Reliability and Validity of the Pediatric Palliative Care Questionnaire for Measuring Self-Efficacy, Knowledge, and Adequacy of Prior Medical Education among Pediatric Fellows

Katharine E. Brock, MD,^{1,2} Harvey J. Cohen, MD, PhD,¹ Rita A. Popat,³ and Louis P. Halamek, MD^{1,4,5}

Abstract

Background: Interventions to improve pediatric trainee education in palliative care have been limited by a lack of reliable and valid tools for measuring effectiveness.

Objective: We developed a questionnaire to measure pediatric fellows' self-efficacy (comfort), knowledge, and perceived adequacy of prior medical education. We measured the questionnaire's reliability and validity.

Methods: The questionnaire contains questions regarding self-efficacy (23), knowledge (10), fellow's perceived adequacy of prior medical education (6), and demographics. The survey was developed with palliative care experts, and sent to fellows in U.S. pediatric cardiology, critical care, hematology/ oncology, and neonatal-perinatal medicine programs. Measures of reliability, internal consistency, and validity were calculated.

Results: One hundred forty-seven fellows completed the survey at test and retest. The self-efficacy and medical education questionnaires showed high internal consistency of 0.95 and 0.84. The test-retest reliability for the Self-Efficacy Summary Score, measured by intraclass correlation coefficient (ICC) and weighted kappa, was 0.78 (item range 0.44–0.81) and 0.61 (item range 0.36–0.70), respectively. For the Adequacy of Medical Education Summary Score, ICC was 0.85 (item range 0.6–0.78) and weighted kappa was 0.63 (item range 0.47–0.62). Validity coefficients for these two questionnaires were 0.88 and 0.92. Fellows answered a mean of 8.8/10 knowledge questions correctly; percentage agreement ranged from 65% to 99%.

Conclusions: This questionnaire is capable of assessing self-efficacy and fellow-perceived adequacy of their prior palliative care training. We recommend use of this tool for fellowship programs seeking to evaluate fellow education in palliative care, or for research studies assessing the effectiveness of a palliative care educational intervention.

Introduction

OVER 45,000 CHILDREN DIE IN THE UNITED STATES each year.¹ Many of these children have complex, chronic, and life-limiting illnesses. Their families face many difficult decisions about medical interventions, resuscitation preferences, and end-of-life choices. Supporting and guiding these families requires skilled physicians with training in the areas of palliative medicine and symptom management.

In 2000, the American Academy of Pediatrics recommended “all general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to

children.” In 2014, the Institute of Medicine issued a report, “Dying in America—Improving Quality and Honoring Individual Preferences Near the End of Life,” of which two chapters are dedicated to clinician-patient communication and professional education and development.

Despite these recommendations, pediatricians and pediatric specialists lack training in palliative care and difficult conversations,^{2–5} lack the skills required to care for these patients,⁶ and in comparison to internal medicine trainees, care for fewer patients who die during their training.^{4,7} Surveys of pediatric residents have found “minimal training, experience, knowledge, competence, and comfort in virtually all areas of palliative care for children.”^{6,8}

¹Department of Pediatrics, ²Division of Hematology/Oncology, ³Department of Health Research and Policy, Division of Epidemiology, School of Medicine, ⁴Division of Neonatal and Developmental Medicine, ⁵Center for Advanced Pediatric and Perinatal Education, Stanford University, Stanford, California.

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While the majority of trainees and program directors feel that more palliative care education is desired and needed, most fellowship programs still lack formalized palliative care education.^{9,10} Prior pediatric palliative care education studies have had several methodological challenges. They have used separate measurement tools, making national comparisons difficult; have had little validity or reliability data, and have not been externally generalizable, as they were designed around an individual institution's intervention.

Therefore, our goal was to design a questionnaire that could (1) be used by pediatric fellowship programs for needs assessments to determine palliative care educational gaps and (2) be used over time for assessing improvement, for example, in pre-post research studies, simulation studies, or randomized trials. The two objectives of this study are (1) to assess reliability and internal consistency and (2) to establish validity of the subscales measuring self-efficacy, knowledge, and prior education in palliative care and symptom management.

Methods

We conducted a confidential and anonymous survey with first-, second-, and third-year fellows in pediatric cardiology, pediatric critical care, pediatric hematology/ oncology, and neonatal-perinatal medicine. This consisted of three phases: (1) development of the Pediatric Palliative Care Questionnaire (PPCQ), (2) determination of the reliability of the questionnaire, and (3) assessment of the validity of the questionnaire. The Stanford University institutional review board approved the study. Consent to participate was explained at the beginning of the survey, and was indicated by questionnaire completion.

Pediatric Palliative Care Questionnaire development

In order to assess what tools are currently used for pediatric palliative care research or medical education research within palliative care, we performed a literature search on pediatric palliative care, palliative care simulation, communication tool, validity, and reliability through PubMed, Scopus, and MedEdPORTAL. Several communication tools are used for medical student education,¹¹ adult palliative care,¹² interdisciplinary education,¹³ and knowledge of adult pain and palliative concepts,^{14–16} but no standard tool with reliability and validity statistics could be found for postgraduate education in pediatric palliative care.

With the goal of creating a generalizable survey, we adapted previously used palliative care surveys^{12,17–19} into one provisional survey which consisted of:

- 23 questions concerning comfort with palliative care topics (self-efficacy), such as conducting a family meeting and controlling symptoms when a patient is dying
- 10 knowledge questions on pediatric palliative care, communication, and symptom management
- 8 questions about the adequacy of prior medical education in pediatric palliative care and symptom management
- A demographic questionnaire to ascertain the number of hours of prior education, types of education received, and number of pertinent patient/ family encounters

A panel of three physicians and one psychologist with expertise in palliative care, one physician/simulation expert, and two medical education scholars reviewed and critiqued

format, survey domains, and individual questions. Format and questions were revised and a final consensus on the PPCQ was reached (available in supplementary material). (See online supplementary materials at www.liebertpub.com/jpm and at www.liebertonline.com.)

Reliability

Reliability is the overall consistency or reproducibility of a measure.²⁰ Reliable instruments minimize random errors in measurement, thereby improving the power of a study for a given sample size. We tested the initial questionnaire on seven third-year pediatric fellows at two academic institutions. Feedback was obtained, questions were revised, and five questions were omitted due to redundancy (three) or no variability in fellow responses (two), leaving 23 self-efficacy questions, 10 knowledge questions, 6 questions about the fellow's perceived adequacy of prior medical education, and demographic questions.

We then identified U.S. program coordinators for Pediatric Cardiology ($n=57$), Pediatric Critical Care ($n=61$), Pediatric Hematology/Oncology ($n=68$), and Neonatal-Perinatal Medicine ($n=95$) using the Fellowship and Residency Electronic Interactive Database (FREIDA), an online database of accredited graduate medical education programs in the United States (freida.ama-assn.org). We excluded programs without current fellows, and two programs where the fellows were part of a pre-/post-intervention study (Stanford University and the University of Colorado).

By e-mail, we asked coordinators to send the PPCQ to the first-, second-, and third-year fellows in their respective programs. Fourth-year fellows and fellows in other subspecialty disciplines were excluded. We sent a reminder e-mail two weeks later. It is unknown how many fellows received the survey from their coordinators, but the maximum possible denominator is 2027 (see Fig. 1). Fellows who completed the PPCQ received a follow-up PPCQ survey five weeks later, with two reminder e-mails for incomplete surveys. No reward was given.

Internal consistency (how closely a set of items in a group are related) was determined by calculating the Cronbach's alpha (α). Internal consistency is unacceptable at $\alpha < 0.5$, poor at $\alpha = 0.50–0.59$, acceptable at $\alpha = 0.60–0.69$, good at $\alpha = 0.70–0.89$, and excellent at $\alpha = 0.9–1.0$.²¹

Test-retest reliability of each item was determined by the percentage agreement (concordance), intraclass correlation coefficients (ICC) (cutoff ICC 0.3), and kappa (κ for binary variables or weighted κ for ordinal variables).²⁰ ICC ranges from 0 (no correlation) to 1 (perfect correlation). Kappa is a measure of inter-rater agreement that ranges from less than 0 (poor agreement) to 1 (perfect agreement). Previously defined thresholds for kappa and ICC are < 0.0 (poor), $0.0–0.2$ (slight), $> 0.2–0.4$ (fair), $> 0.4–0.6$ (moderate), $> 0.6–0.8$ (substantial), and $> 0.8–1.0$ (almost perfect).²²

Study data were collected and managed using REDCap electronic data capture tools hosted at Stanford University.²³ Statistical analysis was performed using statistical software SAS (SAS version 9.4; SAS Institute Inc., Cary, NC).

Validity

Validity, or accuracy, refers to how well a test measures what it is intended to measure.²⁰ Face validity, the extent to

FIG. 1. Participant flowchart. FREIDA, Fellowship and Residency Electronic Interactive Database.

which a test subjectively covers the concept it purports to measure, and content validity, how accurately an instrument measures the various aspects of the construct in question, were established by a panel of palliative care, psychology, simulation, and medical education experts. The questionnaire's ability to discriminate between postgraduate learner levels was assessed using a one-way ANOVA determining if

scores increased by fellowship year. A two-tailed significance level was set at $p < 0.05$.

Since no gold standard exists for trainee education in pediatric palliative care, test-retest reliability (intramethod study) was used to calculate the validity coefficient. Assuming fellows potentially remember their prior responses, the square root of the ICC yields an upper limit of the validity of the measure.²⁴

TABLE 1. DEMOGRAPHIC INFORMATION
ON THE QUESTIONNAIRE RESPONDENTS

	N = 147 (%)
Sex	
Female	91 (61.9%)
Male	56 (38.1%)
Age, years	
Mean (SD)	32.3 (2.6)
Ethnicity	
Hispanic/Latino	12 (8.2%)
Non-Hispanic/Latino	125 (85.6%) ^a
Race	
White	119 (81.0%)
Asian	19 (12.9%)
Mixed	3 (2.0%)
Year of fellowship	
1st year	40 (27.2%)
2nd year	61 (41.5%)
3rd year	46 (31.3%)
Size of fellowship	
1–3 fellows	16 (10.9%)
4–9 fellows	67 (45.6%)
10–15 fellows	47 (32.0%)
16–21 fellows	16 (10.9%)
22+ fellows	1 (0.7%)
Subspecialty	
Critical Care/PICU	40 (27.2%)
Cardiology	13 (8.8%)
Hematology/Oncology	45 (30.6%)
Neonatology	49 (33.3%)
Religion	
Atheist/Agnostic	24 (16.3%)
Catholic/Christian	75 (50.3%)
Jewish	16 (10.9%)
Other ^b	22 (15.0%)
Prior palliative care education	
Medical school	
0–5 hours	81 (55.1%)
6–20 hours	46 (31.3%)
21+ hours	20 (13.6%)
Residency	
0–5 hours	63 (42.9%)
6–20 hours	60 (40.8%)
21+ hours	24 (16.3%)
Fellowship	
0–5 hours	90 (61.2%)
6–20 hours	44 (29.9%)
21+ hours	13 (8.8%)
Prior palliative care discussions	
Observed in fellowship	
0–5	54 (36.7%)
6–20	78 (53.1%)
21+	15 (10.2%)
Led in residency	
0	80 (54.4%)
1–10	60 (40.8%)
11+	7 (4.8%) ^c
Led In fellowship	
0	50 (34.0%)
1–10	79 (53.8%)
11+	18 (12.2%)

(continued)

TABLE 1. (CONTINUED)

	N = 147 (%)
Cared for <i>n</i> patients who died	
As the resident on call/service	
0–5	87 (59.2%)
6–20	58 (39.5%)
21+	2 (1.4%)
As the fellow on call/service	
0–5	55 (37.4%)
6–20	76 (51.7%)
21+	16 (10.9%)
As the primary fellow	
0–5	99 (67.4%)
6–20	44 (29.9%)
21+	4 (2.7%)

PICU, pediatric intensive care unit.

^aNumbers do not total 100% in some categories due to missing data (race, ethnicity, religion) or rounding.^bOther religions include Buddhist, Hindu, and Muslim.^cOf the seven fellows who led 11+ palliative care conversations in residency, five were Internal Medicine/Pediatrics trained, and one pursued significant additional clinical time in pediatric palliative care.

Results

Two hundred seventeen fellows responded, of whom 184 completed the initial questionnaire. For the test-retest investigation, 147 fellows from 57 different institutions completed the second follow-up questionnaire in its entirety (see Fig. 1). These 147 fellows were used for validity and reliability statistics. Table 1 summarizes fellow demographics. Fellows who responded are similar to the pediatric fellow population: mostly white, female, with a mean age 32. The ICC for demographic and prior education experiences ranged from 0.59 to 0.83 (see supplementary material, Table 1). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.)

We found that fellows seldom led palliative care discussions: 95% and 88% had led 0 to 10 palliative care conversations in residency and fellowship, respectively. The majority had cared for five or fewer patients who died during their residency (see Table 1). Most fellows reported receiving palliative education in the form of (1) observing senior physicians or (2) lectures in medical school, residency, or fellowship training, and to a lesser degree, being observed by senior physicians, informal role-playing, workshops, video or online education, and video-recorded simulation (see supplementary material, Table 2). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.)

Reliability

The test-retest reliability, as measured by the ICC for the Self-Efficacy Summary Score was 0.78, with the 23 individual items ranging from 0.44 to 0.81 (see Table 2). Weighted kappa was 0.61, with individual items ranging from 0.36 to 0.70 (see supplementary material, Table 3). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.) For the Adequacy of Medical Education Summary Score, the ICC was 0.85, with the six individual items ranging from 0.60 to 0.78. Weighted kappa was 0.63, with individual items ranging from 0.47 to 0.62

TABLE 2. RELIABILITY AND VALIDITY OF SUMMARY SCORES IN SELF-EFFICACY, ADEQUACY OF PRIOR MEDICAL EDUCATION, AND KNOWLEDGE

	Mean (SD)	Cronbach's alpha	ICC ^a (95% CI)	Weighted kappa (95% CL)	Upper limit of validity coefficient ^b
Self-efficacy , range 23–115	83.5 (16.8)	0.95	0.78 (0.71–0.84)	0.61 (0.54–0.68)	0.88
Adequacy of medical education , range 6–30	19.1 (5.9)	0.84	0.85 (0.80–0.89)	0.63 (0.57–0.69)	0.92
Knowledge , range 0–10	8.8 (1.1)	Not applicable	0.53 (0.40–0.64)	Not applicable	0.73

CI, confidence interval; CL, confidence limit; ICC, intraclass correlation coefficient; SD, standard deviation.

^aKnowledge score ICC should be interpreted cautiously as the percentage of questions answered correctly and percentage agreement very high. Minimal variation between participants depresses ICC values.

^bAssuming correlated errors in responses, upper limit of validity coefficient = $\sqrt{\text{reliability coefficient}}$ where reliability coefficient = ICC.

(see supplementary material, Table 4). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.) Questions regarding barriers to palliative care had lower ICCs (0.39–0.69) and weighted kappa (0.28–0.59) (see supplementary material, Table 5). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.)

Fellows answered most knowledge questions correctly (mean 8.8/10, SD 1.1). Percent agreement ranged from 65% to 99% (see supplementary material, Table 6). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.)

Cronbach's alpha (internal consistency) was 0.95 for the Self-Efficacy questionnaire, and 0.84 for the perceived Adequacy of Medical Education questionnaire (see Table 2). No questions were excluded from either questionnaire, as the Cronbach's alpha was already at a maximum level.

Validity

Face validity and content validity were established by a panel of experts. Scores for self-efficacy increased with fellow level—mean 75.4 (SD 15.6) versus 86.4 (14.7) versus 86.6 (18.4)—as did scores for perceived adequacy of prior medical education in palliative care—mean 16.7 (SD 4.6) versus 19.7 (6.0) versus 20.4 (6.3) for first- versus second- versus third-year fellows, respectively. As expected based on fellowship training structure, a larger difference in self-efficacy and perceived adequacy of prior medical education scores between first- and second-year fellows existed ($p=0.01$ and 0.04 , respectively) compared to the difference between second- and third-year fellows ($p=0.39$ and 0.45). In contrast, there was no difference in knowledge scores by year of fellowship, perhaps limited by a ceiling effect (see supplementary material, Table 7). (See online table at www.liebertpub.com/jpm and at www.liebertonline.com.)

The upper limit of the validity coefficient for the Self-Efficacy questionnaire was 0.88, with individual items ranging from 0.66 to 0.90 (see Table 2 and supplementary material, Table 3), and 0.92 for fellows' perceived Adequacy of Prior Medical Education, with individual items ranging from 0.77 to 0.82 (see Table 2 and supplementary material, Table 4). (See online tables at www.liebertpub.com/jpm and at www.liebertonline.com.)

Discussion

The PPCQ, designed for research studies assessing comfort with palliative care and for fellowship programs assessing

educational gaps, is a reliable and valid instrument for assessing different facets of pediatric palliative care. The PPCQ includes questions on comfort with palliative care and pain management, demographic information including educational history, perception of the adequacy of their training and education in palliative care, their palliative care knowledge, and barriers to palliative care utilization. Based on previously established criteria,^{21,22} the PPCQ has substantial to almost perfect test-retest reliability and good to excellent internal consistency for (1) self-efficacy and (2) perceived adequacy of palliative care education. In addition to face validity, content validity, and the ability to discriminate learner levels, the validity coefficients (0.88 and 0.92) for these two summary measures show that the questionnaire has the potential to accurately estimate the intended parameters.

Depending on the needs of institutions, different components of this PPCQ can be used to assess (1) self-efficacy, (2) perceived adequacy of prior medical education in palliative care, (3) knowledge, (4) barriers to palliative care utilization, and (5) demographic information including education history.

A strength of the study is the relatively large number of fellows who completed both the test and retest components. Compared to other studies, these results are likely an accurate reflection of the comfort level of fellows and the palliative care education that has been provided—in terms of hours and type of education, and the number of patients who die who are cared for by pediatric residents and fellows.^{4,6–10}

There are several limitations to this study. Selection bias could play a part in fellows that completed the survey, and hence we would exercise caution when citing these results to make generalizations about the state of palliative care education in pediatric residencies and fellowships. Many fellows sought out additional palliative care experiences, increasing their comfort; population means are likely even lower than the data presented here.

The ICC normalizes measurement error relative to the heterogeneity of the subjects. Since this was a relatively homogenous group of fellows, between-subjects variability is low. This lowers the ICC values even when the differences between subjects' scores are small.²⁵ When reliability coefficients are lower, a larger sample size could be required for a study to show a statistically significant difference in effect size.²⁵

In addition, test-retest reliability is a valid indicator of reliability if the measures being studied are not changing in the interval between test and retest. Too short of a time frame

between measurements may bias reliability coefficients upward, due to the effect of memory. Here, five weeks between measurements allows for increased educational exposure and true changes in the level of comfort and education the fellow has received (e.g., if a fellow had a one-day palliative care workshop between test and retest). In this latter case, the reliability coefficient should be considered a lower limit.²⁶

We established validity of our survey tool through the use of a multidisciplinary expert panel, and by determining the ability of the questionnaire to discriminate between fellowship levels. Although it is unlikely fellows remember an answer to a question presented over one month prior, we present the conservative estimates of validity assuming that some observations may be correlated. However, the lack of an established gold standard for measuring fellow skills in pediatric palliative care limits the ability to directly assess criterion validity.

While the knowledge questions are from multiple sources with expertise in pediatric palliative care, they are not of an adequate difficulty level to make conclusions about the reliability or validity of the questions. In addition, a ceiling effect contributed to the lack of fellow improvement over training, as the median was 90% correct over all three years. This could mean that fellows' palliative care knowledge is adequate, but that skills are lacking. It could also be necessary to increase the difficulty of questions directed towards subspecialty postgraduate pediatric trainees.

The PPCQ is the first multi-institution survey of a multidisciplinary group of pediatric fellows—including first-, second-, and third-year pediatric cardiology, critical care, hematology/oncology, and neonatal-perinatal medicine fellows from over 57 institutions. We recommend expanding this survey to other groups of pediatric fellows to increase the heterogeneity of responses. This 23-question self-efficacy questionnaire could also be used to assess pediatric resident comfort, although this should be formally tested. We will work to further establish reliability and validity using this questionnaire for fellows undergoing different types of pediatric palliative care educational interventions.

The PPCQ is intended to be used by pediatric fellowship programs performing educational needs assessments, as well as to track fellows over time during the course of a fellowship. This questionnaire can also be used in a research capacity to measure changes pre- and post-intervention. The need and desire for palliative care education and training is growing with the rising number of complex, chronically ill children. It is important that we not only educate fellows in these important topics, but that we have a reliable and valid tool to measure the effectiveness of these curriculum changes and educational interventions. The PPCQ is a psychometrically reliable and valid scale to evaluate the self-efficacy/comfort and adequacy of prior palliative care education in pediatric subspecialty fellows.

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Address correspondence to:

Katharine E. Brock, MD

Division of Pediatric Hematology/ Oncology

Stanford University School of Medicine

1000 Welch Road, Suite 300

Palo Alto, CA 94304-1813

E-mail: kebrock@stanford.edu