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Research

Impact of comprehensive hospice palliative care on end-of-life care: a propensity-score–matched retrospective observational study

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Abstract

Background: Access to hospice palliative care may improve quality of life, reduce the use of potentially aggressive end-of-life care and allow for death to occur outside of an acute care hospital. The aim of this study was to examine the impact of an ambulatory hospice palliative care program on end-of-life care compared to care received by a matched control group of deceased patients.

Methods: This retrospective study included patients who received hospice palliative care through the Symptom Management Program in Sudbury, Ontario, during 2012–2015. Using linked administrative health records, we defined a propensity-matched control group and derived 4 previously defined variables associated with aggressive end-of-life care (chemotherapy received in the last 2 wk of life, > 1 emergency department visit within 30 d of death, > 1 hospital admission within 30 d of death and at least 1 intensive care unit admission within 30 d of death). We also examined place of death. We measured family/caregiver satisfaction with care 3 months after the patient's death using the FAMCARE questionnaire.

Results: Of 914 eligible decedents enrolled in the Symptom Management Program, 754 (82.5%) were matched. Receiving care through the program was protective for most measures of aggressive end-of-life care (absolute risk reduction [ARR] 12.73, 95% confidence interval [CI] 12.65–12.81 for any end-of-life care outcome) and death in an acute care setting (ARR 19.89, 95% CI 19.78–20.00). Of the 450 family caregivers invited to complete the FAMCARE questionnaire, 190 (42.2%) returned completed surveys; following data linkage and matching, 96 (21.3%) were available for analysis. Satisfaction with care received within the program appeared high (mean total score 85.72/100).

Interpretation: Provision of hospice palliative care through this ambulatory program was associated with lower use of aggressive end-of-life care and death outside of an acute care hospital. Improving access could be expected to provide positive benefits at the individual and system level.

For patients with cancer facing terminal illness, a hospice palliative care approach is an important component of quality care and can offer many benefits to patients and their families, including pain and symptom management, coordination of care and improved quality of life.[1–4] In addition, a hospice palliative care approach offers substantial benefits to the health care system, including the decreased use of potentially aggressive end-of-life care,[4] which is costly[5–7] and is often not the wish of patients.[8]

The Symptom Management Program at the Northeast Cancer Centre of Health Sciences North, Sudbury, Ontario, was established in 2011. It is an ambulatory program that uses a hospice palliative care approach for patients with cancer who have terminal disease. Although not restrictive, the primary catchment area of the program includes residents within the Greater Sudbury and District region. The primary purpose of this study was to determine the association between delivery of comprehensive hospice palliative care through the Symptom Management Program and the use of potentially aggressive care in the last month of life as well as place of death, compared to a matched cohort of deceased patients with cancer who had received palliative care and were not participants of the program. A secondary objective was to assess family caregiver satisfaction with the advanced cancer care delivered through the Symptom Management Program.

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Methods

Design and setting

We performed a retrospective study of palliative care decedents who were enrolled in the Symptom Management Program. The Symptom Management Program serves roughly 100–120 active patients per year and receives about 350 referrals per year. The majority of participants reside in Greater Sudbury and District. Enrolment within the program requires a referral from an oncologist, family physician or nurse practitioner, diagnosis of incurable cancer, a prognosis of 1 year or less, and absence of a primary care practitioner who is already providing palliative care to the patient.

We defined our treatment group as all members of the Symptom Management Program who were resident in Greater Sudbury and District, had lived for at least 30 days after receiving the primary diagnoses of cancer and had died in 2012–2015. We calculated duration of disease for each decedent as the number of days from cancer diagnosis to death and converted this to years. We identified matched control patients from the group of decedent residents of Greater Sudbury and District who had received a diagnosis with cancer, had lived for at least 30 days from diagnosis until death, had died in 2012–2015 and were not identified as participants of the Symptom Management Program.

Data sources

Membership in the Symptom Management Program was identified from medical records of the Northeast Cancer Centre at Health Sciences North by program clinic staff. We included identifiers for all program members from 2012 to 2015, as the program became operational in fiscal year 2011/12. This cohort was shared with ICES under the protection of a comprehensive data-sharing agreement and linked to administrative data sets that defined study outcomes and covariates (Figure 1). The ICES is an independent, nonprofit research institute whose legal status under Ontario's Personal Health Information Privacy Act allows it to collect and analyze heath care and demographic data for health system evaluation and improvement.

We accessed data that defined all study outcomes and covariates through the Ontario Cancer Data Linkage Project ("cd-link"), a data release program housed at ICES that provides access to deidentified and anonymous administrative data sets relevant to cancer health care services in Ontario (www.ices.on.ca/DAS/Public-Sector/cd-link). Databases used included the Registered Persons Database, which provides demographic and geographic information on Ontario residents with a valid Ontario health card; the Ontario Cancer Registry, which identifies Ontario residents in whom cancer has been diagnosed; the Ontario Health Insurance Plan physician claims database, which provides data on all physician and laboratory services; the Canadian Institute for Health Information National Ambulatory Care Reporting System, which identifies ambulatory care including visits to the emergency department; and the Canadian Institute for Health Information Discharge Abstract Database, which provides data on hospital discharges. These data sets were linked with the use of unique encoded identifiers.

In addition, we sent the FAMCARE questionnaire to all families for whom addresses were on record. It was mailed to the family or primary caregiver of the decedent 3 months after the patient's death. Family members completed the questionnaire anonymously; all questionnaires were coded by means of a numerical system. The FAMCARE questionnaire is a validated psychometric test developed by Kristjanson[9] that evaluates family satisfaction with care received by family members with advanced cancer.[9–11] We used the original version of the questionnaire, which consists of 20 items measured on a 5-point Likert scale from 1 (very dissatisfied) to 5 (very satisfied). In addition, we added 3 items that addressed areas of the performance of the Symptom Management Program: "Information about possible changes in your emotions," "Timely

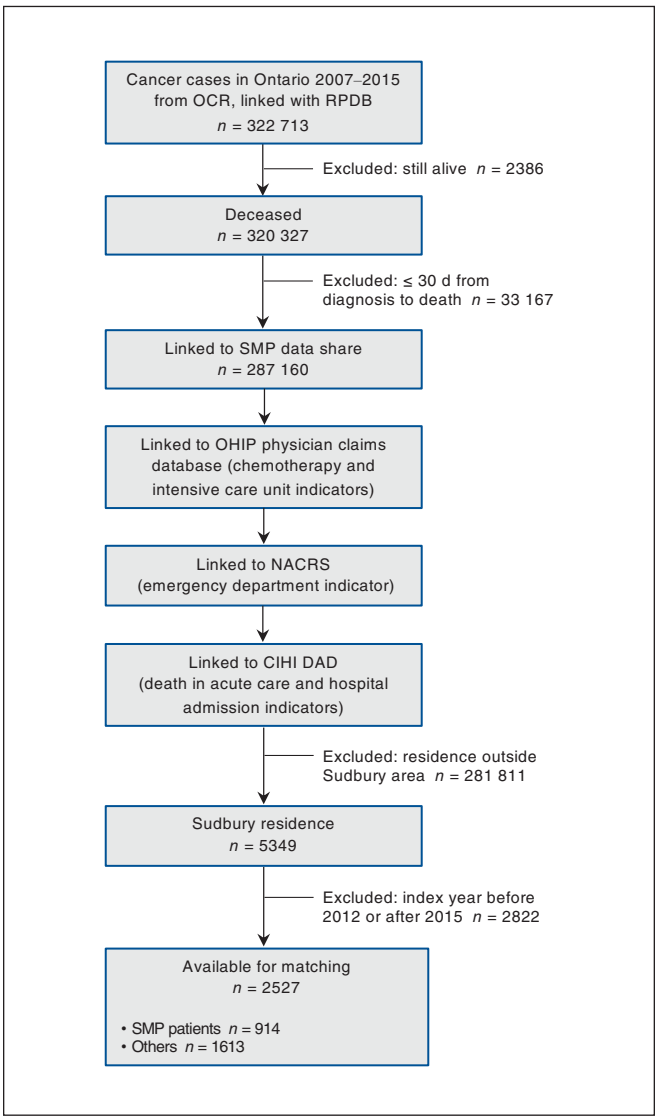

Figure 1: Flow chart outlining data build including linkages. Note: CIHI = Canadian Institute for Health Information, DAD = Discharge Abstract Database, NACRS = National Ambulatory Care Reporting System, OCR = Ontario Cancer Registry, OHIP = Ontario Health Insurance Plan, RPDP = Registered Persons Database, SMP = Symptom Management Program.

referrals to social worker" and "Timely referral to dietician"; these were measured with the same 5-point Likert scale. We also included a comment field where respondents could add any other comments or suggestions they wished to share with the palliative care team (Appendix 1, available at www.cmajopen.ca/content/7/2/E197/suppl/DC1). The 3 additional questions were not included in our analysis of the questionnaire responses. During analysis, we combined the 20 original items to calculate composite scales following recommendations by Kristjanson.[9] Composite scales were classified as Information giving (5 items), Physical patient care (7 items), Psychosocial care (4 items) and Availability of care (4 items) subscales. All subscales were combined into a total score (maximum 100). Results from these scales were submitted and linked within the administrative records.

Exposure

We assumed exposure to comprehensive hospice palliative care for all decedents identified as members of the Symptom Management Program.

Outcomes

We defined study outcomes a priori using definitions and codes published in the scientific literature using the same administrative data sources.[5,12–14] We defined potentially aggressive end-of-life care as 1) chemotherapy administered within 14 days of death, 2) more than 1 emergency department visit within 30 days of death, 3) more than 1 hospital admission within 30 days of death or 4) at least 1 intensive care unit admission within 30 days of death; a composite aggressive end-of-life care variable ("any") was defined as at least 1 occurrence of any of these outcomes. We defined death in an acute care hospital as a discharge disposition of death in the Discharge Abstract Database data set. Administrative codes used to derive outcomes can be found in Appendix 2 (available at www.cmajopen.ca/content/7/2/E197/suppl/DC1).

Covariates

Covariates available for study included age group at death, sex, Charlson Comorbidity Index score, duration of disease, cancer type, rurality, income quintile and index year of death.

Statistical analysis

We used logistic regression to define propensity scores with treatment as the outcome and all covariates as independent measures. Using greedy matching, we matched the treatment group 1:1 to control patients using a caliper width.[15] The suggested initial width was 0.20 times the standard deviation of the logit propensity scores.[16] However, we decreased the caliper width from 0.20 in increments of 0.05 until covariates were adequately balanced after matching (standardized difference [d] < 0.10). The final caliper width used was 0.05 times the standard deviation of logit propensity scores. We calculated d values for each covariate before and after matching. We analyzed propensity-score–matched data for the effect of Symptom Management Program membership on each indicator using the McNemar test.[17] We then used proportions to calculate absolute risk reduction, number needed to treat and relative risk. We compared FAMCARE scores using Wilcoxon tests. All statistical analyses were conducted with SAS v9.4 (SAS Institute).

Ethics approval

This study was approved by the Health Sciences North Research Ethics Board.

Results

A total of 914 decedents who were enrolled in the Symptom Management Program were identified and merged within the ICES holdings. There were 1613 potential control patients available from our data sources (Table 1). Before matching, most covariates appeared unbalanced; however, most program decedents (754 [82.5%]) were matched, and, after matching, covariates appeared adequately balanced (Table 1).

Within the matched cohort, rates of all study outcomes except use of chemotherapy were significantly lower in the Symptom Management Program group than in the control group (Table 2). The largest difference was observed for death in acute care, with an absolute risk reduction of 19.89 (95% confidence interval 19.78–20.00), number needed to treat of 5 and relative risk of 0.55 (95% confidence interval 0.47–0.64).

Of the 450 family caregivers invited to complete the FAMCARE questionnaire, 190 (42.2%) returned completed surveys. Following linkage and matching, 96 (21.3%) were available for analysis. The mean total FAMCARE score was 85.72. Total and all subscale scores were lower, in some cases significantly so, for those who received any aggressive end-of-life care than for those who did not (Table 3). There were no differences in the level of caregiver satisfaction by place of death.

Interpretation

Our study provides 3 key findings: 1) enrolment in the Symptom Management Program was associated with lower rates of measures of potentially aggressive end-of-life care for residents in Greater Sudbury and District, 2) provision of hospice palliative care was associated with lower rates of death in the acute care hospital setting and 3) family caregiver satisfaction with advanced cancer care received through the program, assessed as an overall total satisfaction score or through individual scales, appeared high, although scores were similar to those in other studies assessing caregiver satisfaction with provision of palliative oncology services.[18–20]

Our results suggest that provision of hospice palliative care may be associated with avoidance of high resource costs related to aggressive end-of-life care or death in an acute care hospital. Wodchis and colleagues[6] showed that palliative care is one of the most common reasons for hospital admission among high-cost users in Ontario, and Cheung and colleagues[5] reported that patients with cancer in Ontario who

Table 1: Frequencies, descriptive statistics and standardized differences of each covariate before and after propensity score matching for patients who received hospice palliative care from the Symptom Management Program and a matched control group

	Before matching; no. (%) of patients*			After matching; no. (%) of patients*		
Covariate	SMP *n* = 914	Non-SMP *n* = 1613	d	SMP *n* = 754	Non-SMP *n* = 754	d
Age group, yr			0.58			0.08
< 55	101 (11.0)	68 (4.2)		69 (9.2)	58 (7.7)	
55–64	204 (22.3)	180 (11.2)		145 (19.2)	131 (17.4)	
65–74	283 (31.0)	356 (22.1)		234 (31.0)	234 (31.0)	
≥ 75	326 (35.7)	1009 (62.6)		306 (40.6)	331 (43.9)	
Sex			0.05			0.00
Male	504 (55.1)	926 (57.4)		431 (57.2)	431 (57.2)	
Female	410 (44.9)	687 (42.6)		323 (42.8)	323 (42.8)	
Charlson Comorbidity Index score, mean ± SD	5.23 ± 2.82	3.81 ± 2.88	0.51	4.91 ± 2.83	4.92 ± 2.90	0.01
Duration of disease, yr, mean ± SD	3.45 ± 4.39	6.79 ± 6.35	0.55	3.79 ± 4.64	3.48 ± 4.23	0.07
Cancer type			0.44			0.07
Breast	59 (6.5)	142 (8.8)		48 (6.4)	49 (6.5)	
Lung	264 (28.9)	225 (13.9)		190 (25.2)	170 (22.5)	
Colorectal	96 (10.5)	232 (14.4)		88 (11.7)	87 (11.5)	
Prostate	67 (7.3)	253 (15.7)		65 (8.6)	64 (8.5)	
Other	428 (46.8)	761 (47.2)		363 (48.1)	384 (50.9)	
Rural residence			0.18			0.01
No	842 (92.1)	1397 (86.6)		688 (91.2)	687 (91.1)	
Yes	72 (7.9)	216 (13.4)		66 (8.8)	67 (8.9)	
Income quintile			0.14			0.06
1 (lowest)	208 (22.8)	443 (27.5)		185 (24.5)	165 (21.9)	
2	188 (20.6)	324 (20.1)		159 (21.1)	163 (21.6)	
3	185 (20.2)	269 (16.7)		143 (19.0)	149 (19.8)	
4	175 (19.1)	327 (20.3)		140 (18.6)	147 (19.5)	
5 (highest)	158 (17.3)	250 (15.5)		127 (16.8)	130 (17.2)	
Index year			0.15			0.02
2012	190 (20.8)	407 (25.2)		165 (21.9)	166 (22.0)	
2013	232 (25.4)	436 (27.0)		203 (26.9)	210 (27.8)	
2014	228 (24.9)	397 (24.6)		188 (24.9)	183 (24.3)	
2015	264 (28.9)	373 (23.1)		198 (26.3)	195 (25.9)	

Note: d = standardized difference, SD = standard deviation, SMP = Symptom Management Program.
*Except where noted otherwise.

received aggressive end-of-life care incurred costs that were 43% higher than those for patients managed nonaggressively. Although admission to an acute care hospital may be appropriate for patients with cancer because of disease progression or a need for optimal treatment[21] or caregiver respite, overuse may signal a potential gap in palliative care services.[21,22] The risk difference of almost 20% in our study suggests that enrolment in the Symptom Management Program may be associated with allowing for death to occur outside the acute care hospital setting for patients with cancer in the Sudbury region. In this area of Ontario, 44% of the decedents not enrolled in the program died in an acute care hospital, which is slightly higher than the rate reported for all of Ontario, 40%.[23]

There was no significant difference in the level of satisfaction with care between caregivers of program members who died in acute care and caregivers of program members who

Table 2: Study outcomes related to the use of aggressive end-of-life care in the 2 groups

Outcome	Group; no. (%) of patients		Absolute risk reduction (95% CI)	Number needed to treat (95% CI)	RR (95% CI)
	SMP	Non-SMP			
Hospital admission	36 (4.8)	57 (7.6)	2.79 (2.76–2.82)	36 (35.45–36.25)	0.63 (0.42–0.95)
Emergency department visit	71 (9.4)	99 (13.1)	3.71 (3.66–3.76)	27 (26.57–27.35)	0.72 (0.53–0.97)
Chemotherapy	11 (1.5)	19 (2.5)	–	–	–
Intensive care unit admission	8 (1.1)	92 (12.2)	11.14 (11.11–11.17)	9 (8.95–9.00)	0.09 (0.04–0.18)
Any aggressive end-of-life care	94 (12.5)	190 (25.2)	12.73 (12.65–12.81)	8 (7.81–7.91)	0.50 (0.39–0.62)
Death in acute care	182 (24.1)	332 (44.0)	19.89 (19.78–20.00)	5 (5.00–5.06)	0.55 (0.47–0.64)

Note: CI = confidence interval, RR = relative risk, SMP = Symptom Management Program.

Table 3: Descriptive statistics and results for FAMCARE questionnaire completed by family members of patients who received hospice palliative care from the Symptom Management Program

Subscale (no. of items/ maximum score)	Overall; mean score ± SD *n* = 96	Aggressive end-of-life care (any); mean score ± SD		*p* value	Death in acute care; mean score ± SD		*p* value
		No *n* = 86	Yes *n* = 10		No *n* = 68	Yes *n* = 28	
Information giving (5/25)	21.03 ± 3.39	21.26 ± 3.41	19.10 ± 2.60	0.02	20.88 ± 3.70	21.39 ± 2.50	0.95
Physical patient care (7/35)	29.98 ± 3.88	30.17 ± 3.84	28.30 ± 3.97	0.1	29.75 ± 4.18	30.54 ± 3.01	0.6
Psychosocial care (4/20)	17.24 ± 2.43	17.41 ± 2.41	15.80 ± 2.15	0.04	17.25 ± 2.59	17.21 ± 2.03	0.7
Availability of care (4/20)	17.47 ± 2.53	17.66 ± 2.40	15.80 ± 3.12	0.02	17.34 ± 2.80	17.79 ± 1.75	0.8
Total (20/100)	85.72 ± 11.11	86.50 ± 10.93	79.00 ± 10.94	0.03	85.22 ±12.09	86.93 ± 8.32	0.8

Note: SD = standard deviation.

died elsewhere, which may indicate that the former involved the appropriate use of acute care resources. However, satisfaction with care was significantly lower among the caregivers of program members who received any aggressive end-of-life care, and this finding supports the sparse research on family caregiver satisfaction with care combined with system-level resource use.[8] Although the proportion of program decedents who received any aggressive end-of-life care, 12.5%, was lower than the 22.5% reported for all of Ontario,[5] exploration of factors such as timing of initial palliative care consultations, availability of care and type of information provision may allow the Symptom Management Program to further enhance service delivery.

Limitations

Our study has important limitations. Some key variables that would have allowed us to better characterize and match our cohort, such as stage at diagnosis and cause of death, were not available under the data release program. Although our cohorts were well balanced across the small number of variables we used, a more comprehensive suite of variables would have provided more assurance about the baseline comparability of the groups. We also assumed that all deaths in both groups were due to cancer. In addition, although Symptom Management Program membership defined exposure to comprehensive hospice palliative care in our treatment group, we are less clear about the level of exposure to hospice palliative care that may have occurred in the control patients. However, 90.4% of the matched control group had at least 1 palliative consultation code, slightly less than the 93.1% in the Symptom Management Program group. Also, our estimates of death in an acute care hospital and use of any aggressive end-of-life care in the control group were only marginally higher than Ontario provincial estimates derived with these same administrative sources but using a decedent cancer cohort definition (44% v. 40% for death in an acute care hospital[21] and 25% v. 22.5% for aggressive end-of-life care). Conversely, if members of the control group received comprehensive hospice palliative care through a family physician or group health team, our outcome estimates may be conservative. Although

we had individual-level family caregiver satisfaction scores for a subgroup of our treatment group (n = 96), which appeared high, we are unclear about the generalizability of the results to other program members, given that the original response rate to the FAMCARE survey was low (42%) and that the subgroup represented only 13% of the matched treatment cohort. In addition, our system-level measures used administrative data, and we have no information about the appropriateness or quality of the care received. Although our coded outcomes were based on previously published research,[5,12–14] they were not validated in our population, and we are unclear about the potential degree of misclassification.

Conclusion

Provision of hospice palliative care received from the Symptom Management Program had positive benefits, including enhanced family satisfaction with care and lower occurrence of potentially aggressive end-of-life care, and may allow for death to occur outside of an acute care hospital. A better understanding of the full spectrum of costs associated with the delivery of care at the level of the provider, the family and the community is needed.

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