Feature

Costs of End-of-Life Care: Findings from the Province of Saskatchewan

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As part of the Health Care Use at the End-of-Life in Western Canada Study, the Western Office of the Canadian Institute for Health Information (CIHI) collaborated with the ministries or departments of health in British Columbia, Alberta, Saskatchewan and Manitoba to highlight selected aspects of healthcare at the end of life. In-depth supplementary studies were also conducted for each of the four western provinces. Saskatchewan focused its analysis on healthcare costs in the two years before death. This article provides a summary of data on healthcare costs for persons who died in Saskatchewan in the 2003–2004 fiscal year. It is based on a more in-depth report prepared for CIHI and Saskatchewan Health titled "Final Report of the Saskatchewan End-of-Life Care Project." The full report can be freely accessed at www.hollanderanalytical.com. The CIHI reports can be accessed at http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=PG_930_E&cw_topic=930&cw_rel=AR_1729_E.

Methods

Detailed utilization data were obtained, on an anonymized basis, for the two-year period prior to death for Saskatchewan residents who died in Saskatchewan during the 2003–2004 fiscal year. An extensive set of edit and logic checks were used to clean the data.

Costs were standardized to fiscal 2003–2004 dollars; that is, the 2003–2004 unit costs were applied to the utilization rates, irrespective of the year in which services were used (except for physician services and drugs, where actual costs were used, resulting in a slight underestimate for these services). It should be noted that the administrative data did allow for a fairly complete accounting of total costs, including both the costs to government and the user fees paid by clients for such services. Income tested user fees were charged for long-term care facilities, home care services and drugs. User fees were actuals, or estimates, based on data provided by Saskatchewan Health. However, it should be noted that the data in this article do *not* include goods or services that were completely paid for by the individuals or their families (e.g., out of pocket expenses) or the imputed costs of unpaid caregiving. Thus, the term "total costs" in this article refers only to costs to government plus user fees paid by individuals or family members.

One of the important aspects of this project was that data were collected for the two-year period prior to death for the clients in the study. Most published reports present data on only one time period such as 30 days, six months or one year prior to death. In contrast, this article reports on four commonly referenced time periods prior to death: 30 days, 90 days, 180 days and 365 days.

The number of total individuals included in the analyses for the 30-, 90-, 180- and 365-day cohorts vary as not all people had medical coverage from Saskatchewan Health for the full two-year period prior to death. The total samples for each of

the major cohorts in this project were as follows:

- 30-day cohort: 8,703
- 90-day cohort: 8,693
- 180-day cohort: 8,681
- 365-day cohort: 8,643

Using the full sample represented in the 30 days prior to death cohort, it was found that, overall, there were 4,292 females and 4,411 males. In terms of age, 16.4% of the sample was under 65, 46.3% was 65–84 and 37.3% were 85 years of age or older. For the interested reader, the full methods used in this study are detailed in the report prepared for CIHI and Saskatchewan Health.

Literature Scan

It is important to note that this article focuses on end-of-life care, regardless of the context in which a person died. Thus, while some decedents received palliative care, the majority did not. This article does not analyze specific palliative care contexts or services.

There were some American studies on end-of-life care. Most of the studies analyzed Medicare costs. Scitovski (2005) noted two cautions that need to be considered when assessing end-of-life cost estimates from Medicare data. The first is that the data are limited to persons 65 years of age or older. The second, and major, caution is that the Medicare data sets do not include the majority of costs associated with nursing home care, resulting in an underestimate of costs.

The American literature varied in the cost estimates produced based on the year the study was conducted, the period prior to death that was analyzed, the type of condition leading to death, and other factors. Thus, it is not possible to derive a clear consensus estimate of current costs in the United States. On the low end of the cost spectrum, Liu et al. (2006) estimated a cost of US$40,000 for the year prior to death (in 1995) using both Medicare and Medicaid data. Similarly, Hoover et al. (2002) estimated an overall cost of US$37,581 for 1996 using Medicare data. At the higher end of the range, Lewin et al. (2005) studied patients who died from ovarian cancer. While their study compared hospice to non-hospice groups, the costs for non-hospice *hospital* care in the last *60 days* of life was US$59,316. Daviglus et al. (2005) related costs in the last year of life to cardiovascular risk profiles earlier in the patients' lives. Depending on the risk profiles, annual Medicare costs (in 2002 dollars) ranged from US$86,908 for persons with low risk levels at baseline (1967–1973) to US$95,776 for people with four or more risk factors at baseline.

In an American study, which also relates to this article, Lunney et al. (2002) estimated costs for the groupings developed by Lunney and her colleagues. The costs for the last year of life for each of the Lunney groups for the mid-1990s were as follows:

- Sudden death: US$625
- Terminal illness: US$31,052
- Organ failure: US$36,834
- Frailty: US$24,849
- Other: US$9,225

With regard to Canadian data, perhaps the best known study is that of McGrail et al. (2000). Using British Columbia linked data sets that cover all major aspects of healthcare delivery, including long-term care facilities, the total costs of care in the *last 6 months* of life for people who died in 1993 (in 1995 dollars) ranged from $19,000 to $27,000, depending on age.

Findings

Key New Finding on the Impact of Residential Care in Determining End-of-Life Healthcare Costs

A major, and significant, finding of this study was that long-term care facility costs can have a profound impact on the costs of end-of-life care. For example, for people who were in long-term care facilities at the start of the six-month period prior to death, the average cost was $28,125, whereas the cost for people living independently in the community at the start of the period was $16,068. Thus, the influence of long-term care facility costs can be quite significant on any aggregate cost estimates, particularly if one looks at costs over a six-month to one-year period. The average costs of care also vary in relation to the relative proportion of people in a given study who are in long-term care facilities. To reflect the impact of residential long-term care, the data tables in this article show the impact on the costs of long-term care facilities.

Overall Costs

Table 1 presents data on the costs to government and total costs for the 12 periods of 30 days prior to death. It presents overall costs, costs for individuals with no residential care and costs for people who were primarily in long-term care facilities. The grouping to which an individual was assigned was based on the patient's status at the beginning of the first 30-day period. As can be seen in Table 1, there is a significant difference in costs between individuals with and without residential long-term care. Overall, the average total cost per person, per 30-day period, was $2,639, ranging from $1,641 for the first of the 12 periods to $7,420 for the final 30-day period prior to death. The average cost, per 30-day period, for people with no residential care was $1,655, ranging from $613 to $8,087. The average cost for people who were primarily in residential care was $4,570 ranging from $4,543 to $5,260. As can be seen from Table 1, while average total costs per person increased significantly for all

Table 1. Costs to government and total costs* ($) for 12 periods of 30 days prior to death

	1	2	3	4	5	6	7	8	9	10	11	12†	Average of All Periods
Overall costs													
Average per-person cost to government	1,373	1,394	1,463	1,524	1,587	1,662	1,776	1,951	2,151	2,562	3,429	7,030	2,325
Average per-person total cost	1,641	1,668	1,742	1,809	1,880	1,964	2,086	2,270	2,482	2,911	3,798	7,420	2,639
No facility care													
Average per-person cost to government for persons with no facility care	569	590	639	649	694	761	857	1,013	1,172	1,611	2,699	8,039	1,608
Average per-person total cost for persons with no facility care	613	634	686	694	740	808	905	1,062	1,222	1,662	2,751	8,087	1,655
Facility care													
Average per-person cost to government for persons with facility care >80% of the time‡	3,582	3,571	3,463	3,487	3,472	3,494	3,466	3,467	3,489	3,534	3,629	4,295	3,579
Average per-person total cost for persons with facility care >80% of the time‡	4,543	4,553	4,460	4,486	4,471	4,493	4,465	4,464	4,488	4,533	4,628	5,260	4,570

*Total costs include costs to government plus user fees.

†The 30-day period designated as 12 is the 30 days prior to death.

‡Facility care >80% of the time, in fiscal 2003–2004, is used as a proxy for a full-time facility client.

clients, and for clients without residential care, for the better part of the 12-month period, the costs for clients in long-term care facilities were relatively consistent, reflecting the lower level of use of other health services, such as hospitals, at the end of life. It should also be noted that there is a large discrepancy in the total cost figure, and the cost to government figure, for people in long-term care facilities compared with the other two groups. This difference is due to user fees charged for facility care.

Costs Related to Socio-demographic Characteristics

Overall, except for the costs for the 30-day period prior to death, the average total costs for females were higher than those for males. Thus, while the average total cost for males and females were $7,581 and $7,236, respectively, for the 30 days prior to death, the costs for the 365 days prior to death were $28,649 for males and $35,306 for females. However, this appears to be an artifact related to the higher proportion of females in long-term care facilities.

There was a clear progression in which costs were increasingly higher in accordance with age for the period of 365 days prior to death. However, this was not the case for the other time periods. While costs increased across all time periods for persons aged 19–44, 45–64 and 65–74, they tended to be lower for the 75–84 and 85+ age groups than for the 65–74 age group for the 30-, 90- and 180-day time periods. There were also different patterns of costs across the four time periods by marital status,

although the lowest costs across all four time periods were for people who were single, divorced or separated. For the 365-day period, the costs for persons who were widowed were significantly higher ($37,030) than for those who were married or living in common law relationships ($28,699). (The marital status differentials also appear to be related to the higher use of long-term care facilities by the higher-cost groups.)

Costs Related to the Context of the Client

As noted above, the context of care has a great deal to do with the costs incurred at the end of life. Table 2 presents data for each of the time periods in our analysis, that is, the 30, 90, 180 and 365 days prior to death. For each time period, the table notes the distribution of costs depending on the context of the client at the start of the period – in facility, in hospital, in the

Table 2. Per-person total costs* ($) by type of service at the start of the time period for time periods of 30, 90, 180 and 365 days

Time Period prior to Death	Type of Service at Start of Period	Type of Service						
		Long-Term Care Facility	Home Care	Hospital Service	Pharmacy	Physician Services	Average Total Costs	Average Excluding Facility Care
30 days	In facility	3,999	5	1,023	197	188	5,412	1,414
	In hospital	892	173	15,084	176	845	17,171	16,279
	In the community with home care	185	878	5,130	240	501	6,932	6,748
	In the community without home care	48	48	4,831	119	700	5,746	5,699
90 days	In facility	12,179	32	1,576	545	373	14,704	2,525
	In hospital	3,768	650	23,739	660	1,537	30,354	26,586
	In the community with home care	1,063	1,957	10,655	660	981	15,315	14,252
	In the community without home care	354	227	9,387	394	1,154	11,517	11,163
180 days	In facility	24,598	24	1,931	1,002	569	28,125	3,527
	In hospital	7,797	1,371	29,379	1,602	2,292	42,441	34,644
	In the community with home care	2,774	3,605	13,132	1,287	1,367	22,164	19,391
	In the community without home care	919	422	12,395	755	1,577	16,068	15,149
365 days	In facility	50,001	42	2,231	1,872	939	55,086	5,085
	In hospital	17,229	2,731	32,495	3,148	3,367	58,970	41,742
	In the community with home care	7,325	6,792	15,711	2,307	1,916	34,052	26,727
	In the community without home care	2,157	745	15,463	1,441	2,186	21,992	19,835

*Total costs include costs to government plus user fees.

community with home care or in the community without home care. For each time period, the highest cost was for people who started the time period in the hospital. For the 30- and 90-day periods, the next highest cost group was people living in the community with home care. Most of the costs for this group were related to hospital care.

For the 180- and 365-day groups, the second highest cost was for people in a long-term care facility. What is also interesting, and quite significant, is that the facility care group had consistently lower costs for other parts of the healthcare system. The major cost for people in facilities is the cost of facility care. This is similar to findings by Hollander (2001) in regard to administrative data for British Columbia. The majority of costs for community-living individuals who die is for hospital care.

Costs Related to the Lunney/Fassbender Groupings

In any end-of-life care study, it is important to be able to group individuals into clusters of relatively like individuals for purposes of analysis and comparison. For example, if one combined people who had a sudden death (e.g., in an automobile accident) with those who had a serious chronic illness, the resulting average would be a statistical artifact that represented neither of these groups and could not readily be used for planning or costing purposes.

In the Health Care at the End-of-Life in Western Canada Study, it was decided to use a grouping approach developed by Lunney and her colleagues (2002, 2003). This grouping is used in the current report as well. Table 3 presents the names and descriptions of what are referred to as the Lunney/Fassbender Causes of Death Trajectory Groupings. This terminology is used as Fassbender et al. (2006) adapted the methodology for calculating group membership to the Canadian context.

Table 4 presents data for the five Lunney/Fassbender groupings. It is interesting to note that for the period 30 days prior to death, the highest cost factor for all groupings was hospital care, the next highest was residential long-term care and the third highest was physician services. This pattern changed over time. For the period 365 days prior to death for frailty, organ failure, and other, the highest cost factor was residential long-term care. The clear exception to this pattern was terminal illness, for which hospital care was, by far, the most significant cost factor across all time periods.

Costs for the Five Most Common Causes of Death

A wide range of causes of death were analyzed for this project. Table 5 presents the relative cost distributions, across types of healthcare services and time before death, for the five most common causes of death (in rank order). There are also interesting patterns of costs for the five main causes of death. For the 30 days prior to death, with one exception, the primary cost factor is hospital care. The exception is death due to diseases of the nervous system and sense organs, for which the highest cost

Table 3. Cause of death trajectory groupings

Name of Grouping	Description
Sudden death (e.g., accidental death, falls, trauma)	Decedents in this group are likely to be in good health or to display normal functional ability before the incident that causes death. While it is possible that a condition associated with one of the groups below is present, the underlying cause of death is one of trauma, accident or other unintended causes. Typically, these decedents display low healthcare costs relative to the other groups.
Terminal illness (e.g., cancer, chronic renal failure, HIV-related diseases)	Typically, decedents in this group diagnosed with some form of cancer in the last year of life show substantial physician billings for cancer-related treatment. Functional status information demonstrates a terminal phase for this group. Typically, these decedents demonstrate a short period of evident decline.
Organ failure (e.g., congestive heart failure, COPD)	Organ failure decedents are typically diagnosed with either CHF or COPD. Decedents in this group are likely to experience long-term limitations, exacerbated by acute episodes (with high costs or long hospitalizations) followed by recovery. Episode severity may gradually increase, while post-episode recoveries lessen, eventually leading to death.
Frailty (e.g., neurological decline and other frequent causes of death among the elderly)	Typically, due to their advanced age, decedents in this category may display lower functional status relative to other decedents in the year before death. The pattern of decline over time is typically more gradual, characterized as prolonged dwindling.
Other (e.g., those not elsewhere categorized)	These are the remaining decedents whose conditions are not classified into any of the other four categories and may not exhibit specific patterns in functional decline or service utilization.

CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease; HIV = human immunodeficiency virus.

Sources: Data from Fassbender et al. (2006); Lunney et al. (2002, 2003).

Table 4. Per-person total costs* ($) by the Lunney/Fassbender classification and types of services used for time periods of 30, 90, 180 and 365 days

Time Period prior to Death	Lunney/Fassbender Classification	Type of Service						
		Long-Term Care Facility	Home Care	Hospital Service	Pharmacy	Physician Services	Average Total Costs	Average Excluding Facility Care
30 days	Frailty	1,982	81	3,431	151	406	6,051	4,069
	Organ failure	1,672	115	5,046	157	578	7,568	5,896
	Other	1,807	110	6,234	145	834	9,130	7,323
	Sudden death	570	22	2,245	75	423	3,335	2,765
	Terminal illness	878	440	7,121	238	543	9,219	8,341
90 days	Frailty	5,801	279	5,230	460	686	12,455	6,655
	Organ failure	4,740	362	7,884	489	958	14,431	9,691
	Other	5,150	353	8,577	470	1,198	15,748	10,597
	Sudden death	1,659	76	3,406	220	610	5,971	4,312
	Terminal illness	2,053	949	12,102	606	1,126	16,836	14,783
180 days	Frailty	11,048	614	6,597	898	975	20,131	9,083
	Organ failure	8,833	761	9,943	958	1,317	21,812	12,979
	Other	9,607	669	10,994	943	1,630	23,844	14,236
	Sudden death	3,138	175	4,531	428	807	9,079	5,941
	Terminal illness	3,304	1,382	15,305	1,019	1,661	22,671	19,367
365 days	Frailty	20,981	1,302	8,367	1,707	1,434	33,791	12,810
	Organ failure	16,050	1,570	12,708	1,837	1,907	34,072	18,021
	Other	17,605	1,407	13,404	1,773	2,188	36,376	18,771
	Sudden death	5,607	386	5,815	824	1,195	13,827	8,220
	Terminal illness	5,186	1,961	18,960	1,675	2,433	30,214	25,028

*Total costs include costs to government plus user fees.

was residential long-term care. This could be related to people in long-term care facilities suffering from dementia. For the period 365 days prior to death, the major cost factor for neoplasms was hospital care. For the deaths due to diseases of the circulatory system, the respiratory system and the nervous system and sense organs, the major cost factor was residential long-term care.

Costs for Persons Receiving Palliative Care

Table 6 presents a comparison of people identified as having received palliative care. All clients identified as part of Saskatchewan's palliative drug program and all clients with a palliative care indicator for a hospital stay were characterized as palliative care clients. There were a total of 2,250 such clients. It is interesting to note that the average total cost per client was less

Table 5. Per-person total costs* ($) by five most common causes of death and types of services used for time periods of 30, 90, 180 and 365 days

Time Period Prior to Death	Five Most Common Causes of Death	Type of Service						
		Long-Term Care Facility	Home Care	Hospital Service	Pharmacy	Physician Services	Average Total Costs	Average Excluding Facility Care
30 days	Diseases of the circulatory system	1,519	100	4,032	145	496	6,294	4,775
	Neoplasms	859	434	7,084	237	538	9,152	8,293
	Diseases of the respiratory system	1,914	108	5,655	146	501	8,324	6,410
	External causes of morbidity and mortality	756	44	2,854	84	494	4,233	3,476
	Diseases of the nervous system and sense organs	3,122	99	1,950	156	214	5,541	2,419
90 days	Diseases of the circulatory system	4,339	332	6,124	445	812	12,052	7,713
	Neoplasms	1,982	932	12,094	599	1,128	16,735	14,753
	Diseases of the respiratory system	5,443	366	8,912	473	858	16,051	10,608
	External causes of morbidity and mortality	2,133	161	4,184	242	706	7,426	5,292
	Diseases of the nervous system and sense organs	9,257	280	3,228	459	433	13,656	4,399
180 days	Diseases of the circulatory system	8,141	683	7,742	864	1,131	18,561	10,421
	Neoplasms	3,158	1,349	15,323	1,003	1,664	22,497	19,339
	Diseases of the respiratory system	10,142	842	11,145	959	1,185	24,274	14,132
	External causes of morbidity and mortality	3,930	332	5,405	478	939	11,084	7,154
	Diseases of the nervous system and sense organs	17,821	568	4,276	888	661	24,214	6,393
365 days	Diseases of the circulatory system	15,015	1,387	9,831	1,657	1,641	29,532	14,517
	Neoplasms	4,898	1,903	18,952	1,637	2,433	29,823	24,925
	Diseases of the respiratory system	18,536	1,800	13,369	1,866	1,693	37,264	18,728
	External causes of morbidity and mortality	6,988	689	6,841	934	1,354	16,806	9,818
	Diseases of the nervous system and sense organs	34,177	1,211	5,952	1,678	1,052	44,070	9,893

*Total costs include costs to government plus user fees.

for people who were identified as having received palliative care than for people who did not receive palliative care, except for the group 365 days prior to death. The difference between the two groups appears to diminish in proportion to the length of the period prior to death. This is understandable as most palliative care programs are designed for people near the end of life. One clear finding from the data presented in Table 6 is the relatively lower cost for hospital care for palliative clients across all time periods. This is a significant finding. However, as this was not a study of the cost-effectiveness of palliative care *per se*, further research is indicated to determine the relative cost-effectiveness of palliative care services.

Discussion

It is believed that this study represents one of a relatively few major studies conducted in Canada on the costs of end-of-life care. Future research in other jurisdictions could begin to paint a more complete picture on the costs of end-of-life care in Canada.

This study has pointed out a major new finding related to the relative influence of long-term care facilities on the average cost of end-of-life care. As can be seen from this report, the influence on costs of persons receiving long-term residential care is significant and increases over time. Thus, the relative proportion of people in facilities can impact end-of-life costing for a given geographical entity such as a regional health authority. For example, if all other conditions are identical across two regional health authorities but the proportion of people who are in long-term care facilities prior to death differs, the overall costs also tend to differ. Thus, when making cost comparisons, one needs to control for the impact of facility care across geographical entities such as health authorities, provinces or countries. It is recommended that, in future, researchers clearly show costs separately for people living at home and people living in long-term care facilities as part of their analyses.

Finally, in terms of overall costs, the estimated total healthcare costs for people who died, for the four time periods, in fiscal 03/04 and 09/10 dollars, for Saskatchewan and Canada as a whole are presented in Table 7.

From the data in Table 7, one can see that total healthcare

Table 6. Per-person total costs* ($) by receipt or non-receipt of palliative care and types of services used for time periods of 30, 90, 180 and 365 days

Time Period Prior to Death	Receipt or Non-receipt of Palliative Care	Type of Service						
		Long-Term Care Facility	Home Care	Hospital Service	Pharmacy	Physician Services	Average Total Costs	Average Excluding Facility Care
30 days	Identified as palliative care	1,676	91	4,338	139	514	6,757	5,082
	Not identified as palliative care	951	473	7,062	270	531	9,286	8,336
90 days	Identified as palliative care	4,832	293	6,549	429	832	12,935	8,103
	Not identified as palliative care	2,217	1,032	12,410	695	1,150	17,505	15,288
180 days	Identified as palliative care	9,115	615	8,237	844	1,151	19,963	10,847
	Not identified as palliative care	3,544	1,547	15,821	1,172	1,710	23,793	20,250
365 days	Identified as palliative care	16,966	1,284	10,421	1,624	1,667	31,962	14,996
	Not identified as palliative care	5,482	2,245	19,729	1,917	2,512	31,886	26,404

*Total costs include costs to government plus user fees.

Table 7. Cost Estimates for fiscal 2003/04 and 2009/10 for people who died: Saskatchewan and Canada

	Total Costs (in million $) for Saskatchewan		Extrapolated Costs (in million $) for Canada	
Time Period	Fiscal* 2003–2004	Fiscal† 2009–2010	Fiscal* 2003–2004	Fiscal† 2009–2010
30 days	61.1	99.0	1,698.6	2,753.4
90 days	113.1	183.3	3,114.2	5,048.1
180 days	164.0	265.8	4,599.2	7,455.3
360 days	243.1	394.1	6,758.2	10,955.0

* Extrapolations to Canada for Fiscal 03/04 are based on population estimates for people aged 65 years of age or older. The Canadian population 65+ was 27.8 times as great as the Saskatchewan population 65+, as of December 2003. Thus, Saskatchewan costs were multiplied by 27.8 to obtain the fiscal 03/04 cost estimates for Canada.

† The extrapolations from fiscal 03/04 to fiscal 09/10 were based on cost increases in Saskatchewan for services related to end-of-life care, that is, regional services, medical services (fee-for-service and non-fee-for-service cost only) and costs for drugs and extended benefits (prescription drug plan and aids to independent living only). This represented an increase of 62.1% from fiscal 03/04 to fiscal 09/10. This increase was applied to the fiscal 03/04 estimated costs for Saskatchewan and Canada to obtain the fiscal 09/10 estimates. The figures for Canada for fiscal 09/10 are deemed to be an underestimate as the population aged 65+ increased at a faster rate in Canada than in Saskatchewan, between fiscal 03/04 and fiscal 09/10.

costs (costs to government and user fees) for people who died in fiscal year 2003–2004 extrapolated to Canada ranged from $1.7 billion for the 30 days prior to death to $6.8 billion for the one-year period prior to death. The comparable figures for fiscal 09/10 were $2.8 billion and $11 billion. HQ

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