

EORTC QLQ-COMU26: a questionnaire for the assessment of communication between patients and professionals. Phase III of the module development in ten countries

Juan Ignacio Arraras¹ · Lisa M. Wintner² · Monika Sztankay^{2,3} · Krzysztof A. Tomaszewski⁴ · Dirk Hofmeister⁵ · Anna Costantini⁶ · Anne Bredart⁷ · Teresa Young⁸ · Karin Kuljanic⁹ · Iwona M. Tomaszewska¹⁰ · Meropi Kontogianni¹¹ · Wei-Chu Chie¹² · Dagmara Kulis¹³ · Eva Greimel¹⁴ · Conducted on behalf of the EORTC Quality of Life Group

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Abstract

Purpose Communication between patients and professionals is one major aspect of the support offered to cancer patients. The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group (QLG) has developed a cancer-specific instrument for the measurement of different issues related to the communication between cancer patients and their health care professionals.

Methods Questionnaire development followed the *EORTC QLQ Module Development Guidelines*. A provisional questionnaire was pre-tested (phase III) in a multicenter study within ten countries from five cultural areas (Northern and

South Europe, UK, Poland and Taiwan). Patients from seven subgroups (before, during and after treatment, for localized and advanced disease each, plus palliative patients) were recruited. Structured interviews were conducted. Qualitative and quantitative analyses have been performed.

Results One hundred forty patients were interviewed. Nine items were deleted and one shortened. Patients' comments had a key role in item selection. No item was deleted due to just quantitative criteria. Consistency was observed in patients' answers across cultural areas. The revised version of the module EORTC QLQ-COMU26 has 26 items, organized in 6 scales and 4 individual items.

✉ Juan Ignacio Arraras
jiarraras@correo.cop.es

Lisa M. Wintner
lisa.wintner@tirol-kliniken.at

Monika Sztankay
monika.sztankay@tirol-kliniken.at

Krzysztof A. Tomaszewski
krtomaszewski@gmail.com

Dirk Hofmeister
Dirk.Hofmeister@medizin.uni-leipzig.de

Anna Costantini
annacostantini@alice.it

Anne Bredart
anne.bredart@curie.net

Teresa Young
teresa.young2@nhs.net

Karin Kuljanic
kkuljanic@gmail.com

Iwona M. Tomaszewska
im.tomaszewska@gmail.com

Meropi Kontogianni
mkont@hua.gr

Wei-Chu Chie
weichu@ntu.edu.tw

Dagmara Kulis
dagmara.kulis@eortc.be

Eva Greimel
elfriede.greimel@klinikum-graz.at

¹ Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain

² Department of Psychiatry, Psychotherapy and Psychosomatics, Innsbruck Medical University, Innsbruck, Austria

Conclusions The EORTC COMU26 questionnaire can be used in daily clinical practice and research, in various patient groups from different cultures. The next step will be an international field test with a large heterogeneous group of cancer patients.

Keywords Cancer · Oncology · Communication · Quality of life · Questionnaire · EORTC

Introduction

Effective communication between patients and professionals has positive effects on all involved [1]. Professional's communication skills are especially important in oncological care [2–5]. Good communication is a key to supporting patients along the disease trajectory [6, 7] and contributes to improved pain control, psychological functioning [1, 8] and quality of life (QOL) [9–13].

Patient–professional communication can be understood as a process whose components influence each other, e.g. delivering and receiving bad news involve a two-way process [14]. Patient–professional communication can elicit, explore and construct patient preferences for healthcare and help professionals to understand these preferences [15].

Carlson. et al. [16] discuss two goals of communication based on Feldman-Stewart's theoretical framework for patient–professional communication [17]: primary goals which are directly linked to the communication process (e.g. patient education/understanding, effective decision making, providing support) and secondary goals that are indirect

consequences of effective communication (e.g. reduced depression, improved satisfaction with care).

There has been a shift in recent years in models of care from a paternalistic [18] to a patient-centered approach, where patients' preferences, experiences and needs are the main focus [19]. One major component of patient-centered care is patient-centered communication (PCC), which influences not only the process of the communication between patients and professionals but the associated outcomes as well. According to Epstein and Street [20], the six core functions of PCC comprise fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management. This shift in model of care is especially prevalent in Western countries. Cross-cultural differences in patient–professional communication and its individual aspects (e.g. truth-telling attitudes) [21], which might be linked to the predominant model of care, need to be considered when assessing communication.

Epstein and Street [22] and Carlson et al. [16] suggest that when evaluating patient–professional communication, consideration should be given to the changing needs of patients along the treatment process. A range of professionals may be involved and each will need to convey information relevant to their role. Although different styles of communication have been found between professionals [23, 24], they should be able to communicate effectively irrespective of their personal aptitude.

The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group (QLG) decided to develop an EORTC cancer-specific communication module to assess different aspects of patient–professional communication. It would assess some of the primary goals of communication presented by Carlson et al. [16] and be applicable across different cultures. The Epstein and Street's core functions of the PCC model [20] were considered in the development of the communication module, except the function 'making decisions' that was considered to need a questionnaire of its own, and the area 'content of information', that can be evaluated using the EORTC information questionnaire (QLQ-INFO25) [25]. Although intended to be administered as a stand-alone measure in the setting of daily clinical practice, clinical studies or clinical trials, the communication module could also be administered in combination with the EORTC QLQ-C30, and is suitable for patients with any tumour site, disease stage and treatment (including palliative care).

The development of EORTC questionnaires follows rigorous guidelines, including four distinct phases of development in a cross-cultural setting [26]. Phases I and II of the communication module have been reported elsewhere [27].

Phase I involved a literature search and professionals and patient interviews to determine the key issues. Phase II involved rephrasing the issues as items/questions to construct

³ Leopold-Franzens-University Innsbruck, Innsbruck, Austria

⁴ Health Outcomes Research Unit, Department of Gerontology, Geriatrics, and Social Work, Ignatianum Academy, Krakow, Poland

⁵ University of Leipzig, Leipzig, Germany

⁶ Psycho-Oncology Unit, Faculty of Medicine and Psychology, Sant'Andrea Hospital, Sapienza University, Rome, Italy

⁷ Institut Curie, Paris, France

⁸ Mount Vernon Cancer Centre, Northwood, UK

⁹ Department of Gynecology and Obstetrics, Center of Psychology, University Hospital Center Rijeka, Rijeka, Croatia

¹⁰ Department of Medical Education, Jagiellonian University Medical College, Krakow, Poland

¹¹ Department of Nutrition and Dietetics, Harokopio University, Athens, Greece

¹² Department of Public Health, College of Public Health, Institute of Epidemiology and Preventive Medicine, National Taiwan University, Taipei, Taiwan

¹³ QOL Department, EORTC HQ, Brussels, Belgium

¹⁴ Medical University Graz, Graz, Austria

a provisional module that included 34 items. Respondents indicate the professional category they are evaluating: doctor(s), nurse(s), psychologist(s), radiotherapy technician(s) and other professionals. Additionally, patients indicate the specific treatment period they are evaluating: diagnosis, treatment or follow-up. All items are scored on a 1–4-Likert scale (not at all, a little, quite a bit and very much). The questionnaire has been translated following the EORTC translation procedure [28].

This manuscript describes phase III, which aims at pre-testing the provisional module by (1) identifying and resolving potential problems regarding administration, (2) assessing the cross-cultural applicability and (3) taking into account patients' feedback for addition of new items or deletion of redundant items.

Methods

Patients

Members of the EORTC QLG from ten countries recruited patients. Inclusion criteria were (a) diagnosis of cancer; (b) any stage of disease and on or off treatment—palliative patients receiving treatment for symptom control (except chemotherapy) were eligible as well; (c) ≥ 18 years of age; and (d) giving informed consent. End of Life patients (very frail and with a very short life expectancy) and those with cognitive impairment were excluded. Seven groups of patients were recruited. Combining the two criteria: (a) disease stage (localized or advanced) and (b) treatment phase (before, during and after treatment) resulted in six groups of patients. The seventh group was receiving palliative care for symptoms control (Table 1). We aimed at including 15 patients for each group. The protocol was approved by local ethical committees according to national requirements and followed the Declaration of Helsinki of 1975, as revised in 2008.

Procedure/interviews

Patients received oral and written information before consenting. Clinical data (comorbidity, present treatment, tumour site) and demographic data (age, gender, civil status, level of education) were recorded. The presence of limiting comorbidity (yes, no) was assessed by the treating physician. After questionnaire completion, a structured face-to-face interview assessed the patient-rated relevance (1–4) and importance (yes, no) of each item. Patients were encouraged to state if they considered any of the items to be difficult, annoying, upsetting, confusing or intrusive. In addition, three additional in depth questions on selected items were asked:

1. Patients were asked if items, especially developed to assess the physicians' skills for information disclosure, could be considered to be as well relevant for nurses, psychologists and other professionals or just for doctors (the answer categories were yes or no).
2. Patients were asked if they would keep two similar items on respect or if they had a preference for one of the items: if there had been mutual respect between patient and professional(s) and whether professional(s) treated the patient with respect.
3. Patients were asked about their understanding of the expression 'in a realistic way', included in an item asking whether patients considered professionals had helped them to rely on their treatment. Due to cross-cultural differences, patients might interpret the meaning of this expression differently.

Finally, patients had the opportunity to identify irrelevant items and missing content.

Quantitative and qualitative data analysis and criteria for selection of items

The aim was to select the items that were most relevant to assess communication; that could adequately assess the different levels of communication; that showed consistency across cultures and whose content and expression were considered by patients as acceptable. A balance was sought between patients' burden and the usefulness of each item. The decision process was based both on expert consensus and the QLG module development guidelines defining criteria for item exclusion as listed below [26].

Decision rules: quantitative analysis

To retain an item in the module, the following eight pre-defined numerical criteria were used:

- (a) Relevance ($\geq 60\%$ of patients scored the item 3 or 4)
- (b) Importance ($\geq 60\%$ of patients considered the item important)
- (c) Mean score (> 1.5)
- (d) Prevalence of scores 3 or 4 $> 50\%$
- (e) Score range (> 2 points)
- (f) Floor or ceiling effects ($> 10\%$ of patients rated the item 1 or 2 or $> 10\%$ rated the item as 3 or 4)
- (g) Compliance (at least 95% response)
- (h) Consistency across languages/cultures

The seven quantitative criteria (a to g) were repeated in each of the four European cultural areas (the analysis were not repeated in Taiwan, due to the low number of Taiwanese patients) and compared to see if items that had good

Table 1 Groups and number of patients included

	Before treatment	During treatment	After treatment	Palliative care
Localized disease	17	22	19	
Advanced disease	19	25	17	21

functioning in the global sample continued to perform well in each cultural area. The data were also investigated to see if items that were problematic in the global sample showed difficulties just in one cultural area (this could be a problem in the translation, or the concept and/or the expression of the item might not be adequate for that area) or if problems appeared in several cultural areas (a problem in the item content, criterion h).

Items failing to score adequately on criteria a and b were considered for deletion. Remaining items that met at least four of the six criteria c to h were considered for retention, unless the open interview suggested patients had significant concerns. Frequency counts were used to decide amongst the appropriateness of items on information disclosure and the two items on respect.

After deleting items, a preliminary Cronbach's alpha was calculated for each proposed scale. Psychometric functioning (reliability, validity, structure, responsiveness to changes) will be formally assessed in phase IV, which is a large multicenter field study.

Decision rules: qualitative analysis

Patients' ratings of items being difficult, annoying, upsetting, confusing, intrusive or irrelevant were an additional decision aid alongside the quantitative results. The understanding of the expression 'in a realistic way' was analysed by extracting general topics mentioned by patients and calculating their frequencies. The qualitative analysis was repeated in each of the four European cultural areas, to see if limitations were evenly distributed.

Additional issues needed to be mentioned by at least one third of the patients to be considered as new questions, as new issues raised by a few patients might represent a concern relevant to a particular subgroup of patients or a particular institution. Due to the comprehensive nature of phase I, it was not expected that many patients would suggest the same new issue.

The researchers of the EORTC communication module group meet face to face twice yearly to discuss the progress of projects and make decisions on further steps. Presented results were discussed within this multiprofessional expert group in September 2014. Based on quantitative and qualitative criteria, it was decided whether to keep items, remove them or change their wording.

Results

Between May 2013 and September 2014, 140 patients from ten countries and five cultural areas Northern Europe (Austria, Germany), Southern Europe (Croatia, France, Greece, Italy and Spain), Eastern Europe (Poland), English speaking countries (UK) and one non-European country (Taiwan) (Table 2) were enrolled. At least 17 patients were recruited for each pre-defined subgroup (Table 1).

The mean patient age was 58.1 years and 53.6% were female. Breast (27.1%) and head and neck (24.3%) cancer were the most common diagnoses. A range of civil status, level of education, tumour sites and treatment modalities were represented. Though five different types of professions were evaluated, there was a predominance of doctors (74.3%).

Quantitative analysis

All items met the criteria for a relevance and for b importance, and all items met at least four of the next five inclusion criteria (c to g) (Table 3). Consistency across languages/cultures h was found in most cases. The item with the lowest prevalence and the item with the lowest compliance showed limitations in three of the cultural areas; items with ceiling effect showed limitations in at least two cultural areas. The only inconsistency was three items with limitations in relevance just in one country (Poland). No other item had important or relevant limitations in any cultural area. No item had limitations in three or more of the numerical criteria c to g in any cultural area.

Patients considered the information items were relevant for all professionals (64–77% of patients agreed). Sixty percent of patients preferred to only have one item referring to respect, and 60.7% considered this item should assess whether professional(s) have treated them with respect.

Qualitative analyses

No item was considered upsetting and four were considered annoying by one patient and one by two patients; two were considered intrusive by one patient, four were considered difficult to answer by six to ten patients and four were considered as confusing by three to nine patients. Eleven were considered repetitive by three to five patients (for three of these items, comments were offered in just one country). Eight of these

Table 2 Characteristics of the sample

	Number	Percent
Patients		
Austria	10	7.2
Croatia	10	7.2
France	13	9.3
Germany	16	11.4
Greece	10	7.2
Italy	15	10.7
Poland	18	12.9
Spain	35	25.0
Taiwan	2	1.4
UK	11	7.9
Age		
Min 23, max 87		
Mean(S.D.)		
58.1(14.1)		
Sex		
Male	65	46.4
Female	75	53.6
Civil status		
Living alone	15	10.9
Living with partner	84	60.9
Living with family	35	25.3
Living with other adults	4	2.9
Level education		
Less than compulsory	12	8.8
Compulsory ^a	35	25.5
Post compulsory below university level	44	32.1
University level	46	33.6
Comorbidity	41	29.3
Present treatment		
Surgery	76	54.3
Radiotherapy	77	55.0
Chemotherapy	74	52.9
Hormone therapy	25	17.9
Other	7	5.0
Tumour site		
Breast	38	27.1
Lung	12	8.6
Gynecological	11	7.9
Hematologic	8	5.7
Colo-rectal	10	7.1
Gastric	4	2.9
Prostate	8	5.7
Pancreas	3	2.1
Head and neck	34	24.3
Skin	3	2.1
Testicular	4	2.9
Other	5	3.6
Assessed profession		

Table 2 (continued)

	Number	Percent
Doctor	104	74.3
Nurse	28	20.0
Psychologist	2	1.4
RT technician	5	3.6
Other	1	0.7
Assessed time period		
Diagnosis	38	27.1
Treatment	73	52.1
Follow-up	29	20.8

^a Compulsory school education runs between 14 and 16 years in the participating countries

eleven could be organized in four pairs with one redundant in each pair. One was considered as irrelevant by six patients. Other items have lower frequencies in these four last qualitative areas. Four patients considered there were too many items on emotions. Six patients (from three counties and three cultural areas) considered the questionnaire too long.

In most cases, comments were offered in more than one country and cultural area, indicating there was no cross-cultural issue underlying these comments. Items considered overlapping with another item in only one country, and the three items with low relevance in Poland, were discussed amongst the working group. No cross-cultural issues or problems with the wording or the translation were found.

No new issue was mentioned by at least one third of the patients. Some issues were proposed by one to three patients: issues on the content of the information that is offered by professionals (e.g. information on medical tests) and issues on the coordination amongst professionals when giving information were suggested.

Patients offered four different interpretations of the expression ‘in a realistic way’: (1) to explain the treatment in detail; (2) to explain how the disease, treatment and secondary effects really were likely to be experienced, so that decisions could be made based on facts rather than unlikely hopes (reality); (3) to explain the prognosis and (4) to show sincerity—though there is already a similar item in the questionnaire on sincerity.

Decisions

Deleted items and the reasons for excluding them from the questionnaire are presented in Table 4.

Nine items were deleted and one was shortened. Qualitative analyses had a key role in decisions on item deletion, and no item was deleted just on the basis of quantitative criteria. Due to their low frequency, patients’ ratings of items to be upsetting, annoying or intrusive did not have an influence on item selection. Comments on items being difficult to

Table 3 Replies to the quantitative criteria in the global sample

Criteria	Items that meet the criteria
(a) Relevance	All items One item 62% close to the 60% criteria**
(b) Importance	All items
(c) Mean score >1.5	All items One item mean score 1.84 close to the 1.5 criteria**
(d) Prevalence of scores 3 or 4 >50%	All items except in one (22.3): -being troubled by disturbances or interruptions during sessions with professionals
(e) Range >2 points	All items
(f) No floor effect No ceiling effect	All items Seven items did not meet the criteria: -mutual respect between patient and professionals -professionals show sincerity -professionals treat the patients with respect -professionals take patients' problems seriously -professionals use a language the patient understand -professionals answer patients' questions openly -professionals use a calm voice
(g) Compliance $\geq 95\%$	All items except in one (94.3%): -professionals have helped patients to manage their emotions

** items that have scores a bit higher than the criteria

answer and irrelevant (stated by at least six patients), confusing or having another item with a similar meaning (stated by at least three patients), or that there were too many items on emotions were taken into account despite low frequencies in order to reduce response burden. Seven of the eleven items considered redundant were deleted. Six of these seven redundant items were also deleted because they were considered as confusing or difficult to answer or that there were too many questions on emotional aspects. The item enquiring about allowing time to ask questions and reply was considered as 'double-barreled', covering two issues whilst only offering one response.

One item was divided into two items, as it was considered to include two questions, asking if professionals checked how the patient understood provided information and if misunderstandings had been corrected, if necessary.

Six patients rated an item concerning whether patient's preferences on how and when information should be offered had been taken into account to be difficult to answer and confusing. Although this would suggest the item should be deleted, 40.3% of patients had responded to this item with 'not at all' or 'a little'. We understood these prevalence scores indicated clinical significance, suggesting poor communication from their professional. Following an expert consensus, the item was simplified and retained. No other item was considered to need rephrasing due to low frequencies of comments in the qualitative criteria. The six items on skills for information disclosure were retained for all professionals.

Resulting communication module EORTC QLQ-COMU26

The final version of the communication module has 26 items organized into 6 scales and 4 individual items. The six scales evaluate patient's active role behaviours, aspects of the clinician–patient relationship, professional's qualities for creating a relationship, professional's skills (verbal–nonverbal language), professional's management of patient's emotions and professional's skills related to delivering information. The four individual items assess professionals taking into account patient's preferences on how the information should be offered, correcting misunderstandings in information when necessary, privacy and satisfaction with the communication. All proposed scales have a reliability coefficient >0.78 (Table 5).

Discussion

The EORTC QLQ-COMU26 questionnaire is a newly developed questionnaire evaluating different aspects of cancer patients' communication with professionals. The questionnaire is applicable across patients with any tumour site and in any disease and treatment stage, including palliative care. Patients may be receiving (or have received) treatment in hospitals (as in and out patients), in palliative care units or with home care teams. The questionnaire allows patients to indicate the

Table 4 Details of nine items deleted: content and reasons

Item content	Similar meaning (N)	Confusing (N)	Difficult to answer (N)	Irrelevant (N)	Quantitative analyses	Other reasons for item deletion
Opportunities to express your needs	Yes (3) 2 countries 2 cultural areas	Yes (3) 3 countries 2 cultural areas				
Mutual respect between patients and professionals	Yes (5) 1 country					Patients preferred just one item on respect (See Table 5)
Professionals had spent enough time to ask questions and to reply to them	Yes (4) 2 countries 2 cultural areas					Asking two questions, difficult to interpret and respond
Professionals made patient feel comfortable for communication	Yes (3) 1 country					
Professionals acknowledge patients' emotions	Yes (5) 2 countries 2 cultural areas					Too many questions on emotional aspects (4 patients, 3 countries, 3 cultural areas)
Professionals understand patients' perceptions of their situation	Yes (5) 1 country		Yes (6) 4 countries 2 cultural areas			As above
Professionals offer counseling about possible concerns	Yes (5) 3 countries 3 cultural areas		Yes (6) 3 countries 3 cultural areas			As above
Professionals had helped patients to rely on the treatments in a realistic way		Yes (9) 4 countries 3 cultural areas	Yes (10) 4 countries 3 cultural areas	Yes (6) 3 countries 3 cultural areas		Item not clear: patients offered four different interpretations
Being troubled by disturbances or interruptions during sessions with professionals		Yes (3) 3 countries 2 cultural areas			• 22.3% prevalence scores 3 or 4; • 62% in relevance, close to the 60% criteria; • Mean score 1.84 close to the 1.5 criteria	

All items met the inclusion criteria a and b and at least four of the criteria c to g. Similar meaning: patients considered another item of the provisional questionnaire could have a very similar meaning. The numbers of countries and cultural areas illustrate the cross-cultural distribution of patients' statements of items to be similar, confusing, difficult or irrelevant

professional category and the specific treatment period they are going to evaluate.

The recruited patient sample for the phase III questionnaire pre-testing covers a wide range of demographic and clinical characteristics, demonstrating its applicability and appropriateness for various patient groups. The high proportion of patients who chose to assess their doctors indicates that patients consider their communication with these professionals as particularly important.

The high percentages for importance, relevance and compliance indicate communication with professional is important for cancer patients [6]. Content validity is supported by the fact that no new issue had to be included and only one item was deleted because of patient-rated irrelevance. The results from the other quantitative criteria indicate that items are satisfactory to evaluate different levels of communication. Given the emotive and personal nature of communication between cancer patients and professionals, it was pleasing to note that no item was upsetting and only a small number of patients mentioned few items to be annoying or intrusive. The low level of negative comments presumably is a consequence of a satisfactory

questionnaire development process, where several rounds of interviews and discussions were used to refine and improve the questionnaire [27].

The EORTC questionnaire development approach pays special attention to cross-cultural applicability. For the communication module, this was achieved by collecting phase III data from ten countries and five cultural areas. Earlier phases also included patients and professionals from a variety of cultural areas [27]. Group discussions involved input from researchers representing different cultural areas. Special attention was given to the wording of the items, to ensure that the same concepts were understood in different countries and to avoid expressions that might be annoying for particular cultural or linguistic regions. For this reason, the word 'cancer' was not used, as not all patients (especially in South Europe) are aware of their diagnoses [29, 30].

Patients' comments on the questionnaire items and the scores in the low prevalence item and in the lower compliance item were distributed amongst different cultural areas, indicating no item had difficulties in any area. This can again be attributed to the multicultural development process.

Table 5 Structure of the EORTC-COMU26 and reliability

Scale and content	Alpha
Scale 1 patient's active role behaviours	0.79
Patients have enough opportunities to talk with the professionals	
Feel free to ask questions	
Have the opportunity to express their emotions	
Scale 2 aspects of the clinician-patient relationship	0.85
Shared understanding of the disease and treatment	
Mutual trust between patient and professionals	
Professionals have spent enough time talking with patients	
Scale 3 professional's qualities creating a relationship	0.88
Approach as an equal	
Show sincerity	
Make it easy to talk openly about concerns	
Treat the patient with respect	
Take patient's problems seriously	
Scale 4 professional's skills	0.85
Use language patient understands	
Answer questions openly	
Look at patient	
Calm voice	
Scale 5 professional's management of patient's emotions	0.84
Try to understand patient's situation	
Listen when patient expresses emotions	
Help patient to manage their emotions	
Scale 6 professional's skills related to information	0.83
Check patient's previous level of information.	
Check patient's understanding of information	
Answer difficult questions	
Explain the aims of the treatment	
Individual items	
Professionals take into account patient's preferences on how the information should be offered	
Professionals correct misunderstandings in information	
Enough privacy	
Satisfaction with the communication with professional	

Where items were deleted because they were similar, it is acknowledged that the items that were kept did not have identical meaning to those deleted. Whilst retaining all the items might have enabled assessment of communication in a more detailed way, this may have been at the expense of patient burden with a longer questionnaire.

Communication and information in oncology are two related areas. Much of patient–professional communication is focused on discussions related to conveying disease and treatment information. The success of these discussions depends to a large extent on the communication skills of professionals to help patients understand provided information [31, 32]. The suggestion to include issues on information disclosure was declined as the EORTC QLG has already developed an information module EORTC QLQ-INFO25, which mainly evaluates the content of the information that is delivered [25, 33].

Most patients expressed the opinion that items on skills on information disclosure should not only be addressed to doctors but to other professionals such as nurses, psychologists and radiotherapy technicians as well. This emphasizes the role these professionals have in the information disclosure process [34, 35].

Hack [32] recommends that more research on communication should be performed as the majority of unmet communication needs expressed by patients pertain to the quality of communication with professionals. The EORTC QLQ-COMU26 questionnaire could be used in such research. It might also be useful in carrying out research on cross-cultural differences in communication. Methods to improve communication between patients and professionals should take into account the characteristics of cultural areas [36]. As the model of care is changing in some areas (e.g. Southern Europe countries) [37], there also might be some changes in the model of communication.

Limitations of the present study are the low number of patients who have assessed professionals other than doctors and the low number of patients from non-European areas.

Conclusion

The EORTC QLQ-COMU26 could be used in daily clinical practice, in clinical studies, in clinical trials and in cross-cultural studies. Following the EORTC QLG module development guidelines [26], the next step is to field-test the EORTC QLQ-COMU26 in a larger international study (phase IV), to ensure it is an appropriate and psychometrically valid instrument for use in international studies. More non-European patients will be included to put a focus on the investigation of cross-cultural differences and a higher proportion of allied professionals will be assessed. The development of the EORTC QLQ-COMU26 is a major step towards enabling high quality research on cancer patients' communication with professionals.

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Compliance with ethical standards The protocol was approved by local ethical committees according to national requirements and followed the Declaration of Helsinki of 1975, as revised in 2008.

Conflict of interest The authors declare that they have no competing interests.

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