

End-of-life home care utilization and costs in patients with advanced colorectal cancer

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Objective To determine overall utilization and costs associated with home care services in Ontario, Canada by linking a home care database to a stage IV colorectal cancer cohort.

Methods The names of patients with stage IV colorectal cancer at time of diagnosis (diagnosed from 2005 through 2009) were extracted from the Ontario Cancer Registry. The study cohort comprised those who died before the end of the study. The terminal phase of care was the period of time between diagnosis and death, with a maximum value of 180 days (6 months). Patients were linked to home care services datasets. The type, frequency, and cost of home care services were determined. Regression analysis was used to examine factors associated with utilization and cost.

Results In all, 3,613 stage IV colorectal cancer patients (median age, 71 years) were diagnosed and died during the study's time horizon. During the terminal phase, 79.3% received at least 1 home care visit, and 58.0% had at least 1 palliative visit. Terminal metastatic colorectal cancer patients received an average of 8 home care visits at Canadian \$800 within a 30-day time horizon. Home care costs were highest in the month before death. Male sex, a history of moderate or high utilization of health care services, and hospitalization were associated with lower home care costs.

Limitations Administrative data do not reveal the purpose, efficiency, effectiveness/sufficiency, quality, or appropriateness of home care.

Conclusion Patients with advanced colorectal cancer who were approaching death required a moderate level of home care support, resulting in costs of about \$5,000 over the 6-month time horizon.

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Colorectal cancer is one of the leading causes of morbidity and mortality in Canada with 5-year prevalence counts of 60,700.¹ The number of new colorectal cancer patients diagnosed in the province of Ontario has increased by 117% over the past 3 decades.¹ A recent report of community dwelling seniors showed that 25% received some sort of home care (formal and/or informal), and that the quantity of home care increased with age and disability.² We hypothesized that home care

services would be frequently used by patients with advanced colorectal cancer because of their need for medication administration and end-of-life and/or palliative support. Some studies have provided population-level costs for end-of-life care in terms of overall management across different diseases.³⁻⁶ Yet only a handful of population-based studies have examined home care utilization and the associated costs in persons with cancer.^{7,8} Most of the cancer studies used broadly defined cohorts and did not fo-

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cus on a specific subtype of cancer. Few studies have examined home care in a colorectal-specific population. In 2007, researchers examined end-of-life medical expenditures in a US Medicare population in which patients had been diagnosed with colorectal cancer.⁹ In 2011, researchers examined end-of-life/palliative home care costs in adult oncology (including colorectal) patients in Ontario, based on administrative data.⁸

Ontario has a population of 13.2 million inhabitants, and some home care services for permanent residents are provided through its publicly funded health care system. The Ontario Ministry of Health and Long-term Care funds home care services (such as nursing care, personal support, and respite care) that are provided by and coordinated through community care access centres (CCACs). A record of the type and cost of each home care service delivered is captured in the Ontario Ministry of Health administrative database. This information is linkable to other administrative datasets including the Ontario Cancer Registry, which provides diagnostic and treatment data.¹⁰

The objective of this analysis was to link the Home Care Database the cohort with stage IV colorectal cancer to determine the overall utilization and costs associated with CCAC-delivered home care services that were provided in the 6 months before death.

Methods

Incident patients with stage IV colorectal cancer (International Classification of Disease, ninth revision, ICD-9 153.x, ICD-9 154.x)¹¹ that was diagnosed from January 1, 2005, through December 31, 2009, were extracted from the Ontario Cancer Registry. The Ontario Cancer Registry is a database of all Ontario residents who have been newly diagnosed with cancer, or who have died of cancer in Ontario. Cancer stage was based on the American Joint Committee on Cancer (AJCC) staging system, version 6.¹² Records with missing stage information or an invalid health care number were excluded.

For this stage IV cohort, we focused on the terminal care phase, which was defined as the time between diagnosis and death, with a maximum value of 180 days. As a subanalysis, we also investigated patients who were alive for the entire 180-day period prior to death.

Colorectal cancer patients in the Ontario Cancer Registry were linked, by their encrypted health card number, to a number of administrative datasets for information on demographics, previous health care utilization, hospitalizations, and home care utilization. The administrative data were obtained from the Institute for Clinical Evaluative Sciences, and included the Ontario Home Care Administrative System (later replaced by the Home Care Database); the Registered Persons Database (demographics and death); and the Canadian Institute for Health Information (hospitalizations). The Institute for Clinical Evaluative

Sciences is an independent, not-for-profit organization; its core function is to conduct research that contributes to the effectiveness, quality, equity, and efficiency of health care and health services in Ontario.

Home care activities were defined as provincially funded visits from any of a variety of care providers, including nurses, physiotherapists, occupational therapists, respiratory services providers, nutritionists/dietitians, speech language pathologists, social workers, psychologists, patient management specialists, homemaking/personal support providers, placement services, and respite care providers. Each home care service provision was considered separately and was defined as a visit, and each visit was assumed to last 1 hour. The unit costs (in 2009 Canadian dollars on December 20, 2012, 1.00 Canadian dollar [1 Can\$] = 1.01 US dollar [1 US\$], at an exchange rate of 1.0118, using the nominal rate)¹³ for home care services were obtained from the Ontario Ministry of Health and Long-term Care.¹⁴

Our main analysis included patients who died on or before March 31, 2010, subsequent to a diagnosis of colorectal cancer. The following analyses were conducted:

- Descriptive statistics,
- Mean weighted home care utilization and cost by the length of follow-up for each patient,
- Mean number of home care visits and costs over a 30-day time frame, and
- Factors associated with home care cost per 30-day interval in the terminal care phase, based on multivariate linear regression analysis.

Only patients who received home care services were included in the regression analysis. The variables of interest were age, sex, income group, in-hospital death, and previous health care utilization. All analyses were performed with SAS 9.2 (SAS Institute Inc, Cary, North Carolina). For the subanalysis (namely, patients with a total of 180 days in the terminal care phase), home care visits and costs were examined at each month of the 6 months leading up to a patient's death.

Results

During the study's 2005-2009 time frame, 36,195 cases of new colorectal cancer were diagnosed in Ontario. Staging information was available for 25,224 (69.7%) patients. Of the newly diagnosed patients, 5,282 were classified as stage IV at diagnosis. Demographic information is available in Table 1,^{15,16} and home care visits are described in Table 2. Over a 30-day period, patients with terminal metastatic colorectal cancer received, on average, 8 home care visits, or about 2 visits per week. The average cost of these visits was about Can\$800 per 30 days, or Can\$200 per week (Table 3). We assessed factors associated with 30-day cost (a dependent variable) using regression analysis among stage IV colorectal cancer patients who had utilized home care services. Male sex, moderate to high resource utilization in

TABLE 1 Demographics

Variable	Number	Percentage
Patients with stage IV colorectal cancer	3,613	100
Patients receiving home care during terminal phase	2,866	79.3
Sex		
Female	1,635	45.3
Male	1,978	54.7
Age, y		
Mean	(95%CI)	69.7
Median (IQR)	(69.2-0.1)	NA
	71	NA
	(61-79)	NA
Age group, y		
< 45	114	3.2
45-54	399	11.0
55-64	748	20.7
65-74	945	26.2
75-84	1,021	28.3
≥ 85	386	10.7
Living in urban location		
Yes	3,027	83.8
No	584	16.2
Missing data		20.1
Modified income quintile¹⁵		
Urban residents	613	17.0
Lowest		
Second lowest	596	16.5
Middle	651	18.0
Second highest	575	15.9
Highest	589	16.3
Rural residents	581	16.1
Missing	8	0.2
Resource Utilization Band^{16,a}		
Healthy user	31	0.9
Low	168	4.6
Moderate	1,734	48.0
High	920	25.5
Highest	697	19.3
None	63	1.7
Had at least 1 palliative care code in home care during terminal phase		
No	1,516	42.0
Yes	2,097	58.0
Time between diagnosis and death, days		
Mean (95% CI)	311.2	
	(300.9-321.4)	NA
Median (IQR)	198	NA
	(69-463)	NA
Hospital death		
No	1,757	48.6
Yes	1,856	51.4

CI, confidence interval; NA, not applicable; IQR, interquartile range; y, years

^aJohns Hopkins ACG System's Resource Utilization Band is a Web site tracks an individual's health care utilization in the 2 years before their diagnosis.

the 2 years before diagnosis, and an in-hospital death were associated with decreased home care costs. Among the predictor variables, in-hospital death had the largest effect on 30-day home care cost (Table 4).

For the subanalysis, 1,906 patients were alive for at least 180 days after their diagnosis (Figure 1). Their average 30-day cost over the 180 days was Can\$820. Home care costs and visits increased as patients neared death. The 30-day costs for home care at 1 month prior to a patient's death were almost 3 times higher than were the 30-day home care costs at 6 months prior to a patient's death. The number of visits more than doubled in the last month before death, compared with those in the 30-day period 6 months before a patient died (Figure 2). Over the 180-day period, the most common types of home care services were nursing (63.5%) and personal support services (30.5%); these remained constant in each 30-day period leading up to death.

Discussion

The evaluation is based on a large and representative sample of the Ontario population with stage IV colorectal cancer during the years analyzed. Close to 80% of the study population received publicly funded community home care services during the terminal phase of their illness. Over a 1-month period, metastatic colorectal cancer patients in terminal care received, on average, 8 home care visits, amounting to an average of 48 home care visits over the 6-month terminal phase. The average cost was about Can\$800 per month, or Can\$4,800 during the 6 months leading to death among those who survived at least 6 months. The cost in the terminal phase was made up of additional home nursing care and personal support services, likely for palliative management, treatment of metastatic disease, and/or end-of-life care. More home care visits and higher costs occurred as patients neared death, and these are also thought to be attributed to end-of-life care.

About 60% of the cohort had at least 1 palliative home care service during the terminal phase of care. Although this rate seems to be low, it should be noted that more than half of the cohort died in a hospital, thereby reducing their opportunity to receive home care. Undercoding of palliative services is also a potential explanation for the low rate of palliation observed in this study.

In our study, home care costs decreased if

individuals had higher levels of previous health care utilization and if they died in an acute care hospital. Those who died outside of a hospital had incrementally higher home care costs (Can\$309), although we are unable to determine whether these out-of-hospital deaths occurred in a personal residence, a hospice, or a long-term care facility, which suggests that the differential could be even greater if a clear comparison between home and in-hospital death could be made.

Our results can be compared with those of other phase-based approaches to home care costing. Patients with stage IV colorectal cancer used more home care visits in the terminal phase than did breast cancer patients at the same stage. Results may differ because of sex and differential resource utilization for disease sites.⁷

Studies have shown that care in the community is less expensive than is institutional or residential care.¹⁷⁻²¹ Some of the home care costing work has been specific to palliative and end-of-life care.²²⁻²⁴ For example, researchers examined the cost of end-of-life care in Ontario (from 2002 through 2003) for a number of cancer sites.⁸ This study also used a 6-month time period prior to death in the analysis. Results showed that the average home care costs for individuals at the end of life were Can\$15,886 for all cancer sites and Can\$15,269 for colorectal cancer, costs that are much higher than what we calculated in our study. The reasons for the cost differences include the fact that patients were not stratified by stage of disease, and the investigators did not examine actual utilization but instead applied the maximum number of home care visits allowed by the system. It should be noted that the maximum number of allowable visits in that study greatly exceeded the average number of actual visits found in our cohort, and was based on only 1 region within the province. In another study, researchers examined administrative data from a Belgian health care organization, and reported that cancer patients had home care costs that were similar to ours over a 6-month time horizon, despite differences in the health care systems that were in place in the respective countries.⁴ In the United States, researchers examined end-of-life medical expenditures in a Medicare population who had been diagnosed with colorectal cancer.⁹ Of these, 47% of the cohort who were older than 68 years at death received home care services, compared with almost 80% that we found in this study. Reasons for the differences include access to a different health system model, and the fact that our analysis included persons of all ages.

Unlike the United States, Canada does not have a formalized hospice system.⁵ It is estimated that 16%-30% of Canadians who die have access to or receive palliative and end-of-life care services from hospice.²⁶ We recognize that this represents a significant gap in the health care system, and that home care with a palliative designation may be a surrogate for hospice.

N = 36,195
Incident cases of colorectal cancer (2005–2009)

n = 25,224
Cases with disease staging information

n = 5,283
Cases with stage IV colorectal cancer

n = 3,613
Cases with at least 180 days followup after diagnosis and before their death

n = 1,932
Cases with 180 days followup before their death

FIGURE 1 Breakdown of cohort selection

There are limitations associated with the use of administrative data. These administrative data do not reveal the purpose of the service, access to home care services, the efficiency of delivery of home care services, the effectiveness of patient care, the quality of the care, or even the appropriateness of home care. An examination of treatment-management guidelines for home care service utilization would be required to determine the appropriateness of the care.

In this study, the terminal phase is empirically defined.

TABLE 2 Type of home care services during terminal care phase among stage IV colorectal cancer patients who died during follow-up^a

Type of home care service	No. of services	Percentage
Visiting nurses	92,090	63.8
Homemaking/personal support providers	43,659	30.3
Occupational therapists	2,643	1.8
Physiotherapists	1,542	1.1
Patient management providers	1,327	0.9
Respite workers	995	0.7
Nutritionists/dietiticians	793	0.5
Social workers	732	0.5
Other	354	0.2
Speech language therapists	51	0.0
Psychologists	22	0.0
Placement service providers	14	0.0
Enterostomal therapists	12	0.0

^aN_{total} = 144,234 home care services; 2,866 patients received home care.

TABLE 3 Use of home care services during terminal care period among colorectal cancer stage IV patients^a

Variable	Number
Use of home care services (%)	
No	747 (20.7)
Yes	2,866 (79.3)
Number of visits per 30 days	
Mean (95% CI)	8.36 (7.98, 8.75)
Median (IQR)	5.00 (1-11)
Cost per 30 days (Can\$)	
Mean (95% CI)	795.16 (758.86, 831.46)
Median (IQR)	489.00 (107-1,057)

Can\$, Canadian dollar; CI, confidence ratio; IQR, interquartile range; N, total number

^aN = 3,613

The 6-month time horizon used in this analysis has been used in other studies examining resource utilization and costs associated with end of life care.^{4,6-8} Although other such studies have used 1 week,²⁷ 1 year^{5,9,28} or even 2 years³ to define the terminal phase of care, we chose a 6-month time horizon because of the advanced stage of colorectal

cancer at diagnosis.

The results of this analysis are representative of the colorectal cancer cohort that was selected from this provincial dataset. Population-based studies for other disease-site cohorts are required to examine similarities and differences in utilization and associated costs.^{18,22,24,29-34} Here, the data source was administrative data from Ontario and does not include privately funded home care services or services provided by family and friends. Data collection of primary care and home care records or access to private insurers' databases would be necessary to provide service level details.²⁴

The palliative care flag is initiated by a palliative care team. If the patient is not registered with a palliative care team, it is possible that the service won't be flagged as palliative care at the end of life. This could explain the low rate found in this terminal population. Unfortunately, this is a limitation of the database.

Intercountry comparisons that use race as a covariate are not possible, as patient-level race and ethnicity data for the population are not collected in any of the usual sources of health system administrative data. Access to health care – and, in this context, home care – and the ability to pay are not issues in Ontario because home care is an insured service under the universal health care system.

Finally, our results are presented as overall costs not attributable to net costs. The attributable cost of home care

TABLE 4 Regression coefficients estimate 30-day home care costs for stage IV colorectal cancer patients during terminal phase^{a,b}

Variable	Parameter estimate	Standard error	t value	Replace with P value
Intercept	1,389.83	92.66	15	< .0001
Male	-156.23	43.84	-3.56	.0004
Age group, ^c y				
< 45	-52.91	123.26	-0.43	.6678
45-54	-28.45	76.94	-0.37	.7116
65-74	-69.91	62.60	-1.12	.2642
75-84	32.63	63.47	0.51	.6072
≥ 85	103.32	89.38	1.16	.2478
Income quintile ^d				
Urban residents				
Lowest	-58.61	75.18	-0.78	.4357
Second lowest	-88.14	75.89	-1.16	.2456
Middle	67.47	73.11	0.92	.3562
Second highest	75.84	75.97	1.00	.3183
Rural residents	-88.08	75.24	-1.17	.2419
Resource Utilization Band ^{1,6,e}				
Healthy user	173.17	237.29	0.73	.4656
Low	-109.12	113.82	-0.96	.3378
Moderate	-184.06	61.32	-3.00	.0027
High	-163.54	66.96	-2.44	.0146
None	-22.60	181.93	-0.12	.9011
Hospital death	-308.98	43.61	-7.08	< .0001

^aN = 3,613. ^bAnalysis among stage IV colorectal cancer patients with at least 1 home care visit during terminal period. ^cReference, 55-64 y. ^dReference, 5 (Urban highest). ^eReference, 5 (Highest).

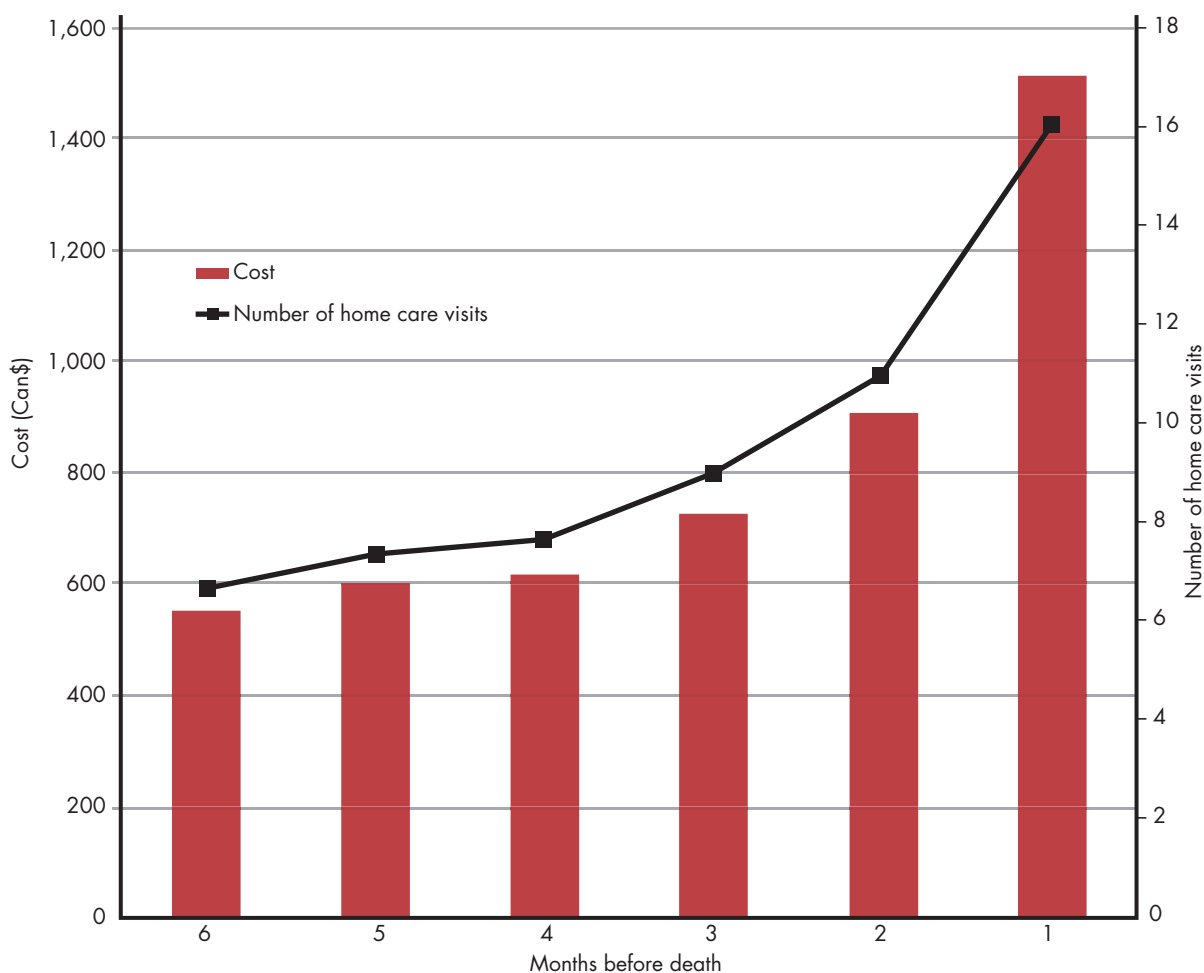


FIGURE 2 Cost and utilization of home care resources

for a cohort with advanced colorectal cancer, compared with those for a matched control group without cancer, was not evaluated. We decided to provide overall rather than incremental costs because of the difficulty of matching an advanced-stage colorectal cancer group to an appropriate control group. A recent report of community dwelling Canadian seniors showed that 25% of the population received some sort of home care (formal and/or informal), and that the amount of home care services provided increased with age and disability.² In that study, only 3% of formal home care was for medical services. The actual type and number of services provided over a specific time horizon were not reported in this community dwelling population, which was assumed to be relatively healthy.

Conclusions

To date, the type and cost of home care services that are specific to the management of a single cancer type by the extent of disease present at diagnosis have not been exam-

ined in a large population cohort. We found that individuals with advanced colorectal cancer at diagnosis cost the publicly funded home care system about Can\$5,000 in the terminal phase of their illness, which would amount to about Can\$28 per day for home care. If we were to apply this level of home care to all advanced-stage colorectal cancer patients (N = 3,613 from 2006 through 2009) in their last 6 months of life, the budget impact would be approximately Can\$3.6 million per year. Better understanding of the home care experience of individuals with advanced colorectal cancer may help inform future resource allocation decisions. Further work will focus on the cost implications of hospitalization for advanced colon cancer patients at the end of life.

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