



Investigación y Educación en Enfermería

ISSN: 0120-5307

revistaiee@gmail.com

Universidad de Antioquia

Colombia

Guimarães Ferreira da Silva, Daniela; Lira Pessoa de Souza, Ana Lucia; Cassia de Freitas Martins, Thalyta; Martins Pedrosa, Thais; Drumond Muzi, Camila; Mendonça Guimarães, Raphael

Quality of information given to surgical patients with abdominal cancer

Investigación y Educación en Enfermería, vol. 35, núm. 2, 2017, pp. 221-231

Universidad de Antioquia

Medellín, Colombia

Available in: <http://www.redalyc.org/articulo.oa?id=105251300011>

- How to cite
- Complete issue
- More information about this article
- Journal's homepage in redalyc.org

redalyc.org

Scientific Information System

Network of Scientific Journals from Latin America, the Caribbean, Spain and Portugal

Non-profit academic project, developed under the open access initiative

# Quality of information given to surgical patients with abdominal cancer

Daniela Guimarães Ferreira da Silva<sup>1</sup>

Ana Lucia Lira Pessoa de Souza<sup>2</sup>

Thalyta Cassia de Freitas Martins<sup>3</sup>

Thais Martins Pedrosa<sup>4</sup>

Camila Drumond Muzi<sup>5</sup>

Raphael Mendonça Guimarães<sup>6</sup>

## Quality of information given to surgical patients with abdominal cancer

**Objective.** To evaluate the need for information in patients with abdominal neoplasms. **Methods.** The sample consisted of 100 patients hospitalized in a surgical ward for patients with abdominal neoplasms at the National Institute of Cancer José de Alencar Gomes da Silva / INCA, in the period between June and December 2016. To collect the data, the Brazilian Portuguese version of the European Organization for Research and Treatment of Cancer (EORTC) information module questionnaire (QLQ-INFO25) was used. **Results.** In general, for most items, the patients showed satisfaction with the amount of information received. The items referring to the disease, examinations,

treatment and general information stand out, with an average score of more than 80%. For some items, however, there is dissatisfaction with the amount of information received, especially those related to the cause of the disease, aspects of out-of-hospital and home care, different places of care and aspects of self-help, with a satisfaction level of less than 40%. **Conclusion.** Despite the high level of satisfaction with the information received, it was observed that almost all patients would like more information, which makes us recommend that, as part of the care, the information offered to these patients about the treatment and the evolutionary process of the disease should be enhanced.

**Descriptors:** abdominal neoplasms; oncology nursing; patient satisfaction.

1 Nurse, Specialist. Instituto Nacional de Câncer -INCa-, Brazil. email: daniguifer@gmail.com

2 Nurse, Specialist. INCa, Brazil. email: analirapessoa@hotmail.com

3 Nurse, Specialist. INCa, Brazil. email: enfermeirathalyta@gmail.com

4 Nurse, Specialist. INCa, Brazil. email: tmpedrosa@gmail.com

5 Nurse, Ph.D. INCa, Brazil. email: camilamuzi@gmail.com

6 Nurse, Ph.D. Oswaldo Cruz Foundation (FIOCRUZ), Brazil. email: raphael.guimaraes@fiocruz.br

**Article linked to research:** Cross-cultural adaptation of measuring instruments in oncology care practice.

**Conflict of interests:** none to declare.

**Receipt date:** February 28, 2017.

**Approval date:** May 10, 2017.

**How to cite this article:** Silva DGF, de Souza ALLP, Martins TSF, Pedrosa TM, Muzi CD, Guimarães RM. Quality of information given to surgical patients with abdominal cancer. Invest. Educ. Enferm. 2017; 35(2): 221-231.

**DOI:** 10.17533/udea.iee.v35n2a11

## Calidad de la información ofrecida a los pacientes quirúrgicos con cáncer abdominal

**Objetivo.** Evaluar la necesidad de información en pacientes con tumores abdominales como proceso continuo para su cuidado. **Métodos.** La muestra consistió en 100 pacientes ingresados en la sala de cirugía, destinada a pacientes con cáncer abdominal del Instituto José de Alencar Gomes da Silva / Instituto Nacional de INCA, entre junio y diciembre de 2016. Para la colección de datos se utilizó la versión portuguesa del cuestionario QLQ-INFO25 la EORTC. **Resultados.** En general, para la mayoría de los artículos, los pacientes se mostraron satisfechos con la cantidad de información recibida. Cabe destacar los artículos relacionados con la enfermedad, examen, tratamiento, e información general, con más del 80% de la media. Sin embargo, para algunos artículos hay insatisfacción en la cantidad de información recibida, especialmente los vinculados a la causa de la enfermedad, los aspectos del hospital y el lugar de cuidado, así como los diferentes sitios de atención y aspectos de autoayuda, con un grado de satisfacción inferior al 40%. **Conclusión.** A pesar del alto nivel de satisfacción de la información recibida, se observó que casi todos los pacientes les gustaría obtener aún más, lo que nos lleva a creer que proporcionar continuamente información sobre el tratamiento y el proceso de evolución de la enfermedad debe ser un proceso constante en el cuidado de estos pacientes.

**Descriptor:** neoplasias abdominales; enfermería oncológica; satisfacción del paciente.

## Qualidade da informação oferecida a pacientes cirúrgicos com câncer abdominal

**Objetivo.** Avaliar a necessidade de informação em pacientes portadores de neoplasias abdominais. **Método.** A amostra foi composta por 100 pacientes internados em enfermagem cirúrgica, destinada aos pacientes portadores de neoplasias abdominais do Instituto Nacional do Câncer José de Alencar Gomes da Silva/INCA, no período entre junho e dezembro de 2016. Para a coleta de dados foi utilizado o questionário versão Português- Brasil QLQ-INFO25 da EORTC. **Resultados.** De uma forma geral, para a maioria dos itens, os pacientes demonstraram satisfação com a quantidade de informação recebida. Destacam-se os itens referentes à doença, exames, tratamento e informações gerais, com mais de 80% de média. Entretanto, para alguns itens há insatisfação na quantidade de informação recebida, especialmente aqueles ligados à causa da doença, aspectos do cuidado extra-hospitalar e domiciliar, diferentes locais de cuidado e aspectos de autoajuda, com grau de satisfação inferior a 40%. **Conclusão.** Apesar do alto nível de satisfação das informações recebidas, observou-se que quase a totalidade dos pacientes gostaria de mais informações, o que nos leva a acreditar que oferecer continuamente informações a respeito do tratamento e do processo evolutivo da doença, deve ser um processo constante no cuidado destes pacientes.

**Descriptor:** neoplasias abdominais; enfermagem oncológica; satisfação do paciente

## Introduction

The incidence of cancer has considerably increased in Brazil. For Brazil, about 596 thousand new cancer cases are estimated for 2016-2017.<sup>(1)</sup> When the disease progresses, important physical and psychosocial changes happen, which gain intensity with the evolution process of the disease.<sup>(2)</sup> Therefore, it is known that approaching a cancer patient is a very difficult task, as it involves the transfer of countless pieces of information inherent in the disease, its diagnosis, prognosis, risks and benefits of the treatment, mutilations and other body image changes, besides the possibility of the irreversible progression of the

disease.<sup>(3)</sup> The information provided to the cancer patient about his disease and treatment can profoundly influence his wellbeing, changing the meaning of the symptoms, problems and the way the patient faces the disease and its treatment.<sup>(4-6)</sup> One can say in this sense that the assessment of the information given to the cancer patient is an indicator of the quality of oncology care provided by the health institution.<sup>(7,8)</sup> One form of clinical, diagnostic and social approach is to use adapted scales and questionnaires.<sup>(9)</sup> To assess the amount of information the patients with different types of cancer receive during the phases of the diagnosis and treatment process, as well as for clinical and

research purposes, the Quality of Life Group of the European Organization for Research and Treatment of Cancer (EORTC) developed the QLQ INFO 25 questionnaire,<sup>(10,11)</sup> which was validated for the Brazilian context by Monique Silva Carvalho concerning the semantic equivalence; and by Claudia Fernandes Rodrigues concerning the test-retest reliability (unpublished).

The abdominal-pelvic tumors include some of the most incident in the general population. They comprise a diversified group of tumors, classified according to the anatomic location, the most incident types between colon and stomach cancer<sup>(1)</sup>. This topography entails some particularities. To give an example, surgical excision permits increasing patients' survival and reduces the possibility that the disease will spread to other organs. Nevertheless, the large majority results in the establishment of stomas.<sup>(11)</sup> The patients demonstrate difficulty to understand the surgery executed and its consequences. Therefore, there is a clear need for information about the disease, the therapeutic conducts, the physical and emotional changes deriving from the treatment, with a view to improving these patients' quality of life. In this context, the objective in this study is to assess the need for information in patients with abdominal and pelvic tumors, using the QLQ- INFO25 questionnaire by EORTC.

## Methods

In this cross-sectional study, a set of data was used about the need to provide information to abdominal cancer patients attended at the Instituto Nacional do Câncer (INCA). The research sample consisted of the universe of 100 adult patients hospitalized at the nursing ward for surgical patients with abdominal tumors of the Instituto Nacional do Câncer José de Alencar Gomes da Silva/INCA, located in the city of Rio de Janeiro. The participants were included between June and December 2016. The inclusion criteria were male or female patients aged 18 years or older with abdominal tumors. The exclusion criteria were patients with cognitive disorders capable of

compromising the veracity of the answers, with central nervous system tumors or metastases. To collect the data, the interview strategy was adopted, after background information about the research objectives, agreement to participate in the study and signing of the free and informed consent form, in accordance with the recommendation of the questionnaire validation study.

Sociodemographic characteristics were assessed (age range, sex, marital status, education level, race, primary diagnosis and presence of metastasis). To assess the need for information, the EORTC-QLQ INFO25 questionnaire about the information the oncology patient received was used, validated for Brazil. This version of the questionnaire, QLQ-INFO25 by EORTC, used in this study, consists of 25 questions and four dimensions. The first refers to information on the disease (4 questions), the second aims to discover information about the medical examinations (3 questions), the third refers to information on the treatment (6 questions) and the fourth investigates information about other services (4 questions). Besides the four multi-item dimensions highlighted, the EORTC QLQ-INFO25 contains eight individual items, which address questions on different care locations, self-help attempts, receipt of written and digital information, satisfaction with the information received, desire to receive further information, desire to receive less information and the utility of the information received. Among the 25 questions, 21 are organized on a Likert scale (1 - None/No; 2 - Little/A little; 3 - Reasonable/Moderately; 4 - A lot/Much), while four have dichotomous answers (20, 21, 23, 24). In addition, items 23 and 24 include a second, open-ended question. Nevertheless, based on the answers obtained, the answers were categorized for analysis purposes. The following categories were created: diagnosis; prognosis; treatment and complications. The subscales and their respective items have been described in Table 1. It should be highlighted that the scale does not have a fixed cut-off point. In this care, the assessment by the expert committee that validated the scale was to recommend the use of the research population's median score as a parameter whenever the scale is applied.

**Table 1.** Characteristics of EORTC QLQ-INFO25 questionnaire

Subscale	Dimensions	Questionnaire items	Items	
Multi-items	Total items	Information about your disease	1; 2; 3; 4	4
		Information on medical examinations	5; 6; 7	3
		Information on the treatment	8; 9; 10; 11; 12; 13	6
		Information on other services	14; 15; 16; 17	4
		Different care locations	18	1
Information on other areas		Self-help	19	1
		Written information	20	1
		Information on CD, cassette/video	21	1
		Satisfaction with the amount of information received	22	1
Qualitative aspects		Desire to receive further information	23	1
		Desire to have received less information	24	1
		Overall utility of the information	25	1

The scores were calculated for each subscale and the association between the subscales and the sociodemographic (sex, age, education, race, marital status) and clinical (tumor location, presence of metastases) variables was assessed. The means and standard deviations were analyzed for the multi-item dimensions in the EORTC QLQ-INFO25 questionnaire, divided and named subscale 1 (information on the diagnosis of the disease), subscale 2 (information on the medical examinations), subscale 3 (information on the treatment) and subscale 4 (information on other services) and the clinical and sociodemographic characteristics.

For the categorical variables, the ANOVA test was used and statistical significance was set at 95%. For the data analyses, the statistical software SPSS, version 22 was applied. This study received authorization from the INCA Ethics and Research Committee (CEP) and did not involve any conflicts of interests. The CEP's opinion, including the approval of this project, is attached, registered under protocol number: 863.339.

## Results

One hundred patients participated in the study. The sample profile consisted of male (52%), white individuals (61%), with a relatively low education level (primary level 35% and secondary

level 49%), married (61%) and elderly (52%). What the tumor location is concerned, the most frequent locations were colon and rectal tumor (64%), followed by stomach tumors (22%). What the disease prognosis is concerned, 40% of the participants present metastases (Table 2).

For most items in the EORTC QLQ-INFO25, the patients demonstrated satisfaction with the amount of information received. The items related to the disease (1 and 2), tests (5 to 7), treatment (8) and general information (25) stand out with averages superior to 80%. For some items, however, the patients demonstrated dissatisfaction with the amount of information received, especially information linked to the cause of the disease (3), transcendental nature of the treatment (12 and 13), aspects of extra-hospital and home care (14 and 15), different care locations (18) and aspects of self-help (19), with satisfaction levels inferior to 40%. It is important to highlight that 100% of negative answers were obtained about receiving information on media (CD, tapes or videos) – as that is not part of the hospital routine. The same was found for the desire to receive less information. As for the desire for more information, the most frequent demand is related to the disease prognosis. Finally, the dimension with greater satisfaction with the amount of information is related to the medical tests, while the lowest satisfaction level is linked to other services (Table 3).

The general average scale score for the study population was 66. This demonstrated that the satisfaction with the amount of information offered is regular to good. When the subscales were assessed, however, a great difference was observed among the averages. For the subscales of information about the disease and the medical tests, the assessment is excellent. For the information about the treatment, the assessment was regular, and information about other services received a bad evaluation. The items that most strongly influenced this bad assessment were related to the treatment effects in social and family life, in sexual activity; and about additional care services beyond the hospital,

including rehabilitation services. Thus, difficulty is observed to obtain information about the continuity of treatment beyond the hospital service, reflecting difficulties to manage the care network.

The analysis of the degree of satisfaction with the information given to the patients according to clinical and demographic characteristics is displayed in Table 4. For the subscale of information about the diagnosis of the disease, a statistically significant difference can be observed for race, with a higher degree of satisfaction among black and mulatto people. For the subscale of information about the treatment, a significant difference was found

**Table 2.** General characteristics of the patients (n=100)

Variables	<i>n</i>
Sex	
Male	52
Female	48
Age range	
20 to 39 years	4
40 to 59 years	44
60 years and older	52
Race	
White	61
Black/Mulatto	39
Education	
Primary	35
Secondary	49
Higher	16
Marital status	
Single	28
Married	61
Widowed/separated	11
Diagnosis	
Colon	42
Rectum	22
Stomach	22
Esophagus	3
Appendix	1
Liver	4
Bile Ducts	2
Pancreas	4
Metastasis	
Yes	40
No	60

**Table 3.** Summary of test statistics for the QLQ-INFO25 items among the interviewed patients (n=100)

Item	% qualification per category				Statistics	
	None	Little	Modderate	A lot	Average	SD
1- The diagnosis of your disease?	0	11	42	47	84.0	16.9
2- The extension of your disease (how much it has spread)?	3	13	44	40	80.3	19.6
3- The possible causes of your disease?	41	39	14	5	48.8	37.2
4- If the disease is under control?	8	19	44	29	73.5	22.4
5- The objective of the tests you underwent or may have to take?	3	4	18	75	91.3	17.5
6- The test procedures?	3	3	14	80	92.8	16.8
7- The results of the tests you have already undergone?	2	8	27	63	87.8	18.3
8- The medical treatment (chemotherapy, radiotherapy, surgery or other treatment form)	1	8	31	60	87.5	17.2
9- The expected benefit of the treatment?	4	16	40	40	79.0	20.9
10- The possible side effects of your treatment?	9	20	49	22	71.0	21.8
11- The expected effects of the treatment on the disease symptoms?	5	32	44	19	69.3	20.4
12- The effects of the treatment on your social and family life?	72	15	6	7	37.0	22.3
13- The effects of the treatment on your sexual activity?	80	11	5	4	33.3	18.8
14-Additional assistance beyond the hospital (e.g. help with activities of daily living, support group, visits by nursing professionals)?	80	14	2	4	23.5	17.6
15- Rehabilitation services (e.g. physiotherapy, occupational therapy)?	74	12	7	7	36.8	22.6
16- Aspects of how to take care of your disease at home?	12	20	51	17	68.3	22.1
17- Possible professional psychological support?	10	30	39	21	67.8	22.8
18- Other locations for medical care (hospital/outpatient clinic/ at home)?	57	32	7	4	39.5	19.8
19- Things you can do to help yourself to get better (rest, contact with other people...)?	47	31	15	7	45.5	23.4
22- Were you satisfied with the amount of information you received?	0	15	53	32	79.3	16.7
25- Overall, was the information you received during the treatment useful?	0	7	32	61	88.5	15.7
<b>Dichotomous items</b>			<b>Yes</b>	<b>No</b>	<b>Mean</b>	<b>SD</b>
20- Did you receive written information?			5	95	48.8	5.5
21- Did you receive information on a CD or tape/video?			0	100	50.0	0.0
23- Would you like to receive more information?			89	11	27.8	7.9
24- Would you like to have received less information?			0	100	50.0	0.0
<b>Open question*</b>	<b>Diag</b>	<b>Prog</b>	<b>Tt</b>	<b>Comp</b>	<b>Mean</b>	<b>SD</b>
23X- If yes, please specify about which themes	15	44	17	13		
<b>Subscales</b>						
Information related to the disease					71.6	16.7
Information related to the medical tests					90.6	15.5
Information related to the treatment					62.8	15.5
Information about other services					51.3	15.3

(\*) Diag - diagnosis; Prog - prognosis; Tt - treatment; Comp - complications;



**Table 4.** Level of satisfaction for the dimensions of satisfaction with the information according to sociodemographic variables among the patients interviewed ( $n=100$ ).

Variables	Subscale											
	Diagnosis			Medical tests			Treatment			Other services		
	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>
Sex												
Male	73.4	15.8	0.25	92.6	14.4	0.17	65.1	15.0	0.13	54.3	17.3	0.04
Female	69.7	17.4		88.4	16.4		60.4	15.7		48.0	12.2	
Age range												
20 to 39 years	65.6	15.7	0.73	83.3	11.8	0.62	59.4	21.6	0.48	43.8	8.8	0.55
40 to 59 years	72.4	17.5		90.4	17.0		65.0	17.4		52.4	14.5	
60 years and older	71.5	16.3		91.2	14.6		61.4	13.5		51.0	16.3	
Race												
White	74.0	15.8	0.03	92.4	14.5	0.87	65.3	15.0	0.22	53.3	15.2	0.05
Black/Mulatto	66.6	17.5		86.7	16.9		57.7	15.5		47.1	15.1	
Education												
Illiterate	81.3		0.74	91.7		0.11	45.8		0.01	25.0		0.02
Primary	67.4	19.2		86.2	16.6		57.9	14.2		48.0	15.1	
Secondary	71.9	13.2		94.4	9.6		64.4	15.0		51.8	13.9	
Higher	80.1	16.6		90.1	23.2		71.1	16.2		59.4	16.8	
Marital status												
Single	69.9	12.2	0.87	89.7	13.3	0.96	59.8	14.9	0.65	50.4	11.6	0.48
Married	72.2	17.3		90.8	16.1		63.1	15.9		52.8	16.7	
Widowed/ separated	71.5	18.2		90.7	15.8		64.2	15.1		48.5	14.2	
Diagnosis												
Colon	73.5	17.1	0.11	90.7	13.3	0.22	64.0	17.4	0.53	49.2	15.6	0.26
Rectum	74.5	15.5		93.8	12.6		62.3	13.4		54.9	17.0	
Stomach	64.9	16.4		87.7	17.0		57.3	14.7		46.4	15.9	
Esophagus	84.4	22.1		100.0	0.0		75.0	17.7		62.5	17.7	
Appendix	57.5	18.4		75.0	29.5		63.3	21.5		57.5	12.0	
Liver	81.3	8.8		100.0	0.0		72.9	8.8		65.6	13.3	
Biliary Ducts	83.3	3.6		100.0	0.0		72.2	9.6		60.4	3.6	
Pancreas	72.2	15.1		90.2	17.8		64.0	13.9		49.4	9.9	
Metastasis												
Yes	71.3	14.2	0.83	90.6	17.8	0.99	62.4	16.1	0.77	52.3	15.6	0.48
No	72.0	19.3		90.6	12.4		63.3	14.8		50.1	15.2	



for education, with greater satisfaction among the patients with higher education levels. For the subscale of information about other services, a significant difference was found for sex and education, with greater satisfaction, respectively, for the male group and individuals with a higher education level. It is highlighted that, for the subscale of information about the medical tests, no statistically significant difference was observed for any sociodemographic variable.

A similar analysis was developed for the isolated scale items (Table 5). For the sex variable, significant differences were found for the items addressing Information about other medical care locations (item 18) and self-care (item 19), with greater satisfaction among men. For race, a difference was found for overall satisfaction (item 22), with greater satisfaction among white patients. The remaining characteristics did not show any significant difference. It is important to mention that items 21 and 24 were excluded from the table because they presented 100% of “no” answers among the interviewees. In addition, no variability measure is shown for the “illiterate” category because there was only one subject.

## Discussion

The amount of information mentioned as received about the disease, the medical tests and treatment was superior to the average score. We believe that this is related to the fact that the sample consists of patients hospitalized at a surgical ward, which means more medical tests and therapeutic conducts, consequently offering information about the test objectives and results and about

the disease and treatment more constantly. This finding is similar to the observations by Adler *et al.*,<sup>(12)</sup> in which the same questionnaire was applied to 72 patients and participants in the German study and to the phase IV study concerning the validation of the EORTC QLQ-INFO25 by Arraras *et al.*<sup>(6)</sup> Almost all participants indicated some knowledge about the diagnosis of their oncologic disease. About 89% of the sample referred having received moderate or plenty of information. Studies in other countries have also evidenced that most patients received a lot of information about their diagnosis.<sup>(6,12)</sup> It should be highlighted, however, that the amount of information referred does not translate the actual knowledge about the disease, as highlighted in the study by Ferraz Gonçalves *et al.*,<sup>(13)</sup> which verified that most patients (72%) indicated knowing the diagnosis; nevertheless, not all patients affirmed the diagnosis in a way that clearly showed that they were aware of the nature of their disease. Although these study results show the predominance of plenty of information about the diagnosis, a difference exists between the information provided and the patients’ needs. The cultural and social differences, emotional issues and the range of communication patterns can characterize this difference.

What the information received about the possible causes of the disease is concerned, (41%) indicates having received no information and (39%) mentions having received little information, suggesting that the team did not even discuss the matter of exposure to the risk factors, an important approach in the prevention of gastrointestinal cancer and in the cases of relapse of the disease. Nunes<sup>(14)</sup> confirms this result in the study developed in Lisbon in 2012,

**Table 5.** Degree of satisfaction for the isolated items of satisfaction with the information according to sociodemographic variables among the patients interviewed ( $n=100$ )

Variables	Item 18			Item 19			Item 20			Item 22			Item 23			Item 25		
	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>	Mean	SD	<i>p</i>
Sex																		
Male	43.3	22.7	0.04	50.0	24.3	0.04	48.6	5.9	0.71	80.3	15.1	0.52	28.4	8.6	0.41	89.9	13.3	0.35
Female	35.4	15.3		40.6	21.7		49.0	5.0		78.1	18.3		27.1	7.0		87.0	17.9	
Age range																		
20 to 39	37.5	25.0	0.94	62.5	25.0	0.20	43.8	12.5	0.14	81.2	12.5	0.94	25.0	0.0	0.76	81.3	12.5	0.22
40 to 59	40.2	20.8		47.6	25.5		49.4	3.9		78.7	18.2		28.0	8.3		91.5	15.4	
60 +	39.1	19.1		42.7	21.3		48.6	5.7		79.5	16.0		27.7	7.9		86.8	15.9	
Race																		
White	40.4	19.3	0.49	47.4	23.3	0.23	48.2	6.6	0.11	82.0	16.1	0.01	28.3	8.5	0.30	91.5	13.4	0.99
Black/ Mulatto	37.5	21.1		41.4	23.4		50.0	0.0		73.4	16.7		26.6	6.1		82.0	18.2	
Education																		
Illiterate	25.0	0.0	0.21	25.0	0.0	0.06	50.0	0.0	0.98	100.0	0.0	0.02	50.0	0.0	0.02	100.0	0.0	0.17
Primary	36.8	17.2		40.1	20.6		48.7	5.7		74.3	16.9		28.3	8.6		84.2	17.8	
Secondary	38.9	20.3		46.1	21.9		48.9	5.2		80.0	14.7		26.7	6.3		91.1	14.3	
Higher	48.4	23.2		57.8	29.9		48.4	6.3		87.5	18.3		28.1	8.5		90.6	12.5	
Marital status																		
Single	33.8	15.2	0.38	39.7	19.9	0.34	48.5	6.1	0.96	79.4	13.2	0.96	27.9	8.3	0.86	94.1	10.9	0.26
Married	41.4	21.7		48.3	25.6		48.7	5.6		78.9	17.4		28.0	8.2		87.1	16.4	
Widowed/ separated	39.0	17.8		43.0	19.8		49.0	5.0		80.0	17.7		27.0	6.9		88.0	16.3	
Diagnosis																		
Colon	40.9	20.6	0.82	50.0	25.0	0.38	48.5	6.1	0.85	80.3	16.2	0.1	28.8	9.1	0.86	88.6	16.6	0.31
Rectum	37.0	19.8		50.0	26.1		48.9	5.2		82.6	14.0		28.3	8.6		91.3	14.3	
Stomach	38.1	18.7		38.1	20.3		48.8	5.5		73.8	18.5		27.4	7.5		83.3	16.5	
Esophagus	37.5	17.7		37.5	17.7		50.0	0.0		75.0	0.0		25.0	0.0		100.0	0.0	
Appendix	35.0	22.4		40.0	22.4		45.0	11.2		65.0	22.4		30.0	11.2		80.0	20.9	
Liver	62.5	17.7		62.5	17.7		50.0	0.0		100.0	0.0		25.0	0.0		100.0	0.0	
Biliary Ducts	41.7	14.4		50.0	25.0		50.0	0.0		91.7	14.4		25.0	0.0		100.0	0.0	
Pancreas	40.9	23.1		36.4	17.2		50.0	0.0		79.5	15.1		25.0	0.0		88.6	13.1	
Metastasis																		
Yes	42.1	21.6	0.15	46.8	23.8	0.56	48.6	5.8	0.78	79.6	16.2	0.8	28.2	8.5	0.5	89.4	15.0	0.55
No	36.4	17.2		44.0	23.1		48.9	5.2		78.8	17.5		27.2	7.1		87.5	16.5	

referring that 70% of the sample indicated not having any information about the possible causes of the disease. With regard to the small amount of information on the effects of the treatment on their sexual activity, a large proportion considered they had not received any information (80%), suggesting the relation with a lesser valuation of this theme in function of the disease and little room, for cultural reasons, to discuss the theme. These findings were also evidenced in another study,<sup>(13)</sup> based on which we conjecture that the theme is difficult to manage in different cultures, as these studies cited were developed in different European countries.

Concerning the items about additional assistance beyond the hospital, such as help with activities of daily living, support groups, visits from nursing professionals, rehabilitation services, and other locations for medical care, outpatient clinic, at home, the results showed that most answers indicated no information about these items, reflecting the insufficient comprehensiveness of the actions and services in the local health system, resulting in the discontinuity of the rehabilitation care and treatments, which are extremely important for the cancer patients' quality of life. These findings were supported by the results of the study by Matos,<sup>(5)</sup> which described the validation process of the QLQ-INFO25 or Portuguese from Portugal, as well as by the results of Arraras *et al.*<sup>(6)</sup> and Pinto *et al.*,<sup>(15)</sup> in the study developed at a Belgian cancer treatment center, involving patients under chemotherapy.

In that study, no association was found between the amount of information received and the sociodemographic and clinical characteristics studied. The validation study of the INFO25, developed by Arraras *et al.*,<sup>(6)</sup> also evidenced the lack of statistical association between the sociodemographic characteristics and the items described above. Bozec *et al.*,<sup>(16)</sup> then, in the multicenter study developed in 2016, involving 200 patients who received chemotherapy and/or radiotherapy for all cancer types, showed in the results that women were more dissatisfied with the items amount and utility of the information

received when compared to men. Although some questions were answered satisfactorily, showing scores far superior to the average, it was observed that 89% of the sample indicates the desire to receive more overall information. This finding is very close to the results presented in other studies,<sup>(12-16)</sup> based on which we can suppose that, to respond to the demand concerning the amount of information, the quality of the information provided should be taken into account, as many variables interfere in the absorption of the information, such as the patient's way of life, the patient and family's ability to understand the information and how they interpret the disease.

The general conclusion of this study is that the satisfaction with the information received was analyzed in patients diagnosed with abdominal cancer using the QLQ-INFO25 scale by EORTC. Despite the high level of satisfaction with the information received, it was observed that all patients would like further information, which shows us that repeating or offering new information continuously should be an ongoing process in care for these patients. The objective for health care should be to find ways of providing information that grant patients the support they need and want for the disease coping process, ranging from the diagnosis until end-of-life care. Thus, measuring the satisfaction with the information the cancer patient receives throughout the various phases of the disease and its treatment enables us to identify and rank the problems: monitor the treatment response and the health changes and promote better communication with the patient by training the care team involved, among other applications.

## References

1. Instituto Nacional de Câncer José Alencar Gomes da Silva. Estimativa 2016: incidência de câncer no Brasil. Rio de Janeiro: INCA; 2016.
2. Dóro MP, Pasquini R, Medeiros CR, Bitencourt, MA, Moura GL. O câncer e sua representação simbólica. *Psicologia: Ciência e Profissão*. 2004; 24(2):120–33.
3. Neufeld KR, Degner LF, Dick JA. A nursing intervention strategy to foster patient involvement

- in treatment decisions. *Oncol. Nurs. Forum.* 1993; 20(4):631–5.
4. Campos MR, Leal M do C, Jr S, De PR, Cunha CB da. Consistency between data sources and inter-observer reliability in the Study on Neonatal and Perinatal Morbidity and Mortality and Care in the City of Rio de Janeiro. *Cad. Saúde Pública;* 2004; (20):34–43.
  5. Matos MAF. Informação ao doente oncológico. Validação da versão Portuguesa do questionário EORTC QLQ-INFO26 [Internet]. Lisboa: Faculdade de Medicina de Lisboa, Portugal; 2010 [cited 18 Apr, 2017]. Available from: [http://repositorio.ul.pt/bitstream/10451/2700/1/603306\\_Tese.pdf](http://repositorio.ul.pt/bitstream/10451/2700/1/603306_Tese.pdf)
  6. Arraras JI, Greimel E, Sezer O, Chie W-C, Bergenmar M, Costantini A, et al. An international validation study of the EORTC QLQ-INFO25 questionnaire: an instrument to assess the information given to cancer patients. *Eur. J. Cancer.* 2010; 46(15):2726–38.
  7. Gilmer JS, Tripp-Reimer T, Buckwalter KC, Andrews PH, Morris WW, Rios H, et al. Translation and validation issues for a multidimensional elderly self-assessment instrument. *West J. Nurs. Res.* 1995; 17(2):220–6.
  8. Byrt T, Bishop J, Carlin J. Bias, prevalence and kappa. *J. Clin. Epidemiol.* 1993; 46(5):423–9.
  9. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of crosscultural adaptation of self-report measures. *Spine.* 2000; 25(24):3186–91.
  10. Arraras JI, Manterola A, Hernández B, Arias de la Vega F, Martínez M, Vila M, et al. The EORTC information questionnaire, EORTC QLQ-INFO25. Validation study for Spanish patients. *Clin. Transl. Oncol.* 2011; 3(6):401–10.
  11. Mendonça SR, Valadão M, Castro L, et al. A Importância da Consulta de Enfermagem em Pré-operatório de Ostomias Intestinais. *Rev. Bras. Cancerol.* 2007; 53(4):431–5.
  12. Adler J, Paelecke-Habermann A, Janh P, Landenberger M, Lepow B, Vordermark D. Patient information in radiation oncology: a cross-sectional pilot study using the EORTC QLQ-INFO26 module. *Radiat. Oncol.* 2009; 4: 40.
  13. Ferraz Gonçalves A, Marques A, Rocha S, Leitão P, Mesquita M. Breaking bad news: Experiences and preferences of advanced cancer patients at a Portuguese oncology centre. *Palliat. Med.* 2005; 19(7):526–31.
  14. Nunes FDBR. Da informação Fornecida ao consentimento informado a doentes oncológicos. [Tese Mestrado em Cuidados Paliativos]. Porto: Faculdade de Medicina, Universidade do Porto; 2012.
  15. Pinto AC, Ferreira-Santos F, dal Lago L, Azambuja E, Pimentel FL et al. Information perception, wishes, and satisfaction in ambulatory cancer patients under active treatment: patient-reported outcomes with QLQ-INFO25. *Ecancermedicalscience.* 2014; (2)8:425.
  16. Bozec A, Schultz P, Gal J, Chamorey E, Chateau Y, Dassonville O et al. Evaluation of the information given to patients undergoing head and neck cancer surgery using the EORTC QLQ-INFO25 questionnaire: A prospective multicentric study. *Eur. J. Cancer.* 2016;(67):73–82