



Patient-reported perceptions of care after the introduction of a new advanced cancer nursing role in Sweden



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ABSTRACT

Purpose: Extensive research results show quality improvements associated with advanced cancer nursing roles. Despite this, these roles are not implemented in many countries. The aim of this cross-sectional, population-based study was to compare patients' perception of care, before and after the introduction of a new advanced nursing role, the coordination contact nurse (CCN), in a region in Sweden.

Method: All patients (with gynaecological, haematological, Head & Neck, upper gastrointestinal cancers) diagnosed in the region the year prior and one-year post introducing the new CCN role were identified from the Swedish Cancer Register. Data were collected using the European Organization of Research and Treatment of Cancer [EORTC] Quality of Life Questionnaire (QLQ-C30 and QLQ-INFO25) and a study specific questionnaire.

Result: The results, based on baseline (n = 869) and follow-up data (n = 1003), show statistically significant patient-reported improvements after the introduction of the CCN role, regarding health-related patient information (EORTC QLQ-INFO25 global mean score increased from 41.23 to 44.16, p = 0.0006). We found statistically significant improvements related to availability of supportive care resources, e.g. increased reported access to contact nurse (from 53% to 66%, p ≤ 0.0001) and individual written care plans (from 40% to 54%, p < 0.0001). We also found some improvements related to patient involvement and care coordination, but also room for further developments.

Conclusion: The implementation of the new advanced cancer nursing role may have contributed to important improvements, but it has also identified areas in need of development. Further research with long-term evaluations of CCN roles in other contexts, are both needed and on-going.

1. Introduction

Advanced nursing roles, such as Clinical Nurse Specialists, (CNS), Nurse Practitioner (NP) and Advanced Nurse Practitioner (ANP) are clinical expert roles with academic degrees, master or higher (European Oncology Nursing Society, 2018). Health care delivered by nurses in these advanced roles have proven to impact important care quality factors such as patients' experiences (Newhouse et al., 2011), safety (Aiken et al., 2014), symptom-burden (Gerrish et al., 2013) and cancer care coordination (Gorin et al., 2017). By improving communication within and between the healthcare teams (McDonnell et al., 2015), advanced nursing care can also reduce readmissions (Bell et al., 2017). Previous research (Gerrish et al., 2013) also shows that advanced nursing roles can contribute to the improvement of other staff members' skills and competences. Advanced nursing roles can contribute to

improving clinical practice and patient-centeredness through education, developing guidelines and spanning organizational boundaries in order to progress the patient through the trajectory safely (Gerrish et al., 2013; Begley et al., 2014). Even if nurses in Sweden often perform tasks associated with these roles, they have not formally been established (Bergman et al., 2013; Kvarnstrom et al., 2017).

One goal described in Sweden's National Cancer plan (Swedish Government Official Reports, 2009) was that every cancer patient should be offered a contact nurse (CN), as their main point of contact through the cancer journey. The relatively new CN role was developed for cancer care. Early evaluations showed the CN function is only partly implemented (Bjuresäter and Larsson, 2017; Regional Cancer Center Stockholm-Gotland, 2013) and highlights issues related to fragmented care (Regional Cancer Center Stockholm-Gotland, 2013; Ullgren et al., 2017). Poor care coordination in relation to cancer care transitions,

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were reported by patients to be major areas of concern (Regional Cancer Center Stockholm-Gotland, 2013; Ullgren et al., 2017). A national CN role description was developed in 2011 (Swedish Association of Local Authorities and Regions, 2013), describing a similar function as the nurse navigators (Campbell et al., 2010; Jeyathevan et al., 2017). The CN is a clinical nursing role with in-depth knowledge in cancer care, supporting patients and their families during the cancer trajectory. Some CN may perform advanced tasks such as nurse-led clinics, independent case-management and are recognized as first point of contact for the patients.

As the implementation of the CN role proved not to reduce the fragmentation in cancer care enough (Regional Cancer Center Stockholm-Gotland, 2013), a new and advanced cancer nursing role was developed and implemented in the Stockholm Gotland region. The Coordination Contact Nurses (CCNs), work very closely with the cancer care team (and also patient representatives) but have a more overarching and leading role, compared with the CNs. The CCNs do not interact with patients daily. Their role is more to support the team to perform better in their interactions with patients and their loved ones. This means that the CCNs sometimes will be consulted by other team members, acting as role models in direct patient care, to guide and support cancer nurses or other professionals in the team. The role is aiming to close the gaps and addressing the barriers in the cancer trajectories and thereby improve coordination, person-centeredness to reduce the fragmentation. For example, the CCNs supported the cancer care teams in introducing a new model of handover, used in care transitions between different health care providers.

The CCN role was first introduced in February 2015 for patients with gynaecological, haematological, head and neck (H&N) and upper gastro-intestinal (GI) cancers. The project was extended in 2017 to include 16 different cancer pathways. In this study, we analyse and compare baseline (patients diagnosed in 2014 before the implementation of the CCN role) and follow-up data (patients diagnosed in 2016) a year after the implementation of the CCN role.

2. Aim

To compare patients' perception of received health-related information, access to supportive care resources, patient involvement and care coordination before and after introduction of a new advanced nursing role in cancer care.

3. Material and methods

3.1. Design

This cross-sectional study includes two cohorts of patients, comparing baseline and follow-up data evaluating introduction of the new CCN role in the Stockholm Gotland region, Sweden.

The evaluation was based on the role description for the new CCN function. The following areas were studied: A) perceived health-related information, B) access to supportive care strategies such as; CN, individual written care plan (IWCP), rehabilitation contacts, palliative care, C) patient involvement and D) coordination of care.

3.2. Eligibility criteria and sampling

All patients, ≥ 18 years old, diagnosed in 2014 and 2016 respectively with gynaecological, haematological, H&N and GI cancer in the Stockholm Gotland area were invited to participate.

Data from the Swedish Cancer Register were cross-referenced with the National Population Register to identify and select the patients. This cross-sectional sampling method was used to minimize the risk of sending the questionnaires to deceased patients. The Swedish Cancer Register includes 99% of all cancer cases and are clinically reported and morphologically verified (Barlow et al., 2009). The patients responded

during the follow-up period after their cancer treatment. These groups of patients were selected as they reflect the first five cancer pathways where the CCN role was introduced in 2015.

3.3. Questionnaires

We collected data using the following questionnaires; the validated Swedish versions of the European Organization of Research and Treatment of Cancer [EORTC] Quality of Life Questionnaire, QLQ-C30 and QLQ-INFO25 and also a study specific questionnaire (designed by the research team). To assess and test the study specific questionnaire for face validity, we tested and discussed the questionnaire with six cancer patients, with a variety of cancer diagnosis and disease stages, prior to data collection. These patients commented on the relevance and their understanding of the study-specific questions. Some minor issues were reported, and changes were made accordingly.

3.4. Data collection

Data were collected in April-May 2015 (baseline) and April-May 2017 (follow-up), ensuring that the patients being in the follow-up phase, after cancer treatment.

The questionnaires were sent out via regular post, with a cover letter explaining the purpose of the research and how patient confidentiality was ensured. The letter explained that a completed and returned questionnaire was considered as consent to participate.

A pre-stamped envelope was included for the completed questionnaires. Three weeks later a written reminder was sent to patients that had not responded. The questionnaires could be completed on-line via a secure internet link or on paper. The study was approved by the Regional Ethical Review Board, Stockholm (Dnr, 2016/5:4).

3.4.1. Health-related information

The patients' perception of received information regarding treatment and care was measured by EORTC QLQ-INFO25 (Arraras et al., 2010). This instrument has been used extensively and consists of the following 4 multi-item scales; information about the disease (4 items), medical tests (3 items), information about treatment (6 items), other services (4 items) and 8 single item scales; care settings, self-help, written information, information on CD/tape, wish to receive more/less information and overall helpfulness of information. Out of the 25 items, 21 are completed by a 4-point Likert scale and 4 items require a yes/no response (Table 2).

3.4.2. Access to supportive care resources

To measure access to supportive care resources, we used the study specific questionnaire, consisting of the following 57 items. General questions (8 items), investigation and cancer diagnosis (11 items), information exchange and patient participation (20 items), palliative care and care transitions (18 items). This instrument includes 5 point Likert scales ("very bad", "bad", "neither good or bad", "good" and "very good"), 4 point Likert scales ("not at all", "a little", "quite a lot" and "a lot") and 3 point Likert scales ("yes", "no", "don't know") and demographic questions (e.g. age, educational status and type of treatment). In this study, we evaluate access to supportive care by analysing 7 items (Table 3) relevant for this purpose; access to CN (1 item), and/or IWCP (1 item), availability to; CN when needed, health care providers outside office hours, family support, rehabilitation contacts and palliative home care (5 items).

3.4.3. Patients involvement

To evaluate the patient's experiences of involvement in their own care, we used the following items in the study specific questionnaire; possibility to ask questions in dialogue with health care providers, being comfortable to provide comments (2 items). We also studied the patients experiences on the possibility to influence health-related

Table 1
Characteristics for responding patients.

Age, mean (min-max)	baseline	follow-up	Differences between baseline and follow-up
	n = (%)	n = (%)	
	68 (23–99)	67 (19–98)	0.0431
Age			
≤ 50	71 (8)	127 (13)	
51–65	200 (23)	238 (24)	
≥ 65	598 (69)	638 (63)	
Cancer site			
Upper GI	170 (20)	248 (25)	
Haematology	241 (28)	220 (22)	
Gynaecology	256 (29)	342 (34)	
Head & Neck	202 (23)	193 (19)	
Sex			0.386
female	500 (58)	598 (60)	
male	369 (42)	405 (40)	
Living situation			0.1787
living alone	247 (32)	316 (35)	
cohabiting	534 (68)	591 (65)	
Birth place			0.0284
Sweden	652 (83)	722 (79)	
abroad	133 (17)	195 (21)	
Occupational status			0.0061
retired	565 (72)	598 (66)	
working	135 (17)	212 (23)	
other ^a	82 (11)	98 (11)	
Education			0.0097
low	514 (66)	540 (60)	
high ^b	262 (34)	360 (40)	
Type of treatment			0.405
single modality	438 (58)	538 (60)	
multi-modality	315 (42)	354 (40)	
Palliative care referral	137 (19)	182 (21)	0.2346
Rehabilitation contacts ^c	62 (9)	94 (11)	0.1079
Global Health ^d	64.37	65.81	0.2116
Total responders	869 (100)	1003 (100)	

^a Sick leave, parental leave or student.

^b University or equivalent.

^c Multichoice question.

^d European Organization of Research and Treatment of Cancer [EORTCs] Quality of Life Questionnaire, QLQ-C30.

decisions (3 items) (Table 4).

3.4.4. Coordination of care

To evaluate the patients' experience of coordination, we focused on care transitions. The purpose was to try to capture the issues around fragmented care, reported in previous evaluations (Regional Cancer Center Stockholm-Gotland, 2013; Ullgren et al., 2017). We used the items described below from the study specific questionnaire. Three items were related to the transfer of information from one health care provider to another. In addition, three items measured the patients' perception of involvement and quality in care transitions (Table 4).

3.5. Statistical methods

Descriptive statistics (frequency and percentage) were used to describe the patient characteristics age, sex, living situation, country of

birth, occupational status, education level, type of cancer treatment and palliative care (yes/no). Differences regarding patient characteristics between baseline and follow-up were calculated using Pearson's Chi-square test. When comparing the study specific questions, the Likert scale format was respectively dichotomized into two levels; 'quite a lot'/'a lot' and 'good'/'very good', and also 'yes' and 'no'. Analyses were performed with Pearson's Chi-square test with significance level $\alpha = 0.05$.

Scoring of the questionnaires were performed according to the EORTC QLQ-C30 scoring manual (Fayers et al., 2001). Item scores of EORTC QLQ-C30 and EORTC QLQ-INFO25 were transformed to a 0–100 scale. In EORTC QLQ-INFO25 a higher score represents higher levels of information received, higher functioning and global quality of life, as well as higher information wishes and higher satisfaction. However, higher scores in EORTC QLQ-C30 represents a heavier symptom burden and higher degree of problems. In addition, a 'global score' in EORTC QLQ-INFO 25 was calculated by averaging all the 12 scales, indicating an overall perception of information (Arraras et al., 2010). Both questionnaires were presented in means and standard deviations. The internal consistency reliability of the questionnaire scales, consisting of two or more items, were evaluated with Cronbach's alpha. A Cronbach's alpha of 0.7 was set as an acceptable level for reliability. Student's t-test was used, with significance level $\alpha = 0.05$, to determine any differences between the two cohorts of baseline and follow-up.

All statistical analyses were performed using the statistical software R version 3.5.1.

4. Results

4.1. Patient characteristics

The total sample consists of baseline data from 869 (response rate 68%) and follow-up data from 1003 (response rate 60%) patients with gynaecological (n = 598, 32%), haematological (n = 461, 25%), upper GI (n = 418, 22%) and H&N cancer (n = 395, 21%). Both at baseline and follow-up, the majority of the responding patients were women (n = 1 098, 59%), co-habiting (n = 1 125, 60%), born in Sweden (n = 1 374, 73%), had non-university education level (n = 1 054, 56%) and were retired (n = 1 163, 62%). Most patients (baseline and follow-up) had undergone single modality cancer treatment (Table 1). When comparing the EORTC QLQ C-30 Global health status and functional scales, we found no statistically significant differences between baseline and follow-up (Table 1).

4.1.1. Health-related information

For the total sample, the baseline EORTC QLQ- INFO25 global mean score were 41.23, and at follow-up, 44.16 (p = 0.0006). We also found the following statistically significant improvements at follow-up (compared with baseline) regarding the EORTC QLQ- INFO25 items; 'other services' (p ≤ 0.0001), 'different places of care' (p = 0.0409) 'things to do to help yourself' (p ≤ 0.0001), written information (p ≤ 0.0001) and 'overall the information has been helpful' (p = 0.0299), Table 2. However, when looking at the patient group separately, haematological patients did not report any statistically significant differences between baseline and follow-up.

4.1.2. Access to supportive care resources

In the total sample, the proportion of patients reported access to CN had significantly improved between baseline (53%) and follow-up (66%), p ≤ 0.0001. When looking at subgroups, we found statistically significant improvements for all patient groups except for patients with H&N cancer (Table 3).

Both at baseline and follow-up, the patients scored the possibility to access CN highly but only 56% stated to have information about 'how to get in contact with the health care team during non-office hours' at baseline. However, the proportion of patients reported to have this

Table 2
Patient reported perceived Information needs European Organization of Research and Treatment of Cancer [EORTCs] Quality of Life Questionnaire, QLQ-C30 and QLQ-INFO25 comparison baseline and follow-up.

Total	baseline			Follow-up			p-value	95% CI lower/upper
	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs		
Information about the disease	54.92	24.63	0.78	55.66	24.12	0.78	0.5467	[-3.15/1.67]
Information about the medical tests	66.71	26.84	0.88	67.61	26.38	0.88	0.5056	[-3.57/1.76]
Information about treatments	50.97	25.41	0.86	53.51	25.21	0.86	0.0510	[-5.10/0.01]
Information about other services	29.87	27.14	0.78	35.42	28.81	0.78	< 0.0001	[-8.33/-2.78]
Information about different places of care	28.63	34.67		32.33	34.89		0.0409	[-7.25/-0.15]
Information about things you can do to help yourself	37.77	34.91		44.99	35.16		< 0.0001	[-10.78/-3.65]
Written information	51.46	50.01		63.03	48.3		< 0.0001	[-16.48/-6.66]
Information on CD tape/video	0.68	8.25		0.84	9.14		0.7208	[-1.02/0.71]
Satisfaction with the information received	66.35	29.79		67.78	29.04		0.3365	[-4.36/1.49]
Wish to receive more information	29.89	45.81		30.67	46.14		0.7421	[-5.42/3.86]
Wish you have received less information	1.26	11.17		2.2	14.69		0.1558	[-2.24/0.36]
Overall the information has been helpful	65.93	27.45		68.95	27.18		0.0299	[-5.74/-0.29]
Global Score	41.23	14.99	0.92	44.16	15.28	0.92	0.0006	[-4.5/-1.27]
Upper GI	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs	p-value	95% CI lower/upper
Information about the disease	54.28	24.97	0.79	54.55	23.56	0.73	0.9173	[-5.45/4.90]
Information about the medical tests	66.31	26.0	0.89	68.59	25.44	0.88	0.4208	[-7.85/3.29]
Information about treatments	49.66	23.43	0.86	54.76	23.32	0.83	0.0469	[-10.13/-0.07]
Information about other services	30.37	26.96	0.77	33.08	27.09	0.79	0.3520	[-8.42/3.01]
Information about different places of care	34.52	36.6		33.67	33.42		0.8292	[-6.83/8.52]
Information about things you can do to help yourself	32.63	34.26		42.18	34.94		0.0127	[-17.04/-2.06]
Written information	37.67	48.62		56.65	49.68		0.0004	[-29.45/-8.50]
Information on CD tape/video	1.34	11.55		1.97	13.93		0.6446	[-3.30/2.05]
Satisfaction with the information received	61.26	32.31		64.67	29.44		0.3137	[-10.05/3.24]
Wish to receive more information	37.06	48.47		35.9	48.09		0.8267	[-9.30/11.63]
Wish you have received less information	0.7	8.36		2.56	15.85		0.1628	[-4.49/0.76]
Overall the information has been helpful	61.9	29.45		65.83	26.82		0.2034	[-9.99/2.14]
Global Score	39.5	15.39	0.92	43.54	14.23	0.92	0.0243	[-7.54/ -0.53]
Haematology	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs	p-value	95% CI lower/upper
Information about the disease	54.26	24.17	0.79	54.34	24.22	0.79	0.974	[-4.95/4.79]
Information about the medical tests	69.32	25.78	0.89	68.15	26.55	0.9	0.6677	[-4.17/6.51]
Information about treatments	50.41	25.43	0.86	51.45	27.09	0.89	0.711	[-6.53/4.46]
Information about other services	27.01	26.16	0.77	31.62	27.93	0.79	0.1005	[-10.12/0.90]
Information about different places of care	27.81	33.85		29.92	33.96		0.5595	[-9.22/5.00]
Information about things you can do to help yourself	37.19	35.59		39.72	34.5		0.4966	[-9.83/4.78]
Written information	57.0	49.63		59.06	49.32		0.6889	[-12.20/8.07]
Information on CD tape/video	0.5	7.04		0.57	7.58		0.9164	[-1.57/1.41]
Satisfaction with the information received	67.32	28.91		66.85	29.41		0.876	[-5.43/6.37]
Wish to receive more information	29.95	45.92		33.53	47.35		0.4644	[-13.19/6.03]
Wish you have received less information	1.53	12.31		2.84	16.66		0.3934	[-4.33/1.71]
Overall the information has been helpful	65.5	26.6		66.67	27.3		0.6768	[-6.67/4.33]
Global Score	41.91	26.6	0.94	42.77	15.61	0.94	0.628	[-4.32/2.61]
Gynaecology	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs	p-value	95% CI lower/upper
Information about the disease	54.05	24.27	0.77	56.02	23.99	0.75	0.3565	[-6.17/2.22]
Information about the medical tests	64.9	27.31	0.88	67.87	26.18	0.86	0.2163	[-7.69/1.74]
Information about treatments	51.34	27.38	0.89	54.63	25.87	0.87	0.1773	[-8.06/1.49]
Information about other services	29.04	27.12	0.79	37.68	29.06	0.78	0.0006	[-13.53/-3.75]
Information about different places of care	23.54	32.51		30.38	35.39		0.0266	[-12.88/-0.80]
Information about things you can do to help yourself	41.16	36.07		47.64	35.52		0.0471	[-12.87/-0.08]
Written information	54.88	49.88		69.57	46.09		0.0007	[-23.17/-6.19]
Information on CD tape/video	0.91	9.53		0.67	8.18		0.7622	[-1.33/1.81]
Satisfaction with the information received	66.2	28.98		70.33	27.89		0.1061	[-9.15/0.88]
Wish to receive more information	29.38	45.66		27.59	44.77		0.6611	[-6.2/9.85]
Wish you have received less information	0.93	9.62		2.43	15.43		0.1815	[-3.7/0.7]
Overall the information has been helpful	68.04	26.06		71.79	27.23		0.1134	[-8.4/0.9]
Global Score	41.28	15.31	0.92	44.9	15.01	0.92	0.0159	[-6.57/-0.68]
Head-neck	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs	p-value	95% CI lower/upper
Information about the disease	57.52	25.41	0.79	57.82	24.97	0.80	0.9148	[-5.81/5.21]
Information about the medical tests	66.28	28.21	0.87	65.24	27.82	0.88	0.744	[-5.20/7.27]
Information about treatments	52.31	24.52	0.83	52.07	24.25	0.87	0.9307	[-5.15/5.63]
Information about other services	34.1	28.23	0.80	38.44	30.93	0.84	0.1908	[-10.85/2.17]
Information about different places of care	31.32	35.98		36.75	36.55		0.1919	[-13.61/2.74]
Information about things you can do to help yourself	38.56	32.7		49.36	34.8		0.0053	[-18.35/-3.24]
Written information	52.5	50.09		63.12	48.4		0.0546	[-21.46/0.21]
Information on CD tape/video	0	0		0	0		-	-
Satisfaction with the information received	69.98	29.16		67.91	30.02		0.5306	[-4.42/8.56]
Wish to receive more information	23.87	42.77		26.75	44.41		0.5599	[-12.59/6.83]
Wish you have received less information	1.89	13.65		0.63	7.96		0.3183	[-1.22/3.72]

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Table 2 (continued)

Total	baseline			Follow-up			p-value	95% CI lower/upper
	Mean	StdDev	Cronbachs	Mean	StdDev	Cronbachs		
Overall the information has been helpful	67.29	28.25		70.0	27.01		0.38	[-8.78/3.36]
Global Score	41.9	14.6	0.92	45.08	16.64	0.95	0.0938	[-6.90/0.54]

Table 3

Patients reported access to supportive care resources.

Patient reported access to	Baseline n (%)	follow-up n (%)	p-value
CN, total	393 (53)	580 (66)	< 0.0001
CN, gynaecology	140 (61)	221 (70)	0.0306
CN, haematology	75 (37)	110 (58)	< 0.0001
CN, H&N	91 (56)	109 (65)	0.106
CN, Upper GI	87 (55)	140 (66)	0.0494
Patient reported access to			
IWCP, total	312 (40)	483 (54)	< 0.0001
IWCP, gynaecology	96 (41)	176 (55)	0.001
IWCP, haematology	74 (35)	85 (44)	0.0713
IWCP, H&N	91 (53)	103 (60)	0.192
IWCP, Upper GI	51 (31)	119 (56)	< 0.0001
How do you experience the access to CN when you needed one? ^a	478 (93)	628 (93)	0.4602
Did you get information about how to contact the health care provider outside office time? ^b	416 (56)	524 (61)	0.0303
Did you get the support you wanted in your parental role? ^b	52 (25)	67 (24)	0.8147
Do you know why you had a referral to palliative care? ^b	113 (74)	152 (75)	0.861

^a 'Very good' and 'good'.^b 'yes'.

information had improved statistically significantly at follow-up (61%, $p = 0.0303$), Table 3.

Overall, the proportion of patients reported access to IWCP (Table 3) had also statistically significantly improved between baseline and follow-up. However, differences were found between the subgroups. Both patients with gynaecological and GI cancer reported statistically significant improvements. The latter group increased most, from 31% to 56% ($p = 0.0001$). For patients with haematological and

Table 4

Patient perception of involvement in and coordination of care.

	Baseline 'quite a lot' and 'a lot' n (%)	Follow-up 'quite a lot' and 'a lot' n (%)	p-value
C) Patients involvement in care			
Did you have the possibility to ask questions regarding your care and treatment if there was something you didn't understand?	608 (82)	733 (83)	0.6638
Did you feel comfortable raising your opinions regarding your care?	482 (68)	611 (71)	0.1379
Did you have possibility to influence decisions regarding your treatment?	213 (29)	294 (34)	0.042
Did you wish to have more influence regarding decision-making related to your treatment?	83 (11)	89 (10)	0.5474
Did the staff take into consideration your preferences when planning the care and health care visits?	484 (68)	586 (70)	0.4641
D) Coordination of care			
Did the health care providers transfer information from acute cancer care and palliative care without the need for you to be responsible?	85 (57)	141 (71)	0.011
Did the health care providers transfer information from palliative care and acute cancer care without the need for you to be responsible?	71 (54)	118 (62)	0.175
Did the health care providers pass on information between the different care units involved in your care, without you needing to be responsible?	418 (65)	520 (67)	0.4441
Did you understand why care transitions were needed? Did the staff explain to you why the care transitions were needed?	268 (61)	357 (63)	0.6354
Did you experience that you were informed and involved in planning of your care transitions?	247 (55)	275 (47)	0.009
In your opinion, were there areas related to your care transitions that needed to be improved?	345 (78)	403 (73)	0.083

H&N cancer, no statistically significant differences were found.

4.1.3. Patient involvement in care

Overall, the patients scored fairly high (proportion of positive responses) on involvement (possibility to ask questions, provide comments in clinical situations and the staff taking preferences in consideration when planning care), both at baseline and follow-up. Only about a third of the patients reported having the possibility to influence decisions regarding their treatment, however we found an improvement from 29% at baseline to 34% at follow-up ($p = 0.042$) Table 4.

4.1.4. Coordination of care

Among the six items related to patients' experience of coordination in care transitions, we found statistically significant differences regarding two of the items (study specific questionnaire) between baseline and follow-up. While the reported involvement in care transitions declined (from 55% at baseline to 47% at follow-up, $p = 0.0096$), the patients' view of how the health care providers transferred information between acute care and palliative care improved from 57% at baseline to 71% at follow-up ($p = 0.011$) Table 4.

5. Discussion

In this large population-based study, we analysed patients' perceptions of aspects of cancer care, before and after the introduction of a new advanced nursing role. At follow-up, we found improvements but also room for further developments, in all of the four aspects of care (discussed below, under separate subheadings) that constitutes the basis of the CCN role description. The improvements we found between baseline and follow-up may be explained by other factors than the introduction of one single CCN function in each of the four cancer patient pathways. However, we are not aware of any general health care changes during the time of the study, that could explain the improvements we found. The improvements reported by the patients in the

study, are highly relevant to the CCNs work priorities (supporting the clinical cancer care team in implementing improvements in direct patient care) during their first year of practice. All CCNs followed the same role description and were offered the same professional support (e.g. supervision, counselling, education). The CCNs were all experienced, specialised and master-prepared cancer nurses. However, other factors that might have impacted their role performance, such as leadership skills, were not evaluated in this study. Nurses adopting a leading role may face challenges being accepted by the team, and also in finding time to undertake the role and being prepared to engage with strategic developments (Anderson, 2018). The CCNs have all reported facing these challenges (personal communication). Factors contributing to the improvements we found could be the CCNs close collaboration with both the cancer care teams and patient representatives, acting as both clinical role models and leaders, thereby being visible in practice when facilitating change. These factors have been previously reported as important factors for how nurses in advanced role can improve clinical outcomes and cost-effectiveness (Anderson, 2018). The extensive support available for the CCNs, such as professional counselling (individual and group), mentorship and education, could also have contributed to their personal development and establishment of this new role. In a literature review (McMullen, 2013), the authors found that advanced oncology nursing navigators, with similar disease-specific knowledge and overarching role as the CCNs, contributed to both the cancer care teams and the patients by improving communication, patient-centeredness and effectiveness in the cancer pathways. Fillion and co-authors (Fillion et al., 2012) also point out the importance of professional cancer navigators and their key position in improving patient empowerment and continuity of care.

5.1. Health-related information

After the introduction of the CCN role, the overall perceived information improved in six of the 13 EORTC QLQ INFO-25 scales. These six items evaluate several aspects of cancer and health-related information, highly relevant to the CCN role (self-care, written information, information about different health care services). Previous research has shown that these areas of information are important factors, facilitating active involvement among patients after cancer treatment (Campbell et al., 2010; Kullberg et al., 2015).

One of the initial tasks for the CCNs, when the project started in 2015, were to further develop and improve health-related information, tailored for the patient group within their responsibility. Each CCN accompanied approximately 10 patients at various care visits throughout the diagnostic and treatment pathway, in order to view the health care system more from the patients' point of view. The gained experience was used by the CCNs, together with a previous project evaluation (Regional Cancer Center Stockholm-Gotland, 2013) in their further development of different sources of health-related information. This may have contributed to more useful and relevant patient information resources, explaining the improvements we found. The CCNs not only developed written information, selfcare advice and IWCPs, they also supported the cancer care team in other efforts, aiming to improve clinical information exchange (e.g. during telephone consultations and multi-professional tumour boards). Previous research (Peckham and Mott-Coles, 2018) have shown that oncology nurse navigators strongly contributed to improved quality of care at inter-professional lung cancer tumour boards.

For the remaining EORTC QLQ INFO-25 scales, we found no relevant improvements, after introduction of the CCN role. Among these were items related to medical tests, disease and treatment. Generally, these areas of information are often provided by physicians, and are not always the focus for nurses. The patients in our study reported fairly moderate at baseline (mean score 51) and only slightly improved at follow-up. These results are in line with previous research from our region (Bergenmar et al., 2014). However, to better meet the patients'

needs, the CCNs could put more effort into improving the disease and treatment specific information.

We also found some interesting differences between the subgroups regarding health-related information. Among patients with haematological malignancies, we found no improvements for any of the EORTC QLQ INFO-25 scales, between baseline and follow-up. This probably reflect some of the challenges for the haematological services that occurred during the study period (high turnover rates among both CNs and CCNs, reorganisations and new management) which resulted in delays in implementing reviewed patient information resources.

5.2. Access to supportive care resources

Among the most important results from our study were that access to both CNs and IWCPs had improved significantly after the implementation of the CCN function. Implementation of new supportive care strategies, from introduction to fully implemented routines, has been shown to be complex and time-consuming. It is also known that implementation of care strategies needs to be supported on a long-term basis to succeed (Svanstrom et al., 2016) and if the goal is communicated and anchored more clearly, a sustainable change will be more likely. The improvements we found are therefore highly encouraging. The CCNs have put great efforts into assisting different cancer services in the region, to better implement the CN role, e.g. performing more in line with the role description (prioritising and increasing involvement level in direct patient contacts, increasing telephone availability and having an active role at multi-professional tumour boards).

Previous research from our group have shown benefits for patients with access to IWCPs (Westman et al., 2018). The IWCPs include written information about diagnosis, self-care advice related to treatment and side-effects and should be introduced at time for diagnose and updated accordingly.

As for health-related information (discussed above), we found no statistically significant increase between baseline and follow-up among patients with haematological malignancies. IWCPs were developed and implemented later for this group, in comparison with the other subgroups. Consequently, some patients in the follow-up sample were not offered an IWCP. Also, among patients with H&N cancer, we failed to find a statistically significant improvement in access to IWCP, between baseline and follow-up. However, the proportion of H&N patients reporting having access to IWCPs were higher compared with the other subgroups, both at baseline and follow-up. This could be explained by the fact that an earlier version of the IWCPs (e.g. care diaries) were well established for this group many years before we performed this study (Sharp et al., 2004).

5.3. Patient involvement in care

It is encouraging that the results from our study indicates that most patients, both at baseline and follow-up, seems to be confident to take active part and be involved in care decisions (asking questions, providing comments and/or impact treatment appointments). In a previous report, based on data from 11 European countries (Swedish Agency for Health and Care Services Analysis, 2017), 70% of Swedish patients (with different health problems) report being involved in care decisions. However, in the current study, only about a third of the patients at baseline reported that they had the possibility to influence treatment decisions. The proportion were significantly higher at follow-up (34%, $p = 0.042$), but still fairly moderate (Table 4). Interestingly, only a small proportion of patients (11 and 10% respectively), stated that they would have preferred more influence on treatment decisions. Similar results were found in another study among cancer patients in the Stockholm region (Kullberg et al., 2015). We interpret our results as most patients felt they could impact care planning and care decisions to quite a good extent, but less in terms of treatment decisions. However, our results regarding patient involvement should be interpreted with

caution as they are only based on a small number of study-specific questions. In a literature review, Tariman and co-authors (Tariman et al., 2012) conclude that the level of patient involvement in cancer treatment decisions are complex processes, influenced by both physician, patient and contextual factors. This is also concluded in a systematic review (Angel and Frederiksen, 2015) that nurses' attitudes and the patient-nurse relationships are fundamental for active patient participation.

5.4. Coordination of care

Improving coordination and reducing the fragmentation in care, are central parts of the CCN function. We chose to study care coordination in relation to cancer care transitions, since these were reported to be major areas of concern prior to the study (Regional Cancer Center Stockholm-Gotland, 2013; Ullgren et al., 2017). Our results showed statistically significant improvements in care coordination between baseline and follow-up for only one of the six study specific questions (Table 4). This perceived improvement relates to how patients experienced clinical information being transferred between acute and palliative care services. The CCNs supported the cancer care teams in adapting and systematically introducing a model for active handovers, based on the SBAR model (Muller et al., 2018), between acute and palliative care teams, which might contribute to this result. However, in the same handover model, the patients should be actively involved. Our results indicate that this part of the handover model has not been successful as the patients' scored their involvement in care transitions significantly lower at follow-up, compared to baseline. Only about half of the patients reported that they were informed about the planned care transitions, both at baseline and follow-up. Also, about 4 of 10 patients reported that they didn't understand why the care transitions were needed. Both these results indicate that the cancer care transitions are still poorly coordinated, leaving room for further improvements. More sophisticated interventions and measurements are needed to better address the issues around care coordination. In a recent systematic review and meta-analysis, (Gorin et al., 2017), the authors conclude that cancer care coordination interventions most often improve the patient-reported outcomes and also reduce the health care costs. The authors also highlight the often-undervalued impact of cancer care coordination, but describe the complexity and challenges involved when evaluating care coordination.

Our study includes a large sample, as well as relatively high response rates, both at baseline and at follow-up. We used population-based, patient-reported data and validated instruments, when available. These factors strengthen our results. There are also limitations, mainly due to the use of a non-validated study-specific questionnaire and lack of control groups (where no CCN function was introduced). The short time period between baseline and follow-up could also be seen a weakness, when aiming to evaluate a new advanced nursing role. To better evaluate complex areas of care (particularly coordination and patient involvement) more sophisticated research methods might have been more optimal.

6. Conclusion

The implementation of the new advanced cancer nursing role may have contributed to important improvements, but also identified areas in need of development. These improvements were mainly related to health-related information, availability to supportive care resources, and also to some extent, patient involvement and coordination of care. Further research, testing and evaluating the CCN role more long-term and in other contexts are both needed and on-going.

Conflicts of interest

No conflict of interest has been declared by the authors.

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