Reliability of the EORTC QLQ-INFO25 to Assess Cancer Patients' Information Needs

Confiabilidade do EORTC QLQ-INFO25 para Avaliar a Necessidade de Informação de Pacientes Oncológicos

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Fiabilidad de la EORTC QLQ-INFO25 para Evaluar las Necesidades de Información de los Pacientes con Cáncer

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ABSTRACT

Introduction: Most patients do not have a satisfactory degree of understanding about cancer. For the information communication process to be truly effective, it is necessary to identify the patient's level of knowledge beforehand. **Objective:** To verify the test-retest stability of the EORTC QLQ-INFO25 instrument, in its Brazilian Portuguese version, to assess cancer patient's information needs. **Method:** The instrument was applied in 253 patients hospitalized in the clinical and surgical wards of a high-complexity cancer treatment hospital located in the city of Rio de Janeiro through the application of a questionnaire in an individual interview. To test the adequacy of the measurement process, 85 patients adhered to the retest, with an interval of 7 to 15 days. Data were entered into a database by independent double typing in the Excel program, and the analysis was performed using simple and weighted Kappa statistics. **Results:** Responses were stable, and test-retest reliability estimates ranged from good to excellent (0.66 to 0.99). The instrument also demonstrated good stability when applied to other populations and patients with different types of cancer. **Conclusion:** The EORTEC QLQ-INFO25 instrument can contribute for the measurement of patient satisfaction in relation to their need for information since the results suggest a high stability of information, making its applicability in the Brazilian population viable.
Key words: patient satisfaction/statistics & numerical data; validation study; reproducibility of results; health communication; neoplasms.

RESUMO

Introdução: A maioria dos pacientes não possui um grau satisfatório de compreensão acerca do câncer. Para que o processo de comunicação de informações seja verdadeiramente efetivo, é necessário identificar anteriormente o nível de conhecimento do paciente. **Objetivo:** Verificar a estabilidade teste-reteste do instrumento EORTC QLQ-INFO25 em sua versão em português do Brasil, para avaliação da necessidade de informação do paciente oncológico. **Método:** O instrumento foi aplicado em 253 pacientes hospitalizados nas enfermarias clínicas e cirúrgicas de um hospital de alta complexidade no tratamento do câncer situado no município do Rio de Janeiro, por meio de um questionário com entrevista individual. Para testar a adequação do processo de aferição, 85 pacientes aderiram ao reteste, com intervalo de sete a 15 dias. Os dados foram inseridos em um banco de dados por dupla digitação independente no programa *Microsoft Excel*. A análise foi realizada por meio da estatística Kappa simples e ponderada. **Resultados:** As respostas mostraram-se estáveis, e as estimativas de confiabilidade teste-reteste variaram de boas a excelentes (0,66 a 0,99). O instrumento também demonstrou boa estabilidade quando aplicado em outras populações e em pacientes com diferentes tipos de câncer. **Conclusão:** O instrumento EORTEC QLQ-INFO25 pode contribuir para a mensuração da satisfação do paciente em relação à sua necessidade de informação, uma vez que os resultados sugerem alta estabilidade das informações, tornando viável a sua aplicabilidade na população brasileira.
Palavras-chave: satisfação do paciente/estatística & dados numéricos; estudo de validação; reprodutibilidade dos testes; comunicação em saúde; neoplasias.

RESUMEN

Introducción: La mayoría de los pacientes no tiene un grado satisfactorio de conocimiento sobre el cáncer. Para que el proceso de comunicación de la información sea realmente efectivo, es necesario identificar de antemano el nivel de conocimiento del paciente. **Objetivo:** Verificar la estabilidad *test-retest* del instrumento EORTC QLQ-INFO25, en su versión portuguesa de Brasil, para evaluar la necesidad de información en pacientes con cáncer. **Método:** El instrumento se aplicó a 253 pacientes hospitalizados en las salas clínico-quirúrgicas de un hospital de tratamiento oncológico de alta complejidad ubicado en la ciudad de Río de Janeiro mediante la aplicación de un cuestionario a modo de entrevista individual. Para probar la idoneidad del proceso de medición, 85 pacientes se adhirieron a la nueva prueba, con un intervalo de 7 a 15 días. Los datos se ingresaron en una base de datos mediante doble entrada independiente, en el programa Excel, y el análisis se realizó utilizando estadísticas Kappa simples y ponderada. **Resultados:** Las respuestas fueron estables y las estimaciones de fiabilidad *test-retest* variaron de buenas a excelentes (0,66 a 0,99). El instrumento también demostró una buena estabilidad cuando se aplicó a otras poblaciones y pacientes con diferentes tipos de cáncer. **Conclusión:** El instrumento EORTEC QLQ-INFO25 puede contribuir a la medición de la satisfacción del paciente en relación a su necesidad de información ya que los resultados sugieren una alta estabilidad de la información, viabilizando su aplicabilidad en la población brasileña.
Palabras clave: satisfacción del paciente/estadística & datos numéricos; estudio de validación; reproducibilidad de los resultados; comunicación en salud; neoplasias.

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INTRODUCTION

Cancer is one of the main public health problems worldwide, it is one of the four major causes of early death in most of the countries. Recent estimates indicate that 18 million new cases of cancer and 9.6 million deaths will occur in the world[1]. According to estimates of the National Cancer Institute José Alencar Gomes da Silva (INCA), 625 thousand new cases of cancer will occur in Brazil until 2022[2]. Both the diagnosis and antineoplastic therapy cause a variety of physical, emotional, social, economic repercussions among others if poorly managed by health teams, possibly leading to depression, fear, anxiety at different intensities. The patient's behavior in its health-disease process hinges on socioeconomic and cultural factors of each individual[3].

The approach to the patient diagnosed with cancer brings up the process of coping imbued with negative aspects due to the disease's social burden, seen as a death sentence and its physiopathological aspects that compel the patient to experience suffering[4]. The patient's literacy has been an effective strategy to boost the understanding of the sickening process making the patient more aware of the repercussions of the pathology, enabling him to take decisions along the sickening, treatment and rehabilitation processes[5].

According to Trintenaro et al.[4], the health team should brief the patients with correct information about the oncologic treatment but not always the communication is effective for several reasons as education level, cognition, culture and age which may compromise its quality. This conception was corroborated by a study which attempted to evaluate the literacy of mastectomized women in face of breast cancer sickening and treatment process; it identified that even after going through the entire treatment process, many women needed further clarifications about the disease as risk factors, different types of treatment, medications among others. Another important aspect brought up by the same study was that the women believed that the information gap on the health-disease process of breast cancer caused embarrassment, fear, nervousness and insecurity when given the diagnosis[6].

Therefore, for effectiveness of the communication process it is necessary to identify earlier the patient's knowledge. For such, there are some instruments available in the literature in cardiology, for example[5]. Currently, the European Organisation for Research and Treatment of Cancer Quality of Life Group information questionnaire (EORTC QLQ-INFO25) to evaluate the volume of information given to the patients with cancer at the diagnosis and treatment and for clinical and research purposes is in the process of transcultural adaptation to be validated in Brazil[7]. The first stage, addressing the phases of semantic and conceptual equivalence has been completed[8]. The objective of this study was to check the test-retest stability of the Brazilian version of EORTC QLQ-INFO25.

METHOD

Six phases were the basis for the transcultural adaptation of the instrument EORTC QLQ-INFO25 into Brazilian Portuguese: 1) conceptual equivalence with literature review encompassing publications of the original instrument and target-population; 2) equivalence of items including the discussion with experts and target-population; 3) semantic equivalence involving translations, re-translations, evaluation of the semantic equivalence among retranslations and the original, discussion with the target-population and experts for final adjustments and pre-test; 4) operational equivalence based on the study group's evaluation for pertinence and consistency of the vehicle and format of the questions/instructions with the scenario where it was administered, how it was applied, and modality of categorization; 5) equivalence of measuring, including psychometric studies to evaluate the dimensional validity and adequacy of the instrument items, reliability and validity of the construct; 6) functioning equivalence obtained from the equivalences identified in other stages of the evaluation[9]. The scope of this study covers the stage of evaluation of the reliability of the test-retest of the instrument EORTC QLQ-INFO25, inserted in the fifth phase of the transcultural adaptation process.

The 25-items instrument is divided in four dimensions: information about the disease; information about medical tests; information about treatment and information about other services. Further to other items covering different care clinics, attempts of self-help, receiving written and digital information, satisfaction with what was received, wish to be given more and less information and worth of the information given. Of the 25 items, 21 are Likert-scale (none/no; scarce/some; fair/slightly; quite/much) and four are polar questions (yes/no). Furthermore, two items present a second open question. For additional data, a proprietary sociodemographic and clinic form was applied.

A questionnaire was applied to collect the data with personal interview with men and women with or older than 18 years affected by many types of cancer hospitalized at INCA's clinic and surgical infirmaries, after been presented the study objectives, agreeing in joining the study and signing the Informed Consent Form (ICF). The exclusion criteria were patients with cognitive

disorders most likely compromising the veracity of the responses with central nervous system (CNS) neoplasm or metastasis.

It was applied in 253 patients who were asked to respond to the questionnaire again in 7 to 15 days to evaluate the process of measurement. It was applied the Statistic Kappa to check the test-retest reliability, score of dimensions and evaluation of the individual variables. For ordinal variables, it was applied the quadratic weighted Kappa[9]. The following cutoff were selected to classify the level of stability of the responses: poor (<0.00); weak (0 to 0.2); fair (0.21 to 0.4); moderate (0.41 to 0.6); good (0.61 to 0.8); almost perfect (0.81 to 1)[10]. The confidence intervals of 95% were estimated for all statistics with the method Bootstrap.

The Institutional Review Board of INCA approved the study in compliance with Ordinance 466/2012[11], Report 863,339/2014 (CAAE: 33237314.2.0000.5274).

RESULTS

The study population (253 patients) had in average 55.2 years of age (standard deviation - SD = 15.9). Nearly half of them (52.2%) were males, 51.0%, Whites, 48.6%, Brown or Black and 0.4%, Yellow. Low education predominated (49.4% have completed elementary school and 2% were illiterate; 40.3% completed high-school and 8.3% finished college). The prevalence was married individuals (53.8%). Clinical treatment (60.9%) prevailed over surgical (39.1%) and 60.9% had no metastasis (Table 1).

The items with polar questions is where the expected answer was yes/no, 1 and 2, respectively for frequency of the categorical variables as shown in Table 2. Items 23 e 24, besides this, had a field where the patient was free to elaborate if the response was "yes". Given that some questions call for open responses where no repetition pattern exists, they were not evaluated for the method of analysis adopted in the present study.

The most frequent category of response was "much". For the open question, a response pattern was detected about the wish to know more about the diagnosis of the disease, the results of the tests and treatment. None of the participants reported the wish to be given less information (Table 2). The summary of the responses for each item – ranging from the first category = 1 up to the last category = 4, and Yes = 1 and No = 0 for dichotomic items – resulted in a mean value for test and retest (Table 3). No great discrepancy was found for the values, revealing a response pattern in the two options. The small variation of the responses was corroborated with low standard deviation for all the items.

Table 1. Clinical and demographic characteristics of the population (n=253)

Characteristics	n	%
Sex		
Male	132	52.2
Female	121	47.8
Race		
White	129	51.0
Black/Brown	123	48.6
Yellow	01	0.4
Education		
Illiterate	05	2.0
Elementary School	125	49.4
High-school	102	40.3
University	21	8.3
Marital Status		
Single	56	22.1
Married	136	53.8
Widow/widower	61	24.1
Type of treatment		
Surgery	99	39.1
Clinical	154	60.9
Metastasis		
Yes	99	39.1
No	154	60.9
	Mean	**Standard Deviation**
Age	55.2	15.9

At last, estimates of reliability measured with quadratic weighted Kappa for categorical variables and simple Kappa for polar questions were calculated. For weighted Kappa, the values ranged between 0.66 and 0.87. Very low estimates were detected for "satisfaction with the volume of information given" and high estimates for "effects of the treatment on social and family life". The values of simple Kappa ranged from 0.89 to 0.99, the lower was related to the wish of receiving more information and the higher to receiving written information or in other format. Lower Kappa values for some items can be explained by the time interval from test and retest because an increase of the level of satisfaction may have occurred as result of information or clarification about the prognosis after the results of the tests, creating discrepancies in the responses for the item related to the wish of being given more information.

DISCUSSION

The reliability of a simplified questionnaire translated in Brazilian Portuguese was evaluated in the present study;

Table 2. Summary of the statistics of the items of QLQ-INFO25 (n=253)

How much information have you been given during your disease or current treatment?	Frequency (%)			
	None	**Scarce**	**Fair**	**Quite**
1. Diagnosis of your disease	0.4	8.7	51.3	39.5
2. Extension of your disease (to what extent did it spread)	2.3	39.9	47.4	10.2
3. Possible causes of your disease	22.9	42.5	22.1	12.2
4. Is the disease controlled?	3.9	38.7	49.1	8.3
5. Objective of the tests you did or might have to do	0.7	44.7	44.6	9.8
6. Procedures of the tests	1.1	21.4	51.7	25.6
7. The results of the tests you did	0.7	16.2	58.1	24.9
8. Medical treatment (chemotherapy, radiotherapy, surgery or other modality of treatment)	-	9.5	53.7	36.7
9. Anticipated benefit of the treatment	0.4	32.4	51.7	15.4
10. Possible side effects of your treatment	2.3	13.0	46.2	38.3
11. Anticipated effects of the treatment on the disease's symptoms	4.3	49.4	39.1	7.1
12. The effects of the treatment on your social and family life	64.4	31.6	3.5	0.4
13. The effects of the treatment on your sexual life	77.1	19.7	3.1	-
14. Additional off-hospital care (daily activities and group support, visits of nurses)	88.1	10.2	1.1	0.4
15. Rehabilitation services (physiotherapy, occupational therapy)	45.8	35.1	17.7	1.1
16. Aspects of managing your disease at home	9.4	40.3	47.4	2.7
17. Possible psychological professional support	13.8	51.3	33.9	0.7
18. Other medical clinics (hospitals/outpatient/home-based)	83.7	15.1	0.7	0.4
19. Things you can do to help yourself (rest, contact with others…)	20.9	28.1	47.4	3.5
	No	**Yes**		
20. Have you received written information?*	32.0	67.9	-	-
21. Have you received information in CD or tape/video?*	0.4	99.6	-	-
	No	**A little**	**Slightly**	**Quite**
22. Did the information received meet your demands?	1.5	19.8	62.7	15.8
	No	**Yes**		
23. Would you prefer more information?*	82.5	17.4	-	-
24. Would you prefer less information?*	-	100.0	-	-
	No	**A little**	**Slightly**	**Quite**
25. Overall, the information offered during the treatment were useful?	0.4	1.1	20.2	78.1

(*) Questions 20, 21, 23 and 24 are binary.

Table 3. Weight Kappa statistic (test-retest) of the responses to INFO 25 (n=253 for test and n=85 for retest)

Variables	Test		Retest		Weighted Kappa	
	Mean	SD	Mean	SD	k	CI 95%
1. Diagnosis of your disease	3.30	0.64	3.33	0.66	0.78	0.67-0.89
2. Extension of your disease (to what extent did it spread)	2.67	0.71	2.62	0.68	0.78	0.71-0.85
3. Possible causes of your disease	2.25	0.96	2.17	0.93	0.76	0.65-0.87
4. Is the disease controlled?	2.63	0.71	2.57	0.70	0.76	0.63-0.89
5. Objective of the tests you did or might have to do	2.65	0.68	2.68	0.69	0.75	0.62-0.88
6. Procedures of the tests	3.04	0.74	3.07	0.75	0.74	0.68-0.81
7. The results of the tests you did	3.08	0.67	3.06	0.65	0.73	0.67-0.79
8. Medical treatment (chemotherapy, radiotherapy, surgery or other modality of treatment)	3.28	0.63	3.23	0.59	0.83	0.78-0.88
9. Anticipated benefit of the treatment	2.83	0.69	2.79	0.66	0.81	0.75-0.87
10. Possible side effects of your treatment	3.22	0.76	3.16	0.75	0.68	0.57-0.79
11. Anticipated effects of the treatment on the disease's symptoms	2.49	0.69	2.55	0.71	0.67	0.55-0.78
12. The effects of the treatment on your social and family life	1.40	0.58	1.41	0.59	0.87	0.85-0.88
13. The effects of the treatment on your sexual life	1.26	0.51	1.28	0.52	0.86	0.84-0.89
14. Additional off-hospital care (daily activities and group support, visits of nurses)	1.14	0.41	1.17	0.44	0.84	0.80-0.88
15. Rehabilitation services (physiotherapy, occupational therapy)	1.74	0.79	1.76	0.83	0.84	0.82-0.86
16. Aspects of managing your disease at home	2.43	0.70	2.38	0.66	0.81	0.77-0.85
17. Possible psychological professional support	2.22	0.68	2.25	0.69	0.81	0.76-0.86
18. Other medical clinics (hospitals/outpatient/home-based)	1.18	0.43	1.20	0.44	0.79	0.75-0.83
19. Things you can do to help yourself (rest, contact with others...)	2.34	0.85	2.27	0.83	0.79	0.80-0.98
20. Have you received written information?***	1.94	0.66	1.96	0.65	0.99	0.98-1.00
21. Have you received information in CD or tape/video?***	0.76	0.08	0.85	0.05	0.98	0.97-0.99
22. Did the information received meet your demands?	3.30	0.64	3.33	0.66	0.66	0.58-0.78
23. Would you prefer more information?***	1.67	0.71	2.62	0.68	0.89	0.88-0.90
24. Would you prefer less information?***	0.05	0.01	0.07	0.03	0.93	0.91-0.95
25. Overall, the information offered during the treatment were useful?	3.76	0.48	3.78	0.47	0.71	0.60-0.82

Captions: SD = standard deviation; K = Kappa; CI = confidence interval.
(**) Weighted Kappa is valid only for the items with Likert-scale with regular categorical responses.
(***) For the binary questions 20, 21, 23 and 24 the Simple Kappa coefficient was applied. For the others with Likert-scale responses, the weighted Kappa was applied.

the instrument addressed the main questions related to the necessity of information of patients in oncologic treatment described in the literature[12]. It was applied as an interview because of the low education level of the population investigated. With Kappa coefficient, the responses were stable and the estimates of reliability ranged from good to excellent (0.66 to 0.99). More than half of the items presented good reliability.

Similar results were obtained in international studies, considering the methodological differences in the evaluation of the data. The instrument was validated for the European (United Kingdom, Germany, Swede, Italy,

Austria and Croatia) and Chinese (Taiwan)[7] populations and in Spain[13]. Later, the psychometric validation of this tool was made for the Polish[14] and Iranian populations[15]. All these studies found good stability and the instrument was approved for these populations in observational and intervention studies. The tool was well accepted when applied to patients with certain types of cancer as multiple myeloma[16], breast cancer[17], prostate[18], among others and in outpatient conditions in specific circumstances[19].

These studies indicate that the necessity patients with cancer have is similar but the level of absorption varies with culture. A study corroborated that higher education level reiterates improved patient's health literacy[20], also encountered in another study which identified that the socioeconomic level, evaluated from the family income and level of education was related to the patient's capacity in acquiring knowledge about its health-disease process[21].

The experience with instruments to validate the necessity of information shows that in general the patients are satisfied with the information given[22]. However, when the approach of these patients is revised as in the present study, there are still some aspects that reflect the complexities related to the literacy of the patient with cancer. This complexity was demonstrated in a study which evaluated the literacy of 480 patients in oncologic treatment. It identified that 54.5% of the patients claimed they failed to know more about the disease when the treatment was initiated and it may be related to the negative impacts of the cancer diagnosis due to its stigma and aggressive treatment[6].

This study has also identified that, overall, many patients wished to have more information about the disease, tests and researches, treatment, side effects, sexuality, psychosocial support and financial issues and most of the topics were deemed important or very important. The responses indicate that the patients are satisfied with the information given, mainly in relation to tests and diagnosis, treatment and general experience but there was necessity of information that should have been treated more effectively. This is clear when, even after been given information, the patients continue to ask for information of the same nature, revealing that the process of information flow should be continuous[23].

It is clear and relevant that further to disclosing information matched to the patient's necessities it should be ensured that they are accessible and understandable. In addition to being a concept that meets the National Humanization Policy (PNH), a transparent and seamless communication empowers the patient while widens his literacy about its disease, making it more aware of the decisions it should take about the treatment and construction of a bond with the health team grounded in reliability and future accomplished care[24].

The issues the patients report are the best way to evaluate to what extent the care is actually patient-centered and not on the diagnosis alone leaving clear that the necessity of information is commensurate to the patient's needs[25]. Only the patient knows whether the volume of information given matches the expectations, if it was understood and if it can be retrieved, mainly when patients are investigated in longitudinal studies. In other words, this tool can be applied in different moments of the treatment and the necessity changes along each step of the therapeutic process[26]. It is essential for that matter the utilization of a dependable and correct instrument to reflect the request of information, however, adjusted to each case specificities.

CONCLUSION

The results confirm that patients in cancer treatment need to receive enough information about the disease and the instrument EORTC QLQ-INFO25 can help to meet their demands. The study suggested that the instrument is highly stable, can be applied to the Brazilian population and additional studies about its validity to complement the psychometric evaluation are ongoing.

CONTRIBUTIONS

DECLARATION OF CONFLICT OF INTERESTS

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REFERENCES

1. Bray F, Ferlay J, Soerjomataram I, et al. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2018;68(6):394-424. doi: https://doi.org/10.3322/caac.21492 Erratum in: CA Cancer J Clin. 2020 Jul;70(4):313. doi: https://doi.org/10.3322/caac.21609

2. Instituto Nacional de Câncer José Alencar Gomes da Silva. Estimativa 2020: incidência de câncer no Brasil.

Rio de Janeiro: INCA; 2019 [acesso 2020 maio 5]. Disponível em: https://www.inca.gov.br/sites/ufu.sti. inca.local/files/media/document/estimativa-2020-incidencia-de-cancer-no-brasil.pdf

3. Jesus LG, Cicchelli MQ, Martins GB, et al. Estudo epidemiológico e nível de conhecimento de pacientes oncológicos acerca da mucosite oral e laserterapia. Cienc Cuid Saúde. 2017;16(1):1-7. doi: https://doi.org/10.4025/cienccuidsaude.v16i1.30871

4. Trintenaro JC, Paes AP, Ventura AS. Paciente oncológico frente ao conhecimento da doença. Rev PSIQUE [Internet]. 2016 [acesso 2020 maio 5];1(2):52-68. Disponível em: https://seer.cesjf.br/index.php/psq/article/view/946

5. Bonin CDB, Santos RZ, Ghisi GLM, et al. Construção e validação do questionário de conhecimentos para pacientes com insuficiência cardíaca. Arq Bras Cardiol. 2014;102(4):364-73. doi: https://doi.org/10.5935/abc.20140032

6. Mendonça FAC, Pinheiro CPO, Quintino ASB, et al. Conhecimento da mulher mastectomizada frente ao processo de adoecimento e tratamento do câncer de mama. Atas Invest Qualitativa Saúde [Internet]. 2018 [acesso 2020 maio 5];2:1479-86. Disponível em: https://www.proceedings.ciaiq.org/index.php/ciaiq2018/article/view/1933/1883

7. Arraras JI, Greimel E, Sezer O, 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. doi: https://doi.org/10.1016/j.ejca.2010.06.118

8. Carvalho MS, Belmiro AAMLM, Rocha LF, et al. Equivalência conceitual, semântica e operacional da versão brasileira do EORTC QLQ-INFOR25. Arch Health Sci [Internet]. 2019 [acesso 2020 maio 5];26(1):32. Disponível em: https://redib.org/Record/oai_articulo2212126-equival%C3%AAncia-conceitual-sem%C3%A2ntica-e-operacional-da-vers%C3%A3o-brasileira-do-eortc-qlq-infor25

9. Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQOL instruments: the universalist approach. Qual Life Res. 1998;7(4):323-35. Cited in: PubMed; PMID 9610216.

10. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics. 1977;33(1):159-74. doi: https://doi.org/10.2307/2529310

11. Conselho Nacional de Saúde (BR). Resolução nº 466, de 12 de dezembro de 2012. Aprova as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos [Internet]. Diário Oficial da União, Brasília, DF. 2013 jun 13 [acesso 2020 abr 6]; Seção 1:59. Disponível em: https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf

12. Singer S, Engelberg PM, Weißflog G, et al. Construct validity of the EORTC quality of life questionnaire information module. Qual Life Res. 2013;22(1):123-9. doi: https://doi.org/10.1007/s11136-012-0114-x

13. Arraras JI, Manterola A, Hernández B, et al. The EORTC information questionnaire, EORTC QLQ-INFO25. Validation study for Spanish patients. Clin Transl Oncol. 2011;13(6):401-10. doi: https://doi.org/10.1007/s12094-011-0674-1

14. Püsküllüoğlu M, Tomaszewski KA, Zygulska AL, et al. Pilot testing and preliminary psychometric validation of the polish translation of the EORTC INFO25 questionnaire: validation of the polish version of INFO25-pilot study. Appl Res Qual Life. 2014;9(3):525-35. doi: https://doi.org/10.1007/s11482-013-9250-x

15. Asadi-lari M, Ahmadi Pishkuhi M, Almasi-Hashiani A, et al. Validation study of the EORTC information questionnaire (EORTC QLQ-INFO25) in Iranian cancer patients. Support Care Cancer. 2015;23(7):1875-82. doi: https://doi.org/10.1007/s00520-014-2510-y

16. Efficace F, Boccadoro M, Palumbo A, et al. A prospective observational study to assess clinical decision-making, prognosis, quality of life and satisfaction with care in patients with relapsed/refractory multiple myeloma: the CLARITY study protocol. Health Qual Life Outcomes. 2018;16(1):127. doi: https://doi.org/10.1186/s12955-018-0953-4

17. Cruz A, Rodrigues A, Ferracini A, et al. Analysis of information received during treatment and adherence to tamoxifen in breast cancer patients. Contemp Oncol (Pozn). 2017;21(4):295-98. doi: https://doi.org/10.5114/wo.2017.72397

18. Cuypers M, Lamers RED, Vries M et al. Prostate cancer survivors with a passive role preference in treatment decision-making are less satisfied with information received: results from the PROFILES registry. Urol Oncol. 2016;34(11):482.e11-482.e18. doi: https://doi.org/10.1016/j.urolonc.2016.06.015

19. Pinto AC, Ferreira-Santos F, Dal Lago L, et al. Information perception, wishes, and satisfaction in ambulatory cancer patients under active treatment: patient-reported outcomes with QLQ-INFO25. Ecancermedicalscience. 2014;8:425. doi: https://doi.org/10.3332/ecancer.2014.425

20. Pereira Junior M, Santos RZ, Ramos AP, et al. Construção e validação psicométrica do câncer-Q: questionário de conhecimentos da doença para pacientes com câncer. Rev Bras Cancerol. 2018;64(2):177-88. doi: https://doi.org/10.32635/2176-9745.RBC.2018v64n2.76

21. Santos RZ, Bonin CDB, Martins EC, et al. Construção e validação psicométrica do HIPER-Q para avaliar o conhecimento de pacientes hipertensos em reabilitação cardíaca. Arq Bras Cardiol. 2018;110(1):60-7. doi: https://doi.org/10.5935/abc.20170183

22. Chua GP, Tan HK, Gandhi M. What information do cancer patients want and how well are their needs being met? Ecancermedicalscience. 2018;12:873. doi: https://doi.org/10.3332/ecancer.2018.873

23. Silva DGF, Souza ALLP, Martins TCF, et al. Quality of information given to surgical patients with abdominal cancer. Investig Educ Enferm. 2017;35(2):221-31. doi: https://doi.org/10.17533/udea.iee.v35n2a11

24. Barbosa AN, Nascimento IA, Carvalho MJS, et al. A importância da assistência humanizada prestada pelo enfermeiro nos cuidados paliativos ao paciente oncológico terminal. Rev Bras Interdiscip Saúde [Internet]. 2019 [acesso 2020 maio 24];1(4):92-6. Disponível em: https://revistarebis.rebis.com.br/index.php/rebis/article/view/58/54

25. Tzelepis F, Sanson-Fisher RW, Zucca AC, et al. Measuring the quality of patient-centered care: Why patient-reported measures are critical to reliable assessment. Patient Prefer Adherence. 2015;9:831-5. doi: https://doi.org/10.2147/PPA.S81975

26. Berger O, Grønberg BH, Loge JH, et al. Cancer patients' knowledge about their disease and treatment before, during and after treatment: a prospective, longitudinal study. BMC Cancer. 2018;18(1):381. doi: https://doi.org/10.1186/s12885-018-4164-5