EUROPEAN JOURNAL OF CANCER 42 (2006) 2310–2317

available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejconline.com

Patient-reported assessment of quality care at end of life: Development and validation of Quality Care Questionnaire–End of Life (QCQ–EOL)

Young Ho Yun[a,*], Soo-Hyun Kim[a], Kyoung-Min Lee[a], Sang Min Park[a], Chang Geol Lee[b], Youn Seon Choi[c], Won Sup Lee[d], Si-Young Kim[e], Dae Seog Heo[f]

[a]Research Institute and Hospital, National Cancer Center, Branch of Quality Cancer Care, 809 Madul-dong, Ilsan-gu, 410-769 Goyang-si, Gyeonggi-do, Republic of Korea
[b]Department of Radiation Oncology, Yonsei University College of Medicine, Seoul, Republic of Korea
[c]Department of Family Medicine, Korea University College of Medicine, Seoul, Republic of Korea
[d]Department of Internal Medicine, Gyeong-Sang National University Hospital, Jinju, Republic of Korea
[e]Department of Internal Medicine, Kyunghee University Hospital, Seoul, Republic of Korea
[f]Cancer Research Institute, Seoul National University College of Medicine, Seoul, Republic of Korea

ARTICLE INFO

Article history:
Received 27 February 2006
Accepted 12 April 2006
Available online 8 August 2006

Keywords:
Quality of care
End of life
QCQ-EOL
Validation

ABSTRACT

Our goal was to validate an instrument with which terminally ill patients could evaluate the quality of care they receive at the end of life (EOL).

Questionnaire development followed a four-phase process: item generation and reduction, construction, pilot testing, and field-testing. Using relevance and priority criteria and pilot testing, we developed a 16-item questionnaire. Factor analyses of data from 235 patients resulted in the Quality Care Questionnaire–End of Life (QCQ–EOL) covering dignity-conserving care, care by health care professionals, individualised care, and family relationships. All subscales and total scores showed high internal consistency (Cronbach alpha range, 0.73–0.89). The ability of total score and selective subscale scores clearly differentiated patients on the basis of clinical situation, sense of dignity, and general rating of care quality. Correlations of scores between patients and caregivers were substantial. The QCQ–EOL can be adopted to assess the quality of care received by terminally ill patients.

1. Introduction

Recent data[1–3] suggest that most people today die of chronic, progressive diseases such as cancer and that it can be difficult to maintain dignity during the terminal phase of an illness. Numerous organisations[4–6] and authors[1–3,7–12] with an interest in the quality of care of dying patients have suggested several areas where end of life (EOL) care can be improved.

To create good intervention strategies, it is critical to identify those dying patients at high risk of suffering[10,12,13] and to focus on measuring the outcomes that are amenable to change and on processes that can change them.[14] To that end, a reliable, valid, and clinically manageable way to measure the quality of EOL care is needed.[1,2,13]

Measures of the quality of EOL care include FAMCARE,[15] Toolkit of Instruments to Measure End-of-Life (TIME),[16] the

---

[*] *Corresponding author*: Tel.: +82 31 920 1705; fax: +82 31 920 2199.
E-mail address: lawyun08@ncc.re.kr (Y.H. Yun).

0959-8049/$ - see front matter © 2006 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2006.04.010

31-item Quality of Dying and Death (QODD),[17] the 30-item Quality of End-of-Life Care and Satisfaction (QUEST),[18] the Care Evaluation Scale (CES),[19] and Problems and Needs in Palliative Care (PNPC),[20] and all have satisfactory psychometric properties. Several studies using FAMCARE, TIME, QODD, and CES have reported on the quality of care EOL patients receive, but they did not focus on the patients' own assessments. Even though poor health and cognitive impairment may limit a patient's ability to respond to a questionnaire and proxies are a good source of information,[21] EOL care is highly individual and patient-provided data are essential for its evaluation.[3,13,18] Family members may not be the best source of information because they often do not agree with the patient,[19,21] or even with each other,[13] and they may show recall bias.[14]

Studies using QUEST and PNPC have reported patient assessments. However, QUEST does not consider symptom burden, existential or spiritual care, and dignity. Additionally, PNPC may not be practical, and further validation is necessary.[20] We therefore developed a tool to assess the patient's perceptions of the quality of EOL care they receive.

In this paper we report on the development and initial validation of that tool, which is a brief but sensitive 16-item instrument. We call it the Quality of Care Questionnaire–End of Life scale (QCQ–EOL). It also explores the validity of family member assessments of EOL care.

2. Methods

2.1. *Study design*

Development and validation of the QCQ–EOL consisted of four phases: 1) item generation and reduction, 2) scale construction, 3) pilot testing, and 4) field-testing. The study was approved by the Institutional Review Board of the National Cancer Center, Korea. Eligible patients and families signed informed consent forms.

2.2. *Phase I: item generation and reduction*

Phase I was aimed at compiling a list of relevant quality-care issues that cover the areas of interest. We performed an extensive literature review using PUBMED, MEDRIC (Korean), and other databases searching the keywords 'end of life', 'terminally ill', 'dying', 'palliative care', 'end of life care', 'terminal care', and 'quality care', and we identified 49 issues. Discussing these with experts in the field (two palliative care specialists, two surgical oncologists, one medical oncologist, and one nurse) we generated a list of 35 potentially relevant issues.

We discussed the 35 issues in semi-structured interviews with 16 health professionals (four medical oncologists, three radiation oncologists, four surgical oncologists, five nurses), one social worker, three members of the clergy, 19 terminal cancer patients, 20 of their family members, and 19 volunteers from the general population. We asked each participant to evaluate the relevance of all 35 issues on a four-point scale ('not at all', 'a little', 'quite a bit', and 'very much'), with the first point being the most relevant, and the priority for inclusion of 15 issues on a dichotomous scale (yes or no). We deleted from the list issues with a mean score <2.0 or <33% yes scores. Based on the results and on comments collected from the interviewees, we deleted 18 issues and combined four issues into two to eliminate content overlap and to shorten the instrument. We adopted strict cut-off criteria to minimise the time and burden required to respond. This produced a total of 15 issues.

2.3. *Phase II: construction*

We constructed a list of items for the QCQ–EOL from the 15 quality care issues. For the rating format, we selected a ten-point numeric analogue scale (from 1 to 10) and a four-point Likert scale for evaluation in phase III.

2.4. *Phase III: pilot testing*

The purpose of pilot testing was to identify potential problems of administration (e.g. poor phrasing of questions) and to determine whether questions needed to be added or eliminated. Prior to the pilot testing, 18 terminal cancer patients had completed the QCQ–EOL and a debriefing questionnaire and then underwent a structured interview. The interview results helped us decide which items to include in the test. While testing, we used a debriefing form to note which items were confusing, difficult to answer, or upsetting to the patient, along with relevant comments. According to those results, we modified the questionnaire. We increased its clarity and ease of response, and we added a psychological care item – a concern expressed in most of the suggestions and articles we reviewed. The result was a 16-item questionnaire. Using input from patients and experts, we decided on a four-point Likert scale (with 0 being 'not at all') to minimise inconvenience and cognitive burden. When we pilot tested that questionnaire on 16 terminal cancer patients, we found no problems.

2.5. *Phase IV: field-testing*

We field-tested the questionnaire to determine its reliability and validity.

To reach the most heterogeneous sample of patients possible, and to evaluate the instrument's sensitivity, we enrolled patients from six conventional care facilities and five hospices in Korea. Eligible patients were required to (1) be 18 or more years old, (2) have been diagnosed as having terminal cancer (cancer was confirmed by oncologists, and terminal status was defined as progressive and no longer treatable), (3) be able to read and understand Korean and to fill out the questionnaire, and (4) provide written informed consent.

We used factor analysis (principal components factor analysis with an orthogonal [varimax] rotation) to examine construct validity, and we used multi-trait scaling analysis to examine the extent to which the QCQ–EOL items could be combined into a more limited multi-item set. We evaluated the convergent validity of QCQ–EOL items by examining the correlation between an item and its own scale (a correlation of $\geqslant 0.4$, corrected for overlap, was evidence of validity). For discriminant validity, we compared the magnitude of the correlation of an item with its own scale compared with other scales. Scaling successes were defined as those cases in which an item correlated significantly higher with its own scale (corrected for overlap) than with a different scale.[22] To test QCQ–EOL reliability, we calculated the Cronbach alpha, a measure of internal consistency of responses. An $\alpha \geqslant 0.70$ was generally regarded as acceptably high for aggregation of responses into a single score. We used known-group comparison to evaluate clinical validity, i.e. the extent to which the questionnaire scores differentiated patients according to clinical situation (conventional care versus hospice care) and performance status (ECOG PSR). We assumed that hospices provided a higher quality of care than conventional facilities.

To assess the clinically meaningful difference, we used the distribution-based approach by calculating an effect size (ES) for statistically significant results between the two groups.[23] Following the recommendations of Cohen,[23] we considered moderate differences (0.5 < ES, 5 points) as clinically meaningful. For example, if the total QCQ–EOL was ⩾5 points higher for hospice care than for conventional care, hospice care was defined as better.

2.6. *Additional evaluation*

We administered an additional packet of questionnaires to the conventional care group (140 patients) to correlate with previously validated scales. It included the following: the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 item (EORTC QLQ–C30),[24,25] the McGill Quality of Life Questionnaire (MQOL),[26] a sense of dignity assessment,[27] and the patients' general rating for quality of care.[28]

To evaluate correlations between a patient's evaluation and that of their family member, we administered the QCQ–EOL to both at the same time. Inclusion criteria for family members were the same as for patients except for the terminal cancer diagnosis. As patients and families were filling out the questionnaires, researchers were present to ensure that information was not shared.

We set the significance level at $P < 0.05$, and all reported P values are two-sided. We used the SAS statistical package, version 9.0 (SAS Institute, Cary, NC, 1990).

3. Results

During a 10-month data collection period, 290 patients were enrolled in the study. Among them, 250 (86.2%) agreed to participate. The most common reasons for nonparticipation were feeling too ill and not being interested in the study. Most (97.9%) of the items were completed by 250 patients. Among the participants, 15 patients who did not respond to three or more items were excluded. Of the 235 patients included in the final analysis, 140 were from six conventional care facilities and 95 were from five hospices.

Missing QCQ–EOL items for 27 subjects were replaced using simple imputation of the mode among subjects completing the item. Additionally, the missing items were replaced using multiple imputations with the Markov Chain Monte Carlo method.[29] For imputation, we used the SAS computer program PROC MI, version 9.0.

Table 1 shows the demographic characteristics of patients and their family members. The majority (73%) of patients

Table 1 – Socio-demographic and clinical characteristics of patients ($n = 235$; mean age, 56.6 ± 12.5 years) and caregivers ($N = 140$; mean age, 45.4 ± 13.4 years)

Characteristic		% of Patients	% of Caregiver
Gender	Female	47.7	63.5
	Male	52.3	36.5
Education	Above completed high school	51.7	80.9
	Below completed high school	48.3	19.1
Occupation	Employed	49.0	33.3
	Housewives	15.3	8.3
	Unemployed	25.5	27.8
	Others	10.2	30.6
Marital status	Married	69.4	80.7
	Not married	30.6	19.3
Cancer site	Colon/rectum	16.0	–
	Lung	18.2	–
	Stomach	16.0	–
	Breast	8.8	–
	Cervix	7.7	–
	Liver	6.1	–
	Head and neck	2.2	–
	Others	24.9	–
Clinical situation	Conventional care group	59.6	65.7
	Hospice care group	40.4	34.3
ECOG PS	0 = Fully active	1.6	–
	1 = Restricted but ambulatory	16.0	–
	2 = Ambulatory, capable of self care	20.9	–
	3 = Capable of only limited self care	32.6	–
	4 = Completely disabled	28.9	–

ECOG PS, Eastern Cooperative Oncology Group performance status.

completed the QCQ–EOL in 10 min or less, but 63% required help, usually with the reading. Table 2 shows the statistics and distribution of QCQ–EOL items.

3.1. *Factor analysis*

We conducted factor analysis on the entire sample of conventional care and hospice care patients ($n = 235$). Four significant factors were extracted, accounting for 62% of the total variance. Table 3 lists the item-to-factor loadings for the 16 items and four factors - dignity-conserving care (factor 1, seven items), care by health care professionals (factor 2, three items), individualised care (factor 3, four items) and relationships with family members (factor 4, two items); all eigenvalues were >1.0. We obtained the same factor analysis results for both multiple imputations and simple imputations.

Table 2 – Item statistics of the QCQ–EOL ($n = 235$ terminal cancer patients)

QCQ–EOL item		n	Mean	SD	% of low (<1) response[b]
No.[a]	Questions				
1	Physical symptoms	235	1.39	0.96	18.3
2	Psychological symptoms	233	1.50	0.99	16.7
3	Control of life	234	1.11	1.02	35.0
4	Relationship with family	233	2.07	0.89	6.0
5	Time with family	235	1.80	1.00	10.6
6	Relationship with health care professionals	231	1.79	0.92	8.7
7	Continuous care	234	2.00	0.93	7.7
8	Clear explanations	235	1.82	0.95	8.5
9	Pride and self-respect	229	1.57	0.97	15.3
10	Financial and other burdens	230	0.99	1.05	42.6
11	Life is meaningful and valuable	232	1.94	0.94	7.8
12	Preparation for death	233	1.50	1.08	21.5
13	Hope and expectations	232	1.28	1.03	25.9
14	Finishing touch on your life	231	1.10	1.02	35.1
15	Respect as a human being	234	2.13	0.82	4.7
16	Life been generally good	235	1.51	0.98	17.4

a Numbers correspond to the item numbers in the QCQ–EOL questionnaire.
b The distribution of the response, ‘not at all’.

Table 3 – Factor analysis of patient’s response from QCQ–EOL Items ($n = 235$ terminal cancer patients)

QCQ–EOL item		Factor[b]			
No.[a]	Questions	1	2	3	4
3	Control of life	**0.74**	0.09	−0.08	0.26
2	Psychological symptoms	**0.72**	0.20	0.11	0.15
1	Physical symptoms	**0.63**	0.27	0.10	−0.16
10	Financial and other burdens	**0.58**	0.29	0.24	0.05
12	Preparation for death	**0.55**	0.31	0.24	0.05
11	Life is meaningful and valuable	**0.51**	−0.19	0.37	0.28
13	Hope and expectations	**0.43**	0.08	0.38	0.25
7	Continuous care	0.17	**0.83**	0.14	0.16
8	Clear explanations	0.21	**0.80**	0.12	0.08
6	Relationship with health care professionals	0.31	**0.68**	0.19	0.29
16	Life been generally good	0.15	0.18	**0.81**	0.11
15	Respect as a human being	−0.01	0.10	**0.77**	0.24
14	Finishing touch on your life	**0.43**	0.26	**0.61**	0.10
9	Pride and self-respect	**0.50**	**0.40**	**0.50**	−0.01
4	Relationship with family	0.17	0.20	0.18	**0.82**
5	Time with family	0.07	0.15	0.19	**0.80**
Proportion of Variance		37.7%	9.2%	7.8%	6.9%

Extraction method was principal component analysis with an orthogonal (varimax) rotation. We employed a decision rule of retaining factors whose eigenvalues were >1.0. Bold type indicates loadings >0.40.
a Numbers correspond to the item numbers in the QCQ–EOL questionnaire.
b Factor 1, dignity-conserving care; 2, care by health care professionals; 3, individualised care; 4, relationships with family members.

3.2. *Reliability*

Table 4 shows descriptive statistics for the QCQ–EOL subscales and the total score. All subscales and total score demonstrated good reliability with high internal consistency (Cronbach alpha range 0.73–0.89).

3.3. *Validity*

3.3.1. *Multi-trait scaling analysis*

In Table 4 , all scales showed good convergent validity since all item-to-self scale correlations exceeded the 0.4 criterion for item-convergent validity. In terms of item-discriminant

Table 4 – Descriptive statistics and subscale reliability of the QCQ–EOL (*n* = 235 terminal cancer patients)

Subscales	Range of Scores	Mean (SD)	α[a]	Item-own scale correlation[b]	Item-other scale correlation	Scaling errors (%)
Dignity-conserving care (items 1–3,10–13)	0–21	9.63 (4.68)	0.79	0.59–0.73	0.29–0.63	0
Care by health care professionals (items 6–8)	0–9	5.61 (2.40)	0.82	0.84–0.88	0.21–0.55	0
Individualised care (items 9,14–16)	0–12	6.25 (2.98)	0.79	0.72–0.82	0.32–0.50	0
Relationship with family (items 4,5)	0–6	3.86 (1.68)	0.73	0.88–0.90	0.12–0.41	0
QCQ–EOL total (items 1–16)	0–48	25.34 (9.50)	0.89	0.59–0.90	0.12–0.63	0

a Cronbach's alpha value ⩾0.7 indicates adequate scale reliability.
b Corrected for overlap.

Table 5 – QCQ–EOL differentiation of clinical situation and eastern cooperative oncology group performance status

Variables	Group	*n*	QCQ–EOL subscale (mean ± SD)				
			Dignity-conserving care	Care by health care professionals	Individualised care	Relationship with family	Total score
Clinical situation	Conventional care	140	8.6 ± 3.7[a]	5.1 ± 2.3[a]	5.6 ± 2.7[a]	3.8 ± 1.7	23.1 ± 7.9[a]
	Hospice care	91	11.1 ± 5.5	6.4 ± 2.4	7.2 ± 3.2	4.0 ± 1.7	28.6 ± 10.7
ECOG PS	4	54	8.3 ± 4.4[a]	5.3 ± 2.3	6.3 ± 2.8	3.6 ± 1.8	23.5 ± 8.8[b]
	0–3	133	10.5 ± 4.8	5.8 ± 2.4	6.5 ± 3.2	4.0 ± 1.7	26.8 ± 10.0

ECOG PS, Eastern Cooperative Oncology Group performance status.
a $P < 0.01$ (*t*-test).
b $P < 0.05$ (*t*-test).

Table 6 – Correlation between the EORTC QLQ–C30, McGill QOL and QCQ–EOL scores in conventional care group (N = 140 terminal cancer patients)

		QCQ–EOL subscale				
		Total score	Dignity-conserving care	Care by health care professionals	Individualised care	Relationship with family
EORTC QLQ–C30 functioning scale	Global health	0.41[a]	0.44[a]	0.14	0.28[a]	0.31[a]
	Physical functioning	0.17	0.25[a]	0.18[b]	−0.03	0.05
	Role functioning	0.29[a]	0.31[a]	0.24[a]	0.14	0.13
	Emotional functioning	0.27[a]	0.22[b]	0.13	0.27[a]	0.20[b]
	Cognitive functioning	0.13	0.21[b]	0.01	0.02	0.11
	Social functioning	0.22[a]	0.19[b]	0.16	0.24[a]	0.02
McGill QOL	Overall	0.49[a]	0.47[a]	0.30[a]	0.36[a]	0.34[a]
	Physical symptoms	0.17	0.16	0.05	0.06	0.24[a]
	Physical well-being	0.28[a]	0.30[a]	0.30[a]	0.10	0.13
	Psychological well-being	0.39[a]	0.34[a]	0.24[a]	0.28[a]	0.35[a]
	Existential well-being	0.50[a]	0.45[a]	0.26[a]	0.38[a]	0.43[a]
	Support	0.33[a]	0.32[a]	0.12	0.27[a]	0.28[a]

EORTC QLQ–C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30; McGill QOL = McGill Quality of Life Questionnaire.
For QOL scale, higher scores represent a better level of functioning.
a $P < 0.01$ (Pearson correlation).
b $P < 0.05$ (Pearson correlation).

Table 7 – QCQ–EOL differentiation of sense of dignity and general rating of quality care

Variables	Group	n	QCQ–EOL subscale (mean ± SD)				
			Dignity-conserving care	Care by health care professionals	Individualised care	Relationship with family	Total score
Sense of dignity[c]	2–6	61	7.8 ± 3.4[a]	4.8 ± 2.4	5.1 ± 2.7[a]	3.6 ± 1.7	21.4 ± 7.6[a]
	0–1	45	10.2 ± 3.8	5.6 ± 2.2	6.7 ± 2.6	4.0 ± 1.6	26.7 ± 8.2
General rating of	0–8	109	8.3 ± 3.6[a]	4.9 ± 2.2[a]	5.4 ± 2.6[a]	3.7 ± 1.7[b]	22.3 ± 7.3[a]
quality care[d]	9–10	14	11.5 ± 4.3	6.7 ± 2.0	7.9 ± 2.9	4.9 ± 0.9	31.1 ± 8.4

a $P < 0.01$ (t-test).
b $P < 0.05$ (t-test).
c Sense of dignity is a single item scale. Scores range from 0 to 6 with 0 being no sense of loss of dignity.
d General rating of quality care is a numeric rating scale consisting of a single item; 'What number would you use to rate the overall medical care you received for illness?' On a scale of 0–10 with 0 as the worst.

Table 8 – Summary of t-test and correlation of QCQ–EOL between patients and caregivers in paired group (n = 140 pairs)

QCQ–EOL subscale	Patients (n = 140)		Caregiver (n = 140)		P –value (t-test)	r[a]
	mean	SD	mean	SD		
Total score	24.29	8.35	24.49	0.84	0.84	0.56[b]
Dignity-conserving care	9.04	4.14	8.72	0.52	0.52	0.58[b]
Care by health care professionals	5.38	2.45	5.41	0.90	0.90	0.38[b]
Individualised care	5.95	2.74	6.41	0.15	0.15	0.61[b]
Relationship with family	3.92	1.60	3.94	0.94	0.94	0.38[b]

a Pearson's correlation coefficients.
b $P < 0.01$.

validity, we found no scaling error, providing strong support for the model structure of the QCQ–EOL.

3.3.2. *Clinical validity*

Table 5 shows clinical validity—the ability to differentiate between groups. Total score and all subscale sores of the 16-item QCQ–EOL, except relationship with family, differentiated patients according to their clinical situation (conventional care versus hospice care). As for ECOG PSR, patients with a more impaired performance status reported statistically significant lower levels of quality care ($P < 0.05$) and dignity-conserving care ($P < 0.01$) than those with a better performance status. However, they did not show clinically significant differences by our criteria.

3.4. *Additional evaluation*

3.4.1. *Comparison with QLQ–C30 and MQOL*

Table 6 presents the correlation of total and subscale scores of the QCQ–EOL and measures of the EORTC QLQ–C30 (functioning subscales) and the MQOL. The QCQ–EOL total scores correlated better with QLQ–C30 than with MQOL. Additionally, the total and dignity-conserving care QCQ–EOL scores correlated moderately with the QLQ–C30 global health score (Pearson correlation [r] range 0.41–0.44) and the MQOL overall and existential well-being score (r range 0.45–0.50).

3.4.2. *Comparisons with sense of dignity and general rating of quality care*

Components of the 16-item QCQ–EOL were able to differentiate patients according to score for sense of dignity (0–1/ 2–6) and score for general quality of care (0–8/ 9–10) (Table 7). As expected, dignity-conserving care, individualised care, and total score were significantly lower for patients with low scores for sense of dignity. As for the patient-reported general rating of quality care, all of the sub and total scores were significantly higher for patients with better general rating of quality of care. There were clinically significant differences of total score ($\geqslant 5$ points) in both comparisons.

3.4.3. *Comparison between patient and family*

Table 8 shows comparison of the scores between the patients and the 140 family members (92 conventional care, 48 hospice care) who completed the questionnaire. The table also shows the correlations for QCQ–EOL of the total and subscale scores ($P< 0.01$). The correlation was strongest for the individualised care subscale ($r = 0.61$), and correlations for total score and dignity-conserving care were substantial ($r = 0.50$). On the other hand, the correlations were relatively weak for health care professionals ($r = 0.38$) and relationship with family ($r = 0.38$).

4. Discussion

In this article, we report on the development and validation of a questionnaire to assess the quality of end-of-life care. It is patient-reported and has satisfactory psychometric properties. We included only 16-items because brevity is critical for terminally ill patients.[14] It includes such important characteristics as clinical setting and sense of dignity in the general care rating.

QCQ–EOL consists of four subscales that focus on the patient and are consistent with previous concepts of EOL care and suggestions.[1–3,6–12] First, conservation of dignity is the most important EOL issue.[12] This reflects the findings of many studies: patients want to manage their physical and psychological symptoms,[2–6,8–14] to control their lives,[2,4,8–11,13] to retain meaning, value, hope, and expectations,[2,3,5,8,11,12] and to die peacefully.[2,3,19,11–13]

Process measures, such as whether certain services are delivered, have a special role in EOL care. Because of lengthening life-spans, smaller families, and the increasing use of supportive and other medical interventions, health-care professionals have become more important to dying patients than they might have been a century ago.[8] In addition, a lack of clear information about their health status and unrealistically optimistic expectations may lead patients to request interventions that physicians believe are inappropriate. Therefore, it is important for health care providers to deliver continuous care across various health care settings, to keep patients informed, and to have good interpersonal relationships with them.[1,3,4,8,10,30] Additionally, EOL care requires that the patient's family be considered part of the care team,[1,3,9,10] and that is a vital domain in the tool.

Achieving closure is also important to patients and their families. [3,7,8,10,12] That involves reviewing life, saying goodbye, and resolving unfinished business.[3] It is also essential that EOL care allows patients to maintain pride and retain self-respect,[10–12] even though that can be difficult under the conditions. These are both vital issues in evaluating and developing effective intervention for quality care of dying patients.

In contrast to existing suggestions, advance care planning and care by family members are not included in QCQ–EOL. Advance care planning may be covered in 'control of life'. The dying process, of course, affects both the patient and those who care about the patient, and programs for EOL care consider the patient and family as the unit of care.[1] Care of family members should be considered in an evaluation of the quality of care provided.[16] From the patient's point of view, however, as measured in our questionnaire, care of family members might mean a close relationship and much time spent together.

Our results indicate that it has especially important psychometric properties such as high internal consistency and convergent construct validity without scaling error. That QCQ–EOL correlates better than EORTC QLQ–C30 with MQOL suggests that it is appropriate for patients receiving terminal care. Most correlations of the QCQ–EOL subscales with QOL subscales, however, were below 0.4, suggesting that QCQ–EOL may evaluate different aspects of EOL care from those that QOL assessment tools evaluate.

Perhaps the most Interesting findings of our study are that QCQ–EOL appears to be sensitive to underlying differences in care, distinguishing between the ratings of quality care, especially dignity-conserving care, individualised care and care given in a conventional care versus a hospice care setting. Using a conceptual model, outcomes such as quality of death/dying and satisfaction can be influenced by structural factors such as clinical setting, e.g. conventional versus hospice.[11] In addition, the total QCQ–EOL score can be broken down into validated subscale scores, which are sensitive to known group differences, especially clinical setting, and subscales allow for a more detailed summary of specific aspects of quality care. From a quality improvement perspective, however, these findings will need to be verified further with community-based intervention study or community-based longitudinal study to improve the quality of care of those at the end of life in other settings. Compared with ECOG PSR, the total and subscale scores did not show clinically significant differences. These findings are not surprising. Though physical performance might be included in quality of care assessment, the condition of most EOL patients gets progressively worse and they finally become bed-ridden, which is the natural course of dying. In spite of worsening physical performance, the quality of EOL social and spiritual care could be better.

Little is known about the validity of family members' reports in EOL care.[13] While a QUEST study[18] showed that surrogate ratings of satisfaction and quality did not correlate with patient ratings, our study showed substantial correlations, especially in total, dignity-conserving, and individualised care scores. Thus, when a patient report is not available, a family member's QCQ–EOL may be a cost-effective way to collect information.

This study has several limitations. First, despite the high participation rate (86.2%), our study, which relied on terminal cancer patients accounts, is potentially biased, and the results may not be fully generalisable. Most of the concepts measured by the QCQ–EOL, however, are not specific to terminal cancer and with some modifications may be applied to measuring the quality of care in the end-stage of other chronic diseases. Second, this study was done in Korea, and, generalisations to other countries should be made cautiously. Notions of dignity may be influenced by cultural issues such as religion or ethnicity.[2,3] Cross-cultural validation studies are necessary.

Nevertheless, this simple and sensitive patient-reported assessment tool with proper psychometric properties should contribute to understanding when adopted by clinicians and the health-care administrators interested in improving the quality of EOL care.

Conflict of interest statement

None declared.

Acknowledgements

We greatly appreciate Charles Cleeland, Ph.D. at the Department of Symptom Research, MD Anderson Cancer Center, for providing counsel.

This work was supported by National Cancer Center Grant 0410160.

Appendix. Quality of Care Questionnaire–End of Life (QCQ–EOL)

These questions are designed to gather important information concerning the quality and appropriateness of end-of-life patient care. Please answer each question by circling the number that applies best to the care you received *during the past week*.

During the past week		Not at all	A little	Quite a bit	Very much
1	Have your pain and other physical symptoms been fairly well-controlled?	1	2	3	4
2	Have your psychological symptoms (such as depression or anxiety) been fairly well-controlled?	1	2	3	4
3	Have you gained control of your life?	1	2	3	4
4	Have you a close relationship with your family?	1	2	3	4
5	Have you spent a lot of time with your family?	1	2	3	4
6	Have you a good relationship with your health care providers?	1	2	3	4
7	Have you received continuous care by competent staff, including doctors and nurses?	1	2	3	4
8	Have health care providers given you clear explanations about your health status?	1	2	3	4
9	Have you been able to retain your pride and self-respect?	1	2	3	4
10	Have you been relieved of financial and other burdens?	1	2	3	4
11	Have you felt that your life is meaningful and valuable?	1	2	3	4
12	Are you prepared for death and able to accept it peacefully?	1	2	3	4
13	Have your hope and expectations been increased?	1	2	3	4
14	Have you been dealing well with finishing touch on your life?	1	2	3	4
15	Have you received respect as a human being from those around you?	1	2	3	4
16	When you think of all its aspects, has your life been generally good?	1	2	3	4

REFERENCES

1. Donaldson MS, Field MJ. Measuring quality of care at the end of life. *Arch Intern Med* 1998;**158**:121–8.
2. Emanuel EI, Emanuel LL. The promise of a good death. *Lancet* 1998;**351**:21–9.
3. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and the other care providers. *JAMA* 2000;**15**:2476–82.
4. Lynn J. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc* 1997;**45**:526–7.
5. Field MJ, Cassel CK. *Approaching death: improving care at the end of life*. Washington, DC: National Academy Press; 1997.
6. American Society of Clinical Oncology. Cancer care during the last phase of life. *J Clin Oncol* 1998;**16**:1986–1996.
7. Byock I, Norris K, Curtis JR, et al. Improving end-of-life experience and care in the community: a conceptual framework. *J Pain Symptom Manage* 2001;**22**:759–72.
8. Saunders Y, Ross JR, Riley J. Planning for a good death: responding to unexpected events. *BMJ* 2003;**327**:204–7.
9. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;**281**:163–8.
10. Teno JM, Casey VA, Welch LC, et al. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001;**22**:738–51.
11. Stewart AL, Teno JM, Patrick DL, et al. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage* 1999;**17**:93–108.
12. Chochinov HM. Dignity-conserving care-a new model for palliative care. *JAMA* 2002;**287**:2253–60.
13. Fowler FJ, Coppola KM, Teno JM. Methodological challenges for measuring quality of care at the end of life. *J Pain Symptom Manage* 1999;**17**:114–9.
14. Morrison RM. The hard task of improving the quality of care at the end of life. *Arch Intern Med* 2000;**160**:743–7.
15. Kristjanson LJ. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med* 1993;**36**:693–701.
16. Teno JM, Clarridge B. Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage* 2001;**22**:752–8.
17. Curtis JR, Patrick DL, Engelberg RA. A measure of the quality of dying and death: initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;**24**:17–31.
18. Sulmasy DP, McIlvane JM. Patients' ratings of quality and satisfaction with care at the end of life. *Arch Intern Med* 2002;**162**:2098–104.
19. Morita T, Hirai K, Sakaguchi Y, et al. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage* 2004;**27**:492–501.
20. Osse BH, Vernooij MJ, Schade E, et al. Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. *J Pain Symptom Manage* 2004;**28**:329–41.
21. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information. *Soc Sci Med* 2003;**56**:95–109.
22. Fayer PM, Machin D. *Quality of life: assessment, analysis and interpretation*. Chichester, West Sussex: John Wiley & Sons; 2000.
23. Cohen J. *Statistical power analysis for the behavioural sciences*. second ed. Hillsdale, NY: Erlbaum; 1988.
24. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ–C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;**85**:365–76.
25. Yun Young Ho, Park Young Suk, Lee Eun Sook, et al. Validation of the Korean version of the EORTC QLQ–C30. *Quality of Life Res* 2004;**13**:863–8.
26. Cohen SR, Mount BM, Tomas JJ, et al. Existential well-being is an important determinant of quality of life: evidence from the McGill Quality of Life Questionnaire. *Cancer* 1996;**77**:576–86.
27. Chochinov HM, Hack T, McClement S, et al. Dignity in the terminally ill; a developing empirical model. *Soc Sci Med* 2002;**54**:433–43.
28. Agency for Healthcare Research and Quality. The CAHPS® improvement guide: practical strategies for improving the patient care experience. Rockville, MD: Department of Health Care Policy; 2003. Also available on AHRQ web site: https://www.cahps-sun.org/Projects/ResultsForQI.asp#utility [Accessed Nov 4, 2005].
29. Gelman A, Rubin DB. Markov chain Monte Carlo methods in biostatistics. *Stat Methods Med Res* 1996;**5**:339–55.
30. Yun YH, Lee CG, Kim SY, et al. The attitudes of cancer patients and their families toward the disclosure of terminal illness. *J Clin Oncol* 2004;**22**:307–14.