

The effect of standardised cancer pathways on Danish cancer patients' dissatisfaction with waiting time

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ABSTRACT

INTRODUCTION: Standardised cancer patient pathways (CPPs) were implemented in Denmark in 2008 to reduce the waiting time during the diagnostic process and hereby improve patient satisfaction. The aim of this study was to investigate whether patient-reported dissatisfaction with long waiting times has changed from "before" to "after" the implementation of CPPs.

METHODS: We conducted a comparative cohort study by comparing the patient-reported dissatisfaction with long waiting time before (2004/2005) and after (2010) CPP implementation. Logistic regression was used to estimate the odds ratios (ORs) for patient-reported dissatisfaction after CPP implementation compared with before.

RESULTS: Fewer patients reported dissatisfaction with long waiting time from the time of referral by their general practitioner (GP) to the first consultation at the hospital across the time of CPP implementation ($p < 0.001$) (adjusted odds ratio (OR) = 0.6 (95% confidence interval (CI): 0.5-0.8)). More patients reported dissatisfaction with long waiting time to get an appointment with their GP across the time of CPP implementation ($p < 0.001$) (adjusted OR = 3.7 (95% CI: 2.5-5.3)).

CONCLUSION: CPP implementation in Denmark was associated with a reduced level of patient-reported dissatisfaction with long waiting time from the time of referral to the first consultation at the hospital. This indicates that the CPP objective of increasing patient satisfaction may have been achieved. Nevertheless, more patients reported dissatisfaction with long waiting time to get an appointment with their GP.

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Cancer is the primary cause of death in Denmark [1]. Public dissatisfaction with the waiting times, and evidence of cancer stage migration during waiting time [2] triggered the implementation of standardised cancer patient pathways (CPPs) in 2008 [3, 4].

The objectives of the CPPs were to improve the prognosis for cancer patients, to increase patient satisfaction and to reduce the psychological distress caused by waiting times and lack of continuity in the diagnostic process. The CPPs are standardised guidelines for the diagnosis and treatment of different types of cancer, in-

cluding maximum time frames. General practitioners (GPs) and other clinicians can refer patients to a CPP in cases with a reasonable suspicion of cancer [3, 4].

Studies on the effect of CPP implementation, which have so far mostly focused on waiting times, have shown that the time from the first presentation to a GP until the date of diagnosis [5] is significantly shorter after CPP implementation [6, 7], mainly for CPP-referred patients [8]. However, it has yet to be investigated whether the CPPs have also increased patient satisfaction. Such investigation should focus on the first part of the diagnostic route as this seems to be the most important aspect when patients evaluate their full trajectory [9].

Evidence from the UK has shown that patient satisfaction is negatively influenced by increased time to diagnosis [10]. Thus, as the time to diagnosis has decreased for Danish cancer patients across the time at which the CPPs were implemented, the patient-reported dissatisfaction with waiting times should also have decreased. However, this might not be the case for all cancer patients. Furthermore, the CPPs do not include the diagnostic workup performed in general practice, and this may affect the patients' evaluation of this first part of the diagnostic journey.

The aim of this study was to investigate whether dissatisfaction with long waiting times reported by cancer patients changed from before (2004-2005) to after (2010) CPP implementation in Denmark.

METHODS

This was a comparative cohort study based on the first (CaP1) and the last (CaP3) sub-cohort of the Danish Cancer in Primary Care (CaP) cohort [11], which consists of newly diagnosed first-time cancer patients from before and after CPP implementation.

Setting

The study was conducted in Denmark, whose approximately 5.6 million citizens have free access to medical aid in a publicly tax-funded healthcare system. Approx. 98% of the Danish population is listed with a GP whom they must consult for medical advice, excepting emergencies [12]. The GP thus serves as a gatekeeper to secondary healthcare.

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TABLE 1

Patient characteristics.
The values are n (%).

	CaP1 (N = 1,002)	CaP3-total (N = 2,290)	p-value ^a	CaP3-CPP (N = 892)	CaP3-non-CPP (N = 1,364)	p-value ^b
<i>Sex</i>			< 0.001			0.021
Male	455 (45.4)	1,198 (52.3)		441 (49.4)	742 (54.4)	
Female	547 (54.6)	1,092 (47.7)		451 (50.6)	622 (45.6)	
<i>Age group, yrs</i>			< 0.001		0.164	
18-44	113 (11.3)	160 (7.0)		57 (6.4)	99 (7.3)	
45-54	148 (14.8)	280 (12.2)		93 (10.4)	182 (13.3)	
55-64	253 (25.3)	569 (24.9)		227 (25.5)	336 (24.6)	
65-74	286 (28.5)	759 (33.1)		296 (33.2)	452 (33.1)	
≥ 75	202 (20.2)	522 (22.8)		219 (24.6)	295 (21.6)	
<i>Cancer diagnosis</i>			< 0.001			< 0.001
Colorectal	153 (15.3)	387 (16.9)		136 (15.3)	246 (18.0)	
Lung	101 (10.1)	205 (9.0)		94 (10.5)	109 (8.0)	
Malignant melanoma	83 (8.3)	146 (6.4)		53 (5.9)	90 (6.6)	
Breast	214 (21.4)	398 (17.4)		238 (26.7)	151 (11.1)	
Prostate	130 (13.0)	422 (18.4)		169 (19.0)	249 (18.3)	
Other	321 (32.0)	732 (32.0)		202 (22.7)	519 (38.1)	
<i>Vital status 1 yr after diagnosis</i>			0.053			0.706
Dead	120 (12.0)	223 (9.7)		84 (9.4)	135 (9.9)	
Alive	882 (88.0)	2,067 (90.3)		808 (90.6)	1,229 (90.1)	

CaP = Danish Cancer in Primary Care cohort; CaP1 = CaP sub-cohort 1, before implementation of CPP; CaP3 = CaP sub-cohort 3, after implementation of CPP; CaP3-CPP = patients urgently referred to a CPP in CaP3; CaP3-non-CPP = patients *not* urgently referred to a CPP in CaP3; CPP = cancer patient pathways.

a) Pearson's χ^2 -test for difference between cohorts.

b) Pearson's χ^2 -test for difference between route of referral: CPP or non-CPP.

TABLE 2

Patient-reported dissatisfaction with the waiting time to get an appointment with a general practitioner, before and after implementation of cancer patient pathways and by route of referral: cancer patient pathways or non-cancer patient pathways. The values are n (%).

	CaP1 (N = 1,002)	CaP3-total (N = 1,741)	p-value ^a	CaP3-CPP (N = 716)	CaP3-non-CPP (N = 996)	p-value ^b
<i>Sex</i>						
Male	15 (3.3)	89 (9.9)	< 0.001	28 (8.2)	60 (11.1)	0.167
Female	20 (3.7)	105 (12.4)	< 0.001	31 (8.3)	70 (15.4)	0.002
Sub-total	35 (3.5)	194 (11.1)	< 0.001	59 (8.2)	130 (13.1)	0.002
<i>Age group, yrs</i>						
18-44	5 (4.4)	14 (10.7)	0.069	4 (7.8)	10 (13.0)	0.361
45-54	6 (4.1)	28 (12.6)	0.005	6 (7.1)	21 (15.8)	0.060
55-64	5 (2.0)	54 (12.5)	< 0.001	13 (7.3)	40 (16.3)	0.007
65-74	9 (3.2)	66 (11.6)	< 0.001	22 (9.4)	42 (12.8)	0.211
≥ 75	10 (5.0)	32 (8.3)	0.135	14 (8.2)	17 (8.1)	0.960
<i>Cancer diagnosis</i>						
Colorectal	7 (4.6)	39 (12.5)	0.007	9 (7.6)	30 (16.0)	0.031
Lung	7 (6.9)	18 (12.2)	0.172	8 (12.1)	9 (11.4)	0.892
Malignant melanoma	2 (2.4)	15 (12.5)	0.011	9 (20.5)	6 (8.2)	0.055
Breast	8 (3.7)	22 (7.2)	0.098	8 (4.0)	14 (14.3)	0.001
Prostate	2 (1.5)	21 (7.6)	0.014	9 (7.8)	12 (7.5)	0.920
Other	9 (2.8)	79 (13.7)	< 0.001	16 (9.4)	59 (14.8)	0.077
Alive 1 yr after diagnosis	25 (2.8)	166 (10.5)	< 0.001	116 (12.8)	46 (7.1)	< 0.001

CaP = Danish Cancer in Primary Care cohort; CaP1 = CaP sub-cohort 1, before implementation of CPP; CaP3 = CaP sub-cohort 3, after implementation of CPP; CaP3-CPP = patients urgently referred to a CPP in CaP3; CaP3-non-CPP = patients *not* urgently referred to a CPP in CaP3; CPP = cancer patient pathways.

a) Pearson's χ^2 -test for difference between cohorts.

b) Pearson's χ^2 -test for difference between route of referral: CPP or non-CPP.

Study population

The identification of patients, data collection and drop-out analysis have been described in detail elsewhere [11]. In brief, patients were identified in hospital registers before (1 September 2004-31 August 2005) and in the Danish National Patient Registry after (1 May-31 August 2010) CPP implementation. Patients were eligible if they were 18 years or older, were listed with a GP, attended general practice as part of their diagnostic route and were registered with a verified first-time diagnosis of cancer. Diagnoses were classified according to the tenth edition of the International Classification of Diseases (ICD)-10 and verified in the Danish Cancer Registry. Non-responding patients and patients with non-responding or non-involved GPs were excluded. The GP's involvement was defined on the basis of the response (yes/no) to the question: "Were you/your general practice involved in diagnosing the cancer?"

Data collection

Data were collected by a patient questionnaire and a GP questionnaire, and this information was supplemented with register data. Non-responding GPs and patients received a reminder, including a new questionnaire, after 3-5 weeks [11].

Two questions in the patient questionnaire focused on the patient's satisfaction with the waiting time during the pre-diagnosis phase: 1) the waiting time to get a consultation with a GP and 2) the waiting time from GP referral to the first consultation at a hospital.

The GP participation rates were 85.7% and 73.8% for CaP1 and CaP3, respectively. The corresponding patient participation rates were 45.3% and 53.0%. The participating patients in both sub-cohorts were more likely to be women, 45-75 years of age and diagnosed with breast cancer or malignant melanoma, and they were also more likely to have higher one-year survival rates, more localised tumours and a higher disposable income than non-participating patients [11].

Variables

The exposure was the sampling time for the sub-cohorts according to the CPP implementation: 2004/2005 = before CPP implementation (CaP1) and 2010 = after CPP implementation (CaP3). Subsequently, patients in CaP3 were categorised into CPP-referred (CaP3-CPP) and non-CPP-referred (CaP3-non-CPP) patients.

The outcome was patient-reported dissatisfaction with waiting time, defined as instances when the patients reported too long waiting times in the questionnaire. The questions used for CaP1 registered only dissatisfaction with long waiting times, whereas the questions used for CaP3 registered four levels of satisfaction ("Too long", "Appropriate", "Too short" and

"Don't know"). The CaP3 response categories were mapped to the CaP1 response categories by dichotomizing CaP3 responses into "Too long" versus "Appropriate" and "Too short" combined. The "Don't know" responses were excluded. The questions were tested by patients to assess their understanding of the items [11, 13].

Statistical analysis

Complete case analyses were performed. Comparisons of the patient characteristics and the distributions of patient-reported dissatisfaction between the sub-cohorts CaP1 and CaP3 as well as between CaP3-CPP and CaP3-non-CPP were made using Pearson's chi-squared test.

Logistic regression was used to estimate the odds ratios (ORs) of reporting dissatisfaction with waiting times depending on: 1) CPP implementation and 2) route of referral (CPP or non-CPP). Three ORs were estimated for each aspect of waiting time: unadjusted OR, OR adjusted for differences in patient characteristics (sex, age group, diagnosis and vital status after one year) and OR adjusted for both patient characteristics and patient's reported dissatisfaction in the other question. Model fit was assessed by Pearson's goodness-of-fit test. A statistical level of $p \leq 0.05$ was considered significant. Analyses were done using Stata statistical software (Version 12).

Trial registration: not relevant.

RESULTS

In total, 3,292 patients were included in the analyses; 2,290 of the patients were included after CPP implementation (CaP3) and 892 of these patients were CPP-referred (**Table 1**). The distribution of sex, age groups and cancer diagnoses differed statistically significantly between CaP1 and CaP3. The distribution of sex and cancer diagnoses differed statistically significantly according to referral route (CPP or non-CPP) (**Table 1**).

Waiting time for general practitioner consultation

More patients after than before CPP implementation reported dissatisfaction with the waiting time to get a consultation with their GP ($p < 0.001$); yet this trend was not statistically significant for all patient categories (**Table 2**). Patient-reported dissatisfaction was associated with



CPP implementation: adjusted OR = 3.7 (95% confidence interval (CI): 2.5-5.3) (Table 3). Overall, CPP-referred patients were less dissatisfied than non-CPP referred patients: adjusted OR = 0.7 (95% CI: 0.5-0.9) (Table 3).

Waiting time from referral to consultation at a hospital

Fewer patients after than before CPP implementation reported dissatisfaction with the waiting time from GP referral to consultation at a hospital ($p < 0.001$), except for breast cancer patients (Table 4). Patient-reported dissatisfaction was associated with CPP implementation:

adjusted OR = 0.6 (95% CI: 0.5-0.8) (Table 3). CPP-referred patients were overall less dissatisfied than non-CPP referred patients: adjusted OR = 0.6 (95% CI: 0.4-0.8) (Table 3).

Impact of patients' tendency to report dissatisfaction

The propensity to report dissatisfaction was, generally, similar when adjusted for the patients' tendency to report dissatisfaction, although an OR of 5.0 (95% CI: 3.4-7.5) was observed for the patients' dissatisfaction with long waiting time to see their GP (Table 3).

TABLE 3

Odds ratios (and related 95% confidence intervals) and p-values for patient-reported dissatisfaction with waiting times after vs. before cancer patient pathways implementation and cancer patient pathways-referred patients versus non-cancer patient pathways-referred patients.

Dissatisfaction with waiting time for	Unadjusted		Adjusted			
	OR (95% CI)	p-value	excl. dissatisfaction ^a OR (95% CI)	p-value	incl. dissatisfaction ^b OR (95% CI)	p-value
<i>CaP3 vs. CaP1</i>						
GP	3.46 (2.40-5.01)	< 0.001	3.66 (2.53-5.33)	< 0.001	5.01 (3.40-7.47)	< 0.001
Hospital	0.63 (0.51-0.78)	< 0.001	0.63 (0.51-0.78)	< 0.001	0.50 (0.39-0.63)	< 0.001
<i>CaP3-CPP vs. CaP3-non-CPP</i>						
GP	0.60 (0.43-0.83)	0.002	0.66 (0.47-0.92)	0.015	0.76 (0.52-1.09)	0.136
Hospital	0.61 (0.46-0.83)	0.002	0.57 (0.41-0.77)	< 0.001	0.61 (0.42-0.87)	0.007

CaP = Danish Cancer in Primary Care cohort; CaP1 = CaP sub-cohort 1, before implementation of CPP; CaP3 = CaP sub-cohort 3, after implementation of CPP; CaP3-CPP = patients urgently referred to a CPP in CaP3; CaP3-non-CPP = patients not urgently referred to a CPP in CaP3; CI = confidence interval; CPP = cancer patient pathways; GP = general practitioner; OR = odds ratio.

a) Adjusted for sex, age group, diagnosis and vital status at 1 year.

b) Adjusted for sex, age group, diagnosis, vital status at 1 year and for dissatisfaction response tendency; the OR for dissatisfaction with GP is adjusted for hospital dissatisfaction response, and the OR for dissatisfaction with hospital is adjusted for GP dissatisfaction response.

TABLE 4

Patient-reported dissatisfaction with the waiting time from referral by a general practitioner until the first consultation at hospital before and after implementation of cancer patient pathways and by referral route: cancer patient pathways or non-cancer patient pathways. The values are n (%).

	CaP1 (N = 1,002)	CaP3, total (N = 1,931)	p-value ^a	CaP3, CPP (N = 766)	CaP3, non-CPP (N = 1,134)	p-value ^b
<i>Sex</i>						
Male	98 (21.5)	120 (11.6)	< 0.001	39 (10.1)	78 (12.3)	0.295
Female	79 (14.4)	110 (12.3)	0.230	29 (7.6)	77 (15.4)	< 0.001
Sub-total	177 (17.7)	230 (11.9)	< 0.001	68 (8.9)	155 (13.7)	0.001
<i>Age group, yrs</i>						
18-44	17 (15.0)	19 (12.9)	0.624	6 (11.5)	13 (14.3)	0.642
45-54	29 (19.6)	36 (15.0)	0.239	10 (11.6)	24 (16.0)	0.357
55-64	45 (17.8)	69 (13.8)	0.146	17 (8.3)	50 (17.2)	0.004
65-74	58 (20.3)	72 (11.3)	< 0.001	24 (9.5)	45 (12.1)	0.301
≥ 75	28 (13.9)	34 (8.3)	0.033	11 (6.5)	23 (9.9)	0.220
<i>Cancer diagnosis</i>						
Colorectal	16 (10.5)	33 (10.5)	0.986	9 (7.6)	24 (12.6)	0.165
Lung	29 (28.7)	14 (8.2)	< 0.001	6 (7.4)	7 (7.7)	0.894
Malignant melanoma	17 (20.5)	6 (5.1)	0.001	1 (2.6)	4 (5.2)	0.526
Breast	23 (10.8)	54 (16.0)	0.084	20 (9.7)	33 (26.6)	< 0.001
Prostate	23 (17.7)	40 (11.1)	0.053	17 (11.6)	22 (10.4)	0.734
Other	69 (21.5)	83 (13.2)	0.001	15 (8.6)	65 (14.7)	0.042
Alive 1 yr after diagnosis	143 (16.2)	208 (11.9)	0.002	63 (9.1)	139 (13.5)	0.005

CaP = Danish Cancer in Primary Care cohort; CaP1 = CaP sub-cohort 1, before implementation of CPP; CaP3 = CaP sub-cohort 3, after implementation of CPP; CaP3-CPP = patients urgently referred to a CPP in CaP3; CaP3-non-CPP = patients not urgently referred to a CPP in CaP3; CPP = cancer patient pathways.

a) Pearson's χ^2 -test for difference between cohorts. b) Pearson's χ^2 -test for difference between route of referral: CPP or non-CPP.

DISCUSSION

In accordance with our hypothesis, fewer patients reported dissatisfaction with long waiting time before being seen at a hospital after CPP implementation than before. However, more patients reported dissatisfaction with long waiting time to get an appointment with their GP in the same period. Furthermore, CPP-referred patients were less likely to report dissatisfaction than non-CPP-referred patients.

Strengths and limitations

The different data sources of the CaP cohort and the collection of data at different points in time [11] allowed us to investigate changes in the patient-reported dissatisfaction across time using a comparative cohort study design. However, this design does not allow us to infer causality, and the associations found could be coincidental.

Selection bias was reduced as the CaP cohort included all incident cancer patients. In fact, the case mix of patients in the CaP cohort resembles the case mix of patients in the Danish Cancer Registry [11].

The exclusion of non-responding and non-involved GPs might have caused selection bias. However, there is no reason to suspect that the GPs' willingness to respond or their level of involvement in the diagnoses were associated with CPP implementation or patient-reported dissatisfaction. Non-response could potentially give rise to selection bias. However, the patients' willingness to respond is considered to be independent of the CPP implementation, and the characteristics of non-participating patients were similar in the sub-cohorts [11].

The GP questionnaires were filled out by GPs based on their patient's medical record, which minimises the possibility of information bias. However, patient information might have been affected by recall bias. Nevertheless, the level of potential recall problems among patients are considered to be similar for both cohorts. This may have led to an underestimation of the associations found.

The wordings of the used items in the two patient questionnaires (CaP1 and CaP3) differed slightly as they were not created for comparative purposes. The dichotomization of the responses from CaP3 into dissatisfied and non-dissatisfied increases the validity of the responses as negative responses are more valid than positive responses [14].

By adjusting for differences in sex, age group, diagnoses and survival status between the cohorts, we aimed to account for known confounders. Still, residual confounding cannot be ruled out. It was not possible to account for other confounders, such as comorbidity in patients and other structural changes in the healthcare sector (e.g. centralisation of treatment and the regional government restructuring in 2007 [3, 4, 15] in the pre-

sent study. Thus, the possible effect of CPPs on the patients' dissatisfaction should be seen as a combination of the structural changes and the actual CPP guidelines and possibly other factors.

Comparison with other findings

Direct comparison with other studies is not possible due to the lack of evidence of the association between CPP implementation and patient-reported dissatisfaction with waiting times. Similar urgent-referral programmes do exist in other countries, e.g. the two-week-wait in the UK, but no studies targeting this specific area could be identified.

Time to diagnosis and patient satisfaction

As studies have shown a decrease in the diagnostic interval after CPP implementation [6-8, 16], we hypothesised that patients would be less dissatisfied with waiting times after CPP implementation. An English study [10] found that cancer patients were more likely to report a poor cancer care experience when experiencing more pre-diagnostic GP consultations, which has been shown to be associated with a longer time to diagnosis [17]. Furthermore, a Dutch study [18] found that lung cancer patients diagnosed through a rapid diagnostic programme experienced a decrease in distress over time, indicating that shortening the time to diagnosis may reduce the level of patient distress. As waiting time is very important to cancer patients [9], a study is needed on how waiting time is associated with dissatisfaction among different sub-groups.

Satisfaction with general practitioners

Surprisingly, patients became more dissatisfied with the waiting time to get an appointment with a GP across time, although the CPPs were aimed at the diagnostic process from GP referral and onwards. As patient satisfaction expresses the agreement between the patients' expectations and their experiences [19], our findings may result from increased public attention to CPP implementation as this may have increased the patients' expectations of shorter waiting times (including the waiting time to see a GP), or the patients' dissatisfaction with GP accessibility may generally have increased from 2004 to 2010. Nevertheless, our findings stress the need for general practice to find ways to meet the expectations of the patients, specifically because GP accessibility is generally rated lower than other factors in primary care [20].

CONCLUSION

This study found that CPP implementation is strongly associated with a lower patient-reported dissatisfaction with long waiting time from GP referral until first consul-

tation at a hospital, both across time and between referral routes. This indicates that the CPPs have increased patient satisfaction with the waiting time patients experience before being seen at a hospital.

Additionally, CPP implementation was strongly associated with a higher patient-reported dissatisfaction with long waiting time to get an appointment with a GP across the time of the CPP implementation, but such dissatisfaction was not found between referral routes. This topic needs further investigation, but the results underpin the need for general practice to consider accessibility.

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LITERATURE

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