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An international validation study of the EORTC QLQ-INFO25 questionnaire: An instrument to assess the information given to cancer patients

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ABSTRACT

Aim: The EORTC Quality of Life (QOL) Group has developed an instrument to evaluate the information received by cancer patients. This study assessed the psychometric characteristics of the EORTC INFO module in a large international/multi-cultural sample of cancer patients.

Methods: The provisional 26-item information module (EORTC INFO26) was administered with the EORTC QLQ-C30 and the information scales of the inpatient satisfaction module EORTC IN-PATSAT32 on two occasions during the patients' treatment and follow-up period. Questionnaire-hypothesised scale structure, reliability, validity and responsiveness to changes were evaluated through standard psychometric analyses. Patient acceptability was assessed with a debriefing questionnaire.

Results: The study comprised 509 patients from 8 countries (7 European countries and Taiwan) with different cancers and disease stages. Multi-trait scaling analysis led to the deletion of one item but confirmed the hypothesised 4 multi-item scales (information about disease, medical tests, treatment and other services) and eight single items. Internal consistency for all scales was good ($\alpha > 0.70$), as was test–retest reliability (intraclass correlations > 0.70). All items can be combined to generate a single score ($\alpha > 0.90$). Convergent validity was supported by significant correlations with related areas of IN-PATSAT32 ($r > 0.40$). Low correlations with EORTC QLQ-C30 scales confirmed divergent validity ($r < 0.30$) The EORTC INFO-25 module discriminated among groups based on gender, age,

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education, levels of anxiety and depression, information wishes and satisfaction. Only one scale captured changes over time.

Conclusions: The *EORTC QLQ-INFO* 25 is a reliable and valid self-reported instrument. The module can be used in cross-cultural observational and intervention studies.

1. Introduction

Information given to cancer patients about the disease and its treatment is a foundation of supportive care.[1] Providing cancer patients with *adequate* information has many benefits: (1) shared decision making; (2) greater satisfaction with care; (3) improvement in patients' sense of control; (4) lower levels of affective distress; (5) better communication with patient's family; and (6) better quality of life.[1–7]

The 'patient-centred communication' model suggests that communication is more effective when health professionals evaluate patients' views on the information provided.[6] Cancer patients do not always report of having received sufficient information.[4] Moreover, clinicians' and patients' priorities on information disclosure may not always coincide and patients' wishes may change over time.[8]

Research in the information field is growing. Recent studies have focused on patients' experience with information,[9–13] professional training,[14], information in specific fields, such as genetic counselling,[1] and information sources other than professional consultations (e.g. booklets, CDs and the Internet).[15,16] More studies are needed on both the type and amount of information offered to patients and families and on finding better ways of providing it.

Validated and culturally sensitive instruments are important when measuring patient perceptions of the information received and patient information needs. Several questionnaires evaluate information disclosure to cancer patients. Most assess patient satisfaction with information[17] and informational needs either using single instruments[2,5,7,12,18] or as part of needs' assessment profiles.[19,20] However, questionnaires that evaluate the level of information received by patients and can be used in an international setting with different cultures and multiple languages are needed.

The EORTC Quality of Life Group has developed the EORTC information module (EORTC INFO module) which assesses cancer patients' perception of information received during different phases of care. The module was developed simultaneously in several European languages following published guidelines. The provisional Phase 3 module has 26 items.[21–24]

Here we test the structure, validity and reliability of the provisional EORTC INFO module in a large international and multi-cultural sample of cancer patients at different stages of disease and treatment.

2. Patients and methods

2.1. *Patients*

Inclusion criteria were broad: adult cancer patients (>18 years) with any tumour site and disease stage (both early and metastatic disease) receiving radiotherapy and/or chemotherapy. Exclusion criteria were concurrent malignancy, psychological morbidity or linguistic difficulty preventing patients from completing the questionnaires. Patients receiving only surgery were excluded because of difficulties in contacting them during longitudinal assessments. Ethics committee approvals were obtained from all participating countries. The patients provided written informed consent for the study.

2.2. *Study design*

This prospective longitudinal study recruited consecutive eligible patients (Fig. 1). Two groups of patients, expected to differ in information received, were recruited: (1) newly diagnosed cancer patients receiving a first treatment line with radiotherapy/chemotherapy; and (2) patients with recurrent/metastatic disease starting a second (or other) line of radiotherapy/chemotherapy. We also expected the perceived information to be different at different treatment stages: before, during and after treatment (at least 1 month after completion). To reduce patient burden and missing data, we included only two assessments per patient. Half the patients were asked to complete the questionnaires before and during treatment (groups A and C) and half during treatment and 1 month after treatment (groups B and D) (Fig. 1).

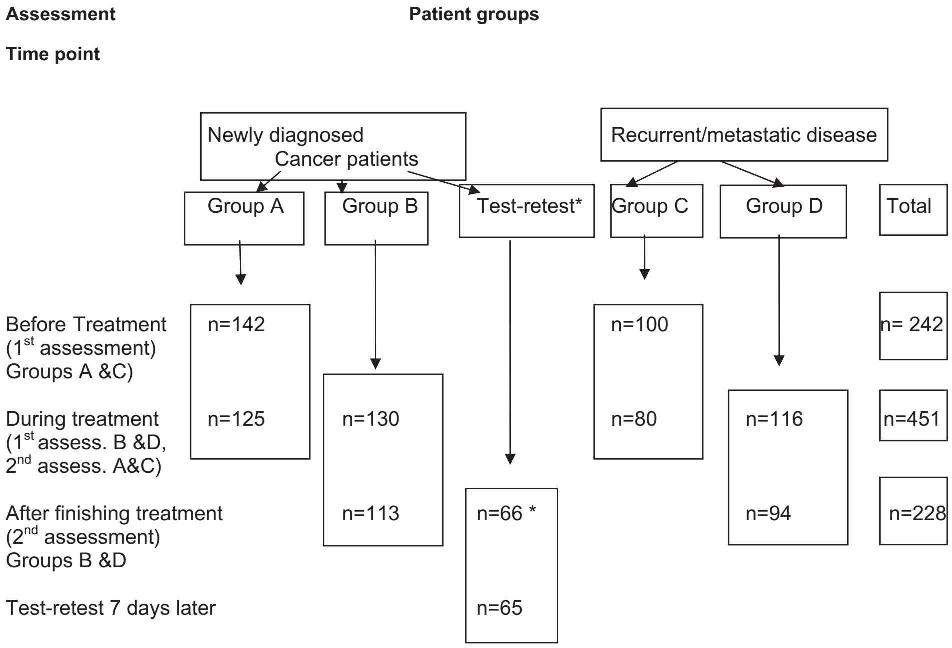
Test–retest study was performed in a subsample of newly diagnosed cancer patients who completed the questionnaires 1 month after treatment and 7 d later, when no changes in information provision were expected.

2.3. *Questionnaires*

Patients completed the provisional EORTC INFO module, the EORTC QLQ-C30 and the information scales of the inpatient satisfaction module EORTC IN-PATSAT32. Scores of these instruments are linearly transformed to a 0–100 scale, according to the EORTC manual.[25]

The provisional EORTC INFO module had 26 items organised in four *hypothesised scales*—information about the disease (4 items), medical tests (3 items), treatment (7 items) and other services (4 items)—and eight single items. The response format is a 4-point Likert scale (1 – not at all, 2 – a little, 3 – quite a bit, 4 – very much), except items 51, 52, 54 and 55, which have a dichotomous response (yes/no).

The EORTC QLQ-C30 (Version 3.0) is a validated, widely used questionnaire containing five functional scales (physical, role, emotional, social and cognitive function), three symptom scales (fatigue, pain and nausea/vomiting), one global quality of life scale and six single items (symptoms and financial impact).[26] Selected scales from the EORTC IN-PATSAT32 were included: provision of information by doctors



* Test-retest was carried out in some of the Group B patients (n=45) and in a further sample of patients (n=21) with the same characteristics as group B, who only did test-retest after finishing treatment. The **global sample** was 509 patients: 488 from groups A to D, and 21 with just the test-retest assessments.

Fig. 1 – Design, data collection and patient progress.

and nurses; kindness of hospital personnel, helpfulness and information giving. EORTC IN-PATSAT32 is an internationally validated instrument measuring cancer inpatients' evaluation of the quality of hospital care.[27]

A short debriefing questionnaire surveyed the time taken to complete the instruments, the need for help in completing the EORTC INFO module and whether any items were difficult, confusing or upsetting.

Patient demographic and clinical data were recorded at the first assessment but, for better accuracy, treatment data were recorded at the second assessment.

2.4. *Statistical analysis*

Standard psychometric analyses were used to evaluate the hypothesised scale structure of the EORTC INFO module, reliability and convergent, divergent and discriminate validity.

Multi-trait scaling analysis was done using the first assessment of all patients (groups A–D, $n = 488$, including a mixture of before and during treatment assessments) to examine whether the individual items comprising the INFO module could be aggregated into hypothesised multi-item scales.[28] Evidence of item convergent validity was defined as an item-own-scale correlation of $\geqslant$0.40 (corrected for overlap). Item discriminant validity was supported and a scaling success counted when the correlation between an item and its hypothesised scale (corrected for overlap) was higher than its correlation with other scales. Scaling failures were identified when an item correlated lower with its hypothesised scale (corrected for overlap) than with another scale.

Internal consistency reliability of the questionnaire scales, the scales excluding each item and the whole instrument was explored in the three main assessment points using Cronbach's alpha coefficients. $\alpha \geqslant 0.70$ was regarded as optimal for group comparison.[29]

The test–retest reliability of scales and single item measures was examined using intraclass correlations (ICC) between the two assessments.

Convergent validity. Hypothesised relationships were examined between the selected scales/items of the EORTC IN-PATSAT32 with the four scales and two items of the INFO module that were expected to be conceptually related. Higher correlations were expected among areas with related content (disease, medical tests, treatment), information that was expected at a specific time during the treatment process (disease, medical tests and admission; other services, things to help yourself get well and discharge) and between the item on satisfaction and the three scales of SAT32. Spearman's Rho > 0.40 was considered indicative of optimal convergent validity.

For *divergent validity*, correlations between the EORTC INFO module and the EORTC QLQ-C30 scales/single items were calculated. Low correlations (Spearman Rho < 0.30) were expected because each instrument evaluates different concepts.

Known groups' validity, like convergent and divergent validity, was evaluated using data from the during-treatment assessment point ($n = 451$) by comparing the scores in the INFO module of subgroups of patients with different demographic and clinical status: gender,[30] age ($\leqslant$50, 51–65, $\geqslant$66),[31] level of education,[32] current treatment (potentially curative, palliative),[33] treatment lines (first versus others), the Emotional Functioning scale of the QLQ-C30 (lowest through mean, mean through highest),[34] and items of the INFO module on the wish to receive more information (yes/no) and the level of satisfaction with the information received (1–2/3–4). Non-parametric statistics were used—Mann–Whitney *U* and Kruskal–Wallis tests (with Mann–Whitney *U* to compare pairs of groups). Comparisons based on language and cultural groups will be the subject of a separate publication.

We expected *higher information levels* to be reported by female patients, younger patients, patients with a higher level of education, those receiving potentially curative treatment, those in second or other treatment lines and those with better emotional functioning, lower information wishes and higher satisfaction with the information received.

Responsiveness to change. Pairs of measurements (first day of treatment-during treatment; during treatment-end of treatment) were compared using the Wilcoxon test. We expected patients to have more information during treatment than at the beginning and more at the end of treatment than during it.

$P < 0.01$ was considered in all analyses to adjust for multiple tests. Analyses were done using SPSS version 17.0.

2.5. *Sample size*

According to Tabachnik and Fidell,[35] at least 10 cases per variable are required for multivariate statistical techniques, so we needed 260 patients (26 items * 10 patients). In the discriminate validity analysis, with 260 patients, a two-sided test at 5% would have 90% power of detecting a 10-point difference.

3. Results

Between February 2006 and January 2009, 509 of 523 registered patients were included in the study. Eight patients were excluded because the measurement was outside the time window and 6 were excluded for other reasons. Table 1 shows patient demographic and clinical characteristics. The patients were from 8 countries (7 European countries and Taiwan).

3.1. *Completion rates*

The questionnaires were completed a second time by 432 patients (82.6%). Reasons for not completing the instruments were death ($n = 26$), patient withdrawal ($n = 18$), administrative failure ($n = 13$), patient too ill ($n = 10$) and others ($n = 10$). In the during-treatment assessment point, there were 186 missing items (1.6% of 11,726 items – 451 patients) evenly distributed among the 26 questions. Only four questionnaires had over 30 % missing items.

3.2. *Debriefing questionnaire*

In the first group of questionnaires, only one item (item 42; *information on the expected effects of the treatment on disease symptoms*) was consistently considered confusing: (32 patients; 6.3%). Twelve of these patients, all from Spain, said that they did not understand it and 3 breast cancer patients said that they had no disease symptoms. Three patients evaluated item 44 (sexuality) as upsetting.

Table 1 – Demographic and clinical characteristics of the patients.

Variable First assessment of all patients	$N = 509$[a]	
Mean age – years (SD)	58.2 (13.1)	
Karnofsky PS – mean (SD)	86.6 (11.7)	
	N	%
Gender		
Male	187	36.7%
Female	322	63.3%
Highest level of education		
Less than compulsory school education	36	7.1%
Compulsory school education	191	37.8%
Post-compulsory education below university	156	30.9%
University level	122	24.2%
Cultural area		
North/Middle Europe	233	45.8%
South Europe	225	44.2%
Other area	51	10.0%
Countries		
Spain	169	33.2
United Kingdom	112	22
Germany	60	11.8
Sweden	50	9.8
Italy	47	9.2
Austria	11	2.2
Croatia	9	1.8
Taiwan	51	10
Primary tumour		
Breast	161	31.6%
Gynaecological	72	14.1%
Haematological	66	13.0%
Gastro-intestinal	61	12.0%
Genito-urinary	51	10.0%
Lung	37	7.3%
Head and neck	35	6.9%
Other responses	27	5.3%
Disease stage		
Local	179	35.2%
Locoregional	130	25.5%
Metastatic	200	39.3%
Comorbidity		
Yes	172	33.8%
No	337	66.2%
Inpatient	112	22.0%
Outpatient	397	78.0%
Groups C and D previous treatments		
Surgery	135	58.3%
Chemotherapy	191	87.0%
Radiotherapy	99	44.3%
Second assessment	$N = 457$[b]	
Karnofsky PS – mean (SD)	80.8 (12.3)	
Aim of the current treatment	N	%
Potentially curative	277	60.6
Purely palliative	180	39.4

(*continued on next page*)

Table 1 – (*continued*)

Variable Second assessment	$N = 457^{b}$	
Treatment modality		
Surgery	152	33.2
Radiotherapy	156	34.1
Chemotherapy	382	83.4
Hormonal therapy	63	13.8

SD – standard deviation.

[a] Demographic and clinical data were recorded with the 1st questionnaires of all patients (groups A–D and retest).

[b] Treatment data were collected when patients were expected to complete the 2nd questionnaires. Treatment data of 457 patients were recorded. Of these, 432 completed the 2nd study questionnaires.

Almost all patients (490, 96.5%) answered the three questionnaires in less than 30 minutes. Of the 509 patients, 229 needed help in completing the questionnaires, which mainly involved reading the items (81.7% of cases). Most patients who needed help were from Spain ($n = 169$). These Spanish patients preferred the research assistant to read the questions out to them and, though it was not really necessary, it was considered polite to do so.

3.3. *EORTC INFO module descriptive statistics*

Mean scores and standard deviations before, during and after treatment are shown in Table 2. Both minimum (1) and maximum (4) values were recorded at each time point in all items. The percentage of respondents at ceiling and floor was low in the three assessment points (at the first assessment: ceiling three areas 24.8–36% and floor two areas 35.5–47%).

The distribution of responses was not normal (Kolmogorov–Smirnov $P < 0.001$ in all areas), so non-parametric tests were used in the psychometric analysis.

Forty-nine percent of patients wanted more information about items already included in the questionnaire: e.g. radiotherapy side-effects and doses.

3.4. *Multi-trait scaling analyses*

All items had item-own-scale correlation > 0.40 except item 39 (non-medical treatments) ($r = 0.32$) (Table 3). Without that item the internal consistency of the scale improved.

Four items correlated higher with other scales than with their own, which suggests some degree of overlap between the hypothesised scales. For example, item 38 (information on medical treatments) correlated higher with the scale on ‘medical tests’ than with the scale on ‘treatment’). These items were discussed at research meetings and it was decided to keep them in their hypothesised scales but to examine the possibility of combining all items in the module to generate a single score.

3.5. *Internal consistency reliability*

Cronbach’s alpha coefficients of all scales and the full INFO module met the ⩾0.7 criteria in all measurements (before, during and after treatment) (see Table 2). The internal consistency estimate of the full questionnaire showed high reliability (0.91), which suggests that all items could be added to generate a score on perceived information provision.

3.6. *Test–retest reliability*

The test–retest reliability of the INFO module scales/items was excellent, with ICC values ranging from 0.71 (written information) to 0.91 (information about disease).

3.7. *Convergent validity*

The selected areas of the EORTC IN-PATSAT32 were significantly correlated to the INFO module scales and items (higher levels of information related to higher satisfaction). Areas whose content was similar (7/12) had a higher correlation coefficient > 0.40 (Table 4).

3.8. *Divergent validity*

As expected, correlations (all below 0.28) were low between the EORTC INFO module and the EORTC QLQ-C30 scales and single items (data not shown).

3.9. *Known group validity (Tables 5A and 5B)*

Table 5A shows comparisons based on gender, age and education. Women were less satisfied and wished more information than men (women had higher levels of education). Younger patients (<50 years) had more information than older patients (51–65, ⩾66) about treatments, other services and written information, and wished more information. Lower education groups received less written information than higher education groups and had fewer wishes for more information.

Table 5B shows known group comparisons by treatment, emotional function, wish for information and satisfaction. No differences were found between patients grouped by treatment purpose (curative versus palliative) and treatment lines. The patients with lower emotional functioning received more information about other services and less about medical tests. They also wanted more information and were less satisfied than patients with higher emotional functioning.

The patients, who wanted more information reported of receiving less information in six areas, were less satisfied and considered the information less helpful. More satisfied patients had received more information in seven areas, considered the information more useful and had fewer wishes to receive more information.

3.10. *Responsiveness to change (Table 6)*

The INFO module detected no differences before, during and after treatment in the level of information received about diagnoses, tests and treatments. However, patients reported of receiving successively more information about other services and places of care at successive measurements.

Table 2 – Descriptive statistics of scales/items and reliability. (First row: assessment before treatment, groups A and C, $n = 242$; second row: assessment during treatment groups A, B, C, D, $n = 451$; third row: assessment after treatment, groups B and D, $n = 228$.)

	Mean[b]	SD	% Ceiling	% Floor	Cronbach's alpha
Whole questionnaire[a]	43.8	14.3	0	0	0.91
	43.6	13.4	0	0	0.91
	43.3	13.4	0	0	0.91
Information about the disease (items 31–34)	57.2	23.5	6.6	1.2	0.76
	57.4	22.7	6.1	0.2	0.73
	58.8	21.2	7	0.4	0.75
Information about medical tests (items 35–37)	70.5	25	24.8	2.5	0.87
	67.7	26.9	23.8	1.4	0.86
	70.6	22.7	21.9	0.9	0.83
Information about treatments (items 38–44)	48.4	21.5	0.8	0.8	0.81
	48.7	20.7	1.2	1	0.8
	48.5	19.3	0.4	0.4	0.8
Information about treatments scale[a]	53.9	23.3	4.8	0.9	0.82
	54.8	21.9	3.4	1.2	0.81
	54	20.6	4.2	0.5	0.81
Information about other services (items 45–48)	26.8	22.3	1.2	17.8	0.7
	29.4	23.1	2	15.6	0.73
	29.2	23.9	1.8	15.8	0.73
Information about different places of care (item 49)	29.7	33	8.7	45.9	
	31.2	32.4	9.8	47	
	34.5	34	9.6	41.2	
Information about things you can do to help yourself get well (item 50)	37.5	34.5	12.4	35.5	
	39.3	33.2	13.1	33.4	
	38.3	34.4	11.8	34.2	
Written information (item 51)[c]	53.8	50			
	50.5	50.1			
	47.8	50.1			
Information on CD tape/video (item 52)[c]	4.6	21			
	5.4	22.6			
	4	19.6			
Satisfaction with the information received (item 53)	65.7	29.5	29.8	7.4	
	63.7	29.1	27.1	5.4	
	64.5	28.4	26.3	7	
Wish to receive more information (item 54)[c]	52.9	50			
	47.7	50.1			
	44.8	49.9			
Wish you have received less information (item 55)[c]	2.5	15.7			
	2	14.1			
	2.1	14.4			
Overall the information has been helpful (item 56)	70.9	27.4	36	4.1	
	68.8	25.5	31.2	2.2	
	70.6	24.4	26.4	2.6	

[a] Statistics and Cronbach's alpha given without item 39.

[b] Scores in the EORTC INFO module scales and items range from 0 to 100. Higher scores mean a higher level of information received, higher information wishes and higher satisfaction. SD – standard deviation.

[c] Items 51, 52, 54 and 55 have a dichotomous answer, and floor and ceiling cannot be presented.

4. Discussion

This study evaluated the psychometric properties of the EORTC INFO module in a large international multi-lingual and multi-cultural sample of cancer patients. Following multi-trait scaling and internal consistency analyses, we confirmed the hypothesised structure of the module but *removed item 39* to produce a module with 25 items: the *EORTC QLQ-INFO25*. The final module has 4 multi-item scales—information about the disease (4 items), medical tests (3 items), treatment (6 items) and other services (4 items)—and 8 single items. Several items in the scales had slightly higher correlations with items from other scales, possibly because they all measure aspects of one underlying concept: information. We therefore examined whether all items in the module can be combined to generate a single score. Internal consistency for the full module was high ($\alpha > 0.90$), so, where appropriate for the purpose of future studies, a single score for the level of information provided to patients can be generated. The internal reliability of the four scales was very good ($\alpha > 0.73$)

Table 3 – Multi-trait analysis: correlation of items with their own scale and other scales (*n* = 488, 1st questionnaire of groups A to D).

Item	Information about the disease	Information about medical tests	Information about treatments	Information about other services
31	**0.61**	0.60	0.50	0.29
32	**0.64**	0.58	0.53	0.26
33	0.40	0.31	**0.41**	0.30
34	**0.52**	0.51	0.47	0.24
35	0.59	**0.73**	0.57	0.35
36	0.57	**0.76**	0.59	0.35
37	0.56	**0.66**	0.57	0.35
38	**0.59**	**0.69**	0.55	0.36
39	0.24	0.22	**0.35**	0.34
40	0.57	0.53	**0.59**	0.30
41	0.47	0.54	**0.63**	0.37
42	0.54	0.55	**0.68**	0.40
43	0.33	0.38	**0.57**	0.46
44	0.27	0.28	0.41	**0.48**
45	0.24	0.27	0.42	**0.52**
46	0.18	0.24	0.38	**0.55**
47	0.38	0.43	**0.51**	0.46
48	0.28	0.29	0.45	**0.48**

Cells in grey: item own scale correlation (corrected for overlap).
Numbers in bold font within the grey cells: item own scale correlation higher than item correlation with the other scales of the area.
Cells in white: correlations between the items and the other scales of the area.
Numbers in bold font within the white cells: item other scale correlation higher than item own scale correlation.

Table 4 – Convergent validity (*n* = 451, during-treatment assessment point).

INFO module scales/items	EORTC IN-PATSAT 32	R Spearman	*P*-value
Information about the disease scale	Item. the information doctors gave you about your illness	**0.46**	<0.001
Information about the disease scale	Item. the information other hospital personnel provided on your admission to the hospital	0.27	<0.001
Information about medical test scale	Item. the information doctors gave you about your medical tests	**0.54**	<0.001
Information about medical test scale	Item. the information nurses gave about your medical tests	**0.47**	<0.001
Information about medical test scale	Item. the information other hospital personnel provided on your admission to the hospital	0.37	<0.001
Information about treatment scale	Item. the information doctors gave you about your treatment	**0.47**	<0.001
Information about treatment scale	Item. the information nurses gave you about your treatment	0.37	<0.001
Information about other service scale	Item. the information other hospital personnel provided on your discharge from the hospital	0.3	<0.001
Item. Information about things you can do to help yourself get well	Item. the information other hospital personnel provided on your discharge from the hospital	0.31	<0.001
Item. Satisfaction with the information received	Doctors' information provision scale	**0.61**	<0.001
Item. Satisfaction with the information received	Nurses' information provision scale	**0.46**	<0.001
Item. Satisfaction with the information received	Other hospital personnel kindness, helpfulness and information giving scale	**0.42**	<0.001

and the test-retest reliability of the module was excellent. Convergent and divergent validity analyses supported our expectations.

The high levels of patient compliance (>80%), the few missing questionnaires and items (<1%) and the answers to the debriefing form indicate that the instrument was understood and well accepted by patients. Reports that item 42 (expected effects of treatment on disease symptoms) was confusing arose mainly because of the Spanish translation. This was solved by reviewing the translation. Although 3

Table 5A – Known group comparisons: demographic variables ($n = 451$).

Scales/items	Gender			Age				Level of education				
	Male mean (SD)	Female	P (1)	⩽50	51–65	⩾66	P (2)	Less than compulsory	Compulsory school	Post-compulsory	University level	P (2)
Information about the disease	60.3 (22.5)	56.7 (21.4)	0.12	60.2 (19.8)	56.6 (22.2)	58.1 (23.3)	0.47	60.6 (23.5)	59.7 (21.3)	56.2 (22.2)	57.4 (22.3)	0.76
Information about medical tests	69.8 (26.2)	68.7 (25.3)	0.56	70.2 (23.4)	68.4 (26.8)	68.8 (26.3)	0.97	67.0 (26.1)	69.0 (25.0)	68.9 (26.0)	69.6 (26.3)	0.91
Information about treatments	50.1 (20.4)	48.7 (20.3)	0.48	55.2 (18.2)	47.0 (20.9)	46.4 (20.6)	**<0.001**	48.1 (25.1)	48.0 (20.7)	50.3 (19.7)	49.8 (19.3)	0.61
Information about other services	29.6 (24.7)	28.2 (23.3)	0.67	31.7 (21.7)	27.3 (24.5)	27.7 (24.7)	**0.05**	29.5 (27.4)	28.9 (24.6)	30.8 (23.2)	25.6 (22.5)	0.29
Information about different places of care	29.5 (32.4)	30.0 (34.5)	0.85	28.9 (32.1)	29.9 (33.5)	30.4 (35.6)	0.98	27.1 (33.3)	34.1 (35.0)	30.1 (34.4)	22.9 (29.7)	0.08
Information about things you can do to help yourself get well	42.4 (35.0	38.2 (34.6)	0.21	42.9 (32.3)	35.7 (35.2)	41.6 (36.1)	0.12	47.1 (35.9)	39.4 (36.0)	42.5 (35.0)	34.0 (31.3)	0.17
Written information	47.0 (50.1)	53.6 (50)	0.17	60.3 (49.1)	49.1 (50.1)	45.3 (49.9)	**0.03**	30.0 (46.6)	44.3 (49.8)	51.8 (50.2)	66.3 (47.5)	**<0.001**
Information on CD tape/video	6.0 (23.8)	6.4 (24.5)	0.86	8.7 (28.2)	3.6 (18.7)	7.2 (25.9)	0.17	2.9 (17.1)	4.2 (20.1)	7.2 (26.0)	7.6 (26.7)	0.48
Satisfaction with the information received	68.3 (26.8)	62.4 (28.6)	**0.03**	61.2 (26.1)	63.6 (30.4)	68.4 (26.6)	0.06	64.7 (31.7)	66.9 (27.2)	63.7 (29.3)	61.5 (26.3)	0.40
Wish to receive more information	38.8 (48.9)	56.2 (49.7)	**<0.001**	59.1 (49.4)	57.2 (49.6)	33.3 (47.3)	**<0.001**	24.2 (43.5)	46.0 (50.0)	55.1 (49.9)	57.1 (49.7)	**<0.004**
Wish you have received less information	3.6 (18.7)	1.5 (12)	0.14	.8 (8.9)	2.4 (15.4)	3.4 (18.1)	0.36	5.9 (23.9)	3.7 (18.9)	.7 (8.6)	1.0 (9.8)	0.12
Overall the information has been helpful	72.3 (23.4)	70.1 (24.6)	0.40	70.1 (21.8)	69.7 (25.1)	72.8 (25)	0.38	70.6 (28.1)	71.9 (21.9)	71.3 (24.4)	68.6 (26.2)	0.86

Table 5B – Known group comparisons: by treatment, emotional function, wish for information and satisfaction with information (*n* = 451).

EORTC INFO module areas	Treatment intent			Treatment line			Emotional function			Wish more information			Satisfaction with information		
	Potentially curative	Purely palliative	*P* (1)	1st line	2nd line	*P* (1)	Lowest through mean	Mean through highest	*P* (1)	Yes	No	*P* (1)	Not at all/A little	Quite a bit/very much	*P* (1)
Information about the disease	57.0 (21.5)	59.0 (21.8)	0.60	56.6 (21.9)	60.2 (21.7)	0.08	56.5 (21.2)	59.3 (22.3)	0.25	51.2 (21.6)	65.1 (20.2)	**<0.001**	43.6 (21.8)	63.7 (19.4)	**<0.001**
Information about medical tests	68.8 (24.5)	69.7 (27.7)	0.42	67.3 (26.0)	71.5 (25.0)	0.08	65.3 (27.5)	71.7 (24.3)	**0.03**	59.0 (26.4)	79.3 (20.6)	**<0.001**	47.1 (25.9)	77.7 (19.9)	**<0.001**
Information about treatments	48.4 (20.1)	49.8 (20.5)	0.49	48.7 (20.5)	49.8 (20.2)	0.49	47.6 (20.7)	50.4 (20.3)	0.23	42.1 (19.0)	56.4 (19.4)	**<0.001**	36.8 (18.9)	54.2 (18.8)	**<0.001**
Information about other services	28.4 (23.9)	28.3 (23.0)	0.87	28.4 (23.9)	29.1 (23.8)	0.71	30.5 (21.5)	27.7 (25.4)	**0.03**	23.7 (20.4)	33.7 (26.0)	**<0.001**	18.2 (18.1)	32.8 (24.7)	**<0.001**
Information about different places of care	28.4 (33.3)	32.3 (34.1)	0.20	27.9 (32.3)	32.3 (35.4)	0.25	29.7 (33.5)	30.2 (34.3)	0.98	23.5 (30.5)	35.9 (35.7)	**<0.001**	18.9 (25.7)	34.3 (35.7)	**<0.001**
Information about things you can do to help yourself get well	38.3 (34.0)	41.7 (34.8)	0.33	39.1 (33.6)	40.8 (36.3)	0.72	40.9 (33.1)	38.8 (35.9)	0.42	34.6 (32.5)	44.6 (36.4)	**<0.001**	26.4 (27.8)	45.1 (35.9)	**<0.001**
Received written information	50.0 (50.1)	54.9 (49.9)	0.33	53.6 (50.0	47.9 (50.1)	0.24	55.2 (49.9)	49.0 (50.1)	0.21	51.4 (50.1)	50.2 (50.1)	0.81	42.3 (49.4)	54.6 (49.9)	**0.01**
Information onCD tape/video	6.7 (25.1)	4.8 (21.5)	0.42	6.3 (24.3)	6.2 (24.2)	0.96	8.0 (27.2)	4.9 (21.7)	0.19	7.3 (26.1)	5.4 (22.7)	0.42	7.3 (26.1)	5.9 (23.7)	0.59
Satisfaction with the information received	63.8 (27.1)	66.5 (29.8)	0.23	63.6 (27.3)	66.0 (29.1)	0.27	60.2 (28.3)	67.7 (27.5)	**<0.001**	50.2 (26.2)	78.4 (22.3)	**<0.001**	26.8 (23.3)	79.2 (16.0)	**<0.001**
Wish to receive more information	50.8 (50.1)	46.9 (50.1)	0.43	51.8 (50.1)	46.8 (50.0)	0.30	60.5 (49.0)	42.5 (49.5)	**<0.001**				86.8 (34.0)	34.9 (47.8)	**<0.001**
Wish you have received less information	.8 (8.9)	2.5 (15.7)	0.16	1.6 (12.6)	3.1 (17.5)	0.28	2.9 (16.9)	1.5 (12.3)	0.32	1.4 (11.7)	3.2 (17.6)	0.21	3.3 (18.0)	1.6 (12.5)	0.25
Overall the information has been helpful.	71.6 (23.7)	71.3 (25.2)	0.96	70.6 (24.0)	71.3 (24.4)	0.83	69.0 (24.6)	72.3 (24.1)	0.15	61.7 (24.4)	79.8 (20.2)	**<0.001**	49.3 (23.9)	78.9 (18.7)	**<0.001**

P (1) Mann–Whitney *U* tests; *P* (2) Kruskal–Wallis.

Emotional function: scores in the emotional functioning scale of the EORTC QLQ-C30. A lower score in this scale means a worse functioning in the area (more anxiety/depression).

Wish more information: answers to the item of the EORTC INFO module on 'wish to receive more information'.

Satisfaction: answers to the item of the EORTC INFO module on the 'satisfaction with the amount of information received'.

In these two last areas higher scores indicate higher information wishes and satisfaction levels.

Table 6 – Responsiveness to change.

EORTC INFO module areas	Before treatment Mean (SD)	During treatment Mean (SD)	P value[c]	During treatment Mean (SD)	After treatment Mean (SD)	P value[c]
	N = 221[a]			N = 216[b]		
Information about the disease	57.2 (23.5)	57.4 (22.7)	0.89	58.8 (21.2)	58.8 (21.2)	0.26
Information about medical tests	70.5 (25.0)	67.7 (26.9)	0.11	70.3 (24.5)	70.6 (22.7)	0.70
Information about treatments	48.4 (21.5)	48.7 (20.7)	0.98	49.6 (20.0)	48.5 (19.3)	0.88
Information about other services	26.8 (22.3)	29.4 (23.1)	**0.04**	28.1 (24.5)	29.2 (23.9)	**0.04**
Information about different places of care	29.7 (33.0)	31.2 (32.4)	0.54	28.7 (34.8)	34.5 (34.0)	**<0.001**
Information about things you can do to help yourself get well	37.5 (34.5)	39.3 (33.2)	0.32	40.2 (36.1)	38.3 (34.4)	0.93
Written information	53.8 (50.0)	50.5 (50.1)	0.28	51.7 (50.1)	47.8 (50.1)	0.23
Information on CD tape/video	4.6 (21.0)	5.4 (22.6)	0.25	7.0 (25.5)	4.0 (19.6)	0.11
Satisfaction with the information received	65.7 (29.5)	63.7 (29.1)	0.08	65.4 (27.2)	64.5 (28.4)	0.89
Wish to receive more information	52.9 (50.0)	47.7 (50.1)	0.33	51.2 (50.1)	44.8 (49.9)	0.19
Wish you have received less information	2.5 (15.7)	2.0 (14.1)	0.71	2.5 (15.6)	2.1 (14.4)	0.57
Overall the information has been helpful	70.9 (27.4)	68.8 (25.5)	0.09	72.7 (22.9)	70.6 (24.4)	0.14

[a] Groups A and C.
[b] Groups B and D.
[c] Wilcoxon paired non-parametric test.

asymptomatic patients with early disease said that the item was inappropriate for their situation, we kept it because most patients in initial stages did not comment on it.

The distribution of the scores was wide, which indicates that the items covered a range of information levels and aspects. The scores in the information areas and the number of patients wanting more information were comparable to those of other studies.[4,13] The extra topics suggested by patients did not indicate a need for new items and supported the instrument's content validity.

The known group validity analyses were generally supported by the data. Like the findings of other studies, the EORTC QLQ-INFO25 detected differences related to age,[33,36] gender,[37] emotional functioning[2,13] and education[38] in the expected directions.

The patients with less desire for information and higher satisfaction reported of higher scores on received information. No differences were found between potentially curative and palliative treatment groups. This is in line with Voogt and colleagues,[13] who found that most incurable patients felt sufficiently informed about important disease-specific issues and were satisfied with the information provided by health care professionals. Our expectations that patients who had received more prior treatments would report of having received more information were not supported. This may reflect a phenomenon similar to response shift, whereby patients' perceptions and internal standards change during the course of disease and treatment.[39] Perhaps patients constantly make subjective evaluations of the information they receive, comparing the actual level of information with their expected level, and perhaps they forget some of the information they received during previous treatments.

Similarly, in the responsiveness to change analysis, no increase in information was found between the beginning and the end of treatment. This could be due to the informed consent procedure, whereby all the information is provided before the treatment begins in order to allow patients to participate in shared decision making. Until further studies are conducted, the INFO25 may not be sensitive enough to detect changes in the amount of information provided on medical matters (diagnoses, tests and treatments). However, it can detect increases in information about other services/places of care.

A strength of this study is the participation of a large international group of unselected patients. This reflects the usual clinical practice in many European countries and Taiwan. A weakness is the lack of an objective measurement of the information provided to participants. It was not possible to collect such data in such a diverse multinational sample, nor was it practical to introduce a standardised information programme. However, a further detailed analysis of cross-cultural differences is planned.

In *conclusion*, the overall positive results in this large linguistically, culturally and clinically diverse sample of cancer patients support the psychometric properties of the EORTC QLQ-INFO25. This questionnaire is a valid measure of patients' perceptions of received information and can be used in clinical practice and research to evaluate information-based interventions and programmes.

During your current disease or treatment, how much information have you received on:	Not at all	A little	Quite a bit	Very much
31. The diagnosis of your disease?	1	2	3	4
32. The extent (spread) of your disease?	1	2	3	4
33. The possible causes of your disease?	1	2	3	4
34. Whether the disease is under control?	1	2	3	4
35. The purpose of any medical tests you have had or may undergo?	1	2	3	4
36. The procedures of the medical tests?	1	2	3	4
37. The results of the medical tests you have already received?	1	2	3	4
38. The medical treatment (chemotherapy, radiotherapy, surgery or other treatment modality)?	1	2	3	4
39. The expected benefit of the treatment?	1	2	3	4
40. The possible side-effects of your treatment?	1	2	3	4
41. The expected effects of the treatment on disease symptoms?	1	2	3	4
42. The effects of the treatment on social and family life?	1	2	3	4
43. The effects of the treatment on sexual activity?	1	2	3	4
44. Additional help outside the hospital (e.g. help with daily activities, self help groups, district nurses)?	1	2	3	4
45. Rehabilitation services (e.g. physiotherapy, occupational therapy)?	1	2	3	4
46. Aspects of managing your illness at home?	1	2	3	4
47. Possible professional psychological support?	1	2	3	4
48. Different places of care (hospitals/outpatient services/home)?	1	2	3	4
49. Things that you can do to help yourself get well (rest, contact with others..)?	1	2	3	4

50.	Have you received written information?	Yes	No
51.	Have you received information on CD or tape/video?	Yes	No

	Not at all	A little	Quite a bit	Very much
52. Were you satisfied with the amount of information you received?	1	2	3	4

53.	(a) Do you wish to receive more information?	Yes	No
	(b) If yes, please specify on which topics?		
54.	(a) Do you wish that you had received less information?	Yes	No
	(b) If yes, please specify on which topics?		

	Not at all	A little	Quite a bit	Very much
55. Overall has the information you have received been helpful?	1	2	3	4

EORTC QLQ – INFO25

We are interested in the information you have received about aspects of your disease and its treatment, in order to improve your health care. Please answer ALL the questions yourself by circling the number that best applies to you. There are no right or wrong answers. The information that you provide will remain strictly confidential.

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Conflict of interest statement

None declared.

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