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Brief Methodological Report

The Development and Validation of a Shorter Version of the Canadian Health Care Evaluation Project Questionnaire (CANHELP Lite): A Novel Tool to Measure Patient and Family Satisfaction With End-of-Life Care

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Abstract

Context. The recently developed Canadian Health Care Evaluation Project (CANHELP) questionnaire, which can be used to assess both patient and family satisfaction with end-of-life care, takes 40–60 minutes to complete. The length of the interview may limit its uptake and clinical utility; a shorter version would make its use more feasible.

Objectives. The purpose of this study was to develop and validate a shorter version of the CANHELP questionnaire.

Methods. Data were collected using a cross-sectional survey of patients with advanced medical diseases and their family members. Participants completed the long version of CANHELP, a global rating of satisfaction with care (GRS), the FAMCARE scale (family members only), and a quality-of-life (QOL) questionnaire. We reduced the items on the long version based on their relationship to the GRS, the frequency of missing data, the distribution of responses, the redundancy of the items, and focus groups with frontline users. With the remaining items, we assessed internal consistency using Cronbach's alpha, and evaluated construct validity by describing the correlation of the new CANHELP Lite with the full version of CANHELP, GRS, FAMCARE, and the QOL questionnaire scores.

Results. A total of 363 patients and 193 family members participated in this study. The patient version was reduced from 37 items to 20 items and the caregiver version was reduced from 38 items to 21 items. Cronbach's alphas ranged from 0.68 to 0.93 for all domains of both the patient and caregiver questionnaires. We

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Accepted for publication: August 1, 2012.

observed a high degree of correlation between CANHELP Lite domains and overall scores and the same domains and overall scores for the full version of CANHELP. In addition, we observed moderate to strong correlation between the CANHELP Lite overall satisfaction scores and the GRS questions. There was moderate correlation between the overall family member CANHELP Lite score and overall FAMCARE score ($r = 0.45$) and this was similar to the correlation between the full version of CANHELP and FAMCARE scores ($r = 0.41$). CANHELP Lite correlated more strongly with the QOL subscale on health care than the other QOL subscales.

Conclusion. The CANHELP Lite questionnaire is a valid and internally consistent instrument to measure satisfaction with end-of-life care. J Pain Symptom Manage 2013;46:289–297. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

End-of-life care, quality care, quality of life, palliative care, quality improvement, outcome assessments

Introduction

Quality end-of-life (EOL) care is espoused as a “right” for all citizens and a responsibility of all governments.¹ Unfortunately, recent studies continue to identify significant care deficiencies and there remain many opportunities for improvement.^{2–6} Historically, improving EOL care has been hampered by inadequate definitions of and a lack of validated measurement tools for quality EOL care, particularly from the perspective of the seriously ill patient and/or their family members.^{7–9} Reliable and valid instruments that measure the patient’s and their family’s experience are urgently needed to illuminate specific areas in need of improvement.

The CANHELP Questionnaire

Recently, we developed and validated a novel questionnaire, the Canadian Health Care Evaluation Project (CANHELP) questionnaire, which can be used to assess both patient and family satisfaction with EOL care provided to patients who have a variety of diagnoses across diverse settings. The details of our initial development of the full version of the CANHELP satisfaction instrument have been published elsewhere¹⁰ and the full version can be found at www.thecarenet.ca/canhelp.

Although CANHELP is reliable, valid, and comprehensively measures the patient’s (and family’s) experience of EOL care, it takes

40–60 minutes to complete. The length of the interview may limit its uptake and clinical utility; a shorter version would make its use more feasible for clinical, research, and administrative purposes. The objective of this report is to document the development of a psychometrically sound shorter version of the CANHELP questionnaire, known as the CANHELP Lite.

Methods

This study is a post-hoc secondary analysis of a cross-sectional survey conducted to validate the full version of the CANHELP. A full description of the methods of this survey used for this analysis has been reported elsewhere.¹⁰ In brief, to be eligible for this study, patients had to be aged 55 years or older with advanced chronic obstructive pulmonary disease, congestive heart failure, cirrhosis, or metastatic cancer. In addition, any patient aged 80 years or older, in hospital or enrolled in a home care program using long-term oxygen therapy, and who had a primary diagnosis of chronic obstructive pulmonary disease, congestive heart failure, or metastatic cancer also was eligible.

Data Collection

At each participating site, a research assistant identified potentially eligible patients and the family members of eligible patients

and obtained written, informed consent prior to administering the questionnaires. The research assistant then conducted separate face-to-face interviews with patients to administer the full version of the CANHELP questionnaire, the McGill Quality of Life Questionnaire for patients (MQOL),^{11,12,14} and a single-item global rating of satisfaction with care (GRS). To family members, they administered the full version of the CANHELP questionnaire and a satisfaction measure that had been developed for caregivers of cancer patients (FAMCARE).¹³ However, this instrument was not developed for family caregivers (FCGs) of patients who are dying of other diseases and thus it is not a “gold standard” measure for EOL care. Family members completed a GRS for satisfaction with care related to the patient (GRS Q1) and another for the care of themselves (GRS Q2), and also a measure of FCG QOL (Quality of Life in Life Threatening Illness–Family [QOLLI-F]).¹⁴

Procedure to Develop the CANHELP Lite

In selecting items for CANHELP Lite, we took the following into consideration:

1. Amount of missing data.
2. Potential redundancy: Pearson correlations of each item with the others were calculated.
3. Distribution of the data: We considered the SD of the item score and the extent to which respondents selected “Completely Satisfied.” Items with extremely high levels of satisfaction and small SDs (<1.0) would not discriminate differential levels of care.
4. Content validity: How important each item was to global satisfaction with EOL care as measured by the GRS. We considered both the Pearson correlation of each item on its own with the GRS and its unique contribution to predicting the GRS when in combination with the other items retained at this stage, via forward stepwise multiple regressions. For the multiple regressions, sporadic missing items were imputed by maximum likelihood as estimated by the expectation maximization algorithm and the stability of results was assessed across 10 (multiple) imputations estimated by the Markov chain Monte Carlo method.¹⁵ For family

members, the regressions were done separately for each of GRS Q1 and GRS Q2.

We then presented the revised shorter version of the questionnaire, highlighting the potential changes, and asked for feedback from frontline users and managers. Specifically, we held two focus groups of two hours’ duration with more than 40 palliative care doctors, nurses, and other practitioners interested in EOL care to ensure that the revised questionnaire was clinically sensible and the remaining items were relevant to their practice. Feedback was reviewed and changes were made accordingly when agreed upon by the investigators.

Evaluating the Psychometric Properties of the CANHELP Lite Questionnaire

In the CANHELP Lite, we emphasized comprehensive coverage of the construct of satisfaction with EOL care over the redundancy of items. Therefore, each item within a subscale was chosen to capture somewhat unique information, and highly redundant items were eliminated. Hence, we believed a priori that a high internal consistency as measured by the Cronbach’s alpha is not essential, and, in fact, a very high Cronbach’s alpha is not desirable. Nevertheless, Cronbach’s alpha is presented for interest and completeness. The next step in the evaluation process was to determine the construct validity of CANHELP Lite. As for the full version of CANHELP, the “overall” CANHELP Lite satisfaction score for each participant was calculated as the unweighted average of all answered questions. The subscale scores are the average of nonmissing responses to items in that subscale; subscale scores were considered missing for an individual if more than half of the responses for that subscale were missing. All scores were rescaled to range between 0 (worst possible value) and 100 (best possible value).

In the absence of a gold standard for measuring patient satisfaction with EOL care, we developed a multidimensional approach to validating our CANHELP questionnaire. As a consequence of the development process used to develop CANHELP Lite, it has both face and content validity. To further evaluate construct validity, we estimated the Pearson correlations between the CANHELP Lite questionnaire and other existing validated questionnaires that were administered at the same time in

the original study. For the patient version, we compared the responses of the shorter version with those of the full version of the CANHELP instrument, as well as those of the GRS and the QOLLI-P. A priori, we hypothesized that we would observe a high degree of correlation between the overall CANHELP Lite score, the overall full version of the CANHELP questionnaire, and the GRS. Furthermore, the extent of the correlation with the GRS would be similar for CANHELP and CANHELP Lite. As there are overlaps between QOL and quality of care, we expected to observe some degree of correlation with the QOL questionnaire but expected that the correlation would be less than that with the GRS. However, the QOL instrument contains a quality of health care subscale. We expected that the correlation between the overall CANHELP Lite score and that subscale would be greater than the correlation with any of the other QOL subscales or with the total QOL score.

To validate the FCG version of CANHELP Lite, we compared CANHELP Lite to FAMCARE, to the CANHELP full version, to a GRS concerning care for the patient (GRS Q1) and to another concerning care for themselves (GRS Q2), and to the QOLLI-F. Because the direction of the FAMCARE questions were opposite to CANHELP, and to be consistent with our prior analysis,¹⁰ we reversed the sign on the FAMCARE correlations. We expected to see the highest correlations between CANHELP Lite and CANHELP and the GRS, a moderate correlation between CANHELP Lite and FAMCARE, and a weaker correlation between CANHELP and the QOLLI-F. Similar to the situation with the patients, we expected to see a stronger relationship between CANHELP Lite and the QOLLI-F subscale measuring quality of health care than between CANHELP Lite and the QOLLI-F total score or other QOL subscales.

All analyses were conducted using SAS version 9.2 (SAS Institute, Inc., Cary, NC). This project was approved by the Research Ethics Boards of all participating institutions.

Results

A total of 363 patients and 193 FCGs consented to participate. Table 1 displays the demographics of the study patients and FCGs.

Table 1
Demographics

Characteristic	Patients (n = 361)	Caregivers (n = 193)
Age	76.6 ± 9.9	61.9 ± 13.3
Gender		
Male	185 (51.2)	48 (24.9)
Female	175 (48.5)	144 (74.6)
Missing	1 (0.3)	1 (0.5)
Race		
Caucasian	313 (86.7)	162 (83.9)
First Nations (Indigenous people)	36 (10.0)	22 (11.4)
Asian/Pacific islander	4 (1.1)	5 (2.6)
African/Black North American	5 (1.4)	1 (0.5)
East Indian	1 (0.3)	0 (0.0)
Other	2 (0.6)	2 (1.0)
Unknown	0 (0.0)	1 (0.5)
Home location		
Urban	256 (70.9)	125 (64.8)
Rural	76 (21.1)	44 (22.8)
Unknown	29 (8.0)	24 (12.4)
Education		
Elementary school or less	50 (13.9)	7 (3.6)
Some high school	118 (32.7)	29 (15.0)
High school graduate	80 (22.2)	43 (22.3)
Some college or trade school	36 (10.0)	23 (11.9)
College diploma or trade school	30 (8.3)	39 (20.2)
Attended university	15 (4.2)	8 (4.1)
University degree	21 (5.8)	27 (14.0)
Postgraduate degree	8 (2.2)	11 (5.7)
Other	0 (0.0)	4 (2.1)
Unknown	3 (0.8)	2 (1.0)
Employment status		
Employed full time	4 (1.1)	39 (20.2)
Employed part time	4 (1.1)	10 (5.2)
On paid leave	5 (1.4)	7 (3.6)
On unpaid leave	4 (1.1)	2 (1.0)
Self-employed	3 (0.8)	7 (3.6)
Retired	304 (84.2)	103 (53.4)
Not employed	25 (6.9)	17 (8.8)
Other	12 (3.3)	6 (3.1)
Unknown	0 (0.0)	2 (1.0)
Primary entry criteria into study		
COPD	128 (35.5)	
CHF	50 (13.9)	
Cirrhosis	5 (1.4)	
Cancer	81 (22.4)	
Age ≥ 80	97 (26.9)	
Marital status of caregiver		
Married or living as married		150 (77.7)
Widowed		4 (2.1)
Never married		22 (11.4)
Divorced or separated not remarried		13 (6.7)
Other		2 (1.0)
Unknown		2 (1.0)
Relationship to patient		
Husband/wife/partner		94 (48.7)
Child		69 (35.8)
In-law		7 (3.6)
Parent		3 (1.6)
Sister/brother		5 (2.6)

(Continued)

Table 1
Continued

Characteristic	Patients (n = 361)	Caregivers (n = 193)
Other		12 (6.2)
Unknown		2 (1.0)
Missing		1 (0.5)
PPS	60.2 ± 15.8	
Charlson Comorbidity Index	2.7 ± 2.3	

PPS = Palliative Performance Scale score; COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure. Values are provided as number (%) or mean ± standard deviation.

Instrument Properties and Domain Structure

The item-specific nonresponse rate ranged from 0.3% to 16.6%. The question that was most often incomplete in both the patient and caregiver versions pertained to home care services. Because various care aspects, such as help with personal care, symptom management, and so forth, remained in the questionnaire and could be used to evaluate the quality of care regardless of location of care, we omitted this question. We considered the Pearson correlation coefficient of each individual item with the other items, the correlation of each item with the GRS, the distribution of responses, and the results of the multivariable models predicting the GRS in making further decisions about which questions to eliminate (data not shown). The patient version was reduced from 37 to 20 items and the entire “Role of the Family” domain was eliminated because all its items had a very low correlation with the GRS. The “Your Well-Being” domain was changed to the “Feeling at Peace” domain because only a single item representing the sense of peace remained in the domain. The caregiver version was reduced from 38 to 21 items and the entire “Your Well-Being” domain was dropped because of low correlations with the GRS. The number of items retained per domain

for the patient and caregiver questionnaires are included in Tables 2 and 3, respectively.

Preliminary results were checked with experts and frontline workers during the focus groups. A final version of the CANHELP Lite was further evaluated for its psychometric properties (see www.thecarenet.ca/CANHELP for the copy of the patient version of the CANHELP Lite). Overall and within each domain for both the patient and caregiver questionnaires, internal item consistency as measured by Cronbach’s alpha ranged from 0.68 to 0.93; results were very similar to the full version of CANHELP (Tables 2 and 3). Cronbach’s alpha did not improve by removing any item from a subscale or the overall questionnaire; therefore, none were removed. The mean overall CANHELP Lite satisfaction score was similar to the mean overall score of the full questionnaires for both the patient (mean ± SD 77 ± 15 vs. 75 ± 14) and the caregiver (74 ± 16 vs. 71 ± 15).

Construct Validity

As we hypothesized, we observed a high degree of correlation between CANHELP Lite domain and overall scores and the same domain and overall scores for the long version of CANHELP. The correlation coefficients were all ≥0.90 except for the “Your Well-Being” domain in the patient version, which was cut from four items to a single item (Tables 4 and 5). In addition, we observed moderate-to-strong correlation between the CANHELP Lite overall satisfaction scores and the GRS questions (correlation coefficients 0.51 [patient], 0.67 [GRS Q1], and 0.65 [GRS Q2] for family). As hypothesized, these correlations were similar to the correlations between the full version of CANHELP and the GRS questions (correlation coefficients

Table 2
Cronbach’s Alpha for CANHELP Lite Patient Questionnaire

CANHELP Patient Questionnaire	Number of Items		Standardized Cronbach’s Alpha	
	Full Version	Lite Version	Full Version	Lite Version
Illness management	14	9	0.89	0.84
Communication	5	3	0.89	0.83
Relationship with the doctors	4	3	0.84	0.83
Your well-being/Feeling of peace	4	1	0.72	Undefined
Decision making	4	4	0.69	0.68
Role of the family	6	0	0.76	—
Overall	37	20	0.93	0.90

Table 3
Cronbach's Alpha for CANHELP Lite Family Caregiver Questionnaire

CANHELP Family Caregiver Questionnaire	Number of Items		Standardized Cronbach's Alpha	
	Full Version	Lite Version	Full Version	Lite Version
Communication and decision making	6	4	0.91	0.87
Illness management	10	9	0.88	0.86
Characteristics of doctors and nurses	5	2	0.88	0.81
Your involvement	7	3	0.78	0.69
Your well-being	6	0	0.75	—
Relationship with the doctors	4	3	0.84	0.84
Overall	38	21	0.94	0.93

0.49 [patient], 0.63 [GRS Q1] and 0.63 [GRS Q2] for family). These correlations were greater than the correlations between CANHELP Lite and the overall and domain scores for both the QOLLI-P and QOLLI-F (Tables 4 and 5). The only exception was the "Quality of Care" domain score in which, as postulated, the correlation between the CANHELP Lite overall score and the QOLLI Quality of Care subscale in both QOL instruments was greater than the correlation with the overall QOLLI or other QOLLI domain scores (Tables 4 and 5). There was moderate correlation between the overall FCG CANHELP Lite score and FAMCARE overall score (0.45) and this was similar to the correlation between the CANHELP long version and FAMCARE scores (0.41). There was moderate correlation between the CANHELP Lite overall scores and the FAMCARE subscale scores (0.39–0.46) but these were less than the CANHELP Lite correlation with the GRS Q1 (0.67) and GRS Q2 (0.65) (Table 6). The correlation between FAMCARE and the GRS was weak-to-moderate and much less than the correlation between both CANHELP instruments and the GRS (Tables 5 and 6).

Discussion

We used the same data collected from the original CANHELP validation study to inform the item reduction process to develop a shorter version of the CANHELP questionnaire. We successfully reduced the number of items in the patient version from 37 to 20 items, and in the caregiver version, from 38 to 21 items, while retaining all but one of the domains. We found that "Role of the Family" in the patient version and "Your Well-Being" in the family member

version had low correlation with the GRS and thus they were eliminated from the shorter version of the questionnaire. Despite the loss of items and some domains, we were able to maintain similar psychometric properties between the full version of CANHELP and CANHELP Lite. Consistent with our a priori hypotheses, we observed moderate-to-strong correlations between CANHELP Lite and the GRS and weaker correlations between CANHELP Lite and the QOLLI instruments. As we predicted, the exception to this rule is the correlation between the quality of care domain of the QOLLI instruments. These observations inform users of the validity of these novel satisfaction instruments.

Another important observation from our data is that the correlation was much greater between CANHELP and GRS than the correlation between FAMCARE and the GRS, suggesting that CANHELP is more closely related to the respondent's concept of overall satisfaction with care than FAMCARE. Another limitation of FAMCARE is that it was initially developed for family members of inpatients with cancer receiving palliative care services. Thus, the applicability and validity to other patients with advanced medical diseases, patients at the end of life not receiving palliative services, and patients in other settings are questionable. Recently, FAMCARE has been updated to include questions pertinent to family satisfaction in both inpatient and outpatient settings. This work demonstrates that FAMCARE 2 is reliable and internally consistent with four subscales or domains.¹⁶ However, there are no studies to evaluate its validity in these other patients or other settings. One important advantage of CANHELP over FAMCARE or FAMCARE 2 is that CANHELP can be used to assess patient satisfaction, not just

Table 4
Correlations for Patients Among the CANHELP Lite and CANHELP Full Versions, the GRS, and the QOLLTI-P

CANHELP Lite	Pearson Correlation Coefficients									
	CANHELP Full Version	GRS Question ^a	MQOL							QOLLTI-P Total Score
			Quality of Care	Physical	Psychological Well-Being	Existential Well-Being	Environment	Cognitive	Relationships	
Illness management	0.97	0.53	0.46	0.19	0.33	0.33	0.36	0.33	0.28	0.45
Communication	0.96	0.37	0.63	0.14	0.17	0.16	0.23	0.23	0.14	0.32
Relationship with the doctors	0.96	0.36	0.53	0.12	0.11	0.13	0.18	0.16	0.10 ^c	0.25
Feeling of peace	0.70	0.32	0.34	0.28	0.36	0.38	0.25	0.30	0.18	0.41
Decision making	0.91	0.27	0.38	0.09 ^b	0.16	0.21	0.26	0.27	0.19	0.30
CANHELP Lite overall	0.97	0.51	0.60	0.20	0.29	0.30	0.34	0.34	0.25	0.45
CANHELP full version overall		0.49	0.59	0.23	0.33	0.35	0.34	0.34	0.27	0.47

GRS = global rating of satisfaction with care; MQOL = McGill Quality of Life Questionnaire.
^aGRS: "In general, how satisfied are you with the quality of care you received during the past month?"
^bCorrelation not significant at $P < 0.05$.

Table 5
Correlations for Family Caregivers Among CANHELP Lite and CANHELP Full Version, the GRS, and the QOLLTI-F

CANHELP Lite	Pearson Correlation Coefficients										
	CANHELP Full Version	GRS Q1 ^a	GRS Q2 ^b	QOLLTI-F							QOLLTI-F Total Score
				Quality of Care	Environment	Patient State	Own State	Outlook	Relationships	Financial Worries	
Communication and decision making	0.98	0.49	0.52	0.43	0.02	-0.01	0.14	0.29	0.28	0.14	0.24
Illness management	0.99	0.64	0.55	0.64	0.22	0.05	0.24	0.33	0.42	0.30	0.44
Characteristics of doctors and nurses	0.91	0.59	0.57	0.55	0.16	0.05	0.22	0.40	0.38	0.23	0.40
Your involvement	0.90	0.43	0.45	0.47	0.18	0.05	0.26	0.44	0.40	0.25	0.40
Relationship with the doctors	0.96	0.60	0.62	0.52	0.10	0.02	0.07	0.19	0.13	0.10	0.21
CANHELP Lite overall	0.96	0.67	0.65	0.65	0.18	0.03	0.23	0.38	0.40	0.26	0.42
CANHELP full version overall		0.63	0.63	0.63	0.25	0.12	0.34	0.46	0.47	0.33	0.52

GRS = global rating of satisfaction with care; QOLLTI-F = Quality of Life in Life Threatening Illness-Family.
 Correlations ≥ 0.15 were significant at $P < 0.05$.
^aGRS Q1: Global rating of satisfaction 1: "In general, how satisfied are you with the quality of care your relative received during the past month?"
^bGRS Q2: Global rating of satisfaction 2: "In general, how satisfied are you with the way you were treated by the doctors and nurses looking after your relative during the past month?"

Table 6
Correlations Between FAMCARE, CANHELP Lite, and GRS Questions

CANHELP Lite	Pearson Correlation Coefficients				
	FAMCARE				
	Information Giving	Patient's Pain Relief	Availability of Care	Psychological Care	FAMCARE Total Score
Communication and decision making	0.44	0.40	0.39	0.46	0.46
Illness management	0.28	0.29	0.28	0.34	0.32
Characteristics of doctors and nurses	0.25	0.21	0.27	0.28	0.26
Your involvement	0.32	0.35	0.36	0.45	0.41
Relationship with the doctors	0.29	0.32	0.32	0.32	0.34
CANHELP Lite overall	0.39	0.40	0.40	0.46	0.45
CANHELP full version overall	0.36	0.37	0.38	0.41	0.41
GRS Q1 ^a	0.23	0.30	0.25	0.33	0.30
GRS Q2 ^b	0.21	0.26	0.29	0.27	0.27

GRS = global rating of satisfaction with care; QOLLI-F = Quality of Life in Life Threatening Illness–Family.

Correlations ≥ 0.15 were significant at $P < 0.05$.

^aGRS Q1: Global rating of satisfaction 1: "In general, how satisfied are you with the quality of care your relative received during the past month?"

^bGRS Q2: Global rating of satisfaction 2: "In general, how satisfied are you with the way you were treated by the doctors and nurses looking after your relative during the past month?"

family satisfaction. Finally, by asking respondents to rate both importance and satisfaction with a given item, the CANHELP tools can be used to drive process improvement on an individual basis.¹⁷

Our study had some limitations. We have derived our understanding of the psychometric properties of both the full version and the shorter version of CANHELP from the same database. Further validation studies are needed in other patient samples, and this psychometric evaluation repeated, to enhance confidence in the validation of this instrument. Importantly, validation of the factor structures of CANHELP Lite has not been done and needs to be assessed in subsequent studies. Also, because responses to the CANHELP Lite were extracted from a single administration of the full CANHELP questionnaire, the estimated correlations between the domains of the full and shorter versions of CANHELP are biased upwards. A subsequent study with separate administrations of the full and shorter CANHELP questionnaires is warranted. Additional limitations of this study relate to the limitations of the original study, that the majority of our patients were Caucasians who had medical diagnoses. The strengths of this study include the relatively large cohort of participants with a range of end-stage medical illnesses spread across several centers in Canada, thus enhancing the generalizability of the study findings.

In conclusion, we found that CANHELP Lite has retained similar psychometric properties to the full version and is half the length of the original instrument. Although further validation is encouraged, CANHELP and CANHELP Lite can be used to assist practitioners, researchers, and administrators to measure satisfaction with EOL care.

Disclosures and Acknowledgments

This study was supported by the Canadian Researchers at the End of Life Network (CARENET). CARENET is supported by a grant from the Canadian Institutes of Health Research and the Heart and Stroke Foundation of Canada. The authors declare no conflicts of interest.

The authors thank all the members of CARENET who have contributed to the evolution and development of this work. The authors also would like to thank the site investigators and research coordinators who collected the data that were used in the analysis (see Heyland et al¹⁰ for a complete listing).

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