

Information received and usefulness of the sources of information to cancer patients at an oncology hospital in Turkey

Patient's cancer information

Büşra İnce¹, Pınar Atak Çakır², Serkan Eti³, Fatma Mutluay⁴¹Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Bandırma Onyediy Eylül University, Balıkesir²Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Istanbul Medipol University³Department of Computer Programming, Vocational School of Health Sciences, Istanbul Medipol University⁴Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Istanbul Medipol University, Istanbul, Turkey

Abstract

Aim: Cancer treatment typically involves a combination of approaches like surgery, chemotherapy, and radiation therapy. Offering accurate and valuable information about cancer plays a crucial role in helping patients prepare for their treatment and improves their adherence to it. To assess the information received by cancer patients, the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life (QL) Group has developed the EORTC INFO module. The objective of this study is to examine the reliability and validity of the Turkish version of the EORTC QLQ-INFO25 system. Specifically, it aims to evaluate how patients perceive the benefits of the information they receive and the duration for which the information remains useful to them.

Material and Methods: We administered the Turkish versions of three questionnaires to 197 patients at various stages of their illness: the EORTC QLQ-INFO25, the EORTC Quality of Life Questionnaire-Core 30 (QLQ-C30), and the EORTC Cancer In-Patient Satisfaction with Care Questionnaire (IN-PATSAT32). These stages included chemotherapy, radiotherapy, and surgery. To ensure the questionnaire's reliability and validity, we utilized Cronbach's alpha, inter-scale correlation, and factor analysis.

Results: The validity analysis revealed that the scale had a sufficient level of explained variance, with 66.68% accounted for by the factor analysis findings. Furthermore, the reliability analysis indicated a high level of reliability for the entire questionnaire, with a Cronbach's alpha coefficient of 0.92. The selected questions from the EORTC IN-PATSAT32 and their correlation with the 4 identified areas and 2 items of the EORTC QLQ-INFO25 demonstrated strong convergent validity. On the other hand, there was a low correlation between the EORTC-QLQ-C30 questionnaire and the different areas of the EORTC QLQ-INFO25 questionnaire, suggesting that these two questionnaires measured distinct concepts.

Discussion: The study found that the Turkish version of the EORTC QLQ-INFO25 scale is a valid and reliable instrument for assessing the knowledge level of cancer patients. These findings suggest that the scale can be effectively utilized within the Turkish society to evaluate the information and understanding of cancer patients.

Keywords

EORTC QLQ-INFO25 Turkish, Information, Cancer, Validity, Reliability

DOI: 10.4328/ACAM.22018 Received: 2023-10-20 Accepted: 2024-02-29 Published Online: 2024-04-05 Printed: 2024-06-01 Ann Clin Anal Med 2024;15(6):383-387

Corresponding Author: Pınar Atak Çakır, Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Istanbul Medipol University, Istanbul, Turkey.

E-mail: pnaratak9340@gmail.com P: +90 536 056 94 04

Corresponding Author ORCID ID: <https://orcid.org/0000-0001-5640-2998>

This study was approved by the Ethics Committee of Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee (Date: 2018-08-15, No: 446)

Introduction

Cancer is a significant global and national health issue, being the second leading cause of death in Turkey [1, 2]. As cancer incidence continues to rise, there is an increasing demand for information among patients and their families regarding the disease. A study conducted by Akgül et al. revealed that patients primarily seek information from doctors and the internet, while finding the communication with assistant health personnel to be insufficient [3]. Similarly, research by Schmid Büchi et al. indicated that cancer patients often lack sufficient information and require professional support regarding disease management and treatment [4]. Compliance with treatment, communication ability, satisfaction level and quality of life of patients who reach reliable and quality information are also increasing [5].

The studies in the field of oncology are increasing day by day and the level of knowledge provided in this field is improving [6, 7]. Tools developed to evaluate the level of knowledge about cancer are very important in clinical research [8]. In our country, a limited number of measurement tools are available to measure the amount of information given to cancer patients. Most of the other scales evaluate the needs and satisfaction levels of patients [3]. The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life (QL) has developed the EORTC Quality of Life Questionnaire-Information Module (EORTC QLQ-INFO25) scale, which assesses the level of knowledge from cancer patients at different stages of care. The structure, validity, and reliability of the EORTC QLQ-INFO25 scale were tested in a large international and multi-cultural cancer population at different stages of the disease and treatment. This scale is used during routine clinical practice in the oncology department in both national and international studies. The EORTC QL working group suggests that the validity studies of their scales should be done for each country [9]. The aim of this study is to translate the EORTC QLQ-INFO25 scale into Turkish, to examine its validity and reliability and to investigate the effect of cultural differences on the patient's level of knowledge.

Material and Methods

Participants

Our study was conducted with the approval of the Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee (dated 15.08.2018, decision 446). All individuals included in the study were given detailed information about the purpose, method, and duration of the study. In addition, patients were signed with an "Informed Consent Form". The identities of the participants were kept strictly confidential and only aggregate data were reported.

Power analysis was applied to calculate the required sample size. As a result of the calculation made using G-power analysis, the minimum sample number required for 95% reliability and 80% power was determined as 220.

Our study is multidisciplinary care center in Turkey Istanbul Medipol University Hospital Complex of Hematology-Oncology section referencing between the years 2018-2020. The study focused on patients diagnosed with cancer based on clinical and radiographic examinations. The participation in the study was

voluntary for the patients. Adult individuals over the age of 18 who received radiotherapy and/or chemotherapy treatment due to the primary tumor at different stages of the disease were included in the study. Individuals who do not have sufficient mental and speaking capacity in terms of understanding and answering the questionnaires and who have psychological morbidity were excluded from the study.

Study design

All questions in the Turkish version of the EORTC QLQ-INFO25 questionnaire were read carefully to the participants by experts in oncology and made sure that the participant understood correctly. Additional information about each patient's disease and medical history was collected from the patient's medical records. The first 10 patients registered were evaluated in a pilot study to confirm the questionnaire and were not included in the statistical analysis of the study.

Questionnaire

A demographic form prepared by the researchers was filled in as the first step. In this form, it included questions giving information about the age, gender, marital status, education level, systemic disease, and diagnosis of the cancerous individual. In addition, a total of three questionnaires were conducted: EORTC QLQ-INFO25, EORTC Quality of Life Questionnaire-Core 30 (QLQ-C30) and inpatient satisfaction module EORTC Cancer In-Patient Satisfaction with Care Questionnaire (IN-PATSAT32) survey. In the EORTC QLQ-C30 and EORTC IN-PATSAT32 surveys both in Turkey and standardization it has been translated before they were surveyed [10, 11].

The EORTC QLQ-INFO25 questionnaire consists of 25 items that cover various aspects of information related to the disease (4 items), medical tests (3 items), treatment (6 items), other services (4 items), and 8 additional topics. In addition to these items, the questionnaire includes questions about self-help, different areas of care, the receipt of written and/or digital information, satisfaction with the information received, preferences for more or less information, and the perceived usefulness of the information received. The response format is made according to 4-point Likert scale (1-nothing, 2-some, 3-quite, 4-very much). Items 52, 53, 54 and 55, which question whether they are satisfied with the level of information they receive and whether they want more information, have a two-way answer as Yes/No. Patients who respond positively to questions about requests for more or less information are asked to provide more detailed information on the subject. The scores of these items are converted linearly to 0-100 scale according to the EORTC guide [12]. The EORTC QLQ-INFO25 questionnaire was translated from English to Turkish using the translation/reversal method and was then translated back to English by a different translator who did not see the original version of the questionnaire. In 10 consecutive interviews with oncology patients, the questionnaire was tested for understanding and clarity, and no changes were made afterwards. The Turkish version of the questionnaire was approved by the EORTC translation unit after careful evaluation of the data from the pilot test.

Statistical analysis

The data were analyzed with SPSS 25.0 version. Categorical and continuous variables were studied using frequencies and

Table 1. Demographic and clinical features of patients

Patient characteristics N=197		
Mean age—years (SD)	53±13	
BMI—mean (SD)	27,9±5,32	
	N	%
Gender		
Female	166	84,3
Male	31	15,7
Marital Status		
Single	32	16,2
Married	165	83,8
Highest level of education		
Illiterate	6	3
Primary school	94	47,7
Middle School	35	17,8
High school	40	20,3
Undergraduate	17	8,6
Postgraduate	2	1
Associated degree	3	1,5
Economic condition		
Low level	13	6,6
Intermediate level	139	70,6
High level	45	22,8
Metastasis		
No	136	69
Yes	61	31
Hypertension		
No	140	71,1
Yes	57	28,9
Diabetes		
No	165	83,8
Yes	32	16,2
Genetic predisposition		
No	145	73,6
Yes	52	26,4
Smoking		
No	139	70,6
Yes	58	29,4
Disease stage		
Chemotherapy	121	61,4
Radiotherapy	24	12,2
Surgical	11	5,6
Control	41	20,8

N: Number of Samples; SD: Standard Deviation; BMI: Body Mass Index

mean±standard deviations. In the study, multivariate statistics were used statistically. Kolmogorov-Smirnov and Shapiro-Wilk tests were used for normality evaluation. Factor analysis for validity, Cronbach's Alfa, which is the internal consistency coefficient for reliability, was calculated. While making the correlation analysis between the scales, nonparametric test (Mann-Whitney test), parametric test (Student t test), and Anova tests were applied for the differences between the groups.

Ethical Approval

This study was approved by the Ethics Committee of the Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee (Date: 2018-08-15, No: 446).

Results

Pilot study

Ten women with a mean age of 54±13 were included in the study. 5 patients were breast, 1 patient bone, 1 patient pancreas, 1 patient lung, 1 patient ovary, 1 patient brain cancer. The internal validity of INFO 25 was analyzed using the Cronbach alpha coefficient (α). Internal consistency showed a reliability of 0.917.

Table 2. The results of multi-trait scale analysis

	Scale 1	Scale 2	Scale 3	Scale 4
I31	0,874	0,643	0,523	0,359
I32	0,881	0,655	0,463	0,37
I33	0,788	0,558	0,463	0,434
I34	0,83	0,659	0,545	0,391
I35	0,69	0,897	0,6	0,392
I36	0,582	0,848	0,599	0,349
I37	0,639	0,815	0,582	0,377
I38	0,507	0,633	0,702	0,415
I39	0,481	0,546	0,843	0,336
I40	0,401	0,471	0,781	0,307
I41	0,475	0,561	0,847	0,387
I42	0,442	0,519	0,763	0,441
I43	0,452	0,513	0,726	0,53
I44	0,374	0,321	0,363	0,655
I45	0,297	0,325	0,329	0,601
I46	0,364	0,436	0,478	0,764
I47	0,238	0,172	0,283	0,674
I48	0,376	0,297	0,315	0,722

Dark colored numbers show that the correlation of the item with its hypothetical scale is greater than its relationship with other fields reflecting the distinctive and convergent validity of the questionnaire.

Table 3. EORTC-INFO25 scales, mean, standard deviation, internal consistency reliability, and intra-class correlations

EORTC-INFO25 scales	Mean	SD	Cronbach's alpha coefficient	ICC	%floor	%ceiling
Scale 1 Information about the disease	2,4873	0,8178	0,864	0,833	2	8,1
Scale 2 Information about medical tests	2,4467	0,8492	0,814	0,768	4,6	11,2
Scale 3 Information about treatments	2,2318	0,7551	0,869	0,795	2	4,6
Scale 4 Information about other services	1,3533	0,4698	0,659	0,571	39,6	0,5
Whole questionnaire	2,0093	0,4959	0,92	0,861	2	0,5

ICC: In-Class Correlation SD: Standard Deviation
EORTC QLQ-INFO25: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Information 25

Patient characteristics

A total of 220 patients were evaluated. 23 patients were excluded from the study because they gave inconsistent answers. Finally, 197 patients were included in the study. 31 of the participants were male (15.7%) and 166 were female (84.3%). The average age of the participants was 53±13 years. The majority of patients were married (83.8%). Considering the education level, 68.5% of the patients were below the compulsory education level (defined as school education for more than 12 years), 20.3% were at the compulsory education level and 11.1% were above the compulsory education level. The most common tumor was breast cancer (49.7%) followed by gynecological (12.7%) and gastrointestinal malignancies (11.6%). 28.8% of the patients had metastasis. The demographic and clinical features of the patients are shown in Table 1.

Debriefing Questionnaire

Most patients in the study demonstrated a clear understanding of the questions. However, there were some specific items that posed challenges for certain patients. For instance, 38 patients found the question about the 'procedures of medical tests' (item 36) confusing despite the researcher's explanation. 12 patients did not answer the question about the 'dimensions of managing the disease at home' (item 46) due to the absence of an explanatory statement. Furthermore, it was observed that questions related to sexual activity elicited feelings of embarrassment and discomfort among the participants. This issue was not identified during the pilot study. The researcher did not have to clarify any confusion and any explanation given was easily understood.

Disclosure of information

For the analysis of the responses of the patients to the questions about the level of knowledge, the answers were compared under two headings as "none"- "a little" and "quite"- "a lot" pairs. "None"- "a little" pair was considered as "insufficient level of knowledge", "fairly"- "very" pair "was considered sufficient level of knowledge. Analysis of the data collected; showed that patients have the highest level of knowledge about diagnosis, medical test results and whether their disease is under control. Patients had the least level of information about rehabilitation services (97.97%), extra hospital assistance (95.43%), different care places (96.95%) and the effects of treatment on sexual activity (85.79%).

According to the results of the multi-trait scale, the correlation measurements of each item with its own scale and other fields are shown in Table 2.

The correlation of each item with its own scale ($Rho \geq 0.6$) represents a high convergent validity. At the same time, the correlation of each item with its hypothetical domain was greater than its relationship with other areas of the scale, reflecting the discriminant validity of the scale. The correlation between the selected questions of EORTC PATSAT32 and the 4 areas and 2 items of EORTC INFO25 were evaluated. Pearson correlation coefficients between areas with similar content showed high convergent validity.

Divergent validity was assessed by calculating the correlation between the EORTC-QLQ-C30 questionnaire and the different domains of the EORTC-INFO25 questionnaire. The findings revealed a low correlation (Spearman $Rho < 0.2$) between the

domains of the two questionnaires, which indicates that they measure distinct concepts.

Factor analysis was used to investigate the structure of the survey. After Bartlett's sphericity test ($P < 0.000$) and Kaiser-Meyer-Olkin sample adequacy criterion, 4 factors were selected after the significance was achieved in terms of sample adequacy. 1st factor, information about the disease (item 31, 32, 33, 34), 2nd factor information about medical tests (item 35, 36, 37), 3rd factor information about treatment (item 38, 39, 40, 41, 42, 43) and factor 4 included information about other services (items 44, 45, 46, 47). These four factors explained a total of 66.68% of the variance.

Cronbach's alpha coefficients for all domains and all surveys were between 85% and 95%. In-class correlation (ICC) ranged between 0.571 and 0.861. In-class correlation (ICC) of total scales and items of the questionnaire, Cronbach's alpha coefficient for the total scale is shown in Table 3. The items included in the questionnaire allowed the classification of information given to patients in terms of different aspects of cancer diagnosis and treatment. The level of education, economic status, and age were examined to determine the amount of information received and whether it affected satisfaction. While there was a significant difference in the level of knowledge about education level, disease, medical tests, and treatments ($p < 0.05$), there was no difference in knowledge level for other services ($p > 0.05$). The economic situation was found to have a significant relationship with all parameters ($p < 0.05$). There was no significant difference in the level of knowledge among those over 50 and those under 50 ($p > 0.05$).

Discussion

In this study, the researcher aimed to assess the quantity and quality of information provided by healthcare personnel to Turkish cancer patients. Furthermore, the study explored the overall satisfaction of Turkish patients regarding the information they received. The statistical analyses conducted indicated that the Turkish version of the EORTC QLQ-INFO25 scale is a valid and reliable tool for measuring the knowledge levels of cancer patients. The high completion rate (>90%) of the surveys suggests that the scale was well understood by the patients and was deemed clear and acceptable. The extra topics suggested by the patients proved that new items are not needed and the content validity of the scale. Group validity analyzes are generally supported by data.

Cronbach's alpha value for each area of the survey provided the criteria (≥ 0.6) that the scale can be used to compare different groups. For the entire survey, Cronbach's alpha coefficient was 0.92, which confirmed that the scale's reliability was high. When the literature is examined, the results of other studies proved the high reliability of the questionnaire. In studies conducted in Lebanon and Iran, Cronbach's alpha coefficient for the entire questionnaire was reported to be more than 0.7 and in Spain and Taiwan 0.7-0.9 [6, 7, 9]. The result of our study was consistent with the results of these studies investigating the reliability of the EORTC QLQ-INFO25 scale. A standard divergent validity was observed in all areas of the scale ($Rho < 0.5$), confirming that the two questionnaires used evaluated different concepts. These findings align with previous studies conducted by EORTC.

Furthermore, the convergent and divergent validity analyses conducted in this study also provided support for the expected outcomes, which is in line with the findings of other relevant studies [13, 14].

The construct validity of the questionnaire was evaluated using factor analysis. In factor analysis, load values between 0.30 and 0.59 are typically considered medium, while values above 0.60 are considered high [15]. In our study, we found that the factor load value was 0.66, indicating a medium to high level of construct validity for the questionnaire. This suggests that the items in the questionnaire are appropriately measuring the intended constructs. In Asadi-lari et al. study was found that the value is 0.79 and this result is in line with our study [9].

The limitation of our study is that the information given to the participants cannot be measured objectively. In addition, test-retest analyzes, which show that the questionnaire does not change over time, were not conducted. It is not practical to apply a standardized information program to patients, but it is not possible to collect all these data in a multinational and diverse example. However, after a more detailed analysis of intercultural differences, a common scale can be developed for each culture.

Limitation

The fact that it was a single-center study may be a limitation for generalizability. Since the study was conducted with a large group, it is recommended to conduct a further study with groups receiving the same treatment or with the same cancer types. In addition, the level of knowledge of the same age groups can be investigated.

Conclusion

According to the results obtained from our study planned and implemented in order to bring the EORTC QLQ-INFO25 scale to the Turkish culture; The validity and reliability of the scale has been determined and it can be used in Turkish society. The questionnaire is a valid scale that can be used by healthcare professionals to evaluate the knowledge level of the person specific to cancer disease in clinical trials.

Acknowledgment

We would like to thank the EORTC Organization for the translation process and all participants who participated in the research.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and Human Rights Statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Funding: None

Conflict of Interest

The authors declare that there is no conflict of interest.

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How to cite this article:

Büşra İnce, Pınar Atak Çakır, Serkan Eti, Fatma Mutluay. Information received and usefulness of the sources of information to cancer patients at an oncology hospital in Turkey. *Ann Clin Anal Med* 2024;15(6):383-387

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