Validity of the End-of-Life Professional Caregiver Survey To Assess for Multidisciplinary Educational Needs

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Abstract

The National Consensus Project for Quality Palliative Care (NCP) has put forth eight domains of clinical practice guidelines that address the multidisciplinary nature of palliative and end-of-life (EOL) care. Extant surveys to assess education needs of palliative and EOL workers, however, have been constructed for individual professions. Thus we developed the End-of-life Professional Caregiver Survey (EPCS) as an instrument for assessing the palliative and EOL care-specific educational needs of multidisciplinary professionals.

Introduction

THE NATIONAL CONSENSUS PROJECT FOR Quality Palliative Care (NCP) has put forth eight domains of clinical practice guidelines that address the multidisciplinary nature of palliative and end-of-life (EOL) care.¹ However, a paucity of trained physicians, nurses, and psychosocial workers continues to impede high-quality palliative and EOL care.²⁻⁴ A strategy to increase the multidisciplinary workforce is to provide educational programs in palliative and EOL care for practicing professionals. The most effective of these educational programs have a multidisciplinary approach, thus allowing clinicians to learn what each other member on the team does.⁵ Extant surveys to assess education needs of palliative and EOL workers, however, have been constructed for individual professions. None assesses educational needs across professions.^{6,7} Thus we developed the End-of-life Professional Caregiver Survey (EPCS) as an instrument for assessing the palliative and EOL care-specific educational needs of multidisciplinary professionals. In this article we report on the validity of the EPCS, its factors, and its ability to discriminate among characteristics of a diverse multidisciplinary sample.

Methods

To develop the EPCS, we reviewed the literature on tools that measure educational needs of professionals providing palliative and EOL care. We identified six domains: scientific and clinical knowledge/technical skills; communication/ interpersonal skills with patients, family members, and other clinicians; spiritual and cultural issues; ethical, professional, and legal principles; organizational skills; and attitudes, values, and feelings of health care professionals. We then evaluated existing survey tools,^{6–11} and selected items that matched the six domains, resulting in 40 items. We edited the items to elicit different perceptions from different disciplines, formatted them to a 5-point Likert scale, transferred them to a web-based medium, and pilot-tested them on laptop computers at an annual meeting of the Connecticut Coalition to Improve End-of-Life Care. From the results of the pilot, we emended the items for clarity. Schulman-Green and colleagues¹² have fully described the development and content validity of the original needs survey.

Between September 2008 and May 2009, we conducted a Connecticut-wide cross-sectional web-based survey of nurses, physicians, and social workers with access to the Internet, aged 21 years or older, who could communicate in English, and who practiced in palliative and EOL care. Participants were invited to participate through a link on the website of the Connecticut Coalition to Improve End-of-Life Care, various state professional organizations, and direct advertisement. This study was approved by the Human Subjects Research Review Committee at the Yale University School of Nursing. We included all complete responses from respondents who met the inclusion criteria, regardless of discipline.

Statistical analyses were performed using SPSS version 17 (SPSS Inc., Somers, NY). Sample characteristics and survey items were described using measures of central tendency. Factors were first screened for interrelation; one factor was eliminated due to singularity (<0.30), and another was eliminated due to extreme multicollinearity (>0.90). Ten other items were deemed redundant. A principal common factor analysis (FA) was performed on the remaining 28 items,

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providing for an unpolluted factor structure. Kaiser-Myer-Olkin (KMO) test was used to determine sampling adequacy, and Bartlett's test was used to test the hypothesis that the variables are uncorrelated among the population sampled. Decisions about the number of factors retained for rotation were formed by Eigen values (≥ 1), the scree plot, and the interpretability of the various factor solutions produced. Item loadings on each factor were estimated by Oblimin (default γ value=0; items ≥ 0.30 were retained), as the factors might correlate due to the survey's theoretical construction. All 28 items were retained. We determined reliability statistics using Cronbach's α ; >0.70 was evidence of adequate scale reliability. We used the Pearson product-moment correlation for assessing degree of association among factors. We compared factors' means across demographic variables excluding race using one-way analysis of variance (ANOVA), with post hoc comparisons by the Bonferroni correction. Thereafter, associations of each hypothesized factor as dependent variables with the total score of each factor were determined using multivariate linear regression.

Results

Three hundred sixty-nine participants comprised the sample: 261 nurses, 93 physicians, and 15 social workers. Participants' age, race, highest level of education, and whether they had advance directives and have received EOL education are described in Table 1. The KMO was 0.95, and Bartlett's was 7456.5 (df 378, p = 0.000); hence, the sample was

adequate for FA and the items were uncorrelated in the sample.

For all 28 items of the EPCS for all participants, the mean was 107.7 ± 18.7 , with an α of 0.96. Three factors, with cumulative variance of 60%, emerged (Table 2): 12-item Patient- and Family-Centered Communication (PFCC) (Eigen value 14.0; variance 50.1%; α 0.95; mean 50.4 ± 8.9; inter-item correlations between 0.37 and 0.50); 8-item Cultural and Ethical Values (CEV) (Eigen value 1.7; variance 5.9%; α 0.89; mean 28.9 ± 5.4; inter-item correlations between 0.55 and 0.75); and 8-item Effective Care Delivery (ECD) (Eigen value 1.1; variance 5.9%; α 0.87; mean 28.4±5.6; inter-item correlations between 0.52 and 0.74). Correlations among the three factors and with the overall EPCS ranged from 0.80 to 0.92 (p=0.01). Results of one-way ANOVA revealed the following significant (p < 0.05) relationships: profession with PFCC and CEV; age with PFCC, CEV, and ECD; highest level of education with CEV and ECD; having advance directives with PFCC; and having had EOL education with PFCC (Table 3). Multivariate linear regression showed that having advance directives was significantly associated (p=0.029) with higher mean scores on the PFCC (Sum of Squares 47.3; df 30; Mean Square 1.6; F 1.9; R^2 0.91).

Discussion

The purpose of this study was to examine the validity of the EPCS, determine its factors, and perform discriminant analysis. To do so, we administered it to a sample of 369

TABLE 1. SAMPLE CHARACTERISTICS

	Total	Nurses	Physicians	Social workers	x^2/t
Age	Mean (SD) 44 (13) years	Mean (SD)	Mean (SD)	Mean (SD)	62.1 ^a
	Range 22–90 years	49 (11) years	31 (13) years	47 (11) years	02.1
Total	N=369	N=261 (71%)	N=93 (25%)	N=15 (4%)	
Gender					50.9 ^a
Male	40 (11%)	11 (4%)	29 (31%)	0	
Female	329 (89%)	250 (96%)	64 (69%)	15 (100%)	
Race					
White	342 (93%)	245 (94%)	82 (88%)	15 (100%)	
Black	6 (1.5%)	5 (2%)	1 (1%)	0	
Asian/Pacific Islander	9 (3%)	4 (2%)	5 (6%)	0	
Hispanic	4 (1%)	3 (1%)	1 (1%)	0	
Other/Combination	6 (1.5%)	2 (1%)	4 (4%)	0	
Highest level of education					71.5 ^a
Vocational/Assoc.	50 (14%)	50 (20%)	0	0	
Bachelor's Degree	86 (23%)	84 (32%)	0	2 (13%)	
Master's Degree	94 (25%)	83 (32%)	0	11 (73%)	
Doctoral Degree	104 (28%)	10 (4%)	93 (100%)	1 (7%)	
Other	35 (10%)	34 (12%)	0	1 (7%)	
Have you had basic end-of-life training?					
Yes	228 (62%)	153 (59%)	65 (70%)	10 (67%)	
No	121 (33%)	90 (35%)	26 (28%)	5 (33%)	
Do you personally have advance directives?					
Yes	141 (38%)	121 (46%)	12 (13%)	8 (53%)	
No	213 (58%)	136 (52%)	70 (75%)	7 (47%)	
Don't know	9 (2.5%)	1 (0.5%)	8 (9%)	0	
Blank	6 (1.5%)	3 (1.5%)	3 (3%)	0	

TABLE 2. FACTOR ANALYSIS C	of the EPCS and Mean Scores	OF EACH FACTOR BY PROFESSION
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		Factors		<i>Total</i> (n=369)	Nurses (n=261)	Physicians (n=93)	Social workers (n=15)
Items	PFCC	CEV	ECD	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1. I am comfortable helping families to accept	0.818			3.7 (0.9) ^a	3.8 (0.9)	3.4 (0.8)	3.9 (0.7)
a poor prognosis2. I am able to set goals for care with patients and families.	0.818			3.9 (1.0)	4.0 (0.9)	3.6 (0.8)	4.3 (0.6)
3. I am comfortable talking to patients and families about personal choice and	0.813			4.0 (0.9)	4.1 (0.8)	3.6 (0.9)	4.5 (0.8)
self-determination.4. I am comfortable starting and participating in discussions about code status.	0.802			3.9 (1.0)	4.0 (0.9)	3.6 (0.9)	3.9 (1.2)
5. I can assist family members and others	0.787			3.8 (0.9)	3.8 (0.9)	3.5 (0.7)	4.4 (0.6)
through the grieving process.6. I am able to document the needs and interventions of my patients.	0.776			4.1 (0.8)	4.2 (0.8)	3.7 (0.7)	4.4 (0.5)
7. I am comfortable talking with other health care professionals about the care of dying patients.	0.761			4.1 (0.8)	4.2 (0.8)	3.9 (0.7)	4.6 (0.5)
 8. I am comfortable helping to resolve difficult family conflicts about end-of-life care. 	0.748			3.6 (0.9)	3.7 (0.9)	3.3 (0.9)	4.1 (1.0)
 I can recognize impending death (physiologic changes). 	0.736			4.0 (0.9)	4.2 (0.8)	3.7 (0.8)	3.4 (1.1)
10. I know how to use nondrug therapies in management of patients' symptoms.	0.657			3.7 (0.9)	3.8 (0.9)	3.3 (0.9)	3.3 (0.9)
11. I am able to address patients' and family members' fears of getting addicted to pain	0.600			3.8 (0.9)	3.5 (0.8)	3.5 (0.8)	3.3 (0.9)
medications. 12. I encourage patients and families	0.576			3.9 (0.8)	3.8 (0.8)	3.8 (0.8)	3.6 (0.9)
to complete advance care planning13. I am comfortable dealing with ethical issues related to end-of-life/hospice/		0.563		3.7 (0.9)	3.7 (1.0)	3.4 (0.8)	4.2 (0.8)
palliative care.14. I am able to deal with my feelings related to working with dying patients.		0.575		4.0 (0.8)	4.1 (0.8)	3.7 (0.8)	4.3 (0.5)
15. I am able to be present with dying patients.16. I can address spiritual issues with patients and their families.		0.557 0.848		4.2 (0.8) 3.5 (0.9)	4.3 (0.7) 3.5 (1.0)	3.8 (0.7) 3.5 (0.8)	4.3 (0.6) 3.9 (0.9)
17. I am comfortable dealing with patients' and families' religious and cultural perspectives.		0.842		3.6 (0.9)	3.6 (0.9)	3.6 (0.8)	4.1 (0.5)
 18. I am comfortable providing grief counseling for families. 		0.676		3.3 (1.0)	3.3 (1.0)	3.2 (0.8)	4.1 (0.9)
19. I am comfortable providing grief counseling for staff.		0.653		3.3 (1.0)	3.4 (1.0)	3.1 (0.8)	3.9 (0.9)
20. I am knowledgeable about cultural factors influencing end-of-life care.		0.649		3.3 (0.9)	3.2 (1.0)	3.4 (0.7)	4.1 (0.5)
21. I can recognize when patients are appropriate for referral to hospice.			0.677	3.9 (1.0)	4.0 (1.0)	3.5 (0.9)	4.3 (0.6)
22. I am familiar with palliative care principles and national guidelines.			0.749	3.4 (1.0)	3.5 (1.1)	3.1 (1.0)	3.7 (1.0)
23. I am effective at helping patients and families navigate the health care system.			0.712	3.7 (0.8)	3.8 (0.9)	3.3 (0.7)	4.1 (0.9)
24. I am familiar with the services hospice provides.			0.669	3.8 (1.0)	3.9 (1.0)	3.4 (1.0)	4.6 (0.5)
25. I am effective at helping to maintain continuity across care settings.			0.660	3.7 (0.8)	3.9 (0.8)	3.4 (0.8)	4.1 (0.7)
26. I feel confident addressing requests for assisted suicide.			0.649	2.7 (1.2)	2.7 (1.3)	2.7 (1.0)	2.6 (1.1)
27. I have personal resources to help meet my needs when working with dying			0.590	3.7 (1.0)	3.8 (0.9)	3.2 (0.9)	4.2 (0.8)
patients and families.28. I feel that my workplace provides resources to support staff who care for dying patients.			0.538	3.5 (1.0)	3.6 (1.1)	3.3 (0.7)	3.5 (1.4)

^aHigher scores reflect greater skills, with 5 reflecting the greatest and 1 reflecting the least. EPCS, End-of-life Professional Caregiver Survey; PFCC, Patient- and Family-Centered Communication; CEV, Cultural and Ethical Values; ECD, Effective Care Delivery.

	EPCS Mean (SD)	Factor 1 Patient- and family- centered communication		Factor 2 Cultural and ethical values		Factor 3 Effective care delivery	
		Mean (SD)	F	Mean (SD	F	Mean (SD)	F
Between multidisciplinary professions			1.5 ^a		1.5 ^a		1.5
Nurses	106.0 (18.2)	47.7 (8.2)		29.2 (5.6)		29.1 (5.6)	
Physicians	96.2 (15.4)	49.7 (7.1)		27.5 (4.5)		25.9 (5.1)	
Social workers	111.8 (14.1)	48.5 (6.5)		32.3 (4.2)		30.9 (4.7)	
Age			2.7^{b}		2.1 ^a		2.8 ^b
Gender			0.9		0.5		0.9
Male	104.3 (17.7)	46.3 (8.6)		29.6 (5.3)	0.0	28.4 (5.4)	
Female	103.6 (18.0)	46.5 (8.1)		28.8 (5.4)		28.3 (5.7)	
Highest level of education	× ,	()	1.2	× /	2.4 ^b	× /	1.7^{a}
Vocational/Assoc.	101.1 (17.5)	45.5 (8.4)		28.2 (5.4)		27.7 (5.3)	
Bachelor's Degree	103.8 (16.8)	46.9 (7.2)		28.3 (5.1)		28.4 (5.6)	
Master's Degree	102.3 (17.5)	45.7 (8.1)		28.8 (5.1)		27.8 (5.6)	
Doctoral Degree	110.9 (14.5)	49.2 (6.2)		30.3 (5.0)		31.5 (4.0)	
Advance directives (Yes)			1.5 ^a		1.2		0.9
Yes	111.4 (16.8)	50.2 (7.4)		30.8 (5.4)		30.5 (5.3)	
No	98.0 (17.2)	44.2 (7.8)		27.7 (5.0)		27.1 (5.5)	
Don't know	101.4 (18.1)	44.8 (7.6)		29.3 (5.9)		27.3 (6.0)	
End-of-life training (Yes)			1.5^{a}		0.9		0.5
Yes	104.2 (17.7)	46.5 (8.0)		29.3 (5.3)	• • •	28.4 (5.6)	0.0
No	103.3 (18.6)	46.6 (8.5)		28.3 (5.4)		28.4 (5.7)	

TABLE 3. COMPARISON OF MEAN SCORES OF FACTORS OF SAMPLE CHARACTERISTICS Excluding Race by One-Way ANOVA

 ${}^{a}_{b}p < .05.$ ${}^{b}_{p} < .000.$

Higher mean scores reflect greater values on the factor.

ANOVA, analysis of variance; EPCS, End-of-life Professional Caregiver Survey.

multidisciplinary palliative and EOL care professionals, and we found that the scale as a whole exhibits strong internal reliability. Each of its three factors is distinct and internally reliable. On discriminate analysis, having advance directives predicted better performance on the PFCC factor.

The EPCS covers all eight domains of the national palliative care guidelines¹ and all modules of the core curriculum of the physician-specific¹³ and nurse-specific¹⁴ EOL education curricula. Although the item "I am able to be present with dying patients" could not be found within the physician-specific EOL education curriculum, it is, we feel, important in that it reflects the spiritual and cultural skills of the professional caregiver. In this way, EPCS is able to move essential EOL skills from one specific professional milieu (nursing, in this case) to include them in the multidisciplinary milieu.

The item "I am confident addressing request for assisted suicide" was scored the lowest among all items by all three professional groups. On factor analysis, this item fell among the items dealing with effective care delivery, not with items that addressed ethical values. This suggests that this item is about a concept other than ethics. Assisted suicide is, after all, in some states and countries a legal question. Another possible reason that the item fell among effective care delivery may have to do with how, for those who question the morality of assisted suicide, the establishment of effective palliative care within mainstream health care is a powerful alternative.¹⁵ Moreover, this item's being in the effective care delivery factor may suggest that in part the professional's confidence in

discussing assisted suicide with patients and families depends on the care-delivery environment and resources available in which the professional works.

That no one professional group (nurse, physician, or social worker) predicted performance on any of the factors bodes well for the EPCS as a scale to assess the educational needs of multidisciplinary professionals. Indeed, only participants having advance directives predicted better mean scores on the PFCC factor. This coheres with the recent finding that better clinician-patient communication predicted better patient preparation for the EOL than did advance directives.¹⁶ Perhaps professionals with advance directives themselves feel freer to discuss EOL preparations and hence have more attuned communication skills.

Our convenience sample drawn from professionals knowledgeable about palliative and EOL care in one state limits the generalizability of our study. The mean score of social workers on the EPCS was higher than those of nurses and physicians. Perhaps this is due social workers' training in psychosocial matters. However, their meager numbers in our sample limits our study. We are uncertain why so few social workers responded to the survey. We solicited responses from social workers in the same venues and using the same means and frequency of contact as we did for all other respondents. Some social workers told us they were too busy to respond. Nonetheless, their lack of response highlights the need to find other methods of recruiting them. These limitations notwithstanding, our study is

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strengthened by the sample's inclusion of nurses, physicians, and social workers. Thus it is psychometrically valid for use as a single (non-discipline specific) scale to evaluate the educational needs of professionals from among different disciplines across its three factors that cover the broad palliative care domains and EOL curricula.

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References

- Ferrell B, Connor RS, Cordes A, Dahlin C, Fine P, Hutton N, Leenay M, Lentz J, Person JL, Meier DE, Zuroski K; National Consensus Project for Quality Palliative Care Task Force Members: The national agenda for quality palliative care: The National Consensus Project and the National Quality Forum. J Pain Symptom Manage 2007;33:737–744.
- Lupu D, on behalf of the American Academy of Hospice and Palliative Medicine Workforce Task Force: Estimate of current hospice and palliative medicine physician workforce shortage. J Pain Symptom Manage 2010;40:899–911.
- Kelly K, Thrane S, Virani R, Malloy P, Ferrell B: Expanding palliative care nursing education in California: The ELNEC Geriatric project. Int J Palliat Nurs 2011;17:188–194.
- Altilio T, Gardia G, Otis-Green S: Social work practice in palliative and end-of-life care: A report from the summit. J Soc Work End Life Palliat Care 2007;3:68–86.
- Otis-Green S, Ferrell B, Spolum M, Uman G, Mullan P, Baird RP, Grant M: An overview of the ACE Project-advocating for clinical excellence: transdisciplinary palliative care education. J Cancer Educ 2009;24:120–126.
- City of Hope/Palliative Care Resource Center: Instruments used in End of Life (EOL) care education. 2011. http:// prc.coh.org/res_inst.asp [Last accessed July 6, 2011.]
- 7. Bradley E, Cicchetti DV, Fried TR, Rousseau DM, Johnson-Hurzeler R, Kasl SV, Horwitz SM: Attitudes about care at

the end of life among clinicians: A quick, reliable and valid assessment instrument. J Palliat Care 2000;16:6–14.

- Massachusetts Commission on End-of-Life Care: End-of-Life Care Survey. 200. http://endoflifecommission.org/ download/MA_Commission_survey_2005.pdf [Last accessed July 6, 2011.]
- 9. Teno JM, Clarridge B, Casey V, Welch LC, Wetle T, Sheild R, Mor V: Family perspectives on end-of-life care at the last place of care. JAMA 2004;291:88–93.
- Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J: Validation of toolkit after-death bereaved family member interview. J Pain Symptom Manage 2001;22:752–758.
- Curtis JR, Patrick DL, Engleberg RA, Norris K, Asp C, Byock I: A measure of the quality of dying of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002;24:17–31.
- 12. Schulman-Green D, Ercolano E, Lacoursiere S, Ma T, Lazenby M, McCorkle R: Developing and testing a Web-based survey to assess educational needs of palliative and end-of-life health care professionals in Connecticut. Am J Hosp Palliat Care 2011;28:219–229.
- Emanuel LL, von Gunten CF, Ferris FD: The Education for Physicians on End-of-Life Care (EPEC) Curriculum. Chicago: American Medical Association. 1999. www.epec.net/epec_ core.php [Last accessed July 6, 2011.]
- American Association of Colleges of Nursing: End-of-life Nursing Education Consortium (ELNEC) Core Curriculum. www.aacn.nche.edu/elnec/curriculum.htm [Last accessed July 6, 2011.]
- 15. Materstvedt LJ, Clark D, Ellershaw J, Forde R, Gravgaard AB, Muller-Busch HC, Porta i Sales J, Rapin CH: Euthanasia and physician-assisted suicide: A view from an EAPC ethics task force. Palliat Med 2003;17:97–101.
- Wentlandt K, Burman D, Swami N, Hales S, Rydall A, Rodin G, Lo C, Zimmermann C: Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers. Psychooncology 2011; doi: 10.1002/pon.1995. [Epub ahead of print]

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