Measuring Intensive Care Nurses' Perspectives on Family-Centered End-of-Life Care: Evaluation of 3 Questionnaires

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- BACKGROUND *Attempts to improve end-of-life care increasingly focus on family-centered care, but few validated assessment tools exist.*
- OBJECTIVES *To evaluate 3 new short questionnaires measuring nurses' perspectives on family-centered end-of-life care in the intensive care unit and to show the usefulness of the questionnaires.*
- METHODS *Principal components analysis of data from 141 critical care nurses evaluating care given to families of 218 patients was used to develop domain scores for number of nursing activities with each family, number of barriers experienced, and nurses' satisfaction that the family's needs were met. Random effects models were used to test associations between critical care processes and outcome.*
- RESULTS *Nursing activities fell into 2 domains: general and culture-related communication/support. Barriers consisted of 2 domains: patient/family barriers and system/team barriers. Meeting the needs of patients' families represented a single dimension. In a path model based on domain scores, general activities had significant associations with both nurse communication and meeting families' needs; patient/family barriers, with nurse communication; and nurse and physician communication, with meeting families' needs. In a path model based on total activities and barriers scores, total activities and total barriers had significant associations with nurse communication ratings and meeting families' needs. Patients' and nurses' characteristics were not significant independent predictors of meeting the needs of patients' families.*
- CONCLUSIONS *The 3 questionnaires provide a consistent, valid picture of nurses' perspectives on family-centered critical care and may be useful in evaluating family care processes and outcomes and in targeting areas for improvement. (American Journal of Critical Care. 2006;15:568-579)*

D eath is a frequent event in the intensive care unit (ICU). In a study of 6 states in the United States, Angus et al[1] found that 22.4% of all deaths occurred during hospitalizations that included an ICU stay. Although some of these deaths most likely occurred in other hospital units after discharge from the ICU, in 4 states that collected ICU length-of-stay information, 40.7% of the decedents spent their entire hospitalization in the ICU.[1] With growing emphasis on measuring and improving quality of ICU care, the care of patients' families (ie, family care) is attracting increased attention.[2,3] Most ICU deaths occur after a decision, often shared by a patient's family and clinicians, to withhold or withdraw life support.[4] Conflict

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is common during this process. Breen et al[5] reported that healthcare providers and patients' family members disagreed in 48% of cases in which withdrawal of life support was considered. In addition, patients' families often experience substantial stress, anxiety, and depression.[6,7] The families need assistance with their own physical and emotional needs, support for their decisions, and help in understanding patients' conditions, treatment options, and likely course.[2] Interventions designed to improve and evaluate the quality of end-of-life care in the ICU must include attention to family-centered care.[8]

> *Family-centered care is integral to high-quality end-of-life care.*

Healthcare evaluations can benefit from multiple perspectives: members of patients' families, members of the healthcare team, and, when possible, patients. Because patients' family members tend to give uniformly high marks to quality of care,[9] thus limiting the usefulness of family members' evaluations in identifying targets for quality improvement, the perspectives of healthcare providers are important. In some studies,[10,11] nurses provided the most negative and therefore potentially the most useful evaluations of ICU care and the quality of patients' deaths. The negative evaluations may be due in part to the role nurses play as a conduit for information exchange between patients' family members and members of the healthcare team.[12] As a result of both this liaison role and the amount of time they spend with patients and patients' families, nurses are in a unique position to observe or hear about unmet needs.

Nurses have identified several activities that may be useful in improving care.[13,14] Among the most important are activities involving communication. Patients' families often cite communication deficiencies as an important source of dissatisfaction with care,[15-18] and evidence[19] indicates that addressing communication problems between nurses and patients' families may improve the families' overall satisfaction with end-of-life care.

A number of studies[13,14,20,21] have enumerated barriers to providing high-quality care at the end of life. These barriers include obstacles related to characteristics of the following 3 groups:

1. patients' families (eg, angry, unrealistic, or excessively demanding families; conflict between family members; families with cultural needs unfamiliar to the healthcare team),[13,14,20]

2. patients (eg, acute care requirements that leave little time for providing end-of-life support),[13] and

3. the system or the healthcare team (eg, space or privacy limitations, restrictive visiting hours, lack of support for culturally sensitive care, poor interdisciplinary communication or collaboration).[13,14,21] Barriers of all 3 kinds may decrease the quality of family-centered care, either directly by reducing the effectiveness of family-centered activities or indirectly by reducing the number of activities undertaken.

While designing an intervention to improve palliative care in the ICU, we noted a lack of tools for assessing nurses' reports of care delivered to patients' families, the challenges encountered, and nurses' perceptions of the quality of family care. To compensate for this deficiency, we developed 3 short questionnaires for nurses. Use of the 3 questionnaires before and after implementation of the intervention would facilitate measurement of changes in important aspects of end-of-life care. The questionnaires focused on 3 aspects of end-of-life care:

1. activities nurses undertook with the families of ICU patients who died (particularly activities related to communication),

2. barriers the nurses experienced in working with these families, and

3. the extent to which the nurses and other members of the healthcare team appeared to meet the families' needs.

In this article, we report our evaluation of the 3 instruments as potential tools for understanding and assessing ICU care for patients and patients' families. In our evaluation, we determined the domain structures of the questionnaires, developed scoring algorithms on the basis of these structures, and provided initial validation of the instruments. The validation exercise included investigation of a simplified model for evaluating ICU family-centered care, which provided the basis for establishing potential targets for quality improvement.

> *Nurses are in a unique position to evaluate the quality of family-centered end-of-life care.*

Methods

The University of Washington Human Subjects Division approved the procedures used in carrying out this research.

Recruitment and Respondents

Nurses who provided data for this study worked in ICUs at Harborview Medical Center, a university-affiliated county hospital in Seattle, Wash. At the time of the study, the hospital had a total of 353 beds, with 65 ICU beds located in 6 ICUs.

Daily between August 11, 2003, and March 16, 2004, we examined hospital admission/discharge/transfer logs and identified all patients who had died in an ICU on the previous day and who had remained in the ICU for at least 6 hours before death. From this pool we excluded patients who experienced brain death within 6 hours of ICU admission. Within 48 hours of an eligible patient's death, the nurses caring for the patient at the time of death and during the shift before death (if the ICU stay exceeded a single shift) received questionnaires about issues related to the amount, types, and quality of nursing care provided to the patient and the patient's family. One week after distribution of the questionnaires, the nurses received a postcard thanking them for participating in the study and reminding them to return the questionnaires if they had not done so already. Nurses who had not returned questionnaires 3 to 4 weeks after distribution received a final reminder along with a replacement questionnaire packet.

If more than 1 nurse provided data for a patient, in the analysis we used the nurse's report that included the most information on the quality of the patient's dying and death experience. If 2 nurses responded to the same number of items, we randomly selected 1 nurse's report for inclusion.

> *Better communication between the healthcare team and patients' families may improve end-of-life care.*

Measures

Nurse Self-report Measures. Nurses completed 3 family-care questionnaires assessing the following areas:

1. nursing activities for communicating with patient's families (NACF, hereafter referred to as Activities),
2. barriers to providing family-centered care (Barriers), and
3. nurses' satisfaction with the extent to which the needs of patients' families had been met (Meeting Family Needs).

Development of the first 2 questionnaires has been described previously.[22] All 3 instruments, developed through review of the literature[23-25] in combination with ideas provided by focus groups that included 21 critical care nurses, are available online at http://depts.washington.edu/eolcare. Nurses responded to 2 other family-care items: their perceptions of the quality of their own communication with the family and the physician's communication with the family (Nurse Communication, Physician Communication). In addition to the family-care measures, nurses answered descriptive questions about themselves, including information about their training, experience, and demographics.

Patient Measures. We obtained patients' dates of birth, ICU admission, and death from ICU logs and computed age and length of ICU stay on the basis of this information. For a subset of the patients, we abstracted sex and racial-ethnic identification from medical records.

Analyses

Identification of Domain Structure and Development of Summary Scores for Each Questionnaire. We used principal components analysis to identify the domains represented by each questionnaire. Details of the principal components analysis and scoring procedures appear in the Appendix. For each analysis, we computed a goodness-of-fit index, with values greater than 0.95 indicating a good fit and values greater than 0.90 indicating an acceptable fit.[26]

When the initial principal components analysis suggested multiple domains for a questionnaire, we ran an additional analysis that forced a single-component solution. This step enabled us to assess the fit of a total score to provide an alternative method for evaluating ICU processes and outcomes.

Preliminary Validation of Domain Scores. Because no validated nurse measures of the quality of family care existed at the time of this study, we could not complete traditional validation analyses for our new measures. However, as an initial step toward validation, we used path analyses to test a conceptual model for evaluating family-centered ICU care. We hypothesized that our processes-of-care measures (ie, the single-item Nurse Communication and Physician Communication ratings along with summary scores computed from the Barriers and Activities questionnaires) would be significantly associated with our primary outcome (a summary score computed from the Meeting Family Needs questionnaire). We used the path models to test the direct effects of the Nurse Communication and Physician Communication ratings on the Meeting Family Needs score and to test both the direct effects of Barriers and Activities on Meeting Family Needs and their

indirect effects through Nurse Communication. Details of the regression procedures used to test this model appear in the Appendix.

In addition, we tested the independent effects of patients' characteristics and nurses' characteristics on Meeting Family Needs. We adjusted each of these associations for the effects of the significant processes-of-care predictors. To correct for multiple tests, we adopted a conservative probability level ($P<.01$) as evidence of significance in all regression models, both those for testing processes of care and those for testing patients' and nurses' characteristics.

Results

During the study period, 354 patients died in the hospital's ICUs; 255 of these patients were in an ICU for at least 6 hours before they died or experienced brain death. Nurses completed 331 (65.0%) of 509 questionnaires distributed, assessing the care provided to 218 (85.5%) of the 255 eligible patients. A total of 180 nurses completed questionnaires; multiple nurses provided data for 112 (51.4%) of the patients: 2 nurses for 111 patients and 3 nurses for 1 patient.

After determining the most complete nurse's report for each patient, we retained data from 141 nurses; 88 nurses (62.4%) had completed 1 questionnaire, 36 (25.5%) had completed 2 questionnaires, 10 (7.1%) had completed 3, and 7 (5.0%) had completed 4. Median elapsed time between a patient's death and nurses' completion of the 255 selected questionnaires was 13 days; mean elapsed time was 21.4 days. Table 1 summarizes characteristics of the nurses and patients included in the analysis sample.

Questionnaire Domain Structure and Summary Scores

Activities. We had complete data for the 17 dichotomous Activities items for 212 nurse-patient pairs. We scored each item 1 if the nurse respondent reported that any nurse had provided the service and 0 if no nurse had provided the service. We extracted 2 components (Table 2), which explained 72.5% of the item variance; General Communication and Support explained 50.8% and Cultural Needs Communication and Support explained 21.7%. The goodness-of-fit index for the 2-component solution was 0.99. Although 2 items (talking with the family about their feelings and addressing the family's spiritual and religious needs) had loadings on the 2 components that differed by less than 0.20, we assigned each item to the dimension on which it had the higher loading.

All 218 nurse-patient records had adequate data for computing the 2 Activities domain scores; each score represented a count of the endorsed items. The Cron-

Table 1 Characteristics of the analysis sample

Characteristic	%	Valid n
Nurses (N = 141)		
Female	82.1	140
Nonwhite or mixed race	11.8	136
Nursing education		139
Diploma	7.2	
Associate degree	20.9	
Bachelor's degree	69.8	
Master's degree	2.2	
	Mean	**SD**
Age (n = 138, median = 39)	39.2	8.3
Years in nursing (n = 140, median = 10)	12.2	8.3
Years in critical care nursing (n = 140, median = 6)	8.9	7.5
Patients (N = 218)	**%**	**Valid n**
Female	36.5	126
Nonwhite or mixed race	15.1	119
	Mean	**SD**
Age (n = 218, median = 60)	60.8	18.0
Days in intensive care unit (n = 218, median = 4)	7.5	9.4

bach α for General Communication and Support was .89, with score range 0 to 15, median 12, mean 11.3, and SD 3.8. The Cronbach α for Cultural Needs Communication and Support was .81, with score range 0 to 2, median 0, mean 0.6, and SD 0.8. On 146 (67.0%) of the records, nurses reported completing at least 12 of the 15 General Communication and Support activities with families; on 143 (65.6%) of the records, they reported no activities related to Cultural Needs Communication and Support.

An additional principal components analysis, forcing a single-component solution, produced loadings between 0.952 (explaining the patient's medical equipment and therapies) and 0.449 (taking actions to address the cultural needs of the patient's family), explained 62.3% of the item variance, and provided a goodness-of-fit index of 0.98. The total Activities score represented a count of the total number of activities undertaken with families (0-17), with median 13, mean 11.9, SD 4.1, and Cronbach α .88.

Barriers. We asked nurses to indicate which of 14 specified barriers they encountered in working with patients' families. Three items received too few endorsements to make the items appropriate for inclusion in

Table 2 Activities, barriers, and meeting family needs questionnaires, principal components analyses, varimax-rotated loadings

Questionnaire and domain(s)	Loadings	
	Component 1	Component 2
Activities questionnaire: 2-component solution		
General communication and support		
Assure family of patient's comfort	0.921	0.234
Explain patient's medical equipment/therapies	0.854	0.421
Support family's decisions	0.851	0.372
Talk about patient's illness/treatment	0.839	0.440
Discuss patient's wishes	0.822	0.132
Encourage talking to/touching patient	0.788	0.481
Talk about patient's values	0.767	0.217
Reminisce about patient	0.744	0.319
Talk with patient's family about spiritual/religious needs	0.743	0.424
Talk about changes in plan of care	0.720	-0.030
Talk with patient's family about family's feelings	0.713	0.605
Locate private place for family communication	0.663	0.247
Talk with patient's family about intrafamily disagreements	0.647	-0.114
Tell family what to expect during conferences	0.637	0.418
Address family's spiritual/religious needs	0.559	0.475
Cultural needs communication and support		
Talk with patient's family about cultural needs	0.171	0.931
Address family's cultural needs	0.019	0.919
Barriers questionnaire: 2-component solution		
Patient/family barriers		
Family had unrealistic expectations of medical treatment	0.863	-0.191
Family was angry	0.828	0.330
Personal difficulty with specific family	0.715	0.511
Patient too sick to allow time for nurse interaction with the family	0.704	-0.043
Language difficulties	0.555	0.309
Family did not visit or call	0.438	0.128
System/team barriers		
Lack of communication between attending physician and nursing staff	-0.088	0.913
Conflict with physician(s)	0.175	0.772
Outside scope of nursing practice	0.072	0.689
Lack of private place for communication	0.300	0.569
Meeting family needs questionnaire: 1-component solution		
Meeting family needs		
Nurse met family's emotional needs	0.916	NA
Nurse met family's physical needs	0.888	NA
Healthcare team met family's needs	0.842	NA

Abbreviation: NA, not applicable.

Table 3 Domain-specific processes of care as predictors of meeting family needs (181 patients clustered under 121 nurses)*

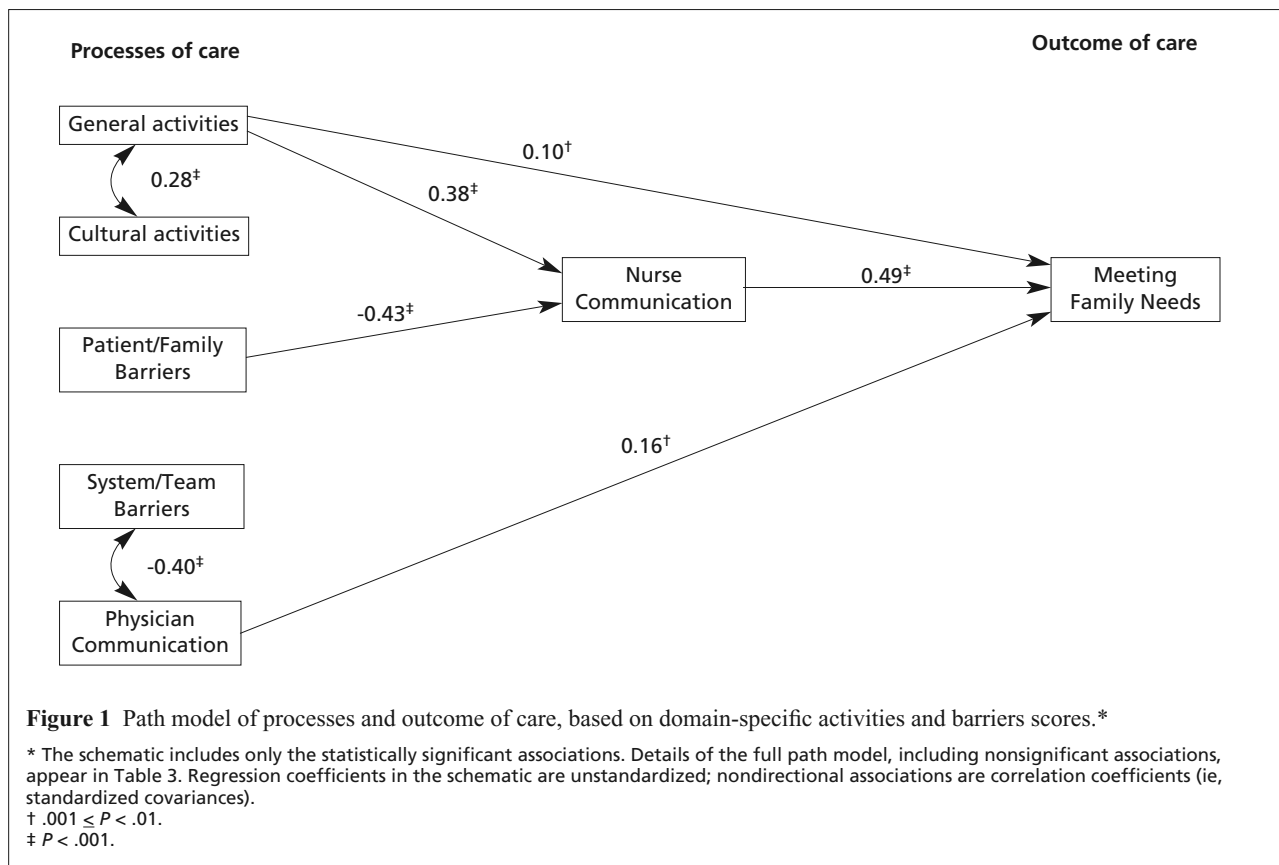| Process of care	Unstandardized estimate (99% CI)	Standardized estimate	*P*
Predictors of nurse communication			
General communication and support activities (0-15)	0.38 (0.20, 0.56)	0.59	<.001
Cultural needs communication and support activities (0-2)	0.13 (-0.19, 0.45)	0.04	.30
Patient/family barriers (0-6)	-0.43 (-0.66, -0.22)	-0.22	<.001
System/team barriers (0-3)	-0.19 (-0.66, -0.20)	-0.06	.33
Predictors of meeting family needs			
Nurse communication rating (0-10)	0.49 (0.35, 0.64)	0.62	<.001
Physician communication rating (0-10)	0.16 (0.01, 0.30)	0.16	.005
General communication and support activities (0-15)	0.10 (0.01, 0.18)	0.19	.003
Cultural needs communication and support activities (0-2)	-0.01 (-0.18, 0.16)	-0.004	.88
Patient/family barriers (0-6)	-0.14 (-0.35, 0.07)	-0.09	.08
System/team barriers (0-3)	-0.11 (-0.40, 0.18)	-0.04	.32
Covariances/correlations			
General activities with cultural activities	0.85 (0.39, 1.31)	0.28	<.001
General activities with patient/family barriers	-0.53 (-1.30, 0.23)	-0.12	.07
General activities with system/team barriers	0.16 (-0.36, 0.69)	0.06	.42
General activities with physician communication	1.73 (-0.40, 3.87)	0.23	.04
Cultural activities with patient/family barriers	0.12 (-0.09, 0.33)	0.12	.13
Cultural activities with system/team barriers	0.03 (-0.08, 0.13)	0.05	.48
Cultural activities with physician communication	0.16 (-0.12, 0.43)	0.10	.14
Patient/family barriers with system/team barriers	0.22 (-0.03, 0.46)	0.24	.02
Patient/family barriers with physician communication	-0.26 (-0.71, 0.18)	-0.11	.13
System/team barriers with physician communication	-0.56 (-0.95, -0.17)	-0.40	<.001
Physician communication with nurse communication	0.70 (-0.11, 1.51)	0.15	.03

* Path model schematic, showing only the significant associations, is presented in Figure 1.

principal components analyses: lack of support from nurse colleagues (4 endorsements), limitations imposed by visitation policy (2 endorsements), and physicians discouraging communication on certain topics (6 endorsements). An initial principal components analysis of the remaining 11 items yielded 2 components; 1 item (not enough nursing staff/heavy patient load) had low loadings on both components. Analysis of the 10 remaining items, for 201 nurse-patient pairs, produced 2 components (Table 2), which explained 58.2% of the item variability (Patient/Family Barriers, 30.7%; System/Team Barriers, 27.5%), and a goodness-of-fit index of 0.94.

Both domain scores were counts of endorsed barriers for 209 nurse-patient pairs. The Cronbach α values for the barriers scales were low: .60 for Patient/Family Barriers and .54 for System/Team Barriers. In general,

nurses reported few barriers of either type in working with patients' families. Almost half reported no barriers related to patient/family characteristics, and more than three quarters reported no system/team barriers. Values for Patient/Family Barriers scores were from 0 to 6, median 1, mean 1.0, and SD 1.2. Values for System/Team Barriers scores were from 0 to 3, median 0, mean 0.3, and SD 0.7.

A principal components analysis of the 10 Barriers items forcing a single-component solution generated loadings between 0.876 (personal difficulty with a specific family) and 0.417 (family did not visit or call), explained 38.7% of the item variance, and produced a goodness-of-fit index of 0.86. Despite the less than acceptable fit, we computed a total Barriers score (0-10) for use as an alternative measure in testing a simplified model for evaluating ICU family-centered care. The

Figure 1 Path model of processes and outcome of care, based on domain-specific activities and barriers scores.*

* The schematic includes only the statistically significant associations. Details of the full path model, including nonsignificant associations, appear in Table 3. Regression coefficients in the schematic are unstandardized; nondirectional associations are correlation coefficients (ie, standardized covariances).
† .001 ≤ *P* < .01.
‡ *P* < .001.

total score had a Cronbach α of .63, median 1, mean 1.3, and SD 1.6. More than 40% of the nurse-patient records indicated no barriers to family-centered care.

Meeting Family Needs. Three items measured nurses' satisfaction with the extent to which the health-care team met the needs of the families of ICU patients. Ratings on each item could range from 0 (not satisfied at all) to 10 (very satisfied). Principal components analysis of 203 cases with complete data yielded a single domain with a goodness-of-fit index of 0.99, which accounted for 77.9% of the variance in the 3 items.

We computed a Meeting Family Needs score for 206 nurse-patient pairs, as the mean of the nurses' valid responses. The Cronbach α was .79, with scale scores ranging from 0 to 10, median 8, mean 7.8, and SD 1.8.

Preliminary Validation of Domain Scores

Association of the Meeting Family Needs Score With Processes-of-Care Predictors. Table 3 provides details of a path model based on domain-specific activities and barriers scores. Figure 1 shows the significant associations from this model in graphic form. The model suggested that increases in the number of activities, decreases in the number of barriers, and improved communication with patients' families all had some

association with improved quality of care. Ratings of both Nurse Communication and Physician Communication with families were significantly associated with Meeting Family Needs. As the quality of communication increased, satisfaction that the needs of patients' families had been met also increased.

Increases in the number of General Communication and Support activities had a significant direct effect on Meeting Family Needs and an additional indirect effect through improved Nurse Communication, whereas the number of Cultural Communication and Support activities was linked to the outcome only through its correlation with General Communication and Support. The number of Patient/Family Barriers had an indirect negative effect on quality of care through nurses' ratings of their own communication with patients' families; increased Patient/Family Barriers reduced Nurse Communication quality and hence the Meeting Family Needs score. The number of System/Team Barriers was linked to the outcome through its correlation with the nurses' ratings of Physician Communication.

Table 4 and Figure 2 summarize a similar path model based on the Total Activities and Total Barriers scores. As in the previous model, the Nurse Communication and Physician Communication ratings both

Table 4 Total processes of care as predictors of meeting family needs (181 patients clustered under 121 nurses)*

Process of care	Unstandardized estimate (99% CI)	Standardized estimate	P
Predictors of nurse communication			
Total activities (0-17)	0.35 (0.20, 0.56)	0.60	<.001
Total barriers (0-9)	-0.38 (-0.66, -0.22)	-0.25	<.001
Predictors of meeting family needs			
Nurse communication rating (0-10)	0.50 (0.35, 0.64)	0.63	<.001
Physician communication rating (0-10)	0.16 (0.01, 0.30)	0.16	.005
Total activities (0-17)	0.08 (0.01, 0.18)	0.18	.007
Total barriers (0-6)	-0.14 (-0.35, 0.07)	-0.12	.008
Covariance/correlations			
Total activities with total barriers	-0.20 (-1.30, 0.23)	-0.03	.66
Total activities with physician communication	1.97 (-0.40, 3.87)	0.24	.05
Total barriers with physician communication	-0.83 (-0.71, 0.18)	-0.27	.002
Physician communication with nurse communication	0.59 (-0.11, 1.51)	0.12	.10

* Path model schematic showing only the significant associations is presented in Figure 2.

had significant associations with the Meeting Family Needs score. Total Activities had both a significant direct effect on Meeting Family Needs and an additional indirect effect through Nurse Communication. Total Barriers had a significant direct negative effect on Meeting Family Needs and additional indirect effects through the Nurse and Physician Communication ratings.

Association of the Meeting Family Needs Score With Characteristics of Patients and Nurses. Table 5 summarizes the independent associations of the characteristics of patients and nurses with the Meeting Family Needs score after adjustment for Total Activities, Total Barriers, Nurse Communication, and Physician Communication. None of the characteristics had a statistically significant independent association with Meeting Family Needs.

Discussion

Few instruments for measuring the processes and quality of care provided to families of dying patients are widely available. To measure the quality of ICU-delivered care, we developed a series of short, easily completed questionnaires to determine nurses' perspectives of different aspects of care provided to the families of critically ill patients. These questionnaires included reports of nursing activities with patients' families, nurse-identified barriers to providing high-quality family care, and nurses' perceptions of the degree to which they and other members of the healthcare team were able to meet the needs of patients' families. In this
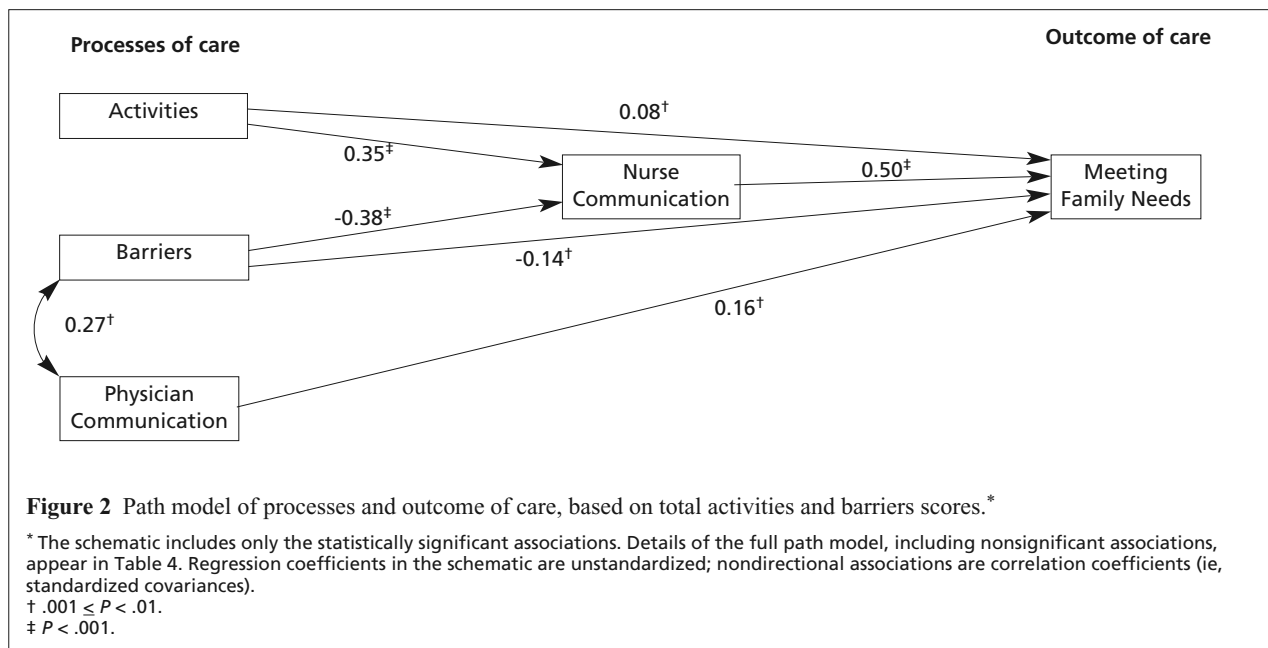
article, we report the results of our evaluation of the questionnaires. We examined the measurement characteristics of the 3 questionnaires and looked at the associations between (1) family care processes, patients' characteristics, and nurses' characteristics and (2) nurses' perceptions of the quality of family care.

Our primary outcome variable summarized a unidimensional set of 3 items measuring nurses' perceptions of the extent to which each patient's healthcare team had met the needs of the patient's family. Tests of the association of this measure with other elements of family care suggested that the set of summary measures from our questionnaires provide a consistent, valid picture of nurses' perspectives of family-centered ICU care and may be useful in evaluating care and designing interventions for quality improvement.

Nurses' reports of the activities pursued with patients' families and the barriers encountered in doing so were significant predictors of the nurses' ratings of the quality of their own communication with patients' families. Moreover, the nurses' ratings of the quality of their own and physicians' communication with patients' families, along with the number of activities and barriers, were significantly associated with the nurses' perceptions of the extent to which the healthcare team had met the needs of the patients' families.

Analysis of a questionnaire used to enumerate activities nurses performed in caring for patients' family members suggested that activities fall into 2 domains: one that addresses specific cultural needs of families

Figure 2 Path model of processes and outcome of care, based on total activities and barriers scores.*

* The schematic includes only the statistically significant associations. Details of the full path model, including nonsignificant associations, appear in Table 4. Regression coefficients in the schematic are unstandardized; nondirectional associations are correlation coefficients (ie, standardized covariances).
† .001 ≤ P < .01.
‡ P < .001.

and one that accounts for all other communication and support activities. Most nurses in this sample reported no inquiries or support specifically targeted to the cultural needs of patients' families. The infrequency of reports of culture-related services indicates an area with potential for considerable improvement in the ICUs we studied. Should interventions be successful in increasing this area of service, an important step will be evaluating whether culture-related activities join the remainder of the activity items in forming a unidimensional domain, or, if they do not, whether culture-related activities remain a distinct subset of activity but have a stronger association with nurses' ratings of the quality of communication or family care. The association of the cultural domain–specific summary score was not a significant predictor of either the quality of nursing communication or of meeting the needs of patients' families in this sample.

> *Few instruments are available that measure quality of care provided to dying patients' families.*

In contrast to the findings for culture-related activities, most nurses reported engaging in most of the other specified activities with patients' families, and the high Cronbach α level for the 15 general commu-

nication and support items reflected relatively high intercorrelations among the items. When members of the nursing staff carried out one of the general support activities with patients' families, the nurses were likely to perform a multitude of other family-related activities as well. Both the number of general communication and support activities and the total number of activities undertaken with patients' families were significantly predictive of nurses' ratings of the quality of the nurses' communication with the families and of the nurses' perception that the families' needs had been met. Assessment and improvement of these activities may be an important target for improving family-centered care in the ICU.

As with nursing activities, barriers to working with patients' families fell into 2 distinct domains: barriers related to characteristics of the patient and the patient's family and barriers related to the characteristics of the system or healthcare team (including institutional or system features and interdisciplinary communication and collaboration). The nurses in the sample reported relatively few barriers of either sort, and individual barriers combined in less consistent ways for different patients than did nursing activities. As a result, the internal consistency of the summary scores, as reflected in the Cronbach α coefficients, was low. Even so, the reported number of patient and family barriers was a significant negative predictor of nurses' ratings of the quality of the nurses' communication with patients' families, and the total barriers score had both a direct effect on meeting the needs of patients' families and an

Table 5 Independent associations of patient and nurse characteristics with meeting family needs score[*]

Characteristic	No. of patients	No. of nurses	Unstandardized estimate (99% CI)	P
Patient				
Female	108	82	0.08 (-0.43, 0.58)	.70
Racial/ethnic minority	102	79	-0.09 (-0.88, 0.69)	.76
Age	180	121	0.002 (-0.01, 0.01)	.60
Days in intensive care unit	180	121	0.002 (-0.02, 0.02)	.76
Nurse				
Female	179	120	-0.01 (-0.45, 0.44)	.96
Racial/ethnic minority	177	118	-0.28 (-0.94, 0.38)	.28
Age	178	119	0.01 (-0.01, 0.03)	.24
Years in nursing	179	120	0.01 (-0.02, 0.03)	.51
Years in intensive care nursing	179	120	0.01 (-0.02, 0.03)	.48
Nursing education (0 = certificate to 4 = master's degree)	178	119	-0.08 (-0.34, 0.17)	.39

[*] Adjusted for Total Activities, Total Barriers, Nurse Communication, and Physician Communication.

indirect effect through nurse communication. System and team barriers, which included items related to nurse-physician dynamics, had a significant correlation with nurses' ratings of the quality of physicians' communication with patients' families, which was significantly associated with meeting the families' needs. These findings suggest that despite the relatively infrequent occurrence of barriers to care, a focus on managing barriers might improve the quality of communication with patients' families and enhance family-centered care.

None of the characteristics of patients and nurses had a significant independent association with meeting the needs of patients' families. This finding suggests that our outcome measure may be valid for a wide range of ICU nurses and patients.

Limitations of the Study

This study has several limitations. First, the 3 questionnaires evolved during a fairly brief period of development and evaluation. Although the questionnaires include items that our nursing focus groups and other researchers considered important in evaluating quality of care, the primary advantages of the questionnaires are brevity and ease of use rather than comprehensiveness.

In particular, the Meeting Family Needs questionnaire would most likely benefit from the addition of items that separately evaluate the contributions of various members of the healthcare team to meeting the physical and emotional needs of patients' families.[24] The battery of nursing measures would also benefit from addition of communication ratings for other members of the

healthcare team, allowing the possibility for development of communication-specific composite measures.

Second, to test these instruments, we used data gathered during a 7-month period from nurses employed in a single hospital. Testing in other institutions and geographic areas and during longer time periods will be necessary to evaluate the generalizability of our findings.

Furthermore, even within the limited population we studied, only 65% of the distributed questionnaires were returned. Studies in several research disciplines have shown significant differences between respondents and nonrespondents (or those slow to respond) in variables such as background characteristics,[27-30] observer ratings,[31] and attitudinal or behavioral outcomes.[29,30,32,33] Characteristics associated with high response rates also tend to be associated with more positive outcomes. In addition, investigators with access to information about behavioral outcomes for nonrespondents have discovered more positive behavioral outcomes for respondents than for nonrespondents. These findings may suggest that compared with ICU nurses who did not respond, the nurses who provided our data embraced a somewhat optimistic view of ICU processes and outcomes. However, researchers[28,30,34,35] also have found that when findings based on respondents are compared with findings based on a combination of respondents and nonrespondents, effects of nonresponse on study findings are often negligible.

Third, almost 18% of the questionnaires had completion dates more than 1 month after patients' deaths. Concerns about the accuracy of late returns have some

basis. However, the absence of extrinsic rewards for returning questionnaires and the lack of an extended series of reminders to nurses make it likely that nurses who completed the questionnaires considerably after patients' deaths believed they were providing accurate and useful data.

Finally, although we found no association between meeting the needs of patients' families and patients' ages, our sample included only 2 patients less than 18 years old. Investigation of this association in samples with greater representation of children will be important for learning whether the needs of the families of children present unique challenges for family-centered care.

> *The instruments evaluated here offer promise in quality-of-care assessments.*

Conclusion

As attention to family-centered care grows and attempts to improve quality of care are made, evaluating healthcare services from various perspectives becomes increasingly important. Our questionnaires are another step in a line of research that has indicated the importance of nurses in providing critical care for patients and patients' families.[12-14] Nurses' opportunity for extended interaction with the members of patients' families and the function of nurses as a liaison between other medical providers and patients' families give nurses a unique, and often exacting, point of view in evaluating the care provided.

Because of the shortage of questionnaires available for assessing family-centered care, the brevity and ease of administration of the ones we used, and the apparent validity of our questionnaires for tapping the perspectives of critical care nurses, these instruments may be useful to others in quality-of-care assessments. Studies in which the instruments are used with other samples of critical care nurses will assist in evaluating the usefulness of the questionnaires for measuring and improving the quality of family-centered care in the ICU.

Appendix

Principal Components Analyses

We conducted principal components analyses of 2 questionnaires, Activities and Barriers, that had dichotomous (yes/no) responses. For these, we based the analyses on tetrachoric correlations. The remaining questionnaire, Meeting Family Needs, had ordinal response options ranging from 0 to 10. For this analysis, we based principal components analysis on polychoric correla-

tions.[36,37] To determine the appropriate number of components to extract in each analysis, we used a parallel analysis technique.[38]

Computation of Domain Scores

Summary scores computed for the Activities and Barriers domains were counts of the number of items endorsed. Scores for the Meeting Family Needs domain were the mean value of the component responses. When the principal components analysis yielded more than a single domain, we assigned each item to the domain on which it had the higher loading, ignoring the criterion for discriminant validity.

Regression Analyses Providing Preliminary Validation of Domain and Total Scores

We explored 2 path models as preliminary validation of composite measures. Because some nurses in the sample completed questionnaires for multiple patients, we used random effects modeling, with patients clustered under nurses. Mplus software[39] was used to generate parameter estimates with SEs corrected for nonnormality and nonindependence of observations.

To test for associations between characteristics of patients and nurses and the Meeting Family Needs score, we used hierarchical linear modeling software,[40] with patients clustered under nurses to control for lack of independence. For each demographic predictor of interest, we built a 5-predictor regression model that included the predictor of interest and 4 adjustment variables: Total Activities, Total Barriers, Nurse Communication, and Physician Communication. For models including at least 100 nurses, we used Huber-corrected SEs to compute P values and CIs. To test the effects of patients' sex and race, which entailed a smaller sample, we used model-based SEs.[40]

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