

Defining priorities for improving end-of-life care in Canada

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ABSTRACT

Background: High-quality end-of-life care should be the right of every Canadian. The objective of this study was to identify aspects of end-of-life care that are high in priority as targets for improvement using feedback elicited from patients and their families.

Methods: We conducted a multicentre, cross-sectional survey involving patients with advanced, life-limiting illnesses and their family caregivers. We administered the Canadian Health Care Evaluation Project (CANHELP) questionnaire along with a global rating question to measure satisfaction with end-of-life care. We derived the relative importance of individual questions on the CANHELP questionnaire from their association with a global rating of satisfaction, as determined using Pearson correlation coefficients. To determine high-priority issues, we identified questions that had scores indicating high importance and low satisfaction.

Results: We approached 471 patients and 255 family members, of whom 363 patients and 193 family members participated, with response rates of 77% for patients and 76% for families. From the perspective of patients, high-priority areas needing improvement were related to feelings of peace, to assessment and treatment of emotional problems, to physician availability and to satisfaction that the physician took a personal interest in them, communicated clearly and consistently, and listened. From the perspective of family members, similar areas were identified as high in priority, along with the additional areas of timely information about the patient's condition and discussions with the doctor about final location of care and use of end-of-life technology.

Interpretation: End-of-life care in Canada may be improved for patients and their families by providing better psychological and spiritual support, better planning of care and enhanced relationships with physicians, especially in aspects related to communication and decision-making.

Although a "quality death" is an espoused right of Canadians,¹ for many dying patients and their families, it is not achieved. Recent reviews and observational studies describe considerable dissatisfaction with end-of-life care, indicating that there are still opportunities for improvement.²⁻⁵

Ideally, initiatives aimed at improving end-of-life care would be informed by the experiences and expectations of patients and their family members. However, such efforts are

often hampered by inadequate definitions of quality of care and by suboptimal tools for measurement.⁶⁻⁸ In a recent, large cross-sectional survey, the Canadian Researchers at the End of Life Network defined what matters most to seriously ill patients as they approach the end of life.⁹ Both patients and their family members reported that it was extremely important that they have trust and confidence in the physicians caring for them or their loved ones.⁹ Avoidance of unwanted life-support measures, effective communication, continuity of care, and feelings of life completion were also rated as highly important.⁹ We used these comprehensive ratings of importance to develop and validate a novel questionnaire to measure satisfaction with end-of-life care.¹⁰ Using this questionnaire, we formally evaluated the care received at the end of life in several Canadian centres.

By targeting initiatives for change at gaps in quality, we can address the highest priorities for improving end-of-life care in Canada. Our objective was to identify high-priority areas for improvement in the care of patients with advanced, life-limiting diseases and in the perceived quality of that care by their families. We identified these areas by focusing on care-related issues that had been rated as important by patients and their family members but were rated low on the questionnaire measuring satisfaction with end-of-life care.

Methods

Participants

We conducted a cross-sectional survey involving patients who had advanced, life-limiting illnesses and their family caregivers. Patients and family caregivers were recruited from both inpatient and outpatient facilities and from affiliated home-care pro-

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grams at the Kingston General Hospital in Kingston, Ontario; St. Joseph's Healthcare in Hamilton, Ontario; St. Paul's Hospital in Vancouver, British Columbia; Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia; the New Brunswick Extra-Mural Program in Saint John, New Brunswick; Royal Alexandra Hospital in Edmonton, Alberta; and the Hôpital Maisonneuve-Rosemont in Montréal, Quebec.

To be eligible, patients had to understand English or French, be capable of giving informed consent, be older than 55 years of age and meet the clinical criteria for advanced chronic obstructive pulmonary disease, congestive heart failure, liver disease or metastatic cancer. In addition, patients in hospital who were 80 years of age or older were considered eligible if they had a medical diagnosis as the primary reason for admission or if they were enrolled in a home-care program using long-term oxygen therapy and had a primary diagnosis of chronic obstructive pulmonary disease, congestive heart failure or metastatic cancer. A detailed description of the inclusion criteria is shown in Appendix 1, available at www.cmaj.ca/cgi/content/full/cmaj.100131/DC1.

Using clinical judgment, we excluded patients who were cognitively impaired or otherwise unsuitable for administration of a detailed questionnaire because of communication problems or physical or emotional frailty. We obtained written informed consent from willing patients and then asked them to identify a family caregiver. If the patient was not competent or declined involvement, we approached eligible family caregivers independently of the patient's involvement (Appendix 1). The research assistant then conducted separate face-to-face interviews with the patient and with family caregivers and administered the questionnaires described below.

Data collection

The Canadian Health Care Evaluation Project (CANHELP) questionnaire

Details of our initial development of the CANHELP questionnaire are published elsewhere.^{2,9,11,12} In brief, we generated items to be included in this questionnaire using a review of the literature, focus groups of experts and interviews with patients. Based on our conceptualization of the major themes emerging from our data, we grouped the items into the following domains: characteristics of the doctors and nurses (8 items), illness management (7 items), health service characteristics (4 items), communication and decision-making (11 items), relationships with others (4 items), and spirituality and meaning (3 items).⁶ Before rating the domain-specific items, respondents were asked to rate their overall level of satisfaction with the care they had received in the past month. We developed one version of the questionnaire for patients and two for family caregivers (i.e., one version for use if the patient was alive, and one for use if the patient had died). Options for responses were the following: 1 = not at all satisfied, 2 = not very satisfied, 3 = somewhat satisfied, 4 = very satisfied and 5 = completely satisfied. We have shown that the CANHELP questionnaire correlates with other established measures of satisfaction with quality of care at the end of life, has good internal consistency (Cronbach $\alpha > 0.70$) and can be grouped into valid subscales.¹⁰

The final version of the questionnaire (available online at www.thecarenet.ca) was used in the current study.

We recorded demographic characteristics of participants at the time of the interview. We assessed patients' functional status using the Palliative Performance Scale.¹³ Comorbidities were categorized and calculated according to the Charlson Comorbidity Index.¹⁴

Statistical analysis

We described the characteristics of patients and family caregivers as counts and percentages for categorical variables and as means with standard deviations for continuous variables. Responses to the CANHELP questionnaire were summarized as means with standard deviations (SDs) and ranges. To enable comparisons with previous work using this instrument, we also reported the percentage of respondents who rated themselves as "completely satisfied." To determine the areas that were high in priority as targets for improvement from our data on satisfaction level, we developed plots of importance versus satisfaction.¹⁵ We defined the relative importance of the items according to their association (as determined by Pearson correlation coefficients) with the global rating of satisfaction.¹⁵ Items not found to be correlated with overall satisfaction were considered unimportant. Scatter plots were used to assess the relationship between this measure of importance and the mean score on level of satisfaction for each CANHELP question. We used horizontal and vertical grid lines placed at the median of the plotted data points for each measure to identify four separate quadrants. Questions in the upper left quadrant were important (i.e., correlated highly with overall satisfaction) and had the lowest satisfaction scores relative to other questions. We deemed the care-related issues identified by these questions to have the highest priority as targets for improvement.¹⁵

We obtained approval of the study from the Queen's University Research Ethics Board. The ethics boards of all other participating sites subsequently approved the study.

Results

From August 2007 to January 2009, 622 patients at participating sites were identified as potentially eligible. Of these, 151 were excluded for reasons related to communication (e.g., inability to understand English or French, inability to speak or hear, or impaired mental status) or unsuitability (i.e., deemed unable to tolerate an interview because of lack of physical stamina or psychological state). Of the 471 remaining eligible patients, 363 consented, for an overall response rate of 77.1%. Two patients withdrew before completing the interview, leaving 361 questionnaires evaluable for analysis. Of the patients who completed the interview, 175 (48.5%) had an eligible family caregiver available to interview. We also approached 80 family caregivers independently of the nonparticipating patients who met the inclusion criteria, for a total of 255 family caregivers. A total of 193 family caregivers consented, for a response rate of 75.7%.

The demographic characteristics of the patients and family caregivers we included are listed in Table 1. Owing to sporadic missing data, the number of responses used to calculate the average scores for items and the correlation of items with

the global scores was slightly less than 100% of the potential total responses for 361 patients and 193 family caregivers. The most frequently missing response was to the item “satisfaction with home care services.” A response to this item was missing in the questionnaire results for 60 (16.6%) patients and 33 (17.1%) caregivers. In both questionnaires, all other items were completed by at least 93.3% of respondents.

Patients

The Pearson correlation coefficients showing the association between the scores on individual items and the global satisfaction rating, and the percentage of respondents who indicated for each question that they were completely satisfied, are listed in Appendix 2 (available at www.cmaj.ca/cgi/content/full/cmaj.100131/DC1). Using the magnitude of the correlation coefficients to determine importance, we identified the following as the five most important issues from the perspective of patients: being treated by doctors and nurses in a manner that preserved the patient’s sense of dignity (Pearson $r = 0.46$, $p < 0.001$), receiving good care when a family member or friend was not able to be with them ($r = 0.42$, $p < 0.001$), aspects of their medical care (e.g., tests that were done and treatments given) ($r = 0.41$, $p < 0.001$), that health care workers worked together as a team to look after them ($r = 0.41$, $p < 0.001$) and that the doctors and nurses looking after them were compassionate and supportive ($r = 0.41$, $p < 0.001$).

The mean score for the global rating of satisfaction was 4.3 (SD 0.8, range 1.0–5.0). Patients were least satisfied with the following issues: doing special things they wanted to do during the past month (mean score 3.08), their level of confidence in their own ability to manage their illness (3.18), their understanding of what to expect in the end stage (3.41), their ability to contribute to others (i.e., help other people) in a meaningful way (3.52), and discussions with their physician about final location of care (3.65) and use of life-sustaining technology at the end of life (3.67) (Appendix 1).

The relationship between the importance-related scores and the mean satisfaction-related scores for each question is

Table 1: Demographic characteristics of study participants

Characteristic	Patients, no. (%) [*] <i>n</i> = 361	Caregivers, no. (%) [*] <i>n</i> = 193
Age, yr, mean (SD)	76.6 (9.9)	61.9 (13.3)
Sex, female	175 (48.5)	144 (74.6)
Location of interview		
Home or retirement home	81 (22.4)	62 (32.1)
Hospital	256 (70.9)	114 (59.1)
Palliative care unit	24 (6.7)	14 (7.3)
Long-term care or nursing home	0	1 (0.5)
Other	0	2 (1.0)
Ethnicity		
White	313 (86.7)	162 (83.9)
Aboriginal	36 (10.0)	22 (11.4)
East Asian or Pacific islander	4 (1.1)	5 (2.6)
African or black North American	5 (1.4)	1 (0.5)
South Asian	1 (0.3)	0
Other	2 (0.6)	2 (1.0)
Unknown	0	1 (0.5)
Education		
Elementary school or less	50 (13.9)	7 (3.6)
Some high school	118 (32.7)	29 (15.0)
High school diploma	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)
Some 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	4 (2.1)
Unknown	3 (0.8)	2 (1.0)
Primary eligibility criteria met		
Age ≥ 80 yr	97 (26.9)	
Chronic obstructive pulmonary disease	128 (35.5)	
Heart failure	50 (13.9)	
Cirrhosis	5 (1.4)	
Cancer	81 (22.4)	
Relative being cared for by caregiver		
Husband, wife or partner		94 (48.7)
Parent		69 (35.8)
Parent-in-law		7 (3.6)
Daughter or son		3 (1.6)
Sister or brother		5 (2.6)
Other		12 (6.2)
Unknown		2 (1.0)
Score on Palliative Performance Scale, mean (SD)	60.2 (15.8)	
Charlson Comorbidity Index, mean (SD)	2.7 (2.3)	

Note: SD = Standard deviation.
*Unless otherwise indicated.

shown in Figure 1. The issues deemed to have the highest priority were localized to the upper left quadrant, and were related to patients' feelings of peace, the availability of their doctor, the assessment and treatment of their emotional problems, whether their doctor took a personal interest in them and listened to them, the consistency of information about their conditions from all doctors and nurses, and whether things were explained in a way they could understand (Table 2).

Family caregivers

The mean global rating of satisfaction by family caregivers with how they were treated was 4.2 (SD 0.8, range 1.0–5.0). The importance-related and satisfaction-related scores for each question on the family caregiver satisfaction survey are shown in Appendix 3 (available at www.cmaj.ca/cgi/content/full/cmaj.100131/DC1). The performance–importance plots of data representing the perspective of family caregivers are

shown in Appendix 4 (available at www.cmaj.ca/cgi/content/full/cmaj.100131/DC1). Issues that were high in priority from the perspective of family caregivers are itemized in Table 2.

Interpretation

In our study involving 361 seriously ill patients and 193 family members in several health care centres, we documented that overall satisfaction with end-of-life care was good. (The overall score on this scale of 1–5 was 4.3 for patients and 4.1 for family members.) However, these results should not be interpreted as suggesting that there are no areas in which end-of-life care for this population can be improved. Respondents of surveys of satisfaction tend to over-report positive responses.¹⁶ Among individual patients and their families and in responses on specific aspects of care, there were many ratings of dissatisfaction; the proportion of respondents rating

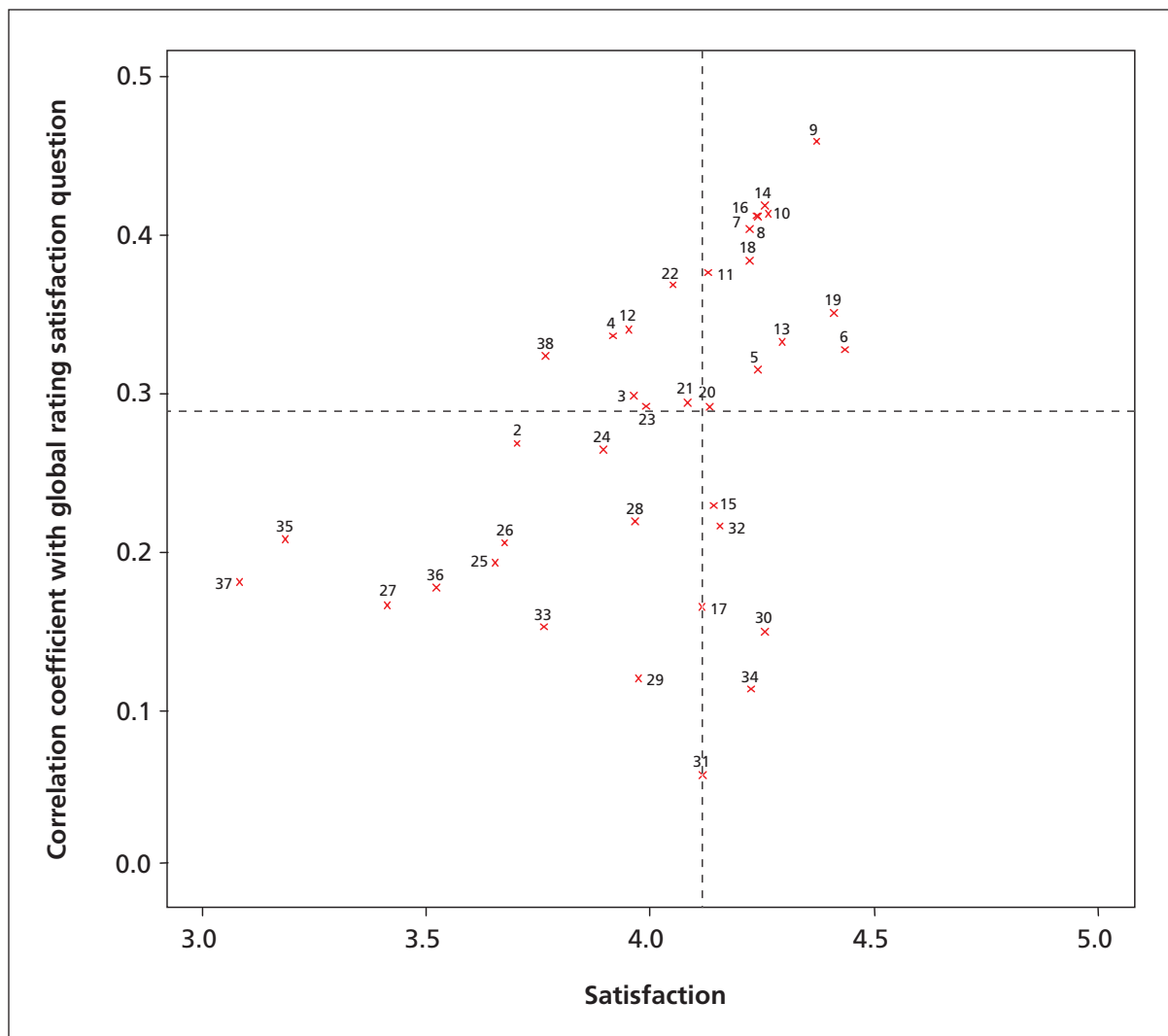


Figure 1: The performance–importance grid, as derived from a plot of the mean score for each question on the Canadian Health Care Evaluation Project (CANHELP) questionnaire for patients (measuring satisfaction with care) and the correlation coefficient for each question's association with overall satisfaction from the patient's point of view. Gridlines correspond to the median of the mean scores on each question (4.12) and the median of the correlation coefficients (0.29). Note: x = the plotted value; the number closest to the x is the corresponding CANHELP question number.

themselves as completely satisfied was as low as 9% and only as high as 57%.

We assessed the extent to which each question was associated with a global rating of satisfaction so that quality improvement initiatives can be focused on issues that matter most to patients. We found that being cared for while experiencing preservation of dignity, being treated with respect and compassion, having trust and confidence in one's doctor, and being well looked after by one's health care team are all important aspects of good-quality end-of-life care. These findings are consistent with those of studies involving other populations and reporting similar aspects of care as being important at the end of life.^{9,17-19}

For both patients and families, the areas needing improvement that were highest in priority were the emotional support provided to patients, the quality of the relationship of the doctor with the patient and patient's family, and communication and decision-making. Deficiencies in relationships with physicians and in communication and decision-making have been highlighted previously.^{2,20-23} In our findings, these deficiencies were centred on physicians' attentiveness, frequency and consistency of interactions with patients and their fami-

lies, and planning of the logistics of end-of-life care, including limitations on life-sustaining therapies. These gaps did not appear related to medical aspects of care; satisfaction with tests and treatments was rated very high by patients.

Whereas high levels of anxiety and depression have been reported previously among patients with cancer,^{24,25} we found that there is a large unmet need for emotional support among patients with advanced medical diseases and their families. This finding underscores the need to improve the assessment and treatment of symptoms of depression and anxiety in this population. Our identification of being at peace as a high-priority issue for improvement is consistent with reports from other studies that existential and spiritual concerns are very prevalent at the end of life.^{26,27} Although being at peace did not have the same importance to family caregivers in our survey, evidence from a longitudinal study¹¹ suggests that this issue is also relevant to family members, whose satisfaction with issues related to their own spirituality and sense of meaning were found to deteriorate substantially in the months after the death of a loved one. We hypothesize that a psychologically or spiritually supportive intervention may help to improve satisfaction with end-of-life care.²⁸

Table 2: Questionnaire items that were high in importance based on responses from patients and their families

Category	Patients' perspective*	Family caregivers' perspective*
Spiritual and emotional needs	38. How satisfied are you that you were at peace during the past month?	
	12. How satisfied are you that emotional problems you had during the past month (e.g., depression, anxiety) were adequately assessed and controlled?	14. How satisfied are you that emotional problems (e.g., depression, anxiety) your relative had during the past month were adequately controlled?
Relationship with doctors	3. How satisfied are you that your doctor(s) took a personal interest in you during the past month?	
	4. How satisfied are you that your doctor(s) were available when you needed them (by phone or in person) during the past month?	5. How satisfied are you that the doctor(s) were available when you or your relative needed them (by phone or in person) during the past month?
Communication and decision-making	23. How satisfied are you that the doctor(s) listened to what you had to say during the past month?	26. How satisfied are you that the doctor(s) listened to what you had to say during the past month?
	22. How satisfied are you that you received consistent information about your condition from all doctors and nurses looking after you during the past month?	24. How satisfied are you that you received consistent information about your relative's condition from all doctors and nurses looking after him or her during the past month?
	21. How satisfied are you that doctor(s) explained things relating to your illness in a way you could understand during the past month?	25. How satisfied are you that you received updates about your relative's condition, treatments, test results, etc. in a timely manner during the past month?
		27. How satisfied are you with discussions during the past month with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if he or she were to get worse?
	29. How satisfied are you with discussions during the past month with the doctor(s) about the use of life-sustaining technologies (e.g., CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?	
Illness management		16. How satisfied are you that, during the past month, your relative received good care when you were not able to be with him or her?

*Numbers shown are the question numbers on the corresponding version of the questionnaire (i.e., patient version or family caregiver version).

Limitations

The limitations of this study are related to the fact that we did not measure importance directly. Asking patients directly to rate the level of importance of each question would have seriously compromised the feasibility of this study by adding to the burden of data collection. In this analysis, we used median scores to identify thresholds on the performance–importance grids. Depending on the institutional resources available, the threshold for these lines could be set elsewhere to identify issues for improvement. Alternatively, institutions could select among items outside of the upper left quadrant to focus on. Although there is no single approach to prioritizing these gaps in quality of care, we suggest that such heuristic divisions provide a useful starting point. Moreover, given the cross-sectional nature of this study, we cannot be certain whether dissatisfaction with care leads to emotional distress or whether emotional distress leads to dissatisfaction with care. Furthermore, we have used the CANHELP questionnaire as a screening tool. Although responses to it may illuminate in general terms where problems lie, more detailed assessments will be required in some cases to understand specific unmet needs. Finally, our study sample primarily comprised a white population; there may be other ethnic groups of patients to which our results do not apply. To overcome this deficiency, we have developed a version of the CANHELP questionnaire that enables individual patients and family caregivers to rate each aspect of care both on its importance and their satisfaction. This version (available at www.thecarenet.ca) allows us to derive a prioritized list of quality-improvement targets individualized to a given patient or patient's family. The strengths of our study include our use of a validated questionnaire and our focus on patients in multiple settings who had diverse medical conditions.

Conclusion

We have identified, from the perspective of patients with advanced, life-limiting diseases and their family members, aspects of care that are high in priority as targets for improvement and that may have the greatest impact in improving overall end-of-life care if so targeted. Psychological interventions, spiritual support, better planning of care, improvements in the nature of physicians' relationships with patients and with patients' families, and enhancement of specific aspects of communication and decision-making could help dying patients and their families realize their right to high-quality care at the end of patients' lives.

This article has been peer reviewed.

Competing interests: None declared.

Contributors: Daren Heyland, Andrew Day, Xuran Jiang and Robin Cohen designed the study protocol with input from other co-investigators. Daren Heyland, Deborah Cook, Graeme Rocker, Peter Dodek, Demetrios Kutsogiannis and Yoanna Skrobik participated in the acquisition, analysis and interpretation of the data and the writing of the manuscript. Xuran Jiang, Andrew Day and Robin Cohen were responsible for the analysis of the data and critically reviewed the manuscript. All of the authors approved the final version of the manuscript submitted for publication.

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