

## Socioeconomic position, referral and attendance to rehabilitation after a cancer diagnosis: A population-based study in Copenhagen, Denmark 2010–2015

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### ABSTRACT

**Background:** Implementation of new cancer services may lead to socioeconomic differences in uptake and despite reports of more unmet needs among patients with low socioeconomic position studies have found that these patients receive less rehabilitation. We aimed to investigate associations between indicators for socioeconomic position and referral as well as attendance to rehabilitation for cancer.

**Methods:** Through the Danish Cancer Registry, we identified all persons diagnosed with cancer in Copenhagen municipality 2010–2015 and obtained information on referral to and visits at the municipal rehabilitation center from municipal records. We linked the population with information on socioeconomic information and vital status through national registries. Associations were analyzed using multivariate Cox regression models.

**Results:** Among 13,059 persons diagnosed with cancer a total of 2523 were referred for rehabilitation within 2.5 years from diagnosis. Compared to persons with short education, men and women with long education and men with medium education had higher adjusted hazard ratios (HR) for being referred to rehabilitation (Long: HR-men, 1.30 (95% CI: 1.06–1.59) and HR-women, 1.33 (95% CI: 1.15–1.53; Medium: HR-men, 1.23 (95% CI: 1.02–1.49)). Both men and women with children living at home had higher HR of referral (HR-men, 1.23 (95% CI: 1.00–1.52) and HR-women, 1.28 (95% CI: 1.11–1.48)). Among patients referred to rehabilitation, 81% attended a visitation consultation. Long education was associated with attendance in both genders while in men, medium education and in women high income, respectively was associated with attendance.

**Conclusion:** Clear socioeconomic differences in referral and attendance to rehabilitation services indicate that socioeconomic inequality exists in patients' transition from cancer treatment into post-treatment care. Systematic needs assessment and clarification of wish for rehabilitation should be a requisite for all cancer patients independent of their socioeconomic position.

### ARTICLE HISTORY

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### Background

Even though the health care system ensures tax-funded and equal access to health care, there is a marked social inequality in cancer prognosis in Denmark. This is documented at all levels from the GP [1,2] to the highly specialized multidisciplinary in-hospital cancer treatments (i.e., [3,4]). The social differences in prognosis are not trivial. If all cancer patients independent of income had the same favorable prognosis, 2000 of all deaths (~12,000 deaths) among Danish cancer patients at 5 years after diagnosis could be avoided [5]. Cancer rehabilitation aims to optimize daily functioning and quality of life by addressing adverse physical, psychological and social symptoms that patients may suffer in parallel with and after cancer treatment [6]. The Danish health authorities have defined rehabilitation as an integral part of cancer treatment. Health staff at both hospitals and in primary care

is responsible for assessing the needs of cancer patients in order to refer to needs-based rehabilitation and survivorship care [7].

A structural reform reorganized the public sector in Denmark in 2007, handing over major responsibility for rehabilitation and palliative care from hospitals to the municipality and community level [8] in line with WHO recommendations to achieve better performance and outcomes in health care and optimize value for money [9]. Evidence suggests that not all patients undergo needs assessment and thus cancer patients and survivors often experience unmet needs [10–12]. Implementation and/or reorganization of services may lead to socioeconomic differences in uptake. This has i.e., been observed for uptake and completion of the newly introduced HPV vaccination program in Danish adolescent girls [2]. Although knowledge about socioeconomic inequality in the provision of community-based rehabilitation

for people with cancer is limited, recently published evidence points to social inequality in referral to rehabilitation [13,14]. From 2009–2012, 16% of cancer patients were referred to rehabilitation in Copenhagen municipality. Patients with longer education or higher income were more likely to be referred than patients with short education or low income (HRs: 1.3 (95% CI: 1.2–1.5) and 1.2 (95% CI: 1.0–1.3), respectively) [14]. A national questionnaire survey ( $N=3439$ ) among cancer survivors found, that patients, particularly women, with long education, high income and who are working to a higher degree have participated in rehabilitation activities up to 14 months after diagnosis (ORs for participation ranging from 1.3–2.6) [15]. Similarly, in a nationwide study of 4346 cancer patients, patients with short education had a greater likelihood of unmet needs in relation to psychological support and practical help, but less unmet needs for physical rehabilitation in comparison with patients with long education, while patients who live alone had higher likelihood of unmet needs, irrespective of education [16].

We hypothesized that previous findings of socioeconomic differences in referral to cancer rehabilitation may reflect early consequences of structural changes to the organization of rehabilitation services; with a combination of health care professionals not familiar with new routes of referral and the contents of rehabilitation services in the municipality setting. Further, the more resourceful patients may be more articulate in their formulation of needs and demands for rehabilitation [17,18]. A decade after the introduction of organizational changes in cancer rehabilitation services we set out firstly, to update and evaluate if there was still socioeconomic differences in referral to cancer rehabilitation in cancer patients diagnosed from 2010 to 2015 in Copenhagen Municipality. Secondly, we evaluated if; given referral, there were socioeconomic differences in attendance in cancer rehabilitation.

## Material and methods

### Study population

We conducted a population-based cohort study based on the entire population of 550,000 persons residing in Copenhagen Municipality, amounting to about 10% of the total Danish population. Responsibility for rehabilitation services after cancer lies with the municipalities in Denmark. Cancer rehabilitation is offered on a needs basis and is free-of-charge for the individual patient. In the Copenhagen Municipality, cancer rehabilitation is offered at the Copenhagen Centre for Cancer and Health upon a referral from a hospital department or general practitioner. In general, referrals are accepted within a window of 2 years since the end of primary treatment. When referred, the Centre for Cancer and Health offers a rehabilitation program based on the individual needs, which may be adjusted throughout the rehabilitation course. Electronic referrals have been in use since the beginning of 2010 for all cancer patients.

From the files of the Danish Cancer Registry, we identified all new cancers diagnosed in persons aged 25 years or more, born after 1920 and residing in Copenhagen Municipality,

Denmark between 2010 and 2015. We obtained information on the date of diagnosis, diagnosis code on all cancers, such that each person could be included with more than one cancer to reflect the real-life setting.

From the files of the Copenhagen Centre for Cancer and Health, we identified all persons who were referred to cancer rehabilitation from 2010 through 2015. The information obtained for each referral included the date of referral and date of attendance. By linking the information about referrals and total cancer population we were able to construct a timeline for each person diagnosed with cancer and follow-up until referral to rehabilitation (outcome), new primary cancer diagnosis, migration out of Copenhagen Municipality, death or end of follow-up which was set at 2.5 years since diagnosis (comprising 96% of all referrals among the study population).

We linked the full population of persons diagnosed with cancer to the administrative registries kept at Statistics Denmark in order to obtain demographic and socioeconomic data. We retrieved information on highest attained education (categorized as short (mandatory school, 7–9 years), medium (senior high school or vocational education, 9–12 years) and long (higher education, >12 years) [19]; disposable income (categorized into quintiles according to the age, sex and calendar-year income distribution of the total Danish population) [20]; cohabitation status (categorized as married/cohabiting or living alone (single, divorced, widow(er)); as well as children living at home (categorized as a yes/no variable) [21]. Information on education and income was retrieved the year prior to cancer diagnosis and information on cohabitation status and children living at home were retrieved 1 January in the year of diagnosis. Persons for whom information on education, income and cohabitation status was missing were excluded (4%).

For the second analysis, the study population comprised all persons diagnosed with cancer who had been referred to cancer rehabilitation in the Copenhagen Centre for Cancer and Health. For these persons we followed each individual until date of attendance, defined as attending a visitation visit in order to clarify needs for rehabilitation (outcome) or date of a new primary cancer diagnosis, migration out of Copenhagen Municipality, death or end of follow-up (defined as 6 months after date of referral, comprising 81% of all attendances). Persons with the date of attendance prior to date of referral were excluded ( $n=2$ ).

### Statistical analysis

Person-years were counted from date of diagnosis/referral until date of referral/attendance (outcome) or migration out of Copenhagen Municipality, new primary cancer diagnosis, death or end of follow-up (2.5 years after diagnosis (first analysis) or 0.5 year after referral (second analysis) or 31 December 2015, whichever came first. Cumulative incidence functions (CIFs) by education were calculated for referrals and attendance, respectively, with death as a competing event. Gray's test was used to evaluate hypotheses of equality of cause-specific cumulative incidence functions between

educational groups. We estimated hazard ratios and 95% confidence intervals for referral to rehabilitation (first study question) or attendance (second study question) according to socioeconomic indicators using Cox proportional hazards models with time since diagnosis or time since referral, respectively, as the underlying timescale. To obtain proportional hazards, all analyses were separated by sex and stratified by age and year of diagnosis. We further adjusted HRs for disposable income and cohabitation for highest attained education and HR for children living at home for cohabitation status. Sub-analyses were performed by cancer type to clarify effect modification. Analyses were performed in SAS 9.4 with the 'proc lifetest' and 'proc phreg' procedures, the proportional hazard assumption was tested by the procedure 'assess ph'.

## Results

A total of 13,617 primary cancers were diagnosed among 13,059 residents aged 25 years or more in Copenhagen Municipality from 2010–2015 (Figure 1 and Table 1) accruing a total of 2523 referrals and 16,176 person-years of follow-up for the analysis of referrals. The number of referrals increased over the first two years of the study period, but was relatively stable thereafter. Most referred persons were less than 52 years of age while only 9% were above 75 years. Equal number of men and women were diagnosed with cancer, but 35% of referrals were of men. Some 40% of referred persons had long education, 47% were cohabiting while 80%

had no children living at home (Table 1). The HRs for being referred were highest for patients diagnosed with breast, buccal cavity or pharynx cancer and lowest for patients with CNS, melanoma or urinary tract cancer (Table 1S).

The cumulative incidence of referral to rehabilitation was higher in patients with long education compared with patients with short and medium education. The cumulative incidence curves suggest that patients with long education are both referred more and earlier according to time since diagnosis than patients with short or medium education (Figure 2). At 200 days after diagnosis, 22% (95% CI: 21%–23%) of patients with long education, 15% (95% CI: 14%–16%) with medium and 12% (95% CI: 10%–13%) with short education had been referred and the cumulative incidences only increased slightly after this with stable differences between groups ( $p < .0001$ ). Both men and women with long education had higher adjusted HRs for being referred to rehabilitation (HRs: 1.30 (95% CI: 1.06–1.59) and 1.33 (1.15–1.53), respectively) as had men with medium education (HR: 1.23; 95% CI: 1.02–1.49) as compared to short education (Table 2). The association between long education and referral was also seen by cancer site, although some estimates failed to reach statistical significance (Table 2S). There was no association with income or cohabitation status, but having children living at home was associated with HR of 1.23 (95% CI: 1.00–1.52) and 1.28 (95% CI: 1.11–1.48) in men and women, respectively (Table 2).

The study population for the analysis of attendance as outcome included 2521 referred patients ( $n = 2$  were

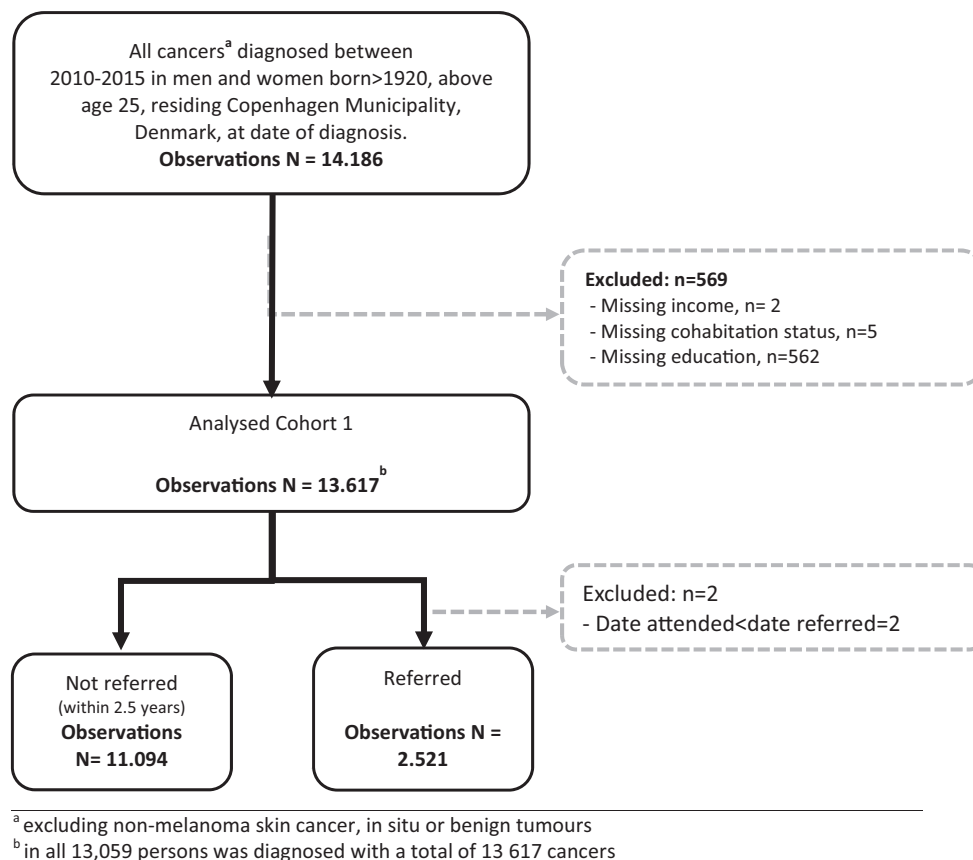


Figure 1. Flow chart for the study population of cancer patients diagnosed in Copenhagen Municipality, Denmark, 2010–2015.

**Table 1.** Characteristics of 13,059 adult men and women diagnosed with a total of 13,617 cancers<sup>a</sup> and of the 2521 cancer patients who received a referral to rehabilitation in Copenhagen Municipality, Denmark, 2010–15.

Characteristics	Among n =13,617 diagnoses				Among n =2521 referred			
	Person		Referrals		Person		Attendances	
	years	(%)	n	(%)	years	(%)	n	(%)
Period of diagnosis								
2010	3850	(24)	36	(1)	4	(1)	26	(1)
2011	3835	(24)	177	(7)	22	(8)	142	(7)
2012	2945	(18)	534	(21)	68	(24)	430	(21)
2013	2788	(17)	575	(23)	65	(23)	482	(24)
2014	1979	(12)	651	(26)	78	(28)	528	(26)
2015	776	(5)	550	(22)	44	(16)	442	(22)
Age at diagnosis (years)								
<=52	3811	(24)	746	(30)	57	(20)	668	(33)
53-62	3198	(20)	665	(26)	65	(23)	564	(28)
63-68	3352	(21)	493	(20)	57	(20)	395	(19)
69-75	2889	(18)	394	(16)	58	(20)	286	(14)
>=76	2924	(18)	225	(9)	44	(16)	137	(7)
Sex								
Male	8179	(51)	891	(35)	105	(37)	697	(34)
Female	7997	(49)	1632	(65)	177	(63)	1353	(66)
Cancer site								
Buccal cavity and pharynx	388	(2)	184	(7)	18	(6)	157	(8)
Gastrointestinal organs	2602	(16)	482	(19)	70	(25)	350	(17)
Respiratory organs	1397	(9)	311	(12)	47	(17)	216	(11)
Melanoma	1949	(12)	59	(2)	6	(2)	49	(2)
Breast	2157	(13)	887	(35)	79	(29)	784	(38)
Female genital organs	1035	(6)	118	(5)	15	(5)	93	(5)
Male genital organs	2428	(15)	140	(6)	11	(4)	118	(6)
Urinary tract	1479	(9)	52	(2)	3	(1)	44	(2)
CNS	1068	(7)	42	(2)	3	(1)	37	(2)
Lymphoma and leukemia	1109	(7)	172	(7)	18	(6)	139	(7)
Other and unspecified cancer <sup>b</sup>	561	(4)	76	(3)	7	(3)	63	(3)
Highest attained education								
Short	3524	(22)	414	(16)	68	(24)	292	(14)
Medium	7524	(47)	1107	(44)	136	(48)	866	(42)
Long	5127	(32)	1002	(40)	79	(28)	892	(44)
Income (quintiles)								
Q1 (lowest)	3463	(21)	545	(22)	75	(27)	417	(20)
Q2	3249	(20)	457	(18)	52	(18)	366	(18)
Q3	3114	(19)	464	(18)	52	(18)	373	(18)
Q4	3115	(19)	506	(20)	52	(18)	423	(21)
Q5 (Highest)	3233	(20)	551	(22)	50	(18)	471	(23)
Cohabiting status								
Living with partner	7659	(47)	1178	(47)	120	(42)	985	(48)
Living alone								
- unmarried	3595	(22)	634	(25)	63	(22)	531	(26)
- divorced	2986	(18)	512	(20)	64	(23)	403	(20)
- widowed	1935	(12)	199	(8)	35	(12)	131	(6)
Children living at home								
No	13983	(86)	2006	(80)	244	(86)	1580	(77)
Yes	2193	(14)	517	(20)	39	(14)	470	(23)

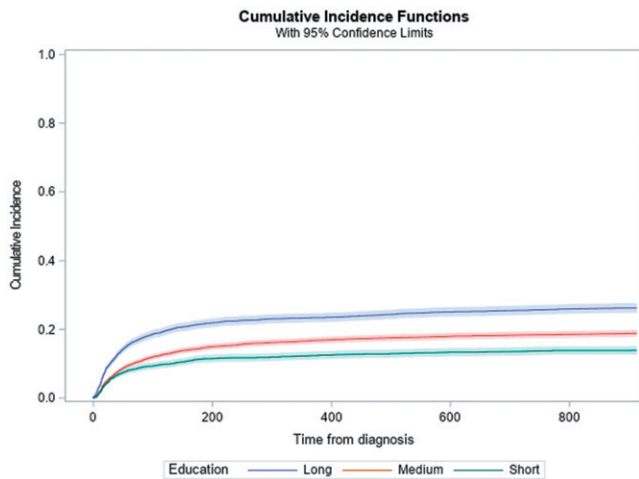
<sup>a</sup>Excluding non-melanoma skin cancer, in situ or benign tumors.

<sup>b</sup>Other and unspecified cancer: bones, joints and articular cartilage, mesothelium, connective tissue, endocrine glands and ill-defined and unspecified cancer.

excluded since attending date was prior to the date of referral). Out of these, 2050 ( $n=81\%$ ) attended rehabilitation within the 6 months from date of referral. Most referred persons were younger (aged <52 years) and only 7% of attendances were above 75 years. The vast majority were women (66%) and diagnosed with cancer of the breast (38%) or gastrointestinal organs (17%). In all, 44% had a short education, 23% were in the highest income quintile, 48% were married and 77% had no children living at home (Table 1).

Most patients who attend rehabilitation after a referral attended within 50 days. At 50 days after referral, 86% (95% CI: 83%–88%), 73% (95% CI: 70%–75%) and 64% (95% CI: 59%–69%) of patients with long, medium and short education had attended and almost no increase in cumulative incidence curves were observed from then onwards (Figure 3)

( $p < .0001$ ). In contrast to the HRs for referral, the HRs for attending rehabilitation were highest for patients diagnosed with urinary tracts, CNS and male genital organ cancers (Table 15). For education, same trends were found as for referral, with both men and women with long education having higher HR for attending rehabilitation (HRs: 1.72 (95% CI: 1.35–2.20) and 1.56 (1.33–1.84)) as well as men with medium education compared to short education (HR: 1.32; 95% CI: 1.04–1.68; Table 3). This was also the case for most cancer sites (Table 35). A minor increased HR for attendance was found among women within the highest income quintiles (HRs Q4: 1.23 (95% CI: 1.03–1.47) and Q5: 1.22 (1.03–1.46)), but no associations with attendance were found for children living at home or those who were cohabitating (Table 3).



**Figure 2.** Cumulated incidence plots for referral to rehabilitation with death as competing event over time since diagnosis among cancer patients diagnosed with cancer in Copenhagen Municipality, Denmark, 2010–2015.

**Table 2.** Hazard ratios (HR) with corresponding 95% confidence intervals (CI) for referral to rehabilitation among 13,059 cancer patients<sup>a</sup>, Copenhagen Municipality, Denmark, 2010–2015.

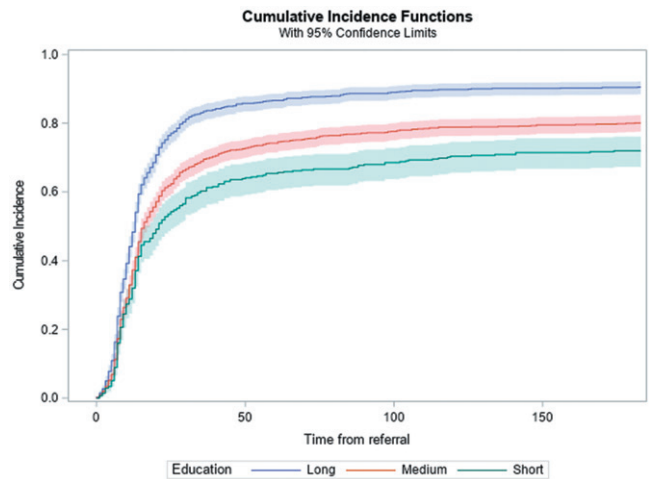
Characteristic	Men		Women	
	HR <sup>b</sup>	(95 % CI)	HR <sup>b</sup>	(95 % CI)
Highest attained education				
Short	1	Ref	1	Ref
Medium	1.23	(1.02–1.49)	1.07	(0.92–1.23)
Long	1.30	(1.06–1.59)	1.32	(1.15–1.53)
Disposable income (quintiles)				
Q1 (lowest)	1	Ref	1	Ref
Q2	0.93	(0.76–1.13)	0.92	(0.78–1.08)
Q3	0.92	(0.75–1.14)	1.01	(0.86–1.19)
Q4	0.98	(0.79–1.21)	1.01	(0.86–1.18)
Q5 (highest)	0.95	(0.78–1.16)	1.03	(0.88–1.21)
Cohabitation status				
Living alone	1	Ref	1	Ref
Living with partner	1.01	(0.88–1.15)	1.01	(0.91–1.12)
Children living at home				
No	1	Ref	1	Ref
Yes	1.23	(1.00–1.52)	1.28	(1.11–1.48)

<sup>a</sup>Excluding non-melanoma skin cancer, in situ or benign tumors.

<sup>b</sup>The HRs are adjusted for age and year of diagnosis; HRs for disposable income and cohabitation status are further adjusted for highest attained education; and the HR for children living at home is further adjusted for cohabitation status.

## Discussion

Although almost 10 years have passed since the Danish municipalities were assigned the responsibility for the provision of rehabilitation of cancer patients, it seems that social disparities in rates of referral as well as attendance in rehabilitation still exist in cancer patients. The disparities in referral were observed according to education and children living at home, while none were observed in terms of income or cohabitation status. Given referral, longer education was associated with more attendance in both sexes while low income was associated with less attendance in women. Approximately 19% of cancer patients were referred within the 2.5 years after diagnosis. Rehabilitation should be provided on a needs basis as defined by the national rehabilitation pathway [22]. Studies suggest however that, depending on cancer site, some 30–90% of cancer patients will have a need for rehabilitation at some point



**Figure 3.** Cumulated incidence plots for attending rehabilitation with death as competing event over time since referral among cancer patients who received a referral to rehabilitation after cancer in Copenhagen Municipality, Denmark, 2010–2015.

**Table 3.** Hazard ratios (HR) with corresponding 95% confidence intervals (CI) for attending rehabilitation among 2521 cancer patients<sup>a</sup> who received a referral to rehabilitation, Copenhagen Municipality, Denmark, 2010–2015.

Characteristic	Men		Women	
	HR <sup>b</sup>	(95 % CI)	HR <sup>b</sup>	(95 % CI)
Highest attained education				
Short	1	ref	1	ref
Medium	1.32	1.04–1.68	1.17	0.99–1.38
Long	1.72	1.35–2.20	1.56	1.33–1.84
Disposable income (quintiles)				
Q1 (lowest)	1	ref	1	ref
Q2	1.15	0.92–1.45	1.18	0.98–1.41
Q3	1.24	0.98–1.57	1.16	0.97–1.39
Q4	1.06	0.83–1.35	1.23	1.03–1.47
Q5 (highest)	1.09	0.87–1.37	1.22	1.03–1.46
Cohabitation status				
Living alone	1	ref	1	ref
Living with partner	0.99	0.85–1.15	0.92	0.82–1.02
Children living at home				
No	1	Ref	1	ref
Yes	1.05	0.83–1.32	1.11	0.95–1.30

<sup>a</sup>Excluding non-melanoma skin cancer, in situ or benign tumors.

<sup>b</sup>The HRs are adjusted for age and year of diagnosis; HRs for disposable income and cohabitation status are further adjusted for highest attained education; and HR for children living at home is further adjusted for cohabitation status.

post-treatment [23–26]. Further, numerous studies document that a substantial proportion of patients experience unmet needs after the end of cancer treatment (i.e., [11,15,27,28]). Therefore, it seems like the needs assessment and subsequent needs-based referral for rehabilitation services in Copenhagen is not fully implemented across all cancer sites in line with what is also suggested by other studies conducted in the Danish setting [16,28,29]; and further, our study indicates that implementation may not be similar across social groups. Staff at the local breast surgery clinic evaluates, as a rule, patients who have received surgery for breast cancer as in need of rehabilitation. This was reflected in our finding as there were no differences in rates of referral by education among women with breast cancer. However, for many other cancer types, like e.g., respiratory cancers, male genital cancers, gastrointestinal cancers and CNS

tumors, evidence of educational differences in referral to rehabilitation is present. This is despite the fact that for some cancer patients were generally more referred (i.e., head and neck cancer patients) or less referred (i.e., CNS cancers). Even though we had no access to individual level needs assessment for this study population, we have no reason to believe that across these cancer sites, patients with short education have fewer needs for rehabilitation than those with long education.

Barriers for implementing needs assessment and referral to rehabilitation may stem from several sources, e.g., factors related to health staff, patients and/or the clinical setting. A recent Danish study of the health staff perspectives on needs assessment in cancer survivors indicate that challenges may be structural rather than attitudinal [29]. Different clinical conditions, traditions and practice in the hospital and the primary care setting create barriers to a seamless link between health care sectors potentially resulting in disconnection of care [29]. Resistance among health care personnel was not related to finding needs assessment of no importance or failure to realize the problem but rather to problems in figuring out how to best do it in practice keeping the patient's best interests at heart. Results of our study indicate that 'transition' problems into rehabilitation services for cancer patients may differ by social position, in particular education.

Added knowledge from this study includes the revealing of how patients attend if they are provided a referral. Although in general rates of attendance were rather high at 80%, we observed a clear social inequality – favoring attendance by patients with longer education and women with high income. Several explanations may contribute to social inequality in the selected group of patients who were referred to needs-based rehabilitation. Educational differences in health care use may be attributed to differences in health literacy [30] but also differences in patients' belief and trust in the health care system may contribute to disparities in rates of attendance. Our population may be referred from any health care professionals attending to the cancer patients, while a previous study finding no inequality by education/income in attendance among patients referred to rehabilitation by primary care physicians [31]. These different findings may point to a more aligned needs assessment with want of help in patients by their GPs.

In many cancer patients, especially in males and the elderly, low levels of spontaneous communication of unmet needs have been observed [32,33]. Further, studies indicate that physicians communicate differently with the patients by age, race, education and income, and indicate that patients who are less educated and older may have a more passive communication style and the physician may misperceive their desire and need for information [17,34].

Strengths of our study include the population-based nature of the data obtained in an urban municipal setting where rehabilitation in parallel with and after cancer is organized in one large center offering a range of evidence-based interventions. The size of the population enabled us to investigate across cancer sites, exploring the

heterogeneity that characterizes the cancer population. Further, our ability to link with a range of individual-level socioeconomic indicators enabled us to evaluate both knowledge-based (education), resource-based (income) and support-based (cohabitation status and children at home) aspects of social position in rehabilitation uptake. Further, the ability to include both information on referrals and attendance contribute with information on the complex processes that patients navigate at during and at the end of cancer treatment. Limitations include lack of information on individual needs assessment which would have enabled us to explore underlying factors in the disparities observed e.g., insufficient implementation of needs assessment, lack of patients' motivation or wish for a referral affecting patients differently by social position. Further, we had no information on relapse in the patient population. If a person with cancer was referred within 2.5 years since diagnosis, we do not know if the referral was due to rehabilitation needs from a relapsed disease. However, we see most referrals rather close to diagnosis, indicating that most patients were referred for their primary disease in our analysis. In addition, the lack of information on referring health professional preclude any assessment of the role of the primary versus secondary care setting may play in social inequalities in rehabilitation in cancer.

The nature of the available data precludes disentangling of underlying causes of inequality in both referral to and attendance in rehabilitation after cancer treatment in a large urban cancer population. However, our results indicate that the transition from cancer treatment and into rehabilitation care is affected by systematic differences by patients' social position not necessarily reflecting on their needs for rehabilitation and survivorship care. Careful and systematic needs assessment also in those patients who may not be as proactive in communicating their symptoms and demanding management of unmet needs as part of their cancer care is a prerequisite of patient-centered care and may reduce social inequalities in uptake of cancer rehabilitation.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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