ONLINE EXCLUSIVE

Predictors of Home Care Expenditures and Death at Home for Cancer Patients in an Integrated Comprehensive Palliative Home Care Pilot Program

Facteurs de prévision des dépenses pour les soins à domicile et les décès à domicile chez les patients atteints du cancer dans le cadre d'un programme pilote de soins palliatifs complets à domicile

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Abstract

Purpose: Empirical understanding of predictors for home care service use and death at home is important for healthcare planning. Few studies have examined these predictors in the context of the publicly funded Canadian home care system. This study examined predictors for home care use and home death in the context of a "gold standard" comprehensive palliative home care program pilot in Ontario where patients had equal access to home care services.

Methods: Secondary clinical and administrative data sources were linked using a unique identifier to examine multivariate factors (predisposing, enabling, need) on total home care expenditures and home death for a cohort of cancer patients enrolled in the HPCNet pilot.

Results: Subjects with gastrointestinal symptoms (OR: 1.64; p=0.03) and those with higher income had increased odds of dying at home (OR: 1.14; p<0.001), whereas age, number of GP visits, gastrointestinal symptoms (i.e., nausea, vomiting, bowel obstruction) and eating problems (i.e., anorexia/cachexia) predicted home care expenditures.

Conclusions: Predictors of home death found in earlier studies appeared less important in this comprehensive palliative home care pilot. An income effect for home death observed in this study requires examination in future controlled studies.

Relevance: Access to palliative home care that is adequately resourced and organized to address the multiple domains of issues that patients/families experience at the end of life has the potential to enable home death and shift care appropriately from limited acute care resources.

Résumé

Objet : La compréhension empirique des facteurs de prédiction pour l'utilisation des services à domicile et pour les décès à domicile est importante pour la planification des services de santé. Peu d'études se sont penchées sur ces facteurs de prédiction dans le contexte des systèmes publiques de soins à domicile au Canada. Cette étude examine les facteurs de prédiction pour l'utilisation des soins à domicile et pour les décès à domicile dans le contexte d'un programme pilote « exemplaire » de soins palliatifs complets à domicile, en Ontario, dans lequel les patients ont un accès égal aux services de soins à domicile.

Méthodologie : Des sources de données secondaires cliniques et administratives ont été couplées entre elles au moyen d'un identificateur unique afin d'étudier les facteurs multivariés (prédisposant, habilitant et nécessaire) des dépenses totales pour les soins à domicile et pour les décès à domicile, et ce pour une cohorte de patients atteints du cancer et inscrits dans un programme pilote du HPCNet.

Résultats : Les sujets qui présentent des symptômes gastrointestinaux (RC: 1,64; p=0,03) et ceux qui ont un revenu plus élevé sont plus susceptibles de décéder à la maison (RC: 1,14; p<0,001) tandis que l'âge, le nombre de visites de l'omnipraticien, les symptômes gastrointestinaux (c.-à-d., la nausée, les vomissements, l'occlusion intestinale) et les troubles de l'alimentation (c.-à-d., anorexie/cachexie) permettent de prévoir les dépenses pour les soins à domicile.

Conclusions : Les facteurs de prédiction pour les décès à domicile, dégagés par les études antérieures, semblent moins importants que ceux qu'on observe dans le cadre de ce projet

pilote de soins palliatifs complets à domicile. L'effet du revenu sur les décès à domicile, observé dans cette étude, devrait faire l'objet d'éventuelles études contrôlées.
Pertinence : Un accès aux soins palliatifs à domicile pourvu des ressources et de l'organisation appropriées, et tenant compte des multiples enjeux qu'expérimentent les patients (et leurs familles) à la fin de la vie, pourrait faciliter les décès à domicile et permettre une réorientation adéquate des soins qui allégerait le secteur des soins de courte durée dont les ressources sont limitées.

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Care at home in the final weeks of life and an adequately supported home death is a goal expressed by most patients with a terminal illness (Higginson and Sen-Gupta 2000; Teirnan et al. 2002; Townsend et al. 1990). It is also a health system policy imperative (Romanow 2000). Studies in the United States and internationally show that realization of this goal depends on diverse demographic and disease factors as well as access to tertiary acute care and community hospital beds (Gallo et al. 2001; Greer et al. 1986; Hearn and Higginson 1998; McWhinney et al. 1995; Polissar et al. 1987; Pritchard et al. 1998; Thorne et al. 1994). These factors may become less relevant as predictors of home death if end-of-life (EOL) patients have equal access to high-quality care that meets the "gold standard" for palliative home care.

Gold standard programs are based on standards and norms of practice for palliative care; they include components considered essential for home care at the end of life, including case management/care coordination and access to skilled palliative medicine physicians, knowledgeable and skilled providers (palliative care nurses, personal support workers), psycho-social counselling and respite care (Ferris et al. 2002; CHPCA 2006). The adequacy of home care providers in addressing multi-system disease management and symptom problems as well as multiple domains of EOL needs – including psychological, social, loss/grief, practical and end-of-life preparation – is critical to high-quality palliative care and enabling home death (Ferris et al. 2002; Coyle et al. 1999; Emanuel et al. 1999; Fainsinger et al. 2000; Thorpe 1993). International studies show that access to specialized palliative care programs or hospice team programs and skilled home care case management or care coordination increases the number of days spent at home and rates of home death (Gallo et al. 2001; Beck-Friis and Strang 1993; Constantini et al. 1993; Hughes et al. 1992; Jordhoy et al. 2000; Pannuti 1988; Peruselli et al. 1997; Smeenk et al. 1998).

This paper reports the findings of a descriptive, secondary data linkage study that examined the pattern of home care use (service visits) and the influence of population characteristics inclusive of predisposing, enabling and need factors, based on Anderson's Behavioural Model of Health Services Utilization (Anderson and Newman 1973), as predictors of home care expenditures and home death for cancer patients enrolled in a gold standard comprehensive and integrated palliative home care program. Empirical understanding of home care use and home death predictors in the context of the publicly funded Canadian home care system, when EOL patients have equal access to gold standard comprehensive palliative home care, could inform healthcare planning and resource allocation decisions. Healthcare services used in these models of care delivery may represent true resource needs for EOL populations because service allocation decisions are tailored to needs as determined by palliative care specialists. Such specialists have clinical expertise that enables them to anticipate needs, especially when they work collaboratively with home care case managers responsible for allocating home care services.

Methods

Over a two-year period, a pilot demonstration project, the Hospice Palliative Care Network (HPCNet), was conducted in the Greater Toronto Area, a large metropolitan city in the province of Ontario. The HPCNet pilot developed an integrated service delivery model that included a partnership between discrete organizations, including five hospice volunteer agencies, a palliative medicine consultation service and a publicly funded home care program (community care access centre, or CCAC). The CCAC was responsible for allocating services of contracted providers – including visiting nurses, personal support workers (PSWs), dietitians, physiotherapists and occupational therapists – and funding equipment allocations (beds, pain pumps, assistive devices for ADL).

Generic CCAC services were enhanced by the HPCNet pilot with the addition of a comprehensive interdisciplinary palliative care team comprising palliative medicine physicians, palliative consultant nurses, psycho-social counsellors and designated CCAC palliative home care case managers/care coordinators who also integrated hospice volunteer care provision. A rapid-response team was accessible 24 hours a day, seven days a week; palliative consultant nurses provided first call, with back-up assistance from on-call palliative medicine specialists as needed. The team also coordinated early referral to alternative care settings, such as palliative care beds in hospital or chronic care facilities, and worked collaboratively with primary care physicians to determine the appropriate level of support required, depending on the complexity of patient/family issues and available formal and informal resources to provide home-based care. The CCAC centrally coordinated service delivery and provided case management services to achieve seamless integration among partner agencies and interdisciplinary palliative care team members for eligible clients. Integration was achieved through a shared governance structure and a collaborative network team care delivery process. Team composition was tailored to the identified needs of patients and their families and the availability of formal and informal resources. Ongoing weekly team meetings and shared care planning facilitated care coordination and continuity. The team was supported by a clinical database accessible on Web-based PalmPilot platforms in real time with updates as they occurred around the clock (e.g., prescription changes).

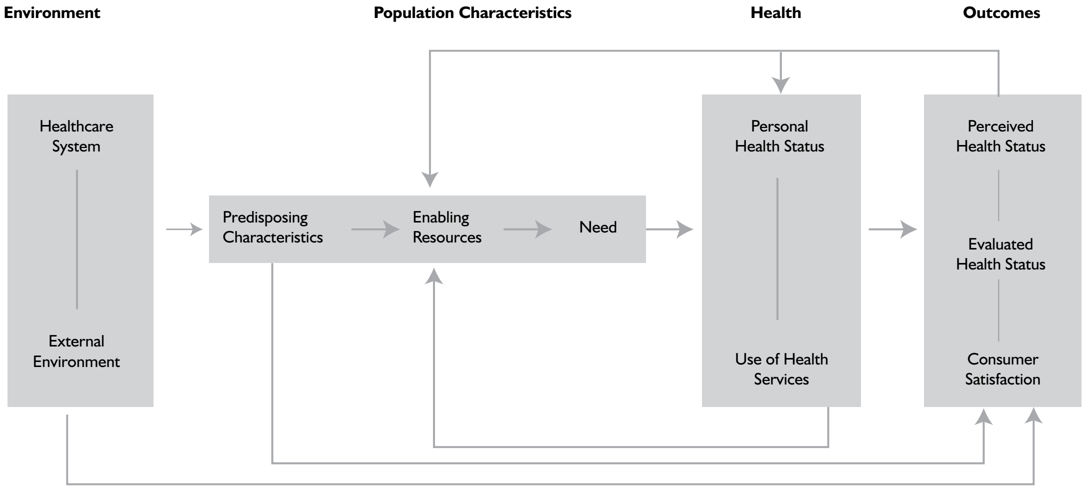
Following ethics approval, an inception cohort of patients, all of whom had a life-threatening cancer diagnosis and a referral to the regional home care program, was screened for eligibility. Consenting patients were enrolled in HPCNet if eligibility criteria were met during the pilot's two-year time frame. Eligibility was based on best practice criteria to ensure identification of palliative patients early in the EOL trajectory (Lynn et al. 1996) as follows:

(1) advanced progressive disease, expectation of death in the next 12 months and (2) unmet symptom management and/or inadequate supportive care. Case finding was initiated within the CCAC to ensure that all patients with advanced, life-threatening illnesses were enrolled in the HPCNet pilot program.

Conceptual framework

The variables included as determinants in this study were based on a commonly used healthcare utilization model. According to Anderson's Behavioural Model of Health Services Utilization (Anderson and Newman 1973), three categories of population characteristics act as determinants of healthcare use, including (1) *predisposing:* demographics, social structure and belief systems; (2) *enabling:* family economic resources and location of residence; and (3) *perception of need for services:* either individually, socially or clinically evaluated. Based on available secondary data sources, these variables were operationalized for purposes of this study as follows: (1) *predisposing:* age, gender, education, living status (alone or with someone); (2) *enabling:* family income and family physician visits; and (3) *need:* clinically determined as type of cancer, presence and counts of symptoms and co-morbidities. More recent iterations of this model (Anderson 1995; see Figure 1) added feedback loops, suggesting a reciprocal relationship between outcomes and health that influences population characteristics, but did not specify theoretical propositions ranking some population characteristics as more important than others (Muramatsu and Campbell 2002). Based on empirical literature regarding recommended order entry of variables (Coulton and Frost 1982; Wolinsky 1978; Kempen and Suurmeijer 1991) and literature on factors predictive of home death, we hypothesized that predisposing variables would explain more of the variance in outcomes of home care expenditures and home death. Our rationale was that need variables would no longer act as drivers for service use in this gold standard model of comprehensive palliative home care, given that all patients had equal access to best care practices by HPCNet palliative specialists.

FIGURE 1. Conceptual framework of factors associated with health services utilization



Source: Anderson 1995.

Sample

For the purposes of identifying a cancer cohort for this study (a substudy of the full program evaluation) and to ensure a complete case file of CCAC services used for each final episode of home care prior to death, an additional set of eligibility criteria were applied as follows: (1) a diagnosis of cancer and (2) both an HPCNet/CCAC enrolment date and date of death during the 13-month pilot evaluation observation time frame.

Data sources

Multiple database sources were linked using a unique identifier to create a complete individual-level case file for this cancer cohort that included these variables: (1) *Patient-related characteristics* (age, living circumstances, diagnosis, symptoms, co-morbidities, place of death) were derived from the HPCNet clinical database that was developed specifically for the HPCNet pilot. Clinical illness characteristics, including ICD-9 codes for type of cancer, symptoms and co-morbidities (recorded by the clinical team for each individual patient at program entry), were grouped according to body systems and symptoms and coded as present or not present, and as a total symptom count. (2) *Home care services* (length of stay in home care program, visits/hours of care, expenditures) were captured in the CCAC administrative home care service database. (3) *Family physician home visits* from the Ontario Hospital Insurance Plan (OHIP) were extracted using billing codes for home visits. (4) *Median household income* was derived through postal code mapping to Canadian census enumeration data, an approach that is considered reliable and valid for estimating income when other sources of information are not available (Krieger 1992).

Pattern of home care service use and outcomes

The pattern of home care use was described as the number of total visits separately for visiting nurses, PSWs (healthcare aides), primary care physicians, multidisciplinary providers (occupational therapy, physiotherapy, social work), laboratory services and equipment. Outcomes examined included (1) *home care expenditures:* calculated as actual total billing charges per client, based on services used during total length of stay (LOS) in home care program from date of enrolment in the pilot until death (entire home care episode) and (2) *home death:* dichotomized as home or institutional death (hospital, palliative care hospital unit, long-term care).

Data analysis

All analyses were conducted using the SPSS 9 data management program (SPSS for Windows 2005). Skewed home care distributions were transformed, and log-transformed values (log 10) were used in data analysis (Norman and Streiner 2000). Data were summarized using descriptive statistics (means, medians, ranges and standard deviations). Correlation tests appropriate to data type were used to examine relationships between population characteristic variables and outcome variables. Entry of variables in multivariate hierarchical regression was based on empirical literature that interpreted Anderson's model and suggested that variables of need should be entered first in the model (block 1), followed by enabling variables (block

2) and, finally, predisposing variables (block 3) (Coulton and Frost 1982; Wolinsky 1978; Kempen and Suurmeijer 1991). This entry order was followed to examine the additional variance explained by each set of variables on outcomes when need is initially controlled, as well as the final contribution of predisposing variables. Prior to entry in multivariate models, an initial parsimonious block model of illness characteristics (symptoms, cancer type, co-morbidities) was derived to reduce the number of independent symptom and illness variables in order to maintain adequate statistical power as recommended for multivariate analysis (Norusis 2000). Tolerance levels were examined to rule out multi-collinearity in final models, and residuals were checked to rule out violations of linearity and leverage as measured by Cook's distance (Norusis 2000).

Results

Participant characteristics

Of the total HPCNet case files for the 13-month evaluation timeframe (n=807), 791 had a cancer diagnosis (other diagnoses not included were end-stage heart failure, chronic obstructive lung disease and other degenerative neuromuscular diseases). Of the 791 cancer patients enrolled during the 13-month period, 604 had a death date recorded during the study observation year. Of these 604 patients, 420 had both a death date and a home care service/ HPCNet enrolment date in the observation year and were considered eligible for this cancer cohort study. Excluded patients did not differ on important demographic or other characteristics from those included. Two of the 420 case files were excluded owing to date entry errors, to achieve a final cancer cohort of 418 unique subject case files.

Characteristics of the cancer cohort are summarized in Tables 1 and 2. The majority of the sample comprised an almost equal number of males and females, primarily older and married, with average income and high school education, and a diagnosis of lung cancer. Symptoms were diverse; nausea, vomiting and anorexia were the most prevalent, followed by generalized symptoms, fatigue and dyspnoea.

TABLE 1. Characteristics of the sample (n=418)[a]

Characteristic	n	%
Age (years): mean = 68.64; standard deviation (SD) =12.91		
<49	56	8.6
50–59	53	12.7
60–69	110	26.3
>70	219	52.4

TABLE 1. Continued.

Characteristic	n	%
Gender		
Male	217	51.9
Marital Status (n=365)		
Married	260	71.2
Single/Widowed/Divorced	105	28.8
Living Status (n=400)		
With someone	319	79.8
Education (n=182)		
College/University	52	28.6
High school	78	42.9
Less than high school	52	28.6
Household Income ($/year, n=413) mean=59,755, median=53,426, SD=30,794		
<30,000	16	3.9
30,000–49,999	189	45.8
50,000–69,999	98	23.7
70,000–89,999	51	12.3
>90,000	59	14.3
Type of Cancer (n=418)		
Lung	112	26.8
Colorectal/Gastrointestinal	83	19.8
Breast	39	9.3
Genitourinary	32	7.7
Other sites (skin, thyroid)	31	7.4
Haematological	24	5.7
Prostate	23	5.5
Head and neck	23	5.5
Unknown primary	21	5.0
Pancreas	19	4.5
Brain	11	2.6

[a] n=sample size/frequency

TABLE 2. Recorded symptoms and co-morbidities for the sample (n=374)[a,b]

Characteristics of Symptom Experience	n	%
Symptoms		
Gastrointestinal (nausea/vomiting, bowel obstruction)	141	33.7
Generalized symptoms	114	27.3
Fatigue/Weakness	109	26.1
Respiratory (e.g., dyspnoea)	107	25.6
Eating problems/Nutrition (e.g., anorexia/cachexia)	89	21.3
Ascites/Edema	51	12.2
Pain	50	12.0
Cardiovascular	41	9.8
Genitourinary (e.g., incontinence)	39	9.3
Neurological	36	8.6
Psychological (anxiety, depression)	34	8.1
Haematological	29	6.9
Other symptoms	29	6.9
Jaundice	23	5.5
Skin (wounds, ulcers)	21	5.0
Musculoskeletal	12	2.9
Co-morbidities		
Cardiovascular	66	15.8
Endocrine	38	9.1
Respiratory (asthma, chronic obstructive pulmonary disease)	33	7.9
Musculoskeletal	20	4.8
Cerebrovascular	17	4.1
Psychological	10	2.4
Senses (sight, hearing)	15	3.6
Symptom Counts		
Presence of Symptoms		
0	18	4.3
1–2	165	39.5
3–4	135	32.3
>4	56	13.4

TABLE 2. Continued.

Characteristics of Symptom Experience	n	%
Presence of Co-morbidities		
0	239	57.2
1–2	117	28.0
>2	18	4.3

[a] n=sample size/frequency

[b] Some of the cases had more than one symptom and co-morbidity in more than one body system.

Length of stay in the home care program for the sample ranged from three to 310 days, with a mean LOS of 62.43 days (median, 42 days). Most of the sample had a final episode of home care of about two months, with the breakdown of the LOS in days as follows: less than 30 days (36.4%), 31–60 days (27.3%) and 61–90 days (15.8%). A very small percentage (6.7%) required home care longer than six months.

Pattern of home care use

Pattern and type of home care services used and total expenditures by the sample are described in Table 3. Most patients received nursing visits (93.8%), with a total of 11,224 visits recorded for the entire cohort – lower than the total number of homemaking visits (31,907). The cohort received a total of 1,817 physician home visits with a mean of 4.35 visits per patient (unadjusted for LOS) for a total estimated expenditure of $200,356. Total expenditures for the cancer cohort was $1,354,677.83 for the final episode of home care from program enrolment to either death or hospitalization, excluding expenditures for palliative consultant nurses and designated case managers. Visits by general practitioners (GPs; primary care physicians) could not be separated between the patients' GPs and the palliative medicine specialists because the billing categories are the same; palliative medicine is not a designated specialty in Canada. However, the clinical team noted that GP visits were primarily made by the HPCNet palliative medicine specialists. Average daily expenditures for palliative home care services, excluding physician visits and palliative team service enhancements (consultant nurses and designated CCAC case managers) and based on a mean LOS of 62 days, was $52 per day.

Associations between each type of home care service used and predisposing, enabling and need variables were correlated according to data type. Only significant associations ($p<0.05$) and the pattern of associations are reported here.

TABLE 3. Home care service type

Service Type	% Receiving	Total Visits	Mean Visits	Median Visits	SD	Min	Max	Total Expenditures ($)
Skilled nursing	93.8	11,224	26.85	13.00	39.97	00	321	447,851.50
Homemaking	72.7	31,907	76.34	19.50	162.98	00	1,321	555,886.71
Physician	82.2	1,817	4.35	3.00	5.30	00	49	200,356.02
Multidisciplinary	19.6	423	1.01	0.00	4.01	00	57	28,427.20
Supplies[a]	52.0	N/A	231.27	18.26	719.85	00	10,282	96,669.00
Equipment[a]	77.8	N/A	518.67	108.35	1,224.70	00	12,284	216,804.00
Lab[a]	27.0	N/A	21.63	0.00	60.49	00	44	9,040.00
Total home care expenditure			3,240.86	1,455.09	5,223.22	15	40,497	1,354,677.83
Total home care expenditures for sample (excludes specialist team)[b]								1,354,677.83

[a] Supplies, equipment and lab are expenditures only and are not captured as visits.
[b] "Total home care expenditure" excludes specialist team coordinators and nurses.

Nursing

A negative correlation was associated with number of nursing visits and household income. As income increased, the number of nursing visits decreased. Those who died at home had higher numbers of visits (17.7 visits) compared to those who died in an institution (12.4 visits). More nursing visits were also associated with the presence of gastrointestinal (GI) symptoms (17.8 vs. 13.4 visits), whereas fewer nursing visits correlated with presence of cerebrovascular co-morbidities (7.6 vs. 15.4 visits).

Personal support

An increased number of PSW visits were associated with greater age, cancer type and home death. Patients who died at home had 51.4 PSW visits compared to 30.9 visits for those dying in institutions. Subjects with brain cancer (mean, 162.2) and those with head and neck cancer (mean, 70.8) used more PSW visits than participants with lung cancer (mean, 38.9), bowel/rectal cancer (mean, 33.9), breast cancer (mean, 51.9), genitourinary cancer (mean, 43.7) and haematological cancer (mean, 22.4). Presence of neurological symptoms was also associated with increased PSW visits (69.2 visits vs. 38 visits).

Physician use

Primary care physician (PCP) visits were positively associated with marital status, presence of co-morbidities (cerebrovascular, musculoskeletal) and GI symptoms (nausea and vomiting). Married subjects used more PCP visits (23.4) compared to non-married subjects (12.6 visits).

Patients with GI symptoms used 26.4 physician home visits compared to those without this symptom (16.6 visits). Fewer GP visits were associated with cerebrovascular (5.8 vs. 20.9 visits) and musculoskeletal co-morbidities (7.2 vs. 20.9 visits).

Medical supplies and equipment

Higher mean equipment expenditures were noted for those living with someone ($234 vs. $115) and lower for those with ascites ($117 vs. $214) or musculoskeletal co-morbidities ($71 vs. $214). Higher expenditures were noted for those who died at home ($282 vs. $126). Those with musculoskeletal co-morbidities had lower total home care expenditures ($73 vs. $191).

Patterns for place of death

The majority of the sample died in a location other than an acute care hospital (70.8%). About half of the patients died at home (50.5%), and the remainder died in a palliative care unit (15.8%) or nursing home (3.8%). An equal number of males (48.4%) and females (52.7%) died at home. In bivariate analysis, living with someone ($p<0.05$), higher income above 90,000 ($p<0.01$), gastrointestinal symptoms ($p<0.01$). were associated with home death.

Predictors for home care expenditure

Results of the multivariate analysis for total home care expenditures are summarized in Table 4. Illness characteristics (cancer type, symptoms, co-morbidities) found to be statistically significant in an initial parsimonious block regression model were entered in hierarchical regression models. In block 1, illness morbidity (need) variables were entered first in the model and accounted for 3% of the variance in total home care expenditures. In block 2, when income was added, about 20% of the variance in total home care expenditures was explained. In a final block with demographic characteristics, age, presence of eating problems (e.g., anorexia and cachexia) and GP visits explained 26% of the variance in total home care expenditures.

TABLE 4. Hierarchical regression analysis: predictors for home care expenditures

Predictor Variable[a]	Beta	Standard Error	Confidence Interval (95%)	*P*-Value
Step 1: Need Variables				
Eating problems	0.17	0.07	0.02–0.31	0.02
Gastrointestinal symptoms	–0.017	0.06	–0.03–0.05	0.007
Step 2: Enabling Variables				
Household income	–0.01	0.01	–0.02–0.01	0.54
General practitioner visits	0.05	0.01	0.04–0.06	<0.0001

TABLE 4. Continued.

Predictor Variablea	**Beta**	**Standard Error**	**Confidence Interval (95%)**	***P*-Value**
Eating problems	0.19	0.07	0.06–0.31	0.01
Gastrointestinal symptoms	–0.13	0.06	–0.24–0.02	0.02
Step 3: Predisposing Variables				
Age	0.01	0.00	0.00–0.01	0.02
Gender	0.04	0.06	–0.07–0.15	0.52
Married (yes)	–0.14	0.08	–0.29–0.01	0.07
Living status (alone)	–0.01	0.09	–0.19–0.17	0.92
Gastrointestinal symptoms	0.08	0.06	–0.04–0.19	0.18
Household income	–0.01	0.01	–0.03–0.01	0.23
General practitioner visits	0.05	0.01	0.04–0.06	<0.0001

[a] R^2 for step 1=0.03; change to R^2 in step 2=0.20; final adjusted R^2 in step 3=0.26

Predictors for home death

Multivariate results are summarized in Table 5. In an initial block with illness (need) variables entered, gastrointestinal symptoms were a significant predictor for home death, explaining 3% of the variance. When enabling variables (household income and number of family physician visits) were entered in block 2, household income and GI symptoms predicted home death, explaining 8% of the variance. In the final model (block 3), GI symptoms and household income predicted home death and explained 7% of the variance. In this final model, subjects with GI symptoms had higher odds of dying at home (OR: 1.64; p=0.03), as did those with higher median household income (OR: 1.14; p<0.001). An increased rate of home death was observed for each $10,000 increment in household income.

TABLE 5. Hierarchical regression analysis: predictors for home death

Predictor Variablea	**Odds Ratio**	**Standard Error**	**Confidence Interval (95%)**	***P*-Value**
Step 1: Need Variables				
Gastrointestinal symptoms	1.82	0.11	0.09–0.51	0.004
Step 2: Enabling Variables				
Household income	1.14	0.04	0-06–0.20	<0.001

TABLE 5. Continued.

Predictor Variablea	Odds Ratio	Standard Error	Confidence Interval (95%)	*P*-Value
General practitioner visits	1.02	–0.02	–0.01–0.06	0.19
Gastrointestinal symptoms	1.86	0.11	0.10–0.52	0.004
Step 3: Predisposing Variables				
Age	1.01	0.009	–0.01–0.02	0.42
Gender	1.16	0.11	–0.14–0.30	0.50
Married (yes)	0.92	0.15	–0.34–0.25	0.79
Living status (alone)	0.75	0.18	–0.50–0.20	0.41
Gastrointestinal symptoms	1.64	0.12	0.02–0.47	0.03
Household income	1.14	0.04	0.05–0.20	<.001
General practitioner visits	1.02	0.02	–0.02–0.06	0.36

[a] R^2 for step 1=0.03; change to R^2 in step 2=0.08; final adjusted R^2 in step 3=0.07

Discussion

This study is one of few that have examined home care use and place of death in the context of a gold standard palliative home care program in the publicly funded home care system in Canada. Study findings regarding predictors for home death and a higher than average out-of-hospital death rate compared to population norms warrant further research and discussion.

Place of death

A common performance metric used as a quality indicator for EOL cancer care in most Canadian provinces is the percentage of patients who die in acute care hospitals based on an assumption that variation in rates is explained by differential access to high-quality palliative home care services. In Ontario, acute care hospital rates for the metropolitan area, where this study was conducted, reported that 55% of cancer deaths occurred in acute care hospitals, with steady rates over four years (Barbera et al. 2006). This finding compares to the lower rate of 25% of cancer deaths in acute care hospitals observed in this study – lower than acute care hospital death rates across Ontario, which ranged from 38% in heavily populated urban areas to 70% in northern communities (Barbera et al. 2006). Slightly more than 50% of the study population realized a home death, a rate that is also higher than population-based rates of 34% in the United States (Bruera et al. 2002) and 39% in the United Kingdom (Grande et al. 2003).

Although different home death rates may reflect differences in data capture, our study findings may serve as a useful benchmark because they suggest that despite equal access to gold standard palliative home care, about 50% of the study population still required or desired alternative care settings. While our results cannot explain this finding, it is consistent with the literature, which suggests that death at home is not always desired. For example, some family values and belief systems may render the home intolerable following a death (Given and Given 1997; Stadjuhur and Davies 1998). Home death may also be inappropriate in situations involving complex symptoms and severe psychological distress (Stearns et al. 1996; Lubin 2000). It is estimated that about 15% of the palliative care population may have complex needs requiring the intensive services of a hospital or hospital-based palliative care unit (National Council for Hospice and Specialist Palliative Care Services 1999). Access to a package of services that includes an adequately resourced palliative home care program, acute/short-stay palliative care units to manage complex symptoms or disease complications, longer-stay palliative care units for protracted dying with physically demanding care needs, or residential hospices for less complicated dying for those whose beliefs or other factors preclude a home death, should be considered in regional service planning (Latimer 1995).

Mechanisms to ensure that patients are identified early and triaged to the appropriate care setting will be a critical component of a well-functioning palliative home care program. More importantly, while home death is considered a desirable outcome of palliative care programs, further research is needed to understand situations in which a home death is inappropriate and may place patients and families at increased risk for poor-quality care. The use of rates of out-of-hospital death as an indicator of quality of EOL care (Barbera et al. 2006) may be premature without adequate explanation of the reasons for variation and whether out-of-hospital death is an appropriate proxy for high-quality palliative care.

Predictors of home death

One interesting finding in our study is that predictors identified in previous research into home death were not observed. In previous studies, older age, male gender, higher socioeconomic status, access to a daughter as a caregiver, stable caregiver health, a preference for home death and the number of informal caregivers have been factors associated with home death (Addington-Hall and McCarthy 1995; Axelson and Christensen 1996; Cantwell et al. 2000; Gomes and Higginson 2006; Grand et al. 1998; Higginson et al. 1999; Karlsen and Addington-Hall 1998; Lock and Higginson 2005; Moinpour and Polissar 1989; Roder et al. 1997; Sims et al. 1997; Tang and McCorkle 2001). In contrast, EOL hospitalization is associated with a diagnosis of haematological cancer, extended period of functional decline preceding death, shorter time from diagnosis to death, unrelieved symptoms such as breathlessness, patient confusion, informal caregiver burden and emotional distress (Berry et al. 1994; Brazil et al. 2002; Bruera et al. 1990; Mann et al. 1993).

Usual drivers for acute care hospitalization observed in previous research may be less important when symptoms are well managed by clinical experts in palliative care and when services are titrated to need. The variation in home care use according to illness characteristics suggests that palliative home care case managers were skilled in tailoring services to meet diverse needs of palliative populations. This skill is considered important in influencing the cost and quality of care (Rafferty et al. 1996). Clinical needs vary according to symptoms and complications that accompany specific cancer diagnoses, particularly in advanced stages of the disease (Ng and von Gunten 1998). For example, gastrointestinal complications such as bowel obstruction from end-stage ovarian cancer create a demand for clinical monitoring and careful titration of pharmaceutical agents to manage related symptoms of pain, nausea/vomiting and anorexia (Fainsinger et al. 1994). In contrast, cancer patients with neurological complications as a result of primary or secondary brain cancer often have impaired physical mobility and cognitive function, and are at high risk for falls or other problems such as seizures, requiring continuous or round-the-clock supervision (Kemp 1999). An age effect for home care service use is likely explained by the increased number of personal support workers noted for older participants, suggesting the need for increased PSW support to sustain older, and thus potentially frailer, informal caregivers.

Income effect

Also of significant interest was our finding of an income effect for home deaths, given that the population had equal access to publicly funded home care and enhanced specialist palliative care. This finding is consistent with studies in other publicly funded healthcare programs (Cartwright 1992; Goddard and Smith 2001; Hanratty et al. 2007). Increased purchasing power for those in higher social positions has been linked to a demand for services (Coyte and Howell 2000). Higher income may be a proxy for higher education, which might influence patients' and families' ability to advocate for needed services or preferences (Coyte and Howell 2000). Those with higher incomes might also be augmenting traditional home care services with purchased services, such as shift nursing (Coyte and Howell 2000), or may be in more flexible work environments where job loss is not threatened by time off. Researchers have suggested the existence of a two-tiered system of home care, as those who can purchase additional services may be better able to facilitate a home death (Dudgeon and Kristjanson 1995). Sustaining care in the home may not be feasible unless respite care and other purchased services are adequate to supplement informal care (Greaves et al. 2002). Reliance on informal care providers is an assumption embedded in healthcare policy (Romanow 2000). Further research is needed to understand the relationship between income and home death, as well as other variables identified in this study, given the secondary data used in our research.

Funding and resource planning

Palliative home care must be adequately resourced if the home is to be a viable alternative to EOL hospitalization. This study showed that home care for a population of 418 cancer patients, excluding overhead administrative or specialist team charges, requires a significant financial investment. Home care expenditures may be a function of both need and length of stay because some patients' LOS exceeded the six-month palliative home care service eligibility criteria. Certain types of cancer are associated with longer duration of terminal illness in which the dying trajectory may be more prolonged and home care dependency needs may be extended (Allard et al. 1995). Length of stay in the US hospice-based system has been shown to vary according to cancer diagnosis, with lung cancer patients having the shortest LOS (54 days) compared to breast cancer patients (74 days) (Frantz et al. 1999). Prevalence rates for certain types of cancer and some flexibility in funding formulas might be important in regional services planning.

Limitations

This study has several limitations, largely reflected in the use of secondary data sources that precluded the examination of potentially significant variables that might predict home care use and home death – for example, preferences for place of death, or other contextual or environmental variables not captured in our research. The presence of symptoms and co-morbidities reported by clinicians may not have been a valid proxy for illness severity or clinical needs, and the grouping of symptoms was based on the clinical expertise of the principal investigator (DMH). Study findings may not be generalizable outside the context of a comprehensive palliative home care program in publicly funded health systems, or in differing configurations of primary home care services.

Conclusions

Access to palliative home care services that are organized and sufficiently financed to meet the multidimensional needs of cancer patients at the end of life is necessary if care is to be shifted from acute care hospitals. More importantly, shifting care to the home should not place patients and families at risk for poor quality of dying or death. Further prospective research to understand home care service needs and reasons for use of alternative care settings is important, because needs unfold along the trajectory of advanced, progressive disease. Future research should also examine the underlying reasons for an income effect for home death observed in this study.

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