The Possibilities and the Realities of Home Care

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ABSTRACT

Background: An analysis of a provincial home care dataset, comparing home care client, service, and providers in 1991/92 through 2000/01, was undertaken to describe changes over the decade, and permit a more informed discussion of home care in relation to Canadian health policy developments and health system reforms.

Methods: After data were obtained upon request from Alberta's Ministry of Health and Wellness, descriptive and comparative statistical analyses were undertaken using the SPSS computer program. Logistic regression was used to compare multiple client characteristics in the first and last years.

Results: Home care clients doubled and the mean hours of care per client increased substantially, although the duration of care provision declined. The mean age of clients also declined. Home care continued to be primarily provided by Home Support Aides, with self-managed care increasing dramatically. Sustained geographical differences in home care were noted.

Conclusion: Although home care has much potential for enabling early discharge from hospital, and for maintaining or improving health, few population-level studies of home care trends exist. In Alberta, although formal home care hours increased, home care expansion was not uniform across the province. Home Support Aides continued to be the primary care provider. In the face of substantial hospital downsizing, these observations could imply that the provision of home care has been off loaded to families. Moreover, home care increases do not appear to be related to an aging population.

MeSH terms: Home care; population data; administrative data; trends; hospital downsizing; health system reform

La traduction du résumé se trouve à la fin de l'article.

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Home care has the potential to maintain or improve the health of frail elderly and chronically-ill persons, reduce hospital admissions, enable early hospital discharge, and permit end-of-life care at home.¹ Given this potential, one might think that home care expansion would have occurred in most if not all developed countries, particularly given concerns about population aging and subsequent rising hospital costs.² Unfortunately, little research on home care, home care trends, and home care outcomes exists.² Not only are these studies needed to ascertain if home care expansion has occurred, but they are also needed to determine the influence of strategic visioning that has aimed since 1978 to shift health systems to proactive health promotion, and from expensive and increasingly limited tertiary care services to more accessible primary health care approaches.^{3,4}

Canada should be no exception, yet although two large-scale cross-sectional studies of home care have been undertaken,^{1,5} no population-based reports of home care trends exist. An analysis of population-level home care services, providers, and client data would therefore be useful for planning and policy purposes. The purpose of this study was to describe population-level home care client, service, and provider changes.

METHODS

Overview

A complete home care dataset (fiscal years 1991/92- 2000/01) was obtained from Alberta's Ministry of Health and Wellness. Alberta is an appropriate focus, as 50% of 13,000 hospital beds were permanently closed in 1993-1995 in response to a series of funding reductions.⁶ A shift to day surgery and outpatient care, and shorter hospital stays were realized outcomes of this downsizing.⁶ In addition, regionalization was introduced, changing the government's role from health service planning and delivery to policy-making alone.⁷ Regional boards were expected to more carefully plan and manage an integrated package of health services within defined geographic regions.⁸ Thus in mid-1995, 17 Regional Health Authorities (RHA) became responsible for providing a comprehensive package of publicly-funded health services to citizens living within

their boundaries.⁶ With these changes, an increase in home care clients and services could be anticipated, although home care trends were never assessed. These health system reform experiments, not unlike what other provinces experienced, coupled with the availability of 10 years of home care data and the lack of population-level home care research, presented an excellent opportunity for knowledge creation.

Data description and data analysis plan

All home care client, services, and service provider data contained within Alberta's Home Care Information System (HCIS) database for the fiscal years 1991/92 through 2000/01 were obtained. The data received included 11,520,251 service event records, as well as demographic information by fiscal years for a total of 462,877 HCIS clients. To preserve researcher access to individual data, yet protect client anonymity and confidentiality of data, a unique Alberta Scrambled Number (ASN) was provided in lieu of client names. This ASN permitted data linkages at the individual level. Ethical approval was received from the University of Alberta to obtain and analyze this dataset.

Data variables were demographic or service oriented. Demographic variables were: sex, age at start of fiscal year, birth date, death date (if applicable), and postal code (the first three integers identify rural or urban residence). Service variables were: HCIS admission date, an Alberta Assessment and Placement Instrument (AAPI) classification-of-need score (1-7 range), type of care received (personal care, skilled care, etc.), provider type (Home Support Aide, Registered Nurse, etc.), hours of direct care received on a monthly basis, HCIS discharge date and reasons (if applicable), and number of days registered from classification date to death date (if applicable) or end of the study period. Indirect or overhead hours were excluded from analysis.

In order to describe home care client, service, and provider trends, data analysis primarily involved descriptive and comparative (chi-square, T test and ANOVA) statistics, as appropriate given the level of variables. Logistic regression was used to compare multiple client characteristics in the first and last years. The SPSS statistical

TABLE I

Home Care Clients by Care-Needs Classification Score

Year	Client N*	Mean Classification Score (SD)†‡
1991/92	30,985	—
1992/93	35,272	—
1993/94	36,660	2.0 (1.3)
1994/95	43,989	2.0 (1.3)
1995/96	49,312	2.4 (1.4)
1996/97	54,241	2.5 (1.5)
1997/98	55,800	2.4 (1.5)
1998/99	58,598	2.5 (1.5)
1999/00	62,158	2.5 (1.5)
2000/01	64,887	2.4 (1.5)
All Years	491,902	2.4 (1.5)
Increase (%)	(109.4)	—

* The total client N is greater in this and other tables than the actual 462,877 clients, as some clients received care for more than one fiscal year

† 63.9% of classification score data were missing

‡ test of mean classification scores over 8 years, $F=190.78$, $df=7$, $p=0.000$

TABLE II

Age and Gender Distributions of Home Care Clients, Findings Limited to the First, Last and All Years Combined

Year	Raw Age*	N (%)	Age† Category	N (%)	Gender‡	N (%)
1991/92	Mean (SD)	73.5 (15.1)	Under 65	5200 (16.8)	Female	20,811 (67.2)
	Median	77.0	65+	25,785 (83.2)	Male	10,160 (32.8)
	Range	0-105	Total	30,985 (100)	Total	30,971 (100)
2000/01	Mean (SD)	69.4 (18.9)	Under 65	18,469 (28.5)	Female	39,748 (61.3)
	Median	75.0	65+	46,418 (71.5)	Male	25,128 (38.7)
	Range	0-111	Total	64,887 (100)	Total	64,876 (100)
All Years	Mean (SD)	70.3 (18.9)	Under 65	98,798 (20.1)	Female	308,644 (62.8)
	Median	76.0	65+	392,726 (79.9)	Male	25,128 (37.2)
	Range	0-114	Total	491,524 (100)	Total	491,524 (100)

* test of mean ages over 10 years: $F=249.48$, $df=9$, $p=0.000$ and test to compare mean scores in first and last years: Tamhane's $T=35.17$, $df=1$, $p=0.000$

† test of age group proportions over 10 years: $\chi^2=412.515$, $df=9$, $p=0.000$

‡ test of gender distributions over 10 years: $\chi^2=271.209$, $df=9$, $p=0.000$

TABLE III

Residence Location of Home Care Clients and Hours of Care by Residence, Findings Limited to the First, Last and All Years Combined

Year	Residence Location	N (% of total)*	Mean Hours of Care Per Client Per Year (SD)†
1991/92	Edmonton	7198 (24.8)	61.5 (107.0)
	Calgary	6977 (24.0)	53.2 (106.5)
	All Other Urban	4525 (15.6)	56.5 (89.4)
	Rural	10,367 (35.7)	44.6 (145.3)
2000/01	Edmonton	16,270 (25.4)	122.3 (324.6)
	Calgary	16,851 (26.3)	145.6 (396.3)
	All Other Urban	16,505 (25.8)	82.3 (283.7)
	Rural	14,418 (22.5)	71.8 (239.45)
All Years	Edmonton	119,151 (25.0)	118.9 (322.0)
	Calgary	120,161 (25.2)	116.2 (335.9)
	All Other Urban	107,148 (22.5)	79.8 (257.9)
	Rural	129,643 (27.2)	60.1 (188.4)

* test of residence proportional changes over 10 years, $\chi^2=2860.696$, $df=27$, $p=0.000$

† test of mean hours of care, all years combined, by residence, $F=1332.9$, $df=3$, $p=0.000$. A significant difference was also found for each distinct fiscal year.

package (version 12) was used to analyze data. Statistical consultation was sought on two occasions to ensure appropriate statistical analysis and interpretation of data.

RESULTS

The number of home care clients served annually doubled over the 10-year period from 1991-2001 (Table I). Although 64%

of care need score data were missing, client care needs increased significantly, although the mean classification score was only 2.0 and 2.4 in the first and last years respectively.

The majority of home care clients each year were seniors (aged 65+), although the proportion who were seniors declined significantly over time; the mean age of clients also declined significantly (Table

TABLE IV

Total Days Registered as Care Recipients and Hours of Direct Care for Home Care Clients Who Died, Findings Limited to the First, Last and All Years Combined

Year	Measure	Days*	Hours†
1991/92	Mean (SD)	223.2 (503.9)	36.7 (67.9)
	Range	1-3,587	0.25-1108.25
2000/01	Mean (SD)	79.7 (69.2)	87.4 (225.1)
	Range	0-349	0.01-4342.5
All Years	Mean (SD)	109.2 (218.2)	74.9 (187.5)
	Range	0-3,587	0.01-4715.75

* test of mean care days over 10 years, $F=15.74$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=27.11$, $df=1$, $p=0.000$

† test of mean care hours over 10 years, $F=20.283$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=18.85$, $df=1$, $p=0.000$

TABLE V

Total Hours of Care and Mean Care Hours by Provider Type, Findings Limited to the First, Last and All Years Combined

Year	Care Provider Type	Total Care Hours, All Clients Combined N (%)*	Direct Service Hours, Per Client Each Year Mean (SD)†
1991/92	Home Support Aide	1,164,543 (72.7)	61.9 (90.9)
	Registered Nurse	345,713 (21.6)	12.2 (32.0)
	Self-managed Care	545 (0.0)	109.0 (71.0)
	All Others	90,901 (5.7)	8.4 (30.2)
	Total	1,601,702 (100)	51.9 (90.5)
2000/01	Home Support Aide	3,898,604 (54.8)	126.0 (259.2)
	Registered Nurse	795,265 (11.2)	13.1 (19.4)
	Self-managed Care	1,917,665 (27.0)	1242.3 (964.8)
	All Others	499,805 (7.0)	12.8 (90.2)
	Total	7,111,340 (100)	105.5 (310.6)
All Years	Home Support Aide	26,716,247 (57.7)	132.0 (274.1)
	Registered Nurse	5,708,095 (12.3)	13.6 (40.6)
	Self-managed Care	11,042,499 (23.9)	1231.6 (976.6)
	All Others	2,817,882 (6.1)	15.0 (99.1)
	Total	46,284,723 (100)	109.7 (323.8)

* hours-of-care data were aggregated, no statistical tests could be performed

† – the mean hours of care per provider do not add to the total, as clients did not receive care from all care providers

- test of mean hours for all providers combined over 10 years, $F=227.24$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=98.23$, $df=1$, $p=0.000$
- test of mean hours for Home Support Aides over 10 years, $F=307.41$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=135.17$, $df=1$, $p=0.000$
- test of mean hours for Registered Nurses over 10 years, $F=14.72$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=5.16$, $df=1$, $p=0.000$
- test of mean hours for self-managed care over 10 years, $F=9.21$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=3.78$, $df=1$, $p=0.000$
- test of mean hours for “all others” over 10 years, $F=10.75$, $df=9$, $p=0.000$, and test to compare mean scores in first and last years: Tamhane's $T=5.7$, $df=1$, $p=0.000$

II). Table II also shows that the majority of clients each year were female, despite a significant increase in male clients.

Table III identifies client residence on the basis of four urban/rural locations. Edmonton and Calgary (the two largest cities in Alberta, each with a population of around 1 million) maintained relatively stable proportions of provincial home care clients over time, with each area accounting for approximately one quarter of all clients. In contrast, a proportional increase in “other urban” clients and decrease in “rural” clients occurred. Table III also shows that while the average hours of care provided on an annual basis to clients in each of these four areas increased over time, this increase varied significantly between areas. Rural areas consistently had

the lowest care hours, followed by “other urban” areas.

Table IV illustrates utilization findings for the 55,696 home care clients who died (12% of clients). Over time, the average number of days registered as a home care client until death declined significantly, while the mean hours of care per client increased significantly. Similarly, Table V indicates that a substantial (244%) increase in province-wide care hours occurred over the 10 years. The hours of care also increased for each service provider. While the majority of care hours each year continued to be provided by Home Support Aides (HSA), the proportion of total care hours provided each year by HSAs declined significantly over time, as it did for Registered Nurses. In contrast, the pro-

portion of total care hours through self-managed care increased significantly. Table V also shows that the average annual hours of care per client doubled over these 10 years, with clients receiving care from HSAs or through self-managed care having the greatest care hour increases.

Table VI illustrates service trends. Personal care increased considerably in proportion of care hours, while home support hours and skilled care hours declined proportionally. Table VI also shows that the mean hours provided per client doubled, with the greatest increase among clients receiving personal care.

Table VII presents logistic regression findings. These illustrate that as compared to 1991/92, home care recipients in 2000/01 were 1.25 times more likely to be male, 1.15 times more likely to be living in Calgary than Edmonton, 1.6 times more likely to be living in “other urban” areas than Edmonton, unlikely to be from a rural area as compared to Edmonton, and 1.89 times more likely to be under than over the age of 65.

DISCUSSION

Although this study was limited by province and missing variables of interest (such as marital status, living arrangement, income, and medical diagnosis), it provided useful client, service, and provider information. The most significant findings were the substantial increase in home care clients and care hours. Clearly, considerable home care expansion had occurred, despite a decline in the duration of care, both in terms of intensity of care (more care per client) and access to care (more clients).

Home care expansion is good news, as unmet home care needs has been a common research finding.^{5,9-12} Unfortunately, this study could not determine if this expansion was enough to address the needs of a growing population, particularly one that experienced hospital downsizing on a grand scale such that one might have expected a significant increase in skilled nursing care hours. Furthermore, although the findings for all 10 years are not provided in the tables (to conserve space), the 1993-1995 hospital downsizing did not have an immediate effect on client numbers or care hours, as client number and

care hour increases were incremental over the years. Studies to identify influences for home care growth may prove useful.

The finding that home care expansion was not uniform across the province, with rural areas and small urban areas continuing to have lower per-client care hours than the two major urban centres, is of concern. Although this could indicate additional challenges in providing home care in sparsely populated areas, it raises concern over equity of access to home care. Ours is not the first study to raise equity of access to home care issues within provinces.¹³

Finding home care services were being provided over an increasingly shorter period was also of concern. This could indicate families are increasingly providing home care, with informal caregiver burden and burnout more likely. On the other hand, it could indicate that short-term home care is increasingly appropriate as a result of population health and health care advances. Regardless of the explanation, it is a change worth watching.

Another potential concern is that home care services were predominantly provided by the least skilled provider – the Home Support Aide. Yet, home care consisted most often of personal care, as opposed to skilled services that need to be provided by Registered Nurses and other professional providers. Although a decline in care hours by HSAs was noted, this was offset by an increase in self-managed care. Self-managed clients hire their own care providers, using publicly-provided funds. In most cases these would be HSAs, as they are cheaper and more readily available than other professional providers. Alberta may be unique in this regard, as Health Canada indicated 38.8% of home care clients (in 6 provinces) were receiving professional nursing services and 26.5% were receiving other professional services, such as occupational therapy, physiotherapy, speech therapy, and social work.¹

The low care need scores indicate that a considerable proportion of home care services could be provided by HSAs, particularly as family members often provide home-based care of this type. Cranswick's study of Canadians needing short-term help found personal care was the most common assistance provided by spouses, mothers, or daughters.¹⁴ Chochinov and

TABLE VI

Total Hours of Care and Mean Care Hours by Care Type, Findings Limited to the First, Last and All Years Combined

Fiscal Year	Home Care Type	Total Care Hours, All Clients Combined N (%)*	Mean Hours, Per Client Mean (SD)†‡
1991/92	Personal Care	456,099 (28.5)	40.1 (78.3)
	Home Support	720,737 (45.0)	53.1 (59.7)
	Skilled Care	325,328 (20.3)	12.4 (37.0)
	Case Coordination	51,484 (3.2)	2.7 (4.7)
	Assessment	46,692 (2.9)	2.2 (2.1)
	Meals	1,363 (0.1)	1.9 (16.7)
	Total	1,601,702 (100)	51.9 (90.5)
2000/01	Personal Care	4,872,870 (68.5)	165.0 (370.3)
	Home Support	1,030,927 (14.5)	109.4 (261.5)
	Skilled Care	736,652 (10.4)	13.8 (82.8)
	Case Coordination	373,852 (5.3)	6.4 (9.8)
	Assessment	96,991 (1.4)	2.4 (3.5)
	Meals	47 (0.0)	1.5 (5.1)
	Total	7,111,340 (100)	109.7 (323.8)
All Years	Personal Care	27988359 (60.5)	126.0 (323.0)
	Home Support	9,957,498 (21.5)	76.4 (195.2)
	Skilled Care	5,366,401 (11.6)	13.0 (61.1)
	Case Coordination	2,245,057 (4.9)	5.3 (8.8)
	Assessment	722,607 (1.6)	2.3 (2.9)
	Meals	4,801 (0.0)	2.2 (17.3)
	Total	46,284,723 (100)	94.3 (281.9)

* hours-of-care data were aggregated, no statistical tests could be performed

† test of mean hours for all care types combined over 10 years, $F=227.24$, $df=9$, $p=0.000$.

‡ test of mean hours by care type over 10 years, and test to compare first and last year:

- for personal care, $F=315.161$, $df=9$, $p=0.000$, Tamhane's $T=113.81$, $df=1$, $p=0.000$
- for home support, $F=112.050$, $df=9$, $p=0.000$, Tamhane's $T=23.78$, $df=1$, $p=0.000$
- for skilled care, $F=2.352$, $df=9$, $p=0.012$, Tamhane's $T=1.22$, $df=1$, $p=0.000$
- for case coordination, $F=775.171$, $df=9$, $p=0.000$, Tamhane's $T=283.9$, $df=1$, $p=0.000$
- for general assessment, $F=30.732$, $df=9$, $p=0.000$, Tamhane's $T=3.34$, $df=1$, $p=0.000$
- for meals, $F=4.255$, $df=9$, $p=0.011$, Tamhane's $T=1.65$, $df=1$, $p=0.000$

TABLE VII

Logistic Regression Findings

		B	S.E.	Wald	df	Sig.	Exp(B)	95% CI for EXP(B)	
Step 1*	gender(1)	0.225	0.015	223.062	1	0.000	1.252	1.216	1.290
	res_nu			2229.576	3	0.000			
	res_nu(1)	0.141	0.020	49.095	1	0.000	1.151	1.107	1.197
	res_nu(2)	0.505	0.022	529.156	1	0.000	1.657	1.588	1.730
	res_nu(3)	-0.446	0.019	542.596	1	0.000	0.640	0.617	0.665
	age_ind(1)	0.641	0.018	1267.044	1	0.000	1.899	1.833	1.967
	Constant	0.577	0.016	1367.445	1	0.000	1.780		

* Variables entered on step 1: gender, residence, and age group.

Kristjansson also indicated that the vast majority of deaths today are among elderly persons, who have been cared for largely by other elderly persons independently and at home.¹⁵ Wilkins and Park's mid-1990s Canada-wide survey revealed formal home care most commonly involved assistance with personal care or activities of daily living (washing, dressing and eating).⁵ Yet, a compelling argument for increased attention to quality is that there is no national legislative basis for home care, with each province free to independently define and provide home care.¹⁶

Two other trends are of interest, these being the decline in client age and increase in male clients. Health Canada's earlier report indicated that the majority of home care clients across Canada were elderly,¹ in

keeping with other studies that found home care was most often provided to persons who were advanced in age and disability.^{5,17} Thus, one might observe that an aging population is not driving home care expansion. Past research has also indicated women comprise two thirds of home care recipients in Canada.⁵ Research on client trends and their implications is needed, particularly as it does not appear that Alberta's home care expansion was designed to support what many believe is the most typical home care client – a frail elderly single woman.

In conclusion, this analysis of data from a 10-year provincial home care database revealed considerable growth in home care clients and care hours. Sustained hospital downsizing was a likely stimulus for home

care growth, although this growth was not uniform across the province. The predominant use of Home Support Aides as care providers, with the least skilled and knowledgeable health care worker thus providing the majority of care hours, may indicate that hospital downsizing was not a driver in increasing home care, as one would have expected increased nursing hours. Although this level of worker may be justified by low care needs scores, particularly as family members often provide similar basic care, quality of care and appropriateness issues may exist. Yet, Alberta's substantial home care expansion may have been possible in large part as a result of the predominant use of the least expensive worker.

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RÉSUMÉ

Contexte : On a entrepris une analyse comparative des données liées aux clients, aux services et aux fournisseurs du secteur des soins à domicile, de 1991-1992 à 2000-2001. L'analyse avait pour but de décrire les changements survenus au cours de cette décennie et de permettre une discussion plus éclairée auprès des intervenants du secteur des soins à domicile, à la lumière des développements de la politique canadienne de la santé et des réformes du système de santé.

Méthodes : Après avoir obtenu du ministère de la santé et du mieux-être (Ministry of Health and Wellness) de l'Alberta les données demandées, on a entrepris des analyses descriptives et comparatives à l'aide du logiciel SPSS. La régression logistique a permis de comparer les caractéristiques de la clientèle au cours de la première année et des dernières années.

Résultats : La clientèle des soins à domicile a doublé et la moyenne d'heures de soins prodigués à chacun des patients a augmenté de façon importante et ce, même si on constate une diminution de la durée de prestation des soins. De plus, on observe une diminution de l'âge moyen des clients. Les soins à domicile continuent d'être prodigués, de façon prédominante, par les aides du soutien à domicile; on observe une augmentation nette de la prise en charge des soins par les clients. On relève des écarts persistants dans la prestation des soins à domicile entre les différentes zones géographiques.

Conclusion : Même si les soins à domicile offrent une possibilité réelle que le patient reçoive un congé précoce de l'hôpital et qu'il maintienne, voire améliore, son état de santé, il existe peu d'études de la population consacrées aux tendances dans le secteur des soins à domicile. En Alberta, même si on note officiellement une augmentation de la prestation de soins à domicile, on observe un manque d'uniformité au chapitre de l'expansion des soins à domicile à l'échelle provinciale. Les aides au soutien à domicile continuent de représenter les principaux fournisseurs de soins. Dans le contexte de la restructuration importante des établissements hospitaliers, une telle situation pourrait inciter à conclure que l'on a transféré aux familles la responsabilité de prodiguer les soins à domicile. De plus, l'augmentation des soins à domicile ne semble pas être liée au vieillissement de la population.

Alzheimer Disease

Dispelling the myths

There are many myths surrounding Alzheimer Disease — about the cause, the prevention and the people who have it.

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Myth 6 Alzheimer Disease is preventable.

Reality: Because there is no known cause for Alzheimer Disease, there is no conclusive evidence that Alzheimer Disease can be prevented. There is, however, a growing amount of evidence that lifestyle choices that keep mind and body fit may help reduce the risk. These choices include physical exercise, a healthy diet including fresh fruits, vegetables and fish, as well as keeping your brain active.