

# Caregiver Out-of-Pocket Costs for Octogenarian Intensive Care Unit Patients in Canada\*

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## RÉSUMÉ

Les problèmes médicaux affectant la population vieillissante sont de plus en plus préoccupants et ont des impacts sur les patients et leurs soignants familiaux. Cette étude a permis de déterminer les coûts directs et indirects encourus par les soignants familiaux de personnes âgées hospitalisées en unités de soins intensifs (USI) au Canada. Les soignants familiaux de patients hospitalisés en USI ont répondu à un sondage portant à la fois sur les coûts directs qu'ils assumaient pour les soins de ces patients et sur les coûts indirects, tels que les heures de travail et de loisirs perdues lors de la prestation de ces soins. Les coûts totaux mensuels des soins ont été stratifiés selon le sexe, l'âge et la région géographique du soignant. La moyenne des coûts directs pour les soignants était de 791 \$ (\$CA en 2016) par patient au cours du premier mois de soins intensifs. Le coût total quotidien moyen par patient était de 162 \$ par jour pour ces soignants. Les hommes ayant le rôle de soignant principal ont payé davantage de frais que les femmes. Des programmes de subvention seraient nécessaires pour aider les soignants familiaux à couvrir les frais considérables liés aux soins qu'ils apportent à des patients en USI, en incluant aussi les frais de déplacements, de repas, d'hébergement et de stationnement.

## ABSTRACT

Medical issues facing the aging population are of growing concern with consequences for patients and their caregivers. This study determined the indirect and out-of-pocket costs incurred by the caregivers of elderly patients in Canadian Intensive Care Units (ICUs). Primary family caregivers were surveyed capturing out-of-pocket costs, hours of work, and hours of leisure forgone in providing patient care while the patient was in the ICU. Total costs of care per month were reported across caregiver sex, age, and geographic region. Average out-of-pocket costs were \$791 (2016 Canadian dollars) in the first month of ICU care. The mean total cost to family caregivers per patient was \$162 per day. Male primary caregivers had higher mean out-of-pocket costs than female caregivers. Subsidization programs covering expenses such as travel, meals, accommodation, and parking are needed to support family caregivers of elderly ICU patients who are incurring considerable out-of-pocket costs.

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## Introduction

As the global population ages, the number of individuals over 80 years of age is increasing (United Nations, Dept. of Economic and Social Affairs, Population Division, 2002). In Canada, individuals over age 80 currently constitute 5 per cent of the population. These individuals have a high demand for health care. Canadians between ages 80 and 84 have a higher rate of intensive care unit (ICU) admission per capita than any other age group (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2013). Providing care for these older patients in the ICU can be costly because they are more likely to have co-morbidities and may require additional care (Merlani, Chenaud, Mariotti, & Ricou, 2007).

The cost of caring for patients in the ICU can be broken down into two categories. The first is direct costs, which are the costs incurred by the medical system. In Canada, the direct costs of treating patients over 80 years of age in the ICU are \$3,560 (2016 CAD) per patient per day (Chin-Yee, D'Egidio, Thavorn, Heyland, & Kyeremanteng, 2017). However, in order to complete our understanding of the costs of treatment for these patients, we need to take indirect costs into account as well.

Indirect costs to the patient include out-of-pocket costs such as parking, food, and travel, and the time that the family caregivers spend caring for the patient (Avery, Ley, Hill, Hershon, & Dick, 2001; Blackwell, Azizzadeh, Ayala, & Rawnsley, 2002; Engoren, Arslanian-Engoren, Steckel, Neihardt, & Fenn-Buderer, 2002; Leader et al., 2003; Rowell et al., 2011; Thalanany, Mugford, & Mitchell-Inwang, 2006). Tools exist to assess indirect costs for ambulatory care and home care, but their application to ICU care is untested (Guerriere & Coyte, 2011). These out-of-pocket expenses for Canadian patients and their caregivers have been increasing over time in all age groups (Sanmartin, Hennessy, Lu, & Law, 2014), but the specific costs for patients age 80 and older are not well established.

Previous studies on out-of-pocket costs to the family caregivers of ICU patients have provided a wide range of expense estimates (Leader et al., 2003; Rowell et al., 2011; Thalanany et al., 2006). A longitudinal study conducted in the United Kingdom estimated the value of time forgone by family caregivers of patients of all ages ( $n = 107$ ) to be \$100.00 per visit in U.S. dollars (2006 USD) (Thalanany et al., 2006), or \$141.81 Canadian (2016 CAD). Rowell et al. surveyed Australian patients ( $n = 30$ ) and found that the total indirect cost to patients and caregivers was \$24,000 Australian (2006 AUD) on average over the course of a year, or \$66.41 per day (2016 CAD) (Rowell et al., 2011). In a survey of 182 families of patients with dementia, family caregiver costs for patient care were found to be US\$380 (1994 USD)

per week (\$98.17/day [2016 CAD]), of which out-of-pocket costs accounted for 29 per cent and time accounted for 71 per cent (Stommel, Collins, & Given, 1994). A study using the first wave of the National Longitudinal Caregiver Study ( $n = 2,043$ ), whose participants were male veterans with female caregivers, found that value of care time was \$18,385 per year (1998 USD), or \$85.08 (2016 CAD) per day (Moore, Zhu, & Clipp, 2001). A 2012 Canadian telephone survey found that the out-of-pocket costs of palliative care amounted to \$16.98 (2015 CAD) per day and the cost of time was approximately \$133.79 (2016 CAD) per day (Yu, Guerriere, & Coyte, 2015). The average Canadian has a disposable income of \$82.93 per day, so long-term expenses greater than this may represent a significant financial burden (de la Statistique du Québec, n.d.).

Although indirect costs of care for the caregiver have been shown to increase with patients' age and number of co-morbid conditions, Canadian evidence is limited (Moore, Zhu, & Clipp, 2001). This study aimed to quantify and categorize the indirect costs (including the value of time spent and out-of-pocket expenses) incurred by both primary and secondary caregivers of ICU patients age 80 and older from 2009 to 2013 in a large sample from the Realities, Expectations and Attitudes to Life Support Technologies in Intensive Care for Octogenarians (Realistic 80) study.

## Methods

### Data Sources

This study is an analysis of survey data collected as part of the Realistic 80 Study, a national multicenter observational cohort study of octogenarians in the ICU (Heyland, 2011). The goals of the Realistic 80 study were to determine the quality of life, functional status, and survival at 12 months of people over 80 years of age who were admitted to ICUs in Canada. Data were collected from September 2009 to January 2013 from caregivers of patients age 80 or older who were admitted to participating ICUs across Canada. Data on one-year survival and quality of life were collected from 613 family caregivers. Patients who were not Canadian citizens or did not have a permanent address were excluded from the study because of their low likelihood of study completion. Patients who stayed in the ICU for less than 24 hours were also excluded from the study, inasmuch as the exposure of family caregivers to the ICU was minimal.

This study focused on the indirect costs of patient care reported by family caregivers of octogenarian ICU patients from their own perspective. All dollar amounts were reported in 2016 Canadian dollars (Statistics Canada, 2017). Family caregivers were defined as family members and close friends of the ICU patient,

who were caring for the patient while he or she stayed in the ICU. The primary family caregiver – the family caregiver with the most patient contact – filled out the survey in more than 99 per cent of the completed surveys. Secondary family caregivers were defined as any other family member or friend over the age of 18 who was involved in patient care and was listed along with their time commitment by the primary family caregiver (Åstedt-Kurki, Paunonen, & Lehti, 1997).

### Measures

We administered a financial burden survey to consenting primary family caregivers. This survey collected information on the patient's sex, age, and geographic region, as well as the sex, age, and occupation of the primary caregiver and secondary caregivers. Geographic region boundaries were chosen to give approximately equal numbers of patients and caregivers in the three regions: Ontario, British Columbia/Alberta, and Manitoba/Saskatchewan.

The survey also documented self-reported time spent by family members in caring for the patient, time taken off from work, and costs incurred by family members during the first month of their care after admission to the ICU. Care, according to the survey, was defined as

anything (unpaid) done for the patient (new tasks, or tasks that take more time) because the patient is seriously ill or frail. Examples are household chores; yard work; errands such as shopping; banking and paperwork; direct care, including bathing and wound care; arranging and attending appointments; transportation; and time spent in hospital.

The self-reported survey was administered two days after patient admission to the ICU, and caregivers were asked to update it throughout the duration of the patient's ICU stay. The use of self-report to capture direct and indirect health care expenditures is well-documented in the literature and is a useful, feasible technique for this population (Browne, 1992; Markle-Reid et al., 2006; Roberts et al., 1995). The complete survey can be found in Appendix A.

### Analysis

Among the few previous studies that have examined the caregivers' costs of care, many have reported the value of time rather than their out-of-pocket costs (Moore et al., 2001; Thalanany et al., 2006). In order to facilitate comparison with these studies, we valued out-of-pocket costs and time spent caring for the patient separately. We valued the time missed from work for family caregivers on the basis of their stated occupation. We collected two values for each caregiver: the number of hours per week that they provided care for

the patient and the number of hours of work missed in order to provide that care. This amount was valued based on the caregiver's self-reported occupation. We assigned a value of 12 Canadian dollars per hour (2016 CAD) to time missed from housework. This was based on the approximate replacement value of the various tasks that constitute housework as determined by a review of the literature (Colman, 1998; Luxton, 1997; Tranmer, Guerriere, Ungar, & Coyte, 2005).

We grouped occupations according to their Statistics Canada-recognized industry and determined average salaries for self-reported occupations by using Statistics Canada data on the national average salary by industry (Statistics Canada, 2013b). In the event that job title data were missing, we used the mean Canadian hourly rate for Canadians aged 25 and older because the data were recorded in February 2013 (Statistics Canada, 2013a). The indirect costs were reported from two different viewpoints. From the family's perspective, we calculated "per patient" costs by adding all caregiver costs (including primary and secondary) and calculating an average per patient; from the caregiver's perspective, we calculated "per caregiver" costs by adding all caregivers' cost and dividing by the total number of caregivers.

For reported out-of-pocket costs, we classified them into eight categories: gas, parking, meals, travel, accommodation, taxi, phone, and "expenses for patient". We tallied within-category and total out-of-pocket costs and calculated the mean cost per patient. Because we were viewing costs from the caregivers' perspective, if the respondent indicated that their employer compensated them for the time lost, the hours missed from work were excluded from the calculation. Five caregivers out of the 126 had their time excluded based on these criteria. We conducted a sensitivity analysis using simulation to evaluate the effect of this exclusion. Cost data were distributed log normally and were therefore log transformed before analysis.

Applying an analysis of variance (ANOVA), we assessed the significance of the differences between mean out-of-pocket costs and value of caregiver time across different regions (as determined by the ICUs that provided the data), sexes of family caregivers, and ages of family caregivers (separated into age categories). We completed all statistical analyses using SAS 9.3. Research ethics approval for the study was obtained from the Queen's University Health Sciences Research Ethics Board.

### Results

We administered the cost survey to caregivers of 264 of the 613 patients enrolled in the Realistic 80 cohort. Of those caregivers, 164 filled in information regarding

**Table 1: Demographic characteristics of the primary caregivers**

Characteristic	<i>n</i>	%
Age		
Under 50	17	12.1%
50–59	63	45.0%
60–69	21	15.0%
70–79	16	11.4%
Over 80	23	16.4%
Sex		
Male	107	71.8%
Female	42	28.2%
Occupation Status		
Employed	75	59.5%
Retired	47	37.3%
Unemployed	4	3.2%
Relationship		
Spouse/ Partner	45	30.2%
Child	96	64.4%
Other	8	5.4%
Education Level		
High School or below	51	34.2%
College or above	98	65.8%
Region		
West (AB and BC)	40	26.5%
Central (MB and SK)	54	35.8%
Ontario	57	37.7%

**Note.** AB = Alberta, BC = British Columbia, MB = Manitoba, SK = Saskatchewan.

out-of-pocket costs (response rate: 62%), and 126 provided information regarding value of time (response rate: 48%). Primary caregivers were more likely to be male. The largest age category of caregivers was 50 to 59 years old. The most common relationship to the patient was “child”. The majority of primary caregivers were employed and had a college education or higher. An investigation of the possibility of response bias is presented in Appendix B. Table 1 lists caregivers’ demographic information; Table 2 summarizes the key findings related to the value of time spent by caregivers.

Among caregivers who lost time from work to care for the patient, the average time missed per month was found to be 87.2 hours. The mean hours missed from work across all caregivers who responded was 43.7 hours per month. The total cost to caregivers per patient per day was \$161.91 (2016 CAD). To value time, we

conducted a sensitivity analysis using province-level salary by industry data versus national-level salary data and determined that using province-wide data resulted in a decrease in the dollar value of time by 0.4%.

Figure 1 shows the out-of-pocket expenses incurred by family caregivers by category. The most common expense categories were parking, meals, and gas. The categories with the highest average expenses were travel and accommodation. Together, these five categories made up 93 per cent% of out-of-pocket expenses incurred by family caregivers while the patient was in the ICU. The average total cost to family caregivers was \$790.99 (2016 CAD).

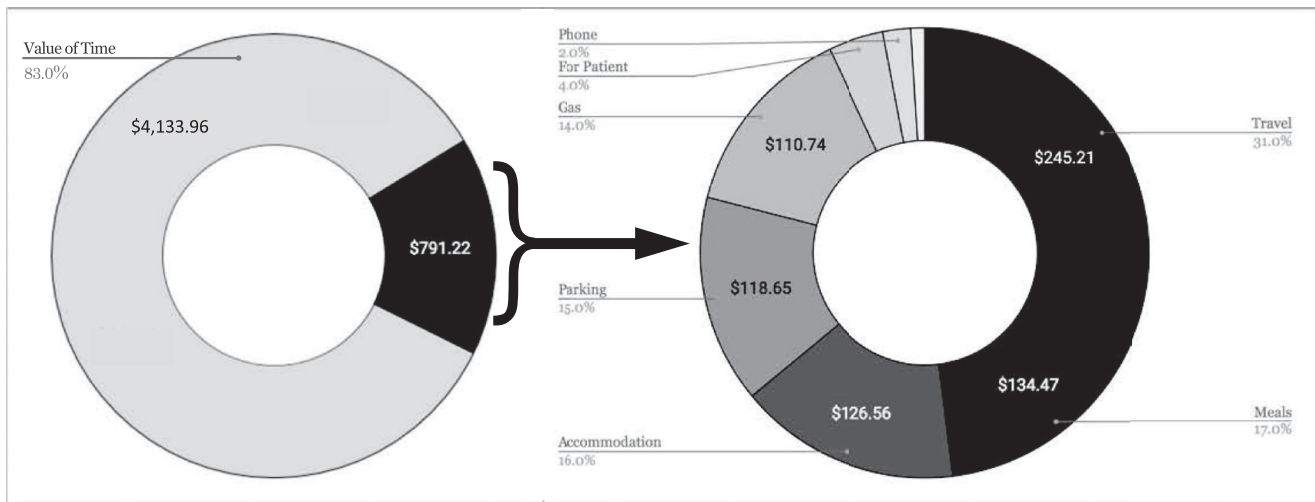
We used ANOVA to determine if out-of-pocket costs and time value varied by region of residence, age of primary caregiver, and sex of primary caregiver. The only significant effect was the sex of the primary caregiver on out-of-pocket costs ( $p = .045$ ). Male primary caregivers showed out-of-pocket costs that were 1.93 times higher than those of female primary caregivers. Age of primary caregiver and region of residence did not result in statistically significant differences on mean out-of-pocket costs. The results of this analysis can be seen in Table 3.

We conducted a probabilistic sensitivity analysis to evaluate the effect of excluding caregiver time if caregivers reported being compensated by their employer ( $n = 5$ ). All of the excluded caregivers were male. Only five caregivers were excluded on the basis of these criteria (of 126). Three were aged 50–59, two were aged 60–69. Three were from Ontario, one from the West region, and one from the Mid region. One of them reported that they were retired; the others reported that they were employed. Three were children of the patient, and two were spouses. All reported having a college-level education or higher. With these data, we simulated the influence that the inclusion of this time would have on our estimate of average value of caregiver time. Average caregiver value of time would be expected to increase by \$36.85 (< 1%) per month (95% CI[-\$710.79, +\$798.35]) based on 100,000 simulated additions of these five people.

**Table 2: Summary of key findings related to value of time spent and out-of-pocket costs**

Cost	<i>n</i>	<i>M</i>	<i>SD</i>
Value of caregiver time (per patient)	126	\$4,133.96	\$4,511.71
Value of caregiver time (per caregiver)	333	\$1,564.20	\$1,658.23
Out-of-pocket costs (per patient)	151	\$791.22	\$1,163.70
Out-of-pocket costs (per caregiver)	151	\$379.00	\$758.76
Hours missed from work (per employed caregiver)	179	87.25	83.00
Hours of care provided (per caregiver)	357	98.74	88.98

**Note.** All values shown are per month spent in the ICU. Costs are reported in 2016 CAD. *M* = mean; *SD* = standard deviation.



**Figure 1: Average expense per month as reported by primary caregivers (by category). Dollar values are reported in 2016 CAD**

**Discussion**

The average caregiver missed 43.7 hours from work and spent 83.7 hours caring for the patient in the month included in this study. The total cost of informal care was found to be \$161.91 (2016 CAD) per day. Of this, \$25.92 (2016 CAD) (16%) was out-of-pocket expenditure, and the remainder, \$135.88 (2016 CAD) (84%), was the value of time. Male caregivers spent significantly more money caring for patients in the ICU than female caregivers did.

The cost of time for caregivers in this study was higher than the costs reported in previous studies wherein the patient population was younger, including among caregivers of patients of all ages in the United Kingdom (\$98.17 Canadian [2016 CAD] per visit) (Thalanany

et al., 2006) and Australia (\$66.41 [2016 CAD] per day) (Rowell et al., 2011), as well as among caregivers of patients with dementia in the United States (\$85.08 [2016 CAD] per day) (Moore et al., 2001). However, Yu et al. derived a similar estimate for time value at \$134 (2016 CAD) per day among caregivers of terminal patients of all ages in Ontario in both hospital and home palliative care (Yu et al., 2015).

A number of plausible explanations exist for the differences among studies. First, higher costs may result from the fact that the patients in this study were older than the patients in any earlier research. Previous studies have indicated that formal spending on care declines with advanced age (Chin-Yee et al., 2017; Shugarman, Decker, & Bercovitz, 2009), so perhaps informal care

**Table 3: Comparison of time value and out-of-pocket costs per patient by region, age category, and sex of primary family caregiver (currency used is 2016 Canadian dollars)**

Group	Out-of-Pocket Costs*			Value of Time Spent*			
	n	M (\$)	SD	n	M (\$)	SD	
<b>Region</b>	BC/AB	40	\$916.61	\$1,314.51	40	\$3,402.76	\$2,652.54
	MB/SK	54	\$898.71	\$1,082.35	45	\$4,887.69	\$5,951.54
	ON	57	\$601.38	\$1,120.80	41	\$4,020.05	\$4,074.44
		<i>p</i> = .164			<i>p</i> = .560		
<b>Age</b>	< 50	16	\$507.99	\$598.82	12	\$5,493.98	\$5,236.71
	50–59	60	\$867.41	\$1,374.70	56	\$3,755.88	\$4,963.17
	60–69	19	\$641.93	\$959.85	18	\$3,597.28	\$3,366.02
	70–79	14	\$826.88	\$1,085.29	14	\$3,147.33	\$3,614.22
	80+	14	\$1,158.57	\$1,602.22	13	\$4,792.93	\$4,031.88
		<i>p</i> = .315			<i>p</i> = .469		
<b>Gender</b>	Male	92	\$957.83	\$1,197.75	85	\$4,699.45	\$5,007.13
	Female	40	\$496.02	\$1,231.33	37	\$3,018.60	\$3,118.69
		<i>p</i> = .045			<i>p</i> = .061		

**Note.** AB = Alberta, BC = British Columbia, MB = Manitoba, ON = Ontario, SK = Saskatchewan.

must increase to compensate. Second, the patients enrolled in this study were likely to be at the end-of-life stage. End-of-life care likely involves great caregiver time commitment and likely increases the number of caregivers who are caring for the patient, which would explain the higher total value of caregiver time. This would be consistent with the similarities found between this study and the results from the Yu et al. (2015) study, which both examined the costs incurred among caregivers of patients at the end of life.

Out-of-pocket costs were similar to those reported in the U.K. dementia study (\$25.92 in 2016 CAD vs. \$28.46 in 2016 CAD per day [Stommel et al., 1994]), but higher than the costs reported by Yu et al. (\$26 in 2016 CAD vs. \$17 in 2016 CAD) (Yu et al., 2015). It makes sense that out-of-pocket costs are similar to previous studies because some of the main cost categories involve travel to see the patient, which is not affected as much by the length of time spent with the patient or the amount of care they may require. Since a proportion of the patients in the Yu et al. study were being cared for at home, the costs of travel would be lower.

This study fills a gap in the literature regarding the financial aspect of caregiver burden for patients at the end of life. Other analyses of the Realistic 80 data have established the direct costs of providing care for this patient group (Chin-Yee et al., 2017), but this study builds on those findings by focusing on indirect costs. The sample size is large compared to previous work in this field: many other studies had sample sizes of fewer than 100 participants.

Furthermore, this study gathered information from multiple ICUs across Canada, which permitted inter-provincial comparisons of caregiver experiences while also increasing the generalizability of the results. In terms of limitations, the survey used did not collect salary information directly, which reduced the accuracy in determining time value. However, classifying time value by occupational industry using relevant salary data available from Statistics Canada helped to mitigate this limitation. Self-reported data introduces greater amounts of missing data and the possibility of recall bias. Efforts were made by the Realistic 80 study to lessen this effect by administering the survey directly after the patient's admission to the ICU. Finally, no information was collected on supplemental medical insurance. If a patient's insurance covered health care aides, the amount of care required from the family could be reduced.

Family caregivers are providing a valuable service by caring for patients aged 80 and older in the ICU. This service could be supported by government programs. The results of this study reveal two potential

avenues for intervention. Programs could target low-cost out-of-pocket expenses, such as parking. One possible intervention towards this expense is expansion of programs which subsidize long-term parking passes for hospitals, such as the programs implemented in Ontario which pay for 50 per cent of parking for visitors staying five days or more, into all geographic regions of Canada (Ferguson, 2016). Alternatively, interventions could target high-cost categories, such as accommodation. Subsidized accommodations near hospitals could help to relieve some of the stress experienced by caregivers of elderly patients in the ICU.

Future studies in this area could assess indirect costs to caregivers once patients leave the ICU. The sex difference seen in this study could also be more carefully studied. It could be that the male primary caregivers in this population had higher disposable incomes than their female counterparts, but this is difficult to assess without directly reported salary data. Explicit questions regarding caregiver income would improve the accuracy of the time valuation; however, because income level tends to be a sensitive topic among survey respondents, this may increase the amount of missing data. Another area that may provide insight is a comparison between ICUs in large urban centres and those in smaller cities, which could improve our understanding of the varying economic impact of this provision of care.

## Conclusions

The results of this study indicate that care for the elderly who are patients in the ICU is associated with substantial time and monetary loss for family caregivers. This study suggests that these losses are greater for the family caregivers of patients over age 80 than for other patient populations as reported in the surveyed literature. When family caregivers are using services, it is important to know what services they are using and when in the patient's care cycle caregivers are experiencing financial burden so that policy implementation and provision of appropriate services can be targeted effectively. This information is crucial for the users of the health care system, and it can also be useful for care providers in efficiently allocating limited health care resources.

## Supplementary Material

To view supplementary material for this article, please visit <https://doi.org/10.1017/S0714980818000387>

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