

End-of-life Care in Acute Care Hospitals in Canada: a Quality Finish?

DAREN K. HEYLAND, Department of Medicine, Kingston General Hospital, and Department of Community Health and Epidemiology, Queen's University, Kingston, Ontario, DIANNE GROLL, Department of Medicine, Kingston General Hospital, Kingston, Ontario, GRAEME ROCKER, Department of Medicine, Queen Elizabeth II Health Sciences Center and Dalhousie University, Halifax, Nova Scotia, PETER DODEK, Program in Critical Care Medicine and Center for Health Evaluation and Outcome Sciences, St. Paul's Hospital and University of British Columbia, Vancouver, British Columbia, AMIRAM GAFNI, Center for Health Economics and Policy Analysis, and Department of Clinical Epidemiology, McMaster University, Hamilton, Ontario, JOAN TRANMER, Department of Community Health and Epidemiology, Queen's University, and Department of Nursing, Kingston General Hospital, Kingston, Ontario, DEB PICHORA, Department of Medicine, Kingston General Hospital, Kingston, Ontario, NEIL LAZAR, Department of Medicine, University Health Network and University of Toronto, Toronto, Ontario, JIM KUTSOGIANNIS, Department of Critical Care, University of Alberta, Edmonton, Alberta, SAM SHORTT, Department of Community Health and Epidemiology, Queen's University, and Center for Health Services and Policy Research, Queen's University, Kingston, Ontario, MIU LAM, Department of Community Health and Epidemiology, Queen's University, Kingston, Ontario, Canada, for the Canadian Researchers at the End of Life Network (CARENET)*

Abstract / Understanding patients' and family members' perspectives on the relative importance of elements of end-of-life (EOL) care and their satisfaction with those elements will help prioritize quality improvement initiatives. We administered a face-to-face questionnaire containing a selection of 28 elements of care to eligible inpatients with advanced lung, heart, or liver disease, or metastatic cancer, and available family caregivers (FCGs) in five tertiary care hospitals across Canada. 440 of 569 (78%) eligible patients and 160 of 176 (91%) FCGs participated. No respondent reported complete satisfaction with all elements of care. The average satisfaction score was 4.6 on a 26 point scale. Medical patients reported lower levels of satisfaction than cancer patients. Elements rated as "extremely important" and anything other than "completely satisfied" most frequently by respondents related to discharge planning, availability of home health services, symptom relief, not being a burden, physician trust, and communication. In conclusion, most patients and their family members in our survey were not completely satisfied with EOL care. Improvement initiatives to target key elements identified by patients and FCGs have the potential to improve satisfaction with EOL care across care settings.

Résumé / C'est à partir d'une bonne compréhension de l'opinion des malades et leurs familles, sur ce qu'ils considèrent comme étant des éléments importants de soins de fin de vie, que nous pourrions accorder la priorité aux initiatives visant à améliorer la qualité des soins. Afin de connaître leur degré de satisfaction vis-à-vis de ces éléments nous avons administré individuellement, dans 5 hôpitaux tertiaires au Canada, un questionnaire comprenant 28 éléments de soins, à des

patients atteints de maladies avancées des poumons, du coeur et du foie ou de cancer avec métastases et à leurs soignants naturels. Ont accepté de participer au projet 440 des 569 (70%) patients éligibles et 160 des 176 (91%) des soignants naturels. Aucun des répondants au questionnaire n'a exprimé une satisfaction totale sur tous les éléments de soins sélectionnés. La note moyenne de satisfaction était de 4,6 sur une échelle de 26 points. Les patients atteints de maladies autres que le cancer ont exprimé un degré de satisfaction moindre que les personnes atteintes de cancer. Les éléments considérés comme « extrêmement importants » et toute réponse autre que « complètement satisfait » avaient trait au congé de l'hôpital, à la disponibilité des services de soins à domicile, au contrôle des symptômes, au fardeau de la maladie pour leur famille, à la communication et à la relation de confiance patient-médecin. En conclusion, la plupart des patients et leur famille ayant répondu à notre questionnaire n'étaient pas totalement satisfaits des soins de fin de vie. Toute initiative visant à améliorer les soins de fin de vie auraient de bonnes chances de réussite si on tenait compte des éléments sur lesquels les répondants ont exprimé de l'insatisfaction.

INTRODUCTION

How satisfied are Canadians and their families with end-of-life (EOL) care? Most of the published epidemiologic, economic, legal, and clinical data on care of the dying comes from countries other than Canada and suggests significant quality problems in the provision of EOL care (1-11). However, it may not be possible to gen-

*see appendix for complete list of authors and contributors

eralize these data to Canada. Different health care systems, societal values or expectations, and cultural issues challenge the applicability of these studies to the Canadian setting.

Five years ago, a Senate subcommittee report on palliative care advanced the notion that a "quality death" is the right of every Canadian (12). This report called for the development of a national strategy on EOL care in Canada. Over the last few years, sponsored by the Secretariat on Palliative and EOL Care at Health Canada, a strategy to improve EOL care that encompasses issues of quality of care, research, surveillance, education, and public awareness has been emerging (13). The Canadian Institutes of Health Research, in conjunction with numerous partners, announced in June 2003 that palliative/EOL care was a top strategic theme and has allocated millions of dollars towards research in the area (14). Recent budgetary announcements have committed increased resources to palliative home care and family caregiver (FCG) support (15). Despite this laudable activity, it would seem from a recent progress report from Senator Sharon Carstairs there is still much opportunity to improve (16). There is limited information to inform decision makers about what constitutes quality care at the end of life, how successfully we provide it, and whether current and future policy and clinical interventions will improve the experience of terminally ill patients and their families in Canada.

Since the dying experience in Canada is largely a hospital experience (17), the population that should be best represented in this exercise of defining and measuring quality EOL care is seriously ill hospitalized patients and their family members. Items of importance to high quality EOL care identified by previous investigators studying largely outpatients with cancer, HIV, and chronic illness may not be generalizable to the perspectives of seriously ill hospitalized patients with end-stage disease such as chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF) (18–20).

The overall objective of this study was to enhance our understanding of what high-quality EOL care means from the perspectives of Canadian hospitalized patients who have end-stage medical disease and their family members. Specifically, we interviewed these patients and family members to understand which key elements of quality EOL care were important to them and how well satisfied they were with current care. The ratings of importance are published elsewhere (21). Herein, we report the ratings of satisfaction with these key elements of EOL care and

illuminate factors associated with (dis)satisfaction with EOL care. We also identify those areas in which there is a discrepancy between perceived degree of importance and satisfaction with care actually received. By targeting change initiatives to elements that are rated as very important but also rated as unsatisfactory, clinicians and policy makers can address the highest priorities in improving the quality of EOL care in Canada.

METHODS

This study was a cross-sectional survey conducted at five tertiary-care teaching hospitals across Canada (see Appendix for list of participating institutions).

Questionnaire Development

We developed a questionnaire to evaluate the level of importance and satisfaction with key elements of EOL care from the perspectives of seriously ill hospitalized patients and their FCGs. We first considered papers published at the time of questionnaire development that attempted to define the domains and items related to quality care at the end of life, either based on expert opinion (22–24) or on interviews with patients and families (18). We then generated additional elements from discussion with the multidisciplinary Kingston General Hospital/Queen's University EOL Research Working Group, and semistructured interviews with seriously ill hospitalized patients who met the inclusion criteria, to determine whether any elements had been overlooked or were ambiguously phrased. From this process, we developed a comprehensive list of 28 elements of care that were organized into five domains: medical and nursing care; communication and decision making; social relationships and support; meaningful existence; and advance care planning (Table 2 and Table 4). We used response options to assess degrees of importance using a 5-point ordinal scale (1=not at all important; 2=somewhat important; 3=important; 4=very important; and 5=extremely important) and degrees of satisfaction (1=not at all satisfied; 2=not very satisfied; 3=somewhat satisfied; 4=very satisfied; and 5=completely satisfied).

Participants

At each hospital, a research assistant screened patient charts to identify potential participants. Patients were eligible for this study if they met the following inclusion criteria:

1. Age >55 years.
2. One or more of the following diseases at an advanced stage:

Chronic obstructive lung disease: at least 2 of the 4 following conditions: baseline PaCO₂ of ≥45 mm Hg, cor pulmonale, respiratory failure episode within the preceding year, forced expiratory volume in 1 sec ≤0.75 L.

Congestive heart failure: New York Heart Association class IV symptoms or left ventricular ejection fraction ≤25%.

Cirrhosis: a diagnosis confirmed by imaging studies or documentation of esophageal varices and at least one of three conditions: a) hepatic coma, b) Child's class C liver disease, or c) Child's class B liver disease with gastrointestinal bleeding.

Cancer: metastatic cancer or Stage IV lymphoma.

3. Minimum expected hospital stay of longer than 72 hours.

These criteria define a group of patients with end-stage disease that is associated with a 50% probability of survival at six months (25) and are similar to those used in other studies of seriously ill patients' care preferences (25,26). We excluded patients with probable communication difficulties, such as those who did not understand English or who had cognitive barriers. Eligible consenting patients identified a family member or other close person who provided some form of care in the home setting, if one existed. Patients with no FCG available were still recruited to the study and were administered only the patient-based questionnaire. Before participation, all study subjects provided written informed consent.

Both patients and FCGs were then administered the questionnaire in separate, face-to-face interviews. Participants were asked to rate the

degree of importance they placed on each of the items in the taxonomy and then rate the degree of satisfaction with care as it related to that item. To facilitate answering the questions with categorical responses, we provided cards that showed the response options. The research assistant then recorded their responses on data collection forms. We also collected the following demographic data: age, sex, comorbid illness, functional status as measured by the Katz score (27), marital status, number of dependents, ethnicity, religion, education, admission diagnosis, and self-reported QOL using one global rating question.

Analyses

As the main purpose of this study was descriptive, we set out to obtain a consecutive sample of 500 eligible patients in five hospitals in Canada. For each question, we described the frequency for each of the response options. To better quantify the degree of satisfaction, individuals were also assigned a satisfaction index. This index is the number of elements rated as "completely satisfied" and ranged from 0 to 26 (completely satisfied with all 26 elements) for each patient, or 0 to 24 for each FCG. Multiple linear regression models were then developed to determine independent associations with patient and FCG satisfaction indices. Index scores, the dependent variables, were not normally distributed (Figure 1) and were therefore transformed using log transformations (satisfaction index + 1). Independent variables entered into the patient models were age, sex, diagnosis, Katz score (27), presence of a caregiver, rural or urban residence, race, living alone, marital status, and employment status. Independent variables entered into the FCGs' model were: age, sex, and patient diagnoses. Variables were entered in both a forward and backward stepwise manner so as not to influence variable selection due to order of entry. Variables were considered significantly associated with the outcome if $p < 0.05$.

We classified an element as an opportunity for improvement when the respondent answered that the element was both "extremely important" and that they were not completely satisfied (response 1-4) with that element. To quantify this opportunity for improvement, we developed the "opportunity index", defined as the number of respondents who rated an element "extremely important" and with which they were not "completely satisfied", divided by the total number of respondents for that question.

Ethics

The research ethics board at each participating institution approved the study.

Figure 1 / DISTRIBUTION OF PATIENT AND CAREGIVER SATISFACTION INDICES SHOWING PERCENT OF PATIENTS AND CAREGIVERS IN EACH RESPONSE OPTION. A HIGH SATISFACTION INDEX INDICATES MORE 'COMPLETELY SATISFIED' RESPONSES

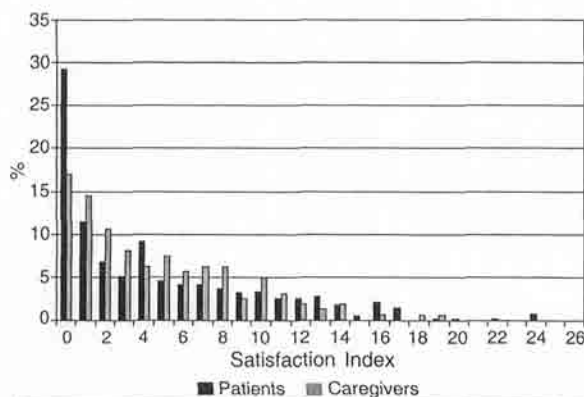


Table 1 / DEMOGRAPHICS OF STUDY SUBJECTS

Characteristic	Patients (n=440)	Family Members (n=160)
Mean age: years (SD)	71.2 (9.1)	56.5 (13.9)
Sex (%)		
female	209 (47)	104 (65)
male	222 (50.5)	54 (33.8)
missing	9 (2)	2 (1.2)
Race (%)		
Caucasian	416 (94.5)	147 (91.9)
Native	1 (0.2)	5 (3.1)
Black	3 (0.7)	0 (0)
East Indian	2 (0.5)	2 (1.3)
Asian	4 (0.9)	4 (2.5)
other	10 (0.9)	1 (0.6)
Primary admission diagnosis (%)		
cancer	166 (37.7)	
CHF	106 (24.1)	
COPD	118 (26.8)	
cirrhosis	50 (11.4)	
Number of comorbid conditions (%)		
none	94 (21.4)	
one	108 (24.6)	
two	81 (18.5)	
three or more	187 (42.6)	
Katz Score	5.0 (1.3)	
Education (%)		
grade school	134 (30.5)	5 (3.1)
high school	184 (41.8)	70 (43.8)
college	61 (13.9)	35 (21.9)
university	35 (8)	35 (21.9)
post grad	8 (1.8)	10 (6.3)
unknown	4 (4.1)	5 (3.1)
Marital Status (%)		
married/common law	234 (53.2)	
widowed	121 (27.5)	
separated/divorced	57 (13)	
never married	12 (2.7)	
unknown	16 (3.6)	
Relationship to patient (%)		
spouse/partner		70 (44.6)
child		75 (47.8)
sibling		5 (3.2)
friend		1 (0.6)
relative		6 (3.8)
unknown		3 (1.3)
Living arrangements (%)		
with spouse/partner	232 (52.7)	
alone	140 (31.8)	
with other family	47 (10.7)	
nursing home	5 (1.1)	
chronic care facility	5 (1.1)	
unknown	11 (2.5)	
Location of home (%)		
rural	104 (23.6)	
urban	323 (73.4)	
Employment (%)		
retired	296 (67.3)	60 (42.6)
unable to work	85 (19.3)	9 (5.6)
employed	25 (5.7)	65 (40.6)
homemaker	20 (4.5)	10 (6.3)
unemployed	4 (0.9)	8 (5.0)
unknown	10 (2.3)	3 (1.9)
Religion (%)		
Protestant	30 (52.3)	70 (43.8)
Roman Catholic	107 (24.3)	39 (24.4)
Jewish	7 (1.6)	3 (1.9)
Muslim	1 (0.2)	0 (0)
other	30 (6.8)	26 (16.3)
none	52 (11.8)	12 (7.5)
unknown	13 (3)	10 (6.3)

Overall QOL	
excellent	16 (3.6)
very good	46 (10.5)
good	76 (17.3)
fair	133 (30.2)
poor	137 (31.1)
unknown	32 (7.3)
Six-month mortality status	
dead	252 (57.3)
alive	175 (39.8)
unknown	13 (3.0)

RESULTS

From November 2001 to June 2003, 569 eligible patients were identified and approached for consent at the five hospitals; 447 consented for an overall response rate of 78%. Six patients withdrew from the study shortly after starting the interview and one patient died the day before the interview. Of the consenting patients, 226 (50%) had a FCG who would potentially be visiting the hospital. For logistical reasons, we were able to approach only 176 for consent; 160 agreed to participate, yielding a response rate of 71%. Table 1 displays the demographics of the study patients and FCGs.

Patient Satisfaction

Table 2 reports the percentage of patient rating the item as "extremely important" and the ratings of satisfaction with each element of EOL care. No patient was completely satisfied with all 26 items and 29% of patients responded that they were not "completely satisfied" with any of the items (satisfaction index=0/26). Three patients (0.7%) were "completely satisfied" with 24/26 items (Figure 1). The average satisfaction index for patients was 4.61 (SD 5.13), and 50% of patients were satisfied with three or fewer items. Variables significantly associated ($p < 0.05$) with a low satisfaction index from a patient's perspective were a diagnosis of COPD or CHF. Patients were more likely to have a higher satisfaction index if they had an FCG who participated in this survey (Table 3). The elements rated "extremely important" and not "completely satisfied" most frequently by the patients were: "To have an adequate plan of care and health services available to look after you at home upon hospital discharge," "To have relief of symptoms," "To not be a physical or emotional burden on your family," "To have trust and confidence in the doctor," and "To receive adequate information" (Table 2).

Family Member's Satisfaction

Table 4 reports the percentage of FCGs rating the item "extremely important" and ratings of satisfaction with each element of EOL care. The aver-

Table 2 / PATIENT RATINGS (%) OF IMPORTANCE AND SATISFACTION OF VARIOUS ELEMENTS RELATED TO QUALITY EOL CARE (Sorted from largest to smallest opportunity index*. Ratings: 1=not at all satisfied; 2=not very satisfied; 3=somewhat satisfied; 4=very satisfied; 5=completely satisfied)

Question	Ratings					Extremely important	Opportunity index*
	1	2	3	4	5		
To have an adequate plan of care and health services available to look after you at home upon hospital discharge	8	25	19	34	14	42	32
To have relief of symptoms: i.e., pain, shortness of breath, nausea, etc.	5	8	29	40	18	39	32
To not be a physical or emotional burden on your family	4	13	25	42	16	42	31
To have trust and confidence in the doctors looking after you	2	6	19	41	32	56	28
To receive adequate information about your disease, including the risks and benefits of treatment options	6	12	24	42	16	32	24
That your doctor is available to discuss your illness and answer questions in a way that you understand	6	13	23	41	17	33	23
To have an opportunity to discuss your fears of dying	4	16	32	35	13	25	22
To have information regarding your medical history and needs be readily available to doctors treating you upon admission to hospital	6	13	24	47	10	30	22
To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)	2	10	25	34	29	44	21
To know which doctor is the main doctor in charge of your care	9	12	16	35	27	37	21
That information about your disease be communicated to you by your doctor in an honest manner	5	9	14	43	29	44	21
To have someone listen to you and be with you when you are feeling sad, frightened, anxious, or confused	4	10	26	47	13	24	19
To receive respectful and compassionate care from health care providers	2	4	20	52	22	32	18
To be treated in a manner that preserves your sense of dignity	3	7	20	53	17	27	17
To be treated as an individual with unique needs, values, and preferences, and not just as a disease	3	3	22	54	18	26	16
To be involved in decisions regarding the treatments and care that you receive	4	8	20	50	18	28	16
That the doctor discuss concerns relating to your illness and care with your family present	9	11	18	34	28	35	15
To have trust and confidence in the nurses looking after you	1	4	19	53	23	29	15
To have an opportunity to strengthen or maintain relationships with people who are important to you	<1	6	20	44	29	35	14
That your illness not create financial problems for your family	3	10	18	44	25	27	12
Have a private room so that your family can be comfortable and discussions relating to your illness are confidential	5	9	29	42	15	16	12
To have your spiritual or religious needs met	3	7	21	45	24	21	12
To receive help to make difficult treatment decisions	3	6	23	56	12	15	11
To be able to contribute to others (gifts, time, knowledge, experience, etc.)	2	8	39	41	10	16	11
To have a sense of control over decisions about your care	4	7	24	47	18	17	10
To have the same nurses looking after you	3	7	31	47	12	14	10
Not to be kept alive on life support when there is little hope for a meaningful recovery	N/A	N/A	N/A	N/A	N/A	56	N/A
To be able to die in the location of your choice (i.e., home or hospital)	N/A	N/A	N/A	N/A	N/A	17	N/A

*Opportunity index for a given element is the number of respondents who rated the element "extremely important" and answered not "completely satisfied", divided by total number of respondents.

Table 3 / MULTIPLE LINEAR REGRESSION ANALYSIS OF SIGNIFICANTLY VARIABLES ASSOCIATED WITH PATIENT SATISFACTION INDEX

Model	Unstandardized Coefficients*		Sig.
	B	Std. Error	
(Constant)	0.602	0.033	0.000
COPD	-0.241	0.050	0.000
Caregiver	0.156	0.043	0.000
CHF	-0.113	0.051	0.029

*Unstandardized beta coefficients are the average amount by which the dependent variable increases (or decreases) when the independent variable changes from 0 (no) to 1 (yes) and other independent variables are held constant.

COPD: chronic obstructive pulmonary disease

CHF: Congestive heart failure

age satisfaction index for FCGs was 4.57 (SD 4.22). No caregivers were completely satisfied with all 24 items, One caregiver (0.7%) was "completely satisfied" with 19/24 items and 17% of caregivers responded that they were not "completely satisfied" with any of the items (satisfaction index=0/24) (Figure 1). In multivariate analysis, no independent variables were found to be significantly associated with caregiver satisfaction. The FCGs' rating of satisfaction with the individual elements is presented in Table 4. The elements rated as "extremely important" and not "completely satisfied" most frequently by the FCGs were: "To

have an adequate plan of care and health services available to look after your family member at home upon hospital discharge," "That your family member has relief of symptoms," and "To receive adequate information" (Table 4).

DISCUSSION

In this multicentre study from five Canadian university-affiliated hospitals, we have identi-

fied elements of EOL care seriously ill hospitalized patients and their FCGs consider most important, and their levels of satisfaction with each element. The majority of patients and their family members in our survey were not completely satisfied with EOL care. Patients with a participating FCG reported higher satisfaction with care. This may be due to the extra personal care and support that the patient receives from the

Table 4 / FAMILY CAREGIVER RATINGS (%) OF IMPORTANCE AND SATISFACTION OF VARIOUS ELEMENTS RELATED TO QUALITY EOL CARE (Sorted from largest to smallest opportunity index*. Ratings: 1=not at all satisfied; 2=not very satisfied; 3=somewhat satisfied; 4=very satisfied; 5=completely satisfied)

Question	Ratings					Extremely important	Opportunity index*
	1	2	3	4	5		
To have an adequate plan of care and health services available to look after him/her at home after discharge from hospital	15	26	24	20	15	72	59
To have relief of symptoms: i.e., pain, shortness of breath, nausea, etc.	1	7	28	45	19	71	55
To receive adequate information about your family member's disease, including the risks and benefits of treatment	10	20	25	29	16	63	53
To have information relating to your family member's illness and needs be readily available to the doctors treating her/him upon admission to hospital	9	17	23	32	19	67	51
To be involved in decisions regarding the treatments and care that the patient receives	11	9	26	37	17	57	49
That your doctor is available to discuss your family member's disease and answer your questions in a way that you understand	13	20	20	25	22	61	47
To know which doctor is the main doctor in charge of your family member's care	9	16	30	24	21	60	45
That information about your family member's disease be communicated to you by the doctor in an honest manner	8	9	20	30	33	72	45
To have trust and confidence in the nurses looking after your family member	0	4	26	48	22	63	43
To have a sense of control over decisions concerning the care your family member receives	7	8	35	36	14	49	42
To have trust and confidence in the doctor looking after your family member	3	4	20	36	37	75	41
That the doctor discuss concerns relating to your family member's illness together as a group	15	20	19	23	23	49	38
To complete things, resolve conflicts, and say goodbye to your family member	5	5	15	40	35	66	37
That you receive respectful and compassionate care from health care providers	2	7	21	45	25	48	36
To receive help to make difficult treatment decisions	8	5	19	52	16	41	34
To have the same nurses looking after your family member	4	11	32	44	9	33	29
To have a private room so you can be comfortable and discussions relating to your family member's illness are confidential	6	10	31	36	17	37	27
To have someone listen to you and be with you when you are feeling sad, frightened, anxious, or confused	7	7	20	47	19	35	27
To have the opportunity to discuss your fears that your family member may die	10	12	27	33	18	33	24
To have the opportunity to strengthen or maintain the relationship with your family member	1	3	17	26	53	70	23
That you do not have financial problems due to your family member's illness.	3	5	26	29	37	37	22
To have your spiritual or religious needs met	3	5	26	44	22	19	14
To be able to contribute to others (time, knowledge, experience)	1	4	33	47	15	15	13
To not have your family member be kept alive on life support when there is little hope for a meaningful recovery	N/A	N/A	N/A	N/A	N/A	73	N/A
To be able to have your family member die in the location of his/her choice (i.e., home or hospital)	N/A	N/A	N/A	N/A	N/A	53	N/A

Opportunity index for a given element is the number of respondents who rated the element as "extremely important" and answered not "completely satisfied", divided by total number of respondents.

FCG that would not be provided by hospital staff. Patients with COPD and CHF seem to have a significantly lower assessment of satisfaction. We have previously found that, while symptom burden in both cancer and noncancer patients is similar, patients with medical diagnoses are much less likely to have palliative care consultation (28). It may be that patients with advanced medical disease are more dissatisfied because they receive inadequate EOL/palliative care, a reflection of the difficulty of prognosticating for such patients. However, if accurate prognostication is a requirement for initiating EOL care, we will miss significant opportunities to provide holistic EOL care to a population with high needs. We recommend a parallel approach of seeking recovery from underlying complications and exacerbations at the same time we attend to the elements of quality EOL care identified in this report. Furthermore, additional research into the underlying issues and causes of dissatisfaction in this medical population is warranted.

There seem to be significant opportunities for improvement of EOL care in the acute care sector in Canada. Moreover, the opportunity index we constructed for each element of care provides a priority score for quality improvement initiatives in EOL care. Patients and their FCGs consistently reported high discordance between the level of importance and degree of satisfaction with issues related to continuity of care ("To have an adequate plan of care and health services available to look after you at home upon discharge" and "Information available at the hospital upon admission"), symptom management ("To have relief of symptoms"), supportive care ("Not to be a burden on family"), patient-physician relationships ("To have trust and confidence in the doctor" and "Doctor be available"), and elements related to communication and decision making ("To have adequate information" and "To be able to participate in decision making"). Patients and family caregivers independently identified similar priority targets. Of the 10 elements that had the highest opportunity index from the patient's perspective and were relevant to the FCGs, eight were similarly rated by the FCGs. Our findings extend those from other studies of patients in diverse settings where the need for better information exchange, communication, symptom management, and access to physicians have emerged as central themes associated with satisfaction with EOL care (2,7,8,29,30).

Improvements in the quality of EOL care in Canada will require a multifaceted approach. Increasing the use of hospice and palliative care

resources may be one approach to improving quality EOL care. However, low levels of public knowledge and awareness of these services, as recently demonstrated in a public opinion poll in Canada, may deter access to and use of these resources (31). Furthermore, historically, these services have been primarily directed to cancer patients in the home environment. However, in Canada, the care of the dying principally occurs in the hospitalized setting with more than 70% of deaths occurring in hospitals (17). Current federal funding initiatives to increase the "basket" of services provided in the home care setting may neglect opportunities to improve EOL care provided to dying patients in hospitals.

At a provincial level, there is an initiative to improve the quality of EOL care on the internal medicine teaching units in academic, tertiary care, teaching hospitals in Ontario (32). This five-year project (sponsored by Associated Medical Services) hopes to develop physician role models, adequate system changes, and integration with palliative care services to allow for exemplary EOL care, with a particular emphasis on training the physicians of tomorrow.

Neither the federal nor provincial initiatives referred to above can succeed in isolation, as it appears that a cause of great anxiety for seriously ill patients and their families is the lack of continuity between the tertiary care and primary care sectors. Discontinuities with patient care occur frequently in the peri-hospital discharge period and are associated with quality of care problems (33). Preliminary evidence in a population similar to our study population would suggest that improving the continuity of care may be associated with a significant reduction in hospital days and emergent admissions (34), and improved satisfaction with care (35), although data are conflicting (36). More research is needed to determine optimal strategies to improve continuity of care and to ensure that these efforts translate into improved patient and family satisfaction.

Our study is notable for some unexpected findings. Previous studies (18,20) of patients with cancer, HIV/AIDS, and chronic diseases suggested that "control over decision making" was an important construct related to quality EOL care. In our study, only 17.3% consider this element to be "extremely important" and it was ranked as 27/28 in terms of the opportunity index. To have help making difficult decisions was also rated as less important and ranked as a low priority item. Promoting tools such as advance directives and/or living wills at the expense of considerate conversations more proximate to the

life-threatening illness may be misguided if the seriously ill, elderly patients, hospitalized with advanced medical disease in our study prefer to engage the physician looking after them in collaborative decision making rather than making decisions autonomously. It is more important for them to know who their doctor is, have him or her available to them, and have trust and confidence in the doctor than to have control of the care provided or be responsible for the decision making.

The strengths of our study include the use of a rigorously developed comprehensive questionnaire to elicit patients' and FCGs' views on EOL care. The process we used to develop the questionnaire provides a degree of face and content validity. However, we have not assessed the reliability of the questionnaire scores. Despite being the first multicentre study of its kind in Canada, the generalizability of our findings may be limited as more than 90% of our patients were Caucasians, representing patients in select urban settings. An additional limitation may be our use of "completely satisfied" as our benchmark to develop the opportunity index. We recognize the tendency to report positive responses in satisfaction surveys of health care recipients and an inability to translate findings into action for quality improvement (37). To deal effectively with this problem, we have only framed "satisfaction" (and not "dissatisfaction"), and have skewed our response options to reflect more degrees of lower levels of satisfaction (3 options) than higher levels of satisfaction (2 options) to encourage greater spread in the reporting of anything less than complete satisfaction. Furthermore, in our previous work, we focused on the maximally satisfied respondent and isolated "completely satisfied" (response option 5) to represent the desired response option or benchmark. Using this approach, we have been able to compare results across sites and highlight opportunities for improvement (38). Finally, each item in our questionnaire was developed to represent an "action item" such that, if anything less than "completely satisfied" is rated, that item reflects an opportunity for improvement. Admittedly, it is not clear whether we have sufficient resources to ensure that all patients and families are completely satisfied with all elements of EOL care, hence the need to prioritize initiatives based on the opportunity index.

Patients who receive terminal care inconsistent with their previously expressed wishes are more likely to be dissatisfied with care and consume considerable health care resources (39). We believe, therefore, that alignment of care

delivery with what matters most to individual patients and their families has the potential to not only improve quality but at reduced costs. In our national survey, we have elicited the perspectives of patients with serious life-limiting illnesses (six-month mortality >50%) and their FCGs to determine which elements of EOL care are most important, and their current satisfaction with those elements. Continuity of care and discharge planning, symptom management, supportive care, communication and decision making, and patient-physician relationship issues emerge as high-priority targets for quality improvement initiatives.

Date received, January 27, 2005; date accepted, May 24, 2005.

REFERENCES

1. Baker R, Wu AW, Teno JM, Kreling B, Damiano AM, Rubin HR, et al. Family satisfaction with end of life care in seriously ill hospitalized adults. *J Am Geriatr Soc* 2000; 48: S61-S69.
2. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004; 291: 88-93.
3. Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, et al. Perceptions by family members of the dying experiences of older and seriously ill patients. *SUPPORT Investigators. Ann Intern Med* 1997; 126: 97-106.
4. Department of General Practice, Medical School, University of Otago, Dunedin, New Zealand. Attitudes towards care of the dying: a questionnaire survey of general practice attenders. *Fam Pract* 1991; 8(4): 356-359.
5. Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, Piper M. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 1990; 301(6749): 415-417.
6. The SUPPORT Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995; 274: 1591-1598.
7. Hanson LC, Danis M, Garrett J. What is wrong with end of life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997; 45: 1339-1344.
8. Malacrida R, Bettelini CM, Degrate A, Martinez M, Badia F, Piazza J, et al. Reasons for dissatisfaction: a survey of relatives of intensive care unit patients who died. *Crit Care Med* 1998; 26: 1187-1193.
9. Azoulay E, Chevret S, Leleu G, Pochard F, Barbotou M, Adrie C, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 2000; 28: 3044-3049.
10. Sjobkist P, Nilstun T, Svantesson M, Berggren L. Withdrawal of life support—Who should decide? Differences in attitudes among the general public, nurses, and physicians [see comments]. *Intensive Care Med* 1999; 25(9): 949-954.
11. Ferrand E, Lemaire F, Regnier B, Kuteifan K, Badet M, Asfar P, et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. *Am J Respir Crit Care Med* 2003; 167(10): 1310-1315.
12. Carstairs S, Beaudoin GA. *Quality End of Life Care: The Right of Every Canadian*. Ottawa, Ontario: Government of Canada, 2000.
13. Health Canada. Health Canada's Secretariat on Palliative and End-of-Life Care: an introduction. http://www.hc-sc.gc.ca/english/care/palliative_secretariat.html

14. Rocker GM, Heyland DK. Dying in Canada: breaking down the traditional barriers in health care research. *CMAJ* 2003; 169: 3-4.
15. Government of Canada, Department of Finance. Highlights of Budget 2003: Economic and Fiscal Prospects. <http://www.fin.gc.ca/news03/03-010e.html#Highlights>
16. Carstairs S. Still Not There. Quality End-of-Life Care: A Progress Report. Ottawa, Ontario: Government of Canada, 2005.
17. Heyland DK, Lavery JV, Tranmer J, Shortt SED, Taylor SJ for the Queen's/KGH End of Life Research Working Group. Dying in Canada: Is it an institutionalized, technologically supported experience? *J Palliat Care* 2000; 16: S10-S16.
18. Singer PA, Martin DK, Kelner M. Quality end-of-life care. Patients' perspectives. *JAMA* 1999; 281: 163-168.
19. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000; 132: 825-832.
20. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001; 22: 738-751.
21. Heyland DK, Dodek P, Rocker G, Groll DL, Gafni A, Pichora D, et al. What matters in end of-life care: perceptions of seriously ill patients and their family members. *CMAJ* [in press].
22. Emanuel EL, Emanuel LL. The promise of good death. *Lancet* 1998; 351(suppl 2): 21-29.
23. Lynn J. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc* 1997; 45(4): 526-527.
24. Field MJ, Cassel CK (eds) for the Institute of Medicine Committee on Care at the End of Life. *Approaching Death: improving care at the end of life*. Washington, DC: National Academy Press, 1997.
25. The SUPPORT Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995; 274: 1591-1598.
26. Danis M, Mutran E, Garrett JM, Stearns SC, Slifkin RT, Hanson L, et al. A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. *Crit Care Med* 1996; 24: 1811-1817.
27. Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. *Gerontologist* 1970; 10(1): 20-30.
28. Tranmer JE, Heyland DK, Dudgeon D, Squires-Graham M, Coulson K. Measuring the symptom experience of seriously ill cancer and noncancer hospitalized patients near the end of life with the memorial symptom assessment scale. *J Pain Symptom Manage* 2003; 25(5): 420-429.
29. Tilden VP, Tolle SW, Garland MJ, Nelson CA. Decisions about life-sustaining treatment. Impact of physician's behaviors on the family. *Arch Intern Med* 1995; 155: 633-638.
30. Curtis JR, Patrick DL, Caldwell E, Greenlee H, Collier AC. The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians. *AIDS* 1999; 13(9): 1123-1131.
31. Hospice Palliative Care Survey. Ipsos Reid, 2004.
32. Associated Medical Services, Toronto, Ontario. <http://www.ams-inc.on.ca/default.htm>
33. van Walraven C, Mamdani MM, Fang J, Austin PC. Continuity of care and patient outcomes after hospital discharge. *J Gen Intern Med* 2004; 19(6): 624-631.
34. Wasson JH, Sauvigne AE, Mogielnicki RP, Frey WG, Sox CH, Gaudette C, et al. Continuity of outpatient medical care in elderly men. A randomized trial. *JAMA* 1984; 252: 2413-2417.
35. Hjortdahl P, Laerum E. Continuity of care in general practice: effect on patient satisfaction. *BMJ* 1992; 304: 1287-1290.
36. Weinberger M, Oddone EZ, Henderson WG. Does increased access to primary care reduce hospital readmissions? Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission. *N Engl J Med* 1996; 334: 1441-1447.
37. Ingram BBL, Chung RS. Client satisfaction data and quality improvement planning in managed mental health care organizations. *Health Care Manage Rev* 1997; 22: 40-52.
38. Dodek PM, Heyland DK, Rocker G, Cook DJ. Translating family satisfaction data into quality improvement. *Crit Care Med* 2004; 32: 1922-1927.
39. Teno JM, Fisher ES, Hamel MB, Coppola K, Dawson NV. Medical care inconsistent with patients' treatment goals: association with 1-year Medicare resource use and survival. *J Am Geriatr Soc* 2002; 50: 496-500.

Appendix / LIST OF CONTRIBUTORS AND PARTICIPATING INSTITUTIONS

A. Contributors

From Queen's University, Kingston, Ontario: Dr. Daren Heyland, principal investigator; Dr. Joan Tranmer, co-investigator; Dr. Sam Shortt, co-investigator; Dr. Sandra Taylor, co-investigator; Dr. Deborah Feldman-Stewart, co-investigator; Deborah Pichora, study coordinator; Dianne Groll, statistician; Dr. Miu Lam, statistician.

From the University of British Columbia, Vancouver, British Columbia: Dr. Peter Dodek, co-investigator; Judith Edgar, research assistant.

From the University of Alberta, Edmonton, Alberta: Dr. Jim Kutsigiannis, co-investigator; Sara Currie, research assistant.

From the University of Toronto, Toronto, Ontario: Dr. Neil Lazar, co-investigator; Andrea Matte-Martin, research assistant.

From Dalhousie University, Halifax, Nova Scotia: Dr. Graeme Rocker, co-investigator; Gail Sloane, research assistant.

B. Institutions

Queen Elizabeth II Health Sciences Center, Halifax, Nova Scotia (400 beds)

Kingston General Hospital, Kingston, Ontario (400 beds)

Toronto General Hospital, Toronto, Ontario (471 beds)

St. Paul's Hospital, Vancouver, British Columbia (400 beds)

Royal Alexandra Hospital, Edmonton, Alberta (520 beds)
