DATA MATTERS

Home Care Evolution in Alberta: How Have Palliative Clients Fared?

Évolution des soins à domicile en Alberta : comment les patients en soins palliatifs s'en tirent-ils?

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Abstract

This study compared palliative and non-palliative home care clients, services and providers, and described changes over a decade of health system reform (1991/92–2000/01). Complete individual-anonymous data from Alberta's home care database were analyzed. Over these 10 years, 7.0% of all home care clients were classified as palliative. The proportion of home care clients who were classified as palliative varied from 2.2% to 9.6% among health regions. The number of palliative clients more than doubled, although this growth was less than that of short-term clients. Home support aides were the most common home care provider, and personal care was the most common service provided to all clients. Although the average number of care hours prior to death for palliative clients increased from 40.9 to 87.9 hours, the relatively small amount of home care provided to dying persons raises concerns about informal caregiver burden and possible overreliance on hospitals to provide end-of-life care.

Résumé

Cette étude comparait des clients, des services et des fournisseurs de soins palliatifs et non palliatifs à domicile, et décrivait les changements survenus sur les dix ans de la réforme du système des soins de santé (1991/1992–2000/2001). Des données individuelles anonymes complètes tirées de la base de données sur les soins à domicile en Alberta ont été analysées. Au cours de ces dix années, 7 % de tous les patients bénéficiant de soins à domicile étaient classés comme recevant des soins palliatifs. La proportion de patients recevant des soins à domicile et classés comme bénéficiant de soins palliatifs a varié de 2,2 % à 9,6 % entre les régions sanitaires. Le nombre de clients en soins palliatifs a plus que doublé, bien que cette hausse soit moindre que chez les clients recevant des soins à court terme. Les aides de soutien à domicile étaient les fournisseurs de soins à domicile les plus courants, et les soins personnels étaient le service le plus courant fourni à tous les clients. Bien que le nombre moyen d'heures de soins avant décès consacrées aux patients en soins palliatifs ait augmenté de 40,9 à 87,9, la quantité relativement faible de soins à domicile fournie aux personnes mourantes soulève des préoccupations, notamment en ce qui concerne le fardeau

que doivent assumer les aidants naturels et, possiblement, une dépendance excessive à l'égard des hôpitaux pour la prestation de soins en fin de vie.

* * *

Canadian mortality statistics show a reduction in hospital death rates since 1994 (Wilson et al. 2001). This finding corresponds with developments in community-based end-of-life (EOL) care and formal home care programming (Health Canada 1999; Shapiro 1985). An increasing desire among terminally ill persons to remain at home is another likely influence for reduced hospital-based EOL care and increasing interest in palliative home care (Grande et al. 1999; Vickers and Carlisle 2000).

With few exceptions (Wilkins and Park 1998; Health Canada 1999; Sheps et al. 2000), Canadian home care research has typically focused on individual programs, with palliative and non-palliative home care recipients not differentiated (Alcock et al. 1998; Chochinov and Kristjanson 1998; Coyte and Young 1999; Dansky et al. 1996; Grande et al. 1999; Markel-Reid et al. 1998; McWhinney et al. 1995). Although all home care recipients may have similar needs for support in the home, terminally ill and dying persons present some unique challenges and care needs. One of the most important is rapidly progressive dependency as the end of life nears (Wilson 2002).

To inform health services planning and policy development, we undertook an analysis of the provincial home care data set for the province of Alberta, distinguishing palliative home care recipients from other recipients, and identifying changes in home care clients, services and providers that occurred from 1991/92 through 2000/01 in response to or in conjunction with health system reforms.

Alberta had a pronounced decline in acute care hospital beds from 1993 through 1995 in response to a series of government funding reductions accompanied by government policy that emphasized a shift from inpatient to ambulatory care. Alberta Health's *Three-Year Business Plan* specified "reducing acute care beds from 4.3/1,000 population to 2.4/1,000 population by closing, downsizing and converting hospitals … increasing day surgery … reducing average length of stay and reducing number of admissions … and shifting most palliative and pre- and post-operative services in the community" (Alberta Health 1994: 8). Self-managed home care was introduced around this time, with a growing number of long-term clients subsequently choosing this option. A targeted reduction in nursing home beds from 55 beds/1,000 seniors to 50 beds/1,000 was also initiated. Regionalization was introduced in 1995, with 17 geographically defined Regional Health Authorities (RHAs), one RHA for mental health services and one RHA for cancer care services expected to implement the government's health reform policies. Although health system funding increases occurred after 1995, minimal hospital bed recovery was noted by the end of the 1990s (Alibhai et al. 2001).

Methods

Following University of Alberta research ethics approval and agency approval of data access, we obtained complete individual-anonymous Home Care Information System (HCIS) data and matching demographic data from Alberta's health plan registry database for the fiscal years 1991/92 through 2000/01. This 10-year time frame was the entire period during which standard home care data were systematically collected on all clients on a provincewide basis. The data received for analysis included 11,520,251 HCIS service event records and demographic information on a fiscal-year basis for all Albertans who received one or more home care services at any point during these 10 years (N=462,877). To preserve anonymity and ensure confidentiality, recipient names and addresses were not provided to the research team. A unique Alberta Scrambled Number (ASN) permitted the linkage of service event and demographic data on an individual level.

The demographic variables were: gender, age at fiscal year start, death date (if applicable), residence RHA and the first three characters of the postal code of residence at fiscal year start. The service variables were: HCIS admission and discharge dates, client classification (short-term, long-term or palliative), type of service (case coordination, assessment, skilled health care, personal care, home support and meals), provider type (RN, LPN, aide, etc.) and direct care service hours aggregated on a monthly basis per client.

Prior to data analysis, and in keeping with standard procedures to assess the accuracy and usefulness of population data, data cleaning and verification procedures were undertaken. Most variables had minimal missing data (<5%), with the exception of postal code (9.7% missing data). We compared palliative clients with short-term and long-term clients, as opposed to all non-palliative clients combined. Short-term clients typically receive home care for one month or less, with this care normally following hospital discharge. Long-term clients generally receive home care over months or years, with some having the option of self-managed home care. Palliative clients are understood as terminally ill, with a life expectancy of around three months.

Results

Home care client comparisons

Only 7.0% of all home care clients were classified as palliative (N=34,384). While the proportion classified as short-term increased substantially over the 10 years (from 25.8% to 41.0%), the proportion comprising palliative clients increased only minimally (from 6.3% to 6.5%), and the proportion comprising long-term clients declined considerably (from 67.8% to 52.4%). The number of palliative clients increased by 115%

(from 1,967 the first year to 4,238 the last year), less than short-term clients (233% increase) but more than long-term clients (62% increase). During the same period, the Alberta population increased 15%, from 2,504,600 in 1991 to 2,879,743 in 2000, with seniors remaining at 10% of the total.

The mean age of palliative clients was 65.7 years (Table 1), increasing slightly over time, while the mean age of both short-term and long-term clients declined. Each year, palliative clients were almost equally as likely to be male or female (Table 1). In contrast, short-term and long-term clients were more often female, although the proportion of male clients increased for both care types.

TABLE 1. Age and gender distribution of home care recipients by client type

Year	Variable	Long-term Clients	Short-term Clients	Palliative Clients
1991/92	Mean age (SD)	77.1 (11.6)	66.1 (19.2)	64.7 (15.3)
	Median/Mode age	79.0/82	72.0/77	67.5/72
	Age Range	0-105	0-99	0-104
	Female N(%)	14,757 (70.3)	5,064 (63.3)	990 (50.4)
	Male N(%)	6,249 (29.7)	2,937 (36.7)	974 (49.6)
2000/01	Mean age (SD)	74.5 (18.1)	63.5 (20.7)	66.4 (15.1)
	Median/Mode age	79.0/85	69.0/78	69.0/74
	Age Range	0-111	0-102	0-107
	Female N(%)	22,464 (66.1)	15,147 (56.9)	2,137 (50.4)
	Male N(%)	11,546 (33.9)	11,482 (43.1)	2,100 (49.6)
All Years	Mean age (SD)	74.8 (16.9)	64.0 (20.4)	65.7 (15.4)
	Median/Mode age	79.0/83	70.0/77	68.0/74
	Age Range	0-114	0-106	0-107
	Female N(%)	187,287 (66.9)	104,255 (58.8)	17,102 (49.8)
	Male N(%)	92,718 (33.1)	72,922 (41.2)	17,240 (50.2)

Notes: 0.06% missing data; age calculations were based on the ages that were recorded at the beginning of each fiscal year.

Table 2 illustrates considerable rural/urban differences, with the city of Calgary having the highest proportion of its home care clients classified as palliative (9.6%), compared to 4.4% for rural areas. Changes over these 10 years were also noted, with palliative clients declining as a proportion of home care clients in the city of Edmonton and in all rural areas combined, while increasing as a proportion of home care clients in Calgary and other urban areas. When compared on the basis of RHA, palliative clients ranged from 2.2% of RHA 17 home care clients (a rural region in northern Alberta) to 9.6% for RHA 4 (Calgary).

TABLE 2. Distribution of home care clients on the basis of residence

Fiscal Year	Residence Location	Long-term Clients N(%)	Short-term Clients N(%)	Palliative Clients N(%)
1991/92	Edmonton	4,883(67.8)	1,675(23.3)	640(8.9)
	Calgary	3,835(55.0)	2,535(36.3)	607(8.7)
	Other Urban	3,022(66.8)	1,221(27.0)	282(6.2)
	Rural	7,964(76.8)	2,095(20.2)	308(3.0)
	Total	19,704(67.8)	7,526(25.9)	1,837(6.3)
2000/01	Edmonton	8,491(52.2)	6,715(41.3)	1,064(6.5)
	Calgary	9,161(54.4)	6,125(36.3)	1,565(9.3)
	Other Urban	8,095(49.0)	7,533(45.6)	877(5.3)
	Rural	7,927(55.0)	5,833(40.5)	658(4.6)
	Total	33,674(52.6)	26,206(40.9)	4,164(6.5)
All Years	Edmonton	65,926(55.3)	43,824(36.8)	9,401(7.9)
	Calgary	63,954(53.2)	44,626(37.1)	11,581(9.6)
	Other Urban	57,842(54.0)	42,861(40.0)	6,445(6.0)
	Rural	83,683(64.5)	40,243(31.0)	5,717(4.4)
	Total	271,405(57)	171,554(36.0)	33,144(7.0)

Note: 9.7% missing data

Amount and types of service

Palliative clients who died during the study period received 79.4 hours of home care service on average (Table 3). Average care hours increased over the 10 years for these palliative clients (from 40.9 hours to 87.8 hours), while the mean number of days registered with the home care program declined.

TABLE 3. Days registered and hours of care for palliative home care decedents

Fiscal Year	Measure	Palliative Clients (N=18,893)
1991/92	Mean hours (SD)	40.9 (78.5)
	Range of hours	.25-890.5
	Mean days (SD)	169.2 (442)
	Range of days	1-3341
2000/01	Mean hours (SD)	87.8 (177.7)
	Range of hours	.02-2331.0
	Mean days (SD)	68.5 (63.4)
	Range of days	1-349
All Years	Mean hours (SD)	79.4 (169.6)
	Range of hours	.02-3363.25
	Mean days (SD)	90.5 (196.5)
	Range of days	1-3341

Note: 2.6% missing data

As shown in Table 4, home support aides provided the largest share of direct care hours for all clients, although this share declined over time. In the last fiscal year, home support aides provided half of all direct care hours for palliative and long-term clients, and one-third of all direct care hours for short-term clients.

Personal care (bathing, dressing, etc.), home support (housecleaning) and skilled care (dressing changes, injections, etc.) were the three most common services provided to all home care clients (Table 5). Over this decade, personal care hours increased and home support hours declined for all three client types. Skilled care hours declined for long-term and palliative clients, while increasing for short-term clients.

TABLE 4. Hours of care by provider type

Fiscal Year	Care Provider	Long-term N(%)	Short-term N(%)	Palliative N(%)
1991/92	Home Support Aide	1,004,143(76.0)	100,308(54.9)	60,092(61.6)
	Registered Nurse	249,135(18.9)	66,977(36.6)	29,601(30.4)
	Self-Managed Care	545(0.0)	0(0.0)	0(0.0)
	All Other Providers	67,596(5.1)	15,515(8.5)	7,790(8.0)
	Total	1,321,420(82.5)	182,801(11.4)	97,482(6.1)
2000/01	Home Support Aide	3,505,013(56.2)	189,655(38.8)	203,936(53.0)
	Registered Nurse	482,519(7.7)	206,063(42.2)	106,683(27.7)
	Self-Managed Care	1,844,701(29.6)	20,349(4.2)	52,615(13.7)
	All Other Providers	405,876(6.5)	72,546(14.8)	21,382(5.6)
	Total	6,238,110(87.7)	488,613(6.9)	384,617(5.4)
All Years	Home Support Aide	23,325,625(58.4)	158,4881(46.0)	180,5741(62.9)
	Registered Nurse	3,688,561(9.2)	1,322,294(38.4)	697,239(24.3)
	Self-Managed Care	10,792,865(27.0)	69,845(2.0)	179,788(6.3)
	All Other Providers	2,160,127(5.4)	470,419(13.6)	187,336(6.5)
	Total	39,967,178(86.4)	3,447,440(7.4)	2,870,105(6.2)

Notes: 2.9% missing data; self-managed care is arranged by the home care client or client's family and this care is normally provided by home support aides.

Discussion

This analysis of administrative data provides information about changes in home care clients, services and providers over a 10-year period marked by hospital downsizing. It is limited in two respects. The findings are confined to one province and cannot be generalized across Canada. Although a national Home Care Reporting System is developing (Canadian Institute for Health Information, online), comparable provincial data are not yet available for analysis. Some important variables, such as medical diagnoses, cause of death, marital status, living arrangements (i.e., lives alone or with another) and type of residence (i.e., apartment, etc.), were not available.

Regardless, several findings are of interest. Over this 10-year period, the number of Albertans receiving home care doubled. This growth is in keeping with the government's 1994 policy to increase home care services, although the magnitude of the desired increase was never specified. It is therefore not known if this increase met or exceeded government expectations. It is also not known whether this home care growth was enough to address the magnitude of home care needs generated by the policy of rapid reduction in acute care beds, particularly since access to nursing home beds was reduced and population growth was occurring over this period. Unfortunately, the current study could not determine whether the number of persons receiving home care services or the types and quantities of services provided were appropriate to either individual or population needs.

TABLE 5. Total hours of care by service category

Fiscal Year	Service Category	Long-term Hours (%)	Short-term Hours (%)	Palliative Hours (%)
1991/92	Personal Care	395,860(30.0)	38,264(20.9)	21,975(22.5)
	Home Support	618,023(46.8)	63,620(34.8)	39,095(40.1)
	Skilled Health Care	235,922(17.9)	61,781(33.8)	27,625(28.3)
	Case Coordination	37,027(2.8)	8,740(4.8)	5,717(5.9)
	Assessment	33,527(2.5)	10,116(5.5)	3,049(3.1)
	Meals	1,061(0.1)	281(0.2)	21(0.0)
	Total	1,321,420(100)	182,801(100)	97,482(100)
2000/01	Personal Care	4,498,259(72.1)	182,899(37.4)	191,711(49.8)
	Home Support	930,922(14.9)	34,011(7.0)	65,994(17.2)
	Skilled Health Care	499,385(8.0)	155,608(31.8)	81,659(21.2)
	Case Coordination	249,359(4.0)	86,372(17.7)	38,122(9.9)
	Assessment	60,182(1.0)	29,678(6.1)	7,131(1.9)
	Meals	2(0.0)	45(0.0)	0(0.0)
	Total	6,238,110(100)	488,613(100)	384,617(100)
All Years	Personal Care	25,560,149(64.0)	1,144,637(33.2)	1,283,573(44.7)
	Home Support	8,716,357(21.8)	528,317(15.3)	712,823(24.8)
	Skilled Health Care	3,689,074(9.2)	1,099,075(31.9)	578,252(20.1)
	Case Coordination	1,521,273(3.8)	476,732(13.8)	247,053(8.6)
	Assessment	476,386(1.2)	197,968(5.7)	48,253(1.7)
	Meals	3,939(0.0)	710(0.0)	152(0.0)
	Total	39,967,178(100)	3,447,440(100)	2,870,105(100)

Note: 2.9% missing data

The final report of the Commission on the Future of Health Care in Canada (Romanow 2002) emphasized the need for enhanced home care, particularly for persons near the end of life, and for national home care standards. This need for standards is illustrated by the large regional variations discovered through our study. Some RHAs appear to have developed capacity in home-based EOL care, while others have not. Although population-density reasons could be cited, as it may be more difficult to deliver home care in sparsely populated areas, considerable rural RHA variability in clients and care hours was also noted. Variability was similarly noted among the urban RHAs. This variability could simply be an outcome of the decentralized planning and programming that accompanies regionalization, and to some extent may reflect variations in need. This issue of equity of access to home care is not confined to Alberta; Coyte and Young (1999) previously reported that equal access to home care does not exist in any Canadian province.

One of the more surprising findings was the predominant use of home support aides as home care providers, the least knowledgeable and skilled healthcare provider. Alberta may differ in this regard from other provinces, as Health Canada (1999) found that 38.8% of home care clients across six provinces were receiving professional nursing services and 26.5% other professional services (occupational therapy, physiotherapy, speech therapy and social work). Although quality concerns could be raised, home support aides may be appropriate service providers for many home care clients, as the most common home care service was basic personal care. The basic care provided by home support aides may not, however, be adequate for palliative home care clients. A UK home care evaluation study by Hinton (1996) found personal support from professionals and communication with professionals were the two most important aspects of care for palliative home care clients.

Client changes are also notable, such as the large increases in the number and proportion of persons receiving short-term care. This finding is not surprising, as home care can facilitate early hospital discharge, and the government's stated policy was to shorten hospital stays.

The number of Albertans receiving palliative home care more than doubled, although palliative clients remained a distinct home care minority (<8% each year). Only 34,384 persons received palliative home care over the study period. Online Vital Statistics information shows 161,320 deaths in Alberta over the same period, which means roughly one in five decedents received some palliative home care. Research on the appropriate level of home care coverage is clearly needed, as informal caregiver burden is a common end-of-life issue (Stajduhar and Davies 1998; Tilden et al. 2004).

Conclusion

This analysis of 10 years of home care data for Alberta identified home care client,

service and provider changes over a decade of health system change. Despite a doubling of palliative home care clients and increased service hours, considerable regional variation in the provision of palliative home care was found across Alberta. The relatively small amount of home care provided to dying persons, particularly in rural regions, raises concerns about informal caregiver burden and potentially inappropriate use of hospitals for end-stage care. Another concern is that the least skilled and educated healthcare worker provided the majority of care to home care clients, including those who were actively dying.

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ACKNOWLEDGMENTS

The competitive research grant funding provided by Health Canada is gratefully acknowledged. The researchers would also like to thank Alberta Health and Wellness personnel for their data assistance. Dr. Colleen Norris's statistical advice was outstanding. This paper was one of many projects completed by a research team that included Margaret Brown, Dr. Lise Fillion, Dr. Katherine Froggatt, Dr. Christopher Justice, Dr. Janice Kinch, Karen Leibovici, Dr. Karen Olson, Pam Reid and Mr. David Shepherd.

DISCLAIMERS

This article is derived from a report completed for a study entitled "Integrated End-of-life Care: A Health Canada Synthesis Research Project" that was funded by Health Canada (#6795-15-2002/4780004). The interpretations and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Canada or Health Canada. Neither the Government of Canada nor Health Canada express any opinion in relation to this study. An overview of this study was previously published: Wilson, D., C. Truman, J. Huang, S. Sheps, R. Thomas and T. Noseworthy. 2005. "The Possibilities and Realities of Home Care." *Canadian Journal of Public Health* 96(5): 385–89.

This portion of the Integrated End-of-Life Care study was based on home care data provided by Alberta Health and Wellness. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Alberta nor Alberta Health and Wellness. Neither the Government of Alberta nor Alberta Health and Wellness express any opinion in relation to this study.

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