Original Article

Community Palliative Care Initiatives to Reduce End-of-Life Hospital Utilization and In-Hospital Deaths: A Population-Based Observational Study Evaluating Two Home Care Interventions

Colleen Webber, PhD, Raymond Viola, MD, MSc, CCPF (PC), FCFP, Christine Knott, PhD, Yingwei Peng, PhD, and Patti A. Groome, PhD

Ottawa Hospital Research Institute (C.W.); Bruyère Research Institute (C.W.), Ottawa; Division of Palliative Medicine (R.V.), Department of Medicine, Queen's University; Centre for Health Services and Policy Research (C.K.), Queen's University; ICES (C.K.); Department of Public Health Sciences (Y.P., P.A.G.), Queen's University; and Division of Cancer Care and Epidemiology (Y.P., P.A.G.), Cancer Research Institute, Queen's University, Kingston, Ontario, Canada

Abstract

Context. The end-of-life period is characterized by increased hospital utilization despite patients' preferences to receive care and die at home.

Objectives. To evaluate the impact of interventions aimed at planning for a home death (Yellow Folder) and managing symptoms in the home (Symptom Response Kit) on place of death and hospital utilization among palliative home care patients.

Methods. This was an ecologic and retrospective cohort study of palliative home care patients in southeastern Ontario from April 2009 to March 2014. Linked health administrative and clinical databases were used to identify palliative home care patients and their receipt of the interventions, hospitalizations, emergency department visits, and place of death. Bivariable and multivariable regressions were used to evaluate outcomes according to patients' receipt of intervention(s).

Results. The proportion of patients who died in the community increased after implementation of the interventions, from 42.8% to 48.5% ($P < 0.0001$). Compared with patients who received neither intervention, patients who received the Yellow Folder or Symptom Response Kit had an increased likelihood of dying in the community, with the largest relative risk observed in patients who received both interventions (relative risk = 2.20, 95% confidence interval 2.05–2.36). Receipt of these interventions was only associated with reductions in hospitalization or emergency department visit rates in the six months before death.

Conclusion. Patients who received the Yellow Folder or Symptom Response Kit were more likely remain at home at the end of life. This association was stronger when these interventions were used together. J Pain Symptom Manage 2019;58:181–189.

Key Words

Palliative care, home care services, hospitalization, retrospective studies, end-of-life care, advance care planning

Patients with life-threatening illnesses prefer to receive care and die at home,[1–4] yet the end-of-life period is characterized by high levels of acute care utilization, in-hospital deaths, and health care costs.[5–12] Reducing high-intensity health care utilization at the end of life through health care delivered in patients' preferred place of care could improve outcomes and reduce costs.

Address correspondence to: Colleen Webber, PhD, 43 Bruyère Street, Ottawa, ON K1N 5C8, Canada. E-mail: cwebber@bruyere.org

Accepted for publication: April 15, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.04.021

Appropriate supports must be in place if patients wish to remain at home at the end of life. Advance care planning initiatives help patients achieve this objective by enabling patients, families, and caregivers to establish care goals and identify relevant resources.[13] Emergency medication kits support symptom management in the home by providing supplies that allow home nurses to rapidly respond to symptom exacerbations, which might otherwise necessitate an emergency department visit or hospitalization.[14] Previous research has indicated that home medication kits and advance care planning initiatives reduce end-of-life hospital use and in-hospital deaths.[13,15–23] However, these evaluations have been limited by small samples and potential recall bias. In this large, population-based study, we evaluated the impact of a home medication kit and home-death planning tool on place of death, hospitalizations, and emergency department visits among palliative home care patients.

Methods

Study Setting and Context

We conducted population-based ecologic and population-based retrospective cohort studies to evaluate a home-death planning tool, known as the Yellow Folder, and an emergency medication kit, or Symptom Response Kit, in palliative home care patients in southeastern Ontario, Canada. This region of the province of Ontario has a population of almost half a million people with universal health care coverage through the provincial publicly funded health insurance program.[24] All publicly funded home care is organized and delivered by the South East Community Care Access Centre (now known as the South East Local Health Integration Network Home and Community Care). Individuals can be referred for home care by health care providers or through self-referral. Home care services include nursing, personal support worker, and other allied health care providers, with the types and intensity of care determined by patients' needs and care coordinator assessment. There is no waitlist for palliative home care in this region, although there may be initial delays in receiving specific services after admission.

The Yellow Folder, implemented on April 1, 2010, contains materials to help home care providers, patients, and families plan for an expected home death, if that is their preference. It includes a do-not-resuscitate form and home-death planning tool that outlines plans for death pronouncement and certification. The Symptom Response Kit, implemented on February 13, 2012, provides medications and supplies, customized to patients' conditions, for home care nurses to use when the patient's condition changes suddenly. Kits are placed in the home based on anticipated future need. Both interventions are meant to be offered when patients' functional status on the Palliative Performance Scale is 50% or lower.[25] Development and implementation of these interventions involved extensive home care provider input and training. Before their implementation, home care providers helped plan for home deaths, but not in a coordinated manner and with no supporting resources. Medical supplies may have been ordered to the home if the need was identified, but there was no systematic approach to ensure supplies were in place based on anticipated, future need. After the implementation of these interventions, palliative home care patients continued to receive their usual home care services, with the additional support of the Yellow Folders and Symptom Response Kits for those patients who were offered and accepted these interventions.

Study Design and Population

The ecologic study evaluated the population-level impact of these interventions by comparing palliative home care patients' outcomes across three time periods corresponding to the intervention implementation dates: April 1, 2009, to March 31, 2010 (preintervention period), April 1, 2010, to February 12, 2012 (Yellow Folder period), and February 13, 2012, to March 31, 2014 (Yellow Folder and Symptom Response Kit period). The eligible cohort included all South East Community Care Access Centre patients aged 18 and older who received palliative home care at any point between April 1, 2009, and March 31, 2014. Patients could have also received palliative home care before April 1, 2009. For the place of death analysis, the cohort was restricted to individuals who died on or before March 31, 2014.

The retrospective cohort study evaluated the individual-level impact of these interventions by comparing outcomes among palliative home care patients who received the Yellow Folder and/or Symptom Response Kit to those who received neither intervention. The eligible cohort included all South East Community Care Access Centre patients aged 18 and older who received palliative home care at any point between April 1, 2010, and March 31, 2014. Patients could also have received palliative home care before April 1, 2010. For the place of death analysis, the cohort was restricted to those who died on or before March 31, 2014. Cohort entry was the earliest date, after April 1, 2010, that a patient was admitted to palliative home care, with those already receiving palliative home care assigned that date as their start.

Palliative home care patients were identified from patients' home care coordination details and service recipient category (SRC).[26] Before May 2011, palliative home care was organized by care coordinators

Table 1
Ecologic Study Results

	Community Death		Hospitalizations		Emergency Department Visits	
Period	*n* (%)	RR (95% CI)	Crude Rate, per 10,000 Patient Days	RR (95% CI)	Crude Rate, per 10,000 Patient Days	RR (95% CI)
Preintervention	321 (42.8)	Reference	36.8	Reference	90.6	Reference
Yellow Folder period	783 (42.5)	0.99 (0.90–1.09)	40.6	1.10 (0.99–1.22)	96.9	1.07 (0.98–1.16)
Yellow Folder and Symptom Response Kit period	1275 (48.5)	1.13 (1.03–1.24)	37.4	1.02 (0.92–1.12)	90.5	1.00 (0.92–1.08)

RR = relative risk; CI = confidence interval.

who had an interest, but not necessarily training, in palliative care, and patients sometimes had multiple care coordinators. After May 2011, palliative home care was organized by the Supportive Care Team, which comprised a team of care coordinators and providers with training in palliative care and which offered patients greater stability in their care. SRCs identify the focus of patients' home care and are determined by care coordinators. For this study, home care patients were defined as palliative on the earliest date that one of the following occurred: 1) SRC 95 (End of life: not responsive to curative treatment; death expected within six months) assignment or 2) SRC 93 (Maintenance: chronic, stable conditions) or SRC 94 (Long-term supportive: progressive decline in functioning) assignment *and* managed by a palliative care coordinator or the Supportive Care Team.

Data Sources and Study Variables

We used administrative and clinical databases from ICES and the South East Community Care Access Centre, brought to ICES via a data-sharing agreement. Databases were linked using unique encoded identifiers and analyzed at ICES. The South East Community Care Access Centre database identified cohort eligibility and intervention receipt. The ICES Registered Persons Database identified patient vital status and demographics. Emergency department visit, hospitalization, and place of death data were obtained from the Canadian Institute for Health Information Discharge Abstract Database, National Ambulatory Care Reporting System, and Continuing Care Reporting System. The primary outcome was place of death, defined as in community or institution. Institutional deaths occurred during an acute care hospitalization, emergency department visit, or complex continuing care admission. Community deaths were defined as decedents with no record of institutional death and included deaths at home or in a hospice or long-term care setting. Secondary outcomes included nonelective hospitalizations and unscheduled emergency department visits.

Covariates for the retrospective cohort were measured at cohort entry and included age, sex, comorbidity in the previous two years using Johns Hopkins ACG® System, version 10, Aggregated Diagnosis Groups and Major Expanded Diagnostic Clusters,[27] rurality using the Rurality Index for Ontario,[28] area-level material deprivation using the Ontario Marginalization Index,[29] region of residence, living arrangement, and 10-year cancer history.

Statistical Analyses

In the ecologic study, we used unadjusted log-binomial regression to compare the proportion of deaths that occurred in the community across the three time periods. Deaths were excluded if patients were not palliative home care patients during the time period of death. We used Poisson regression to compare emergency department visit and hospitalization rates across the three time periods. Rate denominators were a sum of patients' active time during the period, defined as days between patients' first palliative home care admission and death date or period end date (whichever occurred first), subtracting time in hospital. Rate numerators were a sum of emergency department visits or hospitalizations that occurred during patients' active time in the period.

In the retrospective cohort study, we compared the probability of community death by patients' exposure status at death using chi-squared tests and multivariable modified Poisson regression with robust error variance to estimate the relative risk (RR). To analyze emergency department visits and hospitalizations, we summed the person-time that patients spent in the four exposure categories (Yellow Folder, Symptom Response Kit, both interventions, or unexposed) from cohort entry to March 31, 2014, or death, whichever occurred first,

Table 2
Characteristics of Retrospective Cohort

Patient Characteristics	Yellow Folder, $n = 1776$, %	No Yellow Folder, $n = 4124$, %	*P* value	Symptom Response Kit, $n = 898$, %	No Symptom Response Kit, $n = 5002$, %	*P* value
Mean age at cohort entry	73.1 years (SD = 12.8)	70.6 years (SD = 13.4)	<0.0001	72.3 years (SD = 12.7)	71.2 years (SD = 13.3)	0.02
Sex			0.7			0.03
Female	46.7	49.3		45.2	49.0	
Male	53.3	50.7		54.8	51.0	
Number of major Aggregated Diagnosis Groups			0.6			0.4
0–2[a]	39.0	39.5		39.4	39.4	
3–4	46.6	45.6		46.5	45.8	
5+	14.3	14.8		14.0	14.8	
Number of minor Aggregated Diagnosis Groups			0.8			0.8
0–2	5.6	4.6		4.3	4.7	
3–5	24.9	26.0		26.9	25.5	
6–10	61.6	60.8		60.5	61.0	
11+	8.7	8.7		8.2	8.7	
Rurality, based on Rurality Index for Ontario score			<0.0001			0.4
0–9 (most urban)	35.7	34.3		36.1	34.4	
10–30	27.5	28.5		28.9	28.0	
31–45	28.4	32.2		28.7	31.5	
46–55	2.0	1.3		2.0	1.4	
56+ (most rural)	6.3[b]	3.4		4.2[b]	4.2	
Unknown	–[b]	0.3		–[b]	0.3	
Living alone			<0.0001			<0.0001
Lives alone	8.9	12.2		8.3	11.8	
Does not live alone	83.1	76.2		85.4	77.0	
Unknown	7.9	11.6		6.2	11.2	
Socioeconomic status deprivation quintile			0.002			0.06
1	16.7	19.6		17.3	19.0	
2	23.1	24.2		22.6	24.1	
3	20.1	20.6		20.7	20.4	
4	22.4	18.2		23.0	18.9	
5	17.0	16.6		15.9[c]	16.9	
Unknown	0.0	0.7		–[c]	0.7	
South East Community Care Access Centre region			<0.0001			<0.0001
Central	34.1	37.5		31.7	37.3	
East	18.6	30.8		16.2	29.1	
West	46.4	30.7		51.3	32.6	
Out of region	0.8	1.0		0.7	1.0	
10-year history of cancer			<0.0001			0.0003
Prior cancer diagnosis	60.4	69.0		61.2	86.8	
No prior cancer diagnosis	39.6	30.9		38.8	13.2	
Johns Hopkins Major Expanded Diagnostic Cluster = Malignancy			0.01			0.4
Yes	84.2	88.1		87.9	86.8	
No	15.8	11.9		12.1	13.2	

SD = standard deviation.
[a]The Major Aggregated Diagnosis Groups category 0–2 collapsed for reporting because of small cell size.
[b]Unknown rurality and rurality 56+ collapsed for reporting because of small cell size.
[c]Unknown deprivation quintile and quintile 5 collapsed for reporting because of small cell size.

subtracting time in hospital. We compared emergency department visit and hospitalization rates for each exposure category using multivariable Poisson regression models. Potential confounders of place of death were factors hypothesized to impact place of death, including age, sex, rurality, living arrangement, deprivation quintile, region, and cancer history. Similarly, potential confounders of hospitalizations and emergency department visits were factors hypothesized to impact these outcomes, consisting of comorbidity and all potential confounders considered in the place of death analysis. All potential confounders demonstrating a significant ($P < 0.05$) bivariable association with the

Table 3
Retrospective Cohort, Place of Death Analysis in the Decedent Subgroup ($N = 4538$)

Exposure	Number of Patients	% Deaths in Community	Adjusted[a] RR (95% CI) of Death in Community
No interventions received	2787	33.4	Reference
Yellow Folder only	923	58.6	1.66 (1.54–1.78)
Symptom Response Kit only	133	64.7	1.79 (1.55–2.05)
Yellow Folder and Symptom Response Kit	695	75.4	2.20 (2.05–2.36)

RR = relative risk; CI = confidence interval.
[a]Adjusted for age, rurality, living arrangement, region, and history of cancer.

outcome of interest were included in multivariable models. Continuous covariates were modeled as categorical variables because of nonlinearity. Patients with missing covariate data for material deprivation or rurality were excluded from multivariable analyses.

We conducted sensitivity analyses in the retrospective cohort study using more stringent end-of-life cohort definitions. First, we restricted the cohort to patients with an end-of-life service recipient category (SRC 95). Second, we restricted the cohort to patients who died on March 31, 2014, and analyzed this group's hospitalizations and emergency department visits from cohort entry to death and in the two weeks to one month, one to two months, two to three months, and three to six months before death. We chose not to analyze hospital utilization rates in the two weeks immediately preceding death as hospital care in the time immediately preceding death may have been patients' preferred and appropriate place of care.

Informed consent was not required for this study. The use of ICES data was authorized under section 45 of Ontario's Personal Health Information Protection Act, which does not require review by a research ethics board. The use of South East Community Care Access Centre data was approved by the Queen's University Health Sciences Research Ethics Board.

Results

Ecologic Study

There were 6927 patients and 5223 deaths in the ecologic study cohort. In the Yellow Folder period, 19.8% of patients received a Yellow Folder; during the Yellow Folder and Symptom Response Kit period, 49.0% of patients received a Yellow Folder and 30.5% received a Symptom Response Kit. The likelihood of dying in the community was greater when the Yellow Folder and Symptom Response Kit were in use (RR = 1.13, 95% confidence interval [CI] 1.03–1.24), compared with the preintervention period (Table 1). Emergency department visit and hospitalization rates in the two intervention periods were not significantly different from those in the preintervention period (Table 1).

Retrospective Cohort Study

The final cohort included 5900 patients, of which 4538 (76.9%) died on March 31, 2014. Almost one-third (30.1%) received a Yellow Folder and 15.2% received a Symptom Response Kit. Compared with patients who did not receive the intervention, patients who received a Yellow Folder or Symptom Response Kit were younger, more likely to live with others, reside in areas with less socioeconomic marginalization, reside in the western region of the catchment, and less likely to have a history of cancer (Table 2). In addition, patients who received a Yellow Folder were more likely to reside in the most urban and most rural areas and less likely to have cancer as a comorbid condition, whereas patients who received a Symptom Response Kit were more likely to be male. There were no differences in comorbidity between patients who did or did not receive the interventions.

Among the 4538 decedent patients, 15.3% received both interventions, 2.9% received the Symptom Response Kit only, 20.3% received the Yellow Folder only, and 61.4% received neither. After cohort entry, patients waited a median of 39 days to receive a Yellow Folder and 59 days to receive a Symptom Response Kit. Forty-six percent of deaths occurred in the community. After confounder adjustment, compared with patients who received neither intervention, those who received either intervention were more likely to die in the community (Yellow Folder: RR 1.66, 95% CI 1.54–1.79; Symptom Response Kit: RR 1.79, 95% CI 1.55–2.05) and those receiving both interventions were most likely to die in the community (RR 2.20, 95% CI 2.05–2.36) (Table 3).

Unadjusted emergency department visit and hospitalization rates were lowest among unexposed patients (Table 4). After confounder adjustment, these rates remained higher than those in unexposed patients. For both outcomes, the RR 95% CI crossed 1.0 in the two-intervention group but not in the

Table 4
Retrospective Cohort Results, Emergency Department Visits and Hospitalizations ($N = 5900$)

		Emergency Department Visits		Hospitalizations	
Exposure Time Period	Number of Patients[a]	Crude Rate, per 1000 Patient Days	Adjusted[b] RR (95% CI)	Crude Rate, per 1000 Patient Days	Adjusted[b] RR (95% CI)
No interventions received	5646	7.6 (7.5–7.7)	Reference	3.0 (2.9–3.1)	Reference
Yellow Folder only	1378	12.7 (12.0–13.4)	1.46 (1.30–1.65)	5.9 (5.4–6.4)	1.70 (1.48–1.95)
Symptom Response Kit only	284	12.6 (10.2–15.6)	1.50 (1.07–2.11)	6.4 (4.7–8.2)	1.89 (1.33–2.67)
Yellow Folder and Symptom Response Kit	750	10.6 (9.5–11.6)	1.16 (0.98–1.38)	4.5 (3.8–5.1)	1.21 (0.98–1.49)

RR = relative risk; CI = confidence interval.
[a]Number of patients does not add up to total sample size as patients could contribute time to more than one exposure time period.
[b]Adjusted for age, sex, material deprivation quintile, rurality, living arrangement, cancer history, and comorbidity.

single-intervention group, where the differences remained statistically significant.

Sensitivity Analyses

Among the subgroup with an end-of-life (SRC 95) home care designation, the RRs for place of death were smaller than in the primary analysis, although still statistically significant (Supplemental Table 1). There were no significant differences in hospitalization or emergency department visit rates between exposed and unexposed patients, with the exception of patients who received Yellow Folders having higher hospitalization rates than patients who received neither intervention.

Among the subgroup of patients who died on March 31, 2014, the intervention effect estimates for hospitalizations and emergency department visits all moved closer to one, with no significant difference in rates between patients who received a Symptom Response Kit or both interventions compared with patients who received neither (Supplemental Table 2). When these analyses were restricted to the two weeks to six months preceding death, receipt of a Yellow Folder and/or Symptom Response Kit were all associated with significant reductions in hospitalization and emergency department visit rates (Supplemental Table 3).

Discussion

The Yellow Folder and Symptom Response Kit were associated with a reduced risk of dying in hospital among palliative home care patients. This finding was consistent in both the retrospective cohort study, which evaluated the patient-level impact of the interventions, and the ecologic study, which evaluated the population-level program effectiveness. For hospital utilization outcomes, it is reasonable to conclude that the Yellow Folder and Symptom Response Kit have no impact on hospitalization or emergency department visit rates over the full time period in which patients were eligible, although our sensitivity analyses showed reduced hospital utilization in the two weeks to six months preceding death, arguably the more likely time period for these interventions to have an effect. The ecologic study results indicating no population-level impact of these interventions on hospital utilization were likely due to the low uptake of the interventions during the time period of the study.

These findings are in line with previous research that has demonstrated home-based palliative care interventions support death at home.[6,15,18,21,22,30–35] The Yellow Folder facilitates advance care planning by providing information about and establishing procedures that support home deaths. Although the Yellow Folder is unique in that it focuses on a single aspect of end-of-life planning, advance care planning has generally been shown to improve end-of-life outcomes, including reduced hospital deaths and less aggressive care.[21,35] Increased caregiver confidence associated with Symptom Response Kits may explain the added effect of these kits on place of death in this study.[17,20]

In contrast to previous literature, our primary analyses do not support an impact of the Yellow Folder or Symptom Response Kit on acute care utilization. Patients, caregivers, and health care providers have previously reported reduced rates of unscheduled interventions and hospital visits in emergency medication kit recipients, although these studies may be limited by recall bias.[15,17,18,20,23] Although our sensitivity analyses demonstrated reduced hospital utilization rates among intervention recipients when we focused on the period preceding death, these post hoc analyses should be viewed as hypothesis generating.

Strengths and Limitations

The universal single-payer health care system in Ontario allowed us to capture information about all

palliative home care patients in a defined geographic region. Palliative home care delivery in Ontario may differ from that in other countries or even other Canadian provinces because home care is under provincial jurisdiction. However, we think our findings are generalizable to palliative home care patients receiving care from a common provider, such as a hospice organization. Despite being conducted in 2010–2014, we think the findings of this study are still relevant to current palliative care practice because high rates of in-hospital deaths and end-of-life acute care utilization remain problematic.[5,8,36,37] Our study data were of high quality. ICES data provided a complete and unbiased capture of patients' health care utilization. Symptom Response Kit documentation was linked to pharmacy reimbursement and therefore is likely accurate. Although Yellow Folder documentation was not linked to reimbursement, care providers were expected to report its introduction.

The uptake of these interventions was modest and not all patients who received a Yellow Folder also received a Symptom Response Kit. It is possible that care providers were more accustomed to the Yellow Folder, which had been in place for two years when the Symptom Response Kit was implemented. Furthermore, Symptom Response Kits required a physician or nurse practitioner prescription, which could have posed a barrier to their use.

There may be uncontrolled confounding in our results. We were unable to measure patients' and caregivers' preferences for place of death, which is a prerequisite for a home death and a determinant of intervention receipt.[2,38] We were unable to control for cause of death as these data were available for only 64% of those who died in our study. Although we controlled for cancer history, this may not reflect what patients were dying from. The adoption of a Supportive Care Team structure during the period of this study likely improved the quality of palliative home care, which may partially explain our results. Variations in the availability and use of other palliative care services, such as hospices, physician palliative care, and community palliative care consult teams, may partly explain the regional variations in intervention uptake and also impacted patients' likelihood of remaining at home at the end of life. However, we think the confounding effect of these palliative care services would be minimal as they would all complement, rather than replace, home care and the supports provided through our interventions. We adjusted for region and rurality in our multivariable models but were unable to measure and control for availability and use of other health care services. We also lacked details on private home supports that patients paid for out of pocket, which may have affected their hospital utilization and therefore could also be confounding our results.

Finally, our retrospective cohort study design for the primary analyses of hospitalizations and emergency department visits was likely biased against the interventions. Palliative designation, which defined cohort entry and intervention eligibility, was meant to occur when patients' Palliative Performance Scale score was at or below 50%. However, many patients lived a long time and did not receive either intervention until weeks or months after their palliative designation. Palliative status misclassification resulted in the patients who ultimately received one or both of our interventions contributing a lot of unexposed time to the study before receiving the intervention. This is a time when there would be low hospitalization and emergency department visit rates, thus biasing our results toward the null. We addressed this through our post hoc sensitivity analyses in subgroups that were more definitively at their end of life. Notably, sensitivity analyses that examined outcomes in the time shortly preceding death showed reduced rates of hospital services in the presence of our interventions. We suggest that future research should consider focusing on decedent subgroups of patients who had been receiving palliative home care, exploring their outcomes in a limited time period before death.

Conclusion

The Yellow Folder and Symptom Response Kit are associated with an increased likelihood that palliative home care patients will die outside of acute and chronic care hospitals and lower rates of hospital use in the last six months of life. These associations were stronger when these interventions are used together. When provided in conjunction with palliative home care, these interventions can help support patients' preferences to remain at home at the end of life.

Disclosures and Acknowledgments

The authors have no conflicts of interest to declare. The authors would like to acknowledge the following individuals for their provided support throughout this project: Donna Logan, RN, BScPHN—former Hospice Palliative Care Project Manager of the South East Community Care Access Centre, and Margaret George, MHA, BA(H), CHE—former Director of the Southeastern Ontario Palliative and End-of-Life Care Network.

The South East Local Health Integration Network (LHIN) funded the introduction of the Yellow Folder and Symptom Response Kit in southeastern Ontario.

The South East Community Care Access Centre (SECCAC) provided access to data for this study.

This study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results, and conclusions reported in this article are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario MOHLTC is intended or should be inferred. Parts of this material are based on data and/or information compiled and provided by CIHI. However, the analyses, conclusions, opinions, and statements expressed in the material are those of the authors, and not necessarily those of CIHI. Parts of this material are based on data and information provided by Cancer Care Ontario (CCO). The opinions, results, view, and conclusions reported in this article are those of the authors and do not necessarily reflect those of CCO. No endorsement by CCO is intended or should be inferred.

The data set from this study is held securely in coded form at ICES. Although data sharing agreements prohibit ICES from making the data set publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at www.ices.on.ca/DAS. The full data set creation plan and underlying analytic code are available from the authors on request, understanding that the programs may rely on coding templates or macros that are unique to ICES.

This work was supported by the Ontario Academic Health Science Centres Alternate Funding Plan Innovation Fund, Ontario.

References

1. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliat Med 2005;19:492–499.

2. Burge F, Lawson B, Johnston G, et al. Preferred and actual location of death: what factors enable a preferred home death? J Palliat Med 2015;18:1054–1059.

3. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013;12:7.

4. Pollock K. Is home always the best and preferred place of death? BMJ 2015;351:h4855.

5. Barbera L, Seow H, Sutradhar R, et al. Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data. Curr Oncol 2015;22:341–355.

6. Barbera L, Taylor C, Dudgeon D. Why do patients with cancer visit the emergency department near the end of life? CMAJ 2010;182:563–568.

7. Tanuseputro P, Wodchis WP, Fowler R, et al. The health care cost of dying: a population-based retrospective cohort study of the last year of life in Ontario, Canada. PLoS One 2015;10:e0121759.

8. Qureshi D, Tanuseputro P, Perez R, Seow H. Place of care trajectories in the last two weeks of life: a population-based cohort study of Ontario decedents. J Palliat Med 2018;21:1588–1595.

9. Evans WG, Cutson TM, Steinhauser KE, Tulsky JA. Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. J Palliat Med 2006;9:100–110.

10. Wilson D, Truman CD, Thomas R, et al. The rapidly changing location of death in Canada, 1994-2004. Soc Sci Med 2009;68:1752–1758.

11. Broad JB, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health 2013;58:257–267.

12. Dumont S, Jacobs P, Turcotte V, Anderson D, Harel F. The trajectory of palliative care costs over the last five months of life: a Canadian longitudinal study. Palliat Med 2010;24:630–640.

13. Ratner E, Norlander L, McSteen K. Death at home following a targeted advance-care planning process at home: the kitchen table discussion. J Am Geriatr Soc 2001;49:778–781.

14. LeGrand SB, Tropiano P, Marx JD, Davis MP, Walsh D. Dying at home: emergency medications for terminal symptoms. Am J Hosp Palliat Care 2001;18:421–423.

15. Rosenberg JP, Bullen T, Maher K. Supporting family caregivers with palliative symptom management: a qualitative analysis of the provision of an emergency medication kit in the home setting. Am J Hosp Palliat Care 2015;32:484–489.

16. Wowchuk SM, Wilson EA, Embleton L, et al. The palliative medication kit: an effective way of extending care in the home for patients nearing death. J Palliat Med 2009;12:797–803.

17. Bailey FA, Williams BR, Goode PS, et al. Impact of a hospice emergency kit for veterans and their caregivers: a prospective cohort study. J Palliat Med 2014;17:931–938.

18. Schonwetter RS, Clark LD, Leedy SA, et al. Predicting emergency room visits and hospitalizations among hospice patients with cardiac disease. J Palliat Med 2008;11:1142–1150.

19. Bullen T, Rosenberg JP, Smith B, Maher K. The Use of emergency medication kits in community palliative care. Am J Hosp Palliat Care 2014;32:581–587.

20. Walker KA, McPherson ML. Perceived value and cost of providing emergency medication kits to home hospice patients in Maryland. Am J Hosp Palliat Care 2009;27:254–260.

21. Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Support Palliat Care 2013;3:168–173.

22. Ishikawa T, Fukui S, Okamoto Y. Advance care planning and home death in patients with advanced cancer: a structured interview analysis. Int J Palliat Nurs 2018;24:418–426.

23. Bishop MF, Stephens L, Goodrich M, Byock I. Medication kits for managing symptomatic emergencies in the

home: a survey of common hospice practice. J Palliat Med 2009;12:37–44.

24. South East LHIN. Integrated health care for local communities: 2016/17 Annual report. Belleville, ON: South East LHIN, 2018.

25. Victoria Hospice. Palliative Performance Scale (PPSv2) version 2 2001. Available from: https://www.victoriahospice.org/sites/default/files/ppsv2_english_-_sample_-_dec_17.pdf. Accessed August 7, 2018.

26. Health Quality Ontario. Indicator technical specifications for the palliative care at the end of life report: Technical appendix. Toronto, ON: Health Quality Ontario, 2016.

27. Johns Hopkins University School of Public Health. The Johns Hopkins ACG System. Version 10.0 ed. 2011. Baltimore, MD.

28. Kralj B. Measuring rurality - RIO2008_BASIC: Methodology and results. OMA Economics Department, 2009. [cited 2019 March 11]. Available from: https://www.oma.org/wp-content/uploads/2008rio-fulltechnicalpaper.pdf. Accessed March 11, 2019.

29. Matheson FI, Dunn JR, Smith KLW, Moineddin R, Glazier RH. Development of the Canadian Marginalization Index: a new tool for the study of inequality. Can J Public Health 2012;103(Suppl. 2):S12–S16.

30. Seow H, Brazil K, Sussman J, et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. BMJ 2014;348:g3496.

31. Seow H, Dhaliwal G, Fassbender K, et al. The effect of community-based specialist palliative care teams on place of care. J Palliat Med 2016;19:16–21.

32. Aiken LS, Butner J, Lockhart CA, et al. Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. J Palliat Med 2006;9:2006.

33. Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. J Am Geriatr Soc 2007;55:993–1000.

34. Jordhøy MS, Fayers P, Saltnes T, et al. A palliative-care intervention and death at home: a cluster randomised trial. The Lancet 2000;356:888–893.

35. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008;300:1665–1673.

36. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliat Med 2018;32:329–336.

37. Qureshi D, Tanuseputro P, Perez R, Pond GR, Seow H-Y. Early initiation of palliative care is associated with reduced late-life acute-hospital use: a population-based retrospective cohort study. Palliat Med 2019;33:150–159.

38. Gomes B, Higginson I. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332:515–518.

Appendix

Supplemental Table 1

Sensitivity Analysis Results, Patients With End-of-Life Service Recipient Category Designation (SRC 95) ($N = 2915$)

Exposure Time Period	Number of Patients[a]	Death in Community, RR (95% CI)[b]	Hospitalizations, RR (95% CI)[b]	Emergency Department Visits, RR (95% CI)[c]
No interventions received	2696	Reference	Reference	Reference
Yellow Folder only	1081	1.38 (1.27–1.50)	1.21 (1.02–1.43)	1.09 (0.95–1.25)
Symptom Response Kit only	215	1.48 (1.26–1.72)	1.45 (0.95–2.20)	1.10 (0.73–1.66)
Yellow Folder and Symptom Response Kit	608	1.75 (1.62–1.89)	0.86 (0.69–1.09)	0.85 (0.70–1.02)

RR = relative risk; CI = confidence interval.
[a]Number of patients does not add up to total sample size as patients could contribute time to more than one exposure time period.
[b]Adjusted for age, rurality, living arrangement, region, and history of cancer.
[c]Adjusted for age, sex, material deprivation quintile, rurality, living arrangement, cancer history, and comorbidity.

Supplemental Table 2

Sensitivity Analysis Results, Patients Who Died on or Before March 31, 2014 ($N = 4481$)

Exposure Time Period	Number of Patients[a]	Hospitalizations, RR (95% CI)[b]	Emergency Department Visits, RR (95% CI)[b]
No interventions received	4249	Reference	Reference
Yellow Folder only	1246	1.31 (1.16–1.48)	1.17 (1.05–1.30)
Symptom Response Kit only	261	1.34 (0.97–1.85)	1.17 (0.85–1.62)
Yellow Folder and Symptom Response Kit	688	0.89 (0.73–1.09)	0.92 (0.78–1.08)

RR = relative risk; CI = confidence interval.
[a]Number of patients does not add up to total sample size as patients could contribute time to more than one exposure time period.
[b]Adjusted for age, sex, material deprivation quintile, rurality, living arrangement, cancer history, and comorbidity.

Supplemental Table 3

Sensitivity Analysis Results, Patients Who Died on or Before March 31, 2014

	Hospitalizations, RR (95% CI)[a]				Emergency Department Visits, RR (95% CI)[a]			
Exposure Time Period	Two Weeks to One Month, $n = 3621$	One to Two Months, $n = 3301$	Two to Three Months, $n = 2717$	Three to Six Months, $n = 2306$	Two Weeks to One Month, $n = 3621$	One to Two Months, $n = 3301$	Two to Three Months, $n = 2717$	Three to Six Months, $n = 2306$
No interventions received	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Yellow Folder only	0.95 (0.92–0.98)	0.95 (0.91–0.99)	0.96 (0.92–0.99)	0.89 (0.83–0.95)	0.91 (0.87–0.96)	0.89 (0.83–0.95)	0.93 (0.87–1.00)	0.77 (0.67–0.89)
Symptom Response Kit only	0.88 (0.84–0.92)	0.89 (0.82–0.96)	0.9 (0.83–0.97)	0.88 (0.71–1.08)	0.85 (0.76–0.94)	0.73 (0.65–0.81)	0.77 (0.67–0.89)	0.54 (0.42–0.7)
Yellow Folder and Symptom Response Kit	0.88 (0.85–0.90)	0.84 (0.81–0.87)	0.88 (0.84–0.91)	0.89 (0.83–0.95)	0.81 (0.77–0.85)	0.75 (0.70–0.81)	0.78 (0.72–0.85)	0.64 (0.52–0.79)

RR = relative risk; CI = confidence interval.
[a]Adjusted for age, sex, material deprivation quintile, rurality, living arrangement, cancer history, and comorbidity.