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The development of the EORTC QLQ-C15-PAL: A shortened questionnaire for cancer patients in palliative care

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ABSTRACT

This study aimed at developing a shortened version of the EORTC QLQ-C30, one of the most widely used health-related quality of life questionnaires in oncology, for palliative care research. The study included interviews with 41 patients and 66 health care professionals in palliative care to determine the appropriateness, relevance and importance of the various domains of the QLQ-C30. Item response theory methods were used to shorten scales. Patients and health care professionals rated pain, physical function, emotional function, fatigue, global health status/quality of life, nausea/vomiting, appetite, dyspnoea, constipation, and sleep as most important. Therefore, these scales/items were retained in the questionnaire. Four scales were shortened without reducing measurement precision. Important dimensions not covered by the questionnaire were identified. The resulting 15-item EORTC QLQ-C15-PAL is a 'core questionnaire' for palliative care. Depending on the research questions, it may be supplemented by additional items, modules or questionnaires.

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1. Introduction

Palliative care is defined by the World Health Organization as ‘... an approach that improves the quality of life of patients and their families ...’ [1]. It is widely recognised that there is a need for careful evaluation of all aspects of palliative care and for more research in this area. The preferred source of information about patients’ symptoms and functional problems is the patients themselves [2]. However, researchers in this setting need to carefully consider the amount of burden associated with the collection of self-report data from patients with advanced disease and a limited life expectancy. Questionnaires need to be brief, while still capturing the range of issues relevant in a valid and reliable manner.

A large number of patient self-assessment questionnaires has been used in palliative care research [2,3], but unlike oncology where a limited number of instruments (e.g. the EORTC QLQ-C30 [4] and the FACT [5]) enjoy widespread use, there is less consensus in the palliative care field as to which instruments should be recommended [2,3].

The EORTC QLQ-C30 has been used in palliative care research [6–8]. It is one of the most widely used instruments in oncology for assessing physical and psychosocial symptoms and functioning of patients with cancer, in both the curative and palliative settings [6–9]. Advantages of the EORTC QLQ-C30 include extensive validation [10–15], the availability of reference data [16], many published studies for comparison, standardised scoring procedures [17] and translation procedures [18,19], and evidence concerning interpretation of scores [17,20,21]. A possible disadvantage of the EORTC QLQ-C30 when used in palliative care is its *length* (30 items). Additionally, because the questionnaire was not designed specifically for use in palliative care, some of its content may be perceived as inappropriate by patients and health care providers.

Given the many advantages of the EORTC QLQ-C30, the aim of this study was to develop a shortened version of the questionnaire suitable for patients in palliative care. The study had two parts:

1. Shortening multi-item scales by means of item response theory (IRT) and developing algorithms for scoring the shortened scales on the original response scale metric (reported in detail elsewhere [19,22,23]).
2. Interviews with patients and health care professionals to identify scales and/or single items, which were inappropriate or not highly relevant, and therefore could be deleted.

2. Patients and methods

2.1. The EORTC QLQ-C30

The EORTC QLQ-C30 was developed by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group [4]. Version 3 of the QLQ-C30 consists of 30 items forming five multi-item scales assessing physical, role, emotional, cognitive, and social function, three symptom scales measuring fatigue, pain, and nausea/vomiting, one scale assessing ‘global health status and quality of life’, and six single items [4,17].

2.2. Summary of part 1 of the project: shortening of scales

The methodology used to shorten scales is described in detail elsewhere [22,23]. The three scales of the QLQ-C30, which consist of at least three items – physical function, emotional function, and fatigue – had the greatest potential for shortening. Based on the literature, we anticipated that these scales would be judged as relevant in interviews with patients and health care providers. The analyses of these three scales lead to shortened versions (Table 1), and were available before the interviews were completed. The analyses of the remaining 2-item scales suggested that it might be possible to shorten some of these scales. Table 1 displays the shortened scales, which work best from a psychometric perspective. The results of these analyses (including the decisions as to which scales should be shortened) will be interpreted in conjunction with the results of interviews.

2.3. Part 2 of the project: interviews

The aim of the interviews was to identify the most relevant and appropriate issues from those included in the QLQ-C30. In conducting the interviews, we followed the EORTC Quality of Life Group Guidelines for Module Development [24,25], with minor deviations as described below.

2.4. Selection of persons for interviews

We aimed at interviewing at least 10 patients and 10 health-care professionals from at least three countries.

2.4.1. Patients

Eligible patients had to be undergoing specialised palliative care, have advanced cancer, have knowledge of their cancer diagnosis, be mentally and physically capable of participating in an interview, and have given informed consent. ‘Specialist palliative care’ was defined as in-patient or out-patient care (including home care) provided by professionals specialised in palliative care.

2.4.2. Health care professionals

Eligible professionals had to be working in specialised palliative care and have palliative care as their main occupation. In each country, at least three health care professionals were physicians, and three were nurses.

2.5. Procedure for interviews

Interview procedures for patients and professionals were almost identical, except that patients were asked to think of relevance and importance in relation to the care they received. Professionals were specifically asked to rate relevance and importance in the context of evaluating the outcome of palliative care, i.e., not in relation to a specific patient. The full scripts used for the interviews are available from the first author. Throughout the interviews, the QLQ-C30 was available to the interviewee. Each item was reviewed using the following criteria.

Table 1 – Summary of the results of item response theory (IRT) based analyses testing shortened versions of the EORTC QLQ-C30 multi-item scales predicting the ‘original scores’ [22,23]

Scale	Items in short scale	Correct (%) ^a	Mean diff. (SD) ^b	Max. mean diff. ^c	Correlation ^d	Kappa ^d	Test ratio ^e
PA	q9	61.0	–2.5 (14.9)	–10.3	0.92	0.80	0.90
PF	q3,q4,q5	72.1	–0.6 (6.9)	5.2	0.96	0.88	1.05
EF	q21,q24	40.3	–0.5 (9.6)	4.1	0.94	0.79	1.00
FA	q12,q18	64.3	–0.3 (7.4)	2.6	0.97	0.87	0.95
QL	q29	63.5	–1.1 (8.1)	–6.0	0.95	0.85	1.01
NV	q14	68.5	–0.6 (13.2)	7.6	0.91	0.74	0.99
SF	q26	49.7	0.2 (19.1)	14.1	0.88	0.75	0.81
CF	q20	48.4	–1.0 (16.9)	–5.2	0.87	0.66	1.12
RF	q6	73.4	0.3 (10.9)	–6.9	0.95	0.85	0.95

For each scale, only the best combination of items is shown.

Full scale names are given in Table 3.

a Percent correctly predicted scale scores.

b Mean difference between predicted and observed scale scores.

c Maximal mean difference between the predicted and the observed scores across the levels of the observed scale.

d Correlation and weighted kappa between predicted and observed scores.

e Ratio of the mean test size using the shortened scale and the full scale in ‘known groups’ comparisons. Values <1 indicate that the shortened scale has less power. Roughly, a ratio of 0.90 necessitates an increase in sample size using the shortened scale of 25% to maintain the same power, a ratio of 0.95 means an increase of about 10%.

2.5.1. Relevance

Participants were asked to rate each item in terms of its relevance for ‘evaluating the outcome of the palliative care you currently receive’ (patients) and for ‘evaluating the outcome of specialist palliative care’ (professionals). Four response options were available: ‘not at all’, ‘a little’, ‘quite a bit’, and ‘very much’. If an issue was rated ‘not at all’ or ‘a little’ relevant the participant was asked to report the reason(s) for the low ratings.

2.5.2. Appropriateness

Participants were asked whether they perceived any of the items as inappropriate or upsetting (asked of patients) or might be perceived as such by patients in palliative care (professionals).

2.5.3. Breadth of coverage

Participants were asked whether there were any additional issues not included in the questionnaire that are relevant for evaluating the outcome of palliative care.

2.5.4. Relative importance

Finally, among all issues discussed, the participant was asked to choose the 10 issues considered the most important for evaluating the success of palliative care for themselves (asked of patients) or for patients in palliative care (asked of professionals).

2.6. Analysis

The ratings of the relevance of each item were linearly transformed to a 0–100 scale, with ‘not at all’ corresponding to 0 and ‘very much’ to 100 [18].

For each item, the percentage of respondents rating the item as ‘inappropriate or upsetting’, and the percentage selecting each item as one of the 10 most important was calculated. For each multi-item scale we also calculated the percentage selecting at least one item from the scale. The scales and single items were ranked according to the proportion of

patients and professionals selecting the scale/item as one of the 10 most important. This ranking was based on the simple mean: (percentage patients + percentage professionals)/2. In this way the two groups were given equal weight even though there were more professionals included in the study sample.

Based on qualitative information derived from the interviews, content categories were developed to classify both the reasons for the perceived lack of relevance of items, and for the perceived need of additional items.

3. Results

3.1. Participation

Forty-one patients and 66 professionals from 6 countries participated in the study. The participants’ nationalities and demographic and clinical characteristics are given in Table 2.

3.2. Interviews

The quantitative results from the interviews are presented in Table 3 and are discussed for each dimension below in the order they appear in the table. Table 4 categorises the qualitative responses to the question ‘Why do you consider this question not or only a little relevant?’

3.2.1. Pain (PA) scale

This scale was most frequently selected and was rated as highly relevant.

3.2.2. Physical function (PF) scale

The last three items of the PF scale were also frequently selected as important. However, the first two items of the PF scale, addressing strenuous activities and the ability to take a long walk, were rated by many respondents as being inappropriate. This was also reflected in the comments made by respondents that these levels of activity are not appropriate for patients in a palliative care setting.

Table 2 – Demographic and clinical data for 41 patients and 66 professionals participating in interviews

	Patients	Professionals
N	41	66
Country		
Denmark	13	10
The Netherlands	3	10
Norway	4	7
Spain	0	10
Sweden	10	19
United Kingdom	11	10
Age		
Median	73	43
Range	41–86	24–56
Institution		
Hospice	10	11
Department of palliative medicine	20	39
Palliative home care	2	4
Other	5	10
Unknown	4	2
Diagnosis		
Breast cancer	6	
Stomach cancer	7	
Prostate cancer	4	
Colorectal cancer	3	
Other cancer	13	
Unknown	8	
Professionals' education		
Nurse		34
Physician		19
Psychologist		2
Physiotherapist		3
Priest		2
Dietician		2
Social worker		1
Unknown		3

3.2.3. Emotional function scale

The EF scale was rated as more relevant and was selected by more professionals (71%) than by patients (46%). Large differences between items were seen, with the highest score for 'depressed' (item 24) and the lowest for 'irritable' (item 23).

3.2.4. Fatigue (FA) scale

The professionals selected 'Were you tired?' (item 18) most frequently, whereas the three items were selected roughly to the same extent by the patients. More patients than professionals selected fatigue items.

3.2.5. Global health status/quality of life (QL) scale

Patients rated the two items as equally relevant and important whereas professionals clearly preferred item 30 on '... overall quality of life'. Typical comments to item 29 ('overall health') were 'Insulting question when I'm so ill' (patient) and 'An inappropriate outcome measure for palliative care' (professional).

3.2.6. Nausea/vomiting (NV) scale

Professionals rated both items as highly relevant; the ratings from patients were more moderate. The professionals selected 'nausea' (item 14) more frequently.

3.2.7. Single items on lack of appetite, shortness of breath, constipation, and sleeping difficulties

The results for these four items were quite similar. All were rated as highly relevant by professionals and obtained lower ratings of relevance from patients. The patients rated constipation highest and dyspnoea lowest. Some patients rated the dyspnoea item as inappropriate, but the comments showed that this was because they did not have dyspnoea. The patient sample did not include any patients with lung cancer.

3.2.8. Social function (SF) scale

This scale received low ratings of relevance from patients and somewhat higher ratings from professionals. It is important to note that patients considered the topic of social functioning to be important, but found the specific items within the questionnaire to be "off target." That is, these items refer to "normal" contact with family and friends which, almost by definition, is disrupted when a patient is in hospital or hospice care.

3.2.9. Cognitive function (CF) scale

The item on 'difficulties concentrating' (item 20) was judged more relevant and important than 'memory' (item 25). Only about a quarter of the respondents selected items from this scale as among the most important.

3.2.10. The role function (RF) scale

This scale was rated low with regard to relevance and importance by both patients and professionals. Many respondents considered the questions to be inappropriate in that they do not reflect the experience of patients in a palliative care setting.

3.2.11. Financial difficulties (Fi) item

Of all the items, this item obtained the lowest patient rating of relevance whereas the rating by professionals was higher. Twelve professionals stated that financial difficulties were not a common problem in palliative care. Some patients rated it as inappropriate. It was rarely selected as important.

3.2.12. Diarrhoea (Di) item

Despite a relatively high rating of relevance by professionals 'diarrhoea' was rarely selected as one of the most important items.

3.3. Breadth of coverage of the EORTC QLQ-C30

Table 5 indicates the topics not included in the QLQ-C30 that patients and/or professionals found to be of relevance in evaluating palliative care. The patients proposed 15 topics whereas the professionals suggested 103. Twenty-eight of these were topics that were categorised as existential or spiritual issues. Other frequently proposed issues concerned worries related to relatives and the future, additional symptoms, and issues related to information, satisfaction with care, and social support. Each was mentioned by 14–17% of the professionals. In contrast, only five of the 41 patients mentioned any of these issues.

4. The EORTC QLQ-C15-PAL

The steering group of this project took both the results of the IRT analyses (Table 1) and of the interviews (Tables 3 and 4)

Table 3 – Rating of inappropriateness, relevance, and importance in interviews with 41 patients (Pat.) and 66 professionals (Prof.)

Scale/item	Item #	% Inappropriate		Relevance		% Selected as one of 10 most important		
		Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	/2 ^a
Pain (PA)	9	2	2	87	97	78	76	
	19	0	2	70	83	37	30	
Any PA item						80	89	85
Physical function (PF)	1	12	33	51	23	12	2	
	2	5	26	46	32	20	0	
	3	5	3	68	73	24	17	
	4	5	2	70	75	34	21	
	5	5	0	58	86	27	42	
Any PF item						71	50	60
Emotional function (EF)	21	0	0	53	80	10	18	
	22	0	0	71	91	27	33	
	23	2	2	42	77	5	8	
	24	0	2	60	93	29	50	
Any EF item						46	71	59
Fatigue (FA)	10	0	3	78	70	32	6	
	12	0	6	77	75	22	14	
	18	0	2	76	81	34	32	
Any FA item						59	42	50
Global health status/ Quality of life (QL)	29	2	5	81	65	34	18	
	30	2	2	80	84	39	52	
Any QL item						44	53	48
Nausea and vomiting (NV)	14	2	0	71	93	24	52	
	15	2	2	66	90	20	14	
Any NV item						32	56	44
Appetite (ap)	13	2	0	69	91	46	41	44
Dyspnea (Dy)	8	7	2	59	94	41	39	40
Constipation (Co)	16	2	0	78	95	34	41	38
Sleep (Sl)	11	2	0	69	94	32	42	37
Social function (SF)	26	2	9	53	72	17	29	
	27	2	6	49	67	17	18	
Any SF item						22	38	30
Cognitive function (CF)	20	0	3	63	83	24	20	
	25	2	5	50	71	20	6	
Any CF item						29	23	26
Role function (RF)	6	5	18	48	45	20	14	
	7	5	8	49	50	15	11	
Any RF item						24	23	23
Financial difficult. (Fi)	28	7	2	36	68	15	21	18
Diarrhea (Di)	17	2	0	68	83	7	6	7

The scales/items are ranked according to importance.

Note: Values marked in italics indicate items eventually removed from the QLQ-C30 to form the QLQ-C15-PAL.

a The mean of the values for patients and professionals.

into consideration in constructing an abbreviated version of the QLQ-C30, the EORTC QLQ-C15-PAL. The following decisions were taken:

Pain scale. This scale was not modified because it was rated as extremely important, and the 1-item scale could not accurately predict the score of the original 2-item scale without loss of power.

Physical function scale. This 5-item scale was reduced to three items because both statistical analyses and interviews supported the deletion of items 1 and 2 [23].

Emotional function scale. The statistical analyses indicated that items 21 ('tense') and 24 ('depressed') were best in predicting the original scale score [22]. Therefore, these items were retained in the scale.

Fatigue scale. The interviews confirmed the relevance and importance of this scale, which was shortened to items 12

('weak') and 18 ('tired') based on the statistical analyses [23].

Global health status/quality of life scale. Item 29 ('overall health') was rated as least relevant and least important, and thus was deleted. The aim of palliative care is to improve or maintain QL even when health is deteriorating. Therefore, to avoid that the 'overall quality of life score' is affected by 'overall health', the overall QL item will be scored as a single item. This score should be compared with scores of the corresponding item in the EORTC QLQ-C30, and not with the QL scale score.

Nausea/vomiting scale. The two items in this scale, were rated as very relevant by professionals and had lower ratings from patients. 'Nausea' (item 14) was selected more frequently than 'vomiting' (item 15). The statistical analyses showed that the NV score could be predicted very well from the 'nausea'

Table 4 – Categorised qualitative responses from patients (Pat.) (N = 41) and professionals (Prof.) (N = 66) to the question ‘Why do you consider this question not or only a little relevant?’ The categories are described below

Item #	Often/always have problem ^a		Seldom ^b		Relevance ^c		In-appropriate ^d		Technical issues ^e		Difficult ^f		Because of hospital ^g		Not legible		Other		Total
	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	Pat.	Prof.	
PA																			
9			2		1	1			3	3									7
19			6			1			3	7	1		1				2		21
PF																			
1	16	35				7		4		1	1				2		2		68
2	16	32				6		3	3	3	1				2		1		67
3	4	5		1			1	1	4	4					2				22
4	7	4					1	1	1	7					1	1			23
5	2	1	6		1	1			2	8									21
EF																			
21			5		4				5	7					1				22
22			4		2					4									10
23		2	9	3	6	4	1	1		4							1		31
24			5	1	4				1	5						1			17
FA																			
10	4	9				3				9									25
12	5	6	1					1		11							1		25
18	3	5	1						2	5									16
QL																			
29		2			1	1	1	3	3	6	3	4			1		1		26
30						2	1	1	2	4	2	3				2			17
NV																			
14			5	1					1	1							1		9
15			7	1		1			1	2							1		13
Ap																			
13	1	3	5		1										1				11
Dy																			
8			5		1	1			1	3									11
Co																			
16			6	1						1									8
Sl																			
11		2	4																6
SF																			
26	2	5	4		1	1	1	2		4	1	1	6	7	1	1	1		38
27	4	8	3		2	4	1	2		6		1	6	3	1				41
CF																			
20	1	2	4		4	2				2									15
25		1	7	2	3	6	1	1	3		3				1	1			29

Table 5 – Categorised qualitative responses from patients and health care professionals to the open-ended question about whether anything else would be relevant for inclusion in a questionnaire evaluating the outcome of palliative care

	Patients	Professionals
Existential issues		16
Thoughts about death, acceptance of death, guilt		
Spiritual issues	1	11
Spiritual needs, religion, finishing unfinished business, what comes after death		
Worries related to the relatives and the future	2	9
Worries about the future, worries about how the family will manage the future, thoughts about funeral		
Symptoms	2	9
Vertigo, cough, oedema, anxiety, more about pain, mouth problems, impact of symptoms		
Information		11
Information about disease, information about prognosis, satisfaction with information		
Satisfaction with care		11
Satisfaction with health care, satisfaction with health care professionals		
Social support		11
Support from family/relatives, support given to family/relatives, bodily contact		
Physical function/activities of daily living	3	7
Ability to move around on you own at home, ability to get outside the house, need of wheel chair etc., need of help for cooking and self-care		
Emotions	2	6
Anger, emotional impact of disease, feeling of control, sadness, positive things (e.g., did you laugh?)		
Social activities	2	3
Social life, activities outside home, ability to sustain contacts, isolation		
The relatives' situation		2
Body image		2
Dependency		2
Communication with partner and/or children		2
Attitudes of significant others	1	1
Complementary treatment	1	
Other diseases influencing quality of life	1	
Total number of issues	15	103

POS [30], Missoula-VITAS [31], QUAL-E [32] each cover some of these topics).

The EORTC Quality of Life Group plans to develop a range of short, supplementary scales ('mini-modules') assessing topics not covered by the QLQ-C15-PAL. With the availability of such mini-modules, researchers may put together a combination of measures targeted to the specific research questions posed in a given study. We also plan to develop new items addressing role and social functioning in a way that is more appropriate for the palliative care setting.

In conclusion, the QLQ-C15-PAL (Appendix) is an abbreviated 15-item version of the EORTC QLQ-C30 developed for use in palliative care. QLQ-C15-PAL scores are directly comparable with scores derived from the parent instrument, the QLQ-C30. This facilitates interpreting results from the QLQ-C15-PAL in relation to a large published literature (including reference data) using the QLQ-C30. The QLQ-C15-PAL includes those elements of the QLQ-C30 identified as most relevant and important for palliative care, i.e., physical and emotional function, pain, fatigue, nausea/vomiting, appetite, dyspnoea, constipation, sleeping difficulties, and overall QL. It is relevant as a core questionnaire for palliative care studies. As is the case with any brief questionnaire, the QLQ-C15-PAL may benefit from supplementary items or questionnaire modules that address more specific issues relevant to a given study. A number of these supplementary items/scales will be developed in the future.

Conflict of interest statement

None declared.

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Appendix. EORTC QLQ-C15-PAL

The QLQ-C15-PAL is copyrighted by the EORTC Quality of Life Group. It can be used for academic research without cost. Permission for use can be obtained from the Quality of Life Unit, EORTC Data Center, Ave. E. Mounier 83, B.11, 1200 Brussels, Belgium, or <http://www.eortc.be/home/qol/>. The QLQ-C15-PAL is available in the same languages as the QLQ-C30, currently 49 languages. QLQ-C15-PAL scores for the unchanged pain (PA) scale and the four single items are generated using the EORTC QLQ-C30 Scoring Manual [17]. Scores for the remaining scales are produced using an addendum available from the Quality of Life Unit. As for the EORTC QLQ-C30, 'QLQ' refers to 'Quality of Life Questionnaire', 'C' means 'Core', indicating that this too is a core questionnaire, which can and should be supplemented with other items, modules, or questionnaires as needed; '15' denotes the number of items, and 'PAL' refers to palliative care.



EORTC QLQ-C15-PAL (version 1)

We are interested in some things about you and your health. Please answer all of 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.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
2. Do you need to stay in bed or a chair during the day?	1	2	3	4
3. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

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