Prevalence of symptoms at the end of life in an acute care hospital: a retrospective cohort study

Daniel Kobewka MD MSc, Paul Ronksley PhD, Dan McIsaac MD MPH, Sunita Mulpuru MD MSc, Alan Forster MD MSc

Abstract

Background: There is currently debate over the benefits and harms of physician-assisted death. One of the factors influencing this debate is concern about symptoms in the days before death. The objective of this study was to describe the frequency of symptoms before death and determine patient characteristics associated with these symptoms.

Methods: We reviewed the medical record of every patient who died at a multisite academic teaching hospital over a 3-month period. We determined the number of episodes of pain, dyspnea, agitation and nausea during the final 48 hours of life and assessed the patient and encounter characteristics associated with 2 or more episodes of symptoms.

Results: A total of 480 patients died during the study period. Of these patients, 29.2% (140/480) had 2 or more symptoms in the final 48 hours of life. Higher Elixhauser comorbidity scores (relative risk [RR] 1.35, 95% confidence interval [CI] 1.23–1.49), having a family doctor (RR 2.33, 95% CI 1.02–5.38), being admitted to the medical oncology service (RR 1.51, 95% CI 1.11–2.05) and having a documented order for no resuscitation written early during the stay in hospital (RR 1.38, 95% CI 1.01–1.89) were independently associated with symptoms. Admission to intensive care was associated with fewer symptoms (RR 0.39, CI 95% 0.19–0.80).

Interpretation: Symptoms are common in the final 48 hours of life, particularly in patients with multimorbidity who want limitations on the aggressiveness of their care. An integrated palliative approach is needed for select at-risk patients.

The care of terminally ill patients has become a substantial issue facing providers and policy-makers. Heightening this attention are the evolving perspectives on physician-assisted death by various patient advocacy groups and the general public. It is likely these views are driven in part by recognition that many patients experience symptoms at the time of death. Avoiding symptoms is important to patients at the end of life and is likely a primary motivation for physician-assisted death.[1–3]

Our knowledge of terminal patients' experiences is limited. In Canada, as in many countries, most deaths occur in acute care hospitals.[4,5] This may not be the most appropriate location to provide end-of-life care,[6] but it does create an opportunity to evaluate symptoms in a large proportion of dying patients. Previous research is dated or has focused mostly on disease-specific cohorts.[7–11] These studies, although limited in focus, do suggest that a substantial proportion of patients have poor symptom control at the time of death.[12–14]

We performed this study to describe the epidemiology of symptoms before death for patients in a multisite academic health sciences centre. This information will guide better service delivery by instructing providers on the extent of any potential care gap between patient desires and outcomes. More importantly, it will help define target populations to maximize the impact of any interventions, such as enhanced palliative care services and physician-assisted death.

Methods

Study design and population

We conducted this study at The Ottawa Hospital — an academic health sciences centre with 3 campuses, 1065 beds and a catchment area population of about 1 million. We included all adult inpatients who died in hospital between Sept. 5 and

Dec. 16, 2013. The study period was a convenience sample for which baseline data had already been collected as part of a related study. We excluded people who died in the emergency department before admission.

Data sources
Data were extracted from 2 main sources, the Ottawa Hospital Data Warehouse (OHDW), and from direct review of the patient's medical record by a clinician. The OHDW is a relational database that contains clinical and administrative information extracted from the hospital's information systems, including the patient registration system, clinical data repository and patient abstracts. Professional coders use International Statistical Classification of Diseases and Related Health Problems, 10th revision, Canadian version, to enter diagnostic codes.

Study variables
Using a standardized chart extraction form, a clinician reviewed the medical record from the final hospital admission of each patient. The form was initially piloted on 10 charts to ensure usability and feasibility for collecting each data element. Minor modifications were made extracting data for the full cohort. Information on patient decision-making about resuscitation was collected to understand the wishes of people with more symptoms at the end of life. In addition, early documentation of patient preferences for resuscitation is a quality indicator for end-of-life care.[15,16] The variables extracted from the patient's medical record included the patient's wishes for cardiopulmonary resuscitation (CPR) and mechanical ventilation as documented during the first 24 hours of admission, any order to withhold CPR and mechanical ventilation written before the time of death, the number of days before death the resuscitation orders were written, whether family was present at any point in the final 24 hours of life, and symptoms of pain, dyspnea, agitation or nausea occurring in the final 48 hours of life.

Using the OHDW, we extracted information regarding patient demographics, previous inpatient encounters, total length of hospital stay before death, whether the patient had a family physician, hospital service on admission and at the time of death, most responsible diagnosis that caused the patients' hospital stay, Elixhauser comorbidities, Elixhauser score and baseline risk of death at time of admission.[17,18] The Elixhauser comorbidity score is calculated from 30 different medical conditions identified through administrative data. The score summarizes disease burden and is correlated with the risk of in-hospital death. The estimated baseline risk of death in hospital was calculated using a validated risk score that uses laboratory test values, patient demographics and comorbidities.[19]

Outcomes
The primary outcome was the incidence of symptoms during the final 48 hours of life, as documented in the patient chart. We counted each documented episode of pain, dyspnea, nausea or agitation. These symptoms were selected because they are common at the end of life and cause considerable distress for many patients.[1,20] When pain was documented with a rating on a scale anchored at 0 (no pain) and 10 (worst possible pain), we only counted pain scoring 5 or higher. We used this threshold to capture pain that was likely causing distress and not simply a nuisance.[21–23] During the study period, our hospital had an hourly rounding policy that required nurses to assess each patient every hour. There was, however, no standardized treatment pathway to deal with symptoms.

Analysis
We described the frequency of each symptom in the final 48 hours of life. We used means (± standard deviation [SD]), medians (interquartile range [IQR]) and proportions as appropriate to describe the characteristics of patients who died during the study period. We compared characteristics of patients who had 2 or more episodes of symptoms in the final 48 hours of life with those who had fewer than 2 episodes of symptoms in the final 48 hours of life. We chose a cut-off of 2 symptomatic episodes because patients with multiple symptomatic episodes are more likely to have a poor-quality death and have more to gain from symptom-reducing interventions.[24] We used χ^2 or 2-sample t-tests as appropriate for the bivariate analysis.

We developed multivariable logarithmic binomial regression models to identify patient and admission characteristics associated with the presence of 2 or more symptoms in the final 48 hours of life. We chose logarithmic binomial regression because of the intuitive interpretation of relative risks (RRs) and the divergence of odds ratios and RRs when an outcome is common.[25,26] A stepwise model-building approach was selected using RRs with corresponding 95% confidence intervals (CIs) as the common measure of association. All patient and admission characteristics that had p values of 0.10 or below in the bivariate analysis were used for multivariate analysis. Specifically, we tested patient characteristics (age, sex, Elixhauser comorbidity score at admission [modelled as a continuous variable] and presence of a family physician), hospital admission characteristics (admitting service, number of prior admissions in past 6 mo and involvement of a palliative care physician) and patient wishes regarding resuscitation and mechanical ventilation at the time of admission. Variables that had a potential for reverse causation given their timing related to the outcome of interest were not included in multivariate analysis. This included patients' wishes for resuscitation recorded at the time of death and presence of family during the final 24 hours of life. We then used backward elimination techniques (α = 0.05) to develop reduced models. All analyses were completed using SAS version 9.3 statistical software.

To further describe patients who died with symptoms we selected several representative cases to describe in narrative format. These cases were pseudonymized to maintain confidentiality.

Ethics approval
This study was approved by the Ottawa Health Science Network Research Ethics Board.

Results

During the study period, 14 266 patients were admitted to hospital. The mean age of patients was 48.9 (± 27.3) years, 56.5% were female, and the median length of stay was 3 (IQR 2–7) days. There were 480 deaths during the study period (3.4% mortality). Among decedents, the mean age was 73.7 (± 16.1) years, 47.5% were female, and the median length of stay was 7 (IQR 3–17) days. The medical record of 1 patient could not be located and was therefore excluded from further analysis.

The most common comorbidities in the population are presented in Table 1. The 5 most common most responsible diagnoses were palliative care (21.3%), sepsis (5.2%), congestive heart failure (4.8%), pneumonia (2.5%) and exacerbation of chronic obstructive pulmonary disease (2.1%).

Among the 479 patients who died and had complete records, 207 (43.2%) had at least 1 symptom documented in the final 48 hours of life, and 140 (29.2%) had at least 2. Pain and dyspnea were the most common symptoms, while nausea was the least common (Table 2).

Table 3 shows the characteristics of patients with 2 or more episodes of symptoms in the final 48 hours of life compared with those with fewer than 2 episodes. Patients with 2 or more episodes of symptoms in the final 48 hours of life had significantly more inpatient encounters in the preceding 6 months, more inpatient days in the last year, longer length of stay and higher Elixhauser comorbidity scores compared with patients who had fewer than 2 episodes (Table 3).

Patients with 2 or more episodes of symptoms were also more likely to have a family physician, more likely to be admitted to an oncology service and less likely to be admitted to the intensive care unit (ICU). Patients with 2 or more episodes of symptoms were more likely to have a wish for "no resuscitation, no ICU admission" documented within 24 hours of admission (47.1% v. 34.4%, $p = 0.01$), compared with those with fewer than 2 episodes. Patients with symptoms before death were also more likely to have a no resuscitation order documented in the chart at the time of death (90.7% v. 71.1%), were less likely to have this order written within 24 hours of death (12.9% v. 23.9%) and were more likely to be seen by a palliative care physician before death (45.0% v. 23.8%). It is notable that there were no differences in age or the predicted risk of death on admission for patients with or without symptoms before death.

Within our fully adjusted multivariable regression model, we found that higher Elixhauser score (RR 1.35, 95% CI 1.23–1.49), having a family doctor (RR 2.33, 95% CI 1.02–5.38), being admitted to medical oncology (RR 1.51, 95% CI 1.11–2.05) and having a documented wish for no CPR and no intubation during the first 24 hours in hospital (RR 1.38, 95% CI 1.01–1.89) were all associated with symptoms at the end of life. Being admitted to the ICU was associated with fewer symptoms at the end of life (RR 0.39, 95% CI 0.19–0.80) (Figure 1). Table 4 contains 3 representative case vignettes of patients who died with more than 2 episodes of symptoms.

Discussion

We found that almost 1 in 3 people who died in hospital had 2 or more episodes of symptoms in the final 48 hours of life.

Table 1: The 10 most common comorbidities in the decedent cohort

Elixhauser comorbidity	Prevalence, no. (%) n = 479
Hypertension	196 (40.8)
Cancer with no metastases	157 (32.7)
Arrythmia	145 (30.2)
Diabetes with complications	120 (25.0)
Cancer with metastases	113 (23.5)
Chronic heart failure	105 (21.9)
Fluid and electrolyte disorders	99 (20.6)
Chronic obstructive pulmonary disease	77 (16.0)
Diabetes without complications	75 (15.6)
Chronic kidney disease	61 (12.7)

Table 2: Symptoms documented in the medical record during the final 48 hours of life, n = 479

Frequency of symptom(s)	No. (%) of patients with each symptom n = 479				
	Pain	Dyspnea	Agitation	Nausea	Total with any symptom(s)
0	376 (78.5)	373 (77.9)	402 (83.9)	459 (95.8)	272 (56.8)
1	49 (10.2)	54 (11.3)	45 (9.4)	12 (2.5)	67 (14.0)
2	27 (5.6)	32 (6.7)	14 (2.9)	6 (2.5)	45 (9.4)
3	15 (3.1)	13 (2.7)	10 (2.1)	1 (1.3)	44 (9.2)
4	8 (1.7)	4 (0.8)	5 (1.0)	0 (0)	18 (3.8)
≥ 5	4 (0.8)	3 (0.6)	3 (0.6)	1 (0.6)	33 (6.9)

Table 3: Characteristics of patients with and without 2 or more documented episodes of distressing symptoms in the final 48 hours of life

Characteristic	≥ 2 episodes of distressing symptoms before death, no. (%)* $n = 140$	< 2 episodes of distressing symptoms before death, no. (%)* $n = 339$	p value
Age, yr, mean ± SD	74.8 (13.4)	73.6 (17.1)	0.40
Female sex	76 (54.3)	155 (45.6)	0.09
Hospital service at time of death (top 10)			
Intensive care	15 (10.7)	111 (32.7)	< 0.001
General medicine	49 (35.0)	87 (25.6)	0.05
Cardiology	9 (6.4)	33 (6.9)	0.3
Oncology	22 (15.7)	14 (4.1)	< 0.001
Neurology	2 (1.4)	12 (3.5)	0.4
Malignant hematology	6 (4.3)	6 (1.8)	0.1
General surgery	5 (3.6)	7 (2.1)	0.3
Radiation oncology	7 (5.0)	5 (1.5)	0.1
Family medicine	2 (1.4)	8 (2.4)	0.7
Gynecologic oncology	5 (3.6)	4 (1.2)	0.1
No. of inpatient encounters in the last 6 mo			
0	76 (54.3)	231 (67.9)	0.005
1	36 (25.7)	63 (18.5)	0.08
2	15 (10.7)	24 (7.1)	0.20
3	5 (3.6)	17 (5.0)	0.6
≥ 4	8 (5.7)	5 (1.5)	0.007
Inpatient days in the last year, mean ± SD	14.4 ± 27.1	10.1 ± 24.1	0.09
Patient has a family physician	135 (96.4)	299 (87.9)	0.04
LOS, median (IQR)	17.6 (31.6)	13.2 (19.8)	0.05
Predicted mortality	0.29 (0.19)	0.31 (0.20)	0.3
Elixhauser comorbidity score, mean ± SD	15.5 ± 9.3	11.2 ± 8.5	< 0.001
Q1 −3 to 5	27 (19.3)	103 (30.5)	
Q2 6 to 12	25 (17.9)	100 (29.6)	
Q3 12 to 19	39 (27.9)	83 (24.6)	
Q4 19 to 48	49 (35.0)	52 (15.4)	
Patient wishes for resuscitation documented within 24 hr of admission			
Not documented	36 (25.7)	100 (29.7)	0.4
Full resuscitation including CPR	27 (19.3)	71 (20.9)	0.7
Resuscitation but no CPR	11 (7.9)	51 (15.0)	0.04
No resuscitation	66 (47.1)	117 (34.4)	0.01
Family present in the last 24 hr of life	106 (75.7)	272 (80.0)	0.3
Patient wishes for no resuscitation documented in chart at time of death	127 (90.7)	241 (71.1)	< 0.001
Patient wishes for no resuscitation documented ≤ 24 hr before death	18 (12.9)	81 (23.9)	< 0.001
Palliative care consulted	63 (45.0)	81 (23.8)	< 0.05

Note: CPR = cardiopulmonary resuscitation, LOS = length of stay, IQR = interquartile range, SD = standard deviation.
*Unless otherwise specified.

People with symptoms before death had higher comorbidity burden, were more likely to have a family doctor, more likely to be admitted to medical oncology and more likely to have an order for no resuscitation written in their charts within 24 hours of admission.

Consistent with previous research, we found that many patients experience symptoms before death.[20,27,28] In the SUPPORT study, which included hospital patients with life-threatening diseases, 50% of surrogates reported that the patient had experienced moderate to severe pain during the final 3 days of life.[28] In our study, only 21.5% had pain scores of 5 out of 10 or greater documented in the final 48 hours of life. Although not directly comparable, this result suggests an improvement. Another recent study of end-of-life symptoms among inpatients found that 22%–67% of patients experienced pain during their final admission to hospital.[29] This is not directly comparable, but shows that our result is in keeping with published reports of symptoms at the end of life.

Although some patients may choose less aggressive treatment of symptoms in favour of being more lucid, patients
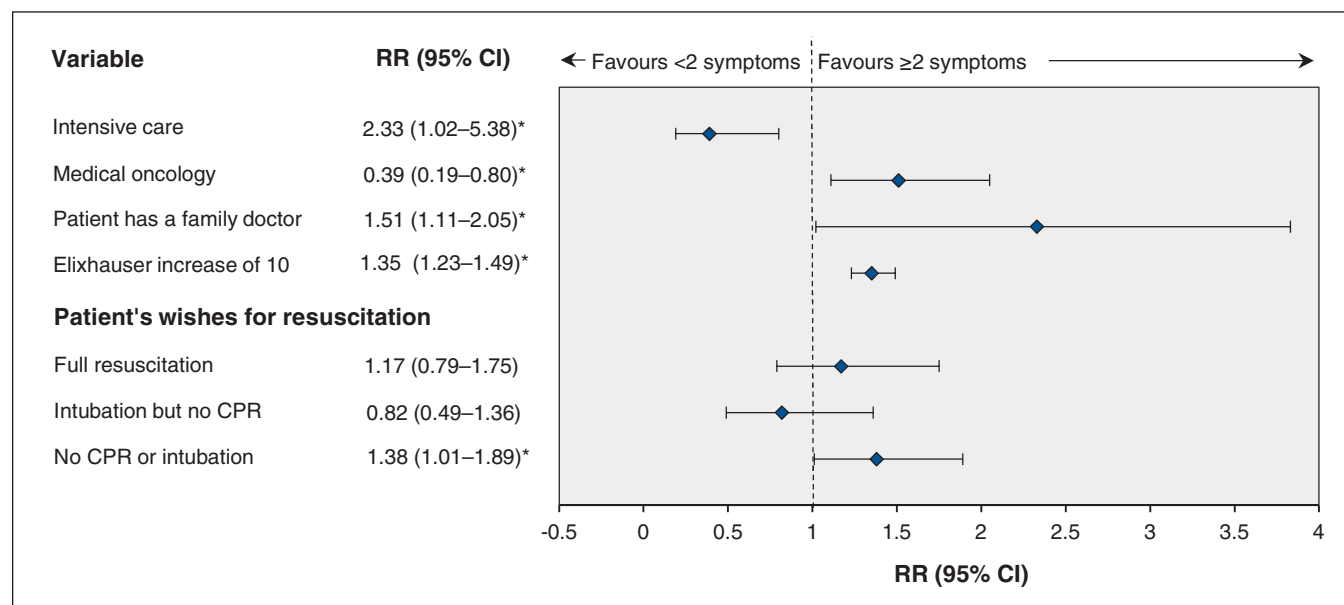

Variable	RR (95% CI)	← Favours <2 symptoms Favours ≥2 symptoms →
Intensive care	2.33 (1.02–5.38)*	
Medical oncology	0.39 (0.19–0.80)*	
Patient has a family doctor	1.51 (1.11–2.05)*	
Elixhauser increase of 10	1.35 (1.23–1.49)*	
Patient's wishes for resuscitation		
Full resuscitation	1.17 (0.79–1.75)	
Intubation but no CPR	0.82 (0.49–1.36)	
No CPR or intubation	1.38 (1.01–1.89)*	

Figure 1: Patient- and encounter-level characteristics associated with presence of 2 or more symptoms in the last 48 hours of life. *For patients' wishes for resuscitation as documented in the chart 24 hours after admission, the reference category was "not documented." CI = confidence interval, CPR = cardiopulmonary rescusitation, RR = risk ratio.

	Symptom			
Pain	Dyspnea	Agitation	Nausea	Case description
4	0	0	0	A 65-year-old woman with metastatic squamous cell carcinoma of the nasopharynx admitted because of dysphagia. The patient received a percutaneous endoscopic gastrostomy tube for feeding. She experienced worsening episodic chest pain and dyspnea that worsened over the next 5 weeks that was treated with narcotics as needed and then continuous narcotics. The chart documents that the patient appeared in distress on numerous occasions, but because of a language barrier, it was difficult to know what symptoms she was experiencing. The patient died after a period of agitation and apparent distress that was treated with more narcotics.
2	5	0	0	An 84-year-old man with metastatic renal cell carcinoma was admitted with delirium secondary to hypercalcemia. He was given intravenous fluids. The patient began experiencing flank pain and dyspnea. Initially, every recorded episode was treated with narcotics, but the following assessment documents that the patient was still complaining of pain. The patient was getting frustrated with the poor pain control. The patient had increasing dyspnea that was treated with benzodiazepines. He died after 3 hours of increasing dyspnea.
3	0	4	0	A 62-year-old woman with metastatic esophageal cancer presented to hospital with diabetic ketoacidosis, acute kidney injury and malignant ascites. The ketoacidosis was treated, and the kidney injury resolved. The patient was waiting to go to hospice, but developed worsening abdominal pain and severe agitation that was treated with phenobarbital. The phenobarbital was titrated up until the patient was obtunded but calm. The patient passed away shortly after.

Table 4: Representative cases of patients who experienced multiple episodes of distressing symptoms in the final 48 hours of life

need to be counselled about the typical frequency and severity of symptoms at the end of life so they can make educated choices. Patients consistently state that freedom from symptoms is one of the most important elements of quality end-of-life care.[1,3] This is in contrast to the reality that many patients do experience symptoms at the end of life. If patients knew they were likely to experience symptoms at the end of life, some may choose more aggressive symptomatic treatment or physician-assisted death.

Comorbidity burden had the strongest association with symptoms before death in our study. This finding is likely because patients with multiple comorbidities experience more symptoms at all times, not just in the days before death.[13,30,31] As other research has suggested, care for patients with multimorbidity is often inappropriately focused on disease-modifying treatments instead of a palliative approach that prioritizes treatment of symptoms along with disease-modifying treatments.[32–35] Further reinforcing the importance of a palliative approach, we found that patients with more symptoms at the end of life wanted limitations on the aggressiveness of care they received. Part of the challenge in implementing a palliative approach to care is the perception that palliative care is only for patients who have predictably terminal illnesses, such as incurable cancer.[36,37] For patients with chronic progressive diseases with frequent exacerbations, a recovery from the current episode is often possible; therefore, focusing on prolonging life may seem appropriate. This is in contrast to the World Health Organization's model for palliative care that recommends therapy to alleviate suffering be started early in the disease course along with disease-modifying therapy.[38]

Patients who were admitted to medical oncology had more symptoms before death than those admitted to other specialties. This finding differs from previous studies that showed no difference in the symptom burden between patients who die from cancer compared with patients who die from other causes.[8,14,39] Our finding may be because only oncology patients with symptoms are admitted for end-of-life care, whereas patients with fewer symptoms remain at home.

We found an association between having a family doctor and more symptoms at the end of life. It is difficult to imagine a causal pathway for this association. Instead, the association could be because patients who have more symptoms and more severe disease are more likely to have a family physician.

Perhaps the most intriguing and concerning finding was that patients who explicitly ask not to be resuscitated are more likely to experience symptoms. This suggests that patients who are asking for limitations in the aggressiveness of care may not be getting the symptom-focused care they want.

Finally, we found that patients admitted to the ICU experience fewer symptoms before death. These patients are sedated and therefore unable to report symptoms. In addition, the 1-to-1 nursing ratio in ICUs may facilitate rapid assessment and treatment of any symptoms.

Strengths and limitations

Our study was single-centre and therefore may not be generalizable to other hospitals or countries. Nevertheless, our large mul-

tifacility hospital provides a substantial proportion of the acute care health services in a large Canadian urban centre, and our findings are unlikely to be unique to our centre. Chart review is retrospective and observational, and differential measurement of the outcome on different wards may have introduced bias. Substantial effort at the Ottawa Hospital has been made to standardize hourly nursing assessments and documentation, which may mitigate some concerns over primary outcome assessment. We believe that, if anything, our outcome ascertainment method will underestimate the prevalence of symptoms because staff will not document symptoms that are not present but may, at times, miss symptoms. Our study did not evaluate whether symptoms were treated effectively, and therefore our results do not reflect on the quality of end-of-life care. Despite this weakness, our results are important because patients value symptom control at the end of life, and information about symptoms is important for both physicians and patients.

Conclusion

In a group of unselected patients who died in hospital, almost 1 in 3 experienced symptoms in the last 48 hours of life. The high incidence of symptoms in patients with high comorbidity, who have asked for less-aggressive care, suggests that further work is needed to integrate a palliative approach into chronic disease care. Future work should seek to understand symptoms experienced at the end of life by people who receive ideal care. Knowledge translation work is needed to determine how accurate expectations about end-of-life symptoms influence patients' decisions about palliative care and physician-assisted death.

References

1. Heyland DK, Dodek P, Rocker G, et al.; Canadian Researchers End-of-Life Network(CARENET). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174:627-33.
2. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281:163-8.
3. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476-82.
4. *Health care use at the end of life in Western Canada*. Ottawa: Canadian Institute for Health Information; 2007.
5. *Health care use at the end of life in Atlantic Canada*. Ottawa: Canadian Institute for Health Information; 2011.
6. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3:287-300.
7. Langford DJ, Tripathy D, Paul SM, et al. Trajectories of pain and analgesics in oncology outpatients with metastatic bone pain. *J Pain* 2011;12:495-507.
8. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage* 2006;31:58-69.
9. McCarthy EP, Phillips RS, Zhong Z, et al. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. *J Am Geriatr Soc* 2000; 48(Suppl):S110-21.
10. Mercadante S, Casuccio A, Fulfaro F. The course of symptom frequency and intensity in advanced cancer patients followed at home. *J Pain Symptom Manage* 2000;20:104-12.
11. Nordgren L, Sorensen S. Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur J Cardiovasc Nurs* 2003;2:213-7.
12. Ellershaw J, Smith C, Overill S, et al. Care of the dying: setting standards for symptom control in the last 48 hours of life. *J Pain Symptom Manage* 2001;21:12-7.
13. Janssen DJ, Spruit MA, Wouters EF, et al. Daily symptom burden in end-stage chronic organ failure: a systematic review. *Palliat Med* 2008;22:938-48.
14. Tranmer JE, Heyland D, Dudgeon D, et al. 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; 25:420-9.

15. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
16. Sinuff T, Dodek P, You JJ, et al. Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators. *J Pain Symptom Manage* 2015;49:1070-80.
17. Elixhauser A, Steiner C, Harris DR, et al. Comorbidity measures for use with administrative data. *Med Care* 1998;36:8-27.
18. van Walraven C, Austin PC, Jennings A, et al. A modification of the Elixhauser comorbidity measures into a point system for hospital death using administrative data. *Med Care* 2009;47:626-33.
19. Escobar GJ, Greene JD, Scheirer P, et al. Risk-adjusting hospital inpatient mortality using automated inpatient, outpatient, and laboratory databases. *Med Care* 2008;46:232-9.
20. Kehl KA, Kowalkowski JA. A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life. *Am J Hosp Palliat Care* 2013;30:601-16.
21. Boonstra AM, Stewart RE, Koke AJ, et al. Cut-off points for mild, moderate, and severe pain on the numeric rating scale for pain in patients with chronic musculoskeletal pain: variability and influence of sex and catastrophizing. *Front Psychol* 2016;7:1466.
22. Hirschfeld G, Zernikow B. Variability of "optimal" cut points for mild, moderate, and severe pain: neglected problems when comparing groups. *Pain* 2013;154:154-9.
23. Gerbershagen HJ, Rothaug J, Kalkman CJ, et al. Determination of moderate-to-severe postoperative pain on the numeric rating scale: a cut-off point analysis applying four different methods. *Br J Anaesth* 2011;107:619-26.
24. Downey L, Curtis JR, Lafferty WE, et al. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. *J Pain Symptom Manage* 2010;39:9-22.
25. McNutt LA, Wu C, Xue X, et al. Estimating the relative risk in cohort studies and clinical trials of common outcomes. *Am J Epidemiol* 2003;157:940-3.
26. Spiegelman D, Hertzmark E. Easy SAS calculations for risk or prevalence ratios and differences. *Am J Epidemiol* 2005;162:199-200.
27. Levin ML, Berry JI, Leiter J. Management of pain in terminally ill patients: physician reports of knowledge, attitudes, and behavior. *J Pain Symptom Manage* 1998;15:27-40.
28. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995;274:1591-8.
29. Yao Y, Keenan G, Al-Masalha F, et al. Current state of pain care for hospitalized patients at end of life. *Am J Hosp Palliat Care* 2013;30:128-36.
30. Currow DC, Clark K, Kamal A, et al. The population burden of chronic symptoms that substantially predate the diagnosis of a life-limiting illness. *J Palliat Med* 2015;18:480-5.
31. Rodriguez KL, Hanlon JT, Perera S, et al. A cross-sectional analysis of the prevalence of undertreatment of nonpain symptoms and factors associated with undertreatment in older nursing home hospice/palliative care patients. *Am J Geriatr Pharmacother* 2010;8:225-32.
32. Fitzsimons D, Mullan D, Wilson JS, et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliat Med* 2007;21:313-22.
33. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000;55:1000-6.
34. Cleary J, Drennan J. Quality of life of patients on haemodialysis for end-stage renal disease. *J Adv Nurs* 2005;51:577-86.
35. Gibbs JS, McCoy AS, Gibbs LM, et al. Living with and dying from heart failure: the role of palliative care. *Heart* 2002;88(Suppl 2):ii36-9.
36. Bruera E. The development of a palliative care culture. *J Palliat Care* 2004;20:316-9.
37. Hanks G. Palliative care: careless use of language undermines our identity. *Palliat Med* 2008;22:109-10.
38. National cancer control programmes — Policies and managerial guidelines. 2nd ed. Geneva: World Health Organization; 2002.
39. Saini T, Murtagh FE, Dupont PJ, et al. Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. *Palliat Med* 2006;20:631-6.

Affiliations: Department of Medicine (Kobewka, Mulpuru, Forster), Division of General Internal Medicine, The Ottawa Hospital, University of Ottawa; Ottawa Hospital Research Institute (Kobewka, McIsaac, Mulpuru, Forster), Ottawa, Ont.; Department of Community Health Sciences (Ronksley), University of Calgary, Calgary, Alta.; Department of Anesthesiology and Pain Medicine (McIsaac) — The Ottawa Hospital, University of Ottawa; Performance Measurement (Forster), The Ottawa Hospital, Ottawa, Ont.

Supplemental information: For reviewer comments and the original submission of this manuscript, please see www.cmajopen.ca/content/5/1/E222/suppl/DC1