Original Article

Measuring the Quality of End-of-Life Care

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Abstract

Context. Although there is a documented need to improve end-of-life care, there are few validated and brief questionnaires that are available as outcome measures for use in improving that care.

Objectives. To examine the measurement characteristics of the Quality of End-of-Life Care (QEOLC) questionnaire.

Methods. In a multisite, cross-sectional study of a mailed questionnaire, patients with life-limiting illnesses, their families, and nurses completed the QEOLC questionnaire. Patients and nurses were identified by physicians, and families were identified by participating patients. Physicians included general internists, oncologists, cardiologists, and pulmonologists from the Southeast and Pacific Northwest of the United States.

Results. Eight hundred one patients, 310 of their families, and 885 nurses were identified by 85 physicians. Using structural equation modeling techniques corrected for clustering under physicians, we identified a patient-specific factor based on 11 items, a family-specific factor based on 22 items, a nurse-specific factor based on 11 items, and a common single-factor solution based on 10 items. Construct validity was supported by significant associations in the hypothesized direction between the identified QEOLC factors and each of the following: physician palliative care knowledge, patients' and families' ratings of overall quality of care, and patients' levels of symptom distress.

Conclusion. Although continued testing in heterogeneous samples is necessary, the current study supported the construct validity of the QEOLC questionnaire to assess physician skill at end-of-life care, thereby providing valid measures of quality end-of-life care. Furthermore, this approach is a model for development and validation of patient- and family-centered assessments of quality of care. J Pain Symptom Manage 2010;39:951−971. © *2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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Quality of care, end of life, questionnaire, psychometrics

Introduction

In a recent systematic review for the National Institutes of Health State of the Science Conference on End-of-Life Care, Lorenz et al. identified the need for measures by which the quality of end-of-life care may be described, evaluated, and improved.[1,2] Despite a significant consensus defining the domains contributing to quality end-of-life care,[3–5] the authors concluded that measures still need to be developed and tested for patients with a variety of diseases, in diverse settings, and representing diverse racial and ethnic groups.[1,6] Similarly, other researchers have called for the development of broadly applicable and generalizable outcome measures to evaluate the quality of end-of-life care.[7–11]

In addition to applicability and generalizability, researchers have suggested that appropriate measures of the quality of end-of-life care must specify which aspects of quality are being measured, that is, whether an instrument is assessing the quality of life, the quality of care, or the quality of dying and death.[12–14] Because these are overlapping but distinct constructs, it is important to differentiate a measure's focus and emphasis. It is also important that the measure's intended purpose be specified.[15–17] All these recommendations incorporate the expectation that quality end-of-life care measures are patient focused and family centered rather than focused on and developed by clinicians.[18,19] Although there is considerable concordance among standards defined by patients, families, and professional experts and organizations,[3,20,21] patients and families have unique perspectives and are centrally important to the definition and assessment of end-of-life care.

In this article, we describe the psychometric characteristics, including the domain structure and construct validity, of a new measure, the Quality of End-of-Life Care (QEOLC) questionnaire, in which respondents rate physicians' skills at providing quality end-of-life care. The items were initially derived from focus groups with patients, families, and clinicians, who were asked to describe physician skills associated with quality end-of-life care.[22–26] This work was completed with patients with life-limiting diseases. The development reported here was similarly performed with patients with life-limiting diseases and across a number of health care sites and regions. Additionally, item development focused on specific tasks and skills appropriate for quality-improvement efforts and, therefore, should be responsive to the effects of interventions. Other goals for development and testing of the QEOLC questionnaire reported here include the following: 1) creating the shortest possible questionnaire to reduce burden on respondents;[27] 2) defining the questionnaire's empirically based factor structure and validity; and 3) assessing the applicability of general item sets for all respondents compared with respondent-specific item sets.

Methods

Subjects

Subjects were recruited from two regions, the Pacific Northwest (Washington and Oregon) and the Southeast (South Carolina and North Carolina), and included physicians, patients with life-limiting illnesses, their families or friends, and nurses. The study was conducted between October 2002 and November 2005.

Physicians. Using American Board of Internal Medicine (ABIM) records of certified internists, we identified all general internists and physicians who were board certified in oncology, pulmonary medicine, and cardiology, between 1970 and 2000 in Washington, Oregon, North Carolina, and South Carolina ($n = 7{,}448$). Eligibility criteria for physicians were as follows: spending at least 50% of their time providing direct patient care and the expectation of ongoing care responsibilities for at least 30 eligible patients over a six-month period.

Patients. Participating physicians identified patients over 12 months. Eligibility criteria for patients were 1) being a patient of the physician-subject for at least three months; 2) having no dementia or delirium limiting the ability to complete instruments; 3) English speaking; 4) disease-specific criteria; and 5) prognosis criteria. Disease-specific criteria were chosen to identify a group with a one-year mortality of approximately 50% and included patients with 1) chronic lung disease and either oxygen dependence (prescribed 24 hour, long-term) or FEV_1 (forced expiratory volume in one second) values less than 35% of the predicted values (for obstructive diseases) or FVC (forced expiratory vital capacity) values less than 60% of the predicted values (for restrictive diseases); 2) patients with metastatic solid cancer, inoperable lung cancer, or terminal blood disorders ineligible for transplantation; and 3) patients with New York Heart Association Class III or IV heart failure. As an additional prognosis entry criterion, physicians were asked to identify patients for whom "they would not be surprised if the patient died from any cause in the next year." This question was intended to help physicians with prognostication and assist in capturing additional prognostic information not associated with disease-specific criteria.[28]

Family Members/Friends. Family members or friends were identified by patients as someone involved in their medical care. Patients provided study staff with the family member or friend's contact information when they returned their questionnaire. Patients were not excluded if they did not identify a family member or friend or if the identified family member or friend declined participation.

Nurses. Physicians identified specific nurses familiar with their work with patients with life-limiting illnesses or settings in which they worked with nurses. Our goal was to receive responses from 15 nurses per physician. Nurses were eligible if they were not employed directly by the physician-subject but had known the physician-subject for at least three months. Although registered nurses were targeted for enrollment, questionnaires were sometimes distributed to other nurses and clinicians, including licensed practical nurses, nurses' aides, and medical social workers. Analyses showed no important differences in ratings by registered nurses compared with others; therefore, all raters were included. For brevity, we will, henceforth, refer to nurses or clinicians as nurses.

Procedures

Physicians. Interested and eligible physicians were initially identified through a screening questionnaire sent to addresses derived from the ABIM database. They were then stratified by region, specialty, race or ethnicity, gender, and rural or urban location, and randomly selected from within these strata for a second follow-up mailing and phone contact, with use of oversampling by self-reported race or ethnicity status, female sex, and rural or urban location. On giving consent, physicians participated in the study for 12 months, during which time they were asked to refer up to 30 patients and 30 nurses, under the assumption that response rates would be approximately 50%. Physicians were provided a $300 honorarium and six Category I CME credits for participating.

Patients, Families, and Nurses. Surveys were mailed to all participants using contact information provided by physicians (for patients and nurses) or patients (for families). Because patients, families, and nurses were referred by others for study participation, we were not able to use random sampling methods. Materials included introductory letters from the participating physician and the study investigators, Health Insurance Portability and Accountability Act-compliant consent forms, a monetary incentive of $10.00, and a booklet containing the study questionnaire. Patient and family members were recontacted by phone if the questionnaire was not returned after a two-week interval and were again contacted by mail at four weeks. Nurses received a reminder postcard. Respondents were assured that their responses were confidential and would not be viewed by their physician or other persons outside the study team.

Human Subjects Committee approval was obtained from institutional review boards at the University of Washington, the Medical University of South Carolina, and all hospitals at which we recruited participants.

Measures

Quality of End-of-Life Care Questionnaire. The QEOLC questionnaire was based on a previously developed conceptual model and items identified for assessing physician skill at end-of-life care using focus groups with patients with life-limiting illnesses (cancer, chronic obstructive pulmonary disease [COPD] and acquired immune deficiency syndrome), family members who had lost a loved one to a life-limiting illness, and nurses and physicians with expertise in end-of-life care.[22–26] The conceptual model identifies five domains of physician skills: communication skills, symptom skills, affective skills, patient-centered values, and patient-centered systems. Using this model, we developed the QEOLC self-report questionnaire with 54 items grouped into five conceptual domains (Appendix 1). Response options range from 0 = "terrible" to 10 = "almost perfect." Respondents were asked to rate their doctor's skills based on their own experiences. Items in each version of the questionnaire (i.e., patient, family member or friend, nurse) were tailored to fit the respondent's perspective.

Validation Measures. Respondents completed additional questionnaires for validation analyses. We used the following measures of conceptually related constructs that we expected to be associated with QEOLC questionnaire domains: 1) physician knowledge of palliative care; 2) patient and family satisfaction with physician's overall care; 3) nurse ratings of physician's overall care; and 4) patients' symptoms.

Palliative Care Knowledge Examination. Because prior research has shown that professional ratings of quality of care correlate significantly and positively with physician performance on Board examinations,[29,30] we included a 36-item palliative care knowledge examination.[31] This measure takes approximately 30 minutes to complete and has been used successfully to assess and design palliative care curricula for medical students and residents.[32] It addresses pain assessment and treatment; drug addiction; nonpain symptom management; communication skills; ethics; transitions and hospice care; and prognosis, hope, and spirituality.

American Board of Internal Medicine Patient Satisfaction Questionnaire. For patients and families, we used a 10-item validated measure of satisfaction with physician skill at providing affective, informational, and communication support.[30] Responses are rated from 1 = "poor" to 5 = "excellent;" there is also a "does not apply" option. A satisfaction score is the average of all valid responses.

Nurse Professional Associate Ratings. Nurses completed the 14-item Professional Associate Ratings (Nurse-PAR) questionnaire.[33] Nurses rated physicians on medical competence, humanistic qualities, and communication skills. The Nurse-PAR has performed well in a study of practicing internists,[33] and each item is scored from 1 for the lowest rating to 9 for the highest rating. A nurse rating score is based on the average of all valid responses.

Patients' Symptoms. The importance of proper pain and symptom control as a measure of quality end-of-life care has been well documented.[18,34–38] We included the short form of the Memorial Symptom Assessment Scale (MSAS-SF),[39] a validated, patient self-report measure of symptom severity, frequency, and distress.[40,41] This version of the MSAS can be completed in about five minutes and yields a total symptom distress score.

Demographic Items. To describe the sample, we collected age, gender, race or ethnicity, and education data for all respondents. Additionally, we collected information regarding income and marital status for patients, relationship to patient for families, and practice settings for physicians and nurses.

For nonparticipating physicians, we obtained demographic information from the ABIM database and from the initial screening questionnaire (i.e., age, gender, rural or urban location, year of medical school graduation, subspecialty, race or ethnicity). These physician data were used to assess whether eligible participants were significantly different from eligible nonparticipants.

Research Aims and Statistical Analyses

Item Reduction. To shorten the questionnaire, the seven investigators used the following criteria to identify items for potential omission: 1) item response rate of 50% or lower; 2) mean greater than 9.5 on a 0–10 scale; 3) standard deviation less than or equal to 1.20; and 4) significant Pitman tests of variance suggesting inadequate test-retest stability ($n = 43$). We omitted items that met three or more of these criteria and also considered omitting items that met one or two of these criteria if we judged the items to have limited face validity. Conversely, we considered for retention items that may have met some of these exclusionary criteria but were judged to be conceptually important. For example, we retained items specifically about dying and death even though some of these items were answered by fewer than 50% of the respondents. Finally, we examined items based on the reliability analyses of the conceptually developed domain scores. We chose a Cronbach's alpha value of 0.75 or higher as criterion for examining items for deletion because of redundancy. Using these criteria, we retained 29–31 items from the original set, the number depending on the respondent type (Appendix 1).

Structure. We used latent variable modeling to evaluate the measurement structure of the reduced patient, family, and nurse questionnaires. Latent variables (often termed "factors") are unmeasurable underlying constructs that are inferred to account for variation and covariation in a set of measured indicators. In our study, indicators are the items in the QEOLC questionnaire and, henceforth, will be referred to as "indicators/items." Because of highly skewed data, we first converted all indicators or items to dichotomies. For patients and family members, contrasting scores of 0–9 ("could be improved") vs. 10 ("perfect") resulted in the most even distribution of the sample into equal groups. For nurses, the contrast was between 0–8 and 9–10.

We began the analysis of each sample with a traditional exploratory factor analysis (EFA), which begins with a pool of indicators and explores the likely number of underlying factors that account for item/indicator variance and covariance. Our EFA models were based on tetrachoric correlations between the dichotomous indicators/items.

Subsequent to the EFA analysis, we used a method called EFA within the confirmatory factor analysis framework (often abbreviated E/CFA). This technique involves beginning with a hypothesized model, including one or more factors (the number determined in our case by the EFA result), with each item or indicator typically loading on only one factor. Successive alterations are then made to that model to improve fit to the observed data. For the current analyses, we sequentially removed from each model the indicators or items associated with the largest correlation residuals until the model met the following criteria for acceptable fit: probability associated with the χ^2 test of fit > 0.05, Bentler's comparative fit index ≥ 0.96, and a root mean square error of approximation ≤ 0.05.[42] Although removal of additional indicators or items from each model could have improved the fit, our initial goal was to generate idiosyncratic models for each of the three samples, where the model retained the maximum number of indicators or items but met the fit criteria.

In addition to generating sample-specific models with adequate fit when the factor loadings were freely estimated (Model 1), we tested an additional model for each sample, using the same sample-specific indicators or items, but constraining the loadings to 1.0 (Model 2). This model offered the advantage of allowing the user to calculate an unweighted composite score, in which the indicators or items might be summed or averaged as each indicator or item has the same weight. In contrast, if only the model with freely estimated factor loadings (Model 1) proved to be valid, composite scores would need to incorporate weights derived from each indicator or item's factor loading.

We then repeated these modeling procedures for the three samples to identify a set of indicators or items that could be retained in all three samples to provide a common, simplified measure of end-of-life care with adequate fit to the three respondent types (patients, families, or nurses). Again, for each sample, we built a model with freely estimated loadings and a model with the loadings constrained to 1.00.

For convenience, we will, henceforth, refer to E/CFA simply as "factor analysis" and refer to EFA as "traditional exploratory factor analysis." All factor analysis models, which we fit with Mplus software (Muthén & Muthén, Los Angeles, CA; www.StatModel.com), used missing-at-random maximum likelihood missing data handling, weighted least square mean- and variance-adjusted (WLSMV) estimation methods, and correction of standard errors for respondent clustering within physicians.

Validity. We evaluated the convergent construct validity of the QEOLC factors using regression models to test bivariate associations between these factors and conceptually related measures. "Within-respondent" regressions predicted the QEOLC factors from measures contributed by the same respondent (e.g., the patient-specific QEOLC factor from patient satisfaction on the ABIM questionnaire), and "between-respondent" regressions predicted the QEOLC factors from measures completed by other respondents (e.g., the patient-specific QEOLC factor from family satisfaction scores on the ABIM questionnaire). Regressions were clustered on physicians to correct standard errors for lack of independence, and parameter estimates were based on the same WLSMV estimation procedure used for the factor analysis measurement models. We accepted the following as evidence of construct validity: significant ($P < 0.05$) positive associations between the QEOLC factors and physician knowledge (palliative care knowledge examination), patient and family satisfaction (ABIM questionnaire), or nurse ratings (Nurse-PAR); significant negative associations between the QEOLC factors and patient symptoms (MSAS-SF); and significant positive associations between QEOLC factors for different samples (e.g., between patient-specific and family-specific QEOLC factor scores). Because "between-respondent" analyses used measures contributed by different individuals, we expected "between-respondent" analyses to show weaker associations than "within-respondent" analyses.

Role of the Funding Source

This study was funded by the Agency for Healthcare Research and Quality (AHRQ). The AHRQ had no role in the design, conduct, or analysis, and was not involved in the decision to submit the manuscript for publication.

Results

Sample

Of 7,448 physicians identified from the ABIM records, 51% were unreachable ($n = 3{,}818$) and 30% were ineligible ($n = 2{,}261$). Of eligible physicians ($n = 1{,}369$), an additional 18% ($n = 249$) were unreachable after the initial screening, and three-quarters ($n = 1{,}035$) declined to participate. Of the final sample of physician-participants, 66 were from the Northwest and 19 were from the Southeast. Eligible participants compared with eligible nonparticipating physicians were more likely to be females (30.6% vs. 17.2%, $P = 0.003$) and represented different specialties ($P = <0.001$), with higher participation rates among pulmonologists and critical care medicine specialists (14.4%) and among oncologists (10.9%) than among cardiologists (5.1%) and general internists (3.5%). Most of the participating physicians were males, whites, and private practitioners, and more than one-third practiced in multispecialty offices of 15 or more practitioners (Table 1). Participants' mean age was 49 years (SD 7.8).

Response rates for patients, families, and nurses who received surveys were 73.1% (801 of 1,096), 83.8% (310 of 370), and 81.2% (885 of 1,090), respectively. Analyses were based on 1,995 questionnaires (Northwest: $n = 1{,}464$; Southeast: $n = 531$). Mean numbers of questionnaires for each physician were as follows: patient questionnaires, 9.4 (SD 6.9); family questionnaires, 4.3 (SD 3.1); and nurse questionnaires, 10.4 (SD 6.7).

Of 801 participating patients, the mean age was 71 years (SD 12.3). Slightly more than half were females and married or living with a partner. Eleven percent were racial or ethnic minorities; the most frequent diagnoses were cancer (35%) and COPD (25%). Of 310 participating families, almost three-quarters were females, half were the patients' spouses or partners, and 10% were self-reported racial or ethnic minorities; their average age was 59 years (SD 15.4) (Table 2). Of the 885 participating nurses, almost all were white and female, with a mean duration of 17 years (SD 10.2) working in health care and a mean age of 46 years (SD 9.8) (Table 1).

Item Reduction

The original 54-item QEOLC questionnaire was reduced to a set of 29 items for patients, 30 items for families, and 31 items for nurses, based on the criteria defined earlier. Complete descriptions of each item's characteristics by respondent type are available in Appendices 2–4.

Table 1
Physician ($n = 85$) and Nurse ($n = 885$) Participants' Characteristics

Characteristics	Physicians ($n = 85$)	Nurses ($n = 885$)
Age, mean (SD)	49.4 (7.78)	46.0 (9.80)
Years since last clinical degree, mean (SD)	21.7 (7.7)	16.7 (10.24)
Site, % (*n*)		
Northwest region	77.6 (66)	74.8 (662)
Southeast region	22.4 (19)	25.2 (223)
Rural, % (*n*)	25.9 (22)	—
Gender, % (*n*)		
Male	69.4 (59)	7.0 (62)
Female	30.6 (26)	92.0 (814)
Missing	0 (0)	1.0 (9)
Race,[a] % (*n*)		
Non-Hispanic white	83.5 (71)	89.3 (790)
African American or black	4.7 (4)	3.5 (31)
Hispanic	2.4 (2)	1.6 (14)
Asian or Pacific Islander	15.3 (13)	4.4 (39)
Native American or Alaskan Native	0.0 (0)	1.2 (11)
Missing	0 (0)	1.7 (13)
Specialty, % (*n*)		
General Internal Medicine	31.8 (27)	—
Pulmonology	30.6 (26)	—
Oncology	23.5 (20)	—
Cardiology	14.1 (12)	—
Practice setting, % (*n*)		
Private practice	87.2 (68)[b]	24.7 (219)[a]
Hospital-based practice	6.4 (5)[b]	76.0 (673)[a]
Home hospice/inpatient hospice	—	12.0 (106)[a]
Home health agency/assisted living facility/nursing home	—	6.7 (59)[a]
Other/missing	6.4 (5)[b]	7.9 (70)[a]
Physicians in practice,[b] % (*n*)		
Solo or small group (1–3 partners)	23.1 (18)	—
4–15 partners, single/multiple specialties	37.2 (29)	—
>15 partners, single/multiple specialties	39.8 (31)	—
Educational preparation,[a] % (*n*)		
Baccalaureate		36.6 (324)
Licensed practical nurse	—	6.8 (60)
Diploma	—	13.9 (123)
Associate	—	44.5 (394)
Medical assistant	—	4.9 (43)
Masters of nursing/nurse practitioner	—	5.5 (49)
Social work	—	1.8 (16)
Other/missing	—	4.7 (42)

SD = standard deviation.
[a] Respondents had the choice of endorsing more than one option.
[b] Based on physician surveys returned ($n = 78$).

Table 2
Patient ($n = 801$) and Family/Friend ($n = 310$) Participants' Characteristics

Characteristics	Patients ($n = 801$)	Families/Friends ($n = 310$)
Age, mean (SD)	71.1 (12.30)	59.0 (15.40)
Site, % (*n*)		
Northwest region	71.7 (574)	73.5 (228)
Southeast region	28.3 (227)	26.5 (82)
Gender, % (*n*)		
Male	44.3 (355)	27.4 (85)
Female	55.1 (441)	72.6 (225)
Missing	0.6 (5)	0 (0)
Race,[a] % (*n*)		
Non-Hispanic white	88.6 (710)	89.7 (278)
African American or black	8.4 (67)	7.1 (22)
Hispanic	0.4 (3)	1.3 (4)
Asian	1.4 (11)	1.3 (4)
Other minority	1.4 (11)	1.0 (3)
Missing	0.7 (6)	0.3 (1)
Education, % (*n*)		
Less than high school	15.8 (127)	6.8 (21)
High school diploma or GED	22.1 (177)	15.5 (48)
Some college or trade school	36.8 (295)	44.5 (138)
4-year college degree	12.9 (103)	15.5 (48)
Graduate or professional school	11.1 (89)	17.4 (54)
Missing	1.2 (10)	0.3 (1)
Married or living with partner	57.2 (458)	
Monthly income, % (*n*)		
Less than $1,000	14.3 (115)	—
$1,001–2,000	22.0 (176)	—
$2,001–4,000	32.3 (259)	—
$4,001 or more	20.8 (167)	—
Missing	10.5 (84)	—
Diagnosis, % (*n*)		
Cancer	34.6 (277)	—
Cardiovascular	18.5 (148)	—
COPD	25.2 (202)	—
Diabetes and complications	3.0 (24)	—
Dementia	0.2 (2)	
Other	7.6 (61)	
Missing	10.9 (87)	
Relationship with patient, % (*n*)		
Spouse/partner	—	50.3 (156)
Child	—	29.4 (91)
Other relative/friend	—	19.4 (60)
Missing	—	1.0 (3)

GED = General Equivalency Diploma.
[a] Respondents had the choice of endorsing more than one option.

Measurement Structure

Patient-Specific Quality of End-of-Life Care Models. The scree plot from a traditional EFA of the 29 dichotomized QEOLC indicators or items showed strong evidence of a single underlying factor. Clustered factor analysis produced a patient model (Fig. 1) with 11 indicators or items (representing all five conceptual domains)

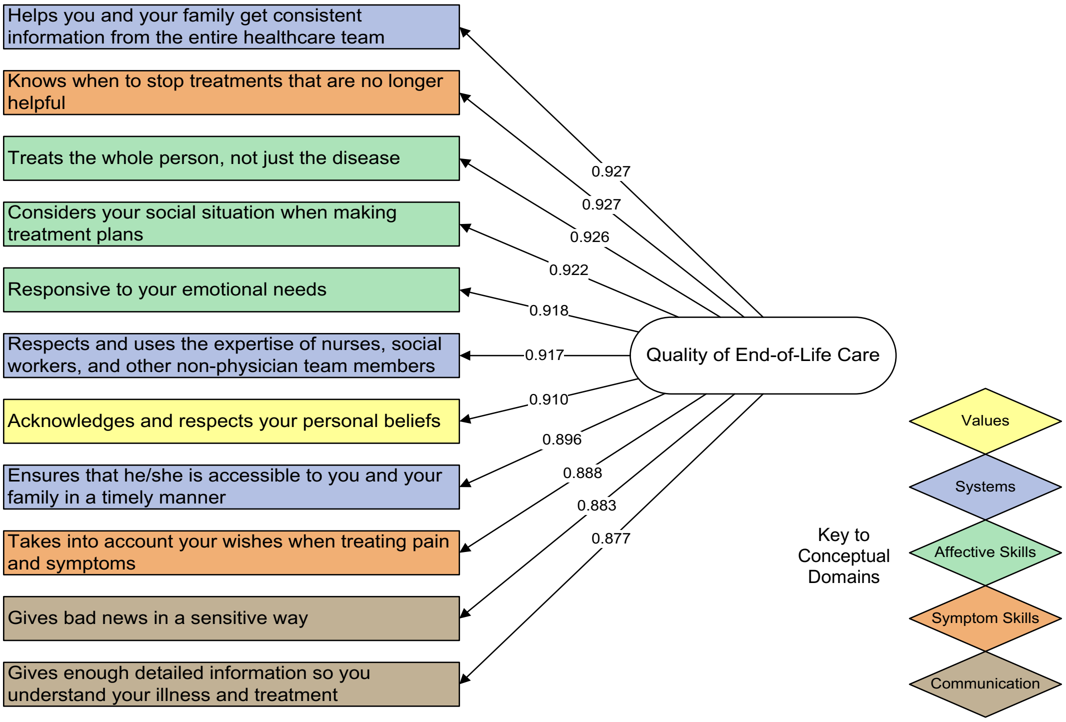


Fig. 1. Patients' ratings of physicians' end-of-life care—11 dichotomous indicators or items and one latent factor.

and excellent fit (Table 3—sample-specific patient Model 1). Although factor scores based on this model were not normally distributed, skew was not statistically significant. A similar model with the factor loadings constrained to 1.00 also fit well (Table 3, sample-specific patient Model 2).

Family-Specific Quality of End-of-Life Care Models. Traditional EFA using 30 dichotomized QEOLC items generated a scree plot suggesting a single underlying factor. The subsequent factor analysis produced a family model (Fig. 2) with 22 indicators or items, representing all five conceptual domains. Model fit was good (Table 3—sample-specific family Model 1), and factor scores displayed almost no skew. When the factor loadings were constrained to 1.00, the model continued to show good fit (Table 3—sample-specific family Model 2).

Nurse-Specific Quality of End-of-Life Care Models. As with the patient and family samples, the traditional EFA generated a scree plot suggesting a single underlying factor. The subsequent factor analysis produced a nurse model (Fig. 3) with 11 indicators or items representing all five conceptual domains. Although model-fit statistics and distribution of the composite score were acceptable when parameter estimates were freely estimated (Table 3—sample-specific nurse Model 1), the model in which factor loadings were constrained to 1.00 did not meet the criteria for acceptable fit, and the composite measure exhibited significant negative skew, suggesting that an unweighted mean score might not accurately represent nurses' quality of end-of-life care ratings (Table 3—sample-specific nurse Model 2).

Simplified Quality of End-of-Life Care Models Common to All Respondents. A simplified 10-indicator model comprising two indicators or items from each of the five conceptual domains provided good fit to each of the three samples when factor loadings were freely estimated (Table 3—common-solution, patient, family, and nurse Model 1). Figure 4 summarizes the model for each of the three respondent samples. Models constraining factor loadings to 1.00 continued to fit the patient and family samples adequately (Table 3—common-solution, patient and family Model 2). However, fit

Table 3

Summary of Factor Analysis Models. Model Fit: Latent Factor and Composite Measure Characteristics

						Latent Factor	Composite Measure[e]		
Sample & Model	χ^2	df	*P*[a]	CFI[b]	RMSEA[c]	Mean (Variance)[d]	Mean (Variance)	Min, Max	Skew (SE)
Sample-specific models									
Patients—11 indicators/items									
Model 1[f]	26.99	23	>0.25	1.00	<0.02	0.00 (0.83)	−0.05 (0.44)	−1.08, 0.77	−0.15 (0.09)
Model 2[g]	26.11	20	>0.16	>0.99	<0.03	0.00 (0.83)	0.56 (0.16)	0.00, 1.00	−0.22 (0.09)
Family—22 indicators/items									
Model 1[f]	33.56	29	>0.25	>0.99	<0.03	0.00 (0.81)	0.01 (0.46)	−0.99, 1.01	0.05 (0.14)
Model 2[g]	37.13	27	>0.09	>0.99	<0.04	0.00 (0.86)	0.49 (0.16)	0.00, 1.00	0.02 (0.14)
Nurses—11 indicators/items									
Model 1[f]	31.17	23	>0.11	>0.99	<0.03	0.00 (0.78)	−0.03 (0.44)	−1.06, 0.84	−0.14 (0.08)
Model 2[g]	104.45	20	<0.001	>0.98	<0.07	0.00 (0.79)	0.56 (0.15)	0.00, 1.00	−0.23 (0.08)
Common-solution models									
Patients—10 indicators/items									
Model 1[f]	24.74	21	>0.25	1.00	<0.02	0.00 (0.79)	−0.07 (0.44)	−1.20, 0.72	−0.29 (0.09)
Model 2[g]	27.05	20	>0.13	>0.99	<0.03	0.00 (0.82)	0.61 (0.15)	0.00, 1.00	−0.42 (0.09)
Family—10 indicators/items									
Model 1[f]	21.17	16	>0.17	>0.99	<0.04	0.00 (0.91)	−0.00 (0.45)	−0.90, 0.88	−0.01 (0.14)
Model 2[g]	25.46	17	>0.08	>0.99	<0.05	0.00 (0.87)	0.52 (0.17)	0.00, 1.00	−0.07 (0.14)
Nurses—10 indicators/items									
Model 1[f]	22.37	20	>0.32	1.00	<0.02	0.00 (0.81)	−0.02 (0.49)	−1.09, 0.89	−0.13 (0.08)
Model 2[g]	57.56	17	<0.0001	>0.99	<0.06	0.00 (0.81)	0.56 (0.15)	0.00, 1.00	−0.27 (0.08)

[a] Probability that the postulated model is true, given the observed data (based on the χ^2 test of fit). Values greater than 0.05 signify adequate fit to the data. Of the three tests of fit shown in this table, the χ^2 test was the most difficult to pass because of its sensitivity to the study's large sample sizes.

[b] Bentler's comparative fit index. Values ≥0.96 suggest adequate fit of the model to the observed data.

[c] Root mean square error of approximation. Values ≤0.05 suggest adequate fit of the model to the observed data.

[d] The estimated mean and variance of the unobserved, but inferred, latent factor. This factor is assumed to represent overall quality of end-of-life care and to "explain" values of the component indicators or items (net unexplained individual variation on the indicators or items).

[e] Characteristics of a measure directly computed for each individual, using the individual's values on the observed indicators or items. For Model 1, these are factor scores. For Model 2, they are unweighted means of the indicator or items.

[f] Parameter estimates were freely estimated. Composite measures were computed as factor scores, with indicators or items weighted according to their estimated contribution to the underlying latent factor. In general, the mean and variance of a factor score approach the estimated mean and variance of the corresponding latent factor as the number of indicators or items increases.

[g] Parameter estimates were constrained to 1.00. Composite measures were computed as the individual's mean on the component indicators or items. The mean of the composite measure differs markedly from the estimated mean of the latent factor by virtue of the fact that the composite measure was not deliberately centered on zero.

deteriorated when this model was applied to the nurse data (Table 3—common solution, nurse Model 2), with three items (Items 18, 26, and 46) contributing substantial misfit.

Construct Validity

Patient-Specific Quality of End-of-Life Care Factor. Six of the seven conceptually related variables showed significant associations in hypothesized directions with the patient-specific QEOLC factor (Table 4). Patients' latent QEOLC factor values were higher when they and their family members indicated higher satisfaction with care (ABIM), when their family member had a higher QEOLC factor score, when their physician scored higher on the palliative care knowledge examination and had higher mean Nurse-PAR ratings, and when the patient reported fewer symptoms (MSAS-SF). Patients' latent QEOLC factor values were also higher when their physician had higher average nurse QEOLC factor scores, but this association fell short of statistical significance (Table 4).

Family-Specific Quality of End-of-Life Care Factor. Three of the seven conceptually related variables were significantly associated in the hypothesized direction with the family-specific QEOLC factor. Family members' latent QEOLC factor values were higher when they and the patient assessed higher satisfaction (ABIM) and when the patient's QEOLC factor score was higher (Table 4).

Nurse-Specific Quality of End-of-Life Care Factor. Four of the six conceptually related variables showed significant associations in hypothesized direction with the nurse-specific QEOLC factor.

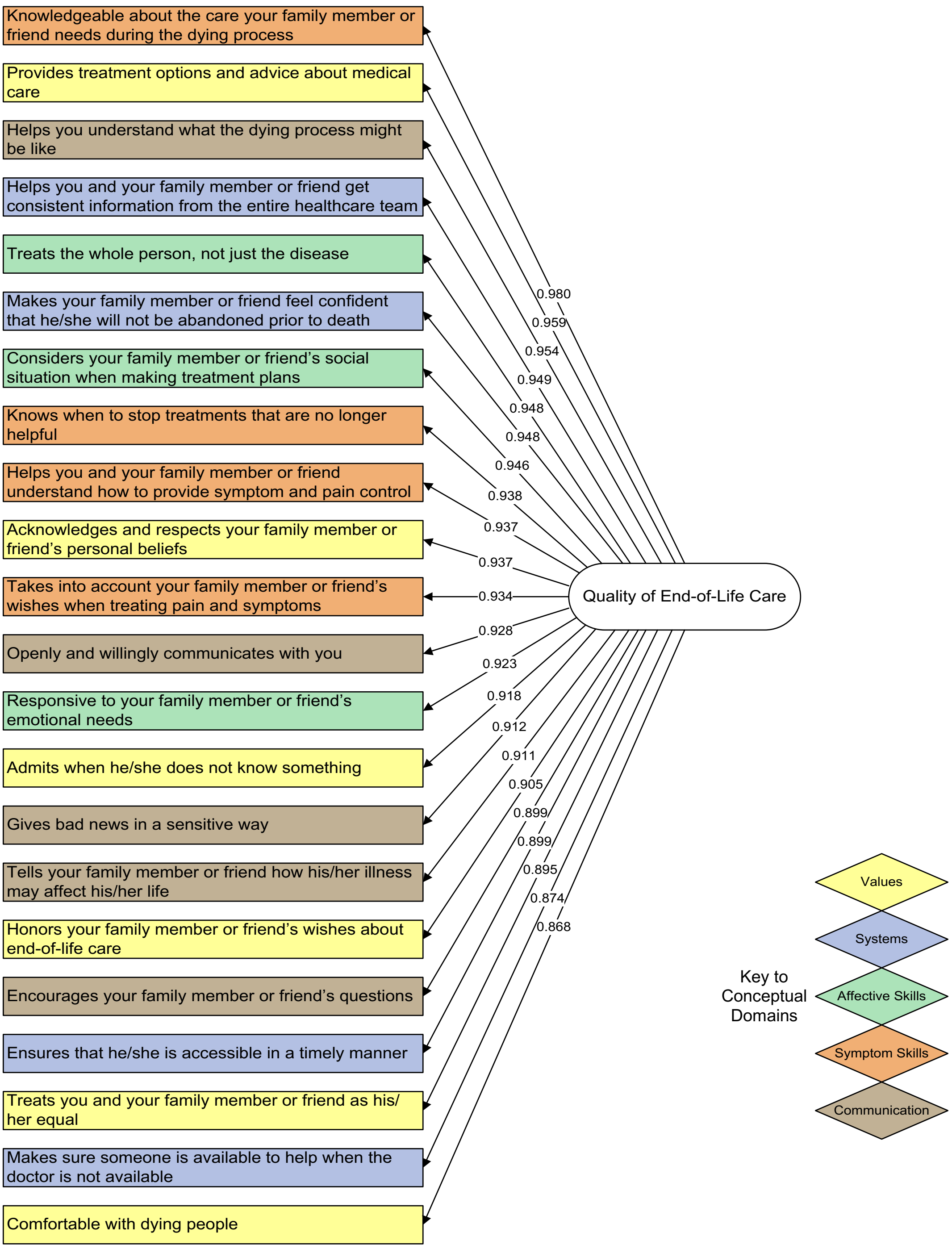


Fig. 2. Family members' ratings of physicians' end-of-life care—22 dichotomous indicators or items and one latent factor.

Nurses' latent QEOLC factor values were significantly higher for physicians whom they rated higher on the PAR, who scored higher on the palliative care knowledge examination, and who had higher average patient ABIM ratings and QEOLC factor scores (Table 4).

Simplified Quality of End-of-Life Care Factor Common to All Respondents. Validity tests of the factors from the 10-indicator common solution produced results identical to those of the tests for the sample-specific factors, except that the 10-indicator patient-specific QEOLC factor was

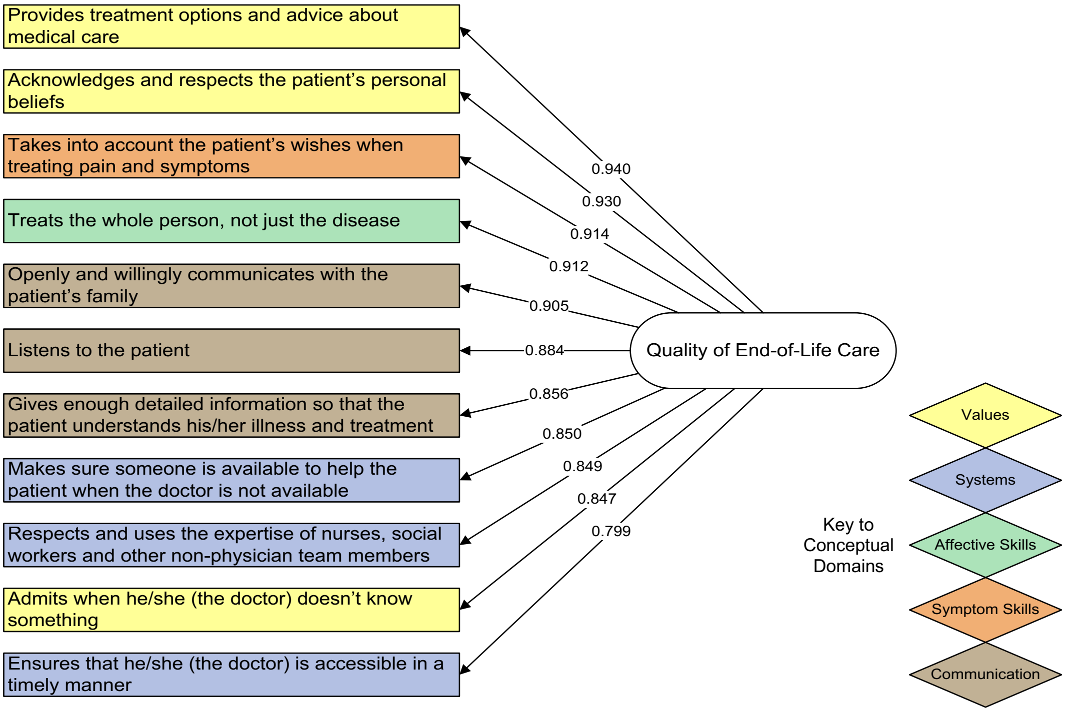


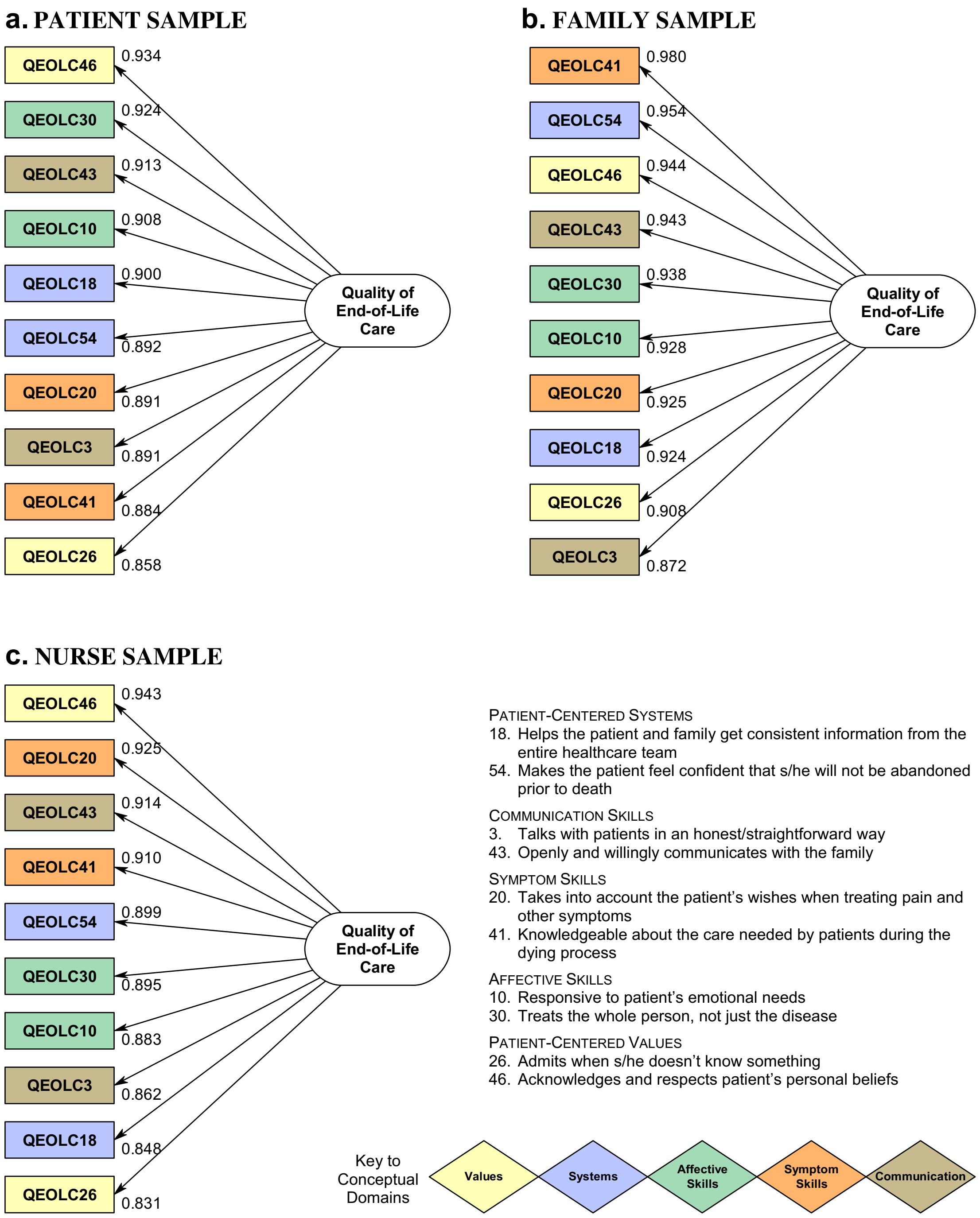
Fig. 3. Nurses' ratings of physicians' end-of-life care—11 dichotomous indicators or items and one latent factor.

not significantly associated with the physician's score on the palliative care knowledge examination (Table 5).

Discussion

The results of these analyses suggest that the QEOLC respondent-specific and common-solution questionnaires offer valid measures of physician skills at providing quality end-of-life care that are applicable to a varied group of respondents and settings and that are short enough to avoid excessive burden. The factor analysis provided evidence that the QEOLC questionnaires, using a selection of items drawn from qualitatively and conceptually identified domains,[22–26] represent a single factor. This single-factor solution was supported for each respondent type (i.e., patients, families, nurses). Loadings for all items were greater than or equal to 0.80, a value that exceeds standards used to support scale development.[43,44] In addition to the models where parameters were freely estimated (designated as "Model 1" for each sample), we evaluated models based on the same indicators as the corresponding Model 1, but with factor loadings constrained to 1.00 (these models designated as "Model 2"). Except for nurse respondents, Model 2 also fit the data adequately. The practical difference between Model 2 and the corresponding Model 1 is that an adequately fitting Model 2 gives added support for using an average or summed total score to reflect the respondent's rating of overall end-of-life care, without using more complex weighted scores, thus enhancing the QEOLC questionnaire's usability. Our findings indicate that unweighted scores are likely appropriate for patients and family members, although, perhaps, not for nurses.

Of the 31 items selected for retention from the larger pool of 54, all but five items (one from each conceptual domain) were included in at least one of the empirically derived models, and all conceptually derived domains were represented in each model, suggesting that the criteria used to select a reduced set of items resulted in a representative item pool. The common solution included 10 items representing all five domains. All of the items and conceptual domains in this solution have been identified as important for quality end-of-life care[3,20,45–47]



PATIENT-CENTERED SYSTEMS
18. Helps the patient and family get consistent information from the entire healthcare team
54. Makes the patient feel confident that s/he will not be abandoned prior to death

COMMUNICATION SKILLS
3. Talks with patients in an honest/straightforward way
43. Openly and willingly communicates with the family

SYMPTOM SKILLS
20. Takes into account the patient's wishes when treating pain and other symptoms
41. Knowledgeable about the care needed by patients during the dying process

AFFECTIVE SKILLS
10. Responsive to patient's emotional needs
30. Treats the whole person, not just the disease

PATIENT-CENTERED VALUES
26. Admits when s/he doesn't know something
46. Acknowledges and respects patient's personal beliefs

Fig. 4. Model of physicians' end-of-life care common to all respondents—10 dichotomous indicators/items and one latent factor: a) patient sample, b) family sample, c) nurse sample.

and are included in other questionnaires assessing the quality of end-of-life care.[17,48–50]

Scores on this single factor, whether developed for particular respondent types or across all respondents, demonstrated excellent construct validity. Construct validity, which is a necessary characteristic of psychometrically sound measures,[44] is supported by significant associations between measures assessing similar constructs, defined *a priori*.[51,52] The patterns in these construct validation analyses provide additional insights. First, the strong but less-than-perfect associations with the quality of overall care ratings on the ABIM questionnaires suggest that the QEOLC factors, although similar to generic measures of quality of care, may offer additional quality-of-care information for patients facing life-limiting illnesses and their families. Second, the close association between reduced symptom burden and higher values on the latent QEOLC factors supports prior research identifying an important link between good pain and symptom control and quality end-of-life care.[18,34–38,53] Third, patient QEOLC values from both the patient-specific and common-solution models were significantly and highly ($P < 0.001$) associated with family QEOLC values from both the family-specific and common-solution models. Because prior research demonstrates that reports and ratings provided by patients and surrogates are closest for observable behaviors,[54–59] the significant association between patient and family QEOLC values may be explained by our focus on items that are behavioral and observable. For example, items in the patient- and family-specific QEOLC models include being accessible in a timely manner, providing consistent information from the health care team, giving bad news sensitively, and knowing when to stop treatments that are no longer useful. These are the events that may be experienced directly by both patients and families and, may, therefore, be more easily assessed. Similarly, the common-solution QEOLC model includes talking to patients in an honest way, communicating openly and willingly with families, assuring the patient that he or she will not be abandoned, and the willingness of the doctor to admit when he or she does not know something. These items suggest skills and behaviors that may be appropriate foci for interventions to improve end-of-life care. Finally, both the nurse-specific and common-solution QEOLC models for nurses were associated with physicians' scores on the palliative care knowledge examination, suggesting that nurses' perceptions of physicians' skills at end-of-life care fairly closely match those competencies that are measured by the more objective palliative and end-of-life care knowledge examination.

Although the respondent-specific and common-solution QEOLC models have demonstrated excellent psychometric properties, there are a number of limitations to our findings. First, our attempts to assess the QEOLC questionnaire's generalizability by using a varied respondent sample were only partially successful. We achieved variability in regions of the United States, physician specialty, and patient diseases. However, despite using a sampling frame designed to oversample to achieve racial and ethnic diversity among physicians (and, therefore, among their patients and families),[60] only 11% of the participants were from racially or ethnically diverse groups. This may be, in part, because of the low response rate that made oversampling impossible; it may also reflect the smaller number of racial and ethnically diverse physicians overall. In a report based on the physician workforce in 2000, racially or ethnically diverse physicians represented 12% of all physicians in the Pacific Northwest and 14% in the Southeast.[60] Additionally, we did not find a significantly different response rate for participating and nonparticipating physicians by race or ethnicity (20.0% vs. 21.6%), suggesting that the differential willingness to participate in research seen in prior studies was not observed.[61,62] Nonetheless, the low response rate for physicians may limit the generalizability of our findings, and further studies are necessary to ensure generalizability. Second, the sample-specific characteristics of the structural equation models pose a limitation. Although the models are well fit to this sample, confidence in the solutions will require confirmation in independent samples. Third, like other measures in which respondents are asked to rate the quality of care, responses to QEOLC questionnaire items were significantly skewed;[50] therefore, we collapsed responses into two categories: "the very best" and "less than the very best." This approach allowed us to develop psychometrically valid models. Additional work is needed to evaluate whether and how changes in the response options may result in more normally distributed responses with different structural solutions. Fourth, although we tested the QEOLC models' construct validity through the use of convergent associations, we did not explore additional aspects of validity, including discriminant, concurrent, or predictive; all of these represent important aspects of construct validity that remain to be examined in future studies. Fifth, although

Table 4

Construct Validation Analyses: Association of Sample-Specific QEOLC Latent Factors With Conceptually Related Variables

Association of 11-Item Patient-Specific QEOLC Latent Factors With Conceptually Related Variables

Measures	Patient, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	**741**	**75**	**0.027**	**<0.04**
Physician's ABIM rating by patient	**799**	**92**	**1.705**	**≈0.00**
Physician's ABIM rating by patient's family	**305**	**78**	**0.799**	**≈0.00**
Physician's mean PAR rating (mean rating by all nurses)	**699**	**71**	**0.189**	**<0.01**
Symptom distress (patient reported MSAS—total score)	**796**	**92**	**−0.229**	**<0.004**
Family member's QEOLC factor score	**308**	**78**	**0.882**	**≈0.00**
Physician's mean value on nurses' QEOLC factor scores	699	71	0.235	<0.07

Association of 22-Item Family-Specific QEOLC Latent Factor With Conceptually Related Variables

	Family, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	241	50	0.016	<0.49
Physician's ABIM score for the family member	**306**	**78**	**1.676**	**≈0.00**
Physician's ABIM score for the patient	**308**	**78**	**0.783**	**≈0.00**
Physician's mean PAR score over all nurses	276	62	0.160	<0.16
Symptom distress (patient-reported MSAS—total score)	307	78	−0.186	<0.18
Patient's QEOLC factor score	**308**	**78**	**0.828**	**≈0.00**
Physician's mean value on nurses' QEOLC factor scores	276	62	0.067	<0.72

Association of 11-item Nurse-Specific QEOLC Latent Factor With Conceptually Related Variables

	Nurse, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	**705**	**66**	**0.041**	**<0.03**
Physician's mean ABIM rating over all patients	**757**	**71**	**0.564**	**<0.006**
Physician's mean ABIM rating over all families	682	62	0.135	<0.06
Physician's PAR rating by the nurse	**883**	**88**	**1.235**	**≈0.00**
Physician's mean value on patients' QEOLC factor scores	**757**	**71**	**0.339**	**<0.03**
Physician's mean value on families' QEOLC factor scores	682	62	0.081	<0.62

[a] Unstandardized slope (number of units of change in the latent variable with one unit change in the predictor). Boldfaced items are significant at $P \leq 0.05$.

differences between eligible participants and nonparticipants were few, our physician response rate was low, and the questionnaire should be tested further in more representative samples. This low response rate limited our ability to oversample specific groups; to assemble our sample, we depleted our entire list of eligible physicians. Sixth, although our results suggested that a composite measure computed as a simple mean of indicator or item values may adequately represent patients' and family members' overall ratings of end-of-life care, the same was less true for nurses. Additional research will be necessary to understand whether it is possible to construct nurse scale scores that are not contingent on sample-specific weights.

Despite the need for additional work, the QEOLC questionnaires provide useful measures for describing, evaluating, and improving end-of-life care. All of the QEOLC questionnaires contain specific items associated with diverse end-of-life care domains; they may, therefore, be useful in identifying problems in end-of-life care and in designing interventions to improve that care. Furthermore, all of the QEOLC questionnaires are short, ranging from a minimum of 10 items for the common solution to 22 for the family-specific solution. These relatively short measures reduce burden compared with longer measures and are easier to administer to respondents who are ill. The choice of which of the QEOLC questionnaires to use will depend on the goals and purpose that they will serve. For example, researchers implementing an intervention for families of patients in critical care settings may choose the family-specific QEOLC questionnaire, as it is their experiences that the researcher is attempting to change. Administrators or clinicians completing quality-improvement assessments may choose the common-solution QEOLC questionnaire, as it may be completed by a variety of respondents involved with and affected by end-of-life care. Responses to the same set of items also make it possible to comparatively evaluate respondents'

Table 5

Association of 10-Indicator or Item Common-Solution QEOLC Latent Factor With Conceptually Related Variables

Patient Sample	Respondent, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	741	75	0.019	<0.11
Physician's ABIM rating by patient	**799**	**92**	**1.594**	**≈0.00**
Physician's ABIM rating by patient's family	**305**	**78**	**0.752**	**≈0.00**
Physician's mean PARS rating (mean rating by all nurses)	**699**	**71**	**0.165**	**<0.03**
Symptom distress (patient reported MSAS—total score)	**796**	**92**	**−0.235**	**<0.004**
Family member's QEOLC factor score (10-indicator)	**308**	**78**	**0.806**	**≈0.00**
Physician's mean value on nurses' QEOLC factor scores	699	71	0.219	<0.07

Family Sample	Respondent, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	241	50	0.016	<0.53
Physician's ABIM score for the family member	**306**	**78**	**1.796**	**≈0.00**
Physician's ABIM score for the patient	**308**	**78**	**0.835**	**≈0.00**
Physician's mean PARS score over all nurses	276	62	0.205	<0.08
Symptom distress (patient-reported MSAS—total score)	307	78	−0.198	<0.20
Patient's QEOLC factor score	**308**	**78**	**0.882**	**≈0.00**
Physician's mean value on nurses' QEOLC factor scores	276	62	0.151	<0.39

Nurse Sample	Respondent, *n*	Physician, *n*	b[a]	2-Tailed *P*
Physician's score on palliative care knowledge examination	**705**	**66**	**0.042**	**<0.03**
Physician's mean ABIM rating over all patients	**757**	**71**	**0.631**	**<0.004**
Physician's mean ABIM rating over all families	682	62	0.161	<0.46
Physician's PARS rating by the nurse	**883**	**88**	**1.192**	**≈0.00**
Physician's mean value on patients' QEOLC factor scores	**757**	**71**	**0.448**	**<0.02**
Physician's mean value on families' QEOLC factor scores	682	62	0.115	<0.52

[a] Unstandardized slope (number of units of change in the latent variable with one unit change in the predictor). Boldfaced items are significant at $P \leq 0.005$.

perceptions of shortcomings in end-of-life care and interventions designed to improve that care. Finally, those seeking to assess and improve their delivery of end-of-life care exclusively to patients may select the patient-specific QEOLC questionnaire. The goal of measurement must guide the choice of the measure, and further research will be needed to determine how effective the QEOLC questionnaires will be in serving these goals.

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Appendix I

Quality of End-of-Life Care Domains, Subdomains, and Items

Items retained after initial item reduction are indicated by an*

I. PATIENT-CENTERED SYSTEMS
  1. Accessibility and Continuity
    - Takes as much time as needed with the patient*
    - Ensures that s/he is accessible to the patient and family in a timely manner*
    - Makes the patient feel confident that s/he will not be abandoned prior to death*
    - Avoids keeping the patient waiting without explanation
    - Minimizes interruptions and focuses on the patient during visits
    - Has contact with the family after the patient's death
  2. Team Communication and Coordination
    - Makes sure there is someone available to help the patient when the physician is not available*

    - Respects and uses the expertise of nurses, social workers, and other non-physician team members*
    - Helps the patient and family get consistent information from the entire healthcare team*
    - Lets the patient know whom to call for different problems
    - Guides patient or family to hospice in a timely manner* (for nurses only)

II. COMMUNICATION SKILLS

3. Communication with Patients
    - Listens to patients*
    - Encourages questions from the patient*
    - Talks with patients in an honest/straightforward way*
    - Gives bad news in a sensitive way*
    - Willing to talk about dying*
    - Sensitive to when patients are ready to talk about dying
4. Patient Education
    - Gives enough detailed information so that patient understands his/her illness and treatments*
    - Tells patient how this illness may affect his/her life*
    - Guides patient and family to helpful resources
    - Talks with patients about what dying might be like
5. Inclusion/Recognition of the Family
    - Openly and willingly communicates with the family*
    - Helps the family understand what the dying process might be like* (for family only)
    - Includes the family in decision making

III. SYMPTOM SKILLS

6. Competence
    - Knowledgeable about the care needed by patients during the dying process*
    - Knows when to stop treatments that are not helpful*
    - Knowledgeable about medical care generally
    - Takes the patient's symptoms seriously
    - Recommends appropriate treatments
    - Has good technical skills
    - Is prepared for appointments
    - Appropriately refers the patient to specialists
7. Relief of Pain and Symptoms
    - Takes into account the patient's wishes when treating pain and symptoms*
    - Helps patients and families understand how to provide symptom and pain control*
    - Acknowledges and treats anxiety and depression* (for nurses and physicians only)
    - Not afraid to prescribe pain medications when needed

IV. AFFECTIVE SKILLS

8. Emotional Support
    - Provides comfort through touch, such as a hug or holding the patient's hand*
    - Responsive to patient's emotional needs*
    - Shows compassion
    - Maintains hope and a positive attitude
9. Personalization
    - Treats the whole person, not just the disease*
    - Considers the patient's social situation when making treatment plans*
    - Makes the patient feel unique and special

V. PATIENT-CENTERED VALUES

10. Attention to Patient's Values
    - Acknowledges and respects patient's personal beliefs*
    - Respects patient's culture and religious beliefs*
    - Respects patient's choices about alternative medicine
    - Not blaming or judgmental about patient's lifestyle
11. Respect and Humility
    - Treats patients (and families) as his/her equal*
    - Admits when s/he doesn't know something*
    - Comfortable with people who are dying*
    - Doesn't view death as a medical or personal failure
    - Polite and considerate
12. Support of Patient Decision-Making
    - Provides treatment options and advice about medical care*
    - Honors the patient's wishes about end-of-life care*
    - Lets patient make decisions about his/her medical care

Appendix II

Quality of End-of-Life Care Questionnaire Item Characteristics—Patient Data ($n = 801$)[a]

Items	Valid n	Valid %	Mean	SD	Pitman Variance Test—P (n)
PATIENT-CENTERED SYSTEMS					
Accessibility and Continuity					
Ensures that he/she is accessible to you and your family in a timely manner	704	87.8	9.05	1.67	0.52 (35)
Makes you feel confident that you will not be abandoned before death	427	53.2	9.31	1.64	0.60 (17)
Team Communication and Coordination					
Respects and uses the expertise of nurses, social workers, and other nonphysician team members	642	80.0	9.09	1.57	0.03 (33)
Helps you and your family get consistent information from the entire health care team[b]	605	75.4	8.59	2.18	0.04 (28)
COMMUNICATION SKILLS					
Communication with Patient					
Talks with you in an honest and straightforward way	795	99.1	9.34	1.26	0.01 (42)
Gives bad news in a sensitive way	656	81.8	9.02	1.59	0.70 (26)
Patient Education					
Gives enough detailed information so you understand your illness and treatment	784	97.8	9.02	1.57	0.08 (42)
Inclusion/Recognition of the Family					
Openly and willingly communicates with your family	636	79.3	9.35	1.44	0.61 (30)
SYMPTOM SKILLS					
Competence					
Knowledgeable about the care you need during the dying process	187	23.3	9.03	1.89	— (3)
Knows when to stop treatments that are no longer helpful	537	67.0	9.21	1.31	0.17 (26)
Relief of Pain and Symptoms					
Takes into account your wishes when treating pain and symptoms[b]	689	85.9	9.20	1.39	0.04 (37)
AFFECTIVE SKILLS					
Emotional Support					
Responsive to your emotional needs[b]	684	85.3	8.65	1.94	0.99 (32)
Personalization					
Treats the whole person, not just the disease[b]	742	92.5	8.85	1.84	0.93 (40)
Considers your social situation when making treatment plans	571	71.2	8.96	1.78	0.21 (26)
PATIENT-CENTERED VALUES					
Respect and Humility					
Admits when he/she does not know something	624	77.8	9.26	1.45	0.11 (28)
Attention to Patients' Values					
Acknowledges and respects your personal beliefs[b]	623	77.7	9.33	1.38	0.12 (29)

[a] Boldfaced items are part of the common-solution QEOLC model.

[b] Item is in both the common-solution and patient-specific QEOLC model.

Appendix III

Quality of End-of-Life Care Questionnaire Item Characteristics—Family/Friend Data (n = 310)[a]

Items	Valid *n*	Valid %	Mean	Standard Deviation
PATIENT-CENTERED SYSTEMS				
Accessibility and Continuity				
Ensures that he/she is accessible in a timely manner	298	96.1	8.84	1.85
Makes your family member or friend feel confident that he/she will not be abandoned prior to death[b]	168	54.2	9.01	1.68
Team Communication and Coordination				
Makes sure someone is available to help your family member or friend when the doctor is not available	277	89.4	8.32	2.31
Helps you and your family member or friend get consistent information from the entire health care team[b]	265	85.5	8.30	2.17
COMMUNICATION SKILLS				
Communication with the Patient				
Encourages your family member or friend's questions	303	97.7	8.64	1.77
Talks with your family member or friend in an honest and straightforward way	306	98.7	9.14	1.40
Gives bad news in a sensitive way	267	86.1	8.86	1.70
Patient Education				
Tells your family member or friend how his/her illness may affect his/her life	289	93.2	8.62	1.95
Inclusion/Recognition of the Family				
Openly and willingly communicates with you[b]	296	95.5	8.95	1.95
Helps you understand what the dying process might be like for your loved one	98	31.6	7.70	3.00
SYMPTOM SKILLS				
Competence				
Knowledgeable about the care your family member or friend needs during the dying process[b]	91	29.4	8.56	2.57
Knows when to stop treatments that are no longer helpful	194	62.6	9.10	1.59
Relief of Pain and Symptoms				
Takes into account your family member or friend's wishes when treating pain and symptoms[b]	278	89.7	8.91	1.69
Helps you and your family member or friend understand how to provide symptom and pain control	229	73.9	8.66	1.97
AFFECTIVE SKILLS				
Emotional Support				
Responsive to your family member or friend's emotional needs[b]	282	91.0	8.28	2.26
Personalization				
Treats the whole person, not just the disease[b]	298	96.1	8.66	2.22
Considers your family member or friend's social situation when making treatment plans	242	78.1	8.73	1.95
PATIENT-CENTERED VALUES				
Respect and Humility				
Treats you and your family member or friend as his/her equal	297	95.8	8.82	1.86
Admits when he/she does not know something[b]	268	86.5	8.87	1.76
Comfortable with dying people	119	38.4	8.77	1.89
Support of Patient Decision-Making				
Provides treatment options and advice about medical care	295	95.2	8.88	1.88
Honors your family member or friend's wishes about end-of-life care	113	36.5	9.41	1.22
Attention to Patients' Values				
Acknowledges and respects your family member or friend's personal beliefs[b]	261	84.2	9.11	1.42
Respects your family member or friend's culture and religious beliefs	184	59.4	9.38	1.07

[a] Bolded items are part of the common-solution QEOLC model.

[b] Item is in both the common-solution and family-specific QEOLC model.

Appendix IV

Quality of End-of-Life Care Questionnaire Item Characteristics—Nurse Data ($n = 885$)[a]

Items	Valid *n*	Valid %	Mean	Standard Deviation
PATIENT-CENTERED SYSTEMS				
Accessibility and Continuity				
Ensures that he/she is accessible in a timely manner	847	95.7	8.13	1.78
Makes the patient feel confident that he/she will not be abandoned before death	813	91.9	8.46	1.79
Team Communication and Coordination				
Makes sure someone is available to help when the doctor is not available	827	93.4	8.12	1.91
Respects and uses the expertise of nurses, social workers, and other nonphysician team members	882	99.7	8.45	1.88
Helps the patient get consistent information from the entire health care team	854	96.5	7.91	1.94
COMMUNICATION SKILLS				
Communication with Patient				
Listens to the patient	878	99.2	8.30	1.60
Talks with the patient in an honest and straightforward way	879	99.3	8.60	1.60
Patient Education				
Gives enough detailed information so the patient understands his/her illness and treatment	879	99.3	8.29	1.66
Inclusion/Recognition of the Family				
Openly and willingly communicates with the patient's family[b]	879	99.3	8.49	1.82
SYMPTOM SKILLS				
Competence				
Knowledgeable about the care the patient needs during the dying process	851	96.2	8.56	1.67
Relief of Pain and Symptoms				
Takes into account the patient's wishes when treating pain and symptoms[b]	871	98.4	8.43	1.73
AFFECTIVE SKILLS				
Emotional Support				
Responsive to the patient's emotional needs	869	98.2	7.63	2.00
Personalization				
Treats the whole person, not just the disease[b]	874	98.8	8.05	1.87
PATIENT-CENTERED VALUES				
Respect and Humility				
Admits when he/she (the doctor) does not know something[b]	823	93.0	8.15	2.02
Support of Patient Decision-Making				
Provides treatment options and advice about medical care	867	98.0	8.36	1.58
Attention to Patients' Values				
Acknowledges and respects the patient's personal beliefs[b]	859	97.1	8.53	1.62

[a] Boldfaced items are part of the common-solution QEOLC model.
[b] Item is in both the common-solution and nurse-specific QEOLC model.