

Improvement of the experience of colorectal cancer patients in Sweden with a regional cancer plan

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Abstract

Aim The Stockholm-Gotland Regional Cancer Plan was launched in 2012 to improve cancer care. A personal contact nurse (CN), an individual written care plan (IWCP) and a standardized care pathway (SCP) were introduced. The aim of the current study was to evaluate whether these efforts have resulted in an improved experience for patients treated for colorectal cancer.

Method Patients treated with bowel resection for colorectal cancer in the Stockholm-Gotland region between 1 January 2013 and 31 December 2017 were identified through the Swedish Colorectal Cancer Registry. Six to eight months postoperatively, the patients received a patient-reported experience questionnaire. Patients were classified as 'satisfied' or 'not satisfied'.

Results The questionnaire was sent to 4465 patients, and 3154 (70.64%) responded. The proportion of patients assigned a CN increased over time (79.84%–88.44%) and so did the proportion of patients receiving an IWCP (39.36%–70.00%). The waiting times were significantly shortened during the study period. In multivariable analysis, access to a CN and an IWCP was

independently associated with increased patient satisfaction (OR 3.03, 95% CI 2.28–4.02 and OR 1.64, 95% CI 1.38–1.94). Patients with a long waiting time were significantly less satisfied than patients with a short waiting time (OR 0.72, 95% CI 0.60–0.88).

Conclusion Implementation of a CN, IWCP and SCP has been successful, measured by a higher proportion of patients gaining access to these assets and shortened waiting times. This has led to an improved patient experience in patients treated for colorectal cancer in the Stockholm-Gotland region.

Keywords Colorectal cancer, Patient-reported experience measures, cancer plan, population-based

What does this paper add to the literature?

This is a population-based study on how organizational projects have improved the experience of colorectal cancer patients. Many projects aimed at improving cancer care are targeted towards patient experience, but scientific evaluations of such projects are scarce. This study aims to fill this void.

Introduction

The first Swedish National Cancer Strategy, introduced in 2009 [1], aimed to improve cancer care, and supportive care strategies were part of it. The six regions in Sweden have since adapted the National Cancer Strategy by defining specific regional cancer plans [2].

In the Stockholm-Gotland Regional Cancer Plan, which included several cancer diagnoses, a supportive care strategy was to allocate a personal contact nurse

(CN) at the time of diagnosis [3]. The CN should have in-depth knowledge about cancer care, be a resource for information and support, and a coordinator of the clinical pathway for cancer patients. Research has shown that similar nursing roles can reduce insecurity, vulnerability and readmissions for cancer patients during cancer care [4].

The Swedish Regional Cancer Plan also recommended an individual written care plan (IWCP) as a supportive care strategy. The IWCP includes data on appointments, examinations, contact information to the caregivers, detailed information on treatment, early and late side-effects, advice of management of symptoms, self-care advice, a rehabilitation plan and information on

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follow-up. The rationale for the IWCP is to improve a patient's knowledge and thus empower him or her to participate in reducing symptoms and concerns [5–7]. Since publication of the National Cancer Strategy, standardized care pathways (SCPs) have been implemented for several types of cancer with the objective of shortening waiting times, increasing patient satisfaction and reducing inequalities.

The Stockholm-Gotland region has 2 million inhabitants and approximately 1200 patients are diagnosed with colorectal cancer annually. The first regional colorectal cancer plan was launched in 2012 and included a strengthened effort to assign a CN to all patients with colorectal cancer. In the autumn of 2015, a regional colorectal cancer IWCP was introduced, and a project for regional implementation was launched. In April 2016, a SCP for colorectal cancer was introduced in an effort to reduce the time between the onset of clinical signs, tumour evaluation and the start of treatment. Patients presenting with one or more of the following symptoms/findings were included in the SCP:

- 1 change in previously stable bowel habits for more than 4 weeks, without another explanation, in people over the age of 40 years;
- 2 visible blood in the stools where rectal examination does not reveal another obvious source of bleeding or when bleeding continues despite treatment of other sources of bleeding;
- 3 iron deficiency anaemia without other explanation;
- 4 finding on rectal examination that raises the suspicion of rectal cancer or findings on radiology giving suspicion of colorectal cancer.

The aim of the current study was to evaluate the effect of implementation of a CN, IWCP and SCP on patient-reported experience measures (PREMs) in patients treated for colorectal cancer in the Stockholm-Gotland region.

Method

This is a population-based cohort study relying on the nationwide Swedish Colorectal Cancer Registry (SCRCR) with coverage exceeding 98%. The SCRCR contains prospectively reported data on patient characteristics such as American Society of Anesthesiologists (ASA) score, age, tumour location and tumour stage as well as treatments given, dates of diagnosis, treatment complications and survival for all patients diagnosed with colorectal cancer in Sweden. Patients treated with curative or palliative segmental bowel resection for colorectal cancer in the Stockholm-Gotland region between 1 January 2013 and 31 December 2017 were identified through the SCRCR. Six to eight months

postoperatively, these patients were contacted by regular mail and asked to fill out the PREM questionnaire. The questionnaire could be filled out on paper or as a web questionnaire. Clinical data including information on patient age, sex, ASA score, tumour location, tumour stage and treatment were retrieved from the SCRCR.

The PREM questionnaire comprised questions from the Swedish National Cancer Questionnaire, designed in collaboration with the regional cancer centres [8]. The items cover patient-reported experiences regarding satisfaction with waiting time, information on the disease and understanding of the information, patient participation in treatment decisions, availability of a caregiver and general respectful treatment from the caregiver. Whether the patients had been assigned a CN and an IWCP was also assessed by the PREM questionnaire. Patients who gave a positive answer to all these questions were classified as 'satisfied'. Patients who gave one or more negative answer were classified as 'not satisfied'. The effect of stepwise introduction of a CN (2012), IWCP (2015) and SCP (2016) on patient satisfaction was evaluated by year of surgery (2013–2017). Time between diagnosis and the start of treatment was calculated and related to patient satisfaction. The date of diagnosis was defined as the first date when any examination showed a tumour in the colon or rectum, often the date of colonoscopy. The start of treatment was defined as the date of whichever came first of surgery, radiotherapy or chemotherapy. Waiting time was categorized into three groups of equal length (short, medium and long).

The study was approved by the regional ethical committee of the Karolinska Institute (2016/146-31).

Statistical methods

Data were analysed with Stata v.14 (StataCorp LP, College Station, Texas, USA). Groups were compared with Kruskal–Wallis and chi-square tests as appropriate. A *P*-value of <0.05 was considered statistically significant. The effect of year of surgery, CN, IWCP, age group, sex, ASA score and waiting time on patient satisfaction (yes/no) was assessed with univariable and multivariable logistic regression models. Age, sex and ASA score were included in the multivariable model for epidemiological/clinical reasons. Other predictors were included if the change-in-estimate criterion of 10% indicated an important confounding effect. Inclusion of a CN and an IWCP changed the point estimate of the odds ratio of year of surgery by more than 10% [9]. Waiting time was included in the model as the SCP specifically targeted waiting times, and satisfaction with waiting times

was a central part of the study. Interactions between year of surgery and covariates of the univariable models were not statistically significant.

Results

The PREM questionnaire was sent to 4465 patients, of whom 3154 responded; this equates to a response rate of 70.64%, ranging from 66.67% to 73.99% for the

times between 2013 and 2017. The characteristics of responders versus nonresponders are displayed in Table 1. Nonresponders had a higher proportion of patients aged over 85 years, ASA score 3–4, emergent surgery and Stage IV disease. Among responders, 91.03% had potentially curative surgery, whereas 65.52% of nonresponders had potentially curative treatment. Thus, a significantly higher proportion of patients in a palliative setting were nonresponders.

Table 1 Patient characteristics in responders to the patient-reported experience measure compared with nonresponders.

	Responders (<i>n</i> = 3154), <i>n</i> (%)	Nonresponders (<i>n</i> = 1311), <i>n</i> (%)	<i>P</i> -value
Tumour location			
Colon	2186 (69.31)	949 (72.39)	0.042
Rectum	968 (30.69)	362 (27.61)	
Sex			
Male	1638 (51.93)	692 (52.78)	0.605
Female	1516 (48.07)	619 (47.22)	
Median age (years)	71	71	
Age category (years)			
<56	190 (6.02)	123 (9.38)	<0.001
56–65	406 (12.87)	185 (14.11)	
66–75	975 (30.91)	322 (24.56)	
76–85	1022 (32.40)	364 (27.77)	
>85	561 (17.79)	317 (24.18)	
ASA grade			
ASA 1	419 (13.28)	131 (10.00)	<0.001
ASA 2	1529 (48.48)	445 (33.94)	
ASA 3–4	1173 (37.19)	624 (47.59)	
ASA missing	33 (1.05)	111 (8.47)	
Elective/emergent surgery			
Elective	2986 (94.67)	992 (75.67)	<0.001
Emergent	168 (5.33)	319 (24.33)	
Year			
2013	625 (19.82)	284 (21.66)	0.005
2014	653 (20.70)	267 (20.37)	
2015	576 (18.26)	288 (21.97)	
2016	660 (20.93)	247 (18.84)	
2017	640 (20.29)	225 (17.16)	
Tumour stage			
I–III	2798 (88.71)	882 (67.28)	<0.001
IV	350 (11.09)	389 (29.67)	
Unknown*	6 (0.20)	40 (3.05)	
Treatment			
Curative	2871 (91.03)	859 (65.52)	<0.001
Palliative/unknown	283 (8.97)	452 (34.48)	
Time from diagnosis to start of treatment			
Short (median 19 days)	874 (27.73)	528 (40.42)	<0.001
Medium (median 35 days)	1189 (37.72)	341 (26.11)	
Long (median 64 days)	1089 (34.55)	437 (33.46)	

ASA, American Society of Anesthesiologists.

The questionnaire was sent to a total of 4465 patients. Numbers in parenthesis are column percentages.

Table 2 presents the characteristics of responders by year of surgery between 2013 and 2017. Tumour location, sex distribution, age and ASA score were

comparable during the study period. The yearly proportion of Stage IV disease and palliative surgery ranged from 9.60% to 11.12% and 4.70% to 11.11%,

Table 2 Patient characteristics in all patients divided into groups according to year of surgery.

	2013 (n = 625)	2014 (n = 653)	2015 (n = 576)	2016 (n = 660)	2017 (n = 640)	P-value
Tumour location						
Colon	424 (67.84)	462 (70.75)	395 (68.58)	462 (70.00)	443 (69.22)	0.815
Rectum	201 (32.16)	191 (29.25)	181 (31.42)	198 (30.00)	197 (30.78)	
Median age (years)	70	71	71	71	71	
Age category (years)						
<56	41 (6.56)	38 (5.82)	36 (6.25)	30 (4.55)	45 (7.03)	0.195
56–65	77 (12.32)	82 (12.56)	82 (14.24)	85 (12.88)	80 (12.50)	
66–75	210 (33.60)	214 (32.77)	153 (26.56)	200 (30.30)	198 (30.94)	
76–85	196 (31.36)	186 (28.48)	197 (34.20)	230 (34.85)	213 (33.28)	
>85	101 (16.6)	133 (20.37)	108 (18.75)	115 (17.42)	104 (16.25)	
Sex						
Male	317 (50.72)	337 (51.61)	300 (52.08)	350 (53.03)	334 (52.19)	0.947
Female	308 (49.28)	316 (48.39)	276 (47.92)	310 (46.97)	306 (47.81)	
ASA score						
ASA 1	93 (14.88)	90 (13.78)	78 (13.54)	76 (11.52)	82 (12.81)	0.195
ASA 2	315 (50.40)	310 (47.48)	277 (48.09)	311 (47.12)	316 (49.37)	
ASA 3–4	210 (33.60)	246 (37.67)	211 (36.63)	272 (41.21)	234 (36.56)	
ASA missing	7 (1.12)	7 (1.07)	10 (1.74)	1 (0.15)	8 (1.26)	
Elective/emergent surgery						
Elective	592 (94.72)	606 (92.8)	547 (94.97)	632 (95.76)	609 (95.16)	0.167
Emergent	33 (5.28)	47 (7.20)	29 (5.03)	28 (4.24)	31 (4.84)	
Tumour stage						
I–III	565 (90.40)	583 (89.28)	490 (85.22)	595 (90.15)	565 (88.98)	0.033
IV	60 (9.60)	70 (10.72)	85 (14.78)	65 (9.85)	70 (11.12)	
Unknown*	0	0	1	0	5	
Treatment						
Curative	562 (89.92)	581 (88.97)	512 (88.89)	629 (95.30)	587 (91.72)	<0.001
Palliative/unknown	63 (10.08)	72 (11.03)	64 (11.11)	31 (4.70)	53 (8.28)	
Assigned contact nurse?						
Yes	499 (79.84)	515 (78.87)	482 (83.68)	581 (88.03)	566 (88.44)	<0.001
No	82 (13.12)	88 (13.48)	42 (7.29)	41 (6.21)	43 (6.72)	
Don't know	37 (5.92)	46 (7.04)	41 (7.12)	36 (5.45)	27 (4.22)	
No answer	7 (1.12)	4 (0.61)	11 (1.91)	2 (0.30)	4 (0.62)	
Access to IWCP?						
Yes	246 (39.36)	283 (43.34)	271 (47.05)	436 (66.06)	448 (70.00)	<0.001
No	299 (47.84)	299 (45.79)	228 (39.58)	159 (24.09)	128 (20.00)	
Don't know	73 (11.68)	63 (9.65)	67 (11.63)	63 (9.55)	60 (9.38)	
No answer	7 (1.12)	8 (1.23)	10 (1.74)	2 (0.30)	4 (0.62)	
Median time from diagnosis to start of treatment (days)	41	40	37.5	34	34	<0.001
Time from diagnosis to start of treatment						
Short (median 19 days)	136 (21.76)	147 (22.51)	148 (25.69)	230 (34.85)	213 (33.28)	<0.001
Medium (median 35 days)	238 (30.08)	262 (40.12)	222 (38.54)	257 (38.94)	210 (32.81)	
Long (median 64 days)	251 (40.16)	243 (37.21)	206 (35.76)	173 (26.21)	216 (33.75)	
Unknown	0	1	0	0	1	

ASA, American Society of Anesthesiologists; IWCP, individual written care plan.

Numbers in parenthesis are column percentages.

respectively. Over the years, a higher proportion of patients were assigned a CN (79.84% in 2013 vs 88.44% in 2017) and the proportion of patients having access to an IWCP also increased (39.36% in 2013 vs 70.00% in 2017). The actual waiting times, calculated from the date of diagnosis to the start of treatment, were significantly shortened during the study period, from a median of 41 days in 2013 to 34 days in 2017.

Answers for the studied items of the PREM questionnaire are displayed in Table 3. Overall patient satisfaction increased during the study period from 49.92% to 59.22%. In 2016 and 2017, a higher proportion of the patients said that they had been given enough information about their disease (91.52% in 2013 vs 94.79% in 2017). A higher proportion of patients in 2016 and 2017 considered the waiting times to be acceptable (75.84% in 2013 vs 84.22% in 2017).

The results of the univariable and multivariable logistic regression analysis are presented in Table 4. The univariable analysis showed increasing patient satisfaction over time with a significant OR of 1.49 (95% CI 1.20–

1.87) for 2017 compared with 2013. Male sex and age category 66–75 years were associated with increased patient satisfaction and an ASA score of 3 or 4 was associated with decreased patient satisfaction compared with an ASA score of 1. A long waiting time (47–64 days) showed a significant impact on satisfaction ($P = 0.019$). The effect of access to a CN and an IWCP was significant, with OR 3.61 (95% CI 2.72–4.79) and OR 1.91 (95% CI 1.64–2.23), respectively. Stage IV disease, palliative surgery and minimally invasive technique were significantly related to patient satisfaction in univariable models and changed the effect of year of surgery on patient satisfaction by 1.6%, 3.2% and 4.3%, respectively. These covariates were not included in multivariable models as they did not change the point estimates for year of surgery by more than 10%.

The multivariable model, adjusted for age, sex, ASA score, CN, IWCP and waiting time, showed no significant effect for year of surgery on patient satisfaction. Access to a CN and an IWCP was independently associated with increased patient satisfaction (OR 3.03, 95%

Table 3 Responses to questions in the patient-reported experience measures questionnaire according to year of surgery.

	2013 (<i>n</i> = 625)	2014 (<i>n</i> = 653)	2015 (<i>n</i> = 576)	2016 (<i>n</i> = 660)	2017 (<i>n</i> = 640)	<i>P</i> -value
How did you experience the waiting times?						
Acceptable	474 (75.84)	499 (76.42)	456 (79.17)	546 (82.73)	539 (84.22)	<0.001
Somewhat long/far too long	143 (22.88)	151 (23.12)	115 (19.96)	113 (17.12)	94 (14.69)	
No answer	8 (1.28)	3 (0.46)	5 (0.87)	1 (0.15)	7 (1.09)	
Did you get enough information about your disease?						
Yes	561 (91.52)	578 (90.31)	527 (92.95)	608 (92.54)	601 (94.79)	0.039
No	52 (8.48)	62 (9.69)	40 (7.05)	49 (7.46)	33 (5.21)	
Not relevant/no answer	12 (1.92)	13 (1.99)	9 (1.56)	3 (0.45)	6 (0.94)	
Was the information given in a way that you could understand it?						
Yes	548 (87.68)	589 (90.20)	515 (89.41)	599 (90.76)	582 (90.94)	0.733
No	66 (9.34)	61 (9.34)	55 (9.55)	60 (9.09)	54 (8.44)	
Not relevant/no answer	11 (1.76)	3 (0.46)	6 (1.04)	1 (0.15)	4 (0.62)	
Did you have the possibility to participate in decisions about your care?						
Right amount	526 (84.16)	555 (84.99)	494 (85.76)	570 (86.36)	549 (85.78)	0.830
Too much/too little	99 (15.84)	98 (15.01)	82 (14.24)	90 (13.64)	91 (14.22)	
Was the caregiver available when you needed contact?						
Yes	572 (91.52)	576 (88.21)	521 (90.45)	605 (91.67)	590 (92.19)	0.305
No	35 (5.6)	48 (7.35)	31 (5.38)	35 (5.30)	31 (4.84)	
No answer	18 (2.88)	29 (4.44)	24 (4.17)	20 (3.03)	19 (2.97)	
Did you experience respectful treatment from the caregiver?						
Yes	600 (96.00)	636 (97.40)	558 (96.88)	648 (98.18)	634 (99.06)	0.084
No	15 (2.40)	11 (1.68)	10 (1.74)	10 (1.51)	3 (0.47)	
No answer	10 (1.60)	6 (0.92)	8 (1.38)	2 (0.31)	3 (0.47)	
Patient satisfaction (yes/no)						
Yes	312 (49.92)	315 (48.24)	316 (54.86)	378 (57.27)	379 (59.22)	<0.001
No	309 (49.44)	337 (51.61)	258 (44.79)	282 (42.73)	260 (40.62)	
Missing	4 (0.64)	1 (0.15)	2 (0.35)	0	1 (0.16)	

Numbers in parenthesis are column percentages.

Table 4 Odds ratio of being satisfied with all of the following: caregiver availability, information on disease and understanding of information, respect from caregiver.

	Univariable analysis			Multivariable analysis		
	Satisfied with everything			Satisfied with everything adjusted		
	OR	95% CI	<i>P</i> -value	OR	95% CI	<i>P</i> -value
Year						
2013	1.0 (ref.)	–	–	1.0 (ref.)	–	–
2014	0.89	0.71–1.11	0.332	0.92	0.73–1.16	0.469
2015	1.23	1.02–1.61	0.032	1.12	0.88–1.42	0.350
2016	1.24	1.00–1.55	0.051	1.03	0.81–1.30	0.814
2017	1.49	1.20–1.87	<0.001	1.14	0.90–1.44	0.290
Age category (years)						
<56	1.0 (ref.)	–	–	1.0 (ref.)	–	–
56–65	1.12	0.79–1.59	0.522	1.30	0.91–1.85	0.154
66–75	1.54	1.12–2.12	0.007	1.80	1.30–2.50	<0.001
76–85	1.27	0.93–1.75	0.125	1.71	1.22–2.38	0.002
>85	1.17	0.84–1.63	0.361	1.81	1.26–2.60	0.001
Sex						
Female	1.0 (ref.)	–	–	1.0 (ref.)	–	–
Male	1.24	1.08–1.43	0.002	1.30	1.12–1.51	0.001
ASA grade						
1	1.0 (ref.)	–	–	1.0 (ref.)	–	–
2	1.08	0.87–1.34	0.470	0.92	0.73–1.16	0.498
3–4	0.80	0.64–0.99	0.049	0.73	0.57–0.94	0.015
Access to contact nurse						
No	1.0 (ref.)	–	–	1.0 (ref.)	–	–
Yes	3.61	2.72–4.79	<0.001	3.03	2.28–4.02	<0.001
Don't know/no answer	1.65	1.10–2.49	0.016	1.59	1.08–2.36	0.023
Had IWCP						
No	1.0 (ref.)	–	–	1.0 (ref.)	–	–
Yes	1.91	1.64–2.23	<0.001	1.64	1.38–1.94	<0.001
Don't know/no answer	1.21	0.94–1.55	0.137	1.27	0.98–1.65	0.066
Waiting time (days)						
Short (0–27)	1.0 (ref.)	–	–	1.0 (ref.)	–	–
Medium (28–46)	1.01	0.85–1.21	0.887	0.93	0.77–1.12	0.419
Long (47–64)	0.80	0.67–0.96	0.019	0.72	0.60–0.88	0.001

Multivariable analysis adjusted for age, sex, American Society of Anesthesiologists (ASA) score, access to contact nurse, access to individual written care plan (IWCP), time to treatment.

CI 2.28–4.02, and OR 1.64, 95% CI 1.38–1.94, respectively). Patients with a longer waiting time were significantly less satisfied than patients with a shorter waiting time (OR 0.72, 95% CI 0.60–0.88, $P = 0.001$). Male sex, age over 65 years and ASA score remained factors associated with patient satisfaction.

Out of all 3154 responders, a total of 1574 (49.9%) answered 'yes' to having both a CN and an IWCP. To study the combined effect of a CN and an IWCP, a multivariable model, adjusted for age, sex, ASA score and waiting time, was made. This model was restricted to the 2627 patients who answered 'yes' or 'no' to the question on a CN and an IWCP. Compared with

patients without a CN and an IWCP, patient satisfaction did not increase with an IWCP alone (OR 0.99, 95% CI 0.52–1.90, $P = 0.985$). Access to a CN alone resulted in an OR of 2.54 (95% CI 1.80–3.60, $P < 0.001$) for patient satisfaction, and the OR for satisfaction was highest for patients with both a CN and an IWCP (OR 4.41, 95% CI 3.14–6.19, $P < 0.001$) (data not shown).

Discussion

This is a population-based study on patient-reported experience measures. Data on patient experiences are

scarce in the scientific literature although the patient experience is a cornerstone in medical healthcare and is targeted in the Swedish National Cancer Strategy [1] and the Swedish Patient Act [10] and patient-reported measures are also requested by patient advocacy groups. There are previous studies showing that a nurse navigator, comparable to the Swedish CN, can improve aspects of the experience for cancer patients [11,12]. It should be possible to improve patient experience with organizational adjustments to patient care. In the Stockholm-Gotland region, such projects of organizational improvement in the care of patients with colorectal cancer have been launched over the past years by implementing the introduction of a CN and an IWCP to all patients together with a SCP. This study shows that these projects have succeeded in their effort to increase the proportion of patients having a CN and an IWCP and the median waiting time from diagnosis to start of treatment has been shortened.

The multivariable analyses showed that a CN had the greatest impact on patient satisfaction. Many aspects of patient experience were superior in patients who had a CN compared with those who did not. Whether this is a result of the actual CN or a surrogate for a generally more elaborate care process cannot be proven in this study, but it seems that the CN is a crucial factor. Most patients who got an IWCP also had a CN, but the IWCP was also an independent factor improving patient satisfaction, indicating that thorough information on the disease is important.

Patient education has been shown to have positive effects on some aspects of patient experience [13–15]. The importance of the patient understanding the diagnosis, the objective for examinations and treatment and knowledge about possible effects of the disease and treatment and how to handle these effects cannot be over-emphasized. The way information is given to patients differs among caregivers, surgeons, oncologists, nurses and paramedical staff. The IWCP was an effort to supply caregivers with structured documentation to standardize and equalize the information that individuals receive about their disease, treatment and rehabilitation. The IWCP is meant to support the personal consultation with doctors, the CN and other healthcare staff. The current study shows that implementation of a regional IWCP has led to a higher proportion of patients getting an IWCP and also that having an IWCP correlates with improved patient satisfaction. Projects on digitizing the IWCP are now ongoing in Sweden, although the IWCP in the current study was in paper format [16].

The SCPs in cancer that were introduced are similar to the Danish cancer patient pathways implemented in 2007 that have shortened waiting times in Denmark

significantly in several cancer diagnoses [17]. In Sweden, shortened waiting times have been reported for some diagnoses [18,19]. The median waiting time from diagnosis to the start of treatment, as shown in this study, has been shortened from 41 to 34 days. However, shortened waiting times in colorectal cancer care are not the only potential benefit from such a programme. Implementation of a SCP in the Stockholm-Gotland region has established new team networks between different professionals and shortened pathways between evaluation and treatment of patients. Dedicated SCP coordinators were appointed to relieve CNs from logistical and administrative tasks. Thus, a SCP has the potential to improve the patient experience in addition to or regardless of shortened waiting times. In the current study, the SCP was launched during 2016 and was up and running in 2017. The satisfaction with waiting times increased over the years, indicating that the implementation of a SCP had a positive effect on patient experience. The actual waiting time from diagnosis to start of treatment was reduced by 1 week during the study period. The chance of being satisfied with waiting times improved over time but was correlated with access to a CN. After adjustment for a CN, the statistical impact of the actual waiting time on patient satisfaction decreased, but patients with a long waiting time were still significantly less satisfied. Whether this was caused by the waiting time per se or by more advanced disease, which led to more extensive pretherapeutic evaluation, cannot be proven by this study.

The patients in this study were diagnosed and evaluated radiologically in nine different hospitals and treated with colorectal surgery in six hospitals, radiotherapy was delivered in two hospitals and medical oncological treatment in four hospitals. The hospitals have different profiles with differences in case mix and proportion of emergent cases. A large proportion of the patients had various parts of their care pathway in different hospitals, and thus analyses on patient experience depending on treating hospital were not possible.

A strength of this study is that it is population-based with a high response rate. The study also focuses on patient experience instead of numbers from the healthcare apparatus; this is another strength of the study, since these specific organizational projects had the aim of improving the subjective patient experience.

A limitation of the study is that there may be a selection of patients responding to the questionnaires, thus giving an incomplete picture of the patient experience. The questions used in the questionnaires were collected from the Swedish National Cancer Questionnaire in an effort to use validated questions developed in an institution with vast knowledge about patient-reported

measures. However, when evaluating the answers the questions came out as rather blunt; the majority of patients were quite satisfied, and more detailed questionnaires, or another method, would be necessary to gain an in-depth understanding of what needs to be done to continue improving the patient experience. Also, the questionnaires were only distributed in Swedish, probably excluding non-Swedish speaking patients.

Patients who went through noncurative treatment were not excluded from this study, since the PREMs from these patients are of the same importance as patients treated with curative intent. The response rate in this group, however, was very low, which could be expected due to their medical condition, making the results difficult to interpret in this subgroup.

It can be questioned which improvement projects have actually had the greatest impact. This study indicates that a CN is of greatest importance, but all projects include multidisciplinary team efforts to improve many aspects of patient care, and thus it is not possible to point out exactly which variable had the greatest impact for any individual patient.

Conclusion

The introduction of CNs and IWCPs to all patients with colorectal cancer in the Stockholm-Gotland region has been successful as measured by a higher proportion of patients gaining access to these assets. The introduction of a SCP has led to shorter waiting times and a higher proportion of patients who consider the waiting times to be acceptable. In all, this has led to an improved patient experience in patients treated for colorectal cancer in the Stockholm-Gotland region.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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