

SUBSTUDY 9

COSTS OF ACUTE CARE AND HOME CARE SERVICES

**A Report Prepared for the
Health Transition Fund, Health Canada**

April 2001



National Evaluation of the Cost-Effectiveness of Home Care



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PREFACE

The National Evaluation of the Cost-Effectiveness of Home Care is an integrated program of research with 15 studies being conducted across Canada. There is an overall strategy for the program of research to make it as useful to administrators and decision makers as possible. The program of research is designed to determine whether or not home care is a cost-effective alternative to institutional care, that is, care in long term care facilities and acute care hospitals. However, the program of research is also designed to provide an educational function to inform decision makers and the public about home care, and to provide advice about issues related to implementing new and cost-effective home care initiatives. Thus, the overall strategy has the following components:

- Conduct studies to determine whether or not home care is a cost-effective alternative to institutional care, and if so, under what conditions it is cost-effective.
- Conduct studies to inform decision makers about the nature and scope of home care services across Canada. These studies provide a baseline of information about home care clients, costs, and utilization. This baseline is important because there is currently no national database on home care in Canada.
- Conduct studies to explore opportunities for potential savings in the hospital sector by substituting home care services. At present, there are relatively few areas noted in the literature where home care has been shown to be a cost-effective alternative to hospital care.
- Conduct studies to provide decision makers with information about some of the issues they may face if they try to implement new initiatives to enhance the cost-effectiveness of the health care system.

This study, *Substudy 9* provides an examination of the cost of home care relative to hospital inpatient care, in a cross-diagnosis study. It provides a cross sectional view of the types of episodes within which home care is provided and isolates the net effect of home care on total episodic costs. It also identifies important determinants of home care, most notably case severity.

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EXECUTIVE SUMMARY

A number of studies have been conducted to determine the cost and effectiveness of home care in connection with acute care hospitalization. Recent reviews of the literature have concluded that the results are mixed, with home care plus hospitalization being less costly than hospitalization alone in some diagnosis, but more costly in others. The patient's condition, measured by primary diagnosis, was identified as a possible determinant of home care cost-effectiveness. We conducted an observational study, using Alberta provincial data for 1996 through 1998, to determine whether cases with home care were more or less costly than cases without home care. Our analysis was conducted on a Case Mix Group (CMG) by CMG basis. We excluded inter-hospital transfer cases, which would bias the results in some CMGs. Using non-transfer cases, and CMGs with high volumes of home care cases we determined the proportion of cases within individual CMGs which had home care, and the hospital and home care cost components for these cases. In virtually all study CMGs, cases with home care were more costly than those without home care.

We further studied the CMGs to determine whether home care cases were similar to cases without home care. For each study CMG, we analyzed the number of diagnoses per case, which served as a severity index. In virtually all CMGs, CMGs, cases with home care had more diagnoses than did cases in the same CMG without home care. This indicates that CMGs with home care have a higher degree of severity than those without. Our results imply that case severity is an important indicator of home care assignment. Under real-world conditions, that is, those in charge of allocating acute care patients to home care have deemed more severe patients to have a greater "need" for these services.

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1. INTRODUCTION

Home care is defined as health care which is provided by an organized or professional group, and delivered in the patient's home (Hollander, 1995). In Canada, home care is an additional health benefit, provided at the discretion of provincial governments, rather than as "insured health services," which are federally mandated, medically necessary (as stipulated by the federal government) hospital and physician services provided by the provincial governments. There are several different uses for home care; these are the provision of maintenance and preventive services including palliative care, and of episodic acute care. Potentially, acute home care can serve as a substitute for days of care at the end of an acute care hospital stay. If the home care portion of the acute treatment episode costs less than the marginal costs of the reduced days, then savings will result (Jacobs et al., 1993).

Home care following acute care can be used for a variety of purposes. Nursing services can be used to assist those individuals who have temporary limitations on functional activity, or to provide medications. The Saskatchewan observational study (HSURC, 1998) identified musculoskeletal conditions, female reproductive conditions, digestive conditions and circulatory conditions as those with the greatest frequency. Soderstrom et al. (1999) also mentioned chronic obstructive pulmonary disease.

With the introduction of health reform in Alberta in 1994, hospital and professional home care organizations were merged into a single entity, the Regional Health Authority (RHA). One of the prime justifications for this policy change was that it would be easier to achieve rational planning, thus making it easier to achieve economies of scope in acute care. Economies of scope refer to the efficiency of production of different types of services within an organization; when joint production costs of home care and acute care are less under one production unit than they are when produced in separate units, then economies of scope are realized.

One of the difficulties in analyzing issues relating to the economies of product scope (in acute inpatient / home care substitution) is the absence of a classification system which includes both inpatient home care and acute home care. In Canada the Case Mix Group (CMG) classification system, maintained by the Canadian Institute for Health Information (CIHI) is used for funding and planning purposes. There is no such system for home care cases in Canada, although one has been developed for home care funding by Medicare in the United States. Currently we have no information on how the two components of care might be cross-classified in a single episode. The CMG potentially can be used as a concept to analyze both types of services together – that is, an acute inpatient care / short term home care episode.

A second issue deals with inter – hospital transfers. Recent health policy goals have emphasized the provision of care closer to home. This may mean transferring patients from higher to level facilities once they have been stabilized. Of course, a transfer may also be to a higher level facility for more specialized care. In either case, the transfer implies that we must include all hospitalizations in order to capture the full cost of the treatment of the episode of care. In this report, we explicitly recognize the issue of dealing with transfers.

In this study we examine the issue of whether an acute care episode with home care costs less than such an episode without home care, for specific diagnostic groups. Using post-health reform data from the province of Alberta for 1997/8, we analysed the cost of acute care episodes, defined as the

admission to hospital for an acute condition until discharge home, through either the hospital or home care. The hypothesis which we tested was that home care will not result in cost savings. We examined a wide variety of individual diagnoses to determine whether this hypothesis held for separate types of care.

2. LITERATURE REVIEW

Several authors have reviewed home care / acute care substitution in a Canadian context (Hollander, 1995; HSURC, 1998; Soderstrom et al., 1999). Soderstrom et al. (1999) conducted a review of those studies which compared home care and no home care following acute care. Referring only to those studies which were judged to be of high quality, the authors concluded that the economic impact of home care will vary by patients' conditions. Home care reduced system-wide costs for hip fractures in a number of studies. For other diagnoses, however (e.g., hip replacement, chronic obstructive pulmonary disease, hysterectomy and knee replacement) home care was associated with higher costs. The authors concluded that home care may be more appropriate for some conditions than for others. The review by Soderstrom et al. underscores the relevance of diagnoses in understanding the economic role of home care.

3. METHOD

3.1 Definitions

Hospitalization refers to an admission for inpatient acute care lasting one day or more. Admissions are also called hospital encounters. A *transfer* refers to a single patient being discharged from one hospital and admitted to another in the same day. *Short term home care* refers to the provision of active acute care in the home. An episode is a set of contiguous inpatient and home care contacts. A contact is also called a visit or home care encounter. A Case Mix Group (CMG) is a classification system which categorizes hospitalizations into groups which use approximately equal amounts of resources. A *resource intensity weight* (RIW) is an index number which measures the relative cost of a CMG.

3.2 Subjects

Subjects for analysis included all Alberta residents who were hospitalized for acute care in the 1996/7 and 1997/8 fiscal years in Alberta hospitals. The following cases were excluded: persons transferred from or to long term care facilities and persons who were discharged to home care for reasons other than receiving short term acute care.

3.3 Data

We used data from the inpatient discharge abstracts of the Canadian Institute for Health Information; these contain data on all hospital discharges including a scrambled unique patient identifier, dates of admission and discharge, coded diagnoses, Case Mix Group and Resource Intensity Weight or RIW (CIHI, 1998). Home care services were obtained from the Alberta Health Home Care Information System, which included the scrambled identifier, service hours by type of service, dates and cost of

service. Cost was based on standard salary costs and supplies. Hospital costs were based on an average provincial per weighted day cost, based on the RIWs, for all hospitals in the province. We estimated costs on a CMG-weighted per diem basis in order to capture length of stay effects.

3.4 Acute Care Episodes

An acute care episode is defined as a set of contiguous inpatient and home care contacts. Two hospital encounters for a single person from different institutions with a discharge and admission on the same day (a transfer) were considered to be in the same episode. A first home care visit which followed a hospital discharge by the same person within 15 days was considered to be in the same acute care episode as the hospitalization. An entire home care episode was taken to last no more than 60 days.

Each episode was assigned to the CMG of the hospitalization. If an episode had two or more hospital admissions, we assigned that episode to that CMG with the highest resource intensity weight (RIW) over all of the hospitalizations in the episode. This was called the “high CMG.”

3.5 Analysis

Data was analyzed by high CMG. Episodes with inter-hospital transfers were analyzed and subsequently excluded; thus for the final analysis we retained cases without transfers, with and without home care services. Case mix groups with less than 50 home care cases were subsequently excluded on the grounds that volumes were insufficient to yield significant conclusions. We placed all cases in the remaining CMGs into two groups: those who did receive home care, and those who did not. The mean cost was estimated for each CMG for the home care, and the no-home care, categories. A comparative analysis was conducted by CMG. In addition, case severity for home care and no-home care cases was analyzed within each CMG. Case severity was measured by the number of recorded diagnoses per case.

4. RESULTS

4.1 General Data

In total there were 516,694 episodes of care, within 583 different Case Mix Groups. The distribution of cases according to whether they received home care, and were transferred, is shown in Table 1. About 3 per cent of all episodes contained an inter-hospital transfer, and about 2.82 per cent of all episodes contained a home care encounter. The frequency of home care encounters within individual CMGs is shown in Table 2. In 23 CMGs there were over 100 home care cases, while in 423 CMGs there were less than 25 home care cases. In Figure 1 we show the distribution of CMGs according to the number of cases within each CMG which received home care. As seen in this figure, and in Table 2, 74 CMGs contained more than 50 home care cases.

In Table 3 we show the frequency of transfer cases within individual CMGs. In Figure 2 we show the distribution of transfer cases within CMGs. In 34 CMGs there were more than 100 transfer cases, while in 413 CMGs there were fewer than 25.

Table 1: Distribution of episodes by transfer and Home care

Category	Frequency	Per cent
Received home care and was transferred	1,349	0.26%
Received home care but was not transferred	13,347	2.56%
Did not receive home care and was transferred	14,072	2.72%
Did not receive home care and was not transferred	475,548	92.03%
Missing	12,378	2.39%
Total, all episodes	516,694	100.00%

Table 2: Frequency of home care cases within individual CMGs

Category	Number of CMGs
More than 100 cases within CMG	23
Between 50 and 99 cases within CMG	41
Between 25 and 49 cases within CMG	96
Less than 25 cases within CMG	423
Missing data	1
Total	583

Table 3: Frequency of transfer cases within individual CMGs

Category	Number of CMGs
More than 100 cases within CMG	34
Between 50 and 99 cases within CMG	43
Between 25 and 49 cases within CMG	70
Less than 25 cases within CMG	413
Total	560

Figure 1: Distribution of Home Care Cases by Case Mix Group

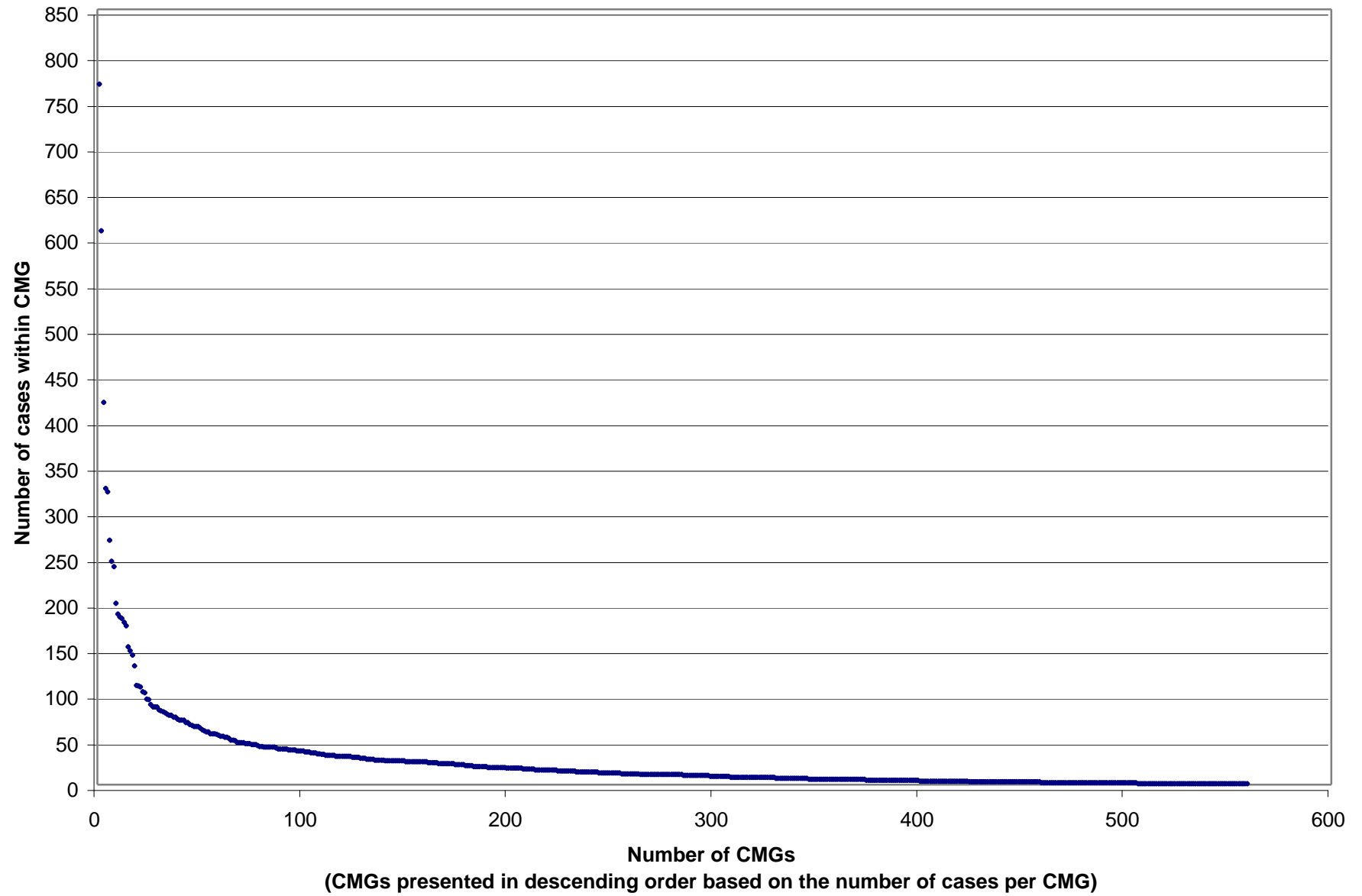
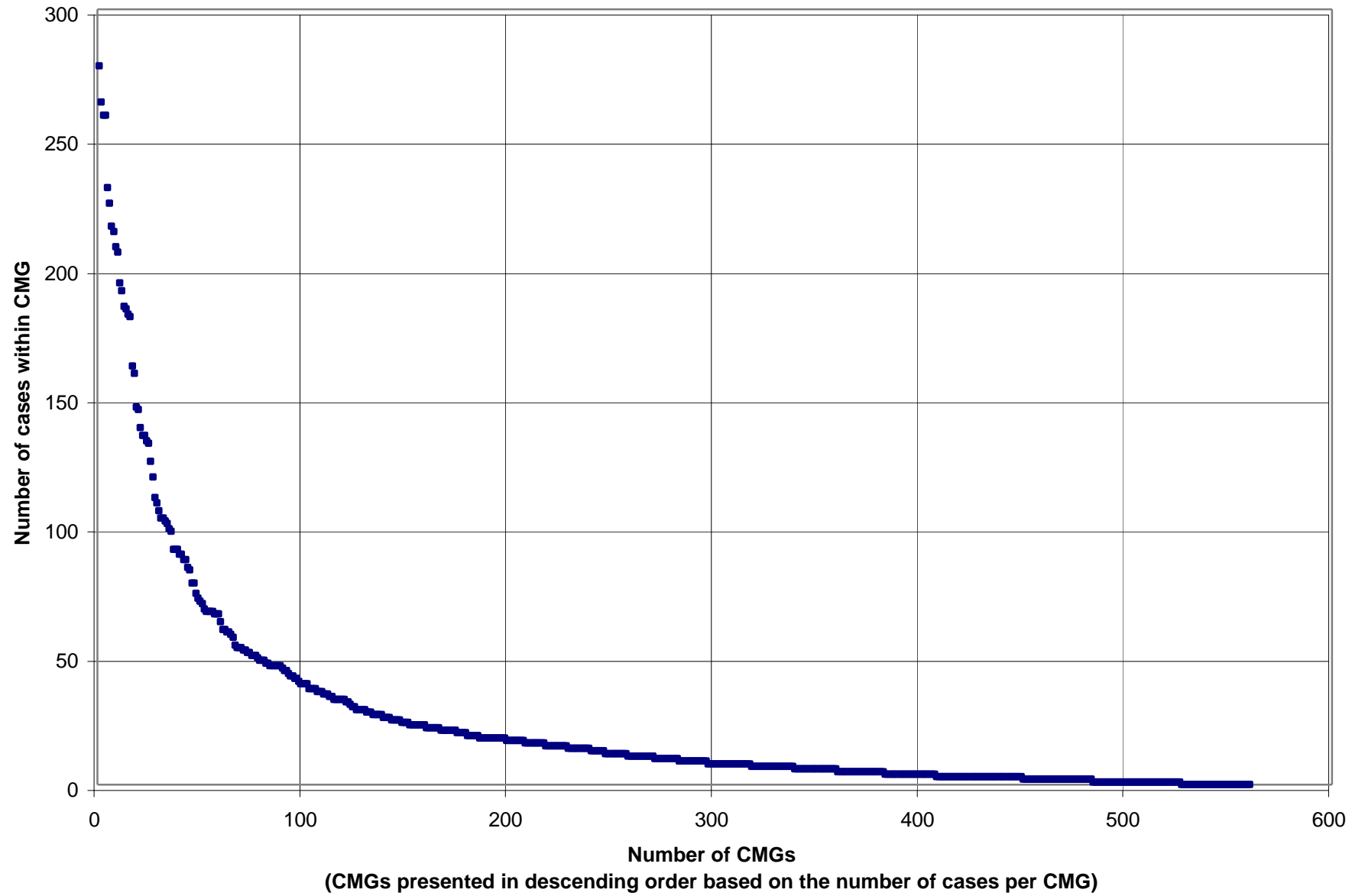


Figure 2: Distribution of Transfer Cases by Case Mix Group



4.2 Inter-Hospital Transfers and Costs

Inter – hospital transfers are an important component of some CMGs. In Figure 3 we show the distribution of CMGs according to the per cent of transfers within each CMG. In about 25 different CMGs there are more than 20 per cent of all cases which are transfers. In Table 4 we show the mean episodic cost for cases with and without transfers, for those CMGs with over 100 transfer cases and within which over 15 per cent of all cases in the CMG are transfers.

In general, cases with transfers cost about 1.75 times those without transfers. Thus if 20 per cent of all cases within a CMG are transfers, the average cost for all cases within that CMG (with and without transfers) would be 15 per cent more than the cost of a CMG without a transfer. If ten per cent of all cases were transfers, the average cost of all cases (with and without transfers) would increase by 7% if we took account of the transfers.

In Table 4 we present the mean cost per episode for CMGs with both large numbers (>100) and a large proportion (>15 per cent) of transferred cases. For cardiac catheterizations (CMG 217) there were 111 transfers, representing 22.9 per cent of all cases within the CMG. As can be seen, the mean cost for transferred cases was \$8,544 compared with \$3,593 for non-transferred cases. For this group of CMGs, transfer cases play a significant role in determining the cost of an episode of care.

Because transfers can significantly effect the cost of an episode, we will subsequently only analyze those home care cases without transfers.

4.3 Which CMGs Use Home Care?

There is a wide variation among CMGs in terms of the use of home care cases. In Figure 4 we show the distribution of the per cent of home care cases, in terms of all cases, by CMG. In about 50 CMGs there were at least 17 per cent of all cases receiving some home care services. On the other hand, 413 CMGs had less than 25 cases which received home care.

In Table 5 we show the distribution of high volume – home care cases by major diagnosis group. We define high volume cases according to the number of cases within each CMG; in this case, we chose the top fifty CMGs. The CMGs with the greatest volume of home care cases were in the musculo-skeletal major group, followed by the cardiovascular / circulatory system group. These conditions reflect a loss of client function of activities of daily living such as mobility, dressing, and bathing which can benefit from professional home care.

4.4 Home Care Episode Costs

For all cases, the average cost of the entire episode of care, including both the hospital and home care components, was \$5,386 (SD, \$5,739). The hospital component accounted for \$5,111 (SD, \$5,680). The average cost of an episode of home care for patients who received home care, but were not transferred is \$275. There was a wide variation, with a standard deviation of \$513 (See Table 6). When we summarize the data by CMG, as in Figure 5, we note that there are a small number of CMGs with home care costs between \$600 and \$1,350 per episode. In the top 50 CMGs (ranked by average home care cost per case), home care costs were in excess of \$450.

Figure 3: Per Cent of Cases with Transfers within CMGs

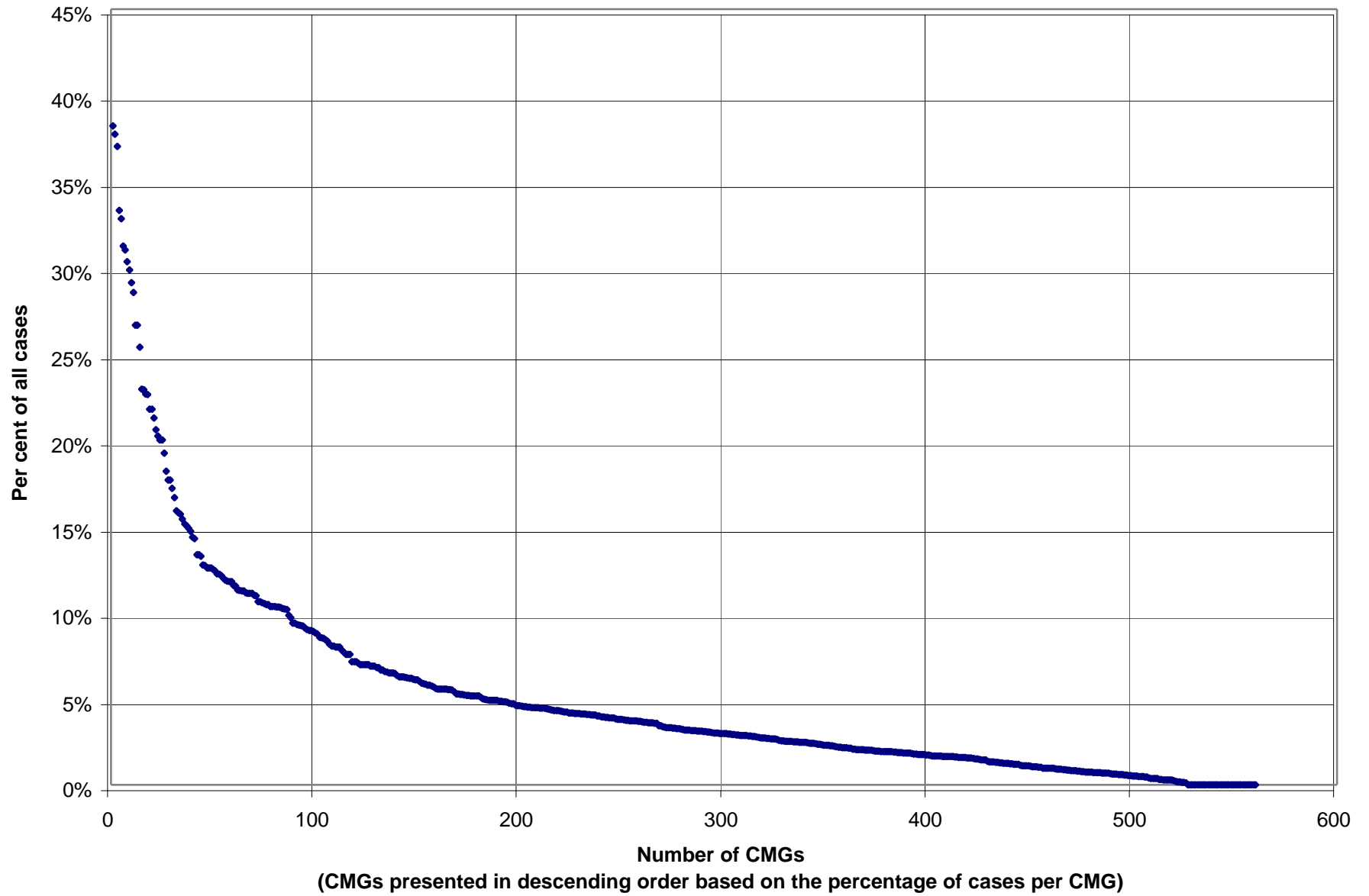


Table 4: Case mix groups with a high proportion and total number of transfer cases (based on High-CMG cases with >100 transfer cases and >15% of cases within the CMG which were Transferred)and episodic costs

Case mix number	Identification	Total transfer cases	Per cent of all cases which are transfer cases	Mean cost of episodes with transfer	Mean cost of episodes without transfer
217	Cardiac catheterization with unstable angina	111	22.9%	\$8,544	3,593
204	Acute myocardial infarction no special cardiac complications	125	22.6%	\$9,832	\$6,200
230	Artherosclerosis age > 70 without complications and comorbidities or age < 70 with complications and comorbidities	109	21.2%	\$7,797	\$2,340
229	Artherosclerosis age > 70 with complications or comorbidities	264	19.2%	\$7,316	\$2,634
179	Coronary bypass with pump but no catheter and with complications and comorbidities	225	17.7%	\$16,005	\$9,724
188	PTCA with complicating cardiac conditions	231	17.7%	\$8,242	\$7,409
356	Fractured femur procedures with complications or comorbidities	103	15.7%	\$13,355	\$5,224

Figure 4: Per Cent of Cases with Home Care within CMGs

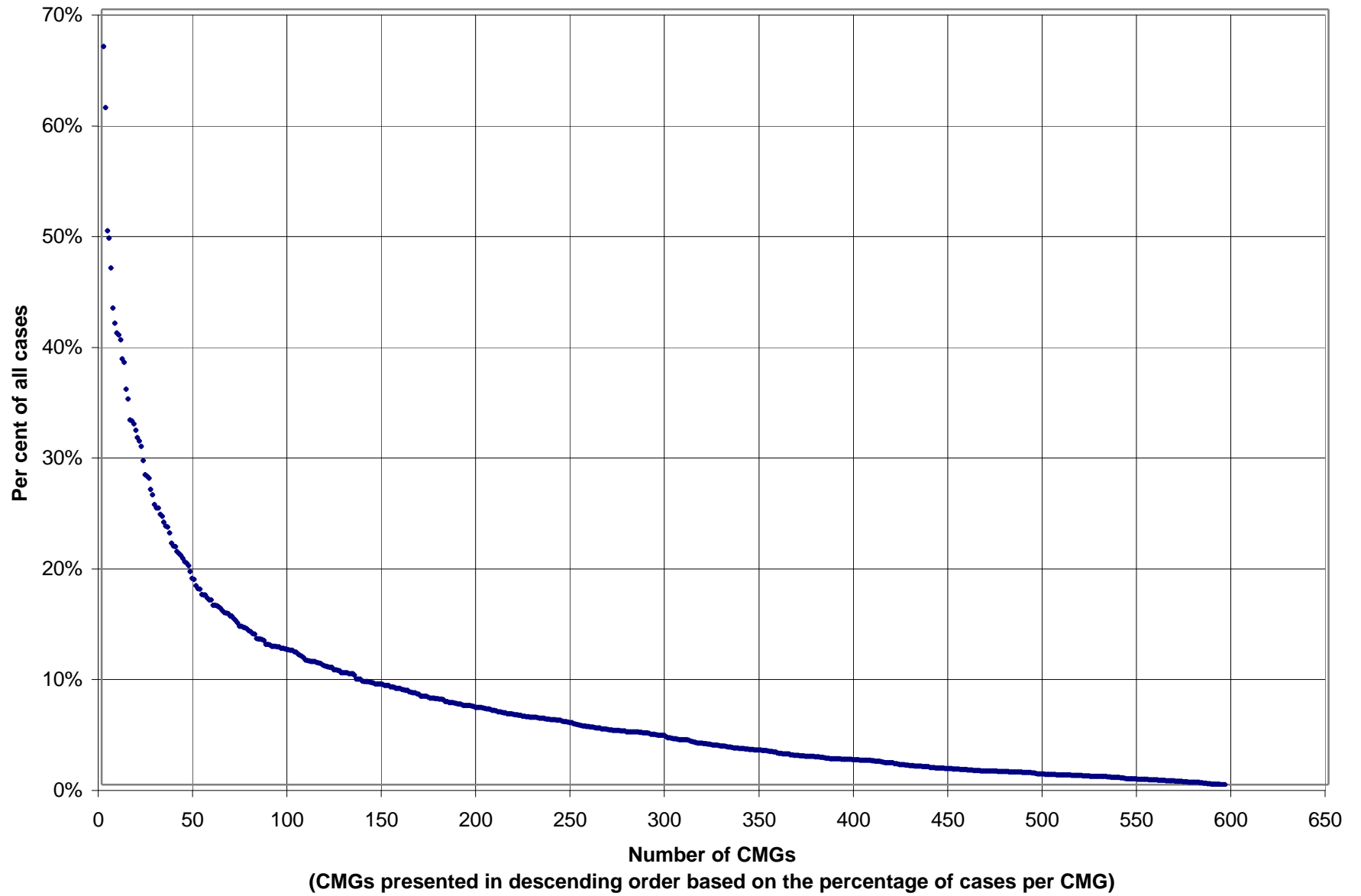


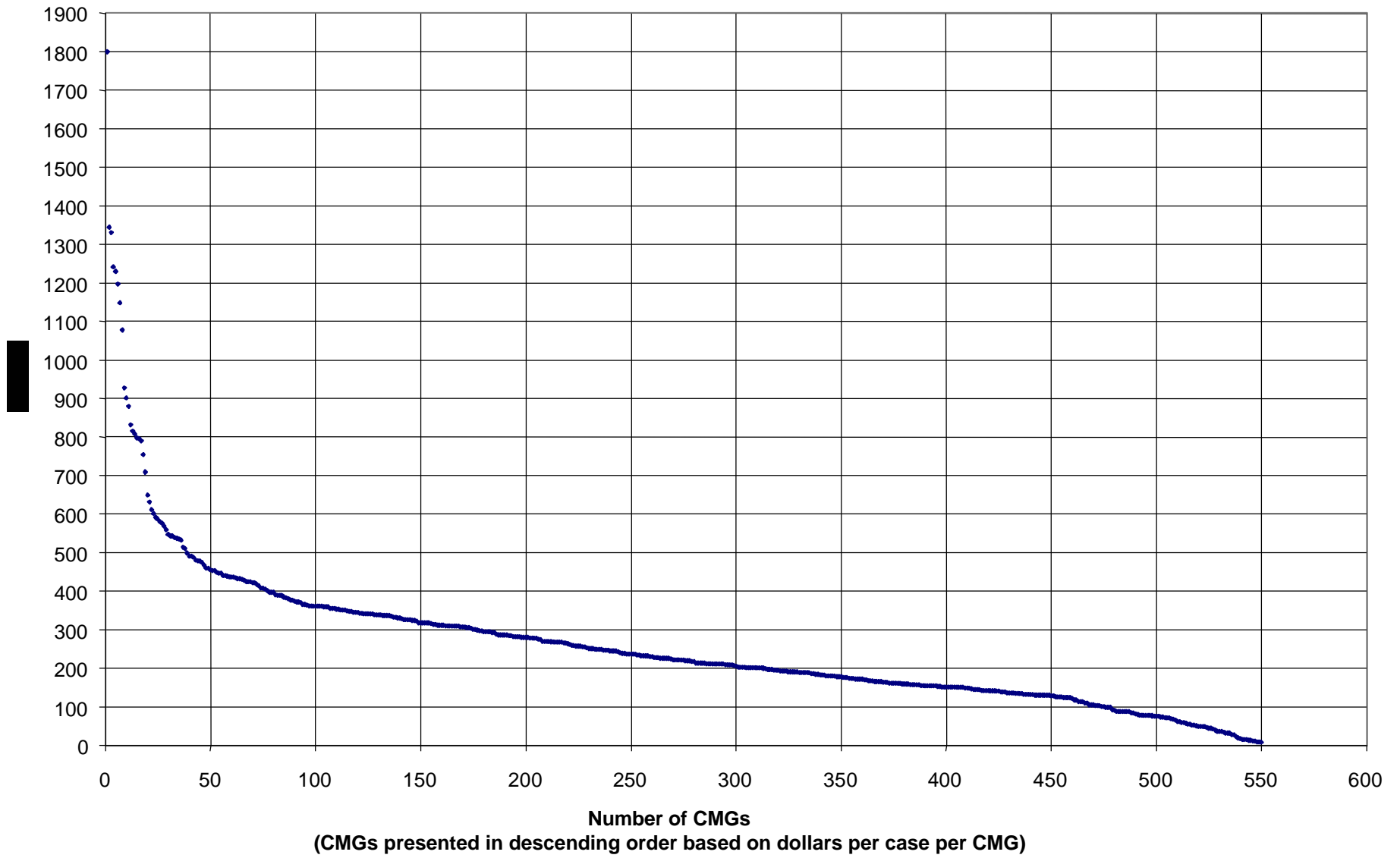
Table 5: Distribution of cases within major diagnostic groupings Tot fifty CMGs according to number of home care cases

Major grouping	Per cent of all cases
Muskulo-skeletal system	22.6%
Cardiovascular system / circulatory system	13%
Digestive system	11%
Skin a subcutaneous tissue	9.2%
Genito-urinary system	8.3%
Malignancy - breast	7%
Gynecological disorders	5.6%
Infections	5%
Diagnostics / treatment / others	4%

Table 6: Cost per episode (standard deviation) For cases without transfers Cases with and without home care

	Cost (standard deviation) of home care	Cost (standard deviation) of hospitalization	Total cost (standard deviation) of episode
Cases with home care	\$275 (513)	\$5,111 (5,680)	\$5,386 (5,739)
Cases without home care	---	\$2,310 (19,375)	\$2,310 (19,375)

Figure 5: Home Care Costs by CMG



Home care costs make up about 5 per cent of the total cost of the episode, but there is a wide variation between CMGs. The variation of the percentage of home care to hospital care costs is shown in Figure 6. In the top fifty CMGs (in this category), home care expenses were 16 per cent or more of the hospital costs, or 14 per cent or more of the cost of the entire episode.

4.5 Costs of Episodes with and without Home Care

In Figure 7 we plotted the episodic costs for cases within a CMG with home care against those costs within the same CMGs without home care. Each point represents a separate CMG. On the vertical axis we measure the cost per episode for those cases in the CMG without home care, and along the horizontal axis we measure the episodic cost for those cases with home care. For example, the Rehabilitation CMG, identified by name in Figure 7, indicates that episodic costs without home care cost about \$12,000; those cases in the same CMG with home care cost about \$10,700.

As an aide to interpreting these results, we have drawn a 45 degree line from the zero axis. All points on this line indicate that, for the given CMG, episodic costs are equal. For points above the 45 degree line, episodes without home care were more costly than those with home care. For points below the 45 degree line, the episodic cost with home care is greater than the costs without home care.

The data in Figure 7 indicate that, for most CMGs, the cost per episode with home care is more expensive than the cost with home careout. Indeed, on average, the cost for episodes with home care are almost twice those without home care. In only a few instances, notably rehabilitation, bypass surgery, and valve replacement, are cases without home care more costly than those with home care.

4.6 Severity of Cases by CMG

In Figure 8 we present the results of our within-CMG analyses of case severity. Each point represents a CMG. Along the vertical axis, we present the mean number of recorded diagnoses per case, for those CMGs which used home care. On the horizontal axis we present the number of diagnoses per case for those cases without home care. If the point represented by any CMG falls along the 45 degree line, those cases with home care, have equal severity. For points above the line, those which used home care have fewer reported diagnoses than those which did not use home care. For those cases below the line, those which used home care have more reported diagnoses than those which did not. The majority of CMGs observed (high home care – volume CMGs) fall below the 45 degree line, indicating that for most CMGs, home care cases have more recorded diagnoses than those cases which do not use home care. Within most CMGS, home care cases have a greater severity than cases which do not use home care.

5. DISCUSSION

5.1 Overview

In this project we analyzed the cost of a home care episode of care, beginning with the first hospital admission and ending with discharge, from either hospital or home care. We used the CMG as the unit of observation. Following examination, we subsequently excluded transfer cases from our analysis because their inclusion would provide a biased view of the hospital component. We further excluded in our analysis only those cases with an insufficient number of home care cases, in order to avoid erratic results.

Figure 6: Home Care Expenses as a Percent of Hospital Expenses, by CMG

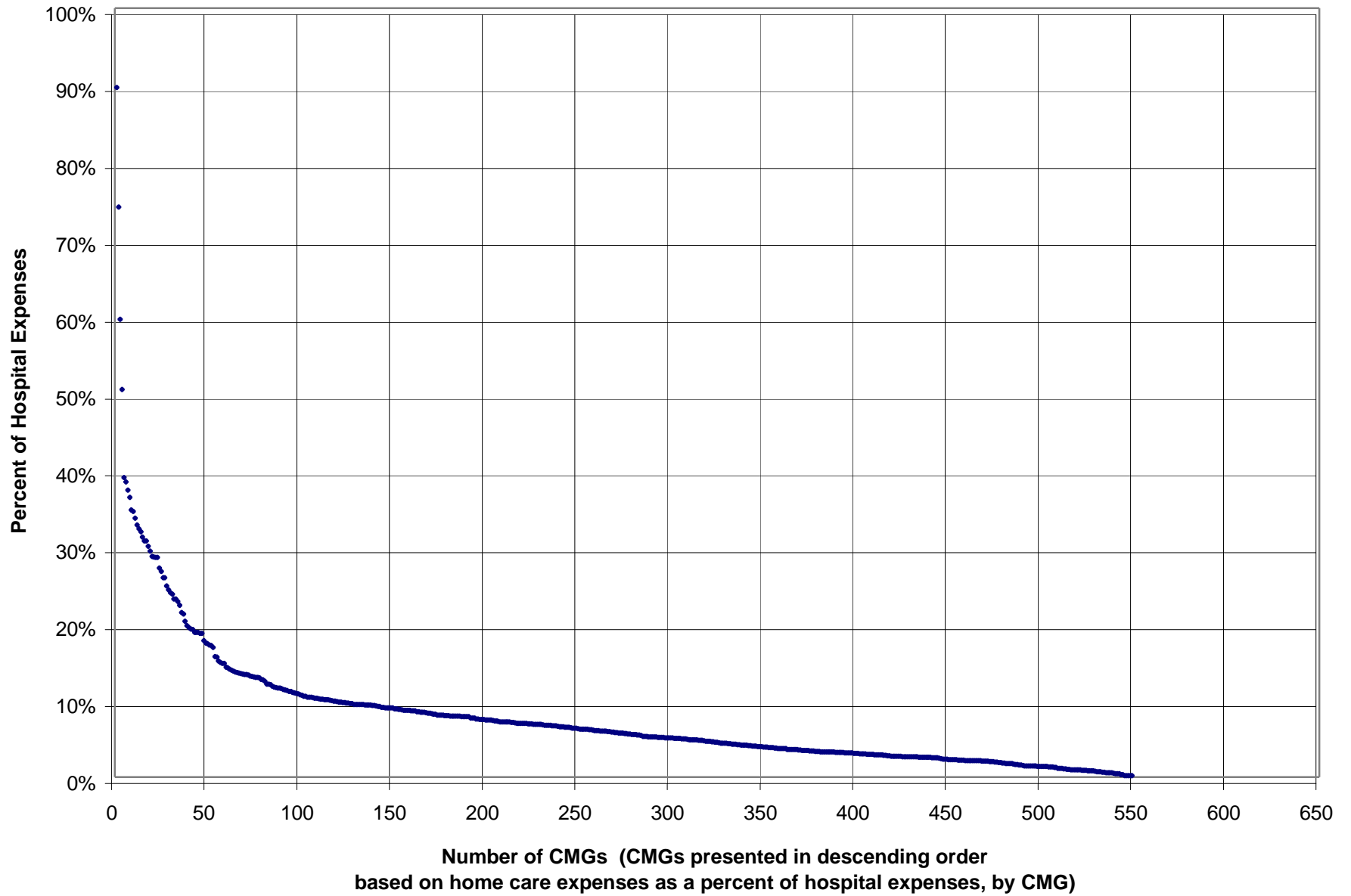


Figure 7: Comparison of Cost per Episode by CMG for CMGs with Most Home Care Cases by Cases with and without Home Care (No Transfers)

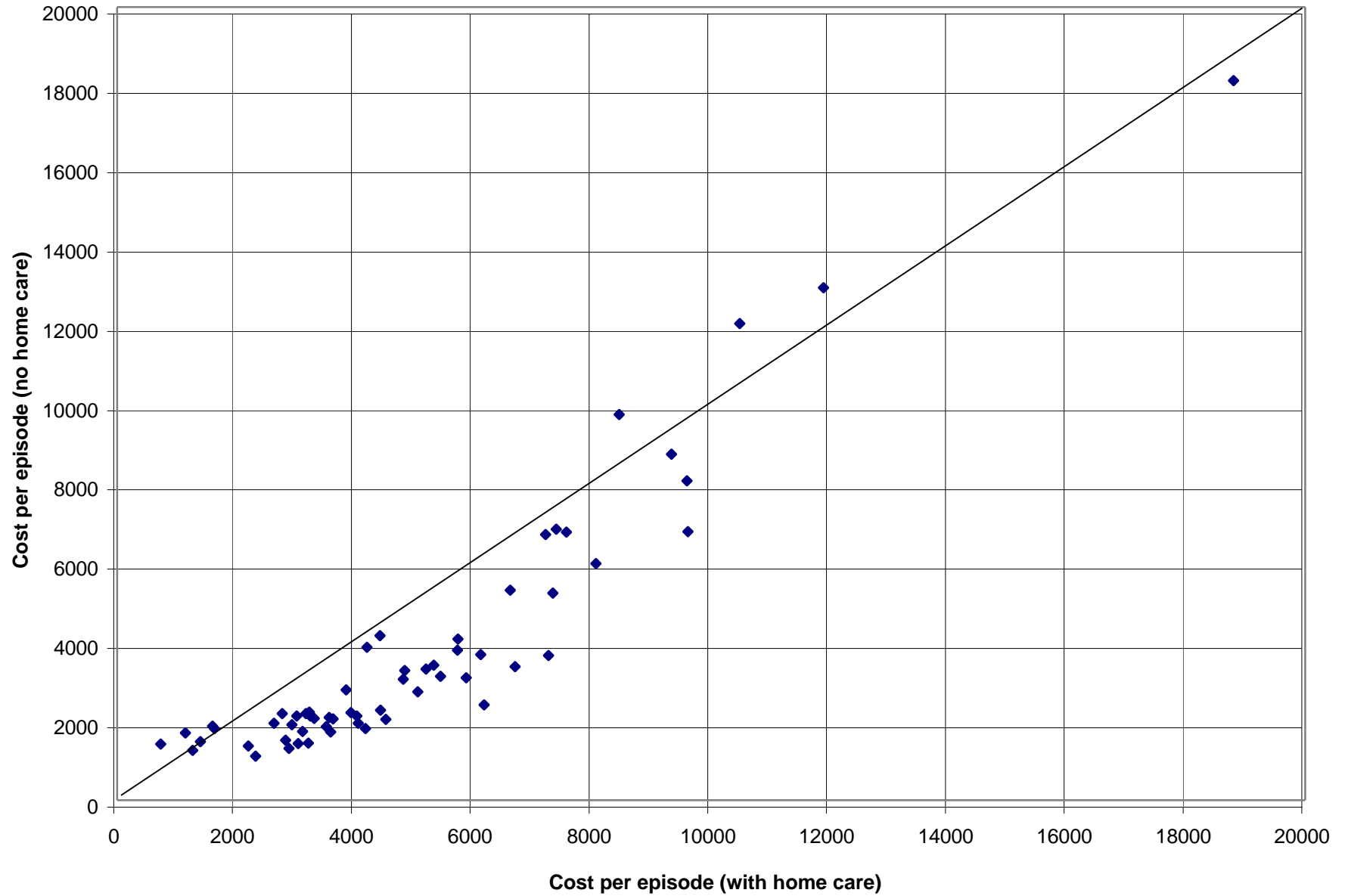
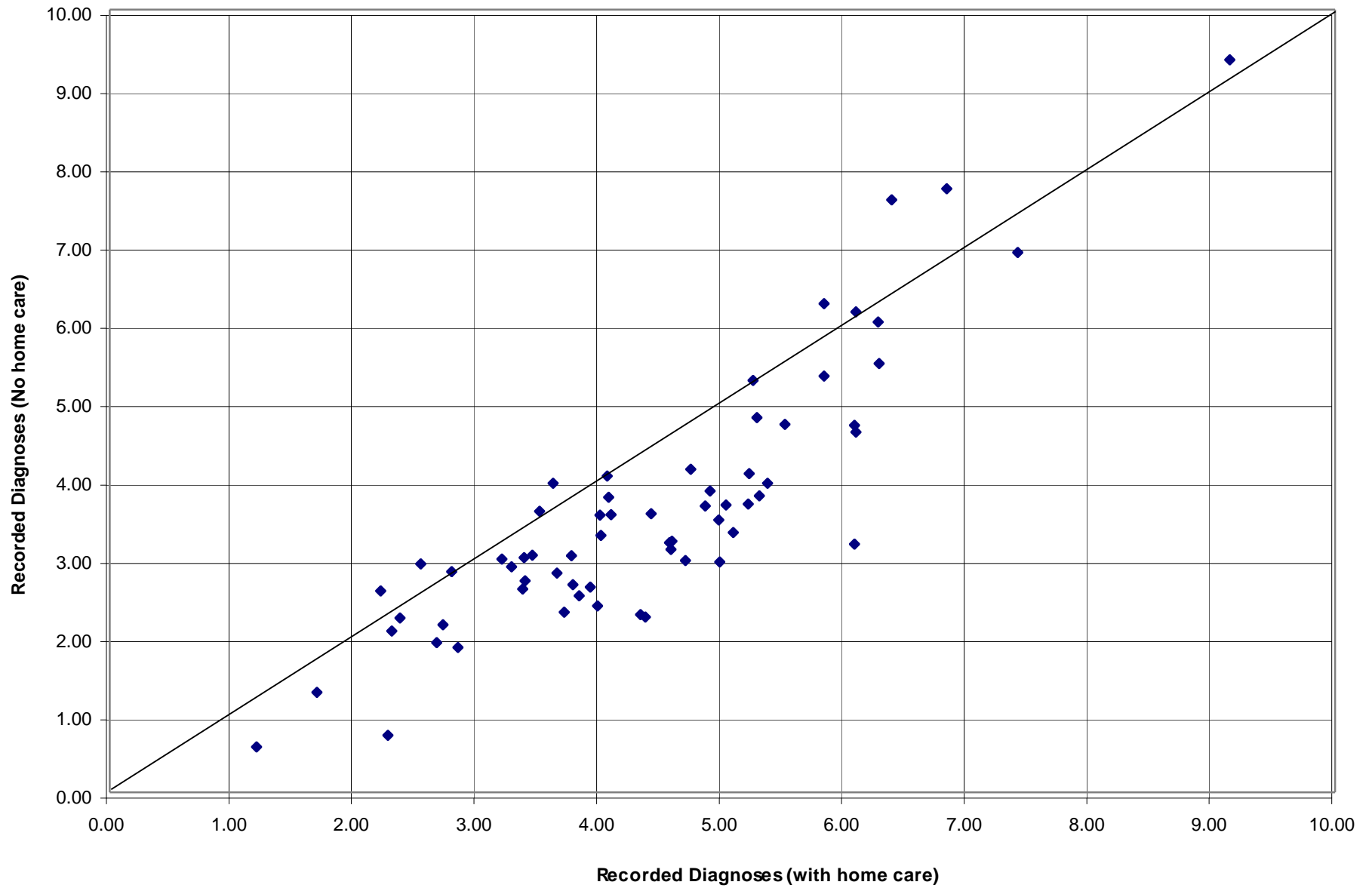


Figure 8: Number of Recorded Diagnoses per Case with and without Use of Home Care, by CMG



Our results indicated that those conditions with the highest number of home care cases were in the musculo-skeletal, cardiovascular, digestive, and skin and tissue groups. For those cases with home care, about five per cent of the cost of the episode was due to home care costs. However, there were a number of CMGs whose ratio of home care to total expenses exceeded ten per cent. Within most CMGs, cases with home care were more costly than those without home care. However, this should not be interpreted as meaning that home care does not efficiently substitute for inpatient acute care. We conducted a sub analysis, CMG by CMG, on the number of diagnoses which were recorded for each case in the hospital discharge abstract summary. For virtually all CMGs, the number of recorded diagnoses was greater for those cases which received home care. We concluded from this that home care episodes are more costly because they have a higher degree of severity.

Our results can be compared with those in the literature. The general findings, based on the three Canadian literature reviews, was that the cost-effectiveness of home care as a substitute for acute care was not proven. Soderstrom et al., basing their analysis on the highest quality reports, indicated that these results will vary according to the patient's primary condition. Our results indicate that case severity is a major contributor to the allocation of cases to home care.

One shortcoming of our study was the absence of an adequate predictor for home care resource intensity. A second was an inadequate predictor for resource intensity for an episode. CMGs are not good predictors of resource use, and must be supplemented by additional considerations such as case mix severity

These findings have an important implication for the design of studies which compare home care versus no-home care cases in acute care settings. Such studies should focus on the more severe cases within a diagnosis, because the less severe cases would be less likely to use home care.

5.2 Omitted Costs Incurred in the Home

Our analysis focused on provincially – provided professional services. Persons who incur health-related costs at home use a much wider variety of services. We conducted a sub-study in which we identified those services which would be used in a home setting. The results of this substudy are contained in Appendix 2, "Personal costs of palliative home care." In this study, we interviewed palliative care patients, caregivers and providers and compiled a list of services which are paid for privately. Using this list, we conducted a cluster analysis to develop categories of services. These categories included travel and communications, financial losses, personal services, consumable supplies, and durable supplies. Using this list as a base, analyses can be conducted to identify the magnitude of these costs in different settings.

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APPENDIX A:

Description of CMGs with Most Home Care Cases

DESCRIPTION OF CMGS WITH MOST HOME CARE CASES		
CMG	DESCRIPTION	HOME CARE CASES
354	KNEE REPLACEMENT	768
352	HIP REPLACEMENT CC	607
179	COR BYPASS W PUMP NO CATH CC	419
253	MAJOR INTEST/RECTAL PROC CC	325
510	TRANSURETH PROSTATECTOMY CC	321
429	TOT MASTECT (MALIG), <70 NOCC	268
251	GASTROSTOMY & COLOSTOMY PROC	245
222	HEART FAILURE AGE > 70 CC	239
13	SPEC CEREBROVASC DISORD(XTIA)	199
353	HIP REPLACEMENT NO CC	187
579	MAJ GYN PROC,UT/AD(NOMAL),>50	184
756	POST-OP AND POST-TRAUM INFECT	182
432	SBTOT MAST/BRST PR(MALIG)NOCC	178
581	GYN RECONSTRUCTIVE PROCEDURES	174
143	INTERSTITIAL DISEASE CC	151
294	ESPHG/GSTRO/MSD DGSTV,<70NOCC	147
177	CRD VLV REP W PUMP NO CATH	142
750	MULTISYS/UNSPEC SITE INF,SURG	130
804	OTH PR.(TRAUMA),<70CC/>70NOCC	109
136	CHR OBSTRUCTIVE PULMONARY DIS	108
483	DIABETES, AGE <35	107
356	FRACTURED FEMUR PROCEDURES CC	102
447	CELLULITIS, AGE <18 NOCC	101
357	FRACTURED FEMUR PROC NOCC	94
365	BACK/NECK PROC NO FUSION > 65	93
502	RADICAL PROSTATECTOMY	88
237	ARRHYTHMIA AGE > 70 CC	85
371	MAJ LOWER EXTRM PR,AGE<70NOCC	85
484	DIABETES, AGE >35	85
846	AFTERCARE FOLLOW SURGERY/TX	82
14	TIA & PRECEREBRAL OCCLUSIONS	81
178	COR BYPASS W PUMP W CARD CATH	80
803	OTH PROC FOR TRAUMA, <70 NOCC	79
511	TRANSURETH PROSTATECTOMY NOCC	77
142	INTERSTITIAL DISEASE NOCC	76
370	MAJ LOW EXT PR,>70NOCC /<70CC	76
427	SKGR&WND DB FOR SKN ULC/CELLU	74
512	OTH TRANSURETHRAL PROC/BX CC	74
140	SMP PNMN/PLRY,18-69CC/>70NOCC	72
141	SMPL PNEUMON/PLRSY, AGE>70 CC	71
358	LOW EXTREMITY PROC W INFECT	71
504	MAJOR URINARY TRACT PROC	71
377	WND DEBRID/SK GRF FOR MS DIS	68
841	REHABILITATION	68
818	COMPL OF TRTMENT, AGE<18 NOCC	66
375	MINOR UPPER EXTREMITY PROC	65
258	LAPAROTOMY WITH CC	64
296	ESPHG/GSTRO/MSD DGSTV, >70 CC	64
580	MAJ GYN PROC,UT/AD(NOMAL),<50	64
374	MINOR LOWER EXTREMITY PROC	62

APPENDIX B:

Personal Costs of Palliative Home-Care

PERSONAL COSTS OF PALLIATIVE HOME-CARE

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SUMMARY

The purpose of this study was to document the types of personal “out of pocket costs” encountered by individuals receiving Palliative Home-care as delivered within Edmonton’s Capital Health region. Personal costs were collected through the use of focus groups, interviews, and surveys of patients, informal, and professional caregivers.

A total of 94 different personal costs were cited by patients and their caregivers.. These 94 personal costs break down into five clusters. The clusters were given the descriptive labels; 1. Travel and Communication, 2. Financial Losses and Expenses, 3. Personal Services, 4. Supplies (Consumable), and 5. Supplies (Durable),

The large number of costs and the frequency with which they were cited suggests that when patients are sent home from hospital they are asked to assume many costs that they wouldn’t be faced with had they remained within hospital. The downloading of these costs are potential sources of patient stress and reasons for resisting care at home. Some of the complexities of understanding patient personal cost data are discussed in the paper. Suggestions are made for future data collection of patient personal costs.

PERSONAL COSTS OF PALLIATIVE HOME-CARE

Purpose of Study

The purpose of this study was to compile a list of the personal “out of pocket” costs which patients and their caregivers encounter while receiving palliative home-care. The separate costs once collected are to be analysed and classified as to similarities. Comments are to be made about the nature of the costs and procedures to be used in the collection of personal cost data from patients.

Background to Study

Cost constraints on health expenditures are forcing the health care system to reevaluate how services are delivered. Considerable focus has been placed on the use of home-care services as a potential cost saving measure. The appropriate use of home-care services has been found to be cost beneficial. The use of home-care services appears to save the health care system money but at the same time shifts some of the financial burden onto the patient and their caregivers. This “downloading” of costs could create an unfair burden on some patients, which could result in a failure to implement or cooperate with it.

At this time few studies have been found which examine the personal costs to patients of home-care and no studies have been found that systematically look at the costs in delivering home-care to palliative patients.

In a previous study by Jacobs, Calder, and Houston (1), the personal costs of persons with HIV/AIDS were assessed. In the first part of that study a focus group as well as personal interviews with individuals who were HIV positive were carried out to collect the different types of personal cost that persons with HIV were faced. Seventy six different costs were cited. Using a process called Concept Mapping (2) that combines the use of the statistical tools of multi-dimensional scaling and cluster analysis, the 76 costs were broken into six different themes that were labelled 1. Loss of Income/Expenditures, 2. Caregiving Assistance, 3. Miscellaneous Costs, 4. Transportation, 5. Personal, and 6. Household Costs. Many of these costs would appear to be similar to the costs that would be encountered by patients receiving palliative home-care.

In the second part of the study, Calder tracked the personal expenses of 26 patients for the period of a month. Individuals were selected to give as wide a range as possible of individuals in different living situations and life styles to illustrate the personal cost. Costs among different patients were found to vary dramatically. The authors were confronted with numerous issues and judgements that can dramatically alter the extent of the personal costs. They found that a cost that might be a legitimate cost in one situation might not be legitimate in a second. It was also found that individuals could not be trusted to keep regular logs and needed considerable supervision in keeping accurate logs. Some patients had difficulty in documenting true costs passing them off as normal living costs. They also report that the use of diaries/logs likely resulted in an underestimation of costs. They also found that through a structured interview with a list of possible costs they were able to collect what appeared to be a fairly accurate assessment of the

patient's true costs. The interview was found to serve the function of eliciting costs that might be overlooked in a personal log, obtaining a higher return rate, and allowing the researcher to make a better judgement as to allowable costs.

Browne et al.(3) used a Health Services Utilization Inventory to collect Direct and Indirect patient personal costs. They found that patient's "consistently reflected adequate levels of agreement between the patients' report and clinic records." This appears to give some validity to the use of interviews in collecting costing data. In their study Browne et al. used conservative approach in collecting costs. They also report that the use of diaries/logs probably resulted in an underestimation of costs.

In their study Browne et al. used a 2 page protocol to collect costs. This lists of costs is considerably less extensive than the list compiled in the Jacobs study. It is also fairly lengthy to fill out and it is doubtful whether Palliative Care Patients could do so. It likely would have to be administered in an interview.

Weinberg et al.(4) collected expenditures for the caring of patients with dementia who live at home. They concluded that health care policy makers need to be aware of the substantial out of pocket costs that are borne directly by patients and their families. In their study they collected data through the use of patient logs and interviews. An analysis of their reported data indicates that they took an admittedly conservative approach in collecting costs. They also report that the use of diaries/logs probably resulted in an underestimation of costs.

Methodology

In order to collect a list of personal costs of patients who received palliative home-care and their caregiver the following procedures were followed.

1. Forty surveys were handed out to palliative home-care patients by their visiting palliative care nurse. The survey was made up of a list of costs that had been collected in the previous study by Jacobs et al. on persons with HIV /AIDS. Twelve items on the original list that pertained to gay life style or intravenous drug user were omitted as it was felt that they might be seen as being offensive to the group to be studied. Patients and care-givers were asked to check any of the costs that either they had incurred or were aware that patient's had incurred and to add any personal costs that were not on the list.
2. A group of palliative care nurses in a focus group were asked to review the list of costs and add to them any personal costs that they were aware that patients incurred. They were also asked to check off any costs that they were aware of patient's facing.
3. A master list of costs was compiled. The final master list of costs were given to 14 different sorters who individually sorted the items into categories of common themes. These sorts were then subjected to multi-dimensional scaling and cluster analysis resulting in a thematic map and a list of costs organized by theme.

Results

A total of 94 different personal costs were collected. All but one of the original 54 HIV costs were endorsed as being a personal cost for palliative care patients. That one cost that was not cited was attendance at educational meetings. Seemingly many of the personal costs faced by persons with AIDS are similar to patients receiving palliative care. It should be noted that some costs that pertained to the gay life style and intravenous drug use were omitted from the palliative care cost list and many of these likely would not have been endorsed.

Patients and nurses added a total of 40 additional costs to the original cost list. The vast majority of these costs were in the supplies area where much more specific items were cited. One should be reminded that not all individuals would be faced with all of these or any of the listed costs

Many of the personal costs cited were costs that related to the dying process and would likely be present to the same degree whether the palliative home-care patient was treated at home or in the hospital. In conducting future studies one might choose to omit those costs. A few of the costs indicated were found to be questionable as there was no knowledge of patients ever having to pay for them (eg pastoral and social worker costs).

The Sort

The sorts were done independently by 14 individuals. Sorters were asked to sort the costs into common themes. All sorters had some knowledge of the palliative-care process. Seven of the sorters were registered nurses, one is a Physician, three are Psychologists, and three were from the public. There appeared to be a fair degree of consistency in the results of the sorts across the different groups.

The sorts were analyzed using multi-dimensional scaling. The results can be seen in Figure One. Each cost item is numbered and is represented by a point on the map. Items that are relatively close to each other have a higher degree of chance of being sorted together than items that are further apart. Items that are sorted closer together are said to share a common theme. Items are given a bridging value from 0 to 1. The lower the bridging value the stronger the relationship among certain items.

A cluster analysis of the sorted items was also done and the results were superimposed on the map resulting from the multi-dimensional scaling. Items making up each of the clusters can be found in Table One along with the bridging index for each item. The authors assigned a descriptive title for each cluster based on the makeup of the cluster.

Analysis of the Clusters

A five cluster solution was chosen as having the best descriptive value for the data.

Travel and Communication was the most widely dispersed cluster suggesting some lack of

commonality of items. One of the items #83 cell phone/pager was not sorted consistently with other items hence it stands somewhat apart in the middle of the map.

Travel costs can be a major expenditure although often could be seen as optional. For example an individual who is dying might choose to fly in their family for a final get together. This could be very costly and likely would only be an option for someone with considerable resources.

The use of an air ambulance was also cited as an observed cost. This is an example of an infrequent cost that might not show up in a sample if only a small sample was drawn. It is also a cost that might or might not be covered by the health care system depending on the situation.

Cluster Two, Financial Cost and Losses is a cluster that Jacobs et al. found to contribute the greatest amount to the Personal cost of HIV/AIDS. This cluster is made up of costs which might be seen as not being integral to the home-care process but rather more related to the dying process. For example the loss of a job can be extremely costly but it would occur whether a person was at home or in the hospital. While associated with palliative home-care it is seen more as a cost of being gravely ill.

One of the large costs in this category is the cost of a needed care-giver who stays at home. In this case the researcher is faced with the dilemma of assigning (or not) a value to this typically 24 hour a day service. Is it the cost of lost income of a partner who has had to stop working?; or Is it the cost of paying a stay at home partner for the work that they do that substitutes for the work of an assigned paid for aide. How one assigns costs will greatly impact on one's final conclusions.

The Personal Services cluster contains some costs that might or not be paid for by the individual patient. Many of the 'cost' of assistance are often covered by the work of friends or partners. These costs could be accounted for by assigning them a fair market value. Cluster four and five deal with Consumable and Durable supplies. If an individual were to remain in hospital they would be supplied with most of these goods free of charge.; yet outside of the hospital they are expected to pay either in full or in part for these supplies. Medications is the one supply that is usually cited as making up the major discrepancy between at home and within hospital care.

Discussion

Limiting the boundaries of Costs

This study dealt with the potential costs that patients could encounter while receiving palliative home-care. In carrying out costing research one is confronted with the problem as to what costs should one allow. The answer(s) to this question will to a large degree depend on the exact purpose of the study. A study looking at the costs that a patient would pay for at home that would be paid for if they were to remain in the hospital, would likely have a much more restrictive definition of allowable costs than a study that would consider all of the personal expenses a patient and their care-giver incur. The researcher has to be clear as to what the purpose of their study is and restrict the allowable costs accordingly. They should be clear to their reader as to

what is being allowed and how they are being accounted for. It will be difficult to interpret the results of different “personal costs” studies without clearly understanding what the allowable costs were.

The issue arises whether the personal costs are integral to palliative home-care. Personal losses of income or loss of a business due to illness could be substantial but arise because of the patient’s condition and not because of whether or not they receive home-care. The authors went through the list of costs and have starred (*) those that likely would have occurred whether or not the patient was receiving day care. This is particularly important as some of these costs such as the loss of salary for a spousal caregiver or a patient were found by Jacobs et al. to be the largest contributor to the total personal costs of home-care.

Questionable Costs

In collecting the costs emphasis was put on allowing the patients to describe the costs. This was done so the list of costs would not only reflect the perception of professional caregivers. Some of the costs cited are however questionable (eg. Social Worker, Pastoral Care) as the authors know of no cases where patients were charged for such costs. These are true costs but costs that are usually borne by the health care system.

Relationship of Resources to Costs

An issue that arises in costing is the issue of need and the relationship to available resources. A family with considerable resources might choose to fly in family members to comfort the dying individual. These transportation costs could be considerable and likely beyond the means of many. They are a personal costs but are they a needed cost? Many of the individuals receiving palliative home-care are elderly on fixed and limited pensions with little disposable income. Others might be more financially well off and be able to afford the luxuries of flying in relatives or purchasing extra comforts. One case was cited where public funding allowed the patient to have either a walker or a wheelchair; supposedly a patient with adequate financial resources could rent or purchase both. Researchers will always be faced with having to decide the limits of acceptable and not acceptable costs. A more stringent rule might be accepting only medically necessary costs which would greatly reduce the cost list and at the same time making the care less palliative. A hair cut might not be medically necessary but be a necessity for the needed self respect of a dying person.

Nature of the payer

One of the more difficult issues confronting the researcher is the nature of the payer. Some patients encounter considerable costs but because the lack the resources the costs are covered in part or in full by either the health care or social service system. Individuals who have private insurance typically have to pay a certain percentage of the costs out of pocket but should one consider that they are paying the full costs as they might have been paying for this insurance for a long time. In some cases the patient is responsible for a “ basic deductible” amount from their total costs. This deductible makes it difficult to attribute the costs for any one particular

expenditure.

Data Collection Techniques

While although it would be nice to be able to construct a pencil and paper survey that could be filled out by the patient and or their caregiver it is likely that such procedures will result in a very poor return rate and collect questionable data. Patients appear to be interested in the topic and willing to cooperate but surveys will be quickly put aside. There is much more merit in collecting the data through a structured interview. This will likely result in a much higher completion rate than will a typical survey. The survey should be done by the researcher or their confederate who should accompany the nurse home visitor. It would be difficult to get a nurse to conduct the costing interview along with the other demands that they have to fulfill.

Table 1: Cluster Items and Bridging Values for Clusters of Costs

Item Number Cost	Bridging Value
Cluster #1 – Travel and Communication	0.48*
29. special transportation (DATS)	0.29
30. chauffeur/driver	0.30
1. air ambulance	0.33
22. automobile: parking	0.33
26. taxi fares	0.33
24. travel accommodation	0.34
27. automobile expenses	0.35
25. airplane tickets	0.38
28. travel meals	0.41
65. ambulance	0.44
9. telephone long distance	0.79
83. cell phone / pager	0.95
31. car: special equipment	1.00
Cluster #2 – Financial Losses Expenses	0.34
5. loss of job	0.28
6. lost working time for caregivers	0.29
51. time off work for helpers	0.29
2. financial support from others	0.31
37. quick sale of assets	0.32
82. insurance	0.37
8. moving costs	0.49
Cluster #3 – Personal Services	0.41
14. cooking assistance	0.18
16. shopping assistance	0.18
18. additional residential help	0.18
54. child care	0.20
11. housekeeping assistance	0.23
15. respite care	0.23
23. accountant services	0.26
46. legal services	0.26
94. social worker	0.26
21. counseling costs	0.28
4. funeral costs	0.30
62. physician documentation	0.35
91. dental care	0.35
10. pastoral services	0.38
7. barber/hair stylist	0.47
13. yard maintenance	0.49
93. hearing care	0.58
92. eye care	0.59
34. alternative therapies	0.61
41. medical insurance	0.79
20. medical literature	0.87
12. nursing visits	0.89

Cluster #4 – Supplies / Consumable	0.27
57. urine bags	0.11
58. catheters	0.12
3. masks	0.14
38. rubber gloves	0.14
40. tubes	0.14
47. diapers	0.20
59. bowel supplies	0.20
50. dressings	0.21
17. oxygen	0.23
32. lotions	0.30
35. medications	0.43
33. prescription drugs	0.44
63. nutritional supplements	0.46
36. special cosmetics	0.69

Cluster #5 – Supplies / Durable	0.06
69. foam wedges	0.00
42. toilet lifts	0.00
87. over-bed table	0.00
19. canes	0.01
61. commode(s)	0.01
88. railings	0.01
89. toilet arms	0.01
72. transfer poles	0.01
60. bed railings	0.01
86. bath seats	0.01
74. furniture blocks	0.01
39. bed pan(s)	0.02
45. bathtub railings	0.02
70. wheelchair cushions	0.02
75. pressure relief devices for limbs	0.02
85. hair wash trays	0.02
76. smoking devices	0.03
66. limb slings	0.03
68. collars	0.03
48. walker	0.03
49. special bed	0.04
84. stair lifts	0.04
64. ramp(s)	0.04
67. splints	0.05
77. show horns	0.05
44. I.V. pumps	0.06
56. spenco pad	0.07
43. intravenous bottle stands	0.08
52. dosette	0.08
81. Sitz baths	0.10
55. side stream (oxygen delivery)	0.11
79. adaptive clothing	0.11
80. special footwear	0.11
73. intercom (monitor)	0.12
53. wheel chair	0.12
90. voice box	0.19
78. reachers	0.23
71. transfer belts	0.30

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