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Symptom-Level Description of Nursing Perceptions About Unwarranted Clinical Variation, Inequality in Access to Cancer Services, Specific-Symptom Knowledge: An Italian Web-Based Survey

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ABSTRACT

Objectives: This study aimed to describe the cancer nurses' views regarding the relevance of cancer symptom-specific knowledge, unwarranted clinical variation, and inequities in access to cancer services. Describing how nurses perceive these aspects could help identify research priorities and a practical framework to prioritize clinical practice guidelines.

Data Sources: A web-based survey was performed using a convenience sample of 810 nurses employed in cancer settings and cross-sectional data collection. The survey adopted a previously validated questionnaire investigating 14 symptoms.

Conclusion: This study revealed which cancer symptoms require priority attention to define evidence-grounded guidance for decreasing unwarranted clinical variation and inequities in access to cancer services. Future multiprofessional and multinational studies are recommended to provide an in-depth description of the investigated phenomena.

Implications for Nursing Practice: Participants reported higher mean scores in pain-specific knowledge than other symptoms. Social functioning alterations and psychological disorders seem to be highly susceptible to unwarranted clinical variation and inequities in access to cancer services. This information could drive tailored interventions to improve nursing practice.

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Introduction

Patient safety of patients with cancer represents a significant challenge across all health care systems, becoming a global health priority. Although numerous research projects have been conducted to address this emerging issue, the literature has been focused on describing the potential factors influencing patient safety for patients with cancer. Among these factors, the role of the high unwarranted clinical variation (UCV), the inequality in access to cancer services, and inadequate nurses' specific-symptom knowledge have been recently described as determinants of unsafe cancer care.

Precisely, UCV concerns the appropriateness of care assessed directly by systematic care process or indirectly throughout outcome

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measures. The UCV has significant implications on quality of care, equity, and efficiency, rising concerns at a health policy level globally. To date, several efforts have been made to evaluate UCV in clinical contexts, acknowledging its relationship with inequality in access to cancer services.³ The inequality in access to cancer services is a complex phenomenon because it depends on several factors, such as social inequalities, diverse income levels, geography, age, and employment status. Overall, UCV could amplify the effects of the factors that lead to inequality in access to cancer services. Higher levels of UCV and inequalities in access to cancer services are common in contexts showing a mismatch between cancer service supply and health care demands.⁸ Researchers have provided a theoretical framework for understanding the causes of UCV, indicating that clinical practice guidelines represent one potential solution to UCV.9 However, the implementation of evidence-based guidelines still faces resistance, 10 acknowledging that significant UCV has been found across cancer type treatments and management. 11

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Establishing priorities for actions to prioritize the implementation of clinical practice guidelines represents a reasonable approach to boost quality and safety improvements. 12-14 In this regard, scientific societies play a paramount role in establishing research priorities. 4-6 Moreover, the key elements of an effective practical approach should focus on understanding the complex interactions between the needs of implementing a clinical practice guideline to guarantee guidance for the decision-making (top-down approach) and the actual perceptions of the individuals regarding these needs (bottom-up approach). This understanding could contribute to creating a keen awareness regarding the strengths and weaknesses of a guideline implementation process. 5 Specifically, the potential alignment between actual needs of implementing a guideline and the professionals' perception of these needs could be of great value.

In the Italian context, the National Institute of Health (Istituto Superiore di Sanità) has provided a framework for prioritizing scientific societies' activities in terms of development, adoption, and implementation of clinical guidelines. The role of the epidemiological relevance of health problems underpinning a guideline implementation, the UCV, and inequalities in receiving services emerged as pivotal.¹⁶ In nursing cancer care, the identification of which aspects require a primary intervention to develop or adapt a guideline, by considering the nurses' perspectives, is currently underdescribed globally. A valid self-report instrument was recently validated in the Italian context, aiming to investigate cancer nurses' perception regarding the perceived relevance of symptom-specific knowledge, UCV, and inequities in access to cancer services. 17 However, research from the cancer nursing field on which aspect of cancer symptoms management requires priority attention in research endeavors to improve perceived critical issues is still lacking. Therefore, this study aimed to describe cancer nurses' perceptions regarding the relevance of symptom-specific knowledge, UCV, and inequities in access to cancer services. This study could be strategic to effectively prioritize scientific societies' activities in the process of definition and implementation of clinical guidelines, which help to overcome health care disparities and deliver highly effective care while describing how nurses perceive relevant aspects of cancer symptoms management.

Methods

Design, participants, and procedure

This research is a cross-sectional multicenter national study. This study's reporting was adherent with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional research (see Supplementary File 1, available online).

Nurses from different geographical areas of Italy with at least 6 months of work experience were involved using a convenience sampling method. Data were collected through an online survey between September 2019 and March 2020. The work experience (equal to or more than 6 months) was the only adopted inclusion criteria. Nurses from the Italian Association of Cancer Nurses (AIIAO) were invited (\approx 1000 contacts) to be involved in this study, and 810 nurses agreed to participate in the survey (response rate higher than 80%). The invitation was sent using emails, highlighting the aim and inclusion criteria of the study. The estimated completion time was about 20 minutes. Data were collected using an online self-administered survey via SurveyMonkey, following the recommendations for conducting web-based surveys. 18 The authors chose to perform a web-based survey because this approach was described as functional to capture responders' perspectives and to facilitate answers, acknowledging the adaptable layout of the web interface developed to fit with the responders' devices like a mobile, laptop, or tablet. The study was approved by the Institutional Review Board of the Italian Association of Cancer Nurses (protocol N. 03/2019).

Survey

The sections of the web survey were (i) the form for collecting sample's sociodemographic and professional characteristics and (ii) the self-administered online questionnaire scale about nursing perceptions of UCV, inequity in access to cancer services, and specific-symptom knowledge validated by Caruso et al. ¹⁷ The sociodemographic and job characteristics were consistent with the validation study, ¹⁷ namely, sex (male, female), educational level (bachelor, post-graduate course, master's degree, PhD, second bachelor degree, other), cancer-specific accredited education (yes/no), work clinical context (medicine, surgery, critical care, home care, outpatient, other), age (years), work experience in the current context (years), and employed in an accredited comprehensive cancer center (yes, no).

The self-report online questionnaire by Caruso et al¹⁷ was employed to assess the perceived relevance of symptom-specific knowledge, perceived UCV, and perceived inequities in access to cancer services. The 14 included symptoms were fatigue, pain, sleep disorders, immune system disorders, cardiovascular alterations, gastrointestinal and oral cavity alterations, central and peripheral nervous system alterations, metabolic and endocrine alterations, tegumentary system alterations, hematopoietic alterations, coagulation disorders, electrolyte alterations, social functioning alterations, and psychological disorders. Participants were asked to rate each symptom using a five-point Likert scale ranging from low (1) to high (5) for assessing the perceived relevance of symptom-specific knowledge, perceived UCV, and perceived inequities in access to cancer services.

Statistical analysis

We employed descriptive statistics to summarize the responders' characteristics, assessing the skewness and kurtosis of the items. As most items showed to have a skewness lower than |1|, we employed the mean plus or minus standard deviation (SD) for the reporting. Missing data were handled with the pairwise function of IBM Statistical Package for the Social Science (SPSS Inc.), version 22. We performed a subgroup analysis, considering the answers of nurses employed in an accredited comprehensive cancer center compared to those who were working in general hospitals. Following previous research, ¹⁷ these comparisons allowed the authors to identify some specific characteristics that could reflect hypothetical differences between accredited comprehensive cancer centers and general hospitals because the standards of care in the accredited cancer centers are strictly monitored over time, while general hospitals often do not require strict accreditation process. Therefore, the nurses' answers to the items were compared using the Student's t-test, while χ^2 tests were employed to compare categorical sociodemographic and professional characteristics between the two groups of nurses. The level of significance was set at P < .05, using two-tailed tests. Statistics were performed using IBM SPSS Inc., version 22.

Results

Demographic and occupational profiles of participants

The sample included 810 nurses, of which 480 (59.3%) nurses were employed in accredited comprehensive cancer centers, and 330 nurses were employed in general hospitals (40.7%); 69.6% were women. The mean age was 40.9 ± 9.82 years. Overall, 91.1% of the nurses had no cancer-specific postgraduate training, and most of them had postgraduate education (80.7%). The majority of the nurses worked in a medical context (31.1%), and their mean work experience in the current context was 8.07 ± 6.78 years (Table 1). Significant differences were found between nurses employed in accredited comprehensive cancer centers and those employed in general hospitals in relation to their educational level (P< .001), the context of practice (P< .001), and age (P< .001).

TABLE 1Sociodemographic characteristics of the sample.

	Total sample $(n = 810)$		Nurses in accre	edited cancer centers ($n = 480$)	Nurses in general hospitals ($n = 330$)		P
	n	%	n	%	n	%	
Sex							
Male	246	30.4	144	30	102	30.9	.781
Female	564	69.6	336	70	228	69.1	
Educational level							
Bachelor degree	156	19.3	96	20	60	18.2	
Postgraduate course	396	48.9	264	55	132	40	<.001
Master's degree	156	19.3	84	17.5	72	21.8	
PhD	42	5.2			42	12.7	
Second Bachelor degree	60	7.4	36	7.5	24	7.3	
Clinical context							
Medicine	252	31.1	156	32.5	96	29.1	
Surgery	174	21.5	108	22.5	66	20	
ICU	120	14.8	96	20	24	7.3	<.001
Home care	48	5.9	36	7.5	12	3.6	
Outpatient	78	9.6	36	7.5	42	12.7	
Research-Education Management	138	170.	48	10	90	27.3	
Specific education							
Cancer education (yes)	72	8.9	48	10	24	7.3	.182
Age							
Years (average; SD)	40.9	9.82	38.98	10.47	41.71	8.56	<.001
Work experience in the current co	ontext						
Years (average; SD)	8.07	6.78	9.33	7.30	6.24	5.46	.000

ICU = intensive care unit; SD = standard deviation.

Epidemiological description of nurses' perception of symptoms management

Table 2 shows the mean scores for the perceived relevance of symptom-specific knowledge, and Table 3 reported the mean scores for the perceived UCV and inequities in access to cancer services. The higher mean score in the section of the relevance of symptom-specific knowledge was concerning pain (mean 4.630 \pm 0.653); furthermore, the pain was reported as the symptom more susceptible to UCV (mean 3.863 \pm 0.947). Social functioning alterations and psychological disorders revealed the highest mean score of inequities in access to cancer services (respectively, mean 3.696 \pm 0.990; mean 3.682 ± 0.924) in both nurses employed in accredited comprehensive cancer centers (mean 3.758 \pm 1.103; mean 3.676 \pm 0.900) and those working in general hospitals (respectively, mean 3.609 \pm 0.795; mean 3.692 \pm 0.967). Overall, specific-knowledge referred to sleep disturbances was considered as the less relevant symptom knowledge (mean 3.815 \pm 0.035), whereas cardiovascular alterations and coagulation disorders presented the lowest UCV mean scores (respectively, mean 3.315 \pm 0.908; 3.294 \pm 0.944). Similarly, cardiovascular

alterations also showed the lowest mean score of inequities in access to cancer services (mean 3.215 ± 1.041).

In the section of the relevance of symptom-specific knowledge, the comparison between the answers of nurses employed in accredited comprehensive cancer centers and those working in general hospitals revealed that nurses from general hospitals reported higher perception of the relevance of knowledge referred to fatigue (P < .001), sleep disturbances (P < .001), metabolic and endocrine alterations (P < .001), integumentary system alterations (P < .001), coagulation disorders (P < .001), electrolyte alterations (P < .001), and psychological disorders (P < .001). Likewise, in the section of the relevance of UCV, nurses from general hospitals reported higher scores referred to fatigue (P < .001), pain (P = .012), cardiovascular alterations (P < .001), alterations of the central and peripheral nervous sys-(P = .021), integumentary system alterations (P = .014), coagulation disorders (P < .001), and social functioning alterations (P< .001). Concerning the inequities in access to cancer services, nurses from general hospitals reported higher scores referred to fatigue (P < .001), pain (P < .001), cardiovascular alterations (P = .001), and coagulation disorders (P < .001).

TABLE 2

Mean scores of the perceived relevance of symptom-specific knowledge

	Total sample $(n = 810)$ Mean	Nurses in accredited cancer centers ($n = 480$)		Nurses in general hospitals ($n = 330$)		P	
		SD	Mean	SD	Mean	SD	
Fatigue	3.956	0.825	3.800	0.782	4.182	0.035	<.001
Pain	4.630	0.653	4.600	0.664	4.673	0.640	.119
Sleep disorders	3.815	0.035	3.675	1.035	4.018	1.001	<.001
Immune system disorder	4.289	0.797	4.250	0.767	4.345	0.837	.094
Cardiovascular alterations	4.022	0.865	4.025	0.881	4.018	0.843	.912
Gastrointestinal and oral cavity alterations	4.237	0.872	4.225	0.852	4.255	0.900	.636
Alterations of the central and peripheral nervous system	3.948	0.773	3.925	0.686	3.982	0.890	.305
Metabolic and endocrine alterations	3.911	0.857	3.775	0.791	4.109	0.910	<.001
Integumentary system alterations	3.904	1.025	3.825	1.023	4.018	1.020	.008
Hematopoietic alterations	4.185	0.819	4.150	0.793	4.236	0.853	.140
Coagulation disorders	3.993	0.839	3.875	0.843	4.164	0.805	<.001
Electrolyte alterations	4.104	0.744	4.000	0.708	4.255	0.770	<.001
Social functioning alterations	4.022	1.146	4.000	1.141	4.055	1.153	.506
Psychological disorders	4.111	0.925	4.025	0.852	4.236	1.010	.001

SD = standard deviation.

TABLE 3Mean scores of UCV, inequities in access to cancer services.

	$\frac{\text{Total sample } (n = 810)}{\text{Mean}}$	Nurses in accredited cancer centers ($n = 480$)			Nurses in general hospitals ($n = 330$)		P
		SD	Mean	SD	Mean	SD	
Unwarranted practice variation							
Fatigue	3.430	0.842	3.306	0.845	3.612	0.805	<.001
Pain	3.863	0.947	3.758	1.017	3.940	0.836	.012
Sleep disorders	3.510	0.923	3.500	0.993	3.525	0.808	.745
Immune system disorder	3.556	0.913	3.586	0.811	3.512	1.041	.331
Cardiovascular alterations	3.315	0.908	3.185	1.021	3.514	0.651	<.001
Gastrointestinal and oral cavity alterations	3.619	0.935	3.657	0.894	3.558	0.997	.181
Alterations of the central and peripheral nervous	3.417	0.831	3.355	0.901	3.512	0.704	.021
system	2.270	0.000	2.255	1 002	2.424	0.000	272
Metabolic and endocrine alterations	3.379	0.886	3.355	1.003	3.424	0.606	.373
Integumentary system alterations	3.527	1.007	3.606	1.101	3.409	0.836	.014
Hematopoietic alterations	3.482	1.124	3.520	1.172	3.424	1.048	.353
Coagulation disorders	3.294	0.944	3.111	0.957	3.613	0.832	<.001
Electrolyte alterations	3.548	0.982	3.538	1.011	3.562	0.936	.790
Social functioning alterations	3.795	0.984	3.971	1.072	3.551	0.785	<.001
Psychological disorders	3.722	0.957	3.722	0.962	3.721	0.950	.986
Inequities in access to cancer services							
Fatigue	3.223	0.945	3.062	0.999	3.487	0.782	<.001
Pain	3.500	0.919	3.419	0.978	3.609	0.822	.009
Sleep disorders	3.299	1.031	3.208	1.119	3.410	0.900	.026
Immune system disorder	3.393	1.013	3.333	1.020	3.486	0.999	.090
Cardiovascular alterations	3.215	1.041	3.083	1.039	3.419	1.012	.001
Gastrointestinal and oral cavity alterations	3.248	1.04	3.233	1.176	3.268	0.990	.702
Alterations of the central and peripheral nervous	3.229	1.016	3.172	1.178	3.316	0.694	.098
system							
Metabolic and endocrine alterations	3.381	0.963	3.370	1.061	3.400	0.759	.741
Integumentary system alterations	3.511	0.939	3.481	1.103	3.550	0.632	.388
Hematopoietic alterations	3.500	1.074	3.500	1.120	3.500	1.003	1.000
Coagulation disorders	3.256	0.893	3.077	0.959	3.529	0.698	<.001
Electrolyte alterations	3.453	0.924	3.400	0.940	3.528	0.899	.121
Social functioning alterations	3.696	0.990	3.758	1.103	3.609	0.795	.055
Psychological disorders	3.682	0.924	3.676	0.900	3.692	0.967	.835

SD = standard deviation; UCV = unwarranted clinical variation.

Discussion

This study describes how Italian cancer nurses perceived the relevance of symptom-specific knowledge, UCV, and inequities in access to cancer services. Furthermore, this study revealed the main differences in nurses' perceptions between those working in accredited comprehensive cancer centers and those working in general hospitals. This information could help address future specific educational and policy interventions of the cancer nursing societies, educators, policy makers, and researchers. This study also provided a bottom-up exploration of which clinical aspect requires more urgent support to decrease UCV and the possible inequities in access to cancer services. This support should be multifaced, and the standardization of the practice (eg, providing guidance to the nurses through the implementation of clinical practice guidelines) could be pivotal for decreasing the perception of (and the actual) UCV and inequities in access to health care services.

Overall, our results show that the relevance of pain-specific knowledge represents the most challenging symptom knowledge along the cancer symptoms management sphere for both nurses working in accredited comprehensive cancer centers and those working in general hospitals. The pain was also reported to be highly subjected to UCV. Accordingly, recent studies underlined the high heterogeneity of pain conditions that require complex and tailored strategies. ¹⁹ In fact, patient treatment goals are highly individual, and self-management behaviors involve the capacity to alleviate the pain with medication, side effects, and personal goals. ²⁰ However, integrating evidence-based guidelines is needed to deliver appropriate management, especially regarding pain effectively assessment. ²¹

Another symptom that in this study was reported as highly subjected to UCV was fatigue. As described in the literature, fatigue is one of the most distressing symptoms among patients with cancer

and a primary research goal in cancer care.²² However, in this study, it seems to be slightly underestimated in terms of the relevance of knowledge for sound clinical practice. This underestimation could reflect cultural components.²³ Similarly, the relevance of knowledge referred to sleep disorders, which are usually described within the same cluster of symptoms with pain and fatigue, 24,25 is perceived as the less relevant symptom knowledge, even though sleep disorders have recently been appointed a research priority by the Oncology Nursing Society.²³ This difference in the perception of the three major cancer symptoms might reflect the local and global awareness campaigns undertaken in the last 20 years, which were principally aimed at improving cancer pain management, including policy implementations.²⁶ In contrast, cardiovascular and coagulation alterations are unlikely to be subjected to UCV and iniquity because they are mostly managed throughout medical approaches, which are much more supported by clinical procedures and guidelines.²⁷

Limitations

This study has some limitations and strengths. The first limit is the convenience sample that might raise concerns about under-representation or over-representation of specific groups within the sample, and it limits the generalizability of the results. The second limit is the cross-sectional approach for collecting the data because we do not have information on the observed variables over time. The third limit is referred to the slight heterogeneous distribution of some professional characteristics between nurses working in accredited comprehensive cancer centers and those working in general hospitals; this could affect some answers of the enrolled nurses because the different professional characteristics, such as higher postgraduate levels in nurses working in general hospitals, could influence their views of the investigated questions. On the other side, the first strength of this

study is the fact that it fulfills an actual gap in knowledge, as the perceptions of Italian nurses about the relevance of symptom-specific knowledge, UCV, and inequities in access to cancer services were underdescribed; to the best of our knowledge, this is the first study on this topic. A second significant strength includes the large sample size

Implication for Nursing Practice

In this study, social functioning alterations and psychological disorders are reported as highly susceptible to UCV and inequities in access to cancer services. Although the psychosocial care in oncology has enhanced over the last 2 decades, ²⁸ the nursing profession may require additional training and clinical guidelines implementation to provide psychosocial care effectively. ²⁹ Besides, current events of the coronavirus pandemic have increased the toned for psychosocial support of patients with cancer, ^{30,31} and nurses could play a crucial role in improving the unmet psychosocial needs by an accurate preliminary assessment and activating specialist consults. ³²

Conclusion

This study provided a portrait of the Italian cancer nurses' views regarding the relevance of symptom-specific knowledge, UCV, and inequities in access to cancer services. The depicted scenario could drive the identification of which areas of oncology nursing demand a higher implementation support initiative, such as clinical guidelines or educational activities. In this study pain-specific knowledge was recognized as the most relevant factor for practicing with patients with cancer. However, it seems that nurses underestimated the relevance of some symptom-specific knowledge, especially for those cancer symptoms epidemiologically recognized as highly distressing from patients, such as fatigue and sleep disturbances. Furthermore, social functioning alterations and psychological disorders seem to be highly susceptible to UCV. Therefore, by combining the epidemiological description of symptoms with nurses' perspective, it emerges that pain, fatigue, sleep disturbances, social functioning alterations, and psychological disorders require priority attention to define evidencegrounded guidance for practice. Moreover, local awareness campaigns should be conducted to increase professional awareness of the relevance of these symptoms to ensure optimal standards of practice. Future research should extend this investigation to other professionals involved in cancer care and perform a questionnaire validation across European countries to allow multiprofessional and crossnational comparisons.

Authors' contributions

SB, AP, CA, and RC conceptualized the study. RC and SB performed the statistical analysis. VB, AP, and FD significantly contributed to data collection. SB and RC drafted the original manuscript and CA, FD, VB, and AP assisted in writing and reviewing the manuscript. All authors read and approved the final manuscript.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.soncn.2021.151138.

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