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EVALUATION OF PERCEPTION OF INFORMATION AND QUALITY OF LIFE IN ONCOLOGIC SURGERY PATIENTS: A CROSS-SECTIONAL STUDY

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Abstract: This study aims to evaluate patients' quality of life (QoL) and perceptions of information after cancer surgery. A descriptive and cross-sectional study was conducted using the European Organization for Research and Treatment of Cancer (EORTC) information module questionnaire (QLQ-INFO25) and the EORTC Core Quality of Life Questionnaire (QLQ-C30), which were given to patients to complete post-surgery. A total of 160 patients completed the questionnaires. There were 82 men and 78 women, with a mean age of 55.29. The average global QoL score, as measured in the QLQ C-30, was 89.76. The symptom with the highest reported score was fatigue. The average total QLQ-INFO25 score was 63.05. The highest level of information provided was perceived to be about "medical tests", while the lowest was about "other services". The extent of the disease had a significant effect on QLQ-INFO25 scores. The global QoL scores among post-operative surgical oncology patients were quite high, and the mean scores of the functional scales were moderate. Patient perceptions of the information provided were above average. Different nurse training techniques should be used to increase patients' information satisfaction and QoL.

Keywords: Information, Quality of life, Surgical oncology nursing, EORTC QLQ INFO25, EORTC QLQ-C30

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1. Introduction

There were an estimated 10.0 million deaths and 20 million new cancer cases worldwide in 2022 (Bray et al., 2024). QoL is considered an important issue in the evaluation of cancer treatments and complex cancer surgeries (Bozec et al., 2018). For many patients, QoL is important during and after treatment (Sitlinger and Zafar, 2018). In cancer patients, symptoms-related disorders resulting from the disease process and treatment side effects adversely impact QoL and treatment compliance (Lither et al., 2015; Guimarães Ferreira et al., 2017; Abegaz et al., 2018).

Information-related issues are among the most frequently reported neglected needs across all stages of cancer (Zhang et al., 2018; Fatiregun et al., 2019; Herrmann et al., 2020). The information that patients receive at discharge is often of lower quality than what they receive during their hospital stay; this lack of information is a key source of stress during recovery at home (Lither et al., 2015). Patients should be informed based on their needs so that they can actively participate in decisions regarding their treatment and follow-up, comply with the treatment plan, be aware of potential side effects, manage any side effects, and control their condition (Berger et al., 2018). Well-informed patients are more compliant with treatment plans, and ensuring patients are well-informed has several benefits, such as enabling better communication with patient families and better coordination with healthcare professionals (Lew et al., 2021). Other benefits for sufficiently informed patients include higher care satisfaction, compliance with controls, lower anxiety levels, and better QoL (Arraras et al., 2010; Bergenmar et al., 2014; Asadi-lari et al., 2015; Berger et al., 2018).

Surgical oncology nurses play a key role in pre- and post-operative patient care, particularly regarding the information provided to patients. In particular, the adequacy of the information provided by health professionals before discharge after the surgical treatment will ensure that the discharge education is reviewed and the patient's highest well-being will be targeted. However, limited studies have evaluated these perceptions and QoL among surgical oncology patients pre-discharge (Majumder et al., 2014; Bozec et al., 2016; Fatiregun et al., 2019; Bozec et al., 2019). By evaluating the impact of cancer on quality of life, it is thought that cancer treatment programs and treatment approaches can be guided (Lither et al., 2015; Bozec et al., 2018; Abegaz et al., 2018). This study is important in terms of assessing the knowledge of surgical oncology patients not only about the surgical treatment but also about adjuvant treatments, follow-ups, coping with side effects, and taking into account the inadequacies by determining their QoL during this period. Therefore, this study aimed to evaluate patients' QoL and perceptions of information after cancer surgery.

2. Materials and Methods

A descriptive and cross-sectional study design was adopted. The sample consisted of individuals who underwent cancer surgery in the surgical oncology service of a tertiary hospital between January and September 2020 and met the inclusion criteria. In the adaptation of a scale to another culture, it is necessary to reach a population at least 5-10 times the number of items in the scale. Since the QLQ-INFO25 Questionnaire was adapted into Turkish in this study since the number of scale items is 25, the sample must be at least 125-250 (Gözüm and Aksayan, 2002).

Patients who were diagnosed with cancer in any region and at any disease stage who underwent cancer surgery demonstrated full orientation (i.e., to time, person, and place), could see and hear, and were discharged were included. Patients who refused to participate in the study and whose cancer diagnosis was not finalized were exclusion criteria. The study was completed with a total of 160 patients. As a result of the post-hoc power analysis, the power of the research was calculated as 0.96% with an effect size of 0.5 and a margin of error of 0.05.

Data were collected by questionnaires developed by the EORTC. We completed modified translations of each questionnaire. Participants were asked to fill in the introductory information form, information module questionnaire (QLQ-INFO25), and the QLQ-C30 questionnaire. Patients who read the disclosure and consent forms and agreed to participate had to complete the questionnaires in approximately 30 minutes. Patients completed the questionnaires post-surgery once they were discharged. The data were collected by the researcher. Questions were read by the researcher to patients who needed assistance in completing the survey.

2.1. Questionnaires

2.1.1. Demographic questionnaire

We created a patient identification form, which included sociodemographic questions on things such as gender, age, sex, education status, primary tumor site, type of surgery, disease extension, and preoperative treatment (Arraras et al., 2010; Arraras et al., 2011; Asadi-lari et al., 2015).

2.1.2. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) with/ Information Module QLQ INFO25

The QLQ-C30 across five functional scales (physical, role, emotional, social, and cognitive functioning), three symptom scales (fatigue, pain, and nausea-vomiting), six single items (dyspnea, insomnia, loss of appetite, constipation, diarrhea, and financial hardship). Responses were scored on a 4-point scale from 1 (not at all) to 4 (very much). However, two items related to global health status were scored from 1 (very poor) to 7 (excellent). The time frame participants were told to use when answering questions was the last week (Bjordal et al., 2000; Fayers et at., 2001; Guzelant et al., 2004). Cronbach's alpha coefficient of the scale was 0.93 in this study.

Patients' perceptions of the information they received regarding their treatment and care were measured by the EORTC QLQ INFO25. The EORTC QLQ-INFO25 is organized into four scales. The first assesses the disease (4 questions), the second assesses medical tests (3 questions), the third assesses the treatment (6 questions), and the fourth assesses other services (4 questions). The questionnaire also measures self-sufficiency, the receipt of written and digital information, satisfaction with the information received, the desire to receive more or less information, and the usefulness of the information received with eight separate questions at different care points. Responses were measured on a 4-point Likert type (1: not at all, 2: a little, 3: a lot, and 4: a lot); however, items 50, 51, 53, and 54 were measured with binary answers (Yes/No) (Arraras et al., 2010). This questionnaire can be used at any time during treatment and follow-up processes and among cancer patients with different disease regions and stages. We used a modified translation of the QLQ-INFO25 with permission from the EORTC QoL working group. QLQ-INFO25 was modified into Turkish by Gezer and Arslan (Gezer and Arslan, 2021). Cronbach's alpha coefficient of the scale was 0.92 in this study.

2.2. Statistical Analysis

Item scores of the QLQ C-30 and QLQ-INFO25 were converted to a 0–100 scale (Fayers et at., 2001). Higher scores represented higher functioning, global QoL, levels of information received, desire to receive more information and satisfaction. However, on the symptom scales of the QLQ C-30, higher scores indicated more symptoms and a heavier symptom burden (Bjordal et al., 2000; Guzelant et al., 2004; Arraras et al., 2010). A frequency analysis was conducted on the introductory information collected. The data was assessed using frequency, percentage, mean, standard deviation, minimum, and maximum values. All analyses were conducted using the R Project software (R Core Team, 2021).

3. Results

3.1. Demographic and clinical Characteristics

In total, 160 patients agreed to participate in the study. These patients underwent oncological surgery and answered the questionnaires when they were discharged from the surgical oncology clinic. The mean participant age was 55 years old, and 51.2% of participants were men. Overall, 39.4% of participants had colorectal cancer, 96.3% underwent curative surgery, 46.3% received preoperative chemotherapy, and 76.3% had localized disease. Patient characteristics are presented in Table 1.

3.2. QoL Outcomes

The mean global health status score was high (89.76±40.83), and the mean scores of the different functional scales were moderate. Fatigue had the highest average symptom score in the QLQ C-30 (62.76±23.22), while diarrhea had the lowest score (34.38±18.12) (Figure 1). The mean scores of the QLQ-C30 are presented in Table 2.

3.3. Information Needs

The total mean QLQ-INFO25 score was 63.05±13.05. The highest levels of knowledge were in the “medical tests” (78.38±19.26) and “disease-related” (77.88±18.35) information, while the lowest levels of knowledge were observed in the “other services” (43.86±21.76) and “different care areas” (45.94±26.73) information (Table 3, Figure 2). Overall, 42.50% of the patients reported that they wanted more information. The subjects for which patients wanted more or less information are shown in Table 4. There were no statistically significant differences in mean QLQ-INFO25 scores based on age, gender, education level, primary tumor region, type of surgery, or preoperative treatment. However, the mean scores of the “medical tests” subdimension were significantly higher in individuals with metastatic cancer (P<0.05), data not shown).

Table 1. Sociodemographic and clinical characteristics of patients (n =160)

Variable	n	%
Gender		
Male	82	51.2
Female	78	48.8
Age		
<50	49	30.6
50-64	76	47.5
≥65	35	21.9
Education status		
Illiterate	10	6.3
Primary school	56	35.0
Secondary school	71	44.3
University	23	14.4
Primary tumor site		
Colorectal	63	39.4
Gastric	32	20.0
Esophagus	9	5.6
Breast	33	20.6
Thyroid	12	7.5
Hepatopancreatobiliary	11	6.9
Type of Surgery		
Curative	154	96.3
Palliative	6	3.7
Disease extend		
Limited	122	76.3
Metastatic	38	23.7
Preoperative treatment		
CT+RT	106	66.3
No treatment	54	33.7

Table 2. Descriptive Statistics and Reliability of Scale / Items of the EORTC QLQ-C30

Scales/items	Mean	SD	Min.-Max.	Cronbach's Alpha
Functioning scale*				
Physical functioning (items 1-5)	54.19	18.68	0-100	0.881
Role functioning (items 6, 7)	51.88	22.86	0-100	0.833
Emotional functioning (items 21-24)	52.46	22.80	0-100	0.905
Cognitive functioning (items 20,25)	41.25	16.46	16-100	0.351
Social functioning (items 26, 27)	55.63	23.20	0-100	0.804
Global quality of life (items 29, 30)	89.76	40.83	0-100	0.939
Symptom Scale**				
Fatigue (items 10, 12, 18)	62.76	23.22	0-100	0.889
Nausea and vomiting (items 14, 15)	45.70	23.63	0-100	0.871
Pain (items 9, 19)	59.61	23.59	0-100	0.844
Dyspnoea (item 8)	41.72	20.36	0-100	-
Insomnia (item 11)	58.91	27.66	0-100	-
Appetite loss (item 13)	59.84	27.20	0-100	-
Constipation (item 16)	36.72	20.01	0-100	-
Diarrhoea (item 17)	34.38	18.12	0-100	-
Financial difficulties (item 28)	58.44	27.60	0-100	-

SD= standard deviation,*scores range from 0 to 100, with a higher score representing a higher level of functioning, **scores range from 0 to 100, with a higher score representing a greater degree of symptoms.

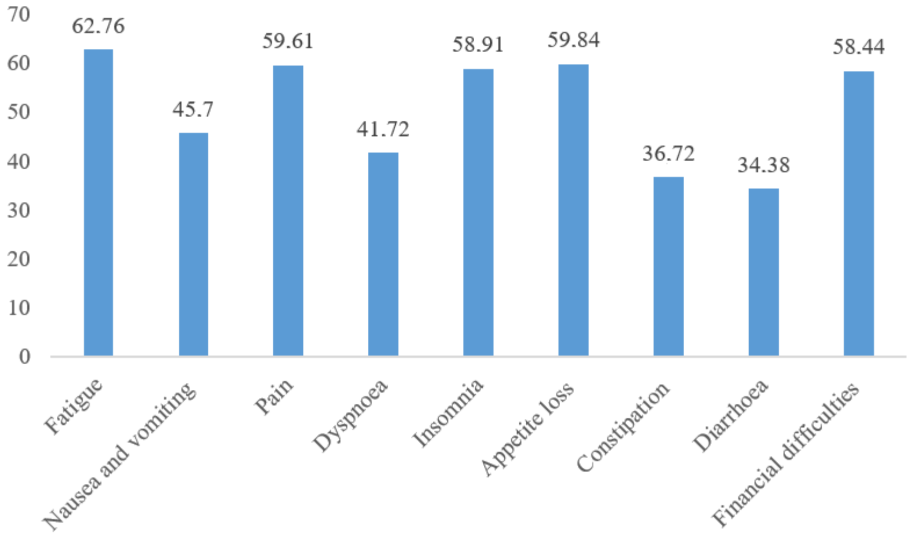

Figure 1. EORTC QLQ-C30 symptom profile.

Table 3. Descriptive statistics and reliability of scale / Items of the EORTC QLQ-INFO25

Scales/items	Mean	SD	Min.-Max.	Cronbach's Alpha
Information about the disease (items 31-34)	77.89	18.36	8-100	0.883
Information about medical tests (items 35-37)	78.38	19.27	11-100	0.902
Information about treatments (items 38-43)	71.64	17.89	0-100	0.872
Information about other services (items 44-47)	43.87	21.77	0-100	0.857
Information about different places of care (item 48)	45.94	26.73	0-100	-
Information about things you can do to help yourself get well (item 49)	54.69	27.07	0-100	-
Written information (item 50)	83.44	23.61	0-100	-
Information on CD tape/video (item 51)	93.13	17.27	0-100	-
Satisfaction with the information received (item 52)	71.72	20.63	0-100	-
Wish to receive more information (item 53)	78.75	24.80	0-100	-
Wish you have received less information (item54)	96.86	12.14	0-100	-
Overall the information has been helpful (item 55)	75.78	16.92	33-100	-
Whole questionnaire (items 31-55)	63.05	13.05	34-92	0.929

SD= standard deviation, Min= minimum, Max= maximum, scores in the EORTC INFO module scales and items range 0–100, a higher score means a higher level of information received, higher information wishes and higher satisfaction, items 52 to 55 have dichotomous answers.

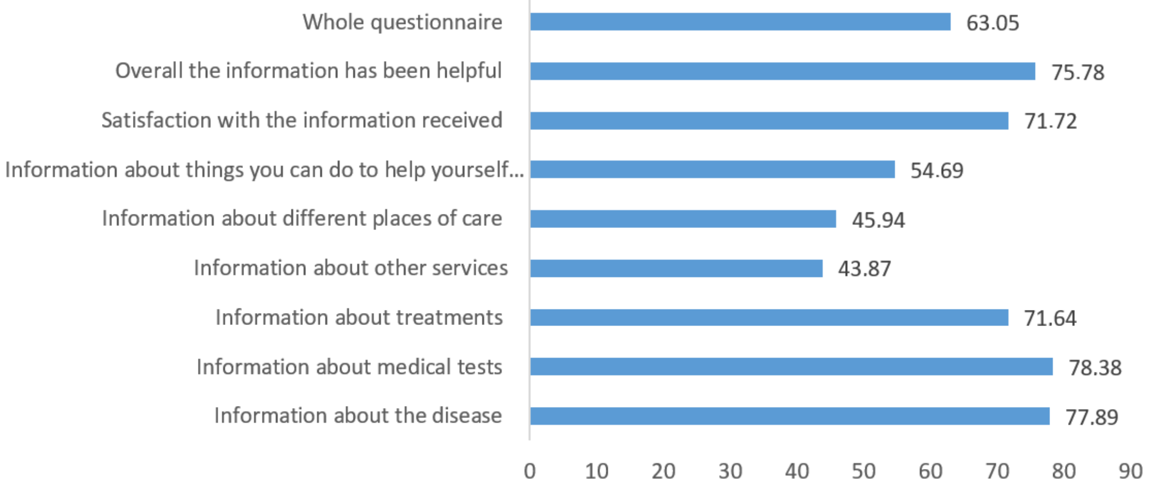

Figure 2. Mean EORTC QLQ-INFO25 scales score.

Table 4. EORTC QLQ-INFO25 information module information topics (binary answers)

	EORTC QLQ – INFO25	Yes		No	
		n	%	n	%
53	Do you wish to receive more information?	68	42.50	92	57.50
	Detailed information about the problems that may arise related to the disease	33	20.63	127	79.37
	Detailed information about eating and drinking	15	9.37	145	90.63
	Detailed information on what to do for the next period of life	15	9.37	145	90.63
	Where to get psychological support	5	3.13	155	96.87
54	Do you wish that you had received less information?	10	6.25	150	93.75
	Those who do not want to receive detailed information about the diagnosis and treatment process	4	2.50	156	97.50
	Unwilling to receive information in case of bad illness	6	3.75	154	96.25

4. Discussion

In this study; perceptions of information and QoL of surgical oncology patients were investigated. Surgical oncology patients' QoL is high and their perception of information is satisfactory. When the literature was examined, no study investigating the perception of information and QoL in surgical oncology patients at the discharge stage after surgical treatment was found. This study is important in terms of taking into account the information provided in the discharge training of all health professionals, especially nurses, and the QoL at this stage.

4.1. QoL Outcomes

Evaluations of patient QoL are conducted to assess physical, psychological, and social well-being, to compare and standardize any applications or treatments, and to determine treatment effectiveness, particularly during the disease process.

The QoL of the participants who underwent oncological surgery was evaluated. The mean global health status sub-dimension score was quite high. It is thought that the use of curative surgery in almost all participants, the small effect on their general performance, the use of current surgical treatment methods, and the use of patient follow-ups positively impacted participants' QoL. In two studies, Bozec et al. (2018; 2019) evaluated the QoL of patients who had undergone total pharynx laryngectomy and oropharyngeal cancer surgery, reporting similar mean global health status scores to those of the current study in both patient groups. The current findings are consistent with the literatüre (Bergenmar et al., 2014; Majumder et al., 2014; Lither et al., 2015; Murnane et al., 2015; Bozec et al., 2016; Ullgren et al., 2017; Bener et al., 2017; Westma et al., 2019; Imran et al., 2019; Jassim and Al Ansari, 2020). Among the functional scale sub-dimensions, the highest QoL score was seen in social function and the lowest in cognitive function. In a study conducted by Akduran and Durna (2021) to measure QoL in patients with colorectal cancer, it was reported that patients had difficulties both in their daily lives and in fulfilling their domestic responsibilities. Although our study group consisted of patients who had cancer and underwent surgery, there was no dramatic decrease in their QoL; however, it was determined that participants experienced some difficulties in their daily lives. Imran et al. evaluated QoL in a cohort of breast cancer patients, and the highest average QoL score among the functional scales was for social function (Imran et al., 2019). In the symptom scales, the most intense symptoms were fatigue, loss of appetite, and pain. QoL has been found to decrease significantly during the diagnosis and treatment process in surgical oncology patients, with the most common symptoms being fatigue, loss of appetite, and pain (Majumder et al., 2014; Murnane et al., 2015; Bozec et al., 2016; Ullgren et al., 2017; Bener et al., 2017; Kiely et al., 2017; Bozec et al., 2018; Imran et al., 2019; Jassim and Al Ansari, 2020). These results suggest a need for a multidisciplinary approach that aims to improve well-being, reduce treatment side effects, and improve long-term QoL in patients who have undergone oncological surgery.

4.2. Information Needs

The information given to the patients affects the joint decision-making process, reduces psychological disorders, improves communication with the family, and increases treatment compliance (Arraras et al., 2010; Bergenmar et al., 2014; Berger et al., 2018; Khoshnood et al., 2019). In the current study, information perceptions were sufficient for the sub-dimensions of "medical tests," "disease," "treatments," and "other services." This high level of information perception could be attributed to the information provided due to legal obligations and the increased patient demand for information as a result of autonomy and patient rights being better understood by patients. Previous studies that have aimed to determine the information perceptions of cancer patients show similar results to the current study (Majumder et al., 2014; Guimarães Ferreira et al., 2017). Berger et al. evaluated cancer patients' perceptions of information about their disease and treatment before, during, and after treatment (Berger et al., 2018). Singer et al. used the EORTC information module on 423 patients in Germany and found that their knowledge levels were similar to the current study (Singer et al., 2013).

Participants' perceptions of information about the disease, medical tests, and treatment were good. These results could be attributed to the sample consisting of patients hospitalized in the surgical clinic, having higher satisfaction with their surgical treatment, receiving more medical tests and therapeutic interventions, and receiving continuous information about their disease and treatment. In two different studies conducted by Lithner et al., patients undergoing colorectal cancer surgery demonstrated the highest information perception scores in the sub-dimensions of "medical tests" and "disease," similar to the current findings (Lither et al., 2012; Lithner et al., 2015). It has been determined that there is a high level of knowledge based on post-surgical treatment evaluations (Bozec et al., 2016; Guimarães Ferreira et al., 2017; Bozec et al., 2019). Participants' perceptions of information in the "other services" sub-dimension were low. This could be due to a lack of knowledge about the additional care services outside the hospital, such as rehabilitation services. This reflects the importance of holistic management for cancer patients, both within the hospital and outside the hospital. Ullgren et al. evaluated the HRQoL and information perceptions in palliative care patients with head and neck cancer. The perception of information was the highest in the sub-dimension of "medical tests" and lowest for "other services," similar to our study findings (Imran et al., 2019). The current results were similar to those of previous studies (Arraras et al., 2011; Singer et al., 2013; Bergenmar et al., 2014; Majumder et al., 2014; Bozec et al., 2016; Guimarães Ferreira et al., 2017; Gillis et al., 2017; Bozec et al., 2019; Westma et al., 2019; Thu Vu et al., 2019).

The level of information about "different care areas" was below average. Similarly, Bergenmar et al. reported a relatively low level of information about "different care areas" (i.e., about hospitals, outpatient services, or home care), which was partially attributed to cultural differences (Lither et al., 2012). Traditionally, more attention is paid to the hospital process in surgical oncology patients and other patient groups. Therefore, although attention is paid to discharge training, the information provided to patients is insufficient. Conversely, in a study conducted in Southern Europe, higher mean scores were observed for information about "different care facilities" (Arraras et al., 2013). These country-based differences in results may be attributed to the use of traditional approaches to health practices and patient demands.

Less than half of the participants answered "yes" to the question "Would you like to learn more?" Regardless of the amount of information given to patients during the treatment process, additional information requests are an issue that can be partially explained by individual characteristics. Bergenmar et al. (2014) evaluated information perceptions among patients receiving adjuvant RT for breast cancer, and 48% stated that they wanted to receive more information. Zhang et al. (2018) reported that more than half of the participants in their study wrote comments and made suggestions to improve the content and way of conveying information. These findings agree with the current findings.

The mean scores for information about "medical tests" were significantly higher in individuals with metastatic disease. This could be explained by these patients receiving more information about the procedures performed as they require more tests and interventions.

Despite the high level of satisfaction participants reported about the information received, they wanted to receive more information. This highlights the need for information sharing to be a continuous process during the care of surgical oncology patients, with information being repeated and new information being provided when necessary. Considering the contributions of information studies to the entire treatment and care process of patients, all health professionals, particularly surgical oncology nurses, must be fully competent in their respective fields.

5. Conclusion

In the post-operative period, the QoL among surgical oncology patients was high, functionally was moderate, and information perceptions were satisfactory. The comprehensive information provided to participants, particularly before the oncological surgery (e.g., information provided by the surgeon at the time of diagnosis, after the initial examination, and before surgery, as well as by the surgical oncology nurse) could explain these encouraging results. Reliable measurement tools specific to cancer patients should be used to evaluate the needs of surgical oncology patients, their satisfaction with the information provided, and their QoL. In a process such as surgical treatment, where the patient's QoL is affected in every aspect of their life, nurses should evaluate the changes in their QoL and develop solutions. Surgical oncology nurses' use of patient information delivery methods, such as written fact sheets and multimedia tools, and support from surgical oncology communities may further improve the quality of information provided to patients. In addition, integrated care for cancer patients and easy access of patients to health services will be possible with the participation of all social actors responsible for ensuring quality in health services, managers of health systems and organizations, service providers, health professionals, patients, families, and the community.

Limitations

The results of this study cannot be generalized to all surgical oncology patients until comparable studies are conducted among patients with different demographic and clinical characteristics. The sample cannot be considered homogeneous as it consists of patients with different types and stages of cancer. Furthermore, the COVID-19 pandemic negatively affected patients' access to healthcare services, which led to disruptions in the data collection process. Future studies should use both qualitative and quantitative methods to evaluate the information needs and QoL of surgical oncology patients throughout their medical and surgical treatment. These assessments should be renewed at all stages of oncologic treatment and at different stages. Furthermore, information should be provided using appropriate techniques.

Author Contributions

The percentage of the author(s) contributions is presented below. All authors reviewed and approved the final version of the manuscript.

	D.G.	S.A.
C	50	50
D	50	50
S	50	50
DCP	100	
DAI	100	
L	50	50
W	50	50
CR	50	50
SR	50	50
PM	50	50
FA	50	50

C=Concept, D= design, S= supervision, DCP= data collection and/or processing, DAI= data analysis and/or interpretation, L= literature search, W= writing, CR= critical review, SR= submission and revision, PM= project management, FA= funding acquisition.

Conflict of Interest

The authors declared that there is no conflict of interest.

Ethical Approval/Informed Consent

This study was performed in line with the Declaration of Helsinki. Permission to conduct the study was obtained from the non-interventional clinical research ethics committee (approval date: April 04, 2019, protocol code: 05.04.2019-87/11), the head physician of the university hospital (approval date: July 07, 2019, protocol code: 30.07.2019-E.107626), and the participants. For data collection, verbal and written informed consent permission from the participants was obtained.

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