



Contact nurses' perceptions of their services, organizational prerequisites and moral stress: A cross-sectional study in Swedish cancer care

Downloaded from: <https://research.chalmers.se>, 2024-11-23 02:15 UTC

Citation for the original published paper (version of record):

Brynskog, E., Larsson, M., Smith, F. et al (2024). Contact nurses' perceptions of their services, organizational prerequisites and moral stress: A cross-sectional study in Swedish cancer care. *Nordic Journal of Nursing Research*, 44. <http://dx.doi.org/10.1177/20571585241290325>

N.B. When citing this work, cite the original published paper.

Contact nurses' perceptions of their services, organizational prerequisites and moral stress: A cross-sectional study in Swedish cancer care

Ellen Brynskog^{1,2} , Maria Larsson¹, Frida Smith^{2,3}, Linn Rosell^{4,5} and Kaisa Bjuresäter¹

Nordic Journal of Nursing Research

Volume 44 1–11

© The Author(s) 2024

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/20571585241290325

journals.sagepub.com/home/njn



Abstract

Contact nursing services have been implemented in Swedish cancer care to increase healthcare quality. Too little is known about the content and quality of these services and the organizational prerequisites provided to contact nurses. The aim of this study was to explore contact nurses' perceptions of their services and organizational prerequisites, as well as the connection between organizational prerequisites and moral stress. A cross-sectional survey was utilized consisting of a study-specific questionnaire and a select part of the Stress of Conscience Questionnaire. The study is reported in accordance with STROBE guidelines for cross-sectional studies. The results showed that contact nursing service content varied across settings and that 84% of contact nurses have what was categorized as satisfactory or moderately satisfactory self-reported organizational prerequisites. Perceived moral stress differed between contact nurses depending on organizational prerequisites. The variability of both services and prerequisites can be described as inequities in care and complicates evaluation and comparison.

Keywords

contact nurse in cancer care, healthcare organization, moral stress, nursing roles, quality of care

Accepted: 25 September 2024

Introduction

Cancer care is characterized by a high degree of complexity and, as diagnostics, treatments and rehabilitation evolve and become more efficient, people live longer with the consequences of cancer.¹ This places high demands on the healthcare professionals who are tasked with supporting people affected by cancer. Nurses constitute the largest profession within cancer care² and are key actors across the entire care trajectory and across cancer care settings.³ Europe's Beating Cancer Plan⁴ highlights the importance of providing healthcare professionals with sufficient support, so that they in turn can deliver high-quality care. To achieve high-quality care, it needs to be organized and resourced in a manner that allows healthcare professionals to optimize the utilization of their skills and knowledge. Donabedian's seminal conceptualization of *structural quality*⁵ is described as 'the conditions under which care is provided' and concerns matters such as formal competency, the suitability of facilities, tools for work, workplace culture, leadership and management, administrative systems, and organization of care.⁶ The term 'organizational prerequisites' is frequently used throughout this paper. It is to be understood as related to Donabedian's concept of structural quality, addressing meso and macro aspects of care provision that are out of the control of the individual nurse.

As cancer care develops, cancer nursing practices evolve and advance.³ A multitude of titles, certifications, and educational programmes for registered nurses (RN) in cancer care have been developed internationally. The titles *Oncology*

nurse navigators,⁷ *Cancer clinical nurse specialists*⁸ and *Advanced nurse practitioners*⁹ are all examples of this. Besides an increased emphasis on academic work (nurses in these positions hold at least a master's degree in nursing science) and healthcare improvement efforts, RNs in such positions work autonomously, monitoring and addressing patients' care needs, and they also collaborate within a multidisciplinary team to coordinate care. These nurse-led services have been shown to have positive effects for patients.¹⁰ In Sweden, the strife towards more advanced and autonomous nursing roles has taken the form of the development of the role contact nurse in cancer care (CNCC).

CNCC services have been successively implemented in Swedish cancer care since the launch of the Swedish National Cancer Strategy in 2009,¹¹ where it was suggested

¹Karlstad University, Department of Health Sciences, Karlstad, Sweden

²Regional Cancer Centre West, Gothenburg, Sweden

³Chalmers University of Technology, Department of Technology Management and Economics, Division of Innovation and R&D Management, Gothenburg, Sweden

⁴Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

⁵Regional Cancer Centre South, Lund, Sweden

Corresponding author:

Ellen Brynskog, Karlstad University, Department of Health Sciences, Universitetsgatan 2, 651 88 Karlstad, Sweden.

Email: ellen.brynskog@kau.se



that everyone diagnosed with cancer was to be offered the services of a CNCC. CNCCs serve patients across the entire clinical trajectory, supporting people with varying care trajectories, diagnoses, symptoms and side effects. CNCCs operate in different types of clinics within secondary care institutions, such as oncological, surgical, neurological, urological, gynaecological and haematological clinics. A national description of the scope of CNCC services has been developed, identifying lowest common denominator for CNCCs across these settings.¹² This description is indicative, but not statutory for operations to adhere to. According to this document, CNCC services include nursing care aimed at providing information and psychosocial support, assessing care needs, ensuring patient participation, establishing individual cancer care plans and facilitating active care transitions. Operating as a CNCC does not require any formal competence apart from being a registered nurse. However, Swedish universities offer non-mandatory advanced level courses to CNCCs.

The implementation of CNCC services in Swedish cancer care has been described as a success.¹³ Access to these services seems to be increasing¹⁴ and studies have reported access to be relatively high (76–88%).^{15–17} Sjövall et al.¹⁶ found that being assigned a CNCC was associated with higher patient satisfaction in a sample of patients with colorectal cancer. However, other studies have not been able to detect positive effects for patients with access to CNCC services.^{18,19} Larsson and Bjuresäter²⁰ identified a substantial variation regarding the scope of practices and the organizational prerequisites of CNCC services. Issues of delimitation and variability of services across settings have also been highlighted in the international literature regarding comparable cancer nursing services.^{8,21,22} This warrants a closer look into whether CNCC services are organized and resourced in a manner that allows CNCC to provide patients with high-quality care.

Furthermore, organizational prerequisites impact not only the quality of care for patients, but also the work environment of CNCCs. A substandard work environment can contribute to feelings of inadequacy, stress and nurse burnout,²³ and may lower retention rates.²⁴ There is a critical interplay between the quality of care provided to patients and the quality of the organizational prerequisites provided to healthcare professionals.²⁵

In sum, CNCC services can be described as a part of an ongoing international endeavour to improve cancer care by advancing nursing practices. To maintain and develop sustainable CNCC services, it is essential to assess them from different perspectives. It has been argued that healthcare improvement studies and projects mainly focus on process improvements (the micro or possibly meso perspective) and too little on the improvement of the healthcare system and organization (meso, macro or structural level).^{6,26} Therefore, the present study utilized the lens of organizational prerequisites, where the structural aspects of care provision take centre stage.

The aim of this study was to explore CNCCs' perceptions of their services, organizational prerequisites and moral stress.

Methods

This is a cross-sectional study. This study is annotated in accordance with The Strengthening the Reporting of Observational

Studies in Epidemiology (STROBE) statement guidelines for cross-sectional studies²⁷ and the guidelines devised by the International Committee of Medical Journal Editors on uniform requirements for manuscripts submitted to biomedical journals.²⁸

Context

The Swedish healthcare system is predominantly public and comprised of 21 self-governing regions. These regions cooperate around the utilization of resources through six so-called healthcare regions. Each healthcare region has a Regional Cancer Centre (RCC), a civil servant organization promoting the development of cancer care. Some types of cancer care are highly specialized and are only performed at a limited number of units regionally or nationally, which requires further cooperation across regional borders. The state governs health care through legislation and fiscal instruments.²⁹

Hospitals are referred to as university hospitals, county hospitals or smaller county hospitals. County hospitals have competence and resources to address care needs within most areas of healthcare, whereas smaller county hospitals have limited offerings and less emphasis on specialized care. University hospitals are responsible for more rare, complex and resource intensive care. They receive referrals from the smaller hospitals and cooperate closely with academia.³⁰ CNCCs can be employed at any of these (and to a small extent also by private clinics). Due to the multimodal treatment approach required for many cancers, it is common for patients to receive care at several different units within a hospital or at different hospitals, depending on the patients' place of residence.

Recruitment

Although no formal registry exists, the RCCs estimate that there are approximately 1500–1800 registered nurses in Sweden that work as CNCCs. The intention was to include all CNCCs operating during the study period. The inclusion criterion was therefore: being identified by one of the RCCs as working as a CNCC in Sweden.

Data collection

The study utilized a convenience sampling strategy. Data were collected between March and December 2020, with a disruption between April and September due to the COVID-19 pandemic. The RCCs distributed the survey link to their networks throughout their respective healthcare regions, either via cancer coordinators, managers or directly to CNCCs, depending on the preferences of the line managers. One region declined participation. In the invitation email containing link to the survey, respondents were given customary information to research participants, including information regarding the voluntary and confidential nature of participation. Respondents gave their informed consent by clicking the survey link. Two reminders were sent.

Instrument

The survey consisted of the study-specific Quality of care and Organizational Prerequisites for Contact Nurses (QOPCoN)

questionnaire and the Stress of Conscience Questionnaire (SCQ).³¹ The survey was programmed and hosted on a secure platform by the survey company IMPROVE-IT (<https://improveit.se>).

The QOPCoN questionnaire consists of 61 questions, divided into five domains: *Demographics* (two items), *Formal competence* (10 items), *Employment* (eight items), *Organization of care* (26 items) and *Work tasks and services* (15 items). The *Formal competence* domain charts respondents' work experience and formal competence (i.e., if they have a specialist nurse degree or have completed a higher education course for CNCCs). In *Employment*, CNCCs report formalities regarding their employment and what patient group(s) they serve. In the domain *Work tasks and services*, each item was answered from two perspectives, referred to as *perceived reality* (PR) and *subjective importance* (SI). PR means respondents position their view regarding a claim, for example, 'I provide psychosocial support to patients', on a four-point Likert scale ranging from 1 ('I do not agree at all') to 4 ('I fully agree'). Thereafter, they position their view regarding how important (SI) they perceive that item to be for patients on a four-point Likert scale ranging from 1 ('Of little or no importance') to 4 ('Of the greatest importance'). A 'Not applicable' option was available for both scales. The *Organization of care* domain assesses how CNCCs perceive issues regarding, for example, availability and continuity across the care trajectory, workload and suitability of facilities. Twelve of the items in this domain follow the same logic as *Work tasks and services*, in that they ask about both perceived reality and subjective importance, whereas the remaining items have answer options that range from 'Completely agree' to 'Do not agree at all', with an option to answer, 'Not applicable'. The questionnaire in its entirety is available as a supplementary file.

The SCQ is composed of nine two-part items (part A and part B). Part A assesses how often the respondent is exposed to a specified situation on a six-point Likert scale ranging from 0 (never) to 5 (every day). Part B assesses the extent to which these situations are perceived as leading to a troubled conscience on a 10-cm visual analogue scale, with the end-points representing 'No, it does not trouble my conscience at all' and 'Yes, it troubles my conscience greatly', respectively. SCQ scores are calculated by multiplying part A (range 0–5) and part B (transformed from the 10-cm visual analogue scale into five groups, thus also a range of 0–5). The possible range per survey item is therefore 0–25.

As it became clear that the COVID-19 pandemic would have a substantial impact on cancer care, an additional area of inquiry, concerning the effects of the COVID-19 pandemic on CNCC services (10 items), was added to the survey as data collection resumed in September 2020. Those data have been published elsewhere³² and are not a part of this study.

Statistical analysis

All statistical analyses were performed using the SPSS, version 28.³³

Subgroups were created according to healthcare region affiliation, what type of hospital CNCCs were employed at and the diagnosis group served. Only respondents serving exclusively one patient group were sorted into that category.

Respondents serving more than one patient group were sorted into a separate category.

Descriptive data analysis methods were applied (specifically frequency, proportions, means and range). The choice of method depended on the characteristics of the respective survey item. Some survey items were formulated as claims, with CNCCs indicating to what degree they agreed with the claims on a four-point Likert scale. The replies 'Completely agree' and 'Agree to a large extent' were grouped to indicate confirmation.

In the domain *Work tasks and services*, both PR and SI of specific aspects of CNCC services were addressed. An index was created where the two dimensions were combined. Percentage in agreement with the PR dimension is calculated by the number of respondents that answered 'Mostly agree' or 'Fully agree' divided by the total number of respondents. Similarly, the respondents that replied 'Of high importance' or 'Of the very highest importance' are categorized as 'high importance' in the SI dimension. All respondents are placed in one out of four categories, labelled 'Deficient quality', 'Low balance', 'High balance' and 'Superfluous quality'.

Survey items regarding availability across the care trajectory were formulated as how often CNCCs typically were in contact with patients at five time points (before start of treatment, during treatment, 0–3 months, 3–6 months and 6–12 months after completion of treatment). Responses were dichotomized as typically never having contact or typically having contact once or more during the five time points.

Exploratory factor analysis (EFA) is a method that can aid the understanding of data by identifying clusters and patterns of variables.³⁴ It was utilized as a tool to identify and compare self-reported organizational prerequisites for CNCCs. Ten survey items explicitly addressing organizational prerequisites were included in the EFA (see the Results section for more detail). The KMO value of 0.812 indicated a strong correlation. Additionally, the chi-squared result from Bartlett's test of sphericity was equivalent to 1017.40 with a significance level of <0.001. Thus, the data were deemed suitable for EFA. An eigenvalue ≥ 1 was set as cut-off to retain a factor. Item loading ≥ 0.45 was considered acceptable. The research team reached consensus regarding labels for the factors through discussion. The analysis yielded two factors, labelled *Prerequisites as provided* and *Prerequisites as perceived*.

Mean sum score for the items placed in factor one, (which was named *Prerequisites as provided*), was used as indicator of organizational prerequisites for CNCCs. The factor consists of the following items: *I have a written assignment, signed by my manager*; *I have allotted time for my assignment as CNCC*; *I have a room allotted to my work as a CNCC*; and *I work independently in a clinic where I assess symptoms and needs and provide care*. All items in factor 1 had answer options that ranged from 1 to 4. Cut-offs were set to indicate *Satisfactory* (top 25% of the response scale, mean value ≥ 3.36), *Moderately satisfactory* (middle 50% of the response scale, mean value 1.75–3.25) and *Unsatisfactory* (bottom 25% of the response scale, mean value ≤ 1.74) organizational prerequisites. See the Results section for further information.

To investigate CNCCs' perception of how moral stress (which is characterized by experiencing incompatible demands and lack of control³⁵) differed according to

Table 1. Overview of the items utilized from the Stress of Conscience Questionnaire (SCQ).

SCQ-item	Question
1	How often do you lack the time to provide the care patients need?
3	Do you ever have to deal with incompatible demands in your work?
7	Is your work in health care ever so demanding that you don't have the energy to devote yourself to your family as you would like?
8	Do you ever feel that you cannot live up to others' expectations of your work?

organizational prerequisites, a study-specific selection of SCQ items were analysed. The SCQ is commonly analysed as a uni-dimensional total score of all nine survey domains. However, Glasberg et al.³¹ suggested a two-domain solution, referred to as *Internal demands* and *External demands and restrictions*. This solution has also been described as theoretically meaningful by Åhlin et al.³⁶ *Internal demands* refer mainly to the internal voice of the caregiver, whereas *External demands and restrictions* focus on the surrounding structures. Given the question under investigation in this study, the survey items related to *External demands and restrictions* were used for analysis, with exception for of item 6 ('*Is your private life ever so demanding that you don't have the energy to devote yourself to your work as you would like?*') (Table 1). The mean score for the four selected survey items was calculated. Thereafter, analysis of variance was utilized to explore differences between groups of CNCCs with different organizational prerequisites, as defined by the factor analysis (see above). Tukey's post-hoc test was applied. $p < 0.05$ was considered statistically significant.

Ethical considerations

The study protocol was approved by the Swedish Ethical Review Authority (Reg. no 2019-04958) and the study was conducted in accordance with the Declaration of Helsinki.³⁷ All data have been stored and processed on secure platforms to safeguard confidentiality, only accessible to the research team.

Results

The survey was completed by 535 CNCCs (132 responded before and 403 responded after the COVID-19 amendment). Assuming the estimation of the number of CNCCs (1500–1800) was correct, this gives a response rate of between 29.7% and 35.7%. Characteristics of respondents are described in Table 2. Half of the respondents (49.7%) had completed a higher education course for CNCCs and less than half (41.7%) had a degree as specialist nurse (equivalent to 60 higher education credits at advanced level). Most respondents had a public employer (95.1%) and it was most common to be employed at a county hospital (44.5%).

Contact nursing services in cancer care

CNCCs' perceptions of the scope of their services are shown in Table 3. The content of CNCC services varied across subgroups and some tasks or aspects of CNCC services were less common than others. For example, only 37.6% agreed that they establish cancer rehabilitation plans, whereas 91.9%

Table 2. Demographical information about survey respondents (N = 535).

Respondent characteristics	n	(%)
Age (years)		
mean, (range)	48	(26–68)
Gender		
Female	524	97.9
Male	11	2.1
Employer		
Public employer	509	95.1
Education		
Higher education course for contact nurses	266	49.7
Specialist nurse degree	223	41.7
Healthcare region		
North	37	6.9
Mid	75	14
Stockholm-Gotland	115	21.5
West	93	17.4
Southeast	97	18.1
South	116	21.7
Hospital type affiliation		
University hospital	176	33.6
County hospital	238	44.5
Smaller county hospital	103	19.3
Other	7	1.3
Patient group(s) served*		
Breast	30	5.6
Central nervous system	13	2.4
Gynaecological	42	7.9
Head and neck	31	5.8
Haematological	23	4.3
Lower GI	53	9.9
Lung	28	5.2
Lymphoma	4	0.7
Melanoma	16	3.0
Neuroendocrinological	2	0.4
Upper GI	28	5.2
Urological	106	19.8
Sarcoma	8	1.5
Unspecified	4	0.7
More than one patient group	147	27.5

*Note, only CNCCs working exclusively with one of the stated patient groups are presented in the respective rows. Many work with several patient groups; see the second to last row.

agreed to the claim that they inform patients about coming steps in the care trajectory. Three quarters (75.5%) of respondents reported that they participate in multidisciplinary team meetings, but there were large variations across groups of CNCCs. Amongst CNCCs serving patients with breast cancer, 86.7% affirmed to participating in multidisciplinary team meetings, whereas the corresponding value for CNCCs serving patients with melanoma was 38%. Regarding the

Table 3. CNCCs' perceptions of their services; proportion (%) of respondents that agree with the claims fully or to a large extent.

	Hospital type*						Patient group served							
	Total (n = 535) %	CH (n = 238) %	SCH (n = 103) %	UH (n = 176) %	BC (n = 30) %	CNS (n = 13) %	GYN (n = 42) %	HN (n = 31) %	HAE (n = 23) %	LGI (n = 53) %	LUNG (n = 28) %	MEL (n = 16) %	UGI (n = 28) %	URO (n = 106) %
VWork task or service aspect†	91.9	89.9	91.2	91.4	100	76.9	95.2	93.5	91.3	98.1	92.8	75	96.4	88.7
	89.1	87.8	90.2	88.6	93.3	76.9	92.9	87.1	91.3	90.6	92.9	68.8	92.9	82.1
Inform	87.5	85.7	82.5	85.7	100	61.5	83.3	90.3	100	94.3	82.1	18.8	82.1	77.3
Psychosocial support, patients														
Assess symptoms/side effects														
Ensure participation	84.8	87.8	79.6	80.6	90	69.2	83.3	87.1	83.7	86.8	89.3	62.5	82.1	80.2
Evidence-based action	84.2	81.9	81.5	82.9	93.3	76.9	80.9	83.9	86.9	90.6	89.3	25	82.1	72.3
Available	75.6	77.7	72.8	72.1	76.7	38.5	88.1	96.8	73.9	75.5	92.9	81.3	89.3	60.4
Multi-disciplinary meetings	75.5	68.9	62.1	75.5	86.7	85	69	58	47.8	83.3	64.3	38	78.6	75.5
Psychosocial support, s/o	71.5	68.9	72.8	71.5	66.7	76.9	66.7	58	73.9	75.5	75	50	82.1	67.9
Monitor lead times	70.8	67.2	63.1	61.3	76.7	53.4	61.9	54.8	43.5	81.1	71.4	62.5	92.9	52.8
Individual cancer care plan	67.1	68.9	60.1	60.2	86.7	76.9	61.9	83.9	56.5	64.2	71.4	43.8	46.4	60.4
Active care transitions	66.1	63.8	67.9	63	66.7	61.5	64.3	74.2	56.5	60.4	57.1	56.3	71.4	49
Cancer rehabilitation plan	37.6	40.7	31	24.4	60	38	33.3	58	43.5	30.2	28.6	6.3	21.4	19.8

*Abbreviations: CH = county hospital; SCH = smaller county hospital; UH = university hospital; BC = breast cancer; CNS = central nervous system tumours; GYN = gynaecological cancers; HN = head and neck cancers; HAE = haematological cancers; LGI = lower gastrointestinal cancers; LUNG = lung cancer; MEL = melanoma; UGI = upper gastrointestinal cancers; URO = urological cancers.

†The tasks have been abbreviated as follows: I inform about coming steps in the care trajectory – **Inform**. I provide psychosocial support to patients – **Psychosocial support, patients**. I assess patients' symptoms and side-effects related to treatment – **Assess symptoms/side-effects**. I ensure patients' participation in and influence on their care – **Ensure participation**. I initiate and execute evidence-based actions based on assessed symptoms, problems and needs – **Evidence-based actions**. I am available to a high degree to the patients – **Available**. I participate in multi-disciplinary team meetings – **Multi-disciplinary meetings**. I provide psychosocial support to significant others – **Psychosocial support, s/o**. I monitor lead times in coordination with coordinators of the standardised cancer care pathways – **Monitor lead times**. I establish and follow up an individual cancer care plan – **Individual cancer care plan**. I facilitate active care transitions to another contact nurse or unit when appropriate – **Active care transitions**. I establish a cancer rehabilitation plan in cooperation with the patient – **Cancer rehabilitation plan**. Participants replying 'Not applicable' were excluded from analysis.

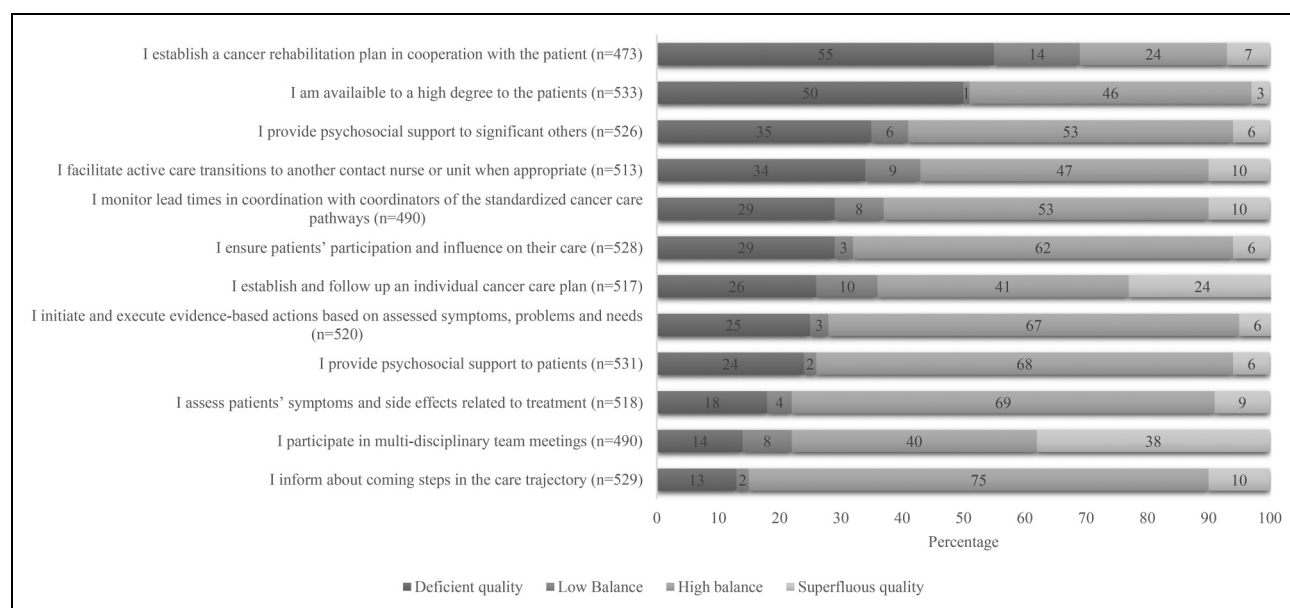


Figure 1. Relationship between perceived reality (PR) and subjective importance (SI) of specific aspects of contact nurse in cancer care (CNCC) services, based on the national description of the CNCC assignment. The index for the two dimensions PR and SI was created accordingly: **Deficient quality:** Respondents with low scores regarding PR and high scores regarding SI. **Low balance:** Respondents with low scores regarding both PR and SI. **High balance:** Respondents with high scores regarding both PR and SI. **Superfluous quality:** Respondents who scored high regarding PR and low regarding SI.

claim 'I monitor lead times in coordination with coordinators of the standardized cancer care pathways', the largest proportion of affirmation was seen amongst CNCCs serving patients with upper gastrointestinal cancers (92.9%), whereas the smallest proportion of affirmation was seen among CNCCs serving patients with haematological cancers (43.5%). CNCCs serving melanoma patients stood out in some respects compared to other groups. For example, only 6.3% affirmed to establishing cancer rehabilitation plans. The smallest variations between subgroups were seen regarding the provision of information about coming steps in the care trajectory (range 76.9–100%) and the provision of psychosocial support to patients (range 75–100%). Differences were less obvious when comparing CNCCs at different types of hospitals, although notably more CNCCs at county hospitals affirmed to establishing cancer rehabilitation plans (40.7%) than CNCCs at university hospitals (24.4%) and smaller county hospitals (31%).

When combining CNCCs' perceptions of reality and the subjective importance ascribed to tasks (Figure 1), the most prominent deficiencies concerned the establishment of cancer rehabilitation plans and perceived availability. Here, 55% and 50% of respondents, respectively, were categorized into the 'deficient quality' group, indicating an imbalance where CNCCs perceive these items to be of great importance to patients, but that they do not perform these tasks to a high degree.

Availability across the care trajectory

CNCCs were asked to state how often they typically had contact with patients at five specified time points across the care trajectory (prior to start of treatment, during treatment, 0–3 months, 3–6 months and 6–12 months after completion of treatment). Half of the respondents (53%) reported typically having contact with

patients on one or more occasion at all five time points. A small group of respondents (7.1%) reported typically having contact with patients at only one of the time points. Similarly, 7.9% of respondents reported typically having contact with patients at two time points, 14.6% at three time points and 17% at four out of the five time points. Figure 2 shows how patterns of contact differed across the care trajectory.

Perceptions of organizational prerequisites

By utilizing the EFA (Table 4) as a basis for comparison, 29.1% of respondents were attributed satisfactory organizational prerequisites, 60% moderately satisfactory organizational prerequisites and 10.9% unsatisfactory organizational prerequisites (Table 4). Being equipped with satisfactory organizational prerequisites was more common amongst CNCCs at university hospitals (29.2%) and amongst CNCCs working with patients with breast and head and neck cancer (40% and 41.9%) compared to other hospital types and diagnosis groups. Only 7.4% of respondents serving patients with upper gastrointestinal cancers were found to have the satisfactory organizational prerequisites (Table 5).

Moral stress and organizational prerequisites

There were statistically significant differences between groups of CNCCs with different organizational prerequisites (satisfactory, moderately satisfactory or unsatisfactory), regarding their perceptions of moral stress, as measured by four SCQ items. The total mean score for the items analysed was 7.3 (SD 5.2) (range 0–23.75). CNCCs who were attributed satisfactory organizational prerequisites reported the lowest scores (mean = 6.0) compared to CNCCs with moderately satisfactory organizational prerequisites (mean = 7.4) and CNCCs with

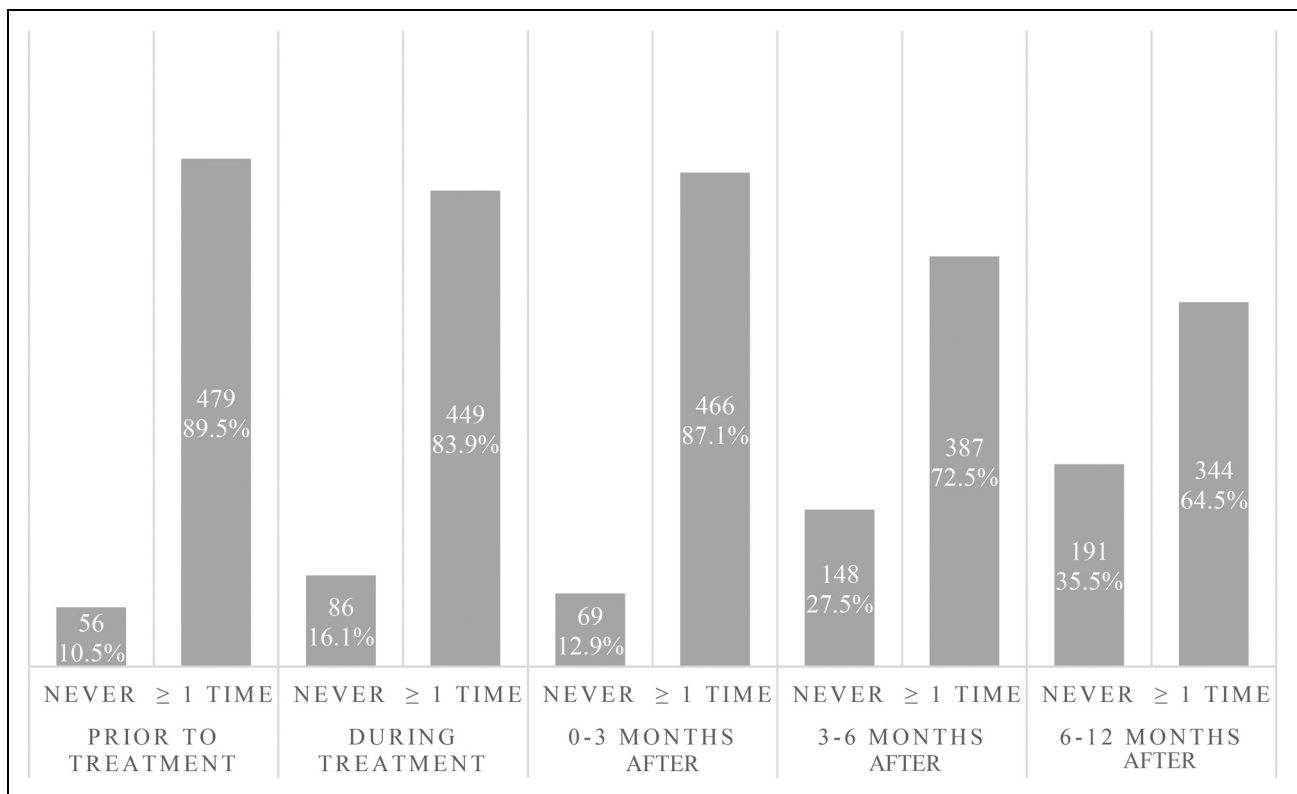


Figure 2. Contact nurse in cancer care (CNCC)'s perceptions of their frequency of interaction with patients across the care trajectory. Interactions are dichotomized as usually having no or ≥ 1 contact at five specified time points.

Table 4. Rotated component matrix of exploratory factor analysis (EFA).

Items	Prerequisites as provided	Prerequisites as perceived
1. I have a written assignment, signed by my manager	0.455	
2. I have especially allotted time for my assignment as contact nurse	0.778	
3. I work independently in a clinic where I assess symptoms and needs and provide care	0.624	
4. I have a room allotted to my work	0.781	
5. I have enough time for my assignment as contact nurse		0.541
6. Does it happen that you do not have the time to give patients the care that they need?		-0.666
7. I facilitate active care transitions to another contact nurse or unit when appropriate		0.585
8. I can speak, uninterrupted, with patients and significant others when they wish		0.547
9. I am available to a high degree to the patients		0.696
10. I can offer patients continuity		0.628

Survey items are sorted into factors and their factor loading to that factor is stated. Rotation matrix for the two-factor structure of the 10 items (nine from the QOPCoN survey, one from SCQ) explicitly addressing essential organizational prerequisites for CNCC services ($n = 475$).

Extraction method: principal component analysis.

Rotation method: varimax with Kaiser normalization.

Total variance explained: 47.9%.

Cronbach's alpha for prerequisites as provided: .651.

unsatisfactory organizational prerequisites (mean = 8.6) ($p = 0.002$) (Table 6). There were no statistically significant differences between CNCCs who reported moderately satisfactory or unsatisfactory organizational prerequisites.

Discussion

The main finding from this study is noteworthy variabilities regarding both CNCCs' perception of their services and their

organizational prerequisites. We also demonstrate an association between organizational prerequisites and CNCCs' perception of moral stress and, to our knowledge, the study is the first of its type to assess CNCC service with such a comprehensive approach.

Regarding services, some tasks from the national description of the CNCC assignment¹² were very common, whereas others, such as monitoring lead times and participating in multidisciplinary team meetings, were less common. We also

Table 5. Proportion of respondents (%) in different subgroups of contact nurses in cancer care (CNCC) attributed satisfactory, moderately satisfactory and unsatisfactory organizational prerequisites.

	Hospital type *					Patient group served								
	Total (n = 535) %	CH (n = 238) %	SCH (n = 103) %	UH (n = 176) %	BC (n = 30) %	CNS (n = 13) %	GYN (n = 42) %	HN (n = 31) %	HAE (n = 23) %	LGI (n = 53) %	LUNG (n = 28) %	MEL (n = 16) %	UGI (n = 28) %	URO (n = 106) %
Satisfactory	29.1	24.4	13.7	29.2	40	7.7	28.6	41.9	21.7	20.8	17.9	12.5	7.4	23.8
Moderately satisfactory	60	59.1	69.6	60	60	69.2	57.1	45.2	65.2	66	57.1	75	81.5	61
Unsatisfactory	10.9	16.5	16.7	10.8	0	23.1	14.3	12.9	13.1	13.2	25	12.5	11.1	15.2

*Abbreviations: CH = county hospital; SCH = smaller county hospital; UH = university hospital; BC = breast cancer; CNS = central nervous system tumours; GYN = gynaecological cancers; HN = head and neck cancers; HAE = haematological cancers; LGI = lower gastrointestinal cancers; LUNG = lung cancer; MEL = melanoma; UGI = upper gastrointestinal cancers; URO = urological cancers.

observed differences regarding practices across subgroups of CNCCs. Clinically relevant differences were most distinct between diagnosis groups rather than between hospital types, but it is important to note that some of the groups were small. When patients are provided with different types of CNCC services depending on their tumour location, this can be described as inequities in care. A certain degree of variability is likely inevitable in any healthcare system, not least a decentralized one, such as the Swedish system. To a certain degree, the CNCC services also need to be dynamic and adaptive to meet the needs of individual patients and the characteristics of different cancer diagnoses. However, too large variations are not something that an ambitious healthcare system, striving towards high-quality equitable care, should accept.

It is possible that some aspects of CNCC services can be sensitive to the specific care trajectory. For example, the structures around multidisciplinary team meetings might differ in a way that can explain the relatively large variation seen in this sample regarding participation in these meetings. It is also relevant to note that previous research has identified that RN can be important actors in the multidisciplinary team meetings, but often have a blurred role.^{38,39} This may explain why a third of the respondents fell into the 'superfluous quality' group regarding this task, indicating that they might not see their place, or are not given sufficient space, in this setting.

Although a certain degree of variation regarding the content of CNCC services across settings might be expedient, it is difficult to justify why CNCCs' organizational prerequisites should vary. Based on self-reported data, we found that a majority of CNCCs have what we refer to as moderately satisfactory organizational prerequisites. Fifteen percent can be said to have unsatisfactory organizational prerequisites. Previous studies emphasize that there is a connection between quality of care and the organizational prerequisites provided to healthcare providers.⁴⁰ These prerequisites are shaped on different structural levels, where not only the closest line manager and the hospital management, but also politicians and decision-makers at a local, regional, national and international level have influence.⁴¹

In this study, CNCCs deemed to have satisfactory organizational prerequisites reported lower levels of moral stress. This is not surprising because the SCQ items utilized to represent moral stress were selected specifically for their connection to the work environment. Nevertheless, it is an important finding, which illuminates the fact that sufficiently organized and resourced care settings are in the interest of both patients and healthcare professionals, affecting their wellbeing and ultimately their ability to provide healthcare services at the top of their capacity. This is why it also is in the interest of healthcare organizations and systems. Moral distress theory⁴² emphasizes the importance of organizational support and a positive nurse practice environment, including the opportunity to work autonomously and influence the working environment, in order to curb RN perceived moral stress. Studies have found that the nurse practice environment is an important factor for job satisfaction and retention.^{43–45} In times of alarmingly low retention rates among RN, the interplay between quality of care and the quality of the organizational prerequisites

Table 6. Mean self-reported moral stress scores among contact nurses in cancer care (CNCC) with different organizational prerequisites (dependent variable = perceived stress of conscience as defined by four Stress of Conscience Questionnaire (SCQ) items).

Mean item scores and SD for CNCC with different organizational prerequisites		Mean difference in SCQ item score compared to the group 'satisfactory'	SE	Significance
Satisfactory (mean 6.0, SD 4.9)	Moderate (mean 7.4, SD 5.2)	+1.4	0.54	0.023
	Unsatisfactory (mean 8.6, SD 5.2)	+2.5	0.73	0.002

provided to CNCCs is of great importance for employers to consider.

If unwanted variation in organizational prerequisites has been identified, it is important to seek explanations as to why these variations occur. In this case, we suggest the governance structures surrounding the implementation process of CNCC services could be of interest to review. The Swedish National Cancer Strategy states that everyone diagnosed with cancer should be guaranteed an assigned a healthcare professional and suggest that this role could be attributed to a CNCC.¹¹ However, that suggestion has not been followed by a structured or formal implementation plan from national or regional governance entities. Little support regarding aspects of both the *what* and the *how* has been offered. The term CNCC is being used to describe a multitude of nursing practices within cancer care. For example, continuity and coordination are described as foundational aspects of these services, and achieving these can be considered the very point of introducing this service.¹¹ Even so, there are RNs with the job description of a CNCC that operate in very isolated parts of the care trajectory. In this study, roughly every third CNCC states that they typically never have contact with patients 3–6 months or 6–12 months after treatment completion. It is worth reflecting on what practices should be referred to as CNCC practices, especially in the context of follow-up, and if a firmer structuring or differentiation could benefit quality-of-care.

In the international movement towards more advanced and autonomous cancer nursing roles, issues regarding mandate, variability and optimization of services are frequently debated.^{3,8,9,22} Dowling et al.⁹ note that the confusion regarding advanced practice nurses' roles in cancer care results in the conflation and underutilization of RNs' skills.

In comparison with internationally comparable roles, the CNCC role in Sweden lack formal competency demands, apart from being a RN. Donabedian suggests that formal competency is a dimension of structural quality.⁵ Our data indicate that, regarding formal competency, a heterogeneous group of RNs are employed as CNCCs, which is in line with previous research.⁴⁶ Approximately half of the sample in our study have completed a degree as specialist nurse or completed a special higher education course for CNCCs. The absence of formal competency demands or certifications for CNCCs makes the Swedish healthcare system stand out in relation to other settings, where the cancer nursing roles have been advancing in recent decades.⁹ We suggest a more stringent approach to qualification to add a layer of quality, harmonize practices with internationally comparable roles and further the development of the CNCC role.

Furthermore, the lack of clarity and formalization of the role of CNCCs makes the evaluation of the service more difficult.

For managers and decision-makers to be able to understand and prioritize CNCC services, a greater focus on monitoring and evaluating services locally, regionally and nationally is mandated. The current format of CNCC services, where the boundaries and content of the services is not clear cut, makes such evaluation fraught with several difficulties.

Strengths and limitations

Methods. A cross-sectional study design was deemed a suitable method, but the findings from this type of observational study should as always be viewed in the light of the shortcomings of the method, not least regarding an inability to assess causal inference, rather being seen as hypothesis-building.⁴⁷

Context and recruitment. Because there is no registry of CNCCs it is not possible to calculate an exact response rate, affecting study validity. An integrative review by LÉcuyer et al.⁴⁸ notes that response rates in nursing research online surveys vary significantly, and that there is no consensus regarding the lowest acceptable rate. The mean response rate of the studies included in their study was 42.46%. In comparison, the present study falls on the lower end, affecting the transferability of the results. However, the sample, consisting of approximately 30% of the total CNCC population, is representative of this population regarding geographical distribution, regional affiliation, hospital type and diagnosis group served. Only one of 21 regions declined participation, which is a strength.

Because healthcare systems and advanced nursing roles in cancer care vary in their shape and form, transferring findings outside of the Swedish setting is discouraged, even if the general issues discussed in the study can be of interest in other settings as well.

A limitation is that CNCCs serving children with cancer were not included. At the time of data collection, the term CNCC was not utilized within the childhood cancer sphere but has subsequently been adopted.

Data collection. Possibly, the fact that most of the data collection occurred during the COVID-19 pandemic might affect the validity of the results in the post-pandemic setting, as CNCCs' everyday work situation can have been affected. It may also have affected the response rate negatively. Therefore, caution is advised when generalizing the findings from this study.

Statistical analysis. A strength of the study is the fact that it takes a broad approach to CNCC services, addressing different

aspects and using different tools to maximize the utilization of the collected data.

It could be considered a limitation in that, because the study only utilized a select part of the SCQ (four out of the original nine items), the results are not comparable to other data sets using this questionnaire.

Conclusion

This study has identified that CNCCs reported varying perceptions regarding their services and their organizational prerequisites. Some aspects of CNCC services described in the national assignment for CNCCs seemed highly prevalent, whereas other aspects were less common. There were also noteworthy differences regarding these issues between CNCCs working at different types of hospitals and caring for different patient groups. Ultimately, these differences may translate into differences in quality-of-care people affected by cancer are offered by their CNCCs.

A majority of CNCCs have what we refer to as moderately satisfactory organizational prerequisites, and we identified a pattern where organizational prerequisites influenced CNCCs' perceptions of moral stress. Through this, the study highlights the important interplay between quality of care provided to patients affected by cancer and the organizational prerequisites provided to CNCCs that are tasked with supporting them throughout an often challenging and complex care trajectory.

The results from the present study can inform future research regarding this topic. Advantageously, future research could focus on developing ways to measure and compare organizational prerequisites and quality of care fairly and comprehensively for CNCCs in different settings, to benchmark services and promote healthcare improvement. Delving deeper into different aspects of outcomes of CNCC services, by making, for example, a health economic evaluation, would also be a useful contribution.

Acknowledgements

We express our gratitude to all survey respondents for the time and effort they invested. The support of Jari Appelgren in the statistical analysis of this research paper has been invaluable. Katarina Graah-Hagelbäck provided valuable support in reviewing the language in this paper.

Data availability statement

The individual participant data that underlie the results reported in this article, are, after deidentification (text, tables, figures, and appendices), available from the corresponding author, EB, to researchers upon reasonable request.

Declaration of conflicting interests


The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work has

been funded by the Regional Cancer Centre South, the Regional Cancer Centre Stockholm-Gotland and the Regional Cancer Centre West.

ORCID iD

Ellen Brynskog  <https://orcid.org/0000-0003-0221-6318>

Supplemental material

Supplemental material for this article is available online.

References

1. Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2024; 74:229–263.
2. World Health Organization. *State of the World's Nursing 2020: Investing in Education, Jobs and Leadership*. Geneva: World Health Organization, 2020.
3. Drury A, Sulosaari V, Sharp L, et al. The future of cancer nursing in Europe: addressing professional issues in education, research, policy and practice. *Eur J Oncol Nurs* 2023; 63: 102271.
4. European commission. *Europe's Beating Cancer Plan: Communication from the Commission to the European Parliament and the Council*. Brussels: European Commission, 2021.
5. Donabedian A. *An Introduction to Quality Assurance in Health Care*. Oxford: Oxford University Press, 2003.
6. Bergman B, Hellström A, Lifvergren S, et al. An emerging science of improvement in health care. *Qual Eng* 2015; 27: 17–34.
7. Baileys K, McMullen L, Lubejko B, et al. Nurse navigator core competencies: an update to reflect the evolution of the role. *Clin J Oncol Nurs* 2018; 22: 272–281.
8. Kerr H, Donovan M and McSorley O. Evaluation of the role of the Clinical Nurse Specialist in cancer care: an integrative literature review. *Eur J Cancer Care* 2021; 30: e13415.
9. Dowling M, Pape E, Geese F, et al. Advanced practice nursing titles and roles in cancer care: a scoping review. *Semin Oncol Nurs* 2024; 22: 151627.
10. Molassiotis A, Liu XL and Kwok SW. Impact of advanced nursing practice through nurse-led clinics in the care of cancer patients: A scoping review. *Eur J Cancer Care* 2021; 30: e13358.
11. Ministry of Social Affairs. *En nationell cancerstrategi för framtiden – Betänkande av Utredningen En nationell cancerstrategi [A National Cancerstrategy for the Future – Report from the Governments Official Investigation a National Cancer Strategy]*. Stockholm: Fritze, 2009.
12. Confederation of Regional Cancer Centers. *Nationell beskrivning av kontaktsjuksköterskans uppdrag [National Description of the Contact Nurse Assignment] [Internet]*. Stockholm, 2019 [cited 7 Mar 2024]. <https://cancercentrum.se/globalassets/patient-och-narstaende/samverkan/kssk/nationellt-uppdrag-for-kontaktsjukskoterska.pdf>
13. National board of Health and Welfare. *Analys av utvecklingen vid Regionala cancercentrum [Analysis of the Development at the Regional Cancer Centers] [Internet]*. Stockholm, 2022 [cited 19 Jun 2024]. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2023-9-8752.pdf>
14. Sharp L, Westman B, Olofsson A, et al. Access to supportive care during and after cancer treatment and the impact of socioeconomic factors. *Acta Oncol* 2018; 57: 1303–1310.
15. Sundbom M, Ekfjord L, Willman M, et al. Patient-reported experience and outcome measures during treatment for gastroesophageal cancer. *Eur J Cancer Care* 2020; 29: e13200.

16. Sjövall A, Söderqvist L, Martling A, et al. Improvement of the experience of colorectal cancer patients in Sweden with a regional cancer plan. *Colorectal Dis* 2020; 22: 1965–1973.
17. Dalhammar K, Malmström M, Sandberg M, et al. Health care utilization among patients with oesophageal and gastric cancer: the impact of initial treatment strategy and assignment of a contact nurse. *BMC Health Serv Res* 2021; 21: 1019.
18. Westman B, Kirkpatrick L, Ebrahim F, et al. Patient-reported experiences on supportive care strategies following the introduction of the first Swedish national cancer strategy and in accordance with the new patient act. *Acta Oncol* 2018; 57: 382–392.
19. Ullgren H, Kirkpatrick L, Kilpeläinen S, et al. Working in silos? – head & neck cancer patients during and after treatment with or without early palliative care referral. *Eur J Oncol Nurs* 2017; 26: 56–62.
20. Larsson M and Bjuresäter K. *Kontaktsjuksköterskor i cancervård – En studie av befintliga verksamheter i Uppsala-Örebroregionen [Contact Nurses in Cancer Care – a Study of Existing Operations in the Uppsala-Örebro Region]*. Uppsala: Regional Cancer Centre Uppsala Örebro, 2016.
21. Cantril C, Christensen D and Moore E. Standardizing roles: evaluating oncology nurse navigator clarity, educational preparation, and scope of work within two healthcare systems. *Clin J Oncol Nurs* 2019; 23: 52–59.
22. Farrell C, Molassiotis A, Beaver K, et al. Exploring the scope of oncology specialist nurses' practice in the UK. *Eur J Oncol Nurs* 2011; 15: 160–166.
23. Schlak AE, Aiken LH, Chittams J, et al. Leveraging the work environment to minimize the negative impact of nurse burnout on patient outcomes. *Int J Environ Res Public Health* 2021; 18: 1–15.
24. Pressley C and Garside J. Safeguarding the retention of nurses: a systematic review on determinants of nurse's intentions to stay. *Nurs Open* 2023; 10: 2842–2858.
25. Dall'Ora C, Ball J, Reinius M, et al. Burnout in nursing: a theoretical review. *Hum Resour Health* 2020; 18: 41.
26. Glickman SW, Baggett KA, Krubert CG, et al. Promoting quality: the health-care organization from a management perspective. *Int J Qual Health Care* 2007; 19: 341–348.
27. von Elm E, Altman DG, Egger M, et al. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol* 2008; 61: 344–349.
28. International Committee of Medical Journal Editors. Recommendations for the conduct, reporting, editing and publication of Scholarly work in medical journals [Internet]. 2024 [cited 21 May 2024]. <https://www.icmje.org/recommendations/>
29. Janlöv N, Blume S, Glenngård AH, et al. Sweden: health system review. *Health Syst Transit [Internet]* 2023; 25: 1–198. www.healthobservatory.eu
30. The Swedish Agency for Health and Care Services Analysis. *En akut bild av Sverige – Kartläggning av akutsjukvårdens organisation och arbetsfördelning [An Acute Picture of Sweden – Mapping the Emergency Healthcare Organization and Division of Labor]* [Internet]. Stockholm, 2018 [cited 10 Mar 2024]. <https://www.vardanalys.se/rapporter/en-akut-bild-av-sverige/>
31. Glasberg AL, Eriksson S, Dahlqvist V, et al. Development and initial validation of the stress of conscience questionnaire. *Nurs Ethics* 2006 Nov; 13: 633–648.
32. Brynskog E, Larsson M, Bjuresäter K, et al. Altered prerequisites: a cross-sectional survey regarding cancer care in Sweden during COVID-19 from the viewpoint of contact nurses in cancer care. *Nord J Nurs Res* 2022; 43: 1–8.
33. IBM SPSS [Internet]. Armonk; 2021 [cited 6 May 2024]. <https://www.ibm.com/products/spss-statistics>
34. Field A. *Discovering Statistics Using IBM SPSS Statistics*. 5th ed. London: Sage, 2018.
35. Lützn K, Cronqvist A, Magnusson A, et al. Moral stress: synthesis of a concept. *Nurs Ethics* 2003; 10: 312–322.
36. Åhlin J, Ericson-Lidman E, Norberg A, et al. Revalidation of the perceptions of conscience questionnaire (PCQ) and the stress of conscience questionnaire (SCQ). *Nurs Ethics* 2012; 19: 220–232.
37. World Medical Association. World medical association declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bull World Health Organ* 2001; 79: 373–374.
38. Rosell L, Alexandersson N, Hagberg O, et al. Benefits, barriers and opinions on multidisciplinary team meetings: a survey in Swedish cancer care. *BMC Health Serv Res* 2018; 18: 249.
39. Rosell L. Multidisciplinary team meetings in cancer care-function and participants' experiences [Dissertation]. [Lund], 2022.
40. Amaliyah E and Tukimin S. The relationship between working environment and quality of nursing care: an integrative literature review. *Br J Health Care Manage* 2021 Jul 2; 27: 194–200.
41. Busse R, Klazinga N, Panteli D, et al. Improving healthcare quality in Europe – characteristics, effectiveness and implementation of different strategies. Health policy series, No 53 [Internet]. 2019 [cited 10 Jun 2024]. <https://iris.who.int/handle/10665/327356>
42. Corley MC. Nurse moral distress: a proposed theory and research agenda. *Nurs Ethics* 2002; 9: 636–650.
43. Twigg D and McCullough K. Nurse retention: a review of strategies to create and enhance positive practice environments in clinical settings. *Int J Nurs Stud* 2014; 51: 85–92.
44. Baernholdt M and Mark BA. The nurse work environment, job satisfaction and turnover rates in rural and urban nursing units. *J Nurs Manag* 2009; 17: 994–1001.
45. Tan AK, Capezuti E, Samuels WE, et al. Intent to stay, moral distress, and nurse practice environment among long-term care nurses: a cross-sectional questionnaire survey study. *J Nurs Scholarship* 2024; 56: 430–441.
46. Bjuresäter K, Olsson C, Larsson M, et al. Self-reported professional competence among Swedish contact nurses in cancer care: a cross-sectional study. *Cancer Care Res Online* 2022; 2: e024.
47. Wang X and Cheng Z. Cross-sectional studies: strengths, weaknesses, and recommendations. *Chest* 2020; 158: S65–S71.
48. L'Ecuyer KM, Subramaniam DS, Swope C, et al. An integrative review of response rates in nursing research utilizing online surveys. *Nurs Res* 2023; 72: 471–480.