26.8% were admitted to hospital-based palliative care team/unit, 17.3% to hospice and 6.8% of the patients were admitted to both types of institutions. Overall and institution type specific admittance to SPC were lower for men, older patients and patients with haematological cancer diagnosis. Differences in admittance to type of institutions were especially found for patients with cancer in the brain and prostate and the sex difference was most pronounced for hospice.

A difference between men and women has also been reported in earlier studies, but conflicting results have been found: in line with this study, several studies found higher admittance to SPC for women(16;31;45;47;49;51-54), several other studies reported no sex difference in admittance to SPC (17;23;26;27;32;38;39;41;42;44;48) whereas lower admittance for women was found in two studies (34;40).

In line with this study most studies found decreasing admittance with increasing age (15-17;21;23;26;27;30;31;33;36;38-42;44;46;48;50;51;54), whereas fewer studies found higher admittance for older (18;37;45;49;53) or no age difference (20;32;35). The difference between age groups found in this study was, however, much stronger than previously reported (16;17;23;26;27;30;31;36;41;42;44;46;50;51).

Similar to previous studies lower admittance to SPC for patients with haematological cancer diagnoses was found in this study (16;22;26;27;31;35;41-44;53). In line with this study, some studies have found higher admittance for patients with gynaecological and gastrointestinal cancer (16;26;38), and lower admittance for patients with breast and lung cancer (31;42;50), but other studies found higher admittance to SPC for patients with breast cancer (16;26;27;33;53) and lung cancer (16;22;33).

Similar to the remaining (sub)studies in this thesis, the study did not include information about need of SPC. The results were therefore interpreted using results from a large Danish study of symptoms and problems using the EORTC QLQ-C30 questionnaire among patients with advanced cancer (stage 3-4) (84;85). Johnsen and colleagues found a sex difference in relation to emotional function, which was worse for women than for men, and in relation to age an increase in symptoms was found with higher age. The symptoms were quite similar in relation to diagnosis. The QLQ-C30 questionnaire covers some of the the most frequent symptoms (86), but does not include information about for example help or social support, which could be other relevant factors in relation to evaluate the need for SPC. The worse emotional function for women could be a possible part of the explanation of higher admittance for women, whereas symptoms and problems could not explain the difference in admittance to SPC between diagnoses and in particular not the large difference between age groups: the group with the highest symptom burden in the survey had the lowest admittance to SPC.

The sex difference could be explained by the traditional roles in the family. More women may have an ambition to take care of their husband (than the other way round), and they may to a larger extent have the skills from their previous experiences (taking care of sick children, older family members etc.) to think that it is possible for them to handle such a situation.

The sex difference was mainly found in relation to hospice and it is also possible that this type of institution is more similar to the wishes for women than for men, or maybe women are more aware of this option and more used to talking about their own needs and death (87;88). Further, in Denmark a higher number of women than men are living alone (89), so the results could reflect the practical conditions as it could be more difficult to be at home close to death when the patient is living alone.

In relation to the marked age difference found in this study, a possible explanation could be that for younger patients dying from cancer the situation may be so extra alarming and dramatic with, e.g., more complicated family relations involving (small) children. Professionals involved may wish to do everything that is possible for the patient, and as a part of this also refer to SPC. It is, however, unknown whether other parts of the health care system (e.g., general practitioner and nursing homes), who possibly have a close contact to the older patient compensate for this difference and whether their needs are adequately covered.

The age difference was stronger for admittance to hospital-based palliative care team/unit than to hospice. SPC from hospital-based palliative care team/unit may be initiated in order to improve care at home. Younger patients may more frequently have a cohabitant who can take care of them at home.

Similar symptom burden has been found for patients with haematological cancer diagnoses compared with patients with other cancer diagnoses (84;85;90). The lower admittance for patients with haematological cancer diagnoses has been explained by the patients being treated aggressively very close to death and referred (too) close to death (16;91-98), by difficulties in deciding when the patients should be referred (99-102), by insufficient knowledge of the function of the health care professionals from SPC departments (99;103-106), and by that the acceptance from SPC units was low (100-102). Differences in admittance between types of institutions was found for patients with cancer in the brain and prostate cancer which may reflect the practical conditions in relation to the type of cancer: compared to other groups, patients with prostate cancer may be easier to manage by in the home of the patients whereas patients with cancer in the brain may have a more complicated trajectory due to personality changes and a need for help day and night. Therefore it may be more difficult for the caregiver to take care of the patient at home and a hospice with professionals to take care of the patient may more often be needed.

Cohabitation status (paper 2)

The main findings in paper 2 were that cohabitation status was associated with overall admittance to SPC, with lower admittance for patients living alone. The institution type specific admittance showed associations in opposite directions, with higher admittance to hospice and lower admittance to hospital-based palliative care team/unit for patients living alone. Sex, region and diagnosis affected the association between cohabitation status and admittance to hospital-based palliative care team/unit and hospice, respectively, e.g. was it more important for men than for women to be living in a relation.

Disagreement in studies investigating cohabitation status and overall admittance to SPC is found. In line with this study half of the studies find higher overall admittance for individuals living in a relation (16;23;51), an Australian study supports the finding in this study of no difference between married and divorced and lower admittance to SPC for single and widows/widowers (23), whereas two studies found no association (31;38).

Looking at type specific admittance, the higher admittance to hospital-based palliative care team/unit for married patients found in this paper is in line with three other studies (27;33;50). However one of these a smaller register based study from Denmark (N=599) found for women only. In paper 2, a stronger association for men was found in this paper (50). Two studies found no association (28;32).

In contrast to the results from this paper, five studies found no difference between cohabitation status and admittance to hospice (18;26;36;45;48) and three studies even found higher admittance for married patients (22;46;47). Similar to the present study, one study found higher admittance for individuals who were divorced or widow/widower (53) and another one study found that never married individuals had higher admittance to SPC (40).

Beccaro et al. found higher admittance to a palliative care team when the caregiver was a women, supporting the results from this paper (28).

The lower admittance for patients living alone to hospital-based palliative care team/unit and higher admittance to hospices may indicate that the two types may substitute each other. This could reflect the practical condition that there are better opportunities for care for the patient at home for patients living in a relation, compared with patients living alone the type of SPC may therefore be related to cohabitation status. It is therefore results for overall admittance that should be looked at as the first step in the interpretation.

Assessment of the need of SPC is not included in this study but it seems unlikely that a person living alone should have a lower overall need for SPC than patients living in a relation and, they probably have an even higher need for inpatient care as they do not have a caregiver to take care of them at home. A study investigating symptoms and problems in advanced cancer patients found more symptoms for divorced and widows/widowers for appetite loss, financial difficulties and loss of quality of life (84), which could indicate a higher need of SPC for patients living alone. On the other hand it is possible that a patient having a caregiver who wants to keep the patient at home (thereby possibly preventing the need for referral to a hospice), may have a higher need for admittance to hospital based palliative care team.

The lower overall admittance to SPC for patients living alone could reflect less ability to obtain care by the specialists, which may be explained by more resources for patients living in a relation. A patient living in a relation may have a person to talk their case and be part of the trajectory, a person to explain their symptoms and problems to the health care professionals, and to communicate their needs and help navigating in an often complex health care system. If this is correct, it is the weakest who are not admitted.

Patients divorced were found to be more similar to patients cohabiting than to the patients living alone in relation to overall admittance to SPC. The institution type specific admittance illustrates that while admittance to hospital-based palliative care team/unit was similar to other groups living alone, divorced patients had markedly higher admittance to hospice. It is unknown whether this group has a higher need for admittance to hospice than other patients living alone, or may have more resources, e.g. a stronger social network. To fully understand the difference between the patients divorced and other patients living alone more research is needed.

Compared with married patients the overall admittance to SPC was lower for patients, who were married but lived alone. This group covers patients who had been married, but now are ‘separated’ before they get divorced (this process can take up to six months), and it includes patients who maybe because of their work, in different places of the country, lives on different addresses but is still married. Thus, at least some of these are not in a functioning relationship, which can explain results similar to other patients living alone.

Education and income (paper 3)

The main findings in paper 3 were that SEP (measured via education and income) was associated with overall and institution type specific admittance, with lower admittance for the most disadvantaged: those with least education and lowest income. In the analysis taking both variables into account, admittance to SPC was found for each education level to increase with increasing income, although among academics highest admittance was found for the academics with the lowest and highest income.

In the literature disagreement has been found in the relation between SEP and SPC. A large part of the studies did not have data at individual level and half of these studies found no association (17;23;32;42;51). In accordance with this study higher admittance to SPC with higher income was found in a Canadian study (significant for two quintiles: low-middle and middle versus upper income) (31), and four American studies (36;45;46;49). One Australian study found that the most advantaged (measured by Socio-Economic Index for Areas - SEIFA) had the lowest admittance to SPC, differently from this study (34).

Studies with SEP data on individual level measured SEP as: social class (e.g. by occupation) (21;26;27;38;39;41;48), education(16;18;28;29;33;40) and income (19;20;40;50).

Similar to this study three studies from Belgium, Italy and USA found that the patients with the highest education level had the highest admittance to SPC (29;33;40), whereas one American study found an association in the opposite direction (18) and two studies (Italy and USA) found no association (16;28).

Four studies investigated the relation between income (individual level data) and admittance to SPC. Three studies support the results from this study (19;20;40), although in two of the studies the information about income was the income for the respondent (Annual random Australian health survey) and not the patient (19;20). Differently from this study one study (also Danish) found no association (50).

The need of SPC is unknown in this study and differences in symptoms and problems for patients with different education level could be a possible explanation for the difference found. A study investigating the most common symptoms and problems found few differences between education level and symptoms but lower pain and better cognitive function for the highest educated (84;85). Although that the study only studied a subset of the relevant needs, it still indicates that it is unlikely that differences in needs can explain the results.

Patients in higher SEP may have more resources or be better informed. A study that investigated the level of knowledge about SPC found that knowledge was lowest for patients with the lowest level of education (107). In line with this study another study found that a higher proportion of people with a lower education wanted more knowledge about SPC (108), possible because of lower levels of knowledge in this group. Additionally, how much information the patient received from the physician is found to be associated with education, with most information provided to patients with the highest education (109). More knowledge about SPC facilities could explain that patients with a higher SEP were more aware of what could be possible and relevant for them and thereby make it more likely for this group to demand SPC.

The ability to explain symptoms and problems very clearly and hereby to elaborate and document the need of SPC may be easier for patients with a higher SEP, who may in their education and working life have used communication professionally as an important part of their everyday life. Better communications skills and possibly also a better communication between persons with similar SEP may also be factors that could explain a higher admittance for patients with a higher SEP.

The referral criteria to SPC institutions differ between institutions and no national referral criteria were available in 2010-12 (national referral criteria are being launched in 2017) (55). This lack of transparency and the higher knowledge among individuals in the highest SEP may mean that these patients will be in front to demand SPC.

In Denmark the SPC capacity is about half the size recommended by EAPC (55;59;60) and the latest annual report from DPD found that one out of five patients having a need of SPC were not admitted and one out of four had their first contact with SPC more than ten days from referral (25). The limited capacity of SPC could make it even more important to communicate well and have a high level of knowledge when the capacity not permits admittance for all the patients with a need of SPC.

Admittance among referred patients (paper 4)

The main findings in paper 4 were that among patients referred to SPC (because they have been judged to have a need for SPC), lower admittance to SPC was found among older patients, patients living in two of the geographic regions (Capital Region of Denmark and Region of Southern Denmark) and among patients with haematological diseases. Lower admittance among men and patients referred from hospital departments was explained by later referral (59).

Previous studies have compared patients admitted to SPC with patients not admitted to SPC without knowledge about some of the patients not admitted had actually referred to SPC (See figure 1, page 19). To our knowledge this is the first study investigating admittance in the entire group of referred patients with an acknowledged need for SPC from both the referring physician and the SPC unit.

In the comparison with other studies it is important to be aware of this difference in study design, which makes it difficult to directly compare the results. On the other hand it is interesting that similar results were found: Lower admittance to SPC in relation to older patients (15-17;21;23;26;27;30;31;33;36;38-42;44;46;48;50;51;54), and for patients with haematological diseases (16;22;26;27;35;41-44;53). Geographic differences have also been found in other studies, especially the difference between rural and urban areas has been investigated; and lower admittance has been found for patients living in rural areas (23;28;31;42;46;49;51).

Possible explanations for lower admittance for patients with haematological malignancies are discussed in relation to paper 1 (see page 38). This paper is the first to demonstrate, that even when this group of patients was referred to SPC they had lower admittance. Moreover lower admittance was still seen after adjusting for time from referral to death, thus, late referral to SPC cannot explain the difference. This may mean that in the SPC units there may be a hesitation to admit patients with haematological diseases, maybe in relation to the management of the symptoms and problems in this patient group. This should be further investigated.

In Denmark the development in the capacity of hospices followed a national strategy, while the establishment of hospital-based palliative care teams/units was more related to local or regional wishes. The difference in capacity between the regions may explain the difference in admittance to SPC found between the regions in this study. This may indicate that there is a need for a national strategy to ensure that the capacity is equal throughout the country and that the establishment of new institutions will be in areas where the capacity is low.

It is not possible to distinguish between differences in needs between the patients in this study. Patients admitted to SPC may have the highest need compared with non-admitted referred patients. The difference in admittance to SPC may thus reflect a fair prioritisation in a health care system with a SPC capacity substantially under the recommendation from EAPC (see table 2) (55;59;60). Prioritisation may thus explain the low admittance in certain patients groups, e.g., older patients, who may be given a lower priority in the ‘competition’ with younger patients – not because they do not have a need for SPC, but simply because the younger are viewed to have a larger need. Even if this is fair seen from the overall perspective, it may be problematic for the patients not admitted: They have received information about SPC, have been told that they need treatment from a SPC unit, and they have accepted being referred, hence they probably have a belief that admittance to SPC would contribute to the best possible care at the end of life e.g., optimal symptom control. Not being accepted may therefore be a frustration in an already vulnerable situation.

Methodological considerations

The methodological strengths and limitations, of studies 1-4 should be taken into consideration when interpreting the results and their implications.

The data source in this thesis was nation-wide registers which ensured an almost complete population and representativeness where the influence of selection bias was minimized. This also ensured a large study population making it possible to investigate subgroups. The data completeness was very high (close to 100 % for all registers) (24;71;72;75;77), only in relation to education (PER) (76) a lower completeness was found with missing information for about 6% (80). In contrast to many other studies especially on SEP that has often been measured at a contextual level (see table 1) the information on all variables included was on individual level which may minor the risk of misclassification. The data was collected prospectively and independently of this study, which means that recall bias was excluded. Furthermore, as the information was from administrative registers, the risk of information bias may be minimized (110), which especially can be a problem in relation to e.g. more personal information such as income (111).

The validity of the RCD is to a large extent unknown (71) and the cancer diagnosis found in RCD was therefore compared with the cancer diagnosis in the CR (which is generally viewed as having a high validity) (72) to ensure that the study population was selected correctly and that those persons registered as dying of cancer had a cancer registration in CR. Additionally, the validity of DPD was ensured via a comparison with the Danish National Patient Register (112) where all contacts to hospital departments (including hospices) are registered.

The outcome, both overall and institution-type-specific admittance to SPC, was dichotomised into whether the patient was admitted or not. It was not possible to subdivide the patients that were admitted to SPC in relation to the quantity of contacts, e.g. the number of inpatient days or the number of home care visits.

The distinction between the two types of institutions, hospital-based palliative care team/unit and hospice, is less clear in mainly the Capital Region of Denmark (see the *Setting section*), as some hospices have outgoing palliative care teams; and some hospital-based palliative care team/units; provide in-patient care. Hospices and hospital-based-palliative care teams/units differ in relation to financing and relation to the rest of the health care system, and in most of Denmark their function is more clearly different; therefore, the division is important. In paper 2, sensitivity analyses were carried out by excluding Capital Region of Denmark to investigate the influence of this distinction this problem and found that including Capital region of Denmark may underestimate the difference between the two types of institutions.

Data on exposures cohabitation status and SEP, is believed to be of high validity, as the data are from administrative systems (75-77). However, it is possible that the validity is lower for persons who completed their education before 1970, as these data were self-reported (76). With individual level data about marital status and living status for each individual it was possible to categorise persons living in a relation without being married, which is relevant in a country where many live in a relationship without being married (paper 2). A limitation in the register data was that persons in homosexual relationships are included as cohabiting if they are married, but if they do live together in a relationship without being married they count as living alone (79).

A limitation of the use of register data is that data are pre-collected and do not include all data that would be relevant in a research project, as it is established with another, often administrative goal (110). Information about the need of SPC was not included in any register and it was therefore not possible to include information about this in studies 1-3. In study 4, only patients who were referred to SPC and met the referral criteria were included; this means that all the patients had been judged to have a need of SPC, but it was unknown whether the magnitude or urgency of the need differed between the patients.

Although need for SPC was not available in papers 1-3, it was an advantage that previous Danish studies have investigated the patterns of symptoms and problems in patients with advanced cancer, which offered the possibility to evaluate whether the differences found in the present studies (1-3) may be explained by e.g. differences in need by length of education (84;85). On the other hand, as described earlier in this thesis, such a comparison could have limitations as symptoms and problems were measuring by the questionnaire EORTC QLQ-C30, and may not include all relevant aspects to evaluate the need of SPC, e.g. the help and support available for the patient.

Additionally, information about social relations was not part of the registers. With inspiration from the model of Due and colleagues (113) about social relations it could be relevant to include information on the structure (number of contacts, type of relations) and function (emotional support, appraisal, conflicts) of the social relation, the quality of the relationship or the size or function of the network (113). It is possible that other aspects could have been relevant to include in the studies, e.g., in another Danish study ethnicity has been found to be associated with access to hospital-based palliative care team (50), and a systematic review including only studies from USA found an association between ethnicity and end-of-life care (114). Finally more detailed information about where the patient was living or the distance to the nearest SPC institution could have been relevant to include in the analyses.

In studies including a large study population, like the papers (papers 1-3: N= around 45,000 and paper 4 N = around 21,500) in this thesis, it is possible to find even small differences to be statistically significant and it is therefore important to be aware of the relevance of the difference that is found in a public health or a clinical perspective (110). On the other hand it is possible that some subgroups may, even in this large study population, be too small to show any differences.

The relevance of the difference found in the logistic regression for cohabitation status (paper 2) was further investigated in standardised absolute prevalences showing the differences between the subgroups in percentages. The standard population used for calculating the standardised absolute prevalences was all cancer patients who died in 2010-12 (similar to the logistic regression). It is possible that another standard population reflecting for example the Danish population or all patients who died in the similar period could have influenced the results. On the other hand it seems relevant to have the same study population in the two different methods (logistic regression and standardised absolute prevalences). The standardisation used in this study was calculated using the four variables included in the logistic regression: sex, age, cancer diagnosis and region. Including the four variables in the calculation of weights meant that the number of combinations was rather high (650). This means that even though a large number of patients were included in this paper, some of the combinations were based on very small groups, and there may therefore be some uncertainty included with this method. It would of course have been possible to include fewer variables in the standardisation, but on the other hand it made the results from the logistic regression more comparable to use all four. In paper 3, a similar standardisation including the same numbers of variables as included in the logistic regression would mean that the number of combinations would be 3250. With the uncertainty related to this huge number of combinations a standardisation was not made in paper 3.

Conclusions

- Men, older patients and patients with haematological cancer diseases had lower admittance to SPC compared with women, younger patients, and patients with other malignant diseases, respectively. These variations cannot be explained by the variation in symptoms and problems among advanced cancer patients in general (paper 1)
- Compared with hospital-based palliative care team/unit, admittance to hospice was lower for men and for patients with prostate cancer. Higher admittance was found for patients with cancer in the brain (paper 1)
- Cohabiting patients were favoured in overall admittance to SPC compared to patients living alone. It is unlikely that lower need for SPC in relation to patients living alone could be the explanation. Especially the results in relation to hospital-based palliative care can be interpreted as inequity (paper 2)
- Individuals with high education and high income had the highest admittance to SPC. It is unlikely that a higher need for SPC for patients with higher income and higher education compared with the most disadvantaged could be the explanation. It is believed that this indicates inequity (paper 3)
- For patients with an assessed need of SPC, differences in admittance to SPC were found in relation to age, diagnosis and region, maybe reflecting a fair prioritisation of the available resources to patients with the most urgent needs. Even if such prioritization is fair, it means that certain groups of patients having a need for SPC, e.g., the oldest, die without admittance to SPC (paper 4)
- The SPC capacity in Denmark is considerably lower than proposed by EAPC and is probably insufficient. This possibly leads to prioritisation between referred patients, thus explaining the lower likelihood of admittance of older patients and patients with haematological cancer diseases. This capacity problem in Denmark should therefore be corrected (paper 4)
- For physicians and departments referring patients to SPC, it is important not to refer patients too late - while this may be a problem for all patient groups, it was more frequent for men and for patients referred from hospitals (paper 4)
- As this study indicates inequity with respect to social factors (disfavouring patients living alone, with short education and low income), efforts to address this problem should be carried out
- The study confirmed the advantages of the good registers in Denmark: The data appeared to be of generally very high quality, both in relation to completeness and validity. Similar quality has not been found for previous studies investigating admittance to SPC in other countries

- Specifically, the Danish registers made it possible to include data at individual level, which in relation to SEP measures have been found in few previous studies
- The very complete data from DPD about admittance to SPC made these national analyses possible, covering all types of SPC institutions in Denmark. As the only national register, DPD includes data about patients referred to but not admitted SPC, thus making analyses as reported in paper 4 possible

Perspectives

Future research

Since its initiation in 2010, DPD has documented annual an increases in the numbers of patients referred to and admitted to SPC, respectively (25). Furthermore, since 2010, DPD has consistently reported that about 20% of the patients were referred but never admitted to SPC, and about 25% waited more than 10 days to have their first contact (25). This limited capacity has been documented while there have been an increase in the capacity until 2015 (55). In the future, it will be important to investigate the development in admittance to SPC over time with data from DPD taking the results from this thesis into account. It will be of particular importance to follow the development over time in relation to SEP in order to ensure equity in admittance (a fair admittance reflecting the need of the patient in line with the definition of Aday et al (66)) to SPC, as also stated by Danish law (63).

In this study we found social inequality in relation to the dichotomous outcome of admittance to SPC. In the future it would be relevant to include more activity based information about the patients admitted to SPC. This could include the number of SPC contacts, the type of SPC contacts and the contacts to non-SPC hospital departments. Activity data about SPC are under development in DPD and with these data, together with data from other nationwide registers as the one used in this thesis, it will be possible to investigate whether there is also social inequality in how much SPC patients receive.

The possible social inequity found in this thesis, an unfair difference between patients difference with regard to education, income and cohabitation status should also be investigated in the group of patients referred to SPC, similar to the design in study 4, to create knowledge about where it will be relevant to carry out interventions. Furthermore, the social inequality found in this study should be investigated in relation to vulnerable groups of patients like immigrants, persons with psychiatric diagnoses, drug addicts, the homeless, prisoners, etc. This could be done using data from registers. In addition qualitative research methods could contribute with experiences (stories) from the individuals who are vulnerable, what do they feel, whether they have special needs in the last part of their life. Recently in Denmark, there has been focus on the group of ‘vulnerable patients’, and in 2016 started a project with the aims to investigate the experiences of this group of patients closer and develop interventions to help them.

Studies investigating the patient’s social life in a broader sense than cohabitation (as studied here), could contribute with relevant information about the role of the social network in admittance to SPC. With inspiration from the model about social relations developed by Due and colleagues (113) it could be relevant to include both the structure (quantity) and the function (quality) of the social relations. To collect detailed data about social relations questionnaire surveys are needed. A relevant study population could be patients with a short life expectation. Alternatively this could be evaluated by bereaved caregivers.

The low admittance for patients with haematological cancer diagnoses needs to be investigated further to collect more knowledge about the trajectory of these patients, to try to understand why this group of patients are less frequently admitted even when they are referred to SPC; and what happens from the referral to death for patients with this cancer diagnosis. Data from medical records, the national patient registry and DPD could be relevant data sources in such an investigation. It could further be relevant to interview the health care professionals to assess their knowledge and attitudes in relation to SPC, and a similar study could be relevant in relation to the patients. Based on knowledge from such studies relevant interventions could be started and DPD could be a relevant data source in order to evaluate whether more patients with this diagnosis are being referred to and admitted to SPC. Furthermore, interviews with staff from SPC institutions should be done in relation to this patient group to investigate reasons for a low admittance for these patients.

For patients referred but not admitted to SPC it would be relevant to investigate the use of the health care system in the last part of their life compared with the group of patients admitted to SPC. The Danish national register data including data from DPD would be relevant data sources in such a study. It would further be relevant to compare how bereaved caregivers evaluate the patients' last lifetime, in relation to whether the patients was admitted to SPC, was only referred and never admitted to SPC, or was never referred to SPC. A questionnaire survey, including DPD as one of the data sources, is in progress and will contribute with knowledge about how the bereaved caregivers view the care patients received in different parts of the health care system.

In addition, it would be relevant to investigate the knowledge about SPC in non-SPC departments to study whether and in relation to which subjects there is a need for more information and education of the health care professionals. Interviews with health care professionals could give an idea of where it could be relevant to arrange meetings with health care professionals from SPC units to increase knowledge and the cooperation between SPC and non-SPC departments.

Since the development of DPD started (2007) it has been the ambition to include data about both basic palliative care and SPC, starting with SPC. In the future data about basic palliative care will hopefully be developed, as such a development could contribute with data to investigate the 'whole' picture of palliative care in Denmark. With such data it seems obvious to ask similar questions as in this thesis: which cancer patients have admittance to which types of basic palliative care? With such data it would also be possible to investigate whether patients, who are not admitted to SPC, have sufficient palliative care elsewhere in the health care system. The guideline for palliative care in Denmark defines the patient population as all patients with a life threating disease, not only cancer patients (3). Therefore it will further be relevant to ask the following questions: which non-cancer patients are admitted to SPC and basic palliative care? Data about non-cancer patients admitted to SPC are included in DPD, so a study like this is already possible.

Finally, the number of older people in the Danish society is increasing, which means that the number of deaths is estimated to increase to 65,930 in 2040, a rise by 24% (115) (similar to what have been found in United Kingdom (116)). In this perspective it will be important and relevant with economical analysis to assess the costs of patients receiving SPC compared with patients not receiving SPC to provide knowledge to plan the future organisation of the health care system, which is likely to meet increasing capacity challenges.

Practical implications

From a political perspective, an obvious practical implication of this thesis would be to increase the capacity of SPC in Denmark: with the limited capacity of SPC in Denmark today it will be difficult to prevent that admittance to SPC is associated with the SEP factors. Even though the capacity has increased since this study was established, the capacity is still low in relation to the EAPC recommendations (55;60). Further the increase should ensure that the SPC capacity is geographically equal. Especially in the Capital Region of Copenhagen there seems to be need of higher capacity. A national strategy for the development of the SPC institutions taking EAPC recommendations (60) into account would be relevant, not least because there is evidence that at least hospital based SPC is cost saving (13;14). National referral criteria are important in order to ensure similarities throughout the country; this is actually being implemented now (probably in part due to findings of problems related to capacity from DPD).

In a health care (organisational) perspective the health care professionals (physicians and nurses) in non-palliative care departments in contact with cancer patient should be aware of the SPC need and further the cohabitation status and SEP of the patient. For the group of patients living alone, especially in relation to hospital-based palliative care teams/units, and for patients from low SEP, the physicians should have extra attention on these patients to ensure that relevant patients with a need of SPC will be referred. The communication with the patients has been found to differ between SEP groups (109) and especially the physicians should in their communication with the patient ensure that all patients receive all relevant information (in accordance with the patient's wish). A check list could be relevant to ensure that every patient is given information about all areas differentiated according to the level of information relevant for each patient. In addition, it would be relevant for physicians working with patients with haematological diseases to focus on the relevance of SPC in relation to their group of patients. Maybe more cooperation between SPC and non-SPC departments might increase admittance to SPC, with advantage for the patients.

Summaries

English summary

Background

Specialised palliative care (SPC) have been found to be valuable for patients and bereaved caregivers and furthermore, economical analyses have indicated lower costs for patients admitted to SPC. In Denmark the knowledge about admittance to SPC is sparse and in the international literature, conflicting results have been found in studies of various size and quality, especially in relation to sex, cohabitation status and socioeconomic position (education, income). With the development of Danish Palliative Care Database (DPD), it was possible to investigate: which cancer patients are admitted to SPC in Denmark.

Aims

In Denmark, SPC institutions include hospital-based palliative care teams/units and hospices. In this thesis admittance to SPC was measured as overall admittance, including both hospital-based palliative care teams/units and hospices, and institution type specific admittance including each institution type separately.

Among patients who died from cancer in Denmark in 2010-12, the following research questions were investigated.

- Are overall and institution type specific admittance to SPC associated with sex, age or diagnosis? (Paper 1)
- Are overall and institution type specific admittance to SPC associated with cohabitation status? (Paper 2)
- Are overall and institution type specific admittance to SPC associated with education or income? (Paper 3)
- Is overall admittance to SPC - among those referred to SPC – associated with sex, age, geographic region, diagnosis or referral unit? (Paper 4)

Methods and materials

In Denmark it is possible to link data from several different nation-wide registers by the unique personal identification number. The following six registers were the data sources for this thesis: DPD, Danish Register of Causes of Death, Danish Cancer Registry, Danish Civil Registration System, The Population's Education Register and The Income Statistics Register. Very high completeness and validity were found in the registers, only the Population's Education Register had a lower completeness (missing data for 6%).

Logistic regression analyses were used to investigate the associations between overall admittance to SPC and the different exposures unadjusted and adjusted. Further, institution type specific admittance to hospital-based palliative care team/unit and hospice, respectively, was investigated. In paper 2 standardised absolute prevalences of admittance to SPC were also applied, standardised in relation to sex, age, diagnosis and geographic region.

Results

In paper 1, 44,548 patients were included and 37.4% of the patients were admitted to SPC (overall), 26.8% were admitted to hospital-based palliative care team/unit, 17.3% to hospice and 6.8% of the patients were admitted to both types of institutions. Overall admittance to SPC was higher for women (OR=1.23; 95%CI: 1.17-1.28), younger patients (OR=6.44 for patients <40 vs 80+ years old) and for patients with sarcoma, pancreas and stomach cancer, whereas lower admittance was found for patients with haematological cancer diagnoses (Hodgkin's disease OR: 0.33 (95%CI: 0.17-0.63), leukaemia 0.34 (0.29-0.40)). Differences in admittance to type of institutions were especially found for patients with cancer in the brain and prostate and the sex difference was most pronounced in relation to hospice (for women OR=1.45; 95%CI: 1.37-1.54).

In paper 2, 44,480 patients were included. In the study population 50% was cohabiting. Patients living alone had lower overall admittance to SPC (e.g., cohabiting 41% vs. never married 30%). The institution type specific admittance showed higher admittance to hospice for patients living alone (e.g., divorced OR=1.41 95%CI: 1.31-1.52) and lower admittance to hospital-based palliative care team/unit (e.g., divorced OR=0.81 95%CI: 0.75-0.87). Sex, region and diagnosis affected the association between cohabitation status and admittance to hospital-based palliative care team/unit and hospice, respectively.

In paper 3, 41,741 patients were included. Education and income were associated with overall and institution type specific admittance, with lower admittance for the most disadvantaged. Compared with patients with primary school only the odds ratio of overall admittance for patients with an academic education was 1.69 (95% CI: 1.51-1.89). Comparing lowest with highest income quartile the association was stronger for hospice OR=1.67 (95% CI: 1.54-1.81). In the analysis taking both variables into account, admittance to SPC was found to increase for each education level with increasing income, although among academics highest admittance was found for the academics in the lowest and highest income quartile (OR=1.97 (95%CI:1.27-3.06); OR=1.96 (95%KI:1.71-2.25)).

In paper 4, 21,597 referred patients were included. Higher admittance to SPC was found among younger patients (OR=5.35; 95%CI 3.24-8.83) and, patients living in two of the geographic regions (Region Zealand OR=1.81; 95%CI: 1.62-2.03, North Denmark Region OR=2.26; 95%CI: 1.99-2.57). The lowest admittance was found among patients with haematological diseases (e.g. leukaemia OR=0.55; 95%CI: 0.42-0.73). Lower admittance found for men and patients referred from hospital departments was explained by later referral (e.g., the mean number of days from referral to death was 67 for women and 62 for men).

Conclusion and perspectives

Nation-wide data of high quality from DPD and several Danish registers made it possible to investigate admittance to SPC in relation to overall and institution type specific (hospital-based palliative care team/unit and hospice) admittance to SPC. In the study it was possible for the first time to investigate admittance to SPC among patients referred to SPC who were judged to have a need of SPC by both the referring physician and the SPC institution. Admittance to SPC was found to vary with several patients characteristics. This study indicates inequity with respect to social factors (disfavouring patients living alone, with short education and low income), and efforts to address this should be carried out.

A practical implication of this thesis would be to increase the capacity of SPC in Denmark in order to ensure a more even geographical distribution: with the limited capacity of SPC in Denmark today it will be difficult to prevent that admittance to SPC is associated with SEP factors. Furthermore, it is important that health care professionals are aware of SPC needs among the most disadvantaged patients, to ensure that all patients with a need of SPC have the possibility to be referred and admitted to SPC.

Danish summary

Baggrund

Specialiseret palliativ indsats (SPI) er værdifuld for patienter og efterladte pårørende, og desuden peger økonomiske analyser i retningen af, at der er lavere omkostninger forbundet med patienter, der modtager SPI. I Danmark er viden om adgang til SPI begrænset. I internationale studier af varierende størrelse og kvalitet, er der fundet divergerende resultater, dette gælder særligt for køn, samlivsstatus og socioøkonomisk position (uddannelse, indkomst). Med udviklingen af Dansk Palliativ Database (DPD) blev det muligt at undersøge, hvilke kræftpatienter, der får adgang til SPI i Danmark.

Formål

I Danmark kan SPI institutioner inddeles i hospitals-baserede palliative teams/enheder og hospicer. I denne afhandling undersøges adgang til SPI samlet (inkluderende begge institutions typer) samt separat for de to institutionstyper.

Følgende forskningsspørgsmål blev undersøgt for personer, der døde i Danmark af kræft i perioden 2010-12:

- Er adgang til SPI samlet og institutions specifikt associeret med køn, alder eller kræft diagnose? (artikel 1)
- Er adgang til SPI samlet og institutions specifikt associeret med samlivsstatus? (Artikel 2)
- Er adgang til SPI samlet og institutions specifikt associeret med uddannelse eller indkomst? (artikel 3)
- Er adgang til SPI samlet – blandt henviste patienter - associeret med køn, alder, kræft diagnose, region eller henvisningsinstitution? (artikel 4)

Metode og materiale

I Danmark er det muligt at sammenkoble data fra forskellige registre via det unikke personnummer. Følgende seks nationale registre udgjorde datagrundlaget for denne afhandling: DPD, Dødsårsagsregisteret, Cancerregisteret, Det Centrale Personregister, Uddannelsesregisteret og Indkomstregisteret. Datakompletheden og validiteten i registrene var høje kun Uddannelsesregisteret havde en lavere datakomplethed (der manglede data for 6%).

Logistisk regressions analyse blev anvendt til at undersøge sammenhængen mellem adgang til SPI samlet i forhold til de forskellige eksponeringer, u-justeret og justeret. Endvidere blev adgang undersøgt institutionsspecifikt for henholdsvis hospitals-baseret palliativ team/unit og hospice. I artikel 2 er der yderligere anvendt standardiserede absolutte prævalenser, standardiseret i forhold til køn, alder, kræft diagnose og geografisk region.

Resultater

I artikel 1 blev der inkluderet 44.548 patienter og 37,4% af patienterne fik adgang til SPI samlet, 26,8% fik adgang til hospital baseret palliativ team/enhed, 17,3% fik adgang til hospice, mens 6,8% fik adgang til begge institutioners typer. Den samlede adgang til SPI var højere for kvinder (OR=1,23; 95%KI: 1,17-1,28), yngre patienter (OR=6,44 for patienter <40 vs 80+årige) og patienter med sarkom, pancreas- eller mavekræft, mens patienter med hæmatologiske kræftformer havde den laveste adgang (Hodgkin's sygdom OR: 0,33 (95%KI: 0,17-0,63), leukæmi 0,34 (0,29-0,40)). Forskelle i adgangen til de to institutionstyper blev især fundet for patienter med hjernetumorer og prostatakræft, og kønsforskellen var mest udbredt for adgang til hospice (for kvinder versus mænd var OR=1,45; 95%KI: 1,37-1,54).

I artikel 2 blev der inkluderet 44.480 patienter, hvoraf 50% var samlevende. Patienter, der boede alene, fik i mindre grad adgang til SPI (fx samlevende patienter 41% versus aldrig gifte patienter 30%). Den institutionsspecifikke adgang viste, at patienter, der boede alene, i højere grad fik adgang til hospice (fx patienter, der var skilt OR=1,41 95%KI: 1,31-1,52) og i mindre grad adgang til hospitals baseret palliativ team/enhed (fx patienter, der var skilt OR=0,81 95%KI: 0,75-0,87). Sammenhængen mellem samlivsstatus og adgang til henholdsvis hospitals baseret palliativ team/enhed og hospice var forskellig i forhold til køn, region og diagnose.

I artikel 3 blev der inkluderet 41.741 patienter. Uddannelse og indkomst var associeret med adgang til SPI samlet og institutionsspecifikt, med den laveste adgang for de mindst privilegerede. Sammenlignet med patienter uden uddannelse efter grundskolen var odds ratioen for adgang til SPI samlet 1,69 (95% KI 1,51-1,89) for patienter med en akademisk uddannelse. For indkomst var der en stærkere sammenhæng med adgang til hospice, OR= 1,67 (95% KI: 1,54-1,81) for patienter i den højeste indkomstkvartil sammenlignet med patienter i den lavest indkomstkvartil. I analysen, der medtog både uddannelse og indkomst, blev der for hvert uddannelsesniveau fundet stigende adgang til SPI med stigende indkomst, dog var adgangen for akademikere højest for patienter i den laveste og højeste indkomstkvartil (OR=1.97 (95%KI:1.27-3.06); OR=1.96(95%KI:1.71-2.25)).

I artikel 4 blev der inkluderet 21.597 patienter, der var henvist til SPC. Yngre patienter (OR=5,35; 95%KI 3,24-8,83) og patienter i to regioner (Region Sjælland OR=1,81 (95%KI: 1,62-2,03), Region Nordjylland OR=2,26 (95%KI: 1,99-2,57)) opnåede i højere grad adgang til SPI. Patienter med hæmatologiske kræftformer havde den laveste adgang til SPI (fx leukæmi OR=0,55 (95%KI: 0,42-0,73)). Den lavere adgang til SPI for mænd og patienter henvist fra hospitalsafdelinger kunne forklares af senere henvisning til SPI (fx var det gennemsnitlige antal dage fra henvisning til død 67 dage for kvinder og 62 dage for mænd).

Konklusion og perspektiver

Det har på baggrund af nationale data fra DPD og flere danske registre, været muligt at undersøge adgang til SPI både samlet og institutionsspecifikt, dvs. fordelt på hospitals baserede palliative teams/enheder og hospicer. Det har desuden for første gang været muligt at undersøge adgang til SPI blandt henviste patienter, der havde et behov for SPI vurderet af både den henvisende læge og SPC institutionen.

Adgangen til SPI blev fundet at variere i forhold til flere patient karakteristika. Studiet tyder på, at der er social ulighed (med dårligst adgang for patienter, der bor alene, kortuddannede og patienter med en lav indkomst), og der er brug for indsatser rettet mod dette problem.

De praktiske implikationer af denne afhandling kunne være at øge SPI kapaciteten i Danmark, så der sikres en lige geografisk fordeling af SPI, da det formentlig vil være vanskeligt at forebygge social ulighed i adgang til SPI med den nuværende kapacitet. Endvidere er det vigtigt, at de sundhedsprofessionelle er opmærksomme på behovet for SPI hos de svageste patienter for at sikre, at alle patienter med et behov for SPI har muligheden for at blive henvist til og modtage SPI.

References

(1) Statistics Denmark. http://www.dst.dk/da/Statistik/emner/befolkning-og-valg/doedsfald-og-middellevetid/doedsfald. 19-8-2017.

(2) The Danish Register of Causes of Death.[Dødsårsagsregisteret]. http://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/andre-analyser-og-rapporter/doedsaarsagsregisteret. 15-8-2017.

(3) Danish Health Authority. Recommendations for palliative care. In Danish: Anbefalinger for den palliative indsats 2011. 2011 Dec.

(4) Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: The world health organization's global perspective. Journal of Pain and Symptom Management 2002 Aug;24(2):91-6.

(5) Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J 2010 Sep;16(5):423-35.

(6) Kavalieratos D, Corbelli J, Zhang D, Dionne-Odom JN, Ernecoff NC, Hanmer J, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. JAMA 2016 Nov 22;316(20):2104-14.

(7) Holmenlund K, Sjogren P, Nordly M. Specialized palliative care in advanced cancer: What is the efficacy? A systematic review. Palliat Support Care 2017 Jun 13;1-17.

(8) Abernethy AP, Currow DC, Fazekas BS, Luszcz MA, Wheeler JL, Kuchibhatla M. Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. Support Care Cancer 2008 Jun;16(6):585-97.

(9) Pottie CG, Burch KA, Thomas LP, Irwin SA. Informal caregiving of hospice patients. J Palliat Med 2014 Jul;17(7):845-56.

(10) Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. Soc Sci Med 2003 Aug;57(3):465-75.

(11) Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004 Jan 7;291(1):88-93.

(12) Henson LA, Gao W, Higginson IJ, Smith M, Davies JM, Ellis-Smith C, et al. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. J Clin Oncol 2015 Feb 1;33(4):370-6.

(13) May P, Normand C, Morrison RS. Economic impact of hospital inpatient palliative care consultation: review of current evidence and directions for future research. J Palliat Med 2014 Sep;17(9):1054-63.

(14) Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. Palliat Med 2014 Feb;28(2):130-50.

(15) Cohen J, Wilson DM, Thurston A, MacLeod R, Deliens L. Access to palliative care services in hospital: a matter of being in the right hospital. Hospital charts study in a Canadian city. Palliative Medicine 2012 Jan;26(1):89-94.

(16) Hui D, Kim SH, Kwon JH, Tanco KC, Zhang T, Kang JH, et al. Access to palliative care among patients treated at a comprehensive cancer center. Oncologist 2012;17(12):1574-80.

(17) Maddison AR, Asada Y, Burge F, Johnston GW, Urquhart R. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care 2012;28(2):90-6.

(18) Chen H, Haley WE, Robinson BE, Schonwetter RS. Decisions for hospice care in patients with advanced cancer. J Am Geriatr Soc 2003 Jun;51(6):789-97.

(19) Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliative Medicine 2004;18(3):239-47.

(20) Currow DC, Agar M, Sanderson C, Abernethy AP. Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine 2008;22(1):43-50.

(21) Grande GE, Farquhar MC, Barclay SI, Todd CJ. The influence of patient and carer age in access to palliative care services. Age Ageing 2006 May;35(3):267-73.

(22) Locher JL, Kilgore ML, Morrisey MA, Ritchie CS. Patterns and predictors of home health and hospice use by older adults with cancer. J Am Geriatr Soc 2006 Aug;54(8):1206-11.

(23) Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia - and who misses out. Palliative Medicine 2006;20(4):439-45.

(24) Groenvold M, Adsersen M, Hansen MB. Danish Palliative Care Database. Clin Epidemiol 2016;8:637-43.

(25) Adsersen M, Hansen MB, Groenvold M. Danish Palliative Care Database Annual report 2016. In Danish: Dansk Palliativ Database Årsrapport 2016. København: DMCG-PAL; 2017.

(26) Addington-Hall J, Altmann D, McCarthy M. Which terminally ill cancer patients receive hospice in-patient care? Social Science & Medicine 1998 Apr;46(8):1011-6.

(27) Addington-Hall J, Altmann D. Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? Journal of Advanced Nursing 2000 Oct;32(4):799-806.

(28) Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). Bmc Public Health 2007 Apr 27;7.

(29) Bossuyt N, Van den Block L, Cohen J, Meeussen K, Bilsen J, Echteld M, et al. Is individual educational level related to end-of-life care use? Results from a nationwide retrospective cohort study in Belgium. J Palliat Med 2011 Oct;14(10):1135-41.

(30) Burge F, Johnston G, Lawson B, Dewar R, Cummings I. Population-based trends in referral of the elderly to a comprehensive palliative care programme. Palliative Medicine 2002 May;16(3):255-6.

(31) Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients. Medical Care 2008 Dec;46(12):1203-11.

(32) Burt J, Plant H, Omar R, Raine R. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. Palliative Medicine 2010 Sep;24(6):641-50.

(33) Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliative Medicine 1993;7(4):323-31.

(34) Currow DC, Allingham S, Bird S, Yates P, Lewis J, Dawber J, et al. Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis. BMC Health Serv Res 2012 Nov 23;12:424.

(35) Fadul N, Elsayem A, Palmer JL, Zhang T, Braiteh F, Bruera E. Predictors of access to palliative care services among patients who died at a comprehensive cancer center. Journal of Palliative Medicine 2007 Oct;10(5):1146-52.

(36) Fairfield KM, Murray KM, Wierman HR, Han PK, Hallen S, Miesfeldt S, et al. Disparities in hospice care among older women dying with ovarian cancer. Gynecol Oncol 2012 Apr;125(1):14-8.

(37) Gagnon B, Mayo NE, Hanley J, MacDonald N. Pattern of care at the end of life: does age make a difference in what happens to women with breast cancer? J Clin Oncol 2004 Sep 1;22(17):3458-65.

(38) Grande GE, McKerral A, Todd CJ. Which cancer patients are referred to Hospital at Home for palliative care? Palliative Medicine 2002 Mar;16(2):115-23.

(39) Gray JD, Forster DP. Factors associated with utilization of specialist palliative care services: a population based study. J Public Health Med 1997 Dec;19(4):464-9.

(40) Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J Am Geriatr Soc 2003 Jul;51(7):970-8.

(41) Hunt R, McCaul K. Coverage of cancer patients by hospice services, South Australia, 1990 to 1993. Aust N Z J Public Health 1998 Feb;22(1):45-8.

(42) Hunt RW, Fazekas BS, Luke CG, Priest KR, Roder DM. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. Palliative Medicine 2002 Sep;16(5):403-9.

(43) Iwashyna TJ, Zhang JX, Christakis NA. Disease-specific patterns of hospice and related healthcare use in an incidence cohort of seriously ill elderly patients. J Palliat Med 2002 Aug;5(4):531-8.

(44) Johnston GM, Gibbons L, Burge FI, Dewar RA, Cummings I, Levy IG. Identifying potential need for cancer palliation in Nova Scotia. CMAJ 1998 Jun 30;158(13):1691-8.

(45) Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. J Natl Cancer Inst 2006 Aug 2;98(15):1053-9.

(46) Lackan NA, Ostir GV, Freeman JL, Mahnken JD, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Medical Care 2004 Feb;42(2):116-22.

(47) Lackan NA, Ostir GV, Kuo YF, Freeman JL. The association of marital status and hospice use in the USA. Palliat Med 2005 Mar;19(2):160-2.

(48) Lammi U.K., Kosunen E., Kellokumpu-Lethtinen P. Palliative cancer care in two health centres and one hospice in Finland. Supportive Care in Cancer 2000 Sep 12;9(1):15-31.

(49) Nayar P, Qiu F, Watanabe-Galloway S, Boilesen E, Wang H, Lander L, et al. Disparities in end of life care for elderly lung cancer patients. J Community Health 2014 Oct;39(5):1012-9.

(50) Neergaard MA, Jensen AB, Olesen F, Vedsted P. Access to Outreach Specialist Palliative Care Teams among Cancer Patients in Denmark. Journal of Palliative Medicine 2013 Aug;16(8):951-7.

(51) Rosenwax L, Spilsbury K, McNamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care 2016 May 10;15:46.

(52) Tang ST. Determinants of hospice home care use among terminally ill cancer patients. Nurs Res 2003 Jul;52(4):217-25.

(53) Tang ST, Huang EW, Liu TW, Wang HM, Chen JS. A population-based study on the determinants of hospice utilization in the last year of life for Taiwanese cancer decedents, 2001-2006. Psychooncology 2010 Nov;19(11):1213-20.

(54) Virnig BA, Mcbean AM, Kind S, Dholakia R. Hospice use before death - Variability across cancer diagnoses. Medical Care 2002 Jan;40(1):73-8.

(55) Timm H, Mikkelsen TB, Jarlbaek L. [Specialized palliative care in Denmark lacks capacity and accessibility]. Ugeskr Laeger 2017 Jun 26;179(26).

(56) Vejlgaard TB, Sjogren P, Maagaard R. [Organisation and development of palliative care in Denmark]. Ugeskr Laeger 2007 Oct 29;169(44):3737-40.

(57) Adsersen M, Thygesen LC, Jensen AB, Neergaard MA, Sjogren P, Groenvold M. Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD). BMC Palliat Care 2017 Mar 23;16(1):21.

(58) Hansen MB., Grønvold M. Danish Palliative Care Database Annual report 2012. In Danish: Dansk Palliativ Database Årsrapport 2012. 2013.

(59) Adsersen M, Thygesen LC, Neergaard MA, Bonde JA, Sjogren P, Damkier A, et al. Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD). Acta Oncol 2017 Sep;56(9):1210-7.

(60) Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 2. European Journal of Palliativ Care 2010;17(1):22-33.

(61) Penchansky R, Thomas JW. The Concept of Access - Definition and Relationship to Consumer Satisfaction. Medical Care 1981;19(2):127-40.

(62) Diderichsen F, Andersen I, Manuel C. Ulighed i sundhed - årsager og indsatser. København: Sundhedsstyrelsen; 2011.

(63) The Danish health Act. LBK nr 1188 of 24/09/2016.

(64) Kawachi I, Subramanian SV, Almeida-Filho N. A glossary for health inequalities. J Epidemiol Community Health 2002 Sep;56(9):647-52.

(65) Rawls J. A theory of justice Revised edition. Oxford: Oxford University Press; 1999.

(66) Aday LA, Bergley CE, Lairson DR, Balkrishman R. Evaluating the healthcare system: Effectiveness, effeciency, and equity. 3 ed. Chicago: Health Administration Press; 2004.

(67) Galobardes B, Shaw M, Lawlor DA, Lynch JW, Davey SG. Indicators of socioeconomic position (part 1). J Epidemiol Community Health 2006 Jan;60(1):7-12.

(68) Krieger N, Williams DR, Moss NE. Measuring social class in US public health research: concepts, methodologies, and guidelines. Annu Rev Public Health 1997;18:341-78.

(69) Vallgårda V. Hvad er social ulighed i sundhed? - om kategoriseringers betydning. In: Vallgårda S, Koch L, editors. Forskel og lighed i sundhed og sygdom.København: Munksgaard Danmark; 2006. p. 15-28.

(70) Gronvold M, Hansen MB, Jensen AB, Neergaard MA, Rasmussen M, Sjogren P. [Danish Palliative Database]. Ugeskr Laeger 2012 Oct 15;174(42):2530.

(71) Helweg-Larsen K. The Danish Register of Causes of Death. Scand J Public Health 2011 Jul;39(7 Suppl):26-9.

(72) Gjerstorff ML. The Danish Cancer Registry. Scand J Public Health 2011 Jul;39(7 Suppl):42-5.

(73) Jensen AR, Overgaard J, Storm HH. Validity of breast cancer in the Danish Cancer Registry. A study based on clinical records from one county in Denmark. Eur J Cancer Prev 2002 Aug;11(4):359-64.

(74) Danish Cancer Society, tatens Serum Institut. Validation of The Danish Cancer Registry and selected Clinical Cancer Databases. Copenhagen: Danish Cancer Society; 2012 Nov 29.

(75) Pedersen CB. The Danish Civil Registration System. Scand J Public Health 2011 Jul;39(7 Suppl):22-5.

(76) Jensen VM, Rasmussen AW. Danish Education Registers. Scand J Public Health 2011 Jul;39(7 Suppl):91-4.

(77) Baadsgaard M, Quitzau J. Danish registers on personal income and transfer payments. Scand J Public Health 2011 Jul;39(7 Suppl):103-5.

(78) Danish Health Authority. The Danish Cancer Registry. 2009. Statistic and analysis. In Danish: Cancerregisteret 2009. Tal og analyse. 2009.

(79) Adsersen M, Thygesen LC, Neergaard MA, Jensen AB, Sjogren P, Damkier A, et al. Cohabitation status and admittance to specialised palliative care (SPC) for cancer patients - A nation-wide study from the Danish Palliaitve Care Database. Draft 2017.

(80) Adsersen M, Thygesen LC, Sjogren P, Neergaard MA, Mondrup L, Nissen JS, et al. Social inequality in admittance to specialised palliative care (SPC) for patients with cancer. A nation-wide study from the Danish Palliaitve Care Database. Draft 2017.

(81) Boyle P, Parkin D. Statistical methods for registries. In: Jensen O, Parkin D, MacLennan R, Muir C, Sheet RG, editors. Cancer Registration: Principles and Methods.Oxford, United Kingdom: Oxford University Press; 1991. p. 126-58.

(82) SAS Institute INC. SAS/STAT 9.3 Users's Guide. SAS Institute Inc.: Cary, NC; 2017.

(83) SAS Institute INC. SAS/STAT 9.4 Users's Guide. SAS Institute Inc.: Cary, NC; 2011.

(84) Johnsen AT, Petersen MA, Pedersen L, Groenvold M. Symptoms and problems in a nationally representative sample of advanced cancer patients. Palliative Medicine 2009 Sep;23(6):491-501.

(85) Johnsen AT, Tholstrup D, Petersen MA, Pedersen L, Groenvold M. Health related quality of life in a nationally representative sample of haematological patients. Eur J Haematol 2009 Aug;83(2):139-48.

(86) Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993 Mar 3;85(5):365-76.

(87) Fletcher K, Prigerson HG, Paulk E, Temel J, Finlay E, Marr L, et al. Gender differences in the evolution of illness understanding among patients with advanced cancer. J Support Oncol 2013 Sep;11(3):126-32.

(88) Skulason B, Hauksdottir A, Ahcic K, Helgason AR. Death talk: gender differences in talking about one's own impending death. BMC Palliat Care 2014;13(1):8.

(89) Statistics Denmark. http://www.dst.dk/da/Statistik/emner/befolkning-og-valg/husstande-familier-boern/husstande. 31-8-2017.

(90) Manitta V, Zordan R, Cole-Sinclair M, Nandurkar H, Philip J. The symptom burden of patients with hematological malignancy: a cross-sectional observational study. J Pain Symptom Manage 2011 Sep;42(3):432-42.

(91) Cheng WW, Willey J, Palmer JL, Zhang T, Bruera E. Interval between palliative care referral and death among patients treated at a comprehensive cancer center. J Palliat Med 2005 Oct;8(5):1025-32.

(92) Good PD, Cavenagh J, Ravenscroft PJ. Survival after enrollment in an Australian palliative care program. J Pain Symptom Manage 2004 Apr;27(4):310-5.

(93) Hui D, Elsayem A, De la Cruz M, Berger A, Zhukovsky DS, Palla S, et al. Availability and integration of palliative care at US cancer centers. JAMA 2010 Mar 17;303(11):1054-61.

(94) Morita T, Akechi T, Ikenaga M, Kizawa Y, Kohara H, Mukaiyama T, et al. Late referrals to specialized palliative care service in Japan. J Clin Oncol 2005 Apr 20;23(12):2637-44.

(95) Osta BE, Palmer JL, Paraskevopoulos T, Pei BL, Roberts LE, Poulter VA, et al. Interval between first palliative care consult and death in patients diagnosed with advanced cancer at a comprehensive cancer center. J Palliat Med 2008 Jan;11(1):51-7.

(96) Ansell P, Howell D, Garry A, Kite S, Munro J, Roman E, et al. What determines referral of UK patients with haematological malignancies to palliative care services? An exploratory study using hospital records. Palliat Med 2007 Sep;21(6):487-92.

(97) Hui D, Didwaniya N, Vidal M, Shin SH, Chisholm G, Roquemore J, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. Cancer 2014 May 15;120(10):1572-8.

(98) Sexauer A, Cheng MJ, Knight L, Riley AW, King L, Smith TJ. Patterns of hospice use in patients dying from hematologic malignancies. J Palliat Med 2014 Feb;17(2):195-9.

(99) Epstein AS, Goldberg GR, Meier DE. Palliative care and hematologic oncology: the promise of collaboration. Blood Rev 2012 Nov;26(6):233-9.

(100) McGrath P, Holewa H. Missed opportunities: nursing insights on end-of-life care for haematology patients. Int J Nurs Pract 2006 Oct;12(5):295-301.

(101) Odejide OO, Salas Coronado DY, Watts CD, Wright AA, Abel GA. End-of-life care for blood cancers: a series of focus groups with hematologic oncologists. J Oncol Pract 2014 Nov;10(6):e396-e403.

(102) Schenker Y, Crowley-Matoka M, Dohan D, Rabow MW, Smith CB, White DB, et al. Oncologist factors that influence referrals to subspecialty palliative care clinics. J Oncol Pract 2014 Mar;10(2):e37-e44.

(103) Hui D, Finlay E, Buss MK, Prommer EE, Bruera E. Palliative Oncologists: Specialists in the Science and Art of Patient Care. J Clin Oncol 2015 Jul 10;33(20):2314-7.

(104) Hui D, Park M, Liu D, Reddy A, Dalal S, Bruera E. Attitudes and Beliefs Toward Supportive and Palliative Care Referral Among Hematologic and Solid Tumor Oncology Specialists. Oncologist 2015 Nov;20(11):1326-32.

(105) Manitta VJ, Philip JA, Cole-Sinclair MF. Palliative care and the hemato-oncological patient: can we live together? A review of the literature. J Palliat Med 2010 Aug;13(8):1021-5.

(106) Wright B, Forbes K. Haematologists' perceptions of palliative care and specialist palliative care referral: a qualitative study. BMJ Support Palliat Care 2017 Mar;7(1):39-45.

(107) Koffman J, Burke G, Dias A, Raval B, Byrne J, Gonzales J, et al. Demographic factors and awareness of palliative care and related services. Palliat Med 2007 Mar;21(2):145-53.

(108) Andersen V, Timm H. Knowledge as a presumption for involvement. What do the population know about palliative care - and do they want to know more? [In Danish: Viden som foudsætning for medbestemmelse. Hvad ved borgerne om palliation - og vil de vide mere?]. Omsorg 2014;2:21-5.

(109) Verlinde E, De LN, De MS, Deveugele M, Willems S. The social gradient in doctor-patient communication. Int J Equity Health 2012 Mar 12;11:12.

(110) Thygesen LC, Ersboll AK. When the entire population is the sample: strengths and limitations in register-based epidemiology. Eur J Epidemiol 2014 Jan 10.

(111) Turrell G. Income non-reporting: implications for health inequalities research. J Epidemiol Community Health 2000 Mar;54(3):207-14.

(112) Lynge E, Sandegaard JL, Rebolj M. The Danish National Patient Register. Scand J Public Health 2011 Jul;39(7 Suppl):30-3.

(113) Due P, Holstein B, Lund R, Modvig J, Avlund K. Social relations: network, support and relational strain. Soc Sci Med 1999 Mar;48(5):661-73.

(114) LoPresti MA, Dement F, Gold HT. End-of-Life Care for People With Cancer From Ethnic Minority Groups: A Systematic Review. Am J Hosp Palliat Care 2016 Apr;33(3):291-305.

(115) Statistics Denmark. http://www.dst.dk/da/Statistik/emner/befolkning-og-valg/befolkning-og-befolkningsfremskrivning/befolkningsfremskrivning. 31-8-2017.

(116) Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med 2017 May 18;15(1):102.

Appendix A:

Type of SPC function(s) in the SPC units delivering data to DPD

Table A Specialised palliative care units delivering data to Danish Palliative Care Database in relation to type of function; palliative care team and in-patient function

	SPC function	
	Palliative care team function	In-patient function
Capital Region of Denmark		
Bispebjerg Hospital	X	X
Herlev Hospital	X	X
Nordsjaellands Hospital, Frederikssund	X	X
Hvidovre Hospital	X	X
Rigshospitalet	X	
Arresoedal (hospice)	X	X
Diakonissestiftelsen (hospice)	X	X
Sankt Lukas Stiftelsen (hospice)	X	X
Soendergård (hospice)	X	X
Region Zealand		
Holbaek Hospital	X	
Koege Hospital	X	
Nykoebing Falster Hospital	X	
Naestved Hospital	X	
Roskilde Hospital	X	
Slagelse Hospital	X	
Filadelfia (hospice)		X
Sjaelland (hospice)		X
Svanevig (hospice)		X
Region of Southern Denmark		
Odense University hospital, Odense	X	
Svendborg Hospital	X	
Sydvestjysk Hospital, Esbjerg	X	

Hospital Lillebaelt, Vejle	X	
Hospital Soenderjylland, Soenderborg	X	
Fyn (hospice)		X
Sydfyn (hospice)		X
Sct. Maria (hospice)		X
Sydvestjylland (hospice)		X
Soenderjylland (hospice)		X
Central Denmark Region		
Region hospital Herning	X	
Region hospital Horsens	X	
Region hospital Randers	X	
Region hospital Silkeborg	X	
Region hospital Viborg	X	
Aarhus University hospital	X	
Ankerfjord (hospice)		X
Djursland (hospice)		X
Limfjord (hospice)		X
Soeholm (hospice)		X
North Denmark Region		
Aalborg University hospital (Farsoe)	X	X
Region hospital Nordjylland (Thisted)	X	
Region hospital Nordjylland (Hjoerring)	X	
Aalborg University hospital (Aalborg)	X	
KamillianerGaarden (hospice)		X
Vendsyssel (hospice)		X

Paper 1

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RESEARCH ARTICLE Open Access

Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD)

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Abstract

Background: Specialised palliative care (SPC) takes place in specialised services for patients with complex symptoms and problems. Little is known about what determines the admission of patients to SPC and whether there are differences in relation to institution type. The aims of the study were to investigate whether cancer patients' admittance to SPC in Denmark varied in relation to sex, age and diagnosis, and whether the patterns differed by type of institution (hospital-based palliative care team/unit, hospice, or both).

Methods: This was a register-based study of adult patients living in Denmark who died from cancer in 2010–2012. Data sources were the Danish Palliative Care Database, Danish Register of Causes of Death and Danish Cancer Registry. The associations between the explanatory variables (sex, age, diagnosis) and admittance to SPC were investigated using logistic regression.

Results: In the study population ($N = 44{,}548$) the overall admittance proportion to SPC was 37%. Higher odds of overall admittance to SPC were found for women (OR = 1.23; 1.17–1.28), younger patients (<40 compared with 80+ years old) (OR = 6.44; 5.19–7.99) and patients with sarcoma, pancreatic and stomach cancers, whereas the lowest were for patients with haematological malignancies. The higher admission found for women was most pronounced for hospices compared to hospital-based palliative care teams/units, whereas higher admission of younger patients was more pronounced for hospital-based palliative care teams/units. Patients with brain cancer were more often admitted to hospices, whereas patients with prostate cancer were more often admitted to hospital-based palliative care teams/units.

Conclusion: It is unlikely that the variations in relation to sex, age and cancer diagnoses can be fully explained by differences in need. Future research should investigate whether the groups having the lowest admittance to SPC receive sufficient palliative care elsewhere.

Keywords: Specialised palliative care, Cancer, End of life care, Hospice, Palliative care team, Admittance

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Background

Specialised palliative care (SPC) takes place in specialised services for patients with complex symptoms and problems [1] and the majority of patients admitted to SPC worldwide and in Denmark have cancer diagnoses (about 95% in Denmark) [2, 3]. In Denmark SPC takes place in hospital-based palliative care teams/units and in hospices, but there are no national guidelines for referral of patients to SPC. Little is known about what determines the admission of patients to SPC [4] and whether there are differences in relation to institution type (hospital-based palliative care teams/units versus hospices).

Differences in symptoms and problems could explain differences in admittance to SPC. In a Danish nationally representative sample of patients with advanced cancer, it was shown that the majority of symptoms and problems were not associated with sex. The only differences reported were that patients with lung cancer had more symptoms and problems than patients with other cancer diagnoses and that older patients had more symptoms and problems compared with younger patients [5, 6].

In an optimally functioning health care system, admittance to SPC would be directly related to the level of needs. Other explanations could be differences in awareness, traditions and attitudes among the referring departments and SPC units. For example, there could be differences in the capacity among hospital departments and thereby in the incentive to refer patients to SPC. If such factors determine the referral, it may result in inequality (i.e., that patients with the same needs have different likelihood of admission) in admittance to SPC.

From the results of the previously mentioned Danish study of symptoms and problems among patients with advanced cancer, we have no reason to believe that certain subgroups defined by sex, age or cancer diagnosis will have higher needs for SPC; exceptions may be older persons and patients with lung cancer since these two groups had more symptoms [5, 6].

The aims of the present study were to investigate whether overall admittance to SPC in Denmark for adults who died from cancer varied with sex, age and cancer diagnosis, and whether the (admittance) patterns were different according to type of institution (admission to hospital-based palliative care teams/units, hospices, or both types of institutions).

Methods

This is a Danish nation-wide register-based study. The unique Danish personal identification number (CPR-number) makes it possible to collect and merge data from different registers.

Setting

There are two types of SPC institutions in Denmark (5.7 million inhabitants) but the characteristics of these are not mutually exclusive. First, there are hospices, and some of these also have a home care team (four out of 18 hospices had a home care team in addition to their in-patient facility). Hospices are free-standing services, separate from the rest of the health care system, and are publicly financed with no payment from patients. Secondly, there are hospital-based palliative care teams/units with or without an in-patient unit (five out of 26 hospital-based palliative care teams/units have an in-patient unit in addition to their home care and out-patient services). The teams/units are placed at hospitals, and are also fully publicly financed. During the study period, the number of SPC units in Denmark increased from 36 to 44 units [2].

About 80% of the patients admitted to SPC had contact with only one SPC unit (either a hospice or a hospital-based palliative care team/unit), whereas about 20% of the patients had contact with two or more SPC units, typically a hospital-based palliative care team followed by a hospice. All of these SPC units are expected to have multidisciplinary teams and to have weekly multidisciplinary meetings about their patients. The median survival time from the first referral to SPC to death was 27 days (mean 55 days) for patients admitted to a hospice, and for those admitted to a hospital-based palliative care team/unit it was 50 days (mean 90 days) [7].

Data sources and variables

Danish Palliative Care Database (DPD) is a national quality of care database, and since 1 January 2010, it has been mandatory for all SPC units in Denmark to register all referred patients in the DPD. The DPD data about admission is validated against the Danish National Patient Register [8] in close collaboration with the SPC units. DPD has a high patient completeness, which has increased from 95.7% in 2010 [9] to 100% in 2012 [2]. Information about sex, age at the time of death, admittance to SPC (hospital-based palliative care team/unit and/or hospice) was collected from DPD.

Deaths among individuals living in Denmark are registered in Danish Register of Causes of Death (RCD). Information on cause of death is reported by the physician certifying the death. More than 99% of the death certificates contain complete data [10]. Data about the underlying cause of death (diagnosis) and date of death were obtained from RCD.

The Danish Cancer Registry (CR) is a population-based research register and contains incident cancer diagnoses since 1943. From 1987 it has been mandatory to report to CR [11]. CR contributed with information about cancer diagnoses.

Variables:

Overall admittance: a dichotomous (yes/no) variable defined as any personal contact with SPC (inpatient, home visit, outpatient or palliative care team visits to inpatients at non-SPC departments). For patients with more than one contact the information from the first contact was included.

Institution type specific admittance: Overall admittance subdivided after type, i.e., hospital-based palliative care team/unit, hospice or both.

Explanatory variables: sex, age at the time of death grouped as: 18–39, 40–49, 50–59, 60–69, 70–79, 80+ years, and cancer diagnosis coded using ICD-10 (Table 1).

Population/sample

From RCD we identified adults (at least 18 years old) with cancer as the underlying cause of death in 2010–2012 including all ICD-10 C-codes and the D-codes for cancers in the brain (see Table 1). The death causes of cancer were validated against the CR [11]: (i) For most patients (84%) the same diagnosis was found in the two registers. (ii) Different diagnoses were found for 12%, these individuals were included in the study with the cancer diagnosis registered in CR. If there was more than one cancer registration, the latest was used. (iii) Patients with no cancer diagnosis registered in the CR were excluded (4%, $N = 1,773$). After these exclusions 44,548 patients were included in the study (Fig. 1).

Data analysis

The associations between the explanatory variables (sex, age and cancer diagnosis) and overall admittance to SPC were investigated using unadjusted and adjusted logistic regression analysis including all the explanatory variables in the model. In addition, three separate multiple logistic regression analyses were made for admittance to hospital-based palliative care team/unit, hospice or both, respectively, adjusted for sex, age and diagnosis. The reference group for diagnosis was the average of admittance for all diagnoses. The results from the logistic regressions are reported as odds ratios (ORs) with 95% confidence intervals (CIs). As level of statistical significance $p < 0.05$ was used. The analyses were carried out using SAS statistical software version 9.3 [12].

Results

In the study population ($N = 44,548$), the overall admittance proportion to SPC was 37.4% of all patients dying of cancer in 2010–12. The institution type specific admittance was 26.8% for hospital-based palliative care team/unit and 17.3% for hospice. Thus, some patients (6.8%) were admitted to hospital-based palliative care team/unit and hospice (Table 1).

Sex

In the study population slightly more than half were men (52.3%). Overall, women had a higher admittance proportion (39.5%) than men (35.5%) (Table 1).

The multiple logistic regression analysis showed that overall, women were more likely to be admitted to SPC than men (OR = 1.23; 95% CI:1.17–1.28) (Table 2). The institution type specific admittance analyses showed that this sex difference was more pronounced in relation to hospice (OR = 1.45; 95% CI:1.37–1.54), than for hospital-based palliative care team/unit (OR = 1.06; 95% CI:1.00–1.11).

Age

Most patients were above the age of 60 years (85%), while only 0.9% were 18–39 years old (Table 1). A much higher admittance proportion to SPC was found for younger compared with older patients; the overall admittance proportion decreased from 65.0% for individuals 18–39 years of age to 24.3% for those age 80+ years old (Table 1).

In the multiple logistic regression analysis a strong association between age and overall admittance was found (Table 2). The odds of admittance to SPC were over six times higher for the youngest (18–39 years old) compared to the 80+ years old (OR = 6.44; 95% CI:5.19–7.99). Looking at institution type specific admittance, the differences between age groups were more pronounced for admittance to hospital-based palliative care team/unit than for hospice.

Diagnosis

The most common cancer diagnoses in the study population were lung (23.2%), colorectal (12.7%) and breast cancer (8.1%) (Table 1).

The highest odds of overall admittance to SPC were found for individuals with sarcoma (OR = 1.90; 95% CI:1.52–2.38), pancreatic (OR = 1.77; 95% CI:1.61–1.94) and stomach cancer (OR = 1.69; 95% CI:1.50–1.90) compared with the average of all diagnoses (Table 2). The lowest odds of overall admittance to SPC were found for patients with haematological malignancies with odds ratios between 0.33 (95% CI:0.17–0.63) and 0.50 (95% CI:0.42–0.61).

The multiple logistic regression analyses of the institution type specific admittance showed a somewhat different pattern in relation to diagnosis. The admittance to hospital-based palliative care team/unit was consistent with the overall admittance to SPC. High admittance to hospice was also found in relation to patients with sarcoma cancer (OR = 1.54; 95% CI:1.20–1.98), but the highest odds were for patients with ovarian cancer (OR = 1.56; 95% CI:1.35–1.80). Again the lowest odds of admittance were found for patients with haematological malignancies

Table 1 The characteristics of the study population overall and institution type specific admittance

	N	Overall admittance to SPC	Admittance to hospital-based palliative care team/unit	Admittance to Hospice	Admittance to both hospital-based palliative care team/unit and hospice
	(%)	%	%	%	%
All cancer diagnoses	44,548 (100)	37.4	26.8	17.3	6.8
Sex					
Men	23,312 (52.3)	35.5	26.8	14.7	6.0
Women	21,236 (47.7)	39.5	26.8	20.2	7.8
Age (years)					
18–39	406 (0.9)	65.0	52.2	30.5	17.7
40–49	1,353 (3.0)	59.7	46.3	29.3	16.0
50–59	4,521 (10.2)	51.1	39.2	22.8	10.8
60–69	11,221 (25.2)	44.3	32.5	20.3	8.5
70–79	13,870 (31.1)	36.7	25.9	16.9	6.1
80+	13,177 (29.6)	24.3	15.9	11.7	3.3
Diagnosis (cancer site)					
Oral cavity, nasopharyngeal (etc.) (C00-C14)	998 (2.2)	37.7	30.0	16.2	8.5
Oesophageal (C15)	1,101 (2.5)	43.0	32.5	17.3	6.8
Stomach (C16)	1,285 (2.9)	47.6	35.4	22.0	9.9
Small intestine (C17)	162 (0.4)	40.1	30.9	17.3	8.0
Colorectal (C18–C20)	5,649 (12.7)	36.0	25.9	16.7	6.6
Liver (etc.) (C22)	845 (1.9)	34.7	24.6	14.0	3.9
Pancreatic (C25)	2,473 (5.6)	49.4	34.9	22.6	8.1
Laryngeal (C32)	280 (0.6)	29.6	22.5	12.9	5.7
Tracheal, bronchial and lung (C33–C34)	10,338 (23.2)	39.5	28.2	18.4	7.1
Melanoma skin cancer (C43)	774 (1.7)	45.1	31.7	23.1	9.7
Sarcoma (C46–C49)	326 (0.7)	54.9	40.8	25.8	11.7
Breast (C50)	3,618 (8.1)	37.3	25.9	18.3	6.9
Cervical (C53)	301 (0.7)	45.2	31.6	26.3	12.6
Uterine (C54–55)	499 (1.1)	42.1	29.1	20.2	7.2
Ovarian (etc.) (C56,C570–C574)	1,109 (2.5)	49.9	33.3	27.7	11.1
Prostate (C61)	3,512 (7.9)	33.9	27.7	12.6	6.4
Testicular (C62)	39 (0.1)	30.8	28.2	12.8	10.3
Kidney (etc.) (C64–C66)	991 (2.2)	44.4	33.5	18.8	7.9
Bladder (C67)	1,378 (3.1)	32.3	24.2	13.4	5.4
Brain/central nervous system (C70–C71, C751–C753)[a]	1,407 (3.2)	40.9	26.0	22.3	7.4
Thyroid (C73)	114 (0.3)	45.6	32.5	21.1	7.9
Unknown primary cancer (C76–C80)	1,802 (4.1)	32.4	21.6	15.8	5.1
Hodgkin disease (C81)	58 (0.1)	19.0	13.8	10.3	5.2
Non-Hodgkin lymphoma (C82-C85)	814 (1.8)	20.2	11.7	11.4	3.0
Multiple myeloma (C 90)	635 (1.4)	20.6	14.0	9.3	2.7
Leukemia (C91–C95)	1,200 (2.7)	15.3	8.4	7.9	1.1
Other cancer (all other C codes)	2,840 (6.4)	29.9	21.4	13.8	5.3

[a] Including the following D-codes: D32, D42, D330–332, D352–354, D430–432, D443–445, D333–339 and D433–439

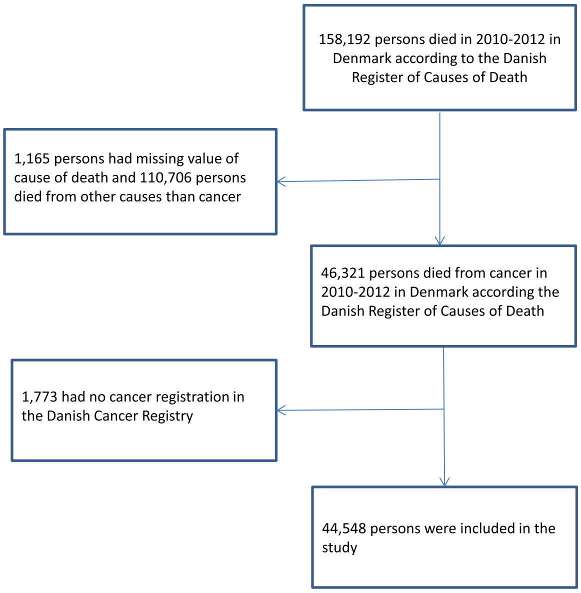

Fig. 1 Flow-chart for sampling the study population

in relation to all types of institutions. For patients with some cancer diagnoses large differences were seen between use of hospital-based palliative care team/unit and hospice: for patients with brain cancer the odds of admittance to hospice were markedly above the average of all diagnoses, whereas the odds of admittance to hospital-based palliative care teams/units were below the average of all diagnoses. In relation to patients with prostate cancer the reverse pattern was found.

Discussion

We found relatively large differences in admittance to SPC: lower admittance to SPC for men (most pronounced for hospice than hospital-based palliative care team/unit), markedly lower admission for older patients (more pronounced for hospital-based palliative care team/unit than hospice) and lower admission for patients with haematological diseases. For two cancer diagnoses the patterns were opposite: there was higher admittance than average to hospice and lower admittance to hospital-based palliative care team/unit for patients with brain cancer whereas there was higher admittance to hospital-based palliative care team/unit and lower to hospice for patients with prostate cancer.

The study was based on data from well-established nation-wide registers with high completeness [2, 7, 9, 11, 13]. This ensured a large national study population (*N* = 44,548) of all patients who died of cancer in 2010–2012 in Denmark, which makes it possible to study the population in detail, e.g. looking at the different diagnoses separately. Further, it ensures representativeness and minimizes the effect of selection bias [14]. We have found no other studies of similar size and quality, and no previous studies have been comparing the patterns of admittance to different types of SPC institutions.

A high validity of the variable “admittance to SPC” from the DPD was ensured by validating the data of admittance from DPD against the Danish National Patient Register [8] and SPC institutions were contacted if uncertainties were present the. Furthermore, the cancer diagnoses registered in the Danish Register of Causes of Death were validated against the Danish Cancer Registry, which has high quality of data with 89% of the tumours being morphologically verified [11]. In the present study only 1,773 (4%) patients were excluded because the registration of the cancer diagnoses in the Danish Register of Causes of Death was not found in the Danish Cancer Registry. This ensured high validity of the diagnosis variable and with the very limited number of cases excluded one must expect only a minor influence on the results.

The results from the present study can be compared with the results from a large Danish study, described in the introduction, investigating symptoms and problems in patients with advanced cancer [5, 6].

We found that women were more often admitted to SPC, especially to hospice (OR 1.45; 1.37–1.54). The Danish study of needs [5, 6] showed only minor differences in symptoms and problems in relation to sex, although there was a tendency towards worse emotional function for women with solid tumours [5, 6]. Such a difference might contribute to the sex difference but it seems unlikely that it explains the marked disparity found in this study. Some earlier studies reported higher admittance to SPC for women [15–18], whereas most studies did not show any differences [3]. The sex difference found in Denmark could be explained by traditional sex roles where women to a larger extent than men provide end of life care at home to their partner. Other possible explanations could be that the needs of women are more compatible with hospice or that more women prefer the hospice option. It might also be that women are better at recognizing and articulating a need for hospice; this would be in line with findings that women are more likely to talk about their own impending death [19] and to acknowledge that their illness is incurable [20].

In the present study admittance to SPC decreased with increasing age, whereas the study of symptoms and problems found that symptoms and problems seemed to increase with increasing age [5, 6]. Our results are in line with earlier studies [21] although the age gradient was much stronger in our study [16, 22–25]. Comparing the youngest with the oldest patients a stronger association was found for hospital-based palliative care team/unit (OR = 6.81; 5.53–8.38) than for hospice (OR = 3.17; 2.57–3.97). With the limited SPC capacity and if we

Table 2 Overall and institution type specific odds of admittance to SPC for Danish cancer patients, mutually adjusted

	Overall admittance to SPC	Admittance to hospital-based palliative care team/unit	Admittance to hospice	Admittance to both hospital-based palliative care team/unit and hospice
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Sex	($P < 0.001$)	($P < 0.033$)	($P < 0.001$)	($P < 0.001$)
Women	1.23 (1.17–1.28)	1.06 (1.00–1.11)	1.45 (1.37–1.54)	1.34 (1.23–1.47)
Men	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Age (years)	($P < 0.001$)	($P < 0.001$)	($P < 0.001$)	($P < 0.001$)
18–39	6.44 (5.19–7.99)	6.81 (5.53–8.38)	3.17 (2.54–3.97)	6.73 (5.08–8.93)
40–49	4.60 (4.09–5.18)	4.80 (4.26–5.41)	2.90 (2.54–3.31)	5.64 (4.72–6.74)
50–59	3.22 (3.00–3.47)	3.48 (3.22–3.76)	2.13 (1.94–2.32)	3.63 (3.16–4.17)
60–69	2.46 (2.32–2.60)	2.56 (2.41–2.73)	1.89 (1.76–2.03)	2.80 (2.49–3.16)
70–79	1.80 (1.70–1.89)	1.86 (1.75–1.97)	1.52 (1.42–1.64)	1.97 (1.74–2.22)
80+	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Diagnosis (cancer site)	($P < 0.001$)	($P < 0.001$)	($P < 0.001$)	($P < 0.001$)
Oral cavity, nasopharyngeal (etc.) (C00–C14)	0.95 (0.83–1.09)	1.07 (0.93–1.23)	0.94 (0.79–1.12)	1.23 (0.97–1.55)
Oesophageal (C15)	1.34 (1.18–1.52)	1.36 (1.19–1.56)	1.09 (0.93–1.29)	1.08 (0.85–1.38)
Stomach (C16)	1.69 (1.50–1.90)	1.63 (1.44–1.85)	1.50 (1.30–1.73)	1.67 (1.37–2.04)
Small intestine (C17)	1.23 (0.89–1.68)	1.34 (0.96–1.87)	1.07 (0.72–1.59)	1.31 (0.75–2.29)
Colorectal (C18–C20)	1.13 (1.05–1.22)	1.16 (1.07–1.26)	1.09 (0.99–1.19)	1.18 (1.03–1.35)
Liver (etc.) (C22)	0.92 (0.80–1.07)	0.91 (0.77–1.07)	0.83 (0.68–1.02)	0.59 (0.42–0.84)
Pancreatic (C25)	1.77 (1.61–1.94)	1.59 (1.44–1.75)	1.47 (1.31–1.64)	1.31 (1.11–1.54)
Laryngeal (C32)	0.75 (0.58–0.97)	0.82 (0.62–1.08)	0.80 (0.57–1.13)	0.93 (0.57–1.53)
Tracheal, bronchial and lung (C33–C34)	1.16 (1.09–1.23)	1.15 (1.07–1.23)	1.12 (1.03–1.21)	1.12 (1.00–1.25)
Melanoma skin cancer (C43)	1.46 (1.26–1.69)	1.31 (1.12–1.54)	1.52 (1.28–1.81)	1.53 (1.19–1.96)
Sarcoma (C46–C49)	1.90 (1.52–2.38)	1.74 (1.39–2.19)	1.54 (1.20–1.98)	1.58 (1.12–2.23)
Breast (C50)	0.96 (0.88–1.05)	0.99 (0.90–1.09)	0.94 (0.84–1.04)	0.93 (0.79–1.08)
Cervical (C53)	1.10 (0.87–1.39)	1.06 (0.83–1.36)	1.30 (1.00–1.69)	1.43 (1.01–2.03)
Uterine (C54–55)	1.35 (1.13–1.62)	1.36 (1.11–1.66)	1.16 (0.93–1.45)	1.15 (0.82–1.62)
Ovarian (etc.) (C56,C570–C574)	1.57 (1.38–1.78)	1.38 (1.20–1.58)	1.56 (1.35–1.80)	1.52 (1.23–1.86)
Prostate (C61)	1.32 (1.21–1.44)	1.54 (1.40–1.69)	1.04 (0.93–1.18)	1.58 (1.34–1.87)
Testicular (C62)	0.50 (0.26–0.99)	0.68 (0.34–1.37)	0.63 (0.25–1.56)	1.11 (0.40–3.06)
Kidney (etc.) (C64–C66)	1.46 (1.28–1.66)	1.49 (1.30–1.71)	1.19 (1.01–1.40)	1.28 (1.01–1.63)
Bladder (C67)	1.04 (0.92–1.17)	1.13 (0.99–1.29)	0.92 (0.78–1.08)	1.06 (0.83–1.35)
Brain/CNS (C70–C71, C751–C753)[a]	1.05 (0.98–1.17)	0.85 (0.75–0.97)	1.30 (1.13–1.49)	0.97 (0.78–1.20)
Thyroid (C73)	1.54 (1.07–2.22)	1.49 (1.01–2.20)	1.29 (0.83–2.00)	1.25 (0.64–2.43)
Unknown primary cancer (C76–C80)	0.93 (0.83–1.04)	0.89 (0.79–1.00)	0.99 (0.86–1.13)	0.86 (0.69–1.07)
Hodgkin disease (C81)	0.33 (0.17–0.63)	0.37 (0.18–0.77)	0.52 (0.23–1.17)	0.65 (0.21–2.03)
Non-Hodgkin lymphoma (C82–C85)	0.49 (0.42–0.60)	0.41 (0.33–0.51)	0.70 (0.56–0.87)	0.50 (0.33–0.74)
Multiple myeloma (C 90)	0.50 (0.42–0.61)	0.52 (0.42–0.65)	0.55 (0.42–0.72)	0.46 (0.28–0.73)
Leukemia (C91–C95)	0.34 (0.29–0.40)	0.29 (0.23–0.35)	0.47 (0.38–0.58)	0.18 (0.10–0.30)
Other cancer (all other C codes)	0.91 (0.83–1.00)	0.96 (0.87–1.07)	0.90 (0,80–1,02)	0.99 (0,83–1,19)
Average of all diagnoses	1 (ref)	1 (ref)	1 (ref)	1 (ref)

[a] Including the following D-codes: D32, D42, D330–332, D352–354, D430–432, D443–445, D333–339 and D433–439

accept that the need is not lower among the oldest, some older patients may not receive the care they need, maybe because symptoms and death are more accepted in relation to older than younger patients. It is unknown whether other parts of the health care system compensate for the lower admission to SPC among the older patients, e.g., whether the needs are adequately covered by primary care, where they may already be in close contact with the general practitioner, or via nursing homes.

Comparing the overall admittance to SPC of patients with different cancer diagnoses, admittance was highest for patients with sarcoma, pancreatic and stomach cancers and lowest for patients with haematological malignancies. According to the previous study of advanced cancer patients the patterns for admittance cannot be explained by differences in needs: the patient groups having higher admittance did not have more symptoms and problems, and patients with haematological malignancies did not have fewer symptoms [5, 6]. However, there may of course be differences in needs that were not revealed in the questionnaires used. Previous studies have also found that, patients with haematological malignancies were less often admitted to SPC [26, 27]. It has also been reported that the patients with haematological cancer are referred closer to death than patients with other cancer diagnoses and receive more aggressive treatment towards the end of life [28–31]. The fact that active cancer treatment of this patient group continues until close to death may explain why these patients less often are admitted to SPC. It may be a wish from the patients to continue their trajectory at the haematological departments and not be referred to a new and unknown SPC unit. More research is needed to better understand the referral of patients with haematological malignancies to SPC. In relation to gynaecological and gastrointestinal cancer we found like Hui et al. higher odds of admittance to SPC [27], especially for ovarian, pancreatic and stomach cancers, but with marked variation between the different cancer types in each subgroup and between admittance to hospital-based palliative care team/unit and hospice. Other studies found lower admittance for breast cancer compared to colorectal cancer patients [22] and lung cancer patients [32], similar to the present study but different from the study by Hui et al. [27].

Differences in admittance in relation to type of institution were primarily found in relation to patients with brain and prostate cancer. Possibly, some types of cancer are more compatible with certain types of care than others. The care of patients with prostate cancer more frequently takes place in hospital-based palliative teams/units, and this may reflect that it can take place in the home of the patient. The care of brain cancer patients may be more demanding, with difficult symptoms such as cognitive impairment and personality changes, which may be more difficult to accommodate by the family caregivers, leading to hospice referral.

It is a recurring discussion in studies of admittance to SPC whether differences between subgroups reflect a real difference in need or an inequality, as the burden of symptoms and problems (reflecting the need) are unknown. It is a strength of this study that it has been possible to compare admittance to SPC against the pattern of symptoms and problems in a nationally sample covering all advanced cancer patient. Of course, the comparison has some limitations, for example the EORTC QLQ-C30 questionnaire, which was used may not cover all relevant aspects, for example the availability of help and social support at home.

Given the large differences in admittance in relation to sex, age and diagnosis, future research should investigate whether the groups having the lowest admittance have uncovered needs of SPC (e.g. via surveys of patients not admitted or by evaluating whether those admitted have more needs, indicating a higher degree of selection). It could also be relevant to compare end of life outcomes reported by bereaved carers. Finally, it would be relevant to compare the geographic patterns in more detail.

This study examines “overall admittance to SPC”. The DPD includes the date and type of initial contact with SPC but does not contain the detailed data about the frequency and nature of additional contacts with SPC. In an ongoing development project we are working on establishing such data from other registries but these data are not yet available. When such detailed data about the number and nature of SPC contacts become available, they can answer important additional research questions.

In this study SPC was separated into the two categories, hospital-based palliative care team/unit and hospice. This is a construction with limitations, because about 20% of the hospices have outgoing palliative teams and 20% of the hospital-based palliative care teams/units have SPC units with in-patients like hospices. On the other hand there are some clear differences between hospices and hospitals e.g. the organisation, financing and whether or not it takes place within the hospital system, which makes the distinction meaningful. However, due to the fact that each of the categories did include aspects from the ‘opposite’, our categorisation may underestimate the differences between hospital-based palliative care team/unit and hospice.

Conclusion

In this first nation-wide register-based study of admittance to SPC among patients with cancer we found lower overall admittance for men, older patients and patients with haematological malignancies. Compared with hospital-based palliative care team/unit, admittance to hospice was lower for men and for patients with prostate cancer whereas admittance to hospice was higher for patients with brain cancers. The large variation in admittance to SPC found in this study in relation to sex, age and cancer types cannot be explained by the variation in symptoms and problems among advanced cancer patients in general. Future research should investigate whether the groups having the lowest admittance to SPC receive sufficient palliative care.

Abbreviations

CR: The Danish Cancer Registry; DPD: Danish Palliative Care Database; OR: Odds ratio; RCD: Danish Register of Causes of Death; SPC: Specialised palliative care

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Availability of data and materials

The data utilized in this study are available at Statistics Denmark and Danish Palliative Care Database. Restrictions apply to the availability of these data which are described under license for the current study.

Authors' contributions

MA and LCT were the major contributors in analysing the register data. MA and MG were the major contributors in writing the manuscript. ABJ, MAN and PS were part of the data collection to the database and contributed with clinical comments to the manuscript, especially in relation to the discussion. All authors have given their approval of the final version of the manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

The study is based on data from registers and a national database; there was no personal contact to the patients. According to Danish law it did not require ethics committee approval.

Publisher's Note

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References

1. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 1. Eur J Palliat Care. 2009;16(6):278–89.
2. Hansen MB, Grønvold M. Danish palliative care database annual report 2012. In: Danish: Dansk Palliativ Database Årsrapport 2012. København: DMCG-PAL; 2013.
3. Walshe C, Todd C, Caress A, Chew-Graham C. Patterns of Access to Community Palliative Care Services: A Literature Review. J Pain Symptom Manage. 2009;37(5):884–912.
4. Broom A, Kirby E, Good P. Referral to specialist palliative care. Intern Med J. 2012;42(9):1040–2.
5. Johnsen AT, Petersen MA, Pedersen L, Groenvold M. Symptoms and problems in a nationally representative sample of advanced cancer patients. Palliat Med. 2009;23(6):491–501.
6. Johnsen AT, Tholstrup D, Petersen MA, Pedersen L, Groenvold M. Health related quality of life in a nationally representative sample of haematological patients. Eur J Haematol. 2009;83(2):139–48.
7. Grønvold M, Hansen MB, Rasmussen M. Danish palliative care database annual report 2011. In: Danish: Dansk Palliativ Database Årsrapport 2011. København: DMCG-PAL; 2012.
8. Lynge E, Sandegaard JL, Rebolj M. The Danish National Patient Register. Scand J Public Health. 2011;39(7 Suppl):30–3.
9. Grønvold M, Rasmussen M, Hansen KH. Danish palliative care database annual report 2010. In: Danish: Dansk Palliativ Database Årsrapport 2010. Københvan: DMCG-PAL; 2011.
10. Helweg-Larsen K. The Danish Register of Causes of Death. Scand J Public Health. 2011;39(7 Suppl):26–9.
11. Gjerstorff ML. The Danish Cancer Registry. Scand J Public Health. 2011;39(7 Suppl):42–5.
12. SAS Institute INC. SAS/STAT 9.3 Users's Guide. Cary: SAS Institute Inc.; 2011.
13. Pedersen CB. The Danish Civil Registration System. Scand J Public Health. 2011;39(7 Suppl):22–5.
14. Thygesen LC, Ersboll AK. When the entire population is the sample: strengths and limitations in register-based epidemiology. Eur J Epidemiol. 2014;29(8):551–8.
15. Fadul N, Elsayem A, Palmer JL, Zhang T, Braiteh F, Bruera E. Predictors of access to palliative care services among patients who died at a comprehensive cancer center. J Palliat Med. 2007;10(5):1146–52.
16. Rosenwax L, Spilsbury K, Mcnamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care. 2016;10:15.
17. Lackan NA, Ostir GV, Freeman JL, Mahnken JD, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Med Care. 2004;42(2):116–22.
18. Virnig BA, Mcbean AM, Kind S, Dholakia R. Hospice use before death - Variability across cancer diagnoses. Med Care. 2002;40(1):73–8.
19. Skulason B, Hauksdottir A, Ahcic K, Helgason AR. Death talk: gender differences in talking about one's own impending death. BMC Palliat Care. 2014;13(1):8.
20. Fletcher K, Prigerson HG, Paulk E, Temel J, Finlay E, Marr L, et al. Gender differences in the evolution of illness understanding among patients with advanced cancer. J Support Oncol. 2013;11(3):126–32.
21. Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. Age and Ageing. 2006;35(5):469–76.
22. Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients. Med Care. 2008;46(12):1203–11.
23. Hunt RW, Fazekas BS, Luke CG, Priest KR, Roder DM. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. Palliat Med. 2002;16(5):403–9.
24. Maddison AR, Asada Y, Burge F, Johnston GW, Urquhart R. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care. 2012;28(2):90–6.
25. Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia - and who misses out. Palliat Med. 2006;20(4):439–45.
26. Howell DA, Shellens R, Roman E, Garry AC, Patmore R, Howard MR. Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. Palliat Med. 2011;25(6):630–41.
27. Hui D, Kim SH, Kwon JH, Tanco KC, Zhang T, Kang JH, et al. Access to palliative care among patients treated at a comprehensive cancer center. Oncologist. 2012;17(12):1574–80.
28. Ansell P, Howell D, Garry A, Kite S, Munro J, Roman E, et al. What determines referral of UK patients with haematological malignancies to palliative care services? An exploratory study using hospital records. Palliat Med. 2007;21(6):487–92.
29. Cheng WW, Willey J, Palmer JL, Zhang T, Bruera E. Interval between palliative care referral and death among patients treated at a comprehensive cancer center. J Palliat Med. 2005;8(5):1025–32.

30. Hui D, Didwaniya N, Vidal M, Shin SH, Chisholm G, Roquemore J, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. Cancer. 2014;15:120(10):1572–8.
31. Sexauer A, Cheng MJ, Knight L, Riley AW, King L, Smith TJ. Patterns of hospice use in patients dying from hematologic malignancies. J Palliat Med. 2014;17(2):195–9.
32. Neergaard MA, Jensen AB, Olesen F, Vedsted P. Access to Outreach Specialist Palliative Care Teams among Cancer Patients in Denmark. J Palliat Med. 2013; 16(8):951–7.

Paper 2

Cohabitation status and admittance to specialised palliative care (SPC) for cancer patients - A nationwide study from the Danish Palliative Care Database

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Keywords: specialised palliative care, hospice care, admittance, marital status, cohabitation, never married, divorced, married, widow.

Abstract

Purpose: To investigate the association between cohabitation status and admittance to specialised palliative care (SPC) and whether this association differed between the two types of SPC institutions in Denmark, hospital-based palliative care team/unit (mainly out-patient/home care) and hospice (mainly in-patient care).

Materials and methods: A register study based on the national Danish Palliative Care Database linked with additional registers including all patients dying from cancer in Denmark 2010-12. The associations were investigated using logistic regression analysis adjusting for sex, age, cancer diagnosis and geographic region. In addition, standardised, absolute prevalences of admittance to the two institution types were calculated.

Results: In the study population (N=44,480) 50% were married or cohabiting, 25% widow/widower, 12% divorced, 7% never married, and 3% married but not living together. Compared with cohabiting persons overall admittance to SPC was lowest in relation to patients who were widow/widower (OR=0.86: 95%CI; 0.81-0.91) and never married (OR=0.74: 95%CI; 0.68-0.80). Persons living alone were more likely to be admitted to hospice (e.g., divorced OR=1.41 (95% CI; 1.31-1.52) and less likely to be admitted to hospital-based palliative care team/unit (e.g., never married OR=0.64 (95% CI; 0.59-0.70)) vs cohabiting persons. The standardised prevalences of overall admittance to SPC showed similar pattern, e.g., admittance was highest (41%) for persons cohabiting and lowest (30%) for individuals never married.

Conclusion: Admittance to SPC was associated with cohabitation status, favouring cohabiting individuals in admittance to SPC. Compared with cohabiting patients it is unlikely that patients living alone have lower needs for SPC, and the results are therefore inequity in admittance to specialist health care; a problem that should be addressed.

Introduction

Having a partner has been identified to affect heath positively (1;2); this includes the incidence of and survival from cancer (3). The utilisation of the health care system varies in relation to cohabitation status and especially never married individuals have less contact to health care (fewer contacts with the general practitioner, fewer preventive health conversations, etc.) (4).

Conflicting results have been found in studies investigating the association between cohabitation status and admittance to specialised palliative care (SPC); approximately half of the studies found higher admittance to SPC for cohabiting individuals (5-13) whereas the other studies found no association (14-21) except for one study with results in the opposite direction (22).

In the SPC literature cohabitation status is mostly dichotomised into either married/non-married or living together/alone (5-7;9;10;12-18;20). We have only found few studies investigating cohabitation status in more detail. Lower admittance to SPC is found for persons who are widow/widower and single whereas no difference is found between divorced and married individuals (11). In relation to hospice conflicting results have been found, with higher and lower admittance for married individuals (8;19;22) and one study find no difference (21). Finally, it is unknown if the patterns are the same for hospital-based palliative care team/unit and hospice, respectively.

The aims of the present study were to investigate whether there was an association between cohabitation status (measured comprehensively) and admittance to SPC among cancer patients and whether this association was similar for the two institution types (hospital-based palliative care team/unit and hospice).

The two hypotheses of the study are a need and a resource based hypothesis, respectively. Our 'need hypothesis' is that high admittance to SPC for patients living alone could be explained by a higher need for this group of patients because they may not have a caregiver to take care of them at home. Our 'resource hypothesis' goes in the opposite direction, suggesting that lower admittance for individuals living alone could be explained by that the patients have fewer resources, that no one speaks on behalf of the patient, and that they are less able to navigate in the health care system compared with individuals living in a relationship.

Methods and material

Setting

In Denmark (population: 5.7 million (23)) the healthcare system is mainly tax financed and SPC is free of charge. There were 26 hospital-based palliative care teams/units and 18 hospices (free-standing institutions) in Denmark in 2012 (24). Five of the hospital-based palliative care teams/units had an inpatient function and four hospices had a home care function. Institutions with both in- and outpatients are mainly placed in Capital Region of Denmark. The characteristics of the SPC institutions are described in more detail elsewhere (25).

Study population

The study population included all adults (18+ years) who died of cancer in Denmark in 2010-2012. The cancer diagnoses found in The Danish Register of Causes of Death (RCD) were compared with The Danish Cancer Registry (CR) and included in the study if the person had a cancer diagnosis in CR. When different cancer diagnoses were found in the two registers, the cancer diagnosis from the CR was used (this happened in 12 %).

Data sources

This study is based on register data, and in Denmark every resident has a unique person identification number making it possible to merge data from different registers. Data concerning admittance to SPC were collected from the Danish Palliative Care Database (DPD) and information on date of death and cancer diagnosis (cause of death) were retrieved from the RCD and CR, respectively. Data concerning sex, age, geographic region, marital and cohabitation status were collected from the Danish Civil Registration System (26). These national registers all have very high completeness (close to 100%) (26-29). The CR has a high validity; 89% of the tumours are morphologically verified (27), and was used to confirm the cancer diagnosis from the RCD.

Variables

Outcome:

Overall admittance: a dichotomous (yes/no) variable defined as any personal contact with SPC (inpatient, home visit, outpatient or palliative care team visits to inpatients at non-SPC departments). For patients with more than one contact the information from the first contact was included.

Institution type specific admittance: Overall admittance subdivided after type, i.e., hospital-based palliative care team/unit or hospice.

Patients with contact to hospital-based palliative care team/unit and hospice were included in both groups, to have the full picture of the admittance to the different types of SPC institutions

Exposure:

In this study cohabitation status in the year before death was defined by a combination of information about marital status (married, divorced, widow/widower, never married) and living status (categories: married, a man and a woman living together with at least one child, a man and a woman living together without children and an age difference less than 15 years and not in close family relations, single). Cohabitation status was grouped in five categories:

1. Cohabiting (married or not, living together with or without children)

Patients living alone were grouped

2. Married, but not living together
3. Divorced
4. Widow/widower
5. Never married

Explanatory variables:

- Sex (men, women)
- Age at the time of death
- Cancer diagnosis using the main ICD-10 groups in the Danish Cancer Registry (30), except that we added separate groups of patients with colorectal cancer and prostate cancer, respectively, and grouped patients with cancer in the male genital organs in 'unknown or other cancer'
- Geographic region where the patient was living the year before death (Capital Region of Denmark, Region Zealand, North Denmark region, Central Denmark Region, Region of Southern Denmark)
- First contact to SPC (inpatient, outpatient)

Statistical analyses

The association between cohabitation status and overall admittance to SPC was investigated using logistic regression analysis, both unadjusted and adjusted for all covariates (sex, age, cancer diagnosis and geographic region). In the next step we performed the same analysis now stratified by type of institution to investigate whether the admittance pattern was similar for hospital-based palliative care team/unit and hospice.

Further, the exposure was dichotomised into individuals living together and alone and in two separate analyses (hospital-based palliative care team/unit and hospice) we tested two-ways-interactions with sex, age, diagnosis and region, respectively, including all other covariates.

In contrast to the other regions, some of the SPC institutions in Capital Region of Denmark offered both in- and outpatient care. Therefore, analyses excluding Capital Region of Denmark were also carried out. Further, to investigate possible misclassification, a separate analysis for Capital Region of Denmark based on type of first contact was made (i.e., patients receiving home care from a hospice were re-classified as 'hospital-based palliative care team/unit' and in-patient care in a hospital-based palliative care team/unit was reclassified as 'hospice').

Finally, a weighting variable was applied for each sex/age group/diagnosis/region to calculate standardised, absolute prevalence (percent) and 95% confidence intervals (31) of overall admittance to SPC.

The statistical significance level used was $P<0.05$. All the analyses were made in SAS statistical software version 9.4 (32).

Results

According to the RCD 158,192 persons died in 2010-2012 in Denmark, of whom 44,480 persons fulfilled our criteria: I) died of cancer according to the RCD, II) had a cancer registration in CR and, III) had information about cohabitation status (see Figure 1).

The study population in relation to cohabitation status

About half (53%) of the study population was cohabiting and 47% was living alone (25% widow/widower, 12% divorced, 7% never married, 3% married but were not living together) (Table 1). The proportion of men was higher in the group of cohabiting persons (63%) and lower among widows/widowers (30%). The proportions of individuals grouped as married but not living together, divorced and never married were highest in the Capital Region of Denmark. Divorced persons more often suffered from cancer in the respiratory system compared with the study population in general (30% versus 24%) and less often from prostate cancer (4% versus 8%).

Admittance to SPC

The logistic regression analysis of overall admittance to SPC showed that, compared with persons living alone, cohabiting individuals were more likely to be admitted to SPC, except for divorced individuals where no difference was found (Table 2). The adjusted analysis showed lowest admittance for never married individuals OR=0.74 (95% CI; 0.68-0.80) compared with persons cohabiting.

Similarly, the institution type specific analysis for hospital-based palliative care team/unit showed significantly lower OR=0.64 (95% CI; 0.59-0.70) for persons never married. However, an opposite pattern was found concerning admittance to hospice. Cohabiting persons were less likely to be admitted to hospice compared with individuals divorced (OR=1.41, 95% CI; 1.31-1.52) and widow/widower (OR=1.20, 95% CI; 1.11-1.28).

Interaction analysis

To test for interactions with sex, age, diagnosis and region, we included two-way-interactions in the logistic regression analysis. We found that three out of four interactions were statistically significant, however the interaction with sex was only statistically significant in relation to hospital-based palliative care team/unit (all $p \leq 0.004$) (Table 3).

The odds ratio of admittance to hospital-based palliative care team/unit was 0.67 (95% CI; 0.63-0.72) for men living alone compared with cohabitating men. The association for women was weaker OR=0.80 (95% CI; 0.75-0.86).

In relation to diagnosis the strongest difference between living together and alone was found for persons with prostate cancer for admittance to hospital-based palliative care team (OR =0.64, 95% CI; 0.53-0.76) and for persons with lymphoid and haematopoietic cancer diagnosis for being admitted to hospice (OR= 1.42, 95% CI; 1.07-1.87). Patients with lymphoid and haematopoietic tissue cancer living alone had higher odds of admittance to hospice compared to a person with similar diagnosis living in a relation. Patients with brain cancer who were living alone had lower admittance to hospice compared with those living in a relationship (OR=0.66, 95% CI; 0.50-0.88). The reverse pattern was seen for all other cancer diagnoses in relation to admittance to hospice.

The strongest difference between living together and living alone was found in Central Region of Denmark (hospital-based palliative care team/unit OR=0.64 (95% CI; 0.58-0.70) and hospice OR= 1.49 (95% CI; 1.33-1.66)). In relation to the Capital Region of Denmark the analyses that were corrected for potential misclassification (out-patient care offered by hospice and vice versa) showed differences similar to the other regions (hospital-based palliative care team/unit/out-patient care OR= 0.84 (95% CI: 0.76-0.91) and hospice/in-patient care OR=1.08 (95% CI: 0.97-1.20).

The prevalence of admittance to SPC

Figure 2 shows the standardised prevalence of overall admittance to SPC according to sex, age, diagnosis and region, respectively. The pattern was similar to the logistic regression analysis: the highest proportion having admittance to SPC was found for married patients (41%) and lowest proportion was found in relation to never married individuals (30%).

Discussion

Main findings

Admittance to SPC was associated with cohabitation status. Compared with cohabiting persons, patients living alone, except patients who were divorced, had statistically significant lower admittance to SPC, measured on both a relative and an absolute scale.

We found that the relations between admittance to SPC and type of SPC unit, respectively, had opposite directions: for cohabiting patients there was higher admittance to hospital-based palliative care team unit and lower to hospice. These findings may reflect better opportunities for care at home for persons living in a relationship than for persons living alone, as someone is taking care of the patient at home. Because of this relation between cohabiting status and type of SPC institution, it is ‘overall SPC’ that should be the focus in relation to inequality in admittance to SPC

We found that the associations between cohabitation status and the two different types of SPC were affected by sex, geographic region and diagnosis. The analyses showed that it meant more to be living in a relation for men compared with women (in relation to hospital-based palliative care team/unit), and this was also seen for patients living in Central Denmark Region, for patients with prostate cancer (hospital-based palliative care team/unit) and for patients with lymphoid and haematopoietic cancer (hospice) compared with the other categories.

Comparisons with previous studies

In the literature conflicting results have been found in studies investigating the association between cohabiting status and overall admittance to SPC. Three studies found higher admittance for individuals who were cohabiting (6;10;11) supporting the findings in this study and one of the studies (Australia) found similar to this study no difference between married and divorced patients and lower overall admittance to SPC for single and widows/widowers (11).

Among studies investigating type specific admittance, three studies investigated admittance to hospital-based palliative care team and found higher admittance for patients living in a relation as in this study (5;9;12). However, an earlier and smaller Danish register-based study (N=599) found the association for women only (9) in contrast to the results of the present study, where an even stronger association was found in men. Two studies (Italy, U.K.) found no association (15;17).

In relation to hospice five studies found no difference (14;16;18;20;21), three studies found higher admittance to hospice for cohabiting individuals (7;8;13), which is the opposite of this study. One study found similar to this study higher admittance for patients divorced or widow/widower (22) whereas one study support the findings with higher admittance for never married individuals, but found lower admittance for widow/widower opposite this study (19). A possible explanation for the conflicting results could be the ’resource hypothesis’ leading to better access due to better resources, despite potentially lower need (see Introduction).

An Italian study found higher admittance to a palliative care team whether the caregiver was a woman (17), which is in line with our result, where it was more important for men to be cohabiting than for women.

Possible explanations for the findings

In this study the need of SPC is unknown, but as persons living alone are unlikely to have fewer needs for SPC than cohabiting persons (in fact they probably have more needs for inpatient care because they are less likely to have somebody to take of them at home), we believe that lower admission of persons living alone reflect that they have less ability to obtain specialist care, possibly because they lack someone to ‘talk their case’ and navigate in the complex health care system. If this is the case, some of the weakest patients have poorer admittance to SPC. It is on the other hand possible that a caregiver who wants to keep the patient at home (which may prevent the need of care from a hospice), may have a higher need of contact to a hospital-based palliative care team.

The difference in admittance to the two types of institutions in relation to cohabitation status may reflect practical conditions. A palliative care team may more often be thought of as possible when someone takes care of the patient at home. The differences in admittance to hospice may be explained by the ‘need hypothesis’: patients living alone have a higher need of hospice care.

In the present study we found lower overall admittance to SPC for patients living alone, which support the ‘resource hypothesis’: that patients living in a relation have a person to talk their case and help them navigate the health care system. The results do not support the ‘need hypothesis’: that patients living alone have higher admittance to SPC because they have a higher need and may not have a caregiver at home to take care of them.

Patients who were divorced were not similar to the other groups of patients living alone. The results from the institution type specific admittance showed markedly higher admittance to hospice for divorced compared with other groups living alone. Further investigation is needed to fully understand this.

Strengths and limitations of the study

We conducted a nationwide register based study including all patients who died of cancer in 2010-12, which almost excluded selection bias and ensured a large study population (N=44,480) where it was possible to include cohabitation status (exposure), not just marital status. As many Danes live together without being married, it minimizes the risk of misclassification, e.g. when a divorced person lives in a new relationship without being married. The cancer diagnoses were compared with the CR, which has a very high validity (27). The data completeness was high and few patients were excluded because of missing data; only 68 persons had no cohabitation status registration. Finally, we used two independent methods; logistic regression analysis and standardisation, with similar results, which makes the conclusion more robust.

A limitation of this register based study is related to the variable ‘living status’ obtained from Danish Civil Registration System: the category ’living together without being married’ only includes couples of a man and a women and not same-sex relationships, and furthermore, a man and a women (around same age) sharing a department without being a couple will count as living together. Misclassification is therefore possible in relation to ‘living status’ but as such misclassification is not very frequent and will tend to weaken differences related to cohabitation, we do not believe that it will change the conclusion.

It is a known limitation that the main part of the registers is not established to research and therefore there can be relevant data that are not available (33). In this study it has not been possible to have data about whether the cohabitation was experienced as a support or a relational strain for the patient (34). Furthermore, it has not been possible to measure other social relations (family, friends etc.) in numbers or function, which could be important especially for patients living alone. It is possible that the difference would be even more pronounced if such information have been available, e.g. among never married individuals with no or few social relations.

Cohabitation status was measured the year before death and it is possible that cohabitation status was affected by the disease trajectory. On the other hand the measure of cohabitating status close to death is central as it represents the life conditions for the patient, at the time where the SPC is established and the physician refers the patient.

To what extent the results can be generalised

Denmark has, like other countries, SPC institutions at the hospital with palliative care teams and units with in-patients and additionally hospices. In the present study marital status is combined with living conditions, so it is less dependent on the cultural living conditions in relation to marriage. We therefore believe that the results may possibly be generalised to other western countries.

Conclusion

Admittance to SPC was associated with cohabitation status, favouring cohabiting individuals in admittance to SPC, possibly because cohabiting patients have more resources. Compared with cohabiting patients it is unlikely that patients living alone have lower needs for SPC. The results can therefore be interpreted as inequity, especially in the admittance to hospital-based palliative care, and this inequity should be addressed.

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Figure1. Flowchart for sampling the study population from the Danish Register of Causes of Death and the Danish Cancer Registry.

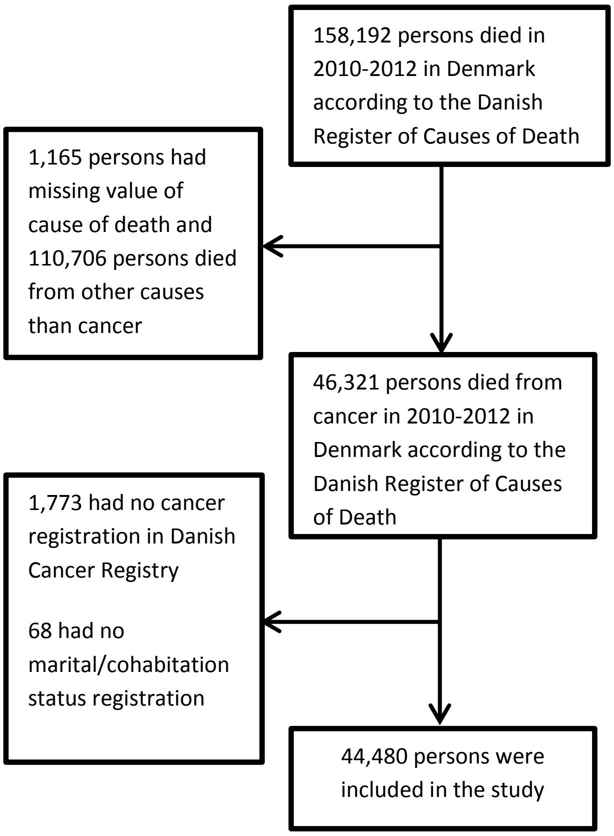


Table 1. The characteristics of the study population in relation to marital status.

	Total	**Living together**	**Living alone**			
		Cohabiting	**Married, but not living together**	**Divorced**	**Widow/ widower**	**Never married**
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Marital status, total	-	23,531 (52.9)	1,244 (2.8)	5,300 (11.9)	11,129 (25.0)	3,276 (7.4)
Sex						
Male	23,270 (52.3)	14,708 (62.5)	755 (60.7)	2,473 (46.7)	3,382 (30.4)	1,952 (59.6)
Female	21,210 (47.7)	8,823 (37.5)	489 (39.3)	2,827 (53.3)	7,747 (69.6)	1,324 (40.4)
Age (years)						
18-49	1,753 (3.9)	1,047 (4.5)	65 (5.2)	182 (3.4)	11 (0.1)	438 (25.0)
50-59	4,509 (10.1)	2,774 (11.8)	172 (13.8)	701 (13.2)	141 (1.3)	721 (22.0)
60-69	11,195 (25.2)	7,180 (30.5)	324 (26.1)	1,879 (35.5)	982 (8.8)	830 (25.3)
70-79	13,854 (31.2)	7,878 (33.5)	324 (26.1)	1,658 (31.3)	3,273 (29.4)	721 (22.0)
80+	13,169 (29.6)	4,642 (19.7)	359 (28.9)	880 (16.6)	6,722 (60.4)	566 (17.3)
Diagnosis (cancer site)						
Oral cavity, nasopharyngeal (etc.) (C00-C14)	995 (2.2)	711 (1.8)	41 (3.3)	203 (3.8)	180 (1.6)	160 (4.9)
Digestive system (C15-17 & C22+25)	5,854 (13.2)	3,361 (14.3)	134 (10.8)	697 (13.2)	1,212 (10.9)	450 (13.7)
Colorectal (C18-C20)	5,638 (12.7)	2,880 (12.2)	171 (13.8)	611 (11.5)	1,601 (14.4)	375 (11.5)
Respiratory system: (C32-34)	10,608 (23.9)	5,646 (24.0)	296 (23.8)	1,606 (30.3)	2,335 (21.0)	725 (22.1)
Melanoma (C43)	772 (1.7)	471 (2.0)	19 (1.5)	65 (1.2)	150 (1.4)	67 (2.1)
Sarcoma (C46-C49)	325 (0.7)	189 (0.8)	6 (0.5)	36 (0.7)	69 (0.6)	25 (0.8)
Breast (C50)	3,616 (8.1)	1,567 (6.7)	98 (7.9)	436 (8.2)	1,220 (11.0)	295 (9.0)
Female genital organs (C53-55 & C56,C570-C574))	1,908 (4.3)	860 (3.7)	40 (3.2)	266 (5.0)	588 (5.3)	154 (4.7)
Prostate (C61)	3,508 (7.9)	2,199 (9.4)	125 (10.1)	227 (4.3)	764 (6.9)	193 (5.9)
Urinary tract (C64-C67)	2,368 (5.3)	1,308 (5.6)	66 (5.3)	253 (4.8)	600 (5.4)	414 (4.3)
Brain/ central nervous system (C70-C71, C751-C753)*	1,401 (3.2)	864 (3.7)	66 (5.3)	123 (2.3)	224 (2.0)	124 (3.8)
Lymphoid & haematopoietic tissue (C81-85 & C90-95)	2,705 (6.1)	1,490 (6.3)	53 (4.3)	273 (5.2)	677 (6.1)	212 (6.5)
Unknown or other cancer (all other C codes)	4,782 (10.8)	2,285 (9.7)	129 (10.4)	504 (9.5)	1,509 (13.6)	355 (10.8)
Geographic region						
North Denmark Region	4,934 (11.1)	2,672 (11.4)	129 (10.4)	488 (9.2)	1,323 (11.9)	322 (9.8)
Region Zealand	7,521 (16.9)	4,136 (17.6)	194 (15.6)	884 (16.7)	1,831 (16.5)	476 (14.5)
Central Denmark Region	9,625 (21.6)	5,308 (22.6)	247 (19.9)	964 (18.2)	2,427 (21.8)	679 (20.7)
Region of Southern Denmark	9,971 (22.4)	5,476 (23.3)	275 (22.1)	1,084 (20.5)	2,487 (22.4)	649 (19.8)
Capital region of Denmark	12,429 (27.9)	5,939 (25.2)	399 (32.1)	1,880 (35.5)	3,061 (27.5)	1,150 (35.1)
Total	44,480 (100)					

*Including the following D-codes: D32, D42, D330-332, D352-354, D430-432, D443-445, D333-339 and D433-439.

Table 2. The odds ratio (OR) of overall and institution type specific admittance to SPC for Danish cancer patients in relation to cohabitation status: unadjusted and adjusted for sex, age, diagnosis and geographic region.

	Cohabitation status OR (95 % CI)				
	Living together	**Living alone**			
	Cohabiting (reference)	**Married but not living together**	**Divorced**	**Widow/ widower**	**Never married**
	(N=23,531)	**(N=**1,244**)**	**(N=5,300)**	**(N=11,129)**	**(N=3,276)**
Overall admittance:					
Unadjusted	1	**0.79** (0.70-0.88)	0.99 (0.93-1.05)	**0.62** (0.59-0.65)	**0.84** (0.78-0.91)
Adjusted*	1	**0.82** (0.75-0.93)	0.96 (0.90-1.02)	**0.86** (0.81-0.91)	**0.74** (0.68-0.80)
Institution type specific admittance					
Admittance to hospital-based palliative care team/unit					
Unadjusted	1	**0.74** (0.65-0.85)	**0.79** (0.74-0.84)	**0.51** (0.48-0.54)	**0.72** (0.66-0.78)
Adjusted*	1	**0.80** (0.70-0.92)	**0.81** (0.75-0.87)	**0.74** (0.69-0.78)	**0.64** (0.59-0.70)
Admittance to hospice					
Unadjusted	1	1.07 (0.92-1.24)	**1.52** (1.41-1.63)	0.96 (0.91-1.02)	**1.23 (1.12-1.35)**
Adjusted*	1	1.09 (0.94-1.27)	**1.41** (1.31-1.52)	**1.20** (1.11-1.28)	1.10 (1.00-1.21)

*Adjusted for sex, age, cancer diagnosis and region.
Bold = statistically significant

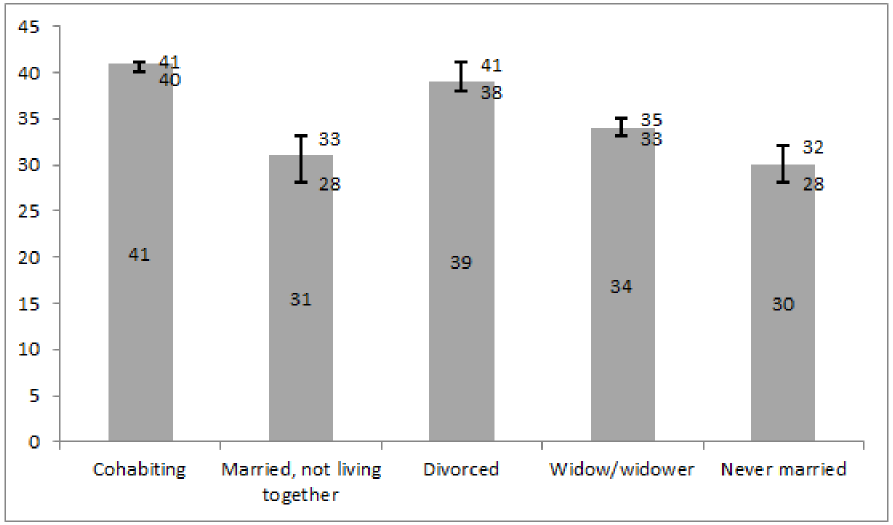
Table 3. The sex, age, diagnosis and region specific admittance to hospital-based palliative care team/unit and hospice, respectively, mutually adjusted. The odds ratios (OR) are reported including (N=44,480) and excluding (N=32,051) Capital Region of Denmark.

	Hospital-based palliative care team/unit OR				**Hospice** OR			
	Living together (ref.)	Living alone	Living alone – excluding Capital Region of Denmark	Test for interaction p-value*	Living together (ref.)	Living alone	Living alone – excluding Capital Region of Denmark	Test for interaction p-value*
Overall	1.00	**0.62**	**0.60**	**-**	1.00	**1.14**	**1.25**	**-**
Sex								
Men	1.00	**0.67**	**0.64**	**<0.001**	1.00	**1.22**	**1.42**	0.830
Women	1.00	**0.80**	**0.74**		1.00	**1.23**	**1.38**	
Age (years)								
18-49	1.00	0.89	0.88	0.054	1.00	1.13	1.21	**0.039**
50-59	1.00	**0.78**	**0.67**		1.00	**1.43**	1.72	
60-69	1.00	**0.74**	**0.69**		1.00	**1.32**	**1.54**	
70-79	1.00	**0.72**	**0.68**		1.00	**1.25**	**1.34**	
80+	1.00	**0.67**	**0.66**		1.00	1.04	**1.24**	
Diagnosis (cancer site)								
Oral cavity, nasopharyngeal (etc.)	1.00	**0.65**	**0.69**	**0.004**	1.00	1.26	1.32	**<0.001**
Digestive System	1.00	**0.65**	**0.56**		1.00	**1.35**	**1.53**	
Colorectal	1.00	**0.69**	**0.69**		1.00	**1.38**	**1.67**	
Respiratory system	1.00	**0.80**	**0.75**		1.00	**1.36**	**1.55**	
Melanoma	1.00	0.98	0.87		1.00	1.35	1.32	
Sarcoma	1.00	0.99	0.83		1.00	1.10	1.59	
Breast	1.00	0.96	0.96		1.00	1.16	**1.29**	
Female genital organs	1.00	**0.65**	**0.53**		1.00	1.08	1.24	
Prostate	1.00	**0.64**	**0.62**		1.00	1.00	1.19	
Urinary tract	1.00	**0.73**	**0.67**		1.00	1.10	**1.42**	
Brain/central nervous system	1.00	0.85	0.82		1.00	**0.66**	0.79	
Lymphoid and haematopoietic tissue	1.00	**0.66**	**0.63**		1.00	**1.42**	**1.44**	
Unknown or other cancer	1.00	**0.72**	**0.70**		1.00	1.16	1.23	
Geographic region								
North Denmark Region	1.00	**0.77**	**0.77**	**<0.001**	1.00	1.16	1.16	**<0.001**
Region Zealand	1.00	**0.73**	**0.73**		1.00	**1.47**	**1.47**	
Central Denmark Region	1.00	**0.64**	**0.64**		1.00	**1.49**	**1.49**	

Region of Southern Denmark	1.00	**0.67**	**0.67**		1.00	**1.39**	**1.39**	
Capital Region of Denmark	1.00	0.93			1.00	0.93		

*Test for interaction with Capital Region of Denmark included in the analysis.
Bold = statistically significant
Ref. = reference

Figure 2. Prevalence (%) of admittance to overall admittance to SPC among Danish patients who died from cancer in 2010-12 in relation to cohabitation status. Standardised by sex, age group, diagnosis and region (N=44,480).



References

(1) Calvillo-King L, Arnold D, Eubank KJ, Lo M, Yunyongying P, Stieglitz H, et al. Impact of social factors on risk of readmission or mortality in pneumonia and heart failure: systematic review. J Gen Intern Med 2013 Feb;28(2):269-82.

(2) Robards J, Evandrou M, Falkingham J, Vlachantoni A. Marital status, health and mortality. Maturitas 2012 Dec;73(4):295-9.

(3) Dalton SO, Schuz J, Engholm G, Johansen C, Kjaer SK, Steding-Jessen M, et al. Social inequality in incidence of and survival from cancer in a population-based study in Denmark, 1994-2003: Summary of findings. Eur J Cancer 2008 Sep;44(14):2074-85.

(4) Christensen AI, Ekholm O, Davidsen M, Juel K. Health and morbidity in Denmark & the development since 1987. In Danish: Sundhed og sygelighed i Danmark 2010 & udviklingen siden 1987. Statens Institut for Folkesundhed, Syddansk Universitet. København; 2012.

(5) Addington-Hall J, Altmann D. Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? Journal of Advanced Nursing 2000 Oct;32(4):799-806.

(6) Hui D, Kim SH, Kwon JH, Tanco KC, Zhang T, Kang JH, et al. Access to palliative care among patients treated at a comprehensive cancer center. Oncologist 2012;17(12):1574-80.

(7) Lackan NA, Ostir GV, Freeman JL, Mahnken JD, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Medical Care 2004 Feb;42(2):116-22.

(8) Lackan NA, Ostir GV, Kuo YF, Freeman JL. The association of marital status and hospice use in the USA. Palliat Med 2005 Mar;19(2):160-2.

(9) Neergaard MA, Jensen AB, Olesen F, Vedsted P. Access to Outreach Specialist Palliative Care Teams among Cancer Patients in Denmark. Journal of Palliative Medicine 2013 Aug;16(8):951-7.

(10) Rosenwax L, Spilsbury K, McNamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care 2016 May 10;15:46.

(11) Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia - and who misses out. Palliative Medicine 2006;20(4):439-45.

(12) Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliative Medicine 1993;7(4):323-31.

(13) Locher JL, Kilgore ML, Morrisey MA, Ritchie CS. Patterns and predictors of home health and hospice use by older adults with cancer. J Am Geriatr Soc 2006 Aug;54(8):1206-11.

(14) Addington-Hall J, Altmann D, McCarthy M. Which terminally ill cancer patients receive hospice in-patient care? Social Science & Medicine 1998 Apr;46(8):1011-6.

(15) Burt J, Plant H, Omar R, Raine R. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. Palliative Medicine 2010 Sep;24(6):641-50.

(16) Chen H, Haley WE, Robinson BE, Schonwetter RS. Decisions for hospice care in patients with advanced cancer. J Am Geriatr Soc 2003 Jun;51(6):789-97.

(17) Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). Bmc Public Health 2007 Apr 27;7.

(18) Fairfield KM, Murray KM, Wierman HR, Han PK, Hallen S, Miesfeldt S, et al. Disparities in hospice care among older women dying with ovarian cancer. Gynecol Oncol 2012 Apr;125(1):14-8.

(19) Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J Am Geriatr Soc 2003 Jul;51(7):970-8.

(20) Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. J Natl Cancer Inst 2006 Aug 2;98(15):1053-9.

(21) Lammi U.K., Kosunen E., Kellokumpu-Lethtinen P. Palliative cancer care in two health centres and one hospice in Finland. Supportive Care in Cancer 2000 Sep 12;9(1):15-31.

(22) Tang ST, Huang EW, Liu TW, Wang HM, Chen JS. A population-based study on the determinants of hospice utilization in the last year of life for Taiwanese cancer decedents, 2001-2006. Psychooncology 2010 Nov;19(11):1213-20.

(23) Statistics Denmark. http://www.dst.dk/da/Statistik/emner/befolkning-og-valg/befolkning-og-befolkningsfremskrivning/folketal. 14-8-2017.

(24) Hansen MB., Grønvold M. Danish Palliative Care Database Annual report 2012. In Danish: Dansk Palliativ Database Årsrapport 2012. 2013.

(25) Adsersen M, Thygesen LC, Jensen AB, Neergaard MA, Sjogren P, Groenvold M. Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD). BMC Palliat Care 2017 Mar 23;16(1):21.

(26) Pedersen CB. The Danish Civil Registration System. Scand J Public Health 2011 Jul;39(7 Suppl):22-5.

(27) Gjerstorff ML. The Danish Cancer Registry. Scand J Public Health 2011 Jul;39(7 Suppl):42-5.

(28) Groenvold M, Adsersen M, Hansen MB. Danish Palliative Care Database. Clin Epidemiol 2016;8:637-43.

(29) Helweg-Larsen K. The Danish Register of Causes of Death. Scand J Public Health 2011 Jul;39(7 Suppl):26-9.

(30) Danish Health Authority. The Danish Cancer Registry. 2009. Statistic and analysis. In Danish: Cancerregisteret 2009. Tal og analyse. 2009.

(31) Boyle P, Parkin D. Statistical methods for registries. In: Jensen O, Parkin D, MacLennan R, Muir C, Sheet RG, editors. Cancer Registration: Principles and Methods.Oxford, United Kingdom: Oxford University Press; 1991. p. 126-58.

(32) SAS Institute INC. SAS/STAT 9.4 Users's Guide. SAS Institute Inc.: Cary, NC; 2011.

(33) Thygesen LC, Ersboll AK. When the entire population is the sample: strengths and limitations in register-based epidemiology. Eur J Epidemiol 2014 Jan 10.

(34) Due P, Holstein B, Lund R, Modvig J, Avlund K. Social relations: network, support and relational strain. Soc Sci Med 1999 Mar;48(5):661-73.

Paper 3

Social inequality in admittance to specialised palliative care (SPC) for patients with cancer. A nationwide study from the Danish Palliative Care Database

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Keywords: Specialised palliative care, socioeconomic position, education, income, admittance

Abstract

Background: Few studies investigating socioeconomic position (SEP) in relation to admittance to specialised palliative care (SPC) included data on SEP at patient level and no nation-wide register-based studies have been identified. This study investigated whether cancer patients' SEP was associated with admittance to SPC (hospital-based palliative care team/unit and/or hospice).

Method: A register-based study with data from several Danish nation-wide registers (2010-12). The association between admittance to SPC and SEP (education and income) among cancer patients was investigated using logistic regression analysis adjusting for sex, age, cancer diagnosis, geographic region and cohabiting status.

Results: In the study population (N=41,741) 45% had primary school as the highest attained education, and 6% had an academic education. Persons with an academic education were more likely to be admitted to SPC than those having completed primary school only (OR=1.69; 95% CI 1.51-1.89). According to income, persons in the highest income quartile (Q4) were more likely to be admitted to SPC than those in the lowest income quartile (Q1) (OR=1.46; 95% CI 1.37-1.56). The results, Q1 vs Q4, subdivided into hospital-based palliative care team/unit (OR=1.23 (95% CI: 1.14-1.31)) and hospice (OR=1.67 (95% CI: 1.54-1.81)) showed a stronger association for hospice.

Conclusion: This nationwide register-based study indicates that admittance to SPC was clearly associated with education and income. We believe that the observed associations indicate inequity. Initiatives to improve access for patients with low SEP should be established.

Introduction

Cancer is the cause of death for around one third of the persons dying in Denmark (1). There has been found social inequality concerning incidence of and survival from cancer with higher incidence and poorer survival for the least advantaged (2-4). Most studies investigating socioeconomic position (SEP) in relation to admittance to specialised palliative care (SPC) did not include SEP data at individual level. Few studies were found to include SEP data on education and income at patient level and no nation-wide register-based studies were identified (5-13). Conflicting results were found for education (5-8;10;13) and income (9;11-13).

Differences in admittance to SPC may be explained by differences in need related to SEP. In a nationally representative sample of advanced cancer patients (stage 3 and 4), symptoms and problems (measured by EORTC-QLQ-C30) were not found to be associated with socioeconomic position, except in relation to pain for patients with solid tumours where patients with an academic education had less pain compared with patients with a short theoretical education and in relation to cognitive function where patients with haematological cancers with an academic education had less reduced cognitive function than patients with short theoretical education (14;15). If the symptoms and problems from patients with advanced cancer equal patients who died of cancer, and if we believe that admittance to health care, and thereby also admittance to SPC, is based upon the need of the patients, we have no reason to believe that there should be a difference in admittance to SPC in relation to socioeconomic position. The hypothesis of the study is that in a social welfare state as Denmark admittance to SPC is equal in relation to SEP.

The aim of the study was to investigate whether SEP for Danish patients who died from cancer was associated with admittance to SPC (overall and subdivided into admittance to hospital-based palliative care team/unit and hospice, respectively).

Method and material

Study population

The study population included adults (18+ years), who died from cancer according to the Danish Register of Causes of Death (RCD) (16) in 2010-2012 and also had a cancer registration in the Danish Cancer Registry (CR) (17). If the cancer diagnosis from the RCD was not found in CR, the cancer diagnosis registered in CR was used. Around 25% (N=1,411) of the patients with disagreement between the registers had more than one cancer registration in CR and in these cases the diagnosis closest to death was used. We excluded individuals with missing values and the study population finally consisted of 41,741 individuals (see Figure 1 for more details).

Setting

Denmark has 5.7 million inhabitants (18). SPC is offered to patients with life-threatening illnesses having complex needs that according to a physician cannot be managed elsewhere (19). The SPC institutions are free of charge and out-patient and in-patient care is provided by multidisciplinary teams. There are two types of SPC institutions (2012); hospital-based palliative care team/unit (N=26) and hospices (N=18); the latter are placed separately from the hospitals. In the Capital Region of Denmark five hospital-based palliative care teams/units and four hospices provide both out and in-patient interventions. In Denmark the SPC capacity was (and is) about half the size recommended by EAPC (20-22).

In 2010-12, 96% of the patients receiving SPC had a cancer diagnosis (23) and 37% of the patients who died of cancer were admitted to SPC (24).

Data sources

We merged data (by the unique person identification number) from several national registers. From the nation-wide database, Danish Palliative Care Database (DPD) (23), we collected data on admittance to SPC. RCD contributed with information about cause of death (diagnosis) (16) and from the Danish Cancer Registry (CR), in which it is mandatory to register every new cancer diagnosis, we used information about cancer diagnosis (17). From the administrative register Danish Civil Registration System (CRS) we obtained data about sex, age, geographic region and cohabitation status (25). All national registers have high completeness, e.g. DPD around 97% (26) and RCD 99% (16)(15).

Data on SEP were collected from the Population's Education Register (PER) and the Income Statistics Register (IR) (placed at Statistics Denmark). PER has systematic registrations since 1974 based on data from administrative records, earlier data and data about immigrants with education from outside Denmark have been collected by self-reported information. The registry has a high validity and completeness (ethnic Danish 97 %, lower for immigrants) (26). IR was established in 1970 and includes information about different types of income, e.g., salary, public transfer payment, pension (both public or private) for economically active persons in Denmark (27).

Variables

Outcome

Overall SPC admittance (yes/no): Personal contact with SPC at home or in a hospital or hospice.

Institution type specific admittance: Overall admittance to SPC divided into type; whether the patient has been in a I) hospital-based palliative care team/unit (yes/no) or II) hospice (yes/no), respectively.

Exposure, SEP:

- Education: the individual highest attained education (primary school, skilled worker, short theoretical (1-3 years), long theoretical (>3 years), academic (5+ years). Persons with a bachelor or high school as highest attained education were included in the group 'long theoretical'. Measured the year before death.
- Income: 'Family equalised disposable income' is the household disposable income divided by the number of members of the household converted into equalized adults. Income was index regulated to level 2010 and was measured two years before death. It was divided into quartiles (Q1: <19,352 EUR/year, Q2: 19,352-22,942 EUR/year, Q3: 22,943-30,643 EUR/year, Q4: >30,643 EUR/year)

Explanatories variables: sex, age (18-39, 40-49…80+ years at the time of death), cancer diagnosis (ICD-10) following the main groups in the CR (exceptions: patients diagnosed with colorectal cancer and prostate cancer was included as separate groups and patients with cancer in the male genital organs was included in the group of other/unknown cancer). Geographic region the year before death (Capital Region of Denmark, Region Zealand, North Denmark region, Central Denmark Region, Region of Southern Denmark). Cohabitation status the year before death (cohabiting, married but not living together, divorced, widow/widower, never married).

Statistical analyses

Descriptive statistics of the study population in relation to education are reported as percentages. Logistic regression analyses were used to investigate the association between SEP (separately for the education and income) and I) overall admittance to SPC, II) hospital-based palliative care team/ unit and III) hospice. The analyses were adjusted for sex, age, region, diagnosis and cohabitation status. As the variable education had missing values, especially for older people, the distribution of the missing values was investigated. The education level has changed through generations and it is possible that the effect of education is different for different age groups. Accordingly, it was investigated whether there was an interaction between age and education. Additionally, to investigate the relation between income and education, the combined effect of the two variables was included in the analysis, with persons with the lowest education and lowest income as reference group.

We conducted the analyses in SAS 9.4 (27) and the results are reported as odds ratios (OR) with 95 % CI. The significance level was $p< 0.05$.

Results

Characteristics of the study population in relation to education and income

In the study population (N=41,741) the highest education level was as follows: 45% primary school, 33% skilled worker, 2% short theoretical, 10% long theoretical, 6% academic and 6% with no education registered (Table 1). The proportion of women was higher in persons with primary school (55%) and long theoretical education (53%), while the proportion of men was higher especially for academic education (73%). In relation to geographic region, a higher proportion in Capital region of Denmark had an academic education. The largest differences for diagnoses were found for cancer in the respiratory system and prostate. Among persons with an academic education versus persons with primary school, fewer had cancer in the respiratory system (14 vs. 27%). The opposite tendency was found in relation to prostate cancer (15% vs.7%).

In relation to income a higher proportion of men were found in the highest income quartile (Q4) (Table 2). The proportion of the oldest age groups (70-80+ years old) was found to be lower in Q4 and higher especially in relation to the 60-69 years old. For diagnosis the biggest difference between the income quartiles was found in relation cancer in the respiratory system (Q1=27% vs Q4=20%). In the Capital Region of Denmark a higher proportion was found to be in Q4, this was also the case in relation to patients cohabiting, while a lower proportion of divorced and widow/widower was found in this quartile (Q4).

The proportion in the highest income quartile increased with increasing education from 12% (primary school) to 74% (academic) (table 1).

Regression analyses with education, income and a combination of the two variables

Concerning education, the adjusted logistic regression analyses showed that overall admittance to SPC increased with increasing education (Table 3). Compared with primary school, skilled workers had higher admittance to SPC (OR= 1.18; 95%CI: 1.13-1.24) and the odds ratio for persons with an academic education was 1.69 (95%CI: 1.51-1.89). Similarly, the institution type specific admittance to hospital-based palliative care team/unit and hospice increased with increasing education. The corresponding values were OR=1.09 (95%CI: 1.03-1.15) and OR=1.29 (95%CI: 1.22-1.37) for skilled worker and OR=1.49 (95%CI: 1.31-1.68) and OR=1.73 (95%CI: 1.51-1.97) for individuals with academic education.

Similar to the results for education the adjusted logistic regression analyses concerning income showed increased overall and type specific admittance to SPC with increasing income (Table 4). Compared with patients with the lowest income (Q1), patients with the highest income (Q4) had OR=1.46 (95%CI: 1.37-1.56) for overall admittance to SPC, OR=1.23 (95%CI: 1.14-1.31) for admittance to hospital-based palliative care team/unit and OR=1.67 (95%CI: 1.54-1.81) for admittance to hospice.

With a general increase in education level over time and as the missing data for education mainly was found for the oldest age groups, we investigated whether the effect of education was different for the different age groups and found no interaction between age and education (p=0.70); the same pattern was found for all age groups (data not shown).

Table 5 shows the results from the adjusted logistic regression model combining education and income. For each education level, admittance to SPC increased with increasing income level and vice versa, with exception of short theoretical education where the opposite pattern was found and for academics in the lowest income group (Q1). Compared with individuals who had primary school as the highest education and the lowest income (Q1) the odds ratio of admittance to SPC among the most affluent academics was 1.96 (95%CI: 1.71-2.25).

Discussion

Main findings

In this nation-wide register-based cohort study the aims were to investigate whether socioeconomic position (SEP) for Danish patients who died from cancer was associated with admittance to SPC (overall) and with admittance to each of the two types of SPC, hospital-based palliative care team/unit and hospice, respectively. Overall admittance to SPC increased with increasing education/income. The same pattern was seen in relation to type specific admittance, whereas in relation to income a stronger association was found for hospice than for hospital-based palliative care team/unit. The combined effect of education and income showed that for all education levels, except in relation to short theoretical education and academics in the lowest income quartile (Q1), higher economic level was associated with higher admittance to SPC.

Supporting and conflicting evidence from other studies

Conflicting results have been found in relation to SEP and admittance to SPC. Half of the studies without data at individual level found no association between SEP and SPC (28-33) and six studies found an association (34;35): Burge et al (Canada) found that admittance to SPC was increasing with higher income, but the difference was statistically significant only for two of the quintiles (low-middel and middle income vs upper income) (34), which is in line with four American studies

(35-38). Thus, these five studies were in line with our findings, whereas one study from Australia found lower admittance for the most advantaged (39).

Nine studies were found with data on education and income at patient level. In relation to education, half of the studies (from Belgium, Italy and USA) found higher admittance to SPC with increasing education level (6;10;13), in line with the results from this study, whereas one study (from USA) found higher admittance for the less educated (7), and two studies from Italy and USA found no association (5;8).

We found four studies that included income data at individual level investigating the association between income and admittance to SPC. Three studies (two from Australia and one from USA) found higher admittance to SPC with higher income (11-13), but two of the studies included data on income from the respondent and not the patient (11;12). One study (also Danish) found, differently from this study, no association between income and admittance to SPC (palliative care team) (9).

No former studies combining education and income have been found.

Differences in the way SEP is measured and the data level could be part of the explanation for the disparate results found in the literature.

Possible explanations for the findings

It is possible that patients with higher SEP have more resources to search information about SPC, which give them more knowledge about SPC; what is offered, when is it relevant, what is possible in their situation etc. A study of Koffman et al found that knowledge about SPC was related to SEP, with the most advantaged having the best knowledge (40). Another study found that a higher proportion of the individuals with a short education want more knowledge about palliative care (41), which could indicate that they have lower knowledge than persons with a higher education. A social gradient has further been found in the doctor-patient communication, where patients with the highest education received more overall communication and more information from the physician compared with patients with a lower education (42). More knowledge and awareness of their possibilities and better communication about symptoms, problems, needs etc., may put patients in higher SEP in a situation where they more often will be admitted to SPC.

In Denmark no national referral criteria for referring a patients to SPC were available when the study took place and the criteria differed between institutions (22). This lack of transparency related to SPC may give the group of patients with higher SEP, who have more knowledge (40-42), an advantage in the ‘competition’ for SPC.

The Danish SPC capacity was (and is) about half the size recommended by EAPC (20-22). Nationally, around 20% of patients who are referred to SPC are not admitted to SPC and around 25% of the patients admitted are not seen by the SPC unit within ten days (43). The limited SPC capacity may be a possible explanation for the social inequality found in this study, as it may be more important to be able to communicate clearly and talk your case in a situation with limited capacity than in a situation where all patients with a need for SPC are admitted.

In relation to short theoretical education decreasing admittance to SPC was found with higher income level, i.e., the opposite pattern compared to all other education groups. It is unknown what could explain the difference for this education group and further investigation is needed to fully understand this.

Strengths and limitations of the study

Our research has several advantages; the study is a large national register-based study, ensuring a study population of about 40,000 individuals. The possibility of linking six national registers enabled the analyses and the completeness of the data was very high (16;17;25;26;44). Further, it was a major strength that it was possible to measure SEP both in relation to education and income and via a combination of the two variables. In relation to patients with cancer, education is a valid measure as cancer often develops later in life when the majority of the people have completed their education (45). In relation to income we used family available income and the income two years before death to reduce the possible effect of the disease trajectory. Over eighty (85 %) percent of the study population was 60+ years old and most of the patients in this age group receive pension, which will not be affected by the disease.

It is a limitation of the study that it has not been possible to include and adjust the analysis for the need of SPC for the patient. On the other hand, previous studies have not found an association between SEP and palliative needs among patients with advanced cancer in Denmark (14;15). In addition, the number of contacts to SPC was not included in the analyses. The Danish Palliative Care Database is developing more detailed, validated data on SPC activity, hence, it will be possible to include this information in future analyses.

Conclusion

In this nationwide register-based study from a country with a tax funded health care system that should ensure admittance for anybody we found clear social inequality in admittance to SPC; the best educated and most affluent cancer patients had the highest admittance to SPC. We believe that the observed associations indicate inequity. Initiatives to secure access to SPC for patients with low SEP and probably also expansion of the SPC capacity are needed in order to correct this.

Figure1.Flowchart for sampling the study population from the Danish Register of Causes of Death and the Danish Cancer Registry.

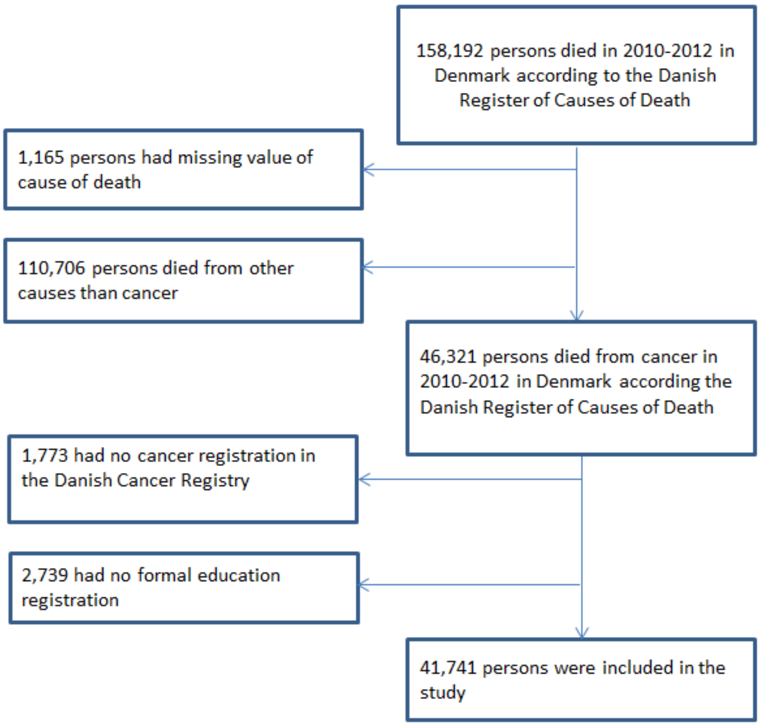


Table 1. The characteristics of the study population in relation to formal education

		Formal education				
	Total	**Primary school**	**Skilled worker**	**Short theoretical**	**Long theoretical**	**Academic**
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Education level, total (Missing N= 2,739; 6%)	41,741 (100)	19,804 (45)	14,675 (33)	1,106 (2)	4,661 (10)	1,495 (6)
Sex						
Male	21,982 (53)	8,931 (45)	9,033 (62)	718 (65)	2,213 (47)	1,087 (73)
Female	19,759 (47)	1,0873 (55)	5,642 (38)	388 (35)	2,448 (53)	408 (27)
Age (years)						
18-49	1,704 (4)	564 (3)	590 (4)	79 (7)	369 (8)	102 (7)
50-59	4,380 (10)	1,596 (8)	1,750 (12)	150 (14)	708 (15	176 (12)
60-69	11,001 (26)	4,361 (22)	4,446 (30)	324 (29)	1,472 (32)	398 (27)
70-79	13,529 (32)	6,722 (34)	4,788 (33)	341 (31)	1,287 (28)	391 (26)
80+	11,127 (27)	6,561 (33)	3,101 (21)	212 (19)	825 (18)	428 (29)
Diagnosis (cancer site)						
Oral cavity, nasopharyngeal (etc.) (C00-C14)	940 (2)	411 (2)	375 (3)	23 (2)	103 (2)	28 (2)
Digestive System (C15-17 & C22+25)	5,573 (13)	2,505 (13)	2,074 (14)	157 (14)	624 (13)	213 (14)
Colorectal (C18-C20)	5,195 (12)	2,419 (12)	1,825 (12)	150 (14)	582 (12)	219 (15)
Respiratory System: (C32-34)	10,253 (25)	5,364 (27)	3,595 (25)	220 (20)	862 (18)	212 (14)
Melanoma skin cancer (C43)	717 (2)	291 (1)	245 (2)	30 (3)	112 (2)	39 (3)
Sarcoma (C46-C49)	311 (1)	143 (1)	91 (1)	7 (1)	49 (1)	14 (1)
Breast (C50)	3,318 (8)	1,556 (8)	1,026 (7)	84 (8)	554 (12)	98 (7)
Female genital organs (C53-55 & C56,C570-C574))	1,818 (4)	909 (5)	546 (4)	43 (4)	259 (6)	61 (4)
Prostate (C61)	3,197 (8)	1,318 (7)	1,224 (8)	87 (8)	347 (7)	221 (15)
Urinary tract (C64-C67)	2,225 (5)	1,088 (5)	791 (5)	66 (6)	209 (4)	71 (5)
Brain/CNS (C70-C71, C751-C753)*	1,368 (3)	545 (3)	496 (3)	47 (4)	208 (4)	72 (5)
Lymphoid & haematopoietic tissue (C81-85 & (C90-95)	2,501 (6)	1,152 (6)	881 (6)	70 (6)	296 (6)	102 (7)
Unknown or other cancer (all other C codes)	4,325 (10)	2,103 (11)	1,499 (10)	122 (11)	456 (10)	145 (10)
Geographic region						
Region Zealand	7,143 (17)	3443 (17)	2598 (18)	203 (18)	710 (15)	189 (13)
North Denmark Region	4,635 (11)	2585 (13)	1448 (10)	99 (9)	397 (9)	106 (7)
Central Denmark Region	9,037 (22)	4501 (23)	3060 (21)	203 (18)	1009 (22)	264 (18)
Region of Southern Denmark	9,356 (22)	4786 (24)	3166 (22)	233 (21)	966 (21)	205 (14)
Capital region of Denmark	11,570 (28)	4489 (23)	4403 (30)	368 (33)	1579 (34)	731 (49)

Cohabitation status						
Cohabiting	22,806 (55)	9,373 (47)	8,960 (61)	723 (65)	2,789 (60)	961 (64)
Married, but not living together	1,150 (3)	494 (2)	392 (3)	30 (3)	170 (4)	64 (4)
Divorced	5,084 (12)	2,485 (13)	1,787 (12)	103 (9)	577 (12)	132 (9)
Widow/widower	9,642 (23)	5,866 (30)	2,729 (19)	186 (17)	649 (14)	212 (14)
Never married	3,059 (7)	1,586 (8)	807 (6)	64 (6)	476 (10)	126 (8)
Family income, quartiles						
Q1 (lowest)	10,435 (25)	6,784 (34)	3,027 (21)	133 (12)	404 (9)	87 (6)
Q2	10,435 (25)	6,198 (31)	3,530 (24)	165 (15)	481 (10)	61 (4)
Q3	10,435 (25)	4,513 (23)	4,187 (29)	314 (28)	1,187 (25)	234 (16)
Q4 (highest)	10,436 (25)	2,309 (12)	3,931 (27)	494 (45)	2,589 (56)	1,113 (74)

*Including the following D-codes: D32, D42, D330-332, D352-354, D430-432, D443-445, D333-339 and D433-439.

Table 2. The characteristics of the study population in relation to family income

		Family income, quartiles			
	Total	**Q1 (lowest)**	**Q2**	**Q3**	**Q4 (highest)**
	N (%)	N (%)	N (%)	N (%)	N (%)
Income, total	41,741 (100)	10,435 (25)	10,435 (25)	10,435 (25)	10,436 (25)
Sex					
Male	21,982 (53)	5,265 (50)	5,290 (51)	5,563 (53)	5,864 (56)
Female	19,759 (47)	5,170 (50)	5,145 (49)	4,872 (47)	4,572 (44)
Age (years)					
18-49	1,704 (4)	333 (3)	250 (2)	472 (5)	649 (6)
50-59	4,380 (10)	501 (15)	602 (6)	1114 (11)	2163 (21)
60-69	11,001 (26)	1,673 (16)	2,246 (22)	3174 (30)	3908 (37)
70-79	13,529 (32)	3,972 (38)	4,026 (39	3229 (31)	2302 (22)
80+	11,127 (27)	3,956 (38)	3,311 (32)	2446 (23)	1414 (14)
Diagnosis (cancer site)					
Oral cavity, nasopharyngeal (etc.) (C00-C14)	940 (2)	238 (2)	258 (2)	237 (2)	207 (2)
Digestive System (C15-17 & C22+25)	5,573 (13)	1,254 (12)	1,332 (13)	1,427 (14)	1,560 (15)
Colorectal (C18-C20)	5,195 (12)	1,304 (13)	1,274 (12)	1,310 (13)	1,307 (13)
Respiratory System: (C32-34)	10,253 (25)	2,798 (27)	2,791 (27)	2,529 (24)	2,135 (20)
Melanoma skin cancer (C43)	717 (2)	132 (1)	138 (1)	177 (2)	270 (3)
Sarcoma (C46-C49)	311 (1)	79 (1)	47 (0)	84 (1)	101 (1)
Breast (C50)	3,318 (8)	738 (7)	811 (8)	818 (8)	951 (9)
Female genital organs (C53-55 & C56,C570-C574))	1,818 (4)	453 (4)	426 (4)	446 (4)	493 (5)
Prostate (C61)	3,197 (8)	831 (8)	773 (7)	782 (7)	811 (8)
Urinary tract (C64-C67)	2,225 (5)	610 (6)	570 (5)	564 (5)	481 (5)
Brain/CNS (C70-C71, C751-C753)*	1,368 (3)	267 (3)	250 (2)	352 (3)	499 (5)
Lymphoid & haematopoietic tissue (C81-85 & (C90-95)	2,501 (6)	614 (6)	588 (6)	644 (6)	655 (6)
Unknown or other cancer (all other C codes)	4,325 (10)	1,117 (11)	1,117 (11)	1,065 (10)	966 (9)
Geographic region					
Region Zealand	7,143 (17)	1,651 (16)	1,893 (18)	1,891 (18)	1,708 (16)
North Denmark Region	4,635 (11)	1,442 (14)	1,195 (11)	1,136 (11)	862 (8)
Central Denmark Region	9,037 (22)	2,269 (22)	2,234 (21)	2,271 (22)	2,263 (22)
Region of Southern Denmark	9,356 (22)	2,705 (26)	2,471 (24)	2,266 (22)	1,914 (18)
Capital region of Denmark	11,570 (28)	2,368 (23)	2,642 (25)	2,871 (28)	3,689 (35)

Cohabitation status					
Cohabiting	22,806 (55)	4,367 (42)	4,408 (42)	6,157 (59)	7,874 (75)
Married, but not living together	1,150 (3)	407 (4)	291 (3)	255 (2)	197 (2)
Divorced	5,084 (12)	1,615 (15)	1,753 (17)	1,110 (11)	606 (6)
Widow/widower	9,642 (23)	3,097 (30)	3,128 (30)	2,101 (20)	1,316 (13)
Never married	3,059 (7)	949 (9)	855 (8)	812 (8)	443 (4)

*Including the following D-codes: D32, D42, D330-332, D352-354, D430-432, D443-445, D333-339 and D433-439.

Table 3. The odds of overall and institution type specific admittance to SPC for Danish cancer patients in relation to formal education: unadjusted and adjusted for sex, age, diagnosis and geographic region and cohabitation status.

N = 41,741	**Formal education** OR (95 % CI)				
	Primary school	**Skilled worker**	**Short theoretical**	**Long theoretical**	**Academic**
Overall admittance:					
Unadjusted	1	1.23 (1.17-1.28)	1.41 (1.25-1.59)	1.65 (1.54-1.76)	1.55 (1.40-1.73)
Adjusted	1	1.18 (1.13-1.24)	1.34 (1.18-1.53)	1.49 (1.39-1.60)	1.69 (1.51-1.89)
Institution type specific admittance					
Admittance to hospital-based palliative care team/unit					
Unadjusted	1	1.14 (1.09-1.20)	1.26 (1.11-1.44)	1.38 (1.29-1.48)	1.27 (1.13-1.43)
Adjusted	1	1.09 (1.03-1.15)	1.20 (1.04-1.38)	1.29 (1.20-1.39)	1.49 (1.31-1.68)
Admittance to hospice					
Unadjusted	1	1.28 (1.21-1.35)	1.61 (1.39-1.86)	1.85 (1.72-2.00)	1.64 (1.45-1.87)
Adjusted	1	1.29 (1.22-1.37)	1.63 (1.40-1.89)	1.70 (1.57-1.84)	1.73 (1.51-1.97)

Table 4. The odds of overall and institution type specific admittance to SPC for Danish patients with cancer in relation to income: unadjusted and adjusted for sex, age, diagnosis, geographic region and cohabiting status (N=44,480).

N=41,741	**Family income, quartiles** OR (95 % CI)			
	Q1 (lowest)	Q2	Q3	Q4 (highest)
Overall admittance:				
Unadjusted	1	1.11 (1.05-1.18)	1.34 (1.27-1.42)	1.79 (1.69-1.89)
Adjusted	1	1.09 (1.03-1.16)	1.20 (1.13-1.27)	1.46 (1.37-1.56)
Institution type specific admittance				
Admittance to hospital-based palliative care team/unit				
Unadjusted	1	1.06 (0.99-1.12)	1.22 (1.15-1.30)	1.52 (1.43-1.62)
Adjusted	1	1.05 (0.98-1.12)	1.07 (1.00-1.14)	1.23 (1.14-1.31)
Admittance to hospice				
Unadjusted	1	1.18 (1.09-1.27)	1.47 (1.36-1.58)	1.77 (1.64-1.90)
Adjusted	1	1.15 (1.06-1.24)	1.43 (1.32-1.54)	1.67 (1.54-1.81)

Table 5. Admittance to SPC in relation to formal education and income: adjusted odds ratios (N=41,741)

		Family income, quartiles			
		Q1 (lowest) OR* (95%CI) N	**Q2** OR* (95%CI) N	**Q3** OR* (95%CI) N	**Q4 (highest)** OR* (95%CI) N
Formal education	**Primary school**	1 (Ref.) 6,571	1.08 (1.00-1.16) 6,206	1.16 (1.07-1.26) 4,614	1.42 (1.28-1.58) 2,416
	Skilled worker	1.18 (1.07-1.30) 2,929	1.27 (1.16-1.39) 3,460	1.34 (1.23-1.46) 4,235	1.47 (1.35-1.61) 4,051
	Short theoretical	1.84 (1.29-2.63) 130	1.75 (1.27-2.40) 161	1.39 (1.09-1.77) 310	1.44 (1.19-1.77) 805
	Long theoretical	1.24 (1.00-1.53) 396	1.55 (1.27-1.88) 466	1.61 (1.41-1.83) 1,170	1.81 (1.64-2.00) 2,629
	Academic	1.97 (1.27-3.06) 84	1.59 (0.94-2.70) 62	1.65 (1.25-2.18) 222	1.96 (1.71-2.25) 1,127

*Adjusted for sex, age, cancer diagnosis, region and cohabitation status

Reference list

(1) The Danish Register of Causes of Death.[Dødsårsagsregisteret]. http://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/andre-analyser-og-rapporter/doedsaarsagsregisteret. 15-8-2017.

(2) Dalton SO, Schuz J, Engholm G, Johansen C, Kjaer SK, Steding-Jessen M, et al. Social inequality in incidence of and survival from cancer in a population-based study in Denmark, 1994-2003: Summary of findings. Eur J Cancer 2008 Sep;44(14):2074-85.

(3) Faggiano F, Partanen T, Kogevinas M, Boffetta P. Socioeconomic differences in cancer incidence and mortality. IARC Sci Publ 1997;(138):65-176.

(4) Kogevinas M, Porta M. Socioeconomic differences in cancer survival: a review of the evidence. IARC Sci Publ 1997;(138):177-206.

(5) Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). Bmc Public Health 2007 Apr 27;7.

(6) Bossuyt N, Van den Block L, Cohen J, Meeussen K, Bilsen J, Echteld M, et al. Is individual educational level related to end-of-life care use? Results from a nationwide retrospective cohort study in Belgium. J Palliat Med 2011 Oct;14(10):1135-41.

(7) Chen H, Haley WE, Robinson BE, Schonwetter RS. Decisions for hospice care in patients with advanced cancer. J Am Geriatr Soc 2003 Jun;51(6):789-97.

(8) Hui D, Kim SH, Kwon JH, Tanco KC, Zhang T, Kang JH, et al. Access to palliative care among patients treated at a comprehensive cancer center. Oncologist 2012;17(12):1574-80.

(9) Neergaard MA, Jensen AB, Olesen F, Vedsted P. Access to Outreach Specialist Palliative Care Teams among Cancer Patients in Denmark. Journal of Palliative Medicine 2013 Aug;16(8):951-7.

(10) Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliative Medicine 1993;7(4):323-31.

(11) Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliative Medicine 2004;18(3):239-47.

(12) Currow DC, Agar M, Sanderson C, Abernethy AP. Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine 2008;22(1):43-50.

(13) Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J Am Geriatr Soc 2003 Jul;51(7):970-8.

(14) Johnsen AT, Petersen MA, Pedersen L, Groenvold M. Symptoms and problems in a nationally representative sample of advanced cancer patients. Palliative Medicine 2009 Sep;23(6):491-501.

(15) Johnsen AT, Tholstrup D, Petersen MA, Pedersen L, Groenvold M. Health related quality of life in a nationally representative sample of haematological patients. Eur J Haematol 2009 Aug;83(2):139-48.

(16) Helweg-Larsen K. The Danish Register of Causes of Death. Scand J Public Health 2011 Jul;39(7 Suppl):26-9.

(17) Gjerstorff ML. The Danish Cancer Registry. Scand J Public Health 2011 Jul;39(7 Suppl):42-5.

(18) Statistics Denmark. http://www.dst.dk/da/Statistik/emner/befolkning-og-valg/befolkning-og-befolkningsfremskrivning/folketal. 14-8-2017.

(19) Danish Health Authority. Recommendations for palliative care. In Danish: Anbefalinger for den palliative indsats 2011. 2011 Dec.

(20) Adsersen M, Thygesen LC, Neergaard MA, Bonde JA, Sjogren P, Damkier A, et al. Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD). Acta Oncol 2017 Sep;56(9):1210-7.

(21) Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 2. European Journal of Palliativ Care 2010;17(1):22-33.

(22) Timm H, Mikkelsen TB, Jarlbaek L. [Specialized palliative care in Denmark lacks capacity and accessibility]. Ugeskr Laeger 2017 Jun 26;179(26).

(23) Groenvold M, Adsersen M, Hansen MB. Danish Palliative Care Database. Clin Epidemiol 2016;8:637-43.

(24) Adsersen M, Thygesen LC, Jensen AB, Neergaard MA, Sjogren P, Groenvold M. Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD). BMC Palliat Care 2017 Mar 23;16(1):21.

(25) Pedersen CB. The Danish Civil Registration System. Scand J Public Health 2011 Jul;39(7 Suppl):22-5.

(26) Hansen MB., Grønvold M. Danish Palliative Care Database Annual report 2012. In Danish: Dansk Palliativ Database Årsrapport 2012. 2013.

(27) SAS Institute INC. SAS/STAT 9.4 Users's Guide. SAS Institute Inc.: Cary, NC; 2011.

(28) Burt J, Plant H, Omar R, Raine R. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. Palliative Medicine 2010 Sep;24(6):641-50.

(29) Hunt RW, Fazekas BS, Luke CG, Priest KR, Roder DM. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. Palliative Medicine 2002 Sep;16(5):403-9.

(30) Maddison AR, Asada Y, Burge F, Johnston GW, Urquhart R. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care 2012;28(2):90-6.

(31) Rosenwax L, Spilsbury K, McNamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care 2016 May 10;15:46.

(32) Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia - and who misses out. Palliative Medicine 2006;20(4):439-45.

(33) Hunt R, McCaul K. Coverage of cancer patients by hospice services, South Australia, 1990 to 1993. Aust N Z J Public Health 1998 Feb;22(1):45-8.

(34) Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients. Medical Care 2008 Dec;46(12):1203-11.

(35) Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. J Natl Cancer Inst 2006 Aug 2;98(15):1053-9.

(36) Fairfield KM, Murray KM, Wierman HR, Han PK, Hallen S, Miesfeldt S, et al. Disparities in hospice care among older women dying with ovarian cancer. Gynecol Oncol 2012 Apr;125(1):14-8.

(37) Lackan NA, Ostir GV, Freeman JL, Mahnken JD, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Medical Care 2004 Feb;42(2):116-22.

(38) Nayar P, Qiu F, Watanabe-Galloway S, Boilesen E, Wang H, Lander L, et al. Disparities in end of life care for elderly lung cancer patients. J Community Health 2014 Oct;39(5):1012-9.

(39) Currow DC, Allingham S, Bird S, Yates P, Lewis J, Dawber J, et al. Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis. BMC Health Serv Res 2012 Nov 23;12:424.

(40) Koffman J, Burke G, Dias A, Raval B, Byrne J, Gonzales J, et al. Demographic factors and awareness of palliative care and related services. Palliat Med 2007 Mar;21(2):145-53.

(41) Andersen V, Timm H. Knowledge as a presumption for involvement. What do the population know about palliative care - and do they want to know more? [In Danish: Viden som foudsætning for medbestemmelse. Hvad ved borgerne om palliation - og vil de vide mere?]. Omsorg 2014;2:21-5.

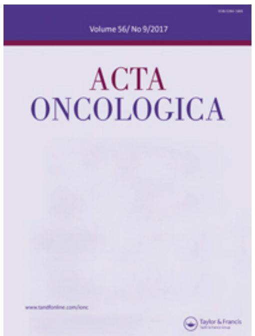
(42) Verlinde E, De LN, De MS, Deveugele M, Willems S. The social gradient in doctor-patient communication. Int J Equity Health 2012 Mar 12;11:12.

(43) Adsersen M, Hansen MB, Groenvold M. Danish Palliative Care Database Annual report 2016. In Danish: Dansk Palliativ Database Årsrapport 2016. København: DMCG-PAL; 2017.

(44) Jensen VM, Rasmussen AW. Danish Education Registers. Scand J Public Health 2011 Jul;39(7 Suppl):91-4.

(45) Galobardes B, Shaw M, Lawlor DA, Lynch JW, Davey SG. Indicators of socioeconomic position (part 1). J Epidemiol Community Health 2006 Jan;60(1):7-12.

Paper 4



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Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD)

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ORIGINAL ARTICLE

Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD)

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ABSTRACT

Background: Admittance to specialized palliative care (SPC) has been discussed in the literature, but previous studies examined exclusively those admitted, not those with an assessed need for SPC but not admitted. The aim was to investigate whether admittance to SPC for referred adult patients with cancer was related to sex, age, diagnosis, geographic region or referral unit.

Material and methods: A register-based study with data from the Danish Palliative Care Database (DPD). From DPD we identified all adult patients with cancer, who died in 2010–2012 and who were referred to and assessed to have a need for SPC ($N = 21{,}597$).The associations were investigated using logistic regression models, which also evaluated whether time from referral to death influenced the associations.

Results: In the adjusted analysis, we found that admittance was higher for younger patients [e.g., 50–59 versus 80 + years: odds ratio (OR) = 2.03; 1.78–2.33]. There was lower odds of admittance for patients with hematological malignancies and patients from two regions: Capital Region of Denmark and Region of Southern Denmark. Lower admittance among men and patients referred from hospital departments was explained by later referral.

Conclusions: In this first nationwide study of admittance to SPC among patients with a SPC need, we found difference in admittance according to age, diagnosis and region. This indicates that prioritization of the limited resources means that certain subgroups with a documented need have reduced likelihood of admission to SPC.

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Introduction

In Denmark, ∼16,000 persons die from cancer every year [1] and as in many other countries it is a public agenda to improve access to palliative care for patients with cancer and other life threatening diseases [2]. Palliative care may be provided everywhere in the health care system, whereas specialized palliative care (SPC) is provided by palliative care teams/units and hospices to patients with complex problems that according to clinical judgment cannot be adequately managed elsewhere [3]. SPC can reduce symptom burden and improve quality of life for patients with cancer and their caregivers, and has been shown to be cost-effective [4–6].

In the literature, lower access to SPC has been reported for men [7–9], older persons [10–17] and in rural areas [8,10,14,15,18–20]. Compared with patients with other diagnoses, patients with cancer had the highest level of access [11,13,14,16,17]. Among patients with cancer the lowest admittance to SPC was found in patients with hematological malignancies [16,17,21,22].

Previous studies have not investigated access to SPC in the entire group of patients referred to SPC. The Danish Palliative Care Database (DPD) registers all referrals to SPC in Denmark, which makes it possible not just to compare patients admitted to SPC with patients who are not admitted, but further to identify the patients who were referred but not admitted to SPC (Figure 1). In contrast to all previous studies of access, it is therefore unique that this database makes it possible to study admittance to SPC in the entire group of patients viewed by their treating physician (who refers the patient) and the SPC unit (who accepts the patient) as having a need for SPC (‘often defined as complex symptomatology that could not be managed outside SPC’).

Being informed and acknowledging that you are a terminally ill patient who is in need of SPC, and accepting this referral, may be a substantial life event. Not being admitted may be a distressing disappointment, as one may fear that it reduces the likelihood of achieving optimal symptom control and end-of-life care.

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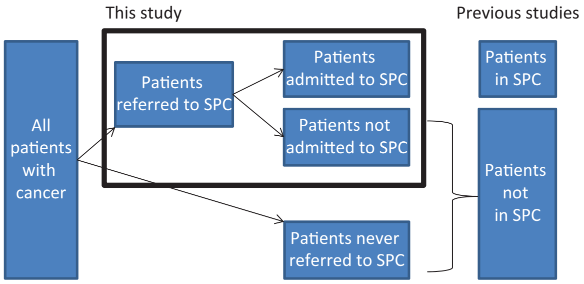

Figure 1. The study design in the present study compared with the design of previous studies.

The aim of this study was to investigate whether sex, age, cancer diagnosis, geographic region or referral unit were related to admittance to SPC in a national population of adult patients with cancer who were referred to and judged by their physician and SPC unit to have a need for SPC.

Material and methods

The study is a population based study based on existing data in DPD and the Danish Cancer Registry (CR). Each individual living in Denmark has a unique personal registration number, which makes it possible to link data from different data sources.

Setting

Denmark has 5.6 million inhabitants. The number of SPC units (hospital-based palliative care team/unit and hospice) increased from 36 units in 2010 to 44 units in 2012. Admittance to the SPC is, as the majority of other healthcare services, free of charge. The recommendations from EAPC stated that the SPC capacity should be; 80–100 beds per 1 million inhabitants and one home palliative care team for every 100,000 inhabitants [23]. In Denmark there are 48 beds per million inhabitants, half the size recommended and 26 palliative care teams, 30 less than suggested from the EAPC. The capacity problem is seen in all regions, with the best SPC capacity in North Denmark Region (Table 1).

Data sources

Since 1 January 2010, it has been mandatory for all SPC units in Denmark to register all referred patients and data concerning these referrals in DPD. To maximize the completeness of the DPD, data were linked with the Danish National Patient Register (DNPR) [24]. Patients registered with a contact to an SPC unit in the DNPR were added to the DPD if the SPC unit confirmed the contact. The data completeness of DPD was high: in 2010–2012 all SPC units registered their patients in DPD (unit completeness: 100%), with annual patient completeness of 96, 99 and 100%, respectively [25]. The DPD was further linked to the Danish Civil Registration System making information regarding date of death available [26].

Information about cancer diagnoses was collected from the Danish Cancer Registry (CR), which is a nationwide

Table 1. Comparison of EAPC recommendations with regard to the number of SPC beds and teams versus the number in Denmark (2012).

		SPC beds, EAPC recommendation versus Denmark			Hospital-based palliative care teams, EAPC recommendation versus Denmark		
Regions in Denmark	Inhabitants N	EAPC; 80–100 beds per one million inhabitants [23], N	Denmark; SPC beds (hospices and SPC units), N	'Deficiency', N	EAPC; one team for 100,000 inhabitants [23], N	Denmark; hospital-based palliative care team/unit, N	'Deficiency', N
Capital region of Denmark	1,729,952	138–173	90	48–63	17	8	9
Region Zealand	816,670	65–82	36	29–46	8	4	4
Region of Southern Denmark	1,201,547	96–120	60	36–60	12	4	8
Central Denmark region	1,271,223	102–127	50	52–77	13	6	7
North Denmark region	580,273	46–58	35	11–23	6	4	2
Total	5,599,665	448–560	271	177–289	56	26	30

research register which contains incident cancer cases since 1943 including data on tumor characteristics [27].

Population

Adult (≥18 years) patients with cancer living in Denmark who were referred to SPC were included if they

- were referred after 1 January 2010
- died between 1 January 2010 and 31 December 2012 and
- were meeting the referral criteria and did not refuse SPC (some patients changed their mind after the referral and did not want SPC) or were unsuitable for treatment (e.g., patients that were too close to death or who could not be accommodated in the unit).

For patients meeting the referral criteria who were not admitted to SPC ($n = 3828$) the most frequent reason was 'died before SPC' ($n = 3111$). For patients not meeting the referral criteria ($n = 922$), the most common reason was 'not complex symptomatology' ($n = 564$). For further details see Figure 2.

If patients were initially rejected but later admitted to SPC they were considered admitted.

Variables

Descriptive variables: Date of referral to SPC, fulfillment of eligibility criteria as evaluated by the SPC unit and date of death.

Outcome variable: Admittance to SPC, defined as any personal contact with SPC: inpatient, home visit, outpatient SPC or palliative care team visits at non-SPC departments (yes/no).

Explanatory variables: Sex, age at the time of death (18–39, 40–49, 50–59, 60–69, 70–79, 80 + years), and geographic region. Diagnosis, coded using ICD-10 following the Danish Cancer Registry [28] and Bray [29]. Differently from Bray we grouped oral cavity, nasopharynx and other pharynx cancers into one group whereas small intestine cancer and sarcomas, were included as separate groups, not in 'other'. The referring unit (general practitioner, hospital department, and other). Additionally, in some analyses, number of days from referral to death (<8, 8–21, 22–59 and 60 + days).

The cancer diagnosis from DPD was validated against CR. For most patients (82%) the same diagnosis was found in the two registers. Different cancer diagnoses were found for 16%, these individuals were included in the study with the cancer diagnosis registered in CR. If there was more than one cancer registration, the latest was used. Patients with no cancer registration in CR were included with the cancer diagnosis from DPD (2%).

Data analysis

The associations between the explanatory variables and admittance to SPC were investigated using univariate ('unadjusted model') and mutually adjusted logistic regression analysis (including all explanatory variables, 'adjusted model 1'). The average for all diagnoses was used as reference group for diagnosis. Diagnoses with < 20

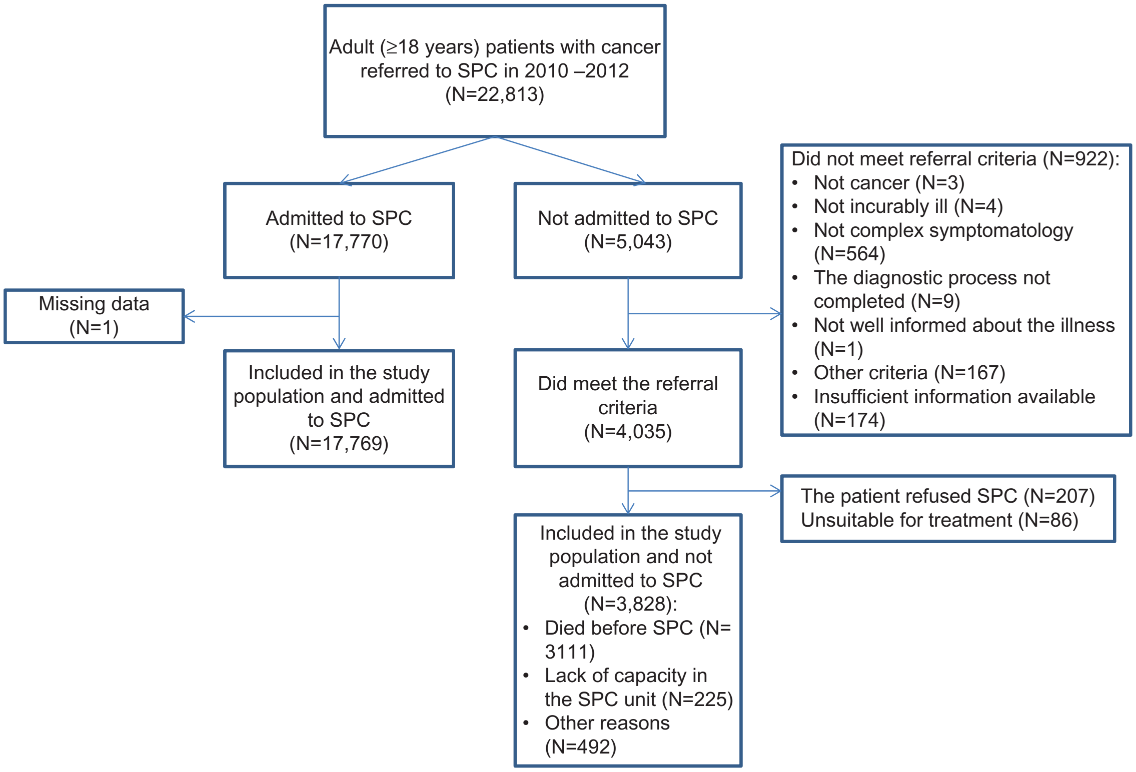

Figure 2. Flow chart of the patients referred to SPC in 2010–2012 and included in the study population.

patients were included in the group of other cancer diagnoses.

The timing of referral (i.e., time from referral to death) may affect admittance to SPC, and may also be related to some of the variables tested here, e.g., if older patients are referred later. Therefore, number of days from referral to death was included in 'adjusted model 2'.

The results from the logistic regression models are reported as odds ratios (ORs) with 95% confidence intervals (CIs). Statistical significance was $p < .05$. All analyses were conducted using SAS statistical software version 9.3 (SAS Inc., Cary, NC, USA) [30].

Results

The study population

From 1 January 2010, 22,813 adult (≥18 years) patients with cancer were referred to SPC and died before 31 December 2012. Excluded from the study were 1216 patients (details in Figure 2). Thus, 21,597 patients judged to have a need for SPC were included in the analyses.

Patient characteristics

Half of the patients were men (50.2%), 80.0% were above the age of 60 years, and 1.3% were below 40 years (Table 2). The most common diagnoses were lung (24.6%), colorectal (12.0%) and breast cancer (8.2%). The majority of the patients were referred from hospital departments (69.3%) and 19.1% survived <8 days from time of referral.

Table 2. Characteristics of the study population.

	N (%)
Sex	
Women	10,763 (49.8)
Men	10,834 (50.2)
Age (years)	
Mean: 69.7; median: 70; SD: 11.9	
18–39	283 (1.3)
40–49	933 (4.3)
50–59	2756 (12.8)
60–69	6200 (28.7)
70–79	6733 (31.2)
80+	4692 (21.7)
Diagnosis (cancer site, ICD-10 code)	
Oral cavity, nasopharyngeal (etc.) (C00–C14)	469 (2.2)
Oesophageal (C15)	599 (2.8)
Stomach (C16)	752 (3.5)
Small intestine (C17)	82 (0.4)
Colorectal (C18–C20)	2582 (12.0)
Liver (etc.) (C22)	434 (2.0)
Pancreatic (C25)	1541 (7.1)
Laryngeal (C32)	93 (0.4)
Trachea, bronchus and lung (C33–C34)	5304 (24.6)
Melanoma skin cancer (C43)	433 (2.0)
Sarcoma (C46–C49)	230 (1.1)
Breast (C50)	1767 (8.2)
Cervical (C53)	179 (0.8)
Uterine (C54–C55)	256 (1.2)
Ovarian (etc.) (C56, C570–C574)	665 (3.1)
Prostate (C61)	1536 (7.1)
Testicular (C62)	13 (0.1)
Kidney (etc.) (C64–C66)	568 (2.6)
Bladder (C67)	579 (2.7)
Brain/CNS (C70–C71, C751–C753)[a]	711 (3.3)
Thyroid (C73)	64 (0.3)
Unknown primary tumor (C76–C80)	888 (4.1)
Hodgkin disease (C81)	12 (0.1)
Non-Hodgkin lymphoma (C82–C85)	223 (1.0)
Multiple myeloma (C90)	175 (0.8)
Leukemia (C91–C95)	253 (1.2)
Other cancer (all other C codes)	1189 (5.5)
Region	
Capital region of Denmark	5657 (26.2)
Region Zealand	3648 (16.9)
Region of Southern Denmark	4709 (21.8)
Central Denmark region	4572 (21.2)
North Denmark region	3011 (13.9)
Referral unit	
General practitioner	5902 (27.3)
Hospital department	14,967 (69.3)
Other	728 (3.4)
Time from referral to death (days)	
Mean: 64.6; median: 29; SD: 97.4	
<8	4122 (19.1)
8–21	4882 (22.6)
22–59	5905 (27.3)
60+	6688 (31.0)
Total	21,597 (100)

[a] Including the following D-codes: D32, D42, D330–332, D352–354, D430–432, D443–445, D333–339 and D433–439.

Admittance to SPC

'Unadjusted model'. The overall proportion of admittance to SPC was 82.3% (17,769/21,597). No association was found between sex and admittance to SPC. However, the association between all other explanatory variables and admittance to SPC was statistically significant (Table 3).

'Adjusted model 1'. In relation to age, diagnosis and geographic region the results from the 'Adjusted model 1' showed only minor differences compared to the unadjusted model (Table 3). Younger patients were much more likely to be admitted to SPC compared to older patients. Relatively large differences according to diagnosis were seen. Cancer patients with non-Hodgkin lymphoma (0.57; 0.42–0.76) and leukemia (0.55; 0.42–0.73) had the lowest odds of admittance to SPC, whereas the highest significant odds ratio were found for patients with laryngeal cancer (2.56; 1.21–5.39) compared to the average of all diagnoses. Compared to Capital Region of Denmark, patients in North Denmark Region had more than two-fold higher OR (2.26; 1.99–2.57) of admittance to SPC.

Including time from referral to death

The odds of admittance to SPC increased markedly as time from referral to death increased ($p < .001$). After adjustment for time from referral to death the associations with sex ($p = .67$) and referral unit ($p = .52$) became insignificant ('adjusted model 2', Table 3): men and patients referred from hospital departments were referred a little later in their trajectory (closer to death) (Table 4). Compared with the 'adjusted model 1', the model showed a slightly weaker association between admittance to SPC and age and a stronger association for region. The association for several diagnoses changed, suggesting a relationship between diagnosis and timing of referral (Table 3).

Table 3. Admittance to SPC of Danish cancer patients with an assessed need for SPC in relation to sex, age, region, diagnosis, referral unit and time from referral to death (*N* = 21,597).

	Admittance to SPC % (*N*)	Unadjusted model[a], OR (95% CI)	*p*	Adjusted model 1[b], OR (95% CI)	*p*	Adjusted model 2[c], OR (95% CI)	*p*
Total	82.3 (17,769)						
Sex							
Women	82.8 (8906)	1.07 (1.00–1.14)	.07	1.16 (1.07–1.26)	<.001	1.02 (0.93–1.12)	.67
Men	81.8 (8863)	1.00 (ref)		1.00 (ref)		1.00 (ref)	
Age (years)							
18–39	94.0 (266)	4.65 (2.83–7.62)	<.001	5.35 (3.24–8.83)	<.001	3.90 (2.22–6.86)	<.001
40–49	90.4 (843)	2.79 (2.22–3.50)		3.13 (2.48–3.95)		2.77 (2.13–3.62)	
50–59	86.4 (2381)	1.89 (1.66–2.15)		2.03 (1.78–2.33)		1.77 (1.52–2.08)	
60–69	84.2 (5221)	1.59 (1.44–1.75)		1.65 (1.50–1.83)		1.46 (1.29–1.64)	
70–79	80.8 (5442)	1.25 (1.15–1.37)		1.29 (1.18–1.42)		1.21 (1.08–1.35)	
80+	77.1 (3616)	1.00 (ref)		1.00 (ref)		1.00 (ref)	
Diagnosis (cancer site)							
Oral cavity, nasopharyngeal (etc.)	85.9 (403)	1.27 (0.98–1.65)	<.001	1.20 (0.92–1.56)	<.001	0.80 (0.59–1.10)	<.001
Oesophageal	83.8 (502)	1.08 (0.87–1.34)		1.15 (0.92–1.43)		1.03 (0.79–1.35)	
Stomach	83.5 (628)	1.06 (0.87–1.28)		1.03 (0.84–1.25)		1.15 (0.91–1.45)	
Small intestine	85.4 (70)	1.22 (0.67–2.20)		1.27 (0.70–2.10)		1.79 (0.89–3.60)	
Colorectal	83.5 (2156)	1.06 (0.94–1.19)		1.10 (0.97–1.24)		1.03 (0.89–1.19)	
Liver (etc.)	74.9 (323)	0.61 (0.49–0.75)		0.62 (0.50–0.77)		0.81 (0.62–1.06)	
Pancreatic	83.8 (1292)	1.08 (0.94–1.25)		1.12 (0.97–1.30)		1.20 (1.00–1.42)	
Laryngeal	92.5 (86)	2.56 (1.22–5.38)		2.56 (1.21–5.39)		2.26 (0.98–5.20)	
Trachea, bronchus and lung	81.8 (4337)	0.94 (0.85–1.03)		0.94 (0.85–1.03)		0.97 (0.87–1.08)	
Melanoma skin cancer	83.8 (363)	1.08 (0.84–1.39)		1.03 (0.80–1.34)		1.13 (0.84–1.53)	
Sarcoma	87.8 (202)	1.50 (1.02–2.21)		1.33 (0.90–1.96)		1.49 (0.94–2.37)	
Breast	82.5 (1458)	0.98 (0.86–1.13)		0.89 (0.77–1.03)		0.92 (0.78–1.09)	
Cervical	86.0 (154)	1.28 (0.86–1.94)		1.05 (0.69–1.59)		0.97 (0.52–1.44)	
Uterine	82.8 (212)	1.00 (0.73–1.38)		0.98 (0.71–1.36)		0.97 (0.65–1.43)	
Ovarian (etc.)	84.8 (564)	1.16 (0.94–1.44)		1.08 (0.87–1.35)		1.10 (0.85–1.42)	
Prostate	84.9 (1304)	1.17 (1.01–1.36)		1.39 (1.18–1.62)		0.97 (0.80–1.17)	
Kidney (etc.)	86.4 (491)	1.33 (1.05–1.69)		1.30 (1.02–1.66)		1.29 (0.97–1.71)	
Bladder	78.8 (456)	0.77 (0.63–0.95)		0.85 (0.69–1.04)		0.89 (0.70–1.14)	
Brain/CNS[d]	86.8 (617)	1.37 (1.10–1.70)		1.16 (0.93–1.45)		0.74 (0.58–0.96)	
Thyroid	82.8 (53)	1.00 (0.54–1.88)		1.04 (0.55–1.96)		1.16 (0.56–2.43)	
Unknown primary tumor	73.8 (655)	0.59 (0.50–0.69)		0.62 (0.53–0.73)		0.89 (0.73–1.08)	
Non-Hodgkin lymphoma	72.2 (161)	0.54 (0.41–0.72)		0.57 (0.42–0.76)		0.58 (0.41–0.83)	
Multiple myeloma	76.0 (133)	0.66 (0.47–0.93)		0.69 (0.49–0.97)		0.60 (0.40–0.91)	
Leukemia	70.0 (177)	0.49 (0.37–0.63)		0.55 (0.42–0.73)		0.63 (0.45–0.87)	
Other cancer	80.1 (972)	0.84 (0.72–0.97)		0.90 (0.77–1.05)		0.99 (0.83–1.19)	
Average of all diagnoses	–	1.00 (ref)		1.00 (ref)		1.00 (ref)	
Region							
Region Zealand	85.7 (3126)	1.75 (1.56–1.95)	<.001	1.81 (1.62–2.03)	<.001	2.29 (1.99–2.63)	<.001
North Denmark region	88.0 (2650)	2.14 (1.89–2.43)		2.26 (1.99–2.57)		2.45 (2.10–2.86)	
Central Denmark region	85.5 (3909)	1.72 (1.55–1.91)		1.74 (1.57–1.94)		2.07 (1.82–2.35)	
Region of Southern Denmark	78.7 (3705)	1.08 (0.98–1.18)		1.04 (0.94–1.14)		1.05 (0.93–1.18)	
Capital Region of Denmark	77.4 (4379)	1.00 (ref)		1.00 (ref)		1.00 (ref)	
Referral unit							
General practitioner	83.6 (4934)	1.00 (ref)	.004	1.00 (ref)	<.001	1.00 (ref)	.52
Hospital department	81.7 (12,229)	0.88 (0.81–0.95)		0.79 (0.73–0.86)		0.96 (0.87–1.06)	
Other	83.2 (606)	0.98 (0.79–1.20)		0.95 (0.79–1.18)		1.06 (0.82–1.36)	
Time from referral to death (days)							
<8	41.5 (1709)	–	–	–	–	0.15 (0.14–0.17)	<.001
8–21	81.2 (3963)	–	–	–	–	1.00 (ref)	
22–59	94.2 (5561)	–	–	–	–	3.78 (3.31–4.31)	
60+	97.7 (6536)	–	–	–	–	9.58 (8.02–11.45)	

[a] Univariate logistic regression.

[b] Multivariate logistic regression including sex, age diagnosis, region, referral unit and year of death.

[c] Multivariate logistic regression model including variables as in model 1 and time from referral to death.

[d] Including the following D-codes: D32, D42, D330–332, D352–354, D430–432, D443–445, D333–339 and D433–439.

Discussion

Main findings

This study examined admittance to SPC at a national level among patients with cancer who were referred to SPC and had been assessed by their physician and the SPC unit to have a need for SPC. We found that admittance to SPC was lower for older patients, patients living in the Capital Region of Denmark and Region of Southern Denmark and patients having hematological malignancies.

Some of the differences found in this study reflect that some groups of patients were referred later in their disease trajectory than others, i.e., that the difference is caused by late recognition of needs for SPC or that the needs occur later in

Table 4. Mean and median time from referral to SPC to death based on sex and referral unit ($N = 21{,}597$).

	Time from referral to death (days)	
	Mean (SD)	Median (IQR)
Sex		
Women	67 (101)	31 (10–73)
Men	62 (94)	28 (11–78)
Referral unit		
General practitioner	68 (95)	34 (12–82)
Hospital department	63 (98)	27 (10–73)
Other	65 (101)	30 (11–72)

SD: standard deviation; IQR: interquartile range.

the trajectory in certain sub-groups. This was the case concerning men and patients referred from hospital departments.

In a health care system with limited resources, a part of the everyday life is to prioritize between the patients referred. This is also the case in relation to SPC. It is fully understandable and a fair utilization of the available resources if those with the most urgent needs are given priority. The difference in need may explain some of the difference found in the present study in relation to e.g., age and diagnosis. The decreasing admittance to SPC with increasing age, may reflect particularly alarming needs in the youngest patients (e.g., problems with children living at home) and thereby a fair difference. As shown in Table 1, the capacity of SCP in Denmark is substantially lower than recommended by the EAPC [23]. It is possible that the relatively limited SPC capacity in Denmark have had important consequences for certain subgroups, e.g., older individuals with a need for SPC.

Previous studies have found that even though the symptom burden is similar to other patients groups [31–33] hematological cancers were less represented in SPC than patients with solid tumors [34,35] and have attributed this to; late referral to SPC [17,36–40], prognostic difficulties to indicate appropriateness of palliative care [41–44], lack of knowledge about the role of SPC [41,45–48], and low acceptability of SPC [42,44]. However, it is notable that the present study shows that even when hematological patients were actually referred to SPC, their chances of admission were lower. This suggests that there may be additional explanations. For example, there might be a reluctance in SPC units to receive patients with hematological cancers due to former experience. This should be further investigated.

The development of SPC in Denmark started relatively late compared with other European countries, and during the study period (2010–2012) it was widely recognized that the capacity was insufficient [49,50]. It is likely that the geographic differences found in this study could be explained by the SPC capacity, which was larger in some regions than others (Table 1). National laws have enforced the establishing of new hospice beds throughout the country. This has not been the case regulating the establishing of hospital palliative care teams/units (hospitals are run by regional councils), and accordingly, the planning probably has been more diverse and determined by local initiatives, economy, and interests. This may explain some of the differences between the regions and could indicate a need of a national strategy in order to ensure an equal geographical distribution of SPC units regionally.

Comparison with the existing literature

We have not identified any studies investigating the admittance rate for patients referred to and assessed to have a need for SPC. The results of the present study are therefore not directly comparable with previous research. On the other hand our results may help explain previous findings in studies looking at the absolute probability of admittance to SPC (i.e., not among those referred as in our study). Those studies have found the same age gradient, where older patients are less likely to be admitted to SPC [10–17], geographic differences [8,10,14,15,18–20], and less likelihood of admittance for patients with hematological cancer [16,17,21,22].

Thus, our study shows that at least part of the underrepresentation of certain subgroups found previously can be attributed to reduced likelihood of admittance among referred patients. We found a sex difference with lower admittance for men, whereas most studies (except [7–9]) have found no sex difference. However, the sex difference was explained by time from referral to death, i.e., a lower proportion of men were admitted reflecting that they were referred later.

Strengths and weaknesses of the study

As DPD is a national database with very high data completeness and covers the entire Danish population, it minimizes the influence of selection bias. The analyses included a large dataset 21,597 patients with an assessed need for SPC. The study concerns to a period of three years, where there have been no major political or legislative changes that could influence the results, although, a steadily growing number of SPC units across the country were seen during the study period. The validity of the assessment of need of SPC is high, because it was done by clinicians, while the patient was still alive, and the patients included in this study all had needs for SPC according to the referring doctor, according the patients themselves (by consenting to referral) and the target SPC unit. On the other hand, it is a limitation of the study that it has not been possible to classify the specific needs of SPC for the patients. Difference in need may explain part of the difference observed, but this does not change the findings that some groups of patients have lower admittance to SPC.

Admittance was measured as a dichotomous variable, independently of the quantity of SPC. This can be seen as an oversimplification. However, we believe that when the patients are admitted to SPC they do get the care they need, why it makes sense to have only two groups; the main difference being whether patients are admitted or not. It would however be interesting to investigate differences in the type and extent of SPC.

Conclusions

In this first ever nationwide study of patients with cancer assessed to have a need for SPC, we found differences in admittance to SPC in Denmark in relation to age, diagnosis and region. The differences concerning sex and referral unit were explained by later referral; men and patients referred from hospital departments were referred later (closer to death). It is possible and we hope that the results reflect a fair prioritization of the available resources to patients with the most urgent needs. On the other hand even if such prioritization is fair, it means that certain groups of patients having a need for SPC, e.g., the oldest, die without admittance to SPC. The SPC capacity problem in Denmark should therefore be addressed.

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References

[1] The Danish Register of Causes of Death [Internet]. [Dødsårsagsregisteret]; [cited 2017, Apr 18]. Available from: http://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/andre-analyser-og-rapporter/doedsaarsagsregisteret.
[2] Danish Health and Medicines Authority. Recommendations for palliative care. [Anbefalinger for den palliative indsats.]; Copenhagen: Danish Health and Medicines Authority; 2011.
[3] Radbruch L, Payne S. Whitepaper on standards and norms for hospice and palliative care in Europe: part 1. Eur J Palliat Care. 2009;16:278–289.
[4] El-Jawahri A, Greer JA, Temel JS. Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. J Support Oncol. 2011;9:87–94.
[5] Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010;16:423–435.
[6] Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med. 2008;168:1783–1790.
[7] Fadul N, Elsayem A, Palmer JL, et al. Predictors of access to palliative care services among patients who died at a comprehensive cancer center. J Palliat Med. 2007;10:1146–1152.
[8] Lackan NA, Ostir GV, Freeman JL, et al. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Med Care. 2004;42:116–122.
[9] Virnig BA, Mcbean AM, Kind S, et al. Hospice use before death - variability across cancer diagnoses. Med Care. 2002;40:73–78.
[10] Burge FI, Lawson BJ, Johnston GM, et al. A population-based study of age inequalities in access to palliative care among cancer patients. Med Care. 2008;46:1203–1211.
[11] Ahmed N, Bestall JC, Ahmedzai SH, et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med. 2004;18:525–542.
[12] Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. Age Ageing. 2006;35:469–476.
[13] Cohen J, Wilson DM, Thurston A, et al. Access to palliative care services in hospital: a matter of being in the right hospital. Hospital charts study in a Canadian city. Palliat Med. 2012;26:89–94.
[14] Maddison AR, Asada Y, Burge F, et al. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care. 2012;28:90–96.
[15] Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia – and who misses out. Palliat Med. 2006;20:439–445.
[16] Walshe C, Todd C, Caress A, et al. Patterns of access to community palliative care services: a literature review. J Pain Symptom Manage. 2009;37:884–912.
[17] Hui D, Kim SH, Kwon JH, et al. Access to palliative care among patients treated at a comprehensive cancer center. Oncologist. 2012;17:1574–1580.
[18] Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). BMC Public Health. 2007;7:66.
[19] Hunt RW, Fazekas BS, Luke CG, et al. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. Palliat Med. 2002;16:403–409.
[20] Kessler D, Peters TJ, Lee L, et al. Social class and access to specialist palliative care services. Palliat Med. 2005;19:105–110.
[21] Currow DC, Agar M, Sanderson C, et al. Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliat Med. 2008;22:43–50.
[22] Howell DA, Shellens R, Roman E, et al. Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. Palliat Med. 2011;25:630–641.
[23] Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 2. Eur J Palliat Care. 2010;17:22–33.
[24] Lynge E, Sandegaard JL, Rebolj M. The Danish National Patient Register. Scand J Public Health. 2011;39:30–33.
[25] Hansen MB, Grønvold M. Danish palliative care database annual report 2012. [Dansk Palliativ Database Årsrapport]; Copenhagen: DMCG-PAL; 2012.
[26] Pedersen CB. The Danish Civil Registration System. Scand J Public Health. 2011;39:22–25.
[27] Gjerstorff ML. The Danish Cancer Registry. Scand J Public Health. 2011;39:42–45.
[28] Danish Health and Medicines Authority. The Danish Cancer Registry. Statistic and analysis. [Cancerregisteret 2009. Tal og analyse]; Copenhagen: Danish Health and Medicines Authority; 2009.
[29] Bray F, Sankila R, Ferlay J, et al. Estimates of cancer incidence and mortality in Europe in 1995. Eur J Cancer. 2002;38:99–166.
[30] SAS Institute Inc. SAS/STAT 9.3 users's guide. SAS Institute Inc.: Cary, NC; 2011.
[31] Johnsen AT, Petersen MA, Pedersen L, et al. Symptoms and problems in a nationally representative sample of advanced cancer patients. Palliat Med. 2009;23:491–501.
[32] Johnsen AT, Tholstrup D, Petersen MA, et al. Health related quality of life in a nationally representative sample of haematological patients. Eur J Haematol. 2009;83:139–148.
[33] Manitta V, Zordan R, Cole-Sinclair M, et al. The symptom burden of patients with hematological malignancy: a cross-sectional observational study. J Pain Symptom Manage. 2011;42:432–442.
[34] Hui D, Didwaniya N, Vidal M, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. Cancer. 2014;120:1572.
[35] Sexauer A, Cheng MJ, Knight L, et al. Patterns of hospice use in patients dying from hematologic malignancies. J Palliat Med. 2014;17:195–199.
[36] Cheng WW, Willey J, Palmer JL, et al. Interval between palliative care referral and death among patients treated at a comprehensive cancer center. J Palliat Med. 2005;8:1025–1032.
[37] Good PD, Cavenagh J, Ravenscroft PJ. Survival after enrollment in an Australian palliative care program. J Pain Symptom Manage. 2004;27:310–315.
[38] Hui D, Elsayem A, De la Cruz M, et al. Availability and integration of palliative care at US cancer centers. JAMA. 2010;303:1054–1061.

[39] Morita T, Akechi T, Ikenaga M, et al. Late referrals to specialized palliative care service in Japan. J Clin Oncol. 2005;23:2637–2644.

[40] Osta BE, Palmer JL, Paraskevopoulos T, et al. Interval between first palliative care consult and death in patients diagnosed with advanced cancer at a comprehensive cancer center. J Palliat Med. 2008;11:51–57.

[41] Epstein AS, Goldberg GR, Meier DE. Palliative care and hematologic oncology: the promise of collaboration. Blood Rev. 2012;26:233–239.

[42] McGrath P, Holewa H. Missed opportunities: nursing insights on end-of-life care for haematology patients. Int J Nurs Pract. 2006;12:295–301.

[43] Odejide OO, Salas Coronado DY, Watts CD, et al. End-of-life care for blood cancers: a series of focus groups with hematologic oncologists. JOP. 2014;10:e396–e403.

[44] Schenker Y, Crowley-Matoka M, Dohan D, et al. Oncologist factors that influence referrals to subspecialty palliative care clinics. JOP. 2014;10:e37–e44.

[45] Hui D, Finlay E, Buss MK, et al. Palliative oncologists: specialists in the science and art of patient care. J Clin Oncol. 2015;33:2314–2317.

[46] Hui D, Park M, Liu D, et al. Attitudes and beliefs toward supportive and palliative care referral among hematologic and solid tumor oncology specialists. Oncologist. 2015;20:1326–1332.

[47] Manitta VJ, Philip JA, Cole-Sinclair MF. Palliative care and the hemato-oncological patient: can we live together? A review of the literature. J Palliat Med. 2010;13:1021–1025.

[48] Wright B, Forbes K. Haematologists' perceptions of palliative care and specialist palliative care referral: a qualitative study. BMJ Support Palliat Care. 2017;7:39–45.

[49] Centeno C, Lynch T, Garralda E, et al. Coverage and development of specialist palliative care services across the World Health Organization European Region (2005–2012): results from a European Association for Palliative Care Task Force survey of 53 Countries. Palliat Med. 2016;30:351–362.

[50] Hoefler JM, Vejlgaard TB. Something's ironic in Denmark: an otherwise progressive welfare state lags well behind in care of patients at the end of life. Health Policy. 2011;103:297–304.