

Abstract word count - 248

Text word count – 2447

**Discussing prognosis with patients and their families near the end of life:
Impact on satisfaction with end of life care**

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Funding provided by the National Health and Research Development Program of Canada for Dr. Daren Heyland. The sponsor played no role in the design, analysis, or interpretation of this study. For all other authors, no financial or other potential conflicts of interest exist.

Key words: prognosis, quality care, end of life care, palliative care, observational study, communication and decision making

Abstract

Background:

Seriously ill patients and their physicians often avoid discussing prognosis; this may compromise optimal End-of -Life (EOL) care planning. The impact of a prognosis discussion on patient and family satisfaction with EOL care is unknown.

Methods:

We surveyed hospitalized patients with cancer or end-stage medical disease (and their families) concerning self-assessed relevance of EOL issues and overall satisfaction with EOL care. We compared their satisfaction with EOL care based on whether or not a physician had discussed the patient's prognosis with them. We used a 5-domain questionnaire developed to measure satisfaction with EOL care; scores were standardized from 0-100 points.

Results:

440 of 569 eligible patients (77%) and 160 of 176 eligible family members (91%) participated in this study. Overall, 18.0% of patients and 30.1% of families recalled a prognosis discussion with a physician. Patients who had discussed prognosis (vs. those who had not) were more satisfied with overall care (76.1 vs. 73.1 points, $p=0.02$), with the communication and decision-making domain (77.9 vs. 72.9 points, $p=0.01$), and were more willing to discuss code status (69.6% vs. 55.3%, $p=0.03$). Family members' overall satisfaction was also higher (75.3 vs. 70.4 points, $p = 0.03$). Multivariate analyses

confirmed the importance of the relationship between the prognosis discussion and overall satisfaction for both patients and family members.

Conclusion:

Discussions about prognosis occur infrequently for patients who have advanced terminal disease. Discussing prognosis at the end of life with patients and their families may facilitate goal setting and improve satisfaction with EOL care.

Abbreviations:

Canadian Association of Researchers at the End of Life Network (CARENET)

End-of -Life (EOL)

ordinary least squares (OLS)

Congestive heart failure (CHF)

chronic obstructive pulmonary disease COPD

Introduction

“I didn’t expect him to die so soon. I got the feeling the doctors weren’t entirely honest with us about his condition. My husband resisted talking about dying and after 40 years of marriage I feel he let me down by not opening up and I guess I let him down for not knowing how to talk about some of the things that I needed to discuss. It would have been nice closure if things had been different in the end. I can never get that time back.”

Truth telling by physicians as death approaches *may* enable patients and families to bring closure and to discuss treatment preferences with their physicians.^{1, 2} Observational studies document that such discussions occur infrequently^{3,4} and are rarely initiated by physicians.^{5,6,7} When these conversations do occur, patients often express dissatisfaction with physician performance and the quality of the interaction.^{8,9} Suboptimal communication at the end of life can increase anxiety and emotional distress, decrease hope, and worsen overall suffering.¹⁰

The impact of prognostic discussions on patients’ perceptions of care is unknown. We sought to enrich our understanding of the relationship between satisfaction with end of life care and discussions regarding the patient’s prognosis. We hypothesized that a prognostic discussions would have no adverse effect and may improve patient and family satisfaction with EOL care. Furthermore, in a secondary analysis, we postulated that when there is agreement between patient and family member on prognosis, both groups would be more satisfied with EOL care than when they have discordant views.

Methods

Design

We administered a cross-sectional survey to inpatients in 5 Canadian tertiary-care teaching hospitals. Eligible patients and methods have been reported in detail elsewhere.^{Error: Reference source not found}¹¹ In brief, we enrolled patients, > 55 years old, who had significant, advanced, end stage pulmonary, cardiac, and hepatic disease or metastatic cancer. Patients identified a family member or person close to them (hereafter referred to as family member) who provided some form of care at home. If no such person was available, patients were given only the patient-based questionnaire. All study participants gave informed written consent before participation; this study was approved by the Research Ethics Boards of all participating institutions.

Questionnaire development

The development of the questionnaires and pre-testing have been explained in detail elsewhere.^{Error: Reference source not found}^{Error: Reference source not found} Briefly, we formulated a list of key EOL care elements based on classifications of quality EOL care. Satisfaction with 26 elements of EOL care was rated overall, and in five distinct domains: medical and nursing care, communication and decision-making, social relationships and support, meaningful existence, and community care. Participants rated their satisfaction on a 5-point Likert scale.

Variables

Individual items in the questionnaire were summed for each of the EOL care domains and for overall satisfaction and then standardized to a maximum score of 100 points by dividing by the maximum possible score and multiplying by 100. Patients and family members were also asked if they had a discussion regarding their prognosis with a physician using the following question: “Have the doctors told you how long you (or the patient) can expect to live?” Response categories for both groups were yes/no. Next, to assess the patient’s own evaluation of their prognosis, all participants were asked if the patient was currently facing issues at the end of life (response options: I/the patient am/is currently facing them or have faced them; will likely face them in the next few weeks to months; will likely face them in the next 6 months; will likely face them in the next year; or not relevant). Patients were asked if they were willing to discuss their cardiopulmonary resuscitation preferences and to rate their current level of care on a scale of 1-10 where 1=comfort measures only and 10=full aggressive curative care. Finally, both patients and family members were asked to state their preference for location of death (response options: home, hospital, or doesn’t matter).

Socio-demographic data collected for the patients included living arrangements, availability of a family member, education, employment status, age, gender, marital status, religion, and type of community in which they lived (rural vs urban). Patient health-related variables included diagnosis, and the Katz Functional Status Tool¹², a 6-item scale measuring functional ability with 0=dependence and 1=independence. Scores

were summed across the items to develop the overall score. Family member socio-demographic data included education, employment status, age, gender, and marital status.

Study participants were categorized in the primary analysis based on whether they had discussed prognosis with the physician. In the secondary analysis, we categorized participants according to agreement between patients and their family members on whether the patient is currently facing end-of-life issues. Satisfaction with EOL care was compared based on these categories.

Statistics

A simple frequency of prognostic disclosure was calculated. T-tests and chi-square tests were used to examine the bivariate relationships between those who did and did not have a prognostic discussion with the physician, from both patient and family member perspectives. No adjustments were made for multiple tests of significance. Ordinary least squares (OLS) regression models were developed to identify significant factors that were associated with satisfaction with EOL care. The dependent variables included overall satisfaction with EOL care, as well as satisfaction with the subscale domains. For all models, the independent variables were the socio-demographic and health-related co-variates for patients and family members listed above. All independent and co-variates were entered as a block into the regression models. Before doing the multivariate analyses, functional impairment was corrected for skewness by squaring the term in both patient and family member models. Finally, in order to compare patient and family

agreement with the relevancy of EOL issues, we repeated the bivariate analyses described above.

Results

Participants

A total of 569 eligible patients were identified and approached for consent at five Canadian hospitals between November 2001 and June 2003. Of these, 447 provided consent for an overall response rate of 78.6%. One patient died the day before the interview and 6 patients withdrew from the study shortly after the start of the interview leaving 440 (77%) completed patient interviews. Only 226 (50.5%) of the participating patients had a family member who visited them in hospital and thus could be invited to participate in the study. Due to logistical reasons, only 176 of these family members were approached for consent and, of these, 160 agreed to participate (90.9% response rate).

Patient demographics and care-related variables based on discussion of prognosis

Four hundred and twelve of the 440 patients responded to the prognosis discussion question. 74 (18.0%) stated that they had discussed prognosis with a physician. Demographic and care-related variables according to the occurrence of a discussion of prognosis are presented in Table 1.

In terms of quality of care, patient satisfaction with overall EOL care was higher in the group who had discussed prognosis with a physician than in those who had not (76.1 vs. 73.1 points, $p = 0.02$). When significance tests were run separately for each of the five satisfaction domains (see Table 1), the results suggest that patients who had a discussion about their prognosis were more satisfied in the communication and decision-making domain than those who did not (77.9 vs 72.4, $p = 0.008$).

Patients who said they had discussed prognosis with their physician were more willing to discuss preferences regarding cardiopulmonary resuscitation (69.6 vs. 55.3%, $p = 0.03$), and there was a trend towards these patients being more likely to state that they were currently facing EOL issues (66.7 vs. 55.7%, $p = 0.054$). Patients were also more likely to prefer a home death if they had discussed EOL issues with their physicians (63.9 vs. 47.9%, $p = 0.024$). Of the 338 patients who had not had a discussion about prognosis with their attending physician, 143 (43.6%) said they would be interested in having such a conversation and 185 (56.4%) said they would not.

Family member demographics and care-related variables based on discussion of prognosis

One hundred and fifty-three of the 160 family members responded to the question about prognosis. Of these, 46 (30.1%) stated that they had discussed the patient's prognosis with the patient's physician. The demographics and care-related variables for family

members according to the presence or absence of a discussion on prognosis are shown in Table 2.

Family members' overall satisfaction was higher in the group that had discussed prognosis compared to those who had not (75.3 vs. 70.4 points, $p = 0.03$). They were also more satisfied with communication and decision-making (72.2 vs. 64.6 points, $p = 0.04$) and the social support domain (80.9 vs. 74.8 points, $p = 0.03$). There was a non-significant trend toward increased satisfaction with the physician/nursing care domain in the group who had discussed prognosis with the physician compared to those who did not (76.4 vs. 72.2 points, $p=0.06$). Of the 108 family members who had not had a discussion about prognosis with the attending physician, 97 (89.8%) said they would like such a discussion and 11 (10.2%) said they would not.

Regression analyses

For both patients and family members, the multivariate analyses confirm the importance of the relationship between having a prognosis discussion and overall satisfaction with EOL care, after controlling for demographic and health-related variables ($p = 0.012$ for patients; $p=0.028$ for family members; see Tables 3 and 4). Patients also exhibited an increased satisfaction with the communication and decision-making, social support, and meaningful existence domains ($p = 0.012$, 0.023 , and 0.038 respectively) if they had discussed prognosis. Family members reported being more satisfied with the physician/nursing care and social support care domains ($p = 0.036$ and 0.005 respectively) if they had discussed prognosis.

Relationship between agreement on facing EOL issues and patient satisfaction with EOL care

Of the 145 pairs of patients and family members who responded to the question about whether the patient was currently facing EOL issues, 102 (70.3%) had the same perspective. As shown in Table 5, patients were more likely to be satisfied with the communication and decision-making domain if they were concordant with their family member with respect to whether the patient was currently facing EOL issues compared to those who were discordant (77.3 vs. 69.3 points, $p = 0.007$). Concordant pairs also tended to have higher overall satisfaction with EOL care than discordant pairs (75.5 vs. 72.2 points, $p=0.07$). Finally, a larger proportion of concordant patients and family member pairs than discordant pairs were willing to discuss preferences regarding cardiopulmonary resuscitation (72.7% vs. 59.0%, $p=0.09$).

From the family member's perspective, there were no significant differences in either demographics or satisfaction with EOL care between the concordant and discordant groups (data not shown).

Discussion

Patients with life-limiting, advanced chronic disease identify that honest information about their condition and having time to prepare for life's end are key aspects of quality end of life care.^{Error: Reference source not found} By increasing the quantity and quality of discussions about prognosis, it should be possible to increase satisfaction with EOL care. However, if knowledge of prognosis is not desired or the discussion is done poorly, there is the potential for harm.

In this study, we surveyed 440 patients and 160 families to examine the relationship between having a conversation with their physician about prognosis and satisfaction with EOL care. Despite the fact that more than 50% of patients died within 6 months of the interview, a minority of patients (18%) and families (30%) recalled having such a conversation with physicians. Those patients who stated they had such a discussion were much more likely to discuss code status, agree that EOL issues were relevant to them, and desire a home death. Others have reported that patient and families who have unrealistic expectations of their prognosis are more likely to choose aggressive terminal care in hospital.¹³

Perhaps our most significant observation was that patients and families who had discussed prognosis with their physicians were equally or more satisfied than those that had not. Furthermore, when patients and families agreed on prognosis, they reported greater satisfaction with care compared to discordant patients and families. We are not aware of other reports in the literature comparing patient satisfaction with prognostic disclosure, but our findings are consistent with numerous other studies of optimal care at

the EOL which suggest that improving communication and decision making will have the greatest impact on quality of care.^{14, 15, 16}

Another important finding was that patients who have medical diagnoses were less likely than their cancer counterparts to have a discussion about prognosis. Given differing and sometimes unpredictable disease trajectories this is not surprising.¹⁷ However symptom burden and short term outcomes for elderly patients who have end stage medical disease is often as poor or worse than that for these patients who have cancer.^{18, 19}

Waiting until a terminal prognosis is certain may limit opportunities for adequate information exchange and time to prepare for death. Patients and families accept prognostic uncertainty²⁰ and honest, timely, and complete communication are key determinants to overall satisfaction with care.^{21, 22} Nevertheless and despite a high risk of mortality in ensuing months, most patients reported that they had not had an EOL discussion. Over half of our study patients said they'd rather not discuss prognosis with their physicians, In contrast, although most caregivers' had not had an EOL discussion, 90% of them would have liked to have had such a discussion, a finding which is congruent with other reports.²³ Our finding that patient and family member congruency on 'facing EOL' and increased satisfaction with care suggests that efforts to align preferences for prognosis disclosure between patients and family *may* increase satisfaction with EOL care.

This study has several limitations. First, we relied on patient and family member recall that a prognosis discussion had or had not occurred. We did not explore whether a prognosis discussion was attempted and discontinued because of patient preference to

avoid such a discussion; thus our findings may not be applicable to patients who do not wish to have prognosis discussions. The study was conducted in academic tertiary care Canadian hospitals with principally white, Anglo-Saxon, Christian subjects; our findings may thus not be applicable to other settings. Given the cross sectional nature of our survey, we cannot attribute increased satisfaction to a prior prognosis discussion. Finally, to measure satisfaction we used a novel instrument; the clinical importance of a difference of 4-5 points on this instrument is unknown.

In summary, this study suggests that when prognosis is discussed with patients and families, satisfaction with their care increases, especially in relation to communication and decision-making. Communicating prognosis with seriously ill patients and their families, and ensuring similar perspectives on end of life issues may have a positive impact on EOL care.

Acknowledgements:

Financial Support: Funding provided by the National Health and Research Development Program of Canada. The sponsor played no role in the design, analysis, or interpretation of this study. We would like to thank all the study personnel and site investigators who participated in this study. See reference #1 for a complete list.

Table 1: Patient demographics and care-related variables based on discussion of prognosis

	Had discussion (n= 74)	Did not have discussion (n=338)	Total (n=412)	p- value
Demographics				
Age	67.6 (7.2)	71.9 (9.4)	71.2 (9.1)	0.001
Gender (female)	36 (48.6)	166 (49.3)	210 (48.4)	0.92
Education (%post secondary)	19 (26.4)	54 (22.5)	96 (23.2)	0.31
Marital status (%married/ common law)	47 (65.3)	175 (52.4)	234 (55.2)	0.003
Lives alone	25 (33.8)	109 (32.5)	140 (32.7)	0.84
Rural Site	9 (12.3)	88 (26.2)	104 (24.4)	0.01
Kingston	24 (32.4)	108 (32.0)	140 (31.9)	0.15
Vancouver	24 (32.4)	106 (31.5)	138 (31.4)	
Edmonton	6 (8.1)	18 (5.3)	26 (5.9)	
Halifax	7 (9.5)	68 (20.2)	75 (17.1)	
Toronto	13 (17.6)	37 (11.0)	60 (13.7)	
Health-related				
Katz Medical group	5.18 (1.43)	4.96 (1.32)	4.99 (1.34)	0.10
Cancer	40 (54.1)	111 (32.8)	164 (37.7)	0.004
CHF	14 (18.9)	85 (25.1)	106 (24.1)	
COPD	10 (13.5)	105 (31.1)	118 (26.8)	
Cirrhosis	10 (13.5)	37 (10.9)	50 (11.4)	
Alive at 6 months	23 (32.9)	147 (44.5)	175 (41.0)	0.07
Care-Related Variables				
Overall Satisfaction index	76.09 (9.65)	73.06 (10.62)	73.13 (10.80)	0.02

Domains

Physician/nurse care	77.27 (12.43)	74.82 (11.89)	74.88 (12.28)	0.11
Community care	65.54 (20.01)	67.17 (18.84)	66.97 (18.78)	0.51
Communication and decision-making	77.86 (15.38)	72.39 (16.16)	72.88 (16.24)	0.008
Social support	75.68 (11.84)	72.68 (13.76)	72.96 (14.00)	0.08
Meaningful existence	76.22 (13.47)	73.59 (13.69)	73.91 (13.71)	0.14
Relevance (%I am currently facing or have faced EOL issues)	46 (66.7)	186 (55.7)	232 (57.6)	0.05
Willing to discuss code status	48 (69.6)	176 (55.3)	224 (57.9)	0.03
Preference for level of care	5.91 (3.94)	6.16 (3.21)	6.10 (3.35)	0.62
Preference for home death	46 (63.9)	158 (47.9)	206 (51.0)	0.02

Legend:

Categorical variables are reported as counts (percent) and continuous variables as mean (standard deviation).

CHF- congestive heart failure

COPD- chronic obstructive pulmonary disease

EOL- End of life

Table 2: Family member demographics and care-related variables based on discussion of prognosis

	Had discussion (n=46)	Did not have discussion (n=107)	Total (n=153)	P-value
Demographics				
Age	56.8 (14.0)	57.4 (13.5)	57.3 (13.5)	.81
Gender (%female)	27 (60.0)	70 (66.0)	104 (65.8)	.48
Relationship (%spouse)	21 (47.7)	45 (42.1)	70 (44.3)	.21
Relationship (%child)	22 (50.0)	51 (47.7)	75 (47.5)	.21
Employment status (%retired)	20 (44.4)	44 (41.1)	65 (41.4)	.67
Care-related				
Satisfaction index	75.24 (13.29)	70.35 (12.16)	71.87 (12.66)	0.03
Domain				
Physician/nurse care	76.41 (14.21)	72.21 (12.07)	73.52 (12.80)	0.06
Community care	66.14 (22.95)	62.48 (22.06)	63.38 (22.42)	0.37
Communication and decision-making	72.15 (20.60)	64.62 (20.76)	67.14 (20.85)	0.04
Social support	80.87 (16.01)	74.80 (14.88)	76.56 (15.34)	0.02
Meaningful existence	78.07 (13.55)	75.96 (16.10)	76.60 (15.26)	0.44
Preference for home death	27 (58.7)	43 (40.6)	71 (45.8)	0.22
Relevance (% Patient is currently facing or have faced EOL issues)	35 (76.1)	70 (67.3)	105 (68.6)	0.10

Legend:

Categorical variables are reported as counts (percent) and continuous variables as mean (standard deviation).

Table 3: Ordinary least squares (OLS) multiple linear regression results: patient satisfaction with EOL care and prognostic discussion

	Unstandardized beta coefficients	SE	P-value
Overall satisfaction			
Discussion of prognosis	3.570	1.419	0.012
Age	0.151	0.067	0.025
Cancer	2.495	1.082	0.022
Rural	2.566	1.226	0.037
F = 2.212 Adj. r^2 =0.036			
Physician/nurse care			
Cancer	2.865	1.287	0.027
Rural	3.272	1.459	0.026
F = 1.992 Adj. r^2 =0 .030			
Communication/decision-making			
Discussion of prognosis	5.888	2.319	0.012
F = 1.340 Adj. r^2 = 0.010			
Social support			
Discussion of prognosis	4.318	1.895	0.023
Female	-3.579	1.457	0.015
Age	0.275	0.090	0.002
Cancer	2.904	1.448	0.046
Retired	-3.701	1.698	0.030
F = 2.782 Adj. r^2 =0 .052			
Meaningful existence			
Discussion of prognosis	3.958	1.904	0.038
Age	0.257	0.091	0.005
Married/common-law	-3.952	1.482	0.008
F = 2.254 Adj. r^2 = 0.038			

Note: The beta estimates the increase in the dependent variables (satisfaction scores) per unit increase of continuous predictors or in the yes versus no group for binary predictors.

Table 4: Ordinary least squares (OLS) multiple linear regression results: Family member satisfaction with EOL care and prognostic discussion

	Unstandardized	SE	P-value
	beta		
	coefficients		
Overall satisfaction			
Discussion of prognosis	5.127	2.304	0.028
F = 1.890			
Adj. r^2 = 0.041			
Physician/nurse care			
Discussion of prognosis	4.734	2.230	0.036
Functional ability	0.232	0.085	0.007
Post-secondary education	-6.209	2.124	0.004
F = 4.112			
Adj. r^2 = 0.131			
Social support			
Discussion of prognosis	7.776	2.726	0.005
Age	0.271	0.133	0.044
F = 1.894			
Adj. r^2 = 0.042			

Note: The beta estimates the increase in the dependent variables (satisfaction scores) per unit increase of continuous predictors or in the yes versus no group for binary predictors.

Table 5: Relationship between agreement with family member on whether patient was currently facing EOL issues and patient satisfaction

	Agree (n=102)	Disagree (n=43)	Total (n=145)	P-value
Demographics				
Age	71.64 (9.00)	70.95 (8.43)	71.43 (8.81)	0.67
Gender (%female)	46 (45.1)	20 (47.6)	66 (45.8)	0.46
Education (%post secondary)	19 (19.0)	10 (24.4)	29 (20.6)	0.57
Marital status (%married/commonlaw)	67 (65.7)	22 (52.4)	89 (61.8)	0.32
Lives alone	23 (22.5)	13 (30.2)	36 (24.8)	0.22
Employment status (retired)	69 (67.6)	30 (69.8)	99 (68.3)	0.38
Rural Site	26 (25.7)	12 (27.9)	38 (26.4)	0.47
Kingston	34 (33.3)	7 (16.3)	41 (28.3)	0.008
Vancouver	33 (32.4)	27 (62.8)	60 (41.4)	
Edmonton	5 (4.9)	2 (4.7)	7 (4.8)	
Halifax	21 (20.6)	3 (7.0)	24 (16.6)	
Toronto	9 (8.80)	4 (9.3)	13 (9.0)	
Health-related				
Katz Medical group	4.63 (1.52)	5.23 (1.31)	4.81 (1.48)	0.02
Cancer	42 (41.2)	16 (37.2)	58 (40.0)	0.55
CHF	27 (26.5)	17 (39.5)	44 (30.3)	
COPD	28 (27.5)	8 (18.6)	36 (24.8)	
Cirrhosis	5 (4.9)	2 (4.7)	7 (4.8)	
Alive at 6 months	41 (40.6)	17 (40.5)	58 (40.6)	0.57
Care-related				
Satisfaction index	75.46 (10.00)	72.18 (9.22)	73.13 (10.80)	0.07

Domains

Physician/nurse care	75.74 (11.71)	74.07 (12.13)	74.88 (12.28)	0.44
Community care	65.15 (20.43)	64.75 (16.33)	66.97 (18.78)	0.91
Communication and decision- making	77.32 (15.09)	69.34 (18.24)	72.88 (16.24)	0.007
Social support	76.13 (12.51)	72.85 (12.31)	72.96 (14.00)	0.15
Meaningful existence	75.61 (14.13)	76.59 (12.76)	73.92 (13.71)	0.70
Preference for level of care	6.50 (3.67)	6.26 (3.08)	6.43 (3.50)	0.72
Preference for home	59 (57.8)	18 (46.2)	77 (54.6)	0.41
death				
Willing to discuss code status	72 (72.7)	23 (59.0)	95 (68.8)	0.09

Contribution of the various authors:

The below authors have participated in the study with the specific contributions cited below, and have approved the final version. They have no conflicting interest (no financial interest or personal relationship with anyone that could inappropriately influence the results).

Author	Contribution
Daren Heyland	Conception and design of the study, data collection, data analysis, manuscript preparation
Diane Allan Deb Pichora	Data analysis, manuscript preparation Conception and design of the study, data collection, manuscript preparation
Peter Dodek	Conception and design of the study, data collection, interpretation of data, manuscript preparation
Graeme Rucker	Conception and design of the study, data collection, interpretation of data, manuscript preparation
Amiram Gafni	Conception and design of the study, interpretation of data, manuscript preparation

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