

SUBSTUDY 5

STUDY OF THE COSTS AND OUTCOMES OF HOME CARE AND RESIDENTIAL LONG TERM CARE SERVICES

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

February 2002



National Evaluation of the Cost-Effectiveness of Home Care



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SUBSTUDY 5

STUDY OF THE COSTS AND OUTCOMES OF HOME CARE AND RESIDENTIAL LONG TERM CARE SERVICES

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

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National Evaluation of the Cost-Effectiveness of Home Care



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 5: Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services*, documents the comparative costs and outcomes of home care versus residential care using a societal perspective that considers both formal and informal costs. The study also provides information regarding the burden on family caregivers in regard to out-of-pocket expenses and time devoted to caring for their loved one.

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EXECUTIVE SUMMARY

Introduction

Concern has been expressed in the media about the cost implications for the health care system of population projections that show a disproportionate increase in the seniors' population in Canada. The implications of the "greying" of Canadians have been seen by health policy makers and planners to pose a significant fiscal challenge for the health care system.

In the past several years, there has been a growing interest in the potential use of home care services as a substitute for long term care residential services. There is some question, however, about whether or not home care can be a cost-effective alternative to residential care. While there appears to be some literature which suggests that home care is not cost-effective relative to residential care, other studies indicate that it is.

The cost-effectiveness literature generally only includes direct costs to funders and does not include either direct or indirect costs to informal care providers such as family members and friends. From a payer's perspective, informal care represents a zero-priced alternative to formal services. From a societal perspective, however, informal caregiving reflects a real use of resources (for example, time spent providing care that could be spent working) and thus an economic social cost. A comprehensive cost-effectiveness analysis therefore requires comparisons of both the formal and informal costs of care and the outcomes of care.

Using a societal perspective that considered both formal and informal costs, this study, the *Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services* (Substudy 5 of the National Evaluation of the Cost-Effectiveness of Home Care) examined the comparative costs and outcomes of home care versus residential care. Specifically, the study examined whether it costs less to provide care in the community than in a facility, and whether the outcomes of care are worse, the same, or better for community clients compared to facility clients. The study also measured the informal costs of care by identifying the psychological, social, and financial burdens shouldered by family, friends, and volunteers looking after clients in the community and in facilities.

Assessment Tools

Five tools were used to examine the impact of care for each client in the study sample. A multi-section Client Questionnaire was used to obtain information about the client directly. This questionnaire obtained information about: the client's sociodemographic background; functional and cognitive abilities; perceptions of quality of life; and use of, and satisfaction with, health related services. A second multi-section instrument, the Caregiver Questionnaire, was used to obtain information from a family member, friend, or other informal caregiver about his or her experience of providing care to the client. This questionnaire obtained information about: the caregiver's sociodemographic background; care-related stress; and satisfaction with the client's use of health related services. In addition, three diaries were used to collect information about time and assistance provided by formal service providers either in the community or in long term

care facilities, time and assistance provided by informal caregivers, and expenditures related to clients' health care needs.

Home Care and Residential Care Clients

The study sample consisted of individuals who were 65 years of age or older who were receiving long term care services either in the community or within a care facility in either Victoria, British Columbia or Winnipeg, Manitoba. Clients who were stable at their level of care and location of care (community or facility) were randomly sampled within each jurisdiction. A total of 580 clients (222 from the community and 358 from facilities) participated in the study.

Approximately 77% of the sample was female. Some 63% of the female clients and 57% of the male clients lived in facilities. About 53% of the sample was 85 years of age or older, and almost 9% was 95 years or older. Some 64% of the sample was widowed. Approximately 29% of the clients had grade 8 education or less and an additional 30% had some post-secondary education. About 57% of the sample had incomes of \$15,000 or less. Over 40% of community clients lived alone and over 80% of facility clients had single rooms.

The primary focus of this study was to determine whether community and facility clients differed with respect to health related care costs. It was, therefore, important to show that the community and facility clients did not differ on the client assessment and outcome measures. A comparison of scores on a measure of functional assessment, however, indicated that community clients in the sample were more functional than facility clients, and that the distributions of clients in the two study sites were substantially different.

Therefore, the study sites were considered to be a replication of each other (as opposed to part of the same sample) and two new samples (a Victoria sample and a Winnipeg sample) were created by dividing the original sample of clients into care levels, making the community and facility clients comparable within each care level, and acknowledging differences between the two study sites.

By analyzing the data from the two study sites separately, similarities and differences between the Victoria and Winnipeg samples were highlighted. In both samples: facility clients felt better about their general health than community clients; community clients had higher cognitive functioning than facility clients and cognitive functioning declined as clients' general functioning declined; community clients indicated they would like more instrumental support than facility clients but community and facility clients were comparable with respect to their desire for more emotional support; facility clients perceived their health related quality of life to be better than community clients; and community and facility clients were comparable with respect to their perceptions of overall quality of life.

In the Victoria sample: community clients had stronger social networks than facility clients; clients generally perceived that their health related quality of life decreased as their care needs increased; and clients' satisfaction with the services they were receiving decreased as their care needs increased.

In the Winnipeg sample: facility clients felt better about their health than community clients; facility clients had higher perceptions of self-esteem than community clients; and community clients were more satisfied with services than facility clients.

Informal Caregivers

A total of 501 caregivers participated in the study, 184 for community clients and 317 for facility clients. The majority of caregivers were female, although approximately 26% of the caregivers were male. Some 30% of the caregivers were under 55 years of age. However, 23% of the caregivers of community clients and 12% of the caregivers of facility clients were 75 years of age or older. Approximately 23% of caregivers had a university degree; fewer than 3% had grade 8 or less.

Over 60% of caregivers were children and were equally likely to provide care to community and facility clients. Spouses and non-family members (such as friends and neighbours) were more likely to care for a community client, while other family members (such as nieces/nephews and grandchildren) were more likely to care for a facility client. Approximately 72% of caregivers were married. Some 16% of caregivers lived with the client. About 74% of caregivers indicated that they received assistance from other informal caregivers in providing care to the client. Approximately 45% of the caregivers reported that they were currently working. While the majority (79%) indicated that they worked 40 hours or less a week, approximately 15% indicated that they worked 50 hours or more. In general, caregivers of facility clients and caregivers of community clients had comparable incomes. Over 60% of the caregivers in the study provided care to someone in a facility.

In both study sites, caregivers indicated that the amount of behavioural disturbances experienced increased as the care level of the clients increased, but there was no difference between community and facility clients. As well, in both study sites, caregivers of facility clients perceived that they had less objective burden but more subjective (emotional) burden than caregivers of community clients. In the Victoria sample, caregivers' satisfaction with the services the clients were receiving was affected by where the clients were living as well as the clients' care requirements. In the Winnipeg sample, caregivers' satisfaction with services was comparable for both community and facility clients and was comparable across care levels. In both study sites, caregivers' satisfaction with the services clients were receiving was higher than clients' satisfaction with the services.

Costs of Care Services

One of the goals of Substudy 5 was to obtain estimates of the costs of formal and informal home care and residential care by examining: the amount of time and type of assistance provided by formal service providers; the amount of time and type of assistance provided by informal caregivers; and out-of-pocket expenses of both clients and informal caregivers. Cost estimates were based on information provided in the various diaries and on an analysis of budget and operational cost data provided by regional health authorities in Victoria and Winnipeg.

The response rate for all of the diaries was very good: 94.1% for the Formal Services – Community diaries; 97.5% for the Formal Services – Facility diaries; 83.3% for the Informal Caregiver diaries; and 87.6% for the Client Expenditure diaries. The majority of the diaries were completed in a comprehensive manner.

The analysis of the cost data revealed two major findings. First, regardless of whether only formal care costs or both formal and informal care costs were considered, the results were the same in both study sites: community care was significantly less costly than residential care. When only formal or public costs (that is, cost to government) were considered, home care costs were, on average, about 50% of residential care costs. However, informal or private costs (such as out-of-pocket expenses and informal caregiver time) were considerable. When a societal approach which included both formal and informal costs was used, families were found to contribute one half or more of overall care costs of home and community care, and approximately one third of the overall care costs of facility care. Policy makers need to consider whether these proportions are reasonable and appropriate given that the government covers 100% of physician and hospital costs.

Second, the analysis of the cost data suggested that different jurisdictions may have different policies regarding the delivery of health care services. For example, it was found that the cost of care increased as the care requirements of the client increased in the Victoria site, a finding that is consistent with the case mix funding approach used in British Columbia. In the Winnipeg site, costs of care were relatively constant across all care levels, a finding that is consistent with the funding approach used in Manitoba. The results indicate that further research and clinical investigation are needed to examine how policy makers in all provincial and territorial jurisdictions in Canada develop and implement policies regarding care provision and funding.

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1. INTRODUCTION

1.1 Context

Vignette: The caregiver is an only child who lives and works in a city 95 kilometres (two and a half hours) away from her parents. Her mother (the client) has advanced dementia; her father is physically frail. The client requires constant supervision which is provided by her husband (the caregiver's father), the caregiver, and home support workers. Each month, the caregiver sacrifices a week's worth of salary and time away from her own family and her busy and demanding job to be with her parents. Medical professionals have indicated that the client should be in a care facility, but the caregiver and her father want to care for the client at home as long as possible. Much of the caregiver's thoughts and energies are focused on her parents and their situation.¹

Concern has been expressed in the media about the cost implications for the health care system of population projections that show a disproportionate increase in the seniors population in Canada. In 1998, there were an estimated 3.7 million seniors 65 years of age and older in Canada, an increase of 57% since 1981.² In 1998, seniors represented 12% of the Canadian population; by 2016, it is anticipated that seniors will represent 16% of the population (Statistics Canada, 1999). The fastest growth is occurring among those in the older age ranges. In 1998, there were an estimated 380,000 seniors 85 years of age and older, almost double the number of seniors in this age group in 1981. In 1998, 10% of seniors were 85 years of age or older; by 2016 it is expected that seniors 85 years of age and older will represent 13.5% of the population of seniors (Statistics Canada, 1999).³

The implications of the “greying” of Canadians have been seen by health policy makers and planners to pose a significant fiscal challenge for the health care system (Foot & Stoffman, 1996). An analysis of demographic trends appears to support the concern expressed, as seniors are increasingly heavy users of the health care system as they become older (Hollander & Pallan, 1995). Barer, Evans, Hertzman and Lomas (1987) have argued, however, that demographic shifts will only increase health costs by one percent per year over the next 40 years. Fries (1989) has also argued that demographic shifts will have little effect on health costs. He stated that, in the future, people will live healthier lives and their need for health services will be “compressed” into the last few years of life, thus reducing the rate of utilization of health services by the elderly.

¹ A number of clients, caregivers, and study personnel expressed their thoughts on several aspects of the current health care system and their experiences with it. These thoughts, which are captured in this report in the form of vignettes such as the one presented here, and in Appendix A, provide a more personal perspective on the use of health care services in Canada.

² By comparison, the population of individuals under 65 years of age grew by 20% in the same time period (Statistics Canada, 1999).

³ By comparison, seniors 65 to 74 represented 56.8% of the population of seniors in 1998 and are expected to represent 57.6% of the population of seniors in 2016; seniors 75 to 84 represented 32.9% of the population of seniors in 1998 and are expected to represent 28.9% of the population of seniors in 2016 (Statistics Canada, 1999).

1.2 Rationale for This Study

In the past several years, there has been a growing interest by policy makers and planners in the potential use of home care services as a substitute for long term care residential services in Canada.⁴

The Federal/Provincial/Territorial Subcommittee on Long Term Care (1990, p. v) identified three major functions of home care:

- The acute care substitution function where home care meets the needs of people who would otherwise have to remain in, or enter, acute care facilities;
- The long term care substitution function, where home care meets the needs of people who would otherwise require institutionalization; and
- The maintenance and preventive function which serves people with health and/or functional deficits in the home setting, both maintaining their ability to live independently, and in many cases preventing health and functional breakdowns, and eventual institutionalization.

There is some question about whether or not home care can be a cost-effective alternative to residential care. For example, while some studies have indicated that it is not cost-effective to substitute home care for care in an institution (see Weissert, Cready & Pawelak, 1988, for example), other studies have suggested that home care is a cost-effective alternative to care in long term care facilities, at least under certain conditions (see Hollander, 1994, 2001, for example). The topic of home care is now on the federal/provincial agenda. The Canadian government has also recognized the cost burden that home care may entail for family members who are caring for elderly or disabled loved ones by instituting a new caregiver tax credit effective as of 1998.⁵

1.3 Relevance of This Study

A comprehensive cost-effectiveness analysis requires comparisons of both the formal and informal costs of care and the outcomes of care.⁶ This study, Substudy 5 of the National Evaluation of the Cost-Effectiveness of Home Care, examines whether there are differences in the formal costs of services and in the health outcomes of clients in home care versus those in residential care. That is, it focuses on the long term care substitution function. The study also measures the informal costs of care by identifying the time and financial burdens shouldered by

⁴ Due to economic restraint, or consideration of demographic trends, or both, provincial policy makers and planners started to consider the potential of home and community based services as alternatives to residential services during the 1980s.

⁵ The Caregiver Tax Credit came into effect for the 1998 taxation year. The maximum personal amount of the claim was a \$4,293 tax credit. To be eligible for the credit, the disabled person had to live with the person paying tax, be resident in Canada, and for the 2000 taxation year, have an income of no more than \$14,047.

⁶ Formal or public costs include cost to government. Informal or private costs include costs to individuals such as time and out-of-pocket expenses.

family members and friends looking after individuals at home and in care facilities.

This study will be of relevance to policy makers, clients, community advocates, and service providers involved with continuing care in the provincial and territorial health systems across Canada. The results will assist provincial ministries of health and regional boards in deciding how to structure their service delivery systems. The results will also enable community groups and individuals to lobby for more efficient and effective services. The study may also be relevant to planners and decision makers in other countries.

1.4 The Research Question

The primary research question for this study was:

- When comparable individuals are used, is home care for elderly persons a cost-effective alternative to care in long term care facilities?

1.5 Organization of This Report

This report is organized as follows: Chapter 2 provides a review of the literature related to the cost-effectiveness of home care versus residential care. Chapter 3 describes the methodology used in the study. Chapter 4 describes the various measurement instruments and data collection tools which were used in Substudy 5. Chapter 5 provides a description of the client sample and presents findings on the outcome measures for clients. Chapter 6 presents similar data for informal caregivers. Chapter 7 presents information regarding the formal and informal costs of home care and residential care. Chapter 8 discusses the policy implications of the outcome and cost data.

2. LITERATURE REVIEW

2.1 Introduction

There is a growing literature on the techniques of economic analysis in health care. Drummond, Stoddart, and Torrance (1987) noted that economic analysis focuses on two aspects: the costs and consequences of activities; and choices between alternatives. There are four methods of economic evaluation, namely, cost-minimization, cost-effectiveness, cost-utility, and cost-benefit analysis.⁷ For ease of reporting, the term *cost-effectiveness* will be used here as a generic term to refer to all four methods.

2.2 Findings that Home Care is Not Cost-Effective

A considerable amount of research has been conducted on studies of home care as a substitute for residential services in the United States. Much of the literature is based on two series of federally funded studies: 14 community care demonstration projects which were funded in the late 1970s and the early 1980s, and an additional 10 projects which were funded between 1982 and 1985.

Given the nature of the American continuing care system in the 1980s, it was considered that the appropriate way to study whether or not home care was a cost-effective alternative to residential care was to introduce case management (often with an enhanced home care program) into a community and then randomly assign eligible clients to existing community services or to enhanced services. Researchers then determined whether or not the enhanced services led to greater quality of life and client satisfaction, decreased morbidity and mortality, increased functional status, and reduced admissions to long term care facilities and hospitals.

Generally, researchers found that the experimental group had greater satisfaction and quality of life and somewhat reduced costs relative to the control group (Mathematica Policy Research Inc., 1986, April). However, when the costs of the enhanced home care program were added into the equation, the overall costs were generally greater for the experimental group than for the control group (Berkeley Planning Associates, May 1985; Mathematica Policy Research Inc., 1986, May).

A study which illustrates the general approach used in the United States to analyze the cost-effectiveness of home and community based services is that of Skellie, Favor, Tudor and Strauss (1984) who analyzed the Georgia Alternative Health Services Project. Enrollees in this study were required to be Medicaid-eligible, at least 50 years of age, and certified as eligible for residential care. The experimental group was comprised of 444 individuals who received a comprehensive range of community based services including alternative living services, adult day rehabilitation and home delivered services. They also received screening and case management services. The control group of 135 individuals were eligible to receive existing community services. Clients were randomly assigned to the two groups.

⁷ For more explanation regarding these various methods of economic evaluation, see Drummond, O'Brien, Stoddart, and Torrance, 1997.

After the first two years of enrolment, 22% of the control group (that is, individuals receiving standard community services) and 21% of the experimental group (that is, individuals receiving enhanced community services) were admitted to a long term care facility. Thus, there was no difference between the groups. It was found that the costs of the experimental group were considerably higher than that of the control group and, as such, constituted “add-on” costs to Medicaid-reimbursed services. The authors noted that the cost per quarter for the experimental group was, however, considerably lower than the cost for residential care and suggested that savings should be possible where home care could be substituted for residential care. The authors also noted that it was difficult, under a voluntary screening system, to select individuals for whom community based services could be cost-effective. In addition, given the low demand for project services, the low volume of clients screened resulted in higher administrative and direct service costs.

In a related study, Vertrees, Manton and Adler (1989) examined the Georgia and California Medicaid waiver programs. These programs were enhancements of earlier programs and placed a greater emphasis on screening to ensure that those receiving community based services would be likely candidates for admission to a long term care facility. The authors found that, for California, the monthly cost of community care was \$350 while monthly long term care facility costs were \$1,144 for a savings of \$794. However, not all individuals admitted to the community program were eligible for residential care and for those who were eligible, community services did not prevent admissions. This also occurred in Georgia. The rate of admission to a long term care facility was similar for controls (that is, individuals receiving standard community services) and for those in the enhanced community program.

Hedrick and Inui (1986) analyzed 12 studies on the cost-effectiveness of home care that used experimental or quasi-experimental research designs and which were deemed to be methodologically sound by the authors. These studies involved chronically ill individuals. Hedrick and Inui found that home care services appeared to have no impact on mortality, patient functioning or long term care facility placements. They also found that home care had either no effect on hospitalization or tended to increase the number of hospital days. In addition, they found that either the cost of home care was not affected or was increased by up to 15 percent.

Given the findings of studies such as those reviewed above, American researchers generally concluded that home care was not a cost-effective alternative to residential care because it did not decrease the rate of admission to long term care facilities and therefore constituted an add-on cost.

Weissert (1985) argued that it is difficult to make home and community based services cost-effective because: community care is an add-on to other services and is not a substitute for residential care; community care does not reduce institutionalization rates; only short long term care facility stays can be avoided by community based care; screening and assessment costs are high; overhead costs can be relatively high particularly when community services are small; and improvements in health status are limited.

Weissert et al., (1988) expanded on this analysis in a study that looked at over 700 citations published since 1960 with regard to the relative costs of community and home based services versus residential long term care services. Of the 700 documents, 150 were selected for review and the 27 most rigorous and generalizable studies were chosen for detailed analysis. Weissert et al. concluded that their analysis indicated that home and community based long term care services usually raised overall health care service use and costs. They also noted that small savings for institutional care were often offset by the costs of the new home and community service.

2.3 Findings that Home Care is Cost-Effective

The research reviewed above suggests that home care is not cost-effective compared to residential care. However, the research generally does not compare the costs of community and home based services versus the costs of long term residential care directly. Rather, the studies tend to compare costs associated with the introduction of a new home care service to existing community services. Several recent studies have shown that when the costs of community based services are compared directly with the costs of long term care services, home care can be a cost-effective substitute for facility care.

Hollander (1994), for example, demonstrated that while the utilization rate of continuing care services (home care and residential care) remained relatively constant in British Columbia over the period from the 1983/1984 fiscal year to the 1991/1992 fiscal year, there was a significant shift in utilization. Facility utilization decreased from 71.6 beds per 1,000 population 65 years of age or older to 57.0 beds. During the same period, community utilization increased from 87.2 clients to 115 clients per 1,000 population 65 years of age and older (Hollander, 1994, p. 100). Hollander also provided a comparative analysis which demonstrated that the cost per year for home care clients is considerably less than for clients in long term care facilities, for each of five levels of care. Using data from four cohorts of clients who were new admissions to the British Columbia continuing care (home care and residential care) system in the 1987/1988, 1990/1991, 1993/1994, and 1996/1997 fiscal years, Hollander (2001) found that on average, costs for clients in home care are about one half to three quarters of the costs for clients in facility care, by level of care. Costs differed by type of client. Home care costs were lowest for individuals who were stable in their type and level of care. The costs of care were higher for home care clients who died than for facility clients who died. Hollander noted that half of the health care costs for home care clients were attributable to their use of acute care hospital services. He also noted that a significant portion of the health costs for home care clients occurred at transition points, for example, when there was a change in the client's type of care and/or level of care.

Weissert, Lesnick, Musliner and Foley (1997) also noted that home care can be cost-effective when home and community-based services are designed to be a substitute for facility care. In a study examining the Arizona Long Term Care System, which was the first capitated, long term care Medicaid program in the United States, Weissert et al. noted that the cost of home and community based services was substantially less than the cost of facility care. The investigators suggested that savings probably came from several sources, including the use of a

payment methodology that encouraged program contractors to place clients in home and community based services rather than risk losing money by using more facility days than their monthly capitated rate allowed.

Several recent studies have focused on the cost-effectiveness of home care for individuals with cognitive impairment. Using data from the Canadian Study of Health and Aging (CSHA),⁸ Østbye and Crosse (1994) calculated the net economic costs of dementia, that is, costs that were incurred because of the dementia, using both direct costs (such as home support, physiotherapy, respite care, day centre care) and indirect costs (such as time spent by informal caregivers in assisting clients with activities of daily living). Østbye and Crosse estimated that the annual direct costs of caring for someone without dementia in the community was \$1,790. In contrast, the annual direct costs of caring for someone with dementia in the community was estimated to be \$4,506 for those with mild dementia and \$8,109 for those with severe dementia. For individuals with dementia, it was estimated that the annual net cost of providing care for those in the community was \$10,100 (\$4,970 for direct costs and \$5,130 for indirect costs). In contrast, it was estimated that the annual net cost of providing care to individuals with dementia in a facility was \$19,100.

In a related study, Hux, O'Brien, Iskedjian, Goeree, Gagnon and Gauthier (1998), also using data from the CSHA, examined the costs of caring for individuals with Alzheimer's disease. The authors found that costs increased significantly in relation to the severity of the disease. The annual societal cost was estimated to be \$9,451 for those with mild Alzheimer's disease and \$36,794 for those with severe Alzheimer's disease. This study provided detailed cost estimates for both formal and informal care services. While the authors did not do a direct comparison of all costs for community and residential services, they did provide comparative costs for component parts of their analysis. A comparison of the community and facility costs for those with severe Alzheimer's disease indicated that the cost of residential care is significantly higher than the cost of care in the community.

2.4 Informal Supports

The cost-effectiveness literature generally includes only direct cost to payers and does not include either direct or indirect costs to informal caregivers such as family members and friends. From a payer's perspective, informal care represents a zero-priced alternative to formal services. Thus, the more individuals are cared for by informal care providers, the less that is spent on formal care services.

⁸ The Canadian Study of Health and Aging Working Group (1994a) estimated that approximately 8% of the population 65 years of age and older are affected by some form of dementia, and that the prevalence of dementia increases with age, affecting about 35% of those 85 years of age and older. Approximately 50% of those with dementia live in the community. A recent study estimated that 60,150 new cases of dementia are identified each year in Canada (Canadian Study of Health and Aging Working Group, 2000). Alzheimer's disease is the most common form of dementia, accounting for 64% of the individuals with dementia (Canadian Study of Health and Aging Working Group, 1994a).

The amount of care provided by family members and friends is substantial. For example, it has been estimated that 80% of the care provided to the elderly is provided by informal supports and that 70% to 90% of the elderly with functional health limitations rely in whole or in part on informal care (Chappell, 1990a, 1990b; Kemper, 1992; Moscovice, Davidson, & McCaffrey, 1988; Penning & Chappell, 1990). Because informal care has typically been valued at zero cost, there is some concern that there has been a process of cost-shifting from the formal care system to the informal care system. Chappell (1992) noted that in Manitoba, and Canada in general, one only receives formal care to the extent that the informal care system cannot look after the individual. For example, Béland (1985) noted that clients who were on home care programs were less likely to have informal support systems. Similarly, Shapiro and Tate (1985) found that individuals without informal supports were more likely to be admitted to long term care facilities than those who had such supports.

From a societal perspective, informal caregiving reflects a real use of resources (for example, time spent providing care that could be spent working or enjoying leisure activities) and therefore an economic social cost.⁹ In order to determine how care provided by informal caregivers should be valued, it is important to determine what constitutes “care provision.” It is necessary to distinguish between those tasks that an informal caregiver has always done and those tasks that are done *because of* an individual’s health care needs. Since only the latter tasks would be provided by the formal care system, only these tasks should be included in the calculation of social costs.

Several different approaches can be used to estimate the value of the time provided by informal caregivers. First, informal care time could be valued at zero cost. As noted above, however, this approach emphasizes the cost to payers, but ignores social costs. Second, informal care time could be valued at the caregiver’s current income level. This approach is not appropriate for an elderly sample in which many of the individuals may never have worked or may be retired. Third, informal care time could be valued at the current minimum wage. However, this approach would underestimate the costs involved if a formal service provider were to replace the informal caregiver. Fourth, informal care time could be valued using a replacement approach in which the wage rate of the appropriate worker who would be hired in the absence of a caregiver is applied to the hours of time spent providing care.

Max, Webber and Fox (1995) noted that individuals with Alzheimer’s disease living in the community received an average of 286 hours per month of unpaid care, while those living in a long term care facility received 36 hours per month. Using a replacement approach, Max et al. estimated the cost to be \$34,517 for the community sample and \$5,542 for the facility sample. In both samples, costs increased with the severity of the disease.

Not surprisingly, how informal care is valued can considerably affect the conclusions one makes about the cost-effectiveness of home care and residential care. For example, Hébert, Dubuc, Buteau, Desrosiers, Bravo, Trottier, St-Hilaire, and Roy (2001), using a representative

⁹ The availability of an informal caregiver is only one of the factors that may impact on whether an elderly individual receives care in the community or in a facility. Most elderly people prefer care at home rather than in a long term care setting and some may feel that community care is less expensive than facility care (Kemper, 1992).

sample of elderly people in Québec, showed that home care is less expensive than facility care when only public costs are considered. However, when both public and private costs (using a replacement approach for caregiver time) are taken into account, home care is generally more expensive than facility care. This finding is due, in part, to the fact that family members and volunteers contribute both out-of-pocket funds (estimated to be \$30 to \$60 per day on average) and substantial amounts of time performing care related tasks. For example, for individuals living in the community who were not receiving public services, family members provided 82% of the nursing care, 73% of the care related to instrumental tasks, and 80% of the supervision. Even for individuals who were receiving public services, family members provided a substantial amount of care: 70% of the nursing care, 57.5% of the care related to instrumental tasks, and 78% of the supervision.

2.5 Conclusions

The issue of whether home care is more cost-effective than care in long term care facilities is still unresolved. There is some literature which suggests that using public costs only, home care is not cost-effective relative to residential care. However, other studies indicate that, under some circumstances, home care may be more cost-effective than facility care. When both formal and informal costs are considered, it also appears that community care may be less cost-effective (that is more costly) than residential care.

The interrelation between formal and informal care requires further study and analysis. Currently, there is a lack of research indicating what would happen to the formal care system if there were a significant decrease in informal supports. At the present time, for example, most caregivers are women, specifically wives and daughters (Canadian Study of Health and Aging Working Group, 1994b). The fact that more women are working outside the home now than in previous generations may mean that fewer women are available to provide informal care to the elderly. This may have major consequences for home care services and for public expenses if care is provided at home with more involvement of public services or in long term care facilities (Hébert et al., 2001).

This study, Substudy 5 of the National Evaluation of the Cost-Effectiveness of Home Care, addressed these two issues by comparing the costs of community care versus facility care using both formal and informal care costs.

3. METHODS

3.1 Study Sites

Data were gathered between July 2000 and April 2001 in two sites in order to examine possible variations due to differences in service delivery systems between jurisdictions and size of community. The two sites were Victoria, British Columbia and Winnipeg, Manitoba. Victoria was considered a small city while Winnipeg was considered an urban centre.

3.2 Sample

The study sample consisted of individuals who were 65 years of age or older who were receiving long term care services either in the community or within a care facility in the two study sites. Informal caregivers of clients (such as family members, friends, or neighbours) were identified in order to obtain information regarding the caregivers' experience of providing care to the clients.

3.2.1 Criteria for the Identification of the Client Sample

Clients were selected for the study based on their level of care. Because of differences between the provincial health jurisdictions, the care levels were similar, but not identical, for the two study sites. In the Victoria site, clients were chosen from the third and fourth levels (that is, from IC2 and IC3) of a five level system. In the Winnipeg site, clients were chosen from the third and fourth levels of a four level system.¹⁰

Clients who were stable at their level and location of care were sampled. A client was considered to be stable if: he or she had been receiving care from the same agency (for example, a home support agency or a long term care facility) for at least the last six months;¹¹ had remained at the same care level for at least the last three months; had not received an increase of more than 20% in the number of hours or resources in the last month; had not been admitted to an acute care hospital more than once in the last two months; and if a hospital admission had occurred, the length of stay had been three days or less. Both cognitively intact and cognitively impaired clients were selected.

¹⁰ The five care levels in the British Columbia health care system are: Personal Care, Intermediate Care 1 (IC1), Intermediate Care 2 (IC2), Intermediate Care 3 (IC3) and Extended Care. The four care levels in the Manitoba health care system are simply referred to as Level 1, Level 2, Level 3, and Level 4.

¹¹ In Victoria, the majority of community clients were receiving health care services from a home support agency. In some cases, however, they were receiving community based health services such as occupational therapy, home nursing or day centre, but were not receiving home support services per se. In these cases, the health region was considered to be the "agency" who was providing services. A client could be receiving services from several individuals and/or agencies simultaneously. For example, a community client could be receiving home support, in-home physiotherapy and attending a day centre on a regular basis. In Winnipeg, all of the community clients were receiving health care services directly from the health region, including services provided by the staff of the Victorian Order of Nurses and Community Therapy Services, Inc.

Cognitively intact clients were excluded from the study if they could not communicate in English. Both cognitively intact and cognitively impaired clients could be excluded from the study because they were considered too frail to participate (see Section 3.2.2 Selection of the Client Sample below).

3.2.2 Selection of the Client Sample

A random sample of community clients was identified from the respective health region databases in the two study sites using the inclusion/exclusion criteria noted above. In the Victoria site, the identified sample was then passed onto case managers and home support agencies to review for appropriateness regarding participation in the sample. At this stage, some of the identified sample were considered ineligible for the study, and no effort was made to contact these individuals.¹² However, for individuals who were considered eligible for the study, either the case manager or a representative of the home support agency obtained consent to pass the individual's name onto study personnel. In the Winnipeg site, case coordinators obtained consent to pass the individual's name onto study personnel. In both sites, the initial contact by case managers/case coordinators/home support staff was made directly with individuals who were considered to be cognitively intact. However, for individuals who were considered to be cognitively impaired, the initial contact was often made with an informal caregiver. The preliminary contact was made by phone and/or letter.

For the facility sample, a staff member within the facility (often an administrator or a director of care) identified a potential pool of clients for the study using the inclusion/exclusion criteria described above. A random sample of clients was then chosen from the identified pool. Once the random sample had been identified, a facility representative (such as the director of care or a nurse) made initial contact with the individual or an informal caregiver in order to obtain permission to pass the client's name onto study personnel. The procedure for making the initial contact with facility clients was similar to that used with the community sample.^{13,14,15}

Some 5.5% of Victoria community clients and 13.5% of Victoria facility clients refused

¹² Reasons for ineligibility included: the client had died, had been recently placed in a facility, had moved out of the service area, had been taken off service, or was considered to be too physically or emotionally frail to participate.

¹³ In both study sites, staff were generally willing to review the list of potential participants. However, there was often a delay of a month or more before this could be done, primarily because of limited time and resources within the agencies. Response rates varied among agencies, but appeared to be better if the staff member(s) were knowledgeable and enthusiastic about the study and when the clients and/or families were reasonably familiar with the staff member.

¹⁴ The staff that recruited the potential respondents were asked to let study personnel know if there was anything unusual about the client or his or her caregiver (for example, that the client would need to have proxy consent, the caregiver was only available in the evenings and on weekends). When accurate information was provided, study personnel were able to use it in implementing the study protocol (for example, contacting a caregiver first regarding a client who was considered to be unable to give consent as opposed to after the client had already been approached). When this information was not provided, provided in part, or was inaccurate, study personnel had substantially more difficulty in recruiting participants.

¹⁵ Because staff of the two health regions and the various organizations reviewed the list of potential participants and made the initial contact regarding the study, it was difficult to determine how many individuals were considered to be inappropriate for the study or refused to have their name forwarded to study personnel.

to participate after being contacted by study personnel. One facility client (0.4% of the sample) died before completing the study. In the Winnipeg site, 9.8% of community clients and 14.3% of facility clients refused to participate. Six facility clients (2.5% of the sample) died before completing the study.

The final sample consisted of 580 clients, 222 community clients and 358 facility clients. The Victoria site had a total of 281 clients; 121 clients lived in the community, 160 lived in a facility. The Winnipeg site had a total of 299 clients; 101 lived in the community, 198 lived in a facility.

3.2.3 Identification of the Caregiver Sample

Where possible, informal caregivers were identified for clients who participated in the study. Cognitively intact clients were asked to identify an individual who provided them with unpaid assistance and who could be approached regarding the study. For cognitively impaired clients, an informal caregiver had often been identified (by a case manager, staff of a home support agency, or staff of a long term care facility) during the selection of the client sample.

A total of 501 caregivers participated in the study, 184 for community clients and 317 for facility clients. That is, 82.9% of the community clients and 88.5% of the facility clients had an informal caregiver participate in the study. In the Victoria site, there were 238 caregivers, 98 for community clients and 140 for facility clients. That is, 81.0% of the community clients and 87.5% of the facility clients in the Victoria site had a caregiver participate in the study. In the Winnipeg site, there were 263 caregivers, 86 for community clients and 177 for facility clients. That is, 85.1% of the community clients and 89.4% of the facility clients in the Winnipeg site had a caregiver who participated.

For the 79 clients for whom caregiver information was not available, 54 clients did not have a caregiver. The remaining 25 clients (4.3% of the full sample of 580 clients) had identified a caregiver, but the caregiver refused to participate.

3.3. **Procedure**

Five tools were used to examine the impact of care for each client in the study sample. A multi-section Client Questionnaire was used to obtain information about the client directly. This questionnaire obtained information about: the client's sociodemographic background; functional and cognitive abilities; use of, and satisfaction with, health related services; and perceptions of quality of life. A second multi-section instrument, the Caregiver Questionnaire, was used to obtain information from a family member, friend, or other informal caregiver about his or her experience of providing care to the client. This questionnaire obtained information about: the caregiver's sociodemographic background; care-related stress; and satisfaction with the client's use of health related services. Both the Client Questionnaire and the Caregiver Questionnaire were interviewer administered in separate sessions.

Diaries were used to collect information about time and assistance provided by formal

service providers either in the community or in long term care facilities, time and assistance provided by informal caregivers, and expenditures related to clients' health care needs. All diaries were kept for two weeks.

A more complete discussion of each of these tools is presented in Chapter 4.

3.3.1 Client Interviews

Study interviewers contacted those individuals who had expressed an interest in learning more about the study. Contact with community clients was generally by phone, while contact with facility clients was generally in person. When clients agreed to participate in the study, interviewers arranged a mutually convenient time for a face-to-face interview to be conducted at a location which was convenient for the client. For community clients, the interview was usually in the client's home. For facility clients, the interview was in a quiet location such as the client's room, a lounge, or other private room. As the nature of the study involved clients who were generally physically and/or mentally frail, it was often necessary to visit the client more than once. In total, each interview took approximately 1.10 hours (range .25 of an hour to 4.25 hours) to complete. The interview took significantly longer for community clients than for facility clients (1.33 hours compared to .95 of an hour, respectively), $t(565) = 6.33, p < .001$. Overall, Victoria clients took longer to complete the interview than Winnipeg clients (1.25 hours compared to .95 of an hour, respectively). This difference was significant, $t(565) = 5.43, p < .001$.

Before leaving community clients at the end of the first visit, interviewers explained the purpose of the various diaries and identified a location in the home where the diaries would be kept for a two week period. For community clients, two diaries (the Client Expenditures diary and the Formal Services – Community diary) were left in the client's home. Home support agencies were asked to notify their workers regarding the purpose of the diaries and to encourage them to complete them when they visited the client's home. Where possible, interviewers also spoke to the home support workers regarding the diaries and encouraged them to complete them during their shifts.

For facility clients, the Client Expenditures and Informal Caregiver diaries were often left by the client's bed, or were given to informal caregivers to keep at home. The Formal Services – Facility diaries were generally kept at the nursing station.

For both community and facility clients, the interviewer made arrangements to contact the client regularly (generally every two or three days) during the two week period to remind them about completing the diaries. In some cases, clients dictated the relevant information to the interviewers and the interviewers completed the diaries on their behalf. This was done when clients felt that they might be unable to complete the diaries on their own, generally because of physical frailty or limited time. The interviewers also checked on the Formal Services – Facility diaries on a regular basis (generally every day or every second day) to ensure that staff were completing them.

In some cases, clients were too ill or cognitively impaired to participate in the study directly. In these instances, proxies (generally informal caregivers) were asked to respond to items addressing factual information regarding the client but not those addressing beliefs, feelings, or perceptions. A similar procedure was used when interviewers judged that clients were not able to give informed consent.

3.3.2 Caregiver Interviews

The interview with the informal caregiver was usually done in one visit which took approximately .80 of an hour (range .25 of an hour to 3.00 hours). On average, the interview took .85 of an hour for community clients and .78 of an hour for facility clients. This difference was significant, $t(482) = 2.11$, $p < .05$. In the Victoria site, the interview took .83 of an hour to complete, while in the Winnipeg site, it took .78 of an hour to complete. This difference was not significant.

At the end of the interview, the interviewer explained the purpose of the Informal Caregiver diary. As with clients, arrangements were made to contact the informal caregivers regularly (generally every two or three days) over the two week period regarding the diaries. In some cases, the caregiver dictated the relevant information and the interviewer completed the diary on his/her behalf.

4. MEASUREMENT INSTRUMENTS AND DATA COLLECTION TOOLS

4.1 Introduction

All of the measurement instruments and data collection tools used in Substudy 5 were developed based on data collected in Substudy 4 of the National Evaluation of the Cost-Effectiveness of Home Care, which was a pilot study for the current study (Hollander, Chappell, Havens, McWilliam, Walker, Shaver, & Miller, 2001). The measurement instruments used in Substudy 4 were selected, in part, based on an extensive review of potential measurement instruments conducted by Hollander, Beebe and Stark (1996). The measures were chosen to assess the typical costs and outcomes of care for clients living in the community compared to clients living in long term care facilities. Measures were also chosen to assess the psychological, social and financial impacts of care provision on informal caregivers. Instruments were developed for areas where no acceptable instruments were found. Except for instruments developed specifically for use in the pilot study, all of the measures had been reported in the literature. Several of the measures used in Substudy 4 were modified for use in Substudy 5.¹⁶

Copies of all the measurement instruments and other data collection forms used in Substudy 5 are included in Appendix B.

4.2 Client Assessment

4.2.1 Demographic Information

The demographic information collected on clients included: gender, age, marital status, primary language, education, ethnic background, occupational background, and income. In addition, information was collected on items that were thought to have some potential clinical significance: the client's height, weight, weight change, and last influenza vaccination.

4.2.2 Functional Assessment and Determination of Care Level

In order to determine the costs and outcomes of care, it was important to assess the amount of care a client requires. In Substudy 5, a client's functional abilities were assessed using the Systeme de mesure de l'autonomie fonctionelle (Functional Autonomy Measurement System or SMAF) developed by Hébert, Carrier and Bilodeau (1988) which was based on the World Health Organization's (1980) classification of disabilities.

The SMAF consists of 29 items which measure functional abilities in five areas: activities of daily living (7 items), mobility (6 items), communication (3 items), mental functions (5 items) and instrumental activities of daily living (8 items). Each item is scored on a four point scale which ranges from 0 (independent) to -3 (dependent) for a maximum total score (using absolute

¹⁶ Reasons for modification included: the length of time required to administer the instrument; difficulties clients, informal caregivers and interviewers had with the wording of questions or response categories; and duplication of items across measures.

values) of 87. Higher scores are indicative of poorer functional ability. Desrosiers, Bravo, Hébert, and Dubuc (1995) reported test-retest and inter-rater reliabilities of .95 and .96, respectively for the total SMAF score. The correlation coefficients were over .74 for all five subscale scores (which correspond to the five areas of functioning) for both types of reliability (Desrosiers et al., 1995). The SMAF total score has been shown to correlate .80 with the Older American Resources and Services (OARS) activities of daily living questionnaire (McCusker, Bellavance, Cardin, & Belzile, 1999). The SMAF total score has also been shown to account for 85% of the variance in required nursing-care time (Hébert, et al., 2001).

4.2.3 Health Status of Clients

The health status of clients was assessed using three items from the standard version of the SF-36. The SF-36 is a short, self-report instrument which is designed to assess a person's perspective on his or her own health status (Ware & Sherbourne, 1992). The SF-36 addresses eight concepts of health (physical functioning, role limitations because of physical health problems, bodily pain, social functioning, general mental health, role limitations because of emotional problems, vitality, and general health perceptions). The reliability of the eight scales (which correspond to the eight health concepts) have been shown to range from .43 to .96 across 14 studies summarized by Ware, Snow, Kosinski, and Gandek (1997).

The three items from the SF-36 which were used as single item indicators in Substudy 5 were: "In general, would you say your health is..." (referred to as General Health); "Compared to one year ago, how would you rate your health in general now?" (referred to as Health Now Versus One Year Ago); and "During the past four weeks, to what extent has your physical health and emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?" (referred to as Health Interferes with Activities). These items were scored using a five point response scale (that varied depending on the question). Lower scores are indicative of perceptions of better health.

4.2.4 Cognitive Status

While it was recognized that the client's *functional* abilities would have a significant impact on both the client and the informal caregiver, it was also recognized that the client's *cognitive* abilities could have an impact on care. One of the most popular instruments used to assess cognitive status is the Mini-Mental Status Examination (MMSE). The MMSE assesses seven different dimensions of cognitive function: orientation to location and time; registration of information; attention; calculation; short-term memory; written and oral language skills; and visuospatial ability (Folstein, Folstein, & McHugh, 1975). The modified MMSE (or 3MS) was developed by adding four more items to the MMSE (Teng & Chui, 1987). These items sample a broader range of cognitive capacity and difficulty levels. The total possible score for the MMSE is 30; the total possible score on the 3MS is 100. Lower scores on both the MMSE and the 3MS are indicative of greater cognitive impairment. In general, individuals are considered to be cognitively intact if the 3MS score is higher than 77/100 (Tombaugh, McDowell, Kristjansson, & Hubley, 1996).

The 3MS was used in Substudy 5 to assess cognitive functioning because it allows for more sophisticated scoring and is more sensitive to subtle losses in cognition than the MMSE (McDowell, Kristjansson, Hill, & Hébert 1997). Teng and Chui (1987) reported a test-retest reliability of .91 for the 3MS. McDowell et al. (1997) reported a Cronbach's alpha of .87¹⁷ and a split-half reliability of .82.

4.2.5 Beliefs Related to Health

The Rosenberg (1965) Self Esteem Scale was used to assess feelings of self-worth or self-acceptance. The scale contains ten items which are scored using a four-point response format which ranges from "Strongly Agree" (1) to "Strongly Disagree" (4). Five of the items are reverse scored. The total possible score is 40. In this study, higher scores represent higher self-esteem. Although originally designed for adolescent populations, this scale has been shown to be a useful measure with older populations as well (e.g., Caserta & Lund, 1993; Gale, 1994). Rosenberg (1965) reported a reproducibility coefficient of .92 and a test-retest reliability over a two week period of .85 for the scale.

4.2.6 Social Relations

Social networks and supports have been shown to have a positive effect on health and well-being (e.g., Mor, Michal, & Miller, 1991; Potts, Hurwicz, Goldstein, & Berkanovic, 1992). While not identical, both social networks and social supports can be considered components of an individual's social relations. Ell (1984) defined *social networks* as including all of an individual's social contacts. Thoits (1982) defined *social supports* as a subset of people within a social network on whom an individual can rely for support. Social support is a more difficult construct to measure than social networks, since it must assess both a need for support as well as evidence of an exchange of instrumental or emotional support in response to that need (Lubben, 1988). Instrumental support refers to direct assistance with household or other daily tasks while emotional support refers to talking over issues and concerns.

Information regarding a client's social networks was assessed using three single items that asked clients about their living situation, the number of people they felt close to, and the number of people they had contact with on a regular basis. These questions were developed by the study investigators.

Four questions from Seeman and Berkman's (1988) Social Support Scale were used to examine both instrumental and emotional support. These questions address the availability and adequacy of both types of support. The questions can be paraphrased as: 1) When you need some extra help, can you count on anyone to help with daily tasks? 2) Could you have used more help with daily tasks than you received? 3) Can you count on anyone to provide you with emotional support? 4) Could you have used more emotional support than you received? The questions addressing availability were answered using "Yes," "No," or "I don't need help." The questions

¹⁷ Cronbach's alpha is a measure of the internal consistency of a scale. Scores over 0.7 are considered adequate, scores above 0.8 are considered to be good, and scores of 0.9 or higher are considered to be excellent with regard to the psychometric properties of a scale.

addressing adequacy of support involved a four point response scale which ranged from “A lot” (1) to “None at all” (4). Higher scores on these latter questions were indicative of better support.

4.3 Use of Services by Clients

The Client Questionnaire also included two sets of questions on the types of health related assistance the client received. The first set of questions was developed by the investigators and addressed assistance with various tasks provided by informal caregivers. The tasks included household maintenance (meal preparation, housework), personal care (dressing, personal hygiene), physical functioning (moving around the house, getting in and out of bed), and finances (managing finances, shopping).

The second set of questions was developed by Browne, Gafni, Roberts and Hoxby (1992) to address health and social service utilization and is referred to here as the Health and Social Services Utilization Tool. The tool consists of questions about the respondent’s use of eight categories of direct health services (such as physicians, home support workers, and therapists). It also includes a number of items related to the cost of health related supplies (such as dressings and equipment) and services (such as household help and transportation) which were designed to assess out-of-pocket expenditures. Browne et al. (1992) reported limited psychometric data for this instrument.

4.4 Outcome Measures for Clients

In addition to collecting information on demographics, functional status, general health status, cognitive status, beliefs about health, social relations, and service utilization, the Client Questionnaire collected information on several measures of quality of life and client satisfaction with care related services.

4.4.1 Quality of Life

Three measures of quality of life were included in Substudy 5: Hadorn, Sorensen and Holte’s (1995) Health Related Quality of Life Scale (interviewer version); the Terrible-Delightful Scale (Centre on Aging, 1995); and a question on general satisfaction with life.

Hadorn et al.’s (1995) Health Related Quality of Life Scale consists of ten questions which focus on four areas: physical suffering; limits on daily activities; emotional outlook on life; and overall quality of life. The first three areas contain three items each. Each item has a four point response scale with higher scores indicating poorer quality of health. The version of the Health Related Quality of Life Scale that was used in Substudy 5 was designed to be administered by an interviewer. While nine of the ten questions are addressed to a respondent, the tenth question is the *interviewer’s* global estimate of the respondent’s quality of life. The test-retest reliabilities for the scale are reasonably good. Hadorn et al. (1995) reported a correlation of .50 between scores obtained at time zero and three months, a correlation of .38 between scores obtained at time zero and six months, and a correlation of .59 between scores obtained at three and six months.

The Terrible-Delightful Scale (Centre on Aging, 1995) consists of nine items which focus on a number of concepts that have been linked to quality of life: health; finances; family relations; friendships; housing; recreation; spirituality; self-esteem; and transportation. For each item, respondents are asked how they would rate their own life with respect to the item using a three-point scale which ranges from “Dissatisfying” (1) to “Satisfying” (3).¹⁸ The maximum score on this measure is 27, with higher scores reflecting greater perceived quality of life. Hollander et al. (2001) reported a Cronbach’s alpha of .69 for this measure.

Satisfaction with life was also assessed using a single item: “How would you describe your satisfaction with life in general at present?”¹⁹ A five-point response scale ranging from “Excellent” (1) to “Bad” (5) was used. Thus, for this scale higher values represent lower satisfaction with life.

4.4.2 Satisfaction with Care Related Services

Satisfaction with care related services was assessed using questions developed by Penning and Chappell (1996). These questions addressed client choice (3 items), worker characteristics (8 items), and care concerns (4 items). Responses are scored using a three point scale which ranges from “Rarely” (1) to “Always” (3). Higher scores are indicative of greater satisfaction. Satisfaction with services was also assessed using a number of questions which focused on the cost of services and the ability of the received services to promote client independence.

4.5 **Informal Caregivers**

Information regarding family members and friends who provide care to clients was collected using a multi-section Caregiver Questionnaire. This questionnaire included: demographic information; information regarding the type of assistance/care required by the client; information regarding the impact of caregiving; and satisfaction with services. Several of the scales on the Caregiver Questionnaire were identical to those on the Client Questionnaire thus allowing for comparisons between the client’s and caregiver’s perceptions on the same aspects of care.

4.5.1 Demographic Information for Caregivers

Demographic information was collected regarding the caregiver’s gender, age, marital status, education, ethnic background, occupational background, income, and caregiving history.

¹⁸ In Substudy 4, a seven-point response scale, similar to that developed by Andrews and Withey (1976) was used. However, many clients in the pilot study found the number of response categories too confusing. Thus, the number of response categories was reduced for Substudy 5.

¹⁹ This question is similar to other global measures of an individual’s perception of his or her satisfaction with life which were reviewed by Sauer and Warland (1982).

4.5.2 Caregiving Assistance Required as a Result of Client's Needs

The type of caregiving assistance required by a client was assessed using two measures. The first measure was developed by the investigators and focused on the types of assistance the informal caregiver provided to the client. It was identical to the scale used to address clients' perspectives on the informal assistance they received. The tasks included household maintenance (meal preparation, housework), personal care (dressing, personal hygiene), physical functioning (moving around the house, getting in and out of bed) and finances (managing finances, shopping).

The second measure was modified from the Dementia Behaviour Disturbance Scale developed by Baumgarten, Becker and Gauthier (1990). The original scale contained 28 items. Cronbach's alpha for the 28 item scale was .83 and the test-retest reliability over a two week period was .71 (Baumgarten et al., 1990). The modified scale used in Substudy 5 included 11 items. The scale used a five point response scale which ranged from "Never" (0) to "All the time" (4). The maximum possible score is 44, with higher scores reflecting greater behavioural disturbance.

4.5.3 Effect of Caregiving

The effect of providing care to a family member or friend was assessed using a modified version of the Montgomery Burden Scale (Montgomery, Gonyea, & Hooyman, 1985). The original scale consisted of 22 items which measured both objective and subjective burden. Montgomery et al. reported Cronbach's alphas of .85 for both subscales.

The modified version contained 14 items. Six items assessed various aspects of objective burden such as: the amount of time the respondent had to himself/herself; the amount of privacy the caregiver had; and the amount of time the caregiver had for recreational activities. The remaining eight items assessed several aspects of subjective burden such as: feeling stressed by one's relationship with the person receiving care; feeling anxious about things; and feeling that one is being manipulated by the person receiving care. Responses were scored using a five point response scale which ranged from "A lot less" (1) to "A lot more" (5). For objective burden, the maximum score was 30 with higher scores reflecting less burden. For subjective burden, the maximum score was 40 with higher scores reflecting greater burden.

4.5.4 Caregiver Satisfaction

The caregiver's satisfaction with the services the client receives was assessed using questions developed by Penning and Chappell (1996). These were similar to the questions used to assess client satisfaction with services and addressed caregiver's satisfaction with client choice (3 questions), worker characteristics (8 questions), and care concerns (4 questions). Responses are scored using a three point scale which ranges from "Rarely" (1) to "Always" (3). Higher scores are indicative of greater satisfaction. As with the Client Questionnaire, satisfaction with services was also assessed using a number of questions which focused on the cost of services and the ability of the received services to promote client independence.

4.6 Diaries

One of the goals of Substudy 5 was to obtain estimates of the costs of formal and informal home care and residential care by examining the amount of time and type of assistance provided by formal service providers, the amount of time and type of assistance provided by informal caregivers, and the out-of-pocket expenses of both clients and informal caregivers. As there is no existing log book method for collecting these data that has been tested for validity and reliability, the investigators developed the diaries based on their own work and experience.²⁰

4.6.1 Time and Assistance Provided by Formal Service Providers

Health care staff in both the community and the facilities were asked to record the amount of time and assistance they provided to clients. The time and assistance spent by health care workers and professionals who provided services to community clients were recorded in the Diary of Formal Care Services Provided to Persons Living in the Community (the “Formal Services – Community” diary). This diary was completed by the client, the informal caregiver, a service provider, or a combination of individuals. The diary was used to record services provided in the home as well as services provided in the community. Examples of activities which could be recorded in this diary included: visits to the doctor; lab tests; home nursing; home support; physiotherapy and occupational therapy; services of mental health staff; and visits to an adult day centre.

The time and assistance spent by health care workers and professionals who provided services to facility clients were recorded in the Diary for Formal Care Services Provided to Persons Living in Facilities (the “Formal Services – Facility” diary). This diary was used to record the amount of formal (or paid) services provided to clients by a variety of staff members, including nurses, care aides, and cleaning and activities staff, as well as physicians or other health providers who visited the facility.

4.6.2 Time and Assistance Provided by Informal Caregivers

Informal caregivers were asked to keep a record of the amount of time and assistance that they provided to clients using the Diary of the Assistance Provided by Family Members and Other Unpaid Helpers to the Person Receiving Care (the “Informal Caregiver” diary). Caregivers were asked to record only time and activities that they provided *because of* the client’s health care needs. Examples of activities which were to be included in the diary included: housekeeping; meal preparation; banking; transportation; giving medication; assistance with medical equipment such as oxygen tanks; assistance with bathing, grooming, and dressing; and supportive help such as visiting and recreational activities.

²⁰ The value of diaries as a data collection method in a study of this nature has been discussed by Hollander et al. (1996).

4.6.3 Client Expenditures

Clients and informal caregivers were asked to keep a record of their expenditures related to the client's health care needs using the Diary for Care Related Expenditures by Client, Family Members, and Other Unpaid Helpers (the "Client Expenditures" diary). This diary was used to estimate the cost of caring for the person in care by adding the health-related costs incurred by the client, family members, or friends of the individual in care to the costs of the services provided by the overall health care system. Care-related expenditures which were to be included in the diary included: food for special diets; medical supplies; prescription and non-prescription drugs; herbs or other remedies; services of care providers not covered by Medicare, such as herbalists and naturopaths; transportation costs related to care; user fees, co-payments, and full cost (where applicable) for health care services such as day centres or physiotherapists; and other care related expenditures.

4.7 **Summary**

In summary, information regarding the impact of needed health care services was addressed using five instruments: the Client Questionnaire, the Caregiver Questionnaire; either the Formal Services – Community or the Formal Services – Facility diary; the Informal Caregiver diary; and the Client Expenditures diary. With the exception of the Formal Services diaries, the same instruments were used for both community and facility clients, and similar instruments were used to collect information from their informal caregivers.

The Client Questionnaire was used to obtain information about the client directly. A variety of measures assessing functional abilities, cognitive abilities, quality of life and satisfaction with services were included in this multi-section questionnaire. These were (in the order in which they appeared on the questionnaire): Demographics; Client Satisfaction with Services (Penning & Chappell, 1996); 3MS (Teng & Chui, 1987); SMAF (Hébert et al., 1988); Health and Social Service Utilization Tool (Browne et al., 1992); Health Related Quality of Life (Hadorn et al., 1995); Terrible-Delightful Scale (Centre on Aging, 1995); General Life Satisfaction (single item); Health Status (SF-36) items (Ware & Sherbourne, 1992); Self-Esteem Scale (Rosenberg, 1965); Social Support (Seeman & Berkman, 1988); and Caregiving (type and amount of assistance provided by informal caregivers to clients).

The Caregiver Questionnaire was used to obtain information from family members, friends, and volunteers about their experience of providing care to the client. This multi-section questionnaire included the following (in the order in which the measures appeared on the questionnaire): Caregiving Questions (type and amount of assistance provided by informal caregivers); (modified) Montgomery Burden Scale (Montgomery et al., 1985); List of Behavioural Problems (modified Dementia Behaviour Disturbance Scale; Baumgarten et al., 1990); Caregiver Satisfaction (with services the client is receiving; Penning & Chappell, 1996); and Demographics.

The diaries were used to assess time and assistance provided by both formal service providers and informal caregivers as well as health related expenditures for the client.

5. DESCRIPTION OF THE SAMPLE AND DISCUSSION OF FINDINGS REGARDING THE OUTCOME MEASURES FOR CLIENTS

In an ideal situation, one would wish to assess the same individuals over a period of time. However, many clients come into care during some form of crisis and this often has a significant impact on the physical, psychological and emotional care requirements of both the client and his or her informal caregivers. In an effort to reduce the potential influence that changes in care needs could have on the costs and outcomes of care, this study involved a cross-sectional survey of both community and facility clients who were relatively stable in their type and level of care. The study also collected information on the effect caregiving had on the informal caregivers of these clients.

This chapter, Chapter 5, provides a description of the client sample and presents findings on the outcome measures for clients. Chapter 6 provides a description of the informal caregiver sample and presents findings on the caregiver measures. Chapter 7 presents information on the formal and informal costs for both community and facility clients using data provided by clients, informal caregivers and formal service providers. Chapter 8 discusses the policy implications of the data presented in Chapters 5 to 7.

5.1 Demographic Information

Table 5-1 provides a description of the client sample in each of the two study sites. Approximately 43% of the sample in the Victoria site and 34% of the sample in the Winnipeg site were from the community. A number of t-test and chi-square analyses were conducted on the demographic data to determine if there were differences between the two study sites (Victoria versus Winnipeg) or between the two types of care (community versus facility).²¹

Overall, 23.4% of the sample was male; 76.6% was female. Some 26.1% of the community sample was male, while 21.8% of the facility sample was male. Over half (57.3%) of the males in the sample lived in facilities. For females, 63.1% lived in facilities. There was no significant difference between the two study sites or between the two types of care with respect to gender.

Some 13.2% of the sample was in the “young-old” group (that is, 65 to 74 years of age), 33.6% of the sample was in the “middle-old” group (75 to 84 years of age). A further 53.3% of the sample was in the “old-old” group (85 years of age and older). Some 8.8% of the sample was over 95 years of age. Overall, the mean age was 84.3 years. The mean age of the Victoria clients was 84.9 years while the mean age for the Winnipeg clients was 83.8 years. This difference was not significant. The mean age for the community sample was 82.5 years, while for the facility sample, the mean age was 85.5 years. This difference was significant, $t(567) = 4.50, p < .001$.

²¹ Because this was an exploratory study, multiple analyses were done on all of the measures used in this study. No Bonferroni corrections were made to the probability levels in order to identify potentially significant findings where none were expected.

Table 5-1: Description of the Client Sample in the Two Study Sites

		Victoria		Winnipeg		Total			
		Community	Facility	Community	Facility	Community		Facility	
		Percent	Percent	Percent	Percent	Number	Percent	Number	Percent
Gender	Male	21.5	24.4	31.7	19.7	58	26.1	78	21.8
	Female	78.5	75.6	68.3	80.3	164	73.9	280	78.2
Age	65 to 74 years	16.5	8.1	23.7	9.9	43	19.7	32	9.1
	75 to 84 years	32.3	28.8	43.3	33.5	81	37.2	110	31.3
	85 to 94 years	46.3	53.1	26.8	45.0	82	37.6	171	48.7
	95+ years	5.0	10.0	6.2	11.5	12	5.5	38	10.8
Education	Grade 8 or less	24.2	23.6	29.5	36.3	57	26.5	102	30.4
	Some high school	24.2	22.9	21.1	22.9	49	22.8	77	22.9
	High school graduation	19.2	19.7	25.3	13.4	47	21.9	55	16.4
	Some technical, trade school or college	25.8	26.1	12.6	21.2	43	20.0	79	23.5
	Bachelor or graduate degree	6.7	7.6	11.6	6.1	19	8.8	23	6.8
Income	< \$15,000	65.1	48.5	48.8	60.7	110	58.2	135	55.6
	\$15,000 to \$29,999	21.1	37.9	28.8	28.6	46	24.3	79	32.5
	\$30,000+	13.8	13.6	22.5	10.7	33	17.5	29	11.9
Marital Status of Client	Never Married, separated or divorced	15.7	13.1	15.8	16.3	35	15.8	53	14.9
	Married/common law	17.4	13.8	40.6	17.9	62	27.9	57	16.0
	Widowed	66.9	73.1	43.6	65.8	125	56.3	246	69.1

Some 28.9% of the sample had grade 8 education or less. A further 29.8% had some post-secondary training, but only 7.6% had obtained a university degree. There was no significant difference between the two study sites or between the two types of care with respect to education.

The majority (86.5%) of the sample indicated that English was their primary language. This is not surprising since the ability to communicate in English (either currently or in the past in the case of someone with dementia) was one of the selection criteria for the study. However, 78 clients (13.4% of the sample) indicated that their primary language was not English (this does not mean that they could not communicate in English, only that in most cases their preferred language was something other than English). Compared to clients in the Winnipeg site, significantly more clients in the Victoria site indicated that their primary language was English, $X^2(1) = 6.69, p < .01$. There was no difference between community and facility clients with respect to language.

Over half (56.7%) of the sample had an income of less than \$15,000 per year, while only 14.4% of the sample had an income of \$30,000 or more per year. The two study sites did not differ with respect to income. As well, there was no difference between community and facility clients with respect to income.

The majority (64.2%) of the sample was widowed; 20.6% of the sample was married or living common law. The remaining 15.2% of the sample was single (never married, separated or divorced). More of the Winnipeg sample than the Victoria sample was married or living common law (63.9% compared to 36.1%, respectively). This difference was significant, $X^2(1) = 7.28, p < .01$. The two study sites were similar with respect to the number of widowed and single clients. Significantly more of the married clients lived in the community than in a facility, $X^2(1) = 9.68, p < .01$. There were no significant differences between the community and facility samples for either the widowed or the single clients.

5.2 Functional Assessment and Determination of Care Level

The Functional Autonomy Measurement System (SMAF) developed by Hébert et al. (1988) was used to assess client functioning. In the current study, study personnel completed the SMAF using information provided by the client, a caregiver proxy, a health care professional (such as a care aide or nurse), or a combination of individuals. Missing responses on the SMAF were estimated using the mean of the client's score for the other items on the same subscale. Using scores on the five subscales and the total SMAF score, individuals can be categorized using a 14 category classification system developed by Dubuc, Hébert, Desrosiers, Buteau, & Trottier (1999). The categories are related to the amount of assistance the client requires; clients in Category 1 require the least amount of assistance, while those in Category 14 require the most. Thus, each of the categories can be considered a "level of care."

Given that both community and facility clients were sampled from the same care levels within each individual study site, it was expected that community and facility clients would be identical with respect to care level. Because clients were sampled from the third and fourth levels of a five level system in B.C. and from the third and fourth levels of a four level system in

Manitoba, it was expected that the clients would be concentrated in the middle to upper categories of the Dubuc et al. (1999) SMAF classification system. Moreover, it was expected that despite differences between jurisdictions, clients were sampled at comparable care levels in the two study sites.

Using the Dubuc et al. approach with the current data revealed that clients were captured in each of the 14 categories with 23.6% of the sample falling into the four lowest care levels. As well, many more community clients than facility clients were in one of the four lowest care levels (49.5% versus 7.3% for community and facility clients, respectively) while more facility than community clients were in one of the four highest care levels (32.7% versus 18.5% for facility and community clients, respectively). In the Victoria site, 36.3% of the clients were in the four lowest care levels, while 11.4% were in the four highest care levels. In contrast, in the Winnipeg site, 11.5% of the clients were in the four lowest care levels and 42.2% were in the four highest levels. Thus, the distribution of scores on the SMAF was substantially different from what had been expected.

5.2.1 Creation of Care Levels

Because of the findings noted above, a decision was made to use total SMAF scores²² rather than the Dubuc et al. classification system. A Pearson correlation conducted between category allocations using the Dubuc et al. classification system and total scores on the SMAF was significant ($r = .95$, $p < .001$) indicating that the two scales were closely related.

Using total SMAF scores, seven “care level” categories were created. The first category included SMAF scores of less than 14.0. The second category included SMAF scores of 14.0 to 22.5. The third category included SMAF scores of 23.0 to 35.0. The fourth category included SMAF scores of 35.5 to 45.5. The fifth category included SMAF scores of 46.0 to 61.0. The sixth category included SMAF scores of 61.5 to 68.5 and the seventh category included scores of more than 68.5.

Since the primary focus of this study was to determine whether community and facility clients differed with respect to health related care costs, it was important to show that community and facility clients did not differ on the client assessment and outcome measures. Using total SMAF scores as the dependent variable, a 2 (type of care; community versus facility) by 7 (care levels) ANOVA was conducted. It was expected that the analysis would show a significant main effect for care levels indicating that the seven groups were distinctly different. However, it was also expected that neither a significant main effect for type of care nor a significant interaction would be obtained.²³ The results were as expected. The ANOVA revealed a significant main

²² Many care level systems use the client’s ability to function on activities of daily living (ADLs) as the base. However, Thomas, Rockwood, and McDowell (1998) have argued that by using ADLs only, one underestimates both dysfunction and disability. It was felt, therefore, that the total SMAF score would be a better measure of overall client function than any one of the subscales alone since it is based on a wider range of abilities.

²³ A significant main effect of type of care would indicate that community clients were different from facility clients while a significant interaction would indicate that community and facility clients were different from each other, but only for one or more of the care levels.

effect of care levels ($F(6, 563) = 1423.51, p < .001$). Neither the main effect of type of care nor the type of care by care levels interaction was significant.²⁴

A further examination of the data, however, indicated that there was only 1 facility client at Level 1 (compared to 28 community clients) and only 9 community clients in Level 7 (compared to 30 facility clients). It was also noted that for the Victoria sample, there were 23 community clients and 1 facility client in Level 1, 0 community clients and 6 facility clients in Level 6, and 2 community clients and 1 facility client in Level 7. In the Winnipeg sample, there were 5 community clients and 0 facility clients in Level 1, 10 community clients and 2 facility clients in Level 2, and 7 community and 29 facility clients in Level 7. Thus the distribution of SMAF scores in the two study sites was quite different. More of the Victoria sample was in the lower end of the distribution while more of the Winnipeg sample was in the upper end. That is, Victoria clients were generally more functional (as measured by the SMAF) than Winnipeg clients.

5.2.2 Creation of Two Separate Samples

It had initially been anticipated that the data from the two study sites would be combined to obtain a larger sample size and thus increase the robustness of the statistical analyses. Given the findings discussed above, however, it was decided that the data from the two study sites should be analyzed separately. Therefore, the two study sites were considered to be a replication (as opposed to part of the same sample) and two new samples were created.

First, a Victoria sample was created by eliminating clients from Levels 1, 6 and 7. This resulted in a total loss of 33 out of 281 clients (or 11.7% of the sample).²⁵ These clients represent 25 out of 121 community clients (or 20.7% of the community sample); 23 of these clients were in Level 1 and 2 were in Level 7.²⁶ The remaining clients who were eliminated from the Victoria sample were all facility clients and represented 8 out of 160 facility clients or 5.0% of the facility sample. One of these clients was in Level 1, 6 were in Level 6 and 1 was in Level 7. Thus, in the analyses reported below on the Victoria sample, the data were obtained from 248 clients in Levels 2 to 5.

Second, a Winnipeg sample was created by eliminating clients from Levels 1, 2 and 7.

²⁴ A 2 (type of care) by 7 (care levels) ANOVA conducted on each of the study sites individually supported these findings.

²⁵ One might question whether, given the numbers in these cells, the cut-points used for the various care levels were appropriate. Several other cut-points were tried. These other approaches resulted in the elimination of more clients from the sample.

²⁶ Analyses comparing the Victoria community clients in Level 1 (who were eliminated from the analyses reported below) with those in Levels 2 to 5 (who were retained for the analyses reported in the following sections) were conducted. There were no differences between the community clients in Level 1 and those in Levels 2 to 6 with respect to gender, age, education level, ethnic background, income, or marital status. Clients in Level 1 scored significantly higher on the 3MS than clients in Levels 2 to 5, $t(83) = 2.14, p < .05$. Clients in Level 1 were likely to live with fewer people than clients in Levels 2 to 5, $t(59) = 2.06, p < .05$. Clients in Level 1 did not differ from Clients in Levels 2 to 5 on any of the other measures.

This resulted in a total loss of 53 out of 296 clients (or 17.9% of the sample).²⁷ These clients represent 22 out of 101 community clients (or 21.8% of the community sample); 5 of these clients were in Level 1, 10 were in Level 2, and 7 were in Level 7. The remaining clients who were eliminated represented 31 out of 195 facility clients (or 15.9% of the facility sample); 2 of these were in Level 2 and 29 were in Level 7.²⁸ Thus, in the analyses reported below on the Winnipeg sample, the data were obtained from 243 clients in Levels 3 to 6.

Data for the two new samples are presented in Table 5-2. Note that in this table, the care levels were relabelled such that data in Level A represent the Somewhat Independent clients in these samples with original SMAF scores of 14.0 to 22.5; the data in Level B represent the Slightly Independent clients with SMAF scores of 23.0 to 35.0; the data in Level C represent the Slightly Dependent clients with SMAF scores of 35.5 to 45.5; the data in Level D represent the Somewhat Dependent clients with SMAF scores of 46.0 to 61.0; and the data in Level E represent the Largely Dependent clients with SMAF scores of 61.5 to 68.5.

Table 5-2: Means and Standard Deviations for Total SMAF Scores by Care Levels for the Two New Samples

Care Level ²⁹		Victoria Sample			Winnipeg Sample		
		Community	Facility	Total	Community	Facility	Total
Level A: Somewhat Independent (14.0 to 22.5)	Mean	18.60	19.06	18.73			
	Standard Deviation	2.56	2.46	2.52			
	Number	43	17	60			
Level B: Slightly Independent (23.0 to 35.0)	Mean	28.47	29.21	28.95	29.85	30.73	30.25
	Standard Deviation	3.73	3.43	3.53	3.11	3.41	3.24
	Number	29	53	82	20	17	37
Level C: Slightly Dependent (35.5 to 45.5)	Mean	39.73	39.97	39.93	40.30	40.84	40.67
	Standard Deviation	2.24	3.16	2.99	3.44	3.04	3.15
	Number	13	56	69	20	45	65
Level D: Somewhat Dependent (46.0 to 61.0)	Mean	53.05	52.48	52.65	53.17	53.22	53.20
	Standard Deviation	5.35	5.05	5.08	4.95	4.85	4.86
	Number	11	26	37	29	66	95
Level E: Largely Dependent (61.5 to 68.5)	Mean				64.85	64.71	64.74
	Standard Deviation				2.47	1.82	1.95
	Number				10	36	46
Total for Victoria Sample (Levels A to D)	Mean	28.39	36.02 ³⁰	33.07			
	Standard Deviation	11.92	10.66	11.75			
	Number	96	152	248			
Total for Winnipeg Sample (Levels B to E)	Mean				45.49	50.01	48.54
	Standard Deviation				12.42	11.30	11.84
	Number				79	164	243

²⁷ SMAF scores were not available for three facility clients in the Winnipeg sample. Any of the analyses involving care levels or SMAF scores do not include these individuals.

²⁸ Analyses were conducted which compared the Winnipeg facility clients in Level 7 (who were eliminated from the analyses reported below) with those in Levels 3 to 6 (who were retained for the analyses reported in the following sections). There were no differences between the facility clients in Level 7 and those in Levels 3 to 6 with respect to gender, age, education level, ethnic background, income, or marital status. As proxies were used for all of the clients in Level 7, it was not possible to do analyses on any of the assessment or outcome measures as data were not collected from proxies for these instruments.

²⁹ The values in parentheses following the Care Level label refer to the range of scores on the SMAF for that care level. The total possible SMAF score is 87. Higher scores are indicative of poorer functioning.

³⁰ The means for community and facility clients differ slightly in both samples because of the differential cell sizes.

In the discussion of the study results presented below on each measure, analyses of the data in the Victoria sample (Levels A to D in Table 5-2) are presented first, followed by analyses of the data in the Winnipeg sample (Levels B to E in Table 5-2).³¹ Except where otherwise noted, any discussion of care levels in the remainder of this report will use the care levels defined in Table 5-2.

The analyses reported above for the seven care levels (see Section 5.2.1) were rerun on both of the new samples. The main effect of care levels was significant in both samples; for the Victoria sample, $F(3, 240) = 690.55, p < .001$, and for the Winnipeg sample, $F(3, 235) = 589.34, p < .001$. Neither the main effect of type of care nor the type of care by care levels interaction was significant in either of the samples. These analyses indicated that in both samples, there is a difference between clients in the different care levels, but community and facility clients within each care level are comparable.

Thus, by using SMAF total scores and eliminating some clients in both study sites from the sample, the number of categories being used in the analyses was reduced, the functional abilities of community and facility clients was comparable within each care level, and differences in the distribution of SMAF scores between the two study sites were acknowledged.

5.3 Involvement of Proxies

As noted in Chapter 3, a proxy was used when a client was considered to be too physically or cognitively frail to participate in the study directly. Proxies were asked to provide only factual information regarding the client. In some cases, both the client and a proxy may have answered sections of the Client Questionnaire. In other cases, one or more proxies answered the questionnaire on behalf of the client. When only proxies were used, data were not obtained for many of the measures on the Client Questionnaire.

When clients in the new samples were considered (that is, those described in Table 5-2), one or more proxies were used for 137 of the 248 clients (55.2%) in the Victoria sample, and 190 of the 243 clients (78.2%) in the Winnipeg sample.³²

Given the large proportion of each sample that involved proxy input, it was important to determine whether clients who responded to the Client Questionnaire themselves (the non-proxy group) differed from clients where information was provided by a proxy (the proxy group). Several analyses were conducted to determine if the non-proxy group differed from the proxy

³¹ The correlations between the care levels in the two new samples and the 14 categories in the Dubuc et al. (1999) classification system were rerun to determine whether there was a substantial loss of information by creating these samples. For the care levels in the Victoria sample, the correlation with the 14 categories was $r = .88, p < .001$. For the care levels in the Winnipeg sample, the correlation between the two scales was $r = .85, p < .001$. Thus, it appears that there was no substantial loss of information in either of the samples.

³² In comparison, proxies were used for 379 out of the original sample of 580 clients (65.3% of the sample). One or more proxies were used for a total of 146 of the 281 clients in the Victoria site (52.0% of the sample). One or more proxies were used for 233 of the 299 clients in the Winnipeg site (77.9% of the sample).

group on the only data that could be compared between the two groups of clients – the demographic variables and total SMAF scores.

For the Victoria sample, the proxy and non-proxy groups did not differ with respect to age, education, primary language, ethnic background, income, and marital status. They did, however, differ with respect to gender and SMAF score. With respect to gender, the proxy and non-proxy groups in the Victoria sample contained approximately the same number of females. However, the non-proxy group contained significantly fewer males than the proxy group, $X^2(1) = 4.41$, $p < .05$. With respect to SMAF score, the non-proxy group scored significantly lower on the SMAF (mean score 26.21) than the proxy group (mean score 38.62), $t(244) = 10.02$, $p < .001$.

For the Winnipeg sample, the proxy and non-proxy groups did not differ with respect to gender, education, ethnic background, and marital status. They did, however, differ with respect to age, income, primary language, and SMAF score. With respect to age, the non-proxy group was significantly younger (mean age 81.1 years) than the proxy group (mean age 84.4 years), $t(234) = 2.56$, $p < .01$.³³ The annual income of the non-proxy group was significantly higher than the annual income of the proxy group, $t(218) = 2.19$, $p < .05$. More of the proxy group than the non-proxy group indicated that their primary language was something other than English, $X^2(1) = 5.64$, $p < .05$. The non-proxy group had lower scores on the SMAF (mean score 36.89) than the proxy group (mean score 51.79), $t(118) = 11.54$, $p < .001$.

Taken together, the findings indicated that the proxy and non-proxy groups in both samples generally do not differ with respect to the demographic variables. As might be expected, however, in both samples the non-proxy group was more functional (that is, had lower scores on the SMAF) than the proxy group. This finding is not unexpected given that proxies were used when clients were considered to be very physically and/or cognitively frail.

5.4 Health Status of Clients

Three single item indicators, taken from the standard version of the SF-36 (Ware & Sherbourne, 1992), were used to assess the health status of clients. Only clients were asked to respond to the questions; no data were obtained for those clients where proxies provided information.

An attempt was made to combine the three questions into a single measure. However, Cronbach's alpha for the combined measure was quite poor for both samples. For the Victoria sample it was .50 and for the Winnipeg sample it was .57. The alpha value did not improve with the deletion of any of the questions individually in either of the samples. Therefore, the three

³³ Since proxies were used when clients were considered to be too frail to participate directly, it could be expected that scores on the SMAF would be significantly correlated with age. However, the correlation between client age and SMAF total for the Winnipeg sample was not significant, $r = .10$.

items were treated individually in the following analyses.³⁴

5.4.1 General Health

A two-factor (type of care by care levels) ANOVA was conducted on both samples for the item regarding perceptions of one's general health. Similar findings were obtained in each analysis: the main effect of type of care was significant, but neither the main effect of care levels nor the type of care by care levels interaction was significant. The main effect of type of care for the Victoria sample was $F(1, 137) = 5.92, p < .05$, and for the Winnipeg sample it was $F(1, 79) = 9.59, p < .01$. In both cases, the analyses indicated that facility clients perceived their general health to be significantly better than community clients. Clients at the various care levels were comparable.

5.4.2 Health Now Versus One Year Ago

A two-factor (type of care by care levels) ANOVA was conducted on each sample for the item assessing perceived health now compared to one year ago. The main effect of type of care was significant in the Winnipeg sample ($F(1, 78) = 15.13, p < .001$), but not in the Victoria sample. Neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample. The findings indicated that in the Winnipeg sample, relative to community clients, facility clients felt that their health was better now than it was a year ago. In the Victoria sample, community and facility clients were comparable with respect to their perceptions of their health now compared to one year ago. Clients at the various care levels were comparable.

5.4.3 Health Interferes with Activities

Two-factor (type of care by care levels) ANOVAs were conducted on the two samples for the item assessing how one's health had interfered with his or her social activities. The main effect of type of care was significant in the Winnipeg sample ($F(1, 77) = 9.54, p < .01$), but not in the Victoria sample. Neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample. Although the main effect of type of care was not significant for the Victoria sample, the pattern of results was similar in both samples: community clients felt that their health interfered more with their social activities than facility clients did. Clients at the various care levels were comparable in both samples.

5.4.4 Summary of Findings on Health Status

In summary, analyses of the Health Status items for both samples indicated that compared to community clients, facility clients generally felt better about their health. This may have been

³⁴ Proxies could not provide data for the health status items and many of the other measures included on the Client Questionnaire. For many of the measures, there was minimal or no data for clients in Level D in the Victoria sample and in Level E in the Winnipeg sample. These clients were eliminated from the analyses reported in the main body of the text. All analyses were run with and without these clients included. In every case, similar findings were obtained (although the degrees of freedom were reduced when the clients were eliminated).

due, in part, to facility clients feeling they were in a more structured and controllable environment compared to community clients (see Appendix A for more information). Clients across the different care levels were comparable on all of the Health Status items in both samples.

5.5 Cognitive Status

The cognitive status of clients was assessed using the 3MS (Teng & Chui, 1987). The 3MS was administered to clients who were deemed to be capable of giving informed consent and when the cognitive status of clients was unclear. In the latter case, a client's score on the 3MS may have been used as a reason for obtaining proxy consent. When it was known prior to the study that the client would not be capable of giving informed consent because of cognitive impairment, the 3MS was not administered.

A two-factor (type of care by care levels) ANOVA was conducted on each sample. Similar findings were obtained in the two analyses: both the main effect of type of care and the main effect of care levels were significant, although the type of care by care levels interaction was not significant. For the Victoria sample, the main effect of type of care was $F(1, 135) = 5.89, p < .05$; the main effect of care levels was $F(2, 135) = 6.44, p < .01$. For the Winnipeg sample, the main effect of type of care was $F(1, 90) = 9.42, p < .01$; the main effect of care levels was $F(2, 90) = 3.66, p < .05$.

Taken together, the findings indicated that, in both study sites, community clients were less cognitively impaired than facility clients. In both study sites, as might be expected, the findings also indicated that cognitive functioning decreased as care level increased (that is, as clients became less functional).³⁵ These findings are not unexpected in that decreased cognitive ability may be one reason an individual is placed in a facility.

5.6 Beliefs Related to Health

The Rosenberg (1965) Self-Esteem Scale was used to assess beliefs related to health. Responses on this scale were obtained from clients only. Cronbach's alpha for the Rosenberg Self-Esteem Scale for the Victoria sample was .77, and for the Winnipeg sample it was .79.

Two-factor (type of care by care levels) ANOVAs were conducted on the two samples. The main effect of type of care was significant in the Winnipeg sample ($F(1, 70) = 6.83, p < .01$), but not in the Victoria sample. Neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample. These findings indicate that facility clients had higher perceived self-esteem than community clients, but only in the Winnipeg sample. In the Victoria sample, community and facility clients were comparable with respect to

³⁵ This was confirmed by correlating scores on the 3MS with scores on the SMAF. For the Victoria sample, the correlation was $r = -.43, p < .001$, and for the Winnipeg sample, the correlation was $r = -.40, p < .001$. In both cases, the findings indicated that lower cognitive status (as measured by the 3MS) is associated with lower functional status (as measured by the SMAF).

perceived self-esteem. In both study sites, clients across the different care levels were comparable.

5.7 Social Relations

As noted in Chapter 4, both social networks and social supports were considered components of an individual's social relations in this study.

5.7.1 Social Networks

In Substudy 5, information regarding social networks was assessed using three single items. Clients were asked about their living situation, the number of people they felt close to,³⁶ and the number of people they had contact with on a regular basis.

In the Victoria sample, the majority (67.7%) of community clients lived alone. In the Winnipeg sample, the number of clients who lived alone was approximately equal to the number of clients who lived with one other person (43.0% versus 44.3%). Not surprisingly, in both sites more community clients were likely to live with at least one other person as their care needs increased. In both sites, over 80% of facility clients lived alone (that is, had single rooms); approximately 6% lived with two or more individuals (that is, in multiple bed wards).

In the Victoria sample, community clients were likely to have more people that they felt close to than facility clients. In the Winnipeg sample, community and facility clients were comparable with respect to the number of individuals they felt close to.

In both samples, there was little difference between community and facility clients with respect to the number of people they interacted with on a regular basis.

Taken together, the findings indicated that in the Victoria site, community clients tended to have stronger social networks than facility clients. In the Winnipeg site, community and facility clients were similar with respect to their social networks.

5.7.2 Social Support

Four questions from Seeman and Berkman's (1988) Social Support Scale were used to examine the availability and adequacy of both instrumental and emotional support. Chi-square analyses of the data from the Social Support items in both samples suggested that more community clients than facility clients would like increased instrumental support (although the difference was not significant in the Victoria sample). For the Winnipeg sample, $X^2(1) = 6.06, p < .05$. Community and facility clients were comparable with respect to their desire for more emotional support in both samples.

³⁶ The literature typically uses the number of people one feels close to as a measure of emotional support. In this study it was used as a measure of the amount of contact an individual had with others.

5.8 Outcome Measures

Four outcome measures were used. Three of these assessed different aspects of quality of life, while the fourth measure assessed clients' satisfaction with the services they were receiving. The three quality of life measures were the Hadorn et al. (1995) Health Related Quality of Life Scale, the Centre on Aging's (1995) Terrible-Delightful Scale, and a single question on general satisfaction with life. Clients' contentment with services they were receiving was assessed using the Satisfaction with Services Scale (Penning and Chappell, 1996). Data were not collected from proxies for these measures.

5.8.1 Health Related Quality of Life Scale

The Health Related Quality of Life Scale consisted of ten questions which were designed to examine four areas: physical suffering; limits on daily activities; emotional outlook on life; and overall quality of life. The total score was the sum of scores on each of the first nine items. The tenth item reflected the interviewer's perceptions of the client's quality of life. For the Victoria sample, Cronbach's alpha for the full scale was .64, and for the Winnipeg sample it was .71.

For the Victoria sample, the correlation between the client's perceptions of his or her own quality of life (the total score) and the interviewer's perception of the client's quality of life was significant, $r = -.40$, $p < .001$ (note that for clients higher scores reflect poorer quality of life, while for interviewers higher scores reflect better quality of life). For the Winnipeg sample, the correlation between the client's perceptions and the interviewer's perceptions was $r = -.42$, $p < .001$. Thus, in both samples, the client's perception of his or her own quality of life meshed with the interviewer's perception of the client's quality of life.

A two-factor (type of care by care levels) ANOVA was conducted on each sample. In both analyses, the main effect of type of care was significant. For the Victoria sample, the main effect of type of care was $F(1, 136) = 7.20$, $p < .01$. For the Winnipeg sample, it was $F(1, 72) = 15.55$, $p < .001$. The main effect of care levels was significant for the Victoria sample ($F(2, 136) = 4.17$, $p < .05$), but not for the Winnipeg sample. The type of care by care levels interaction was not significant in either sample. The findings indicated that facility clients perceived their quality of health (as measured by the Health Related Quality of Life Scale) to be better than community clients did. However, these results should be interpreted with caution as the internal consistency of this measure was not good.

5.8.2 Terrible-Delightful Scale

The Terrible-Delightful Scale focused on a variety of concepts that have been linked to quality of life, such as health, finances, and family relations. As assessed by Cronbach's alpha, the internal consistency of the Terrible-Delightful Scale was .76 for the Victoria sample and .75 for the Winnipeg sample.

A two-factor (type of care by care levels) ANOVA was conducted on each sample. There

were no significant effects in either analysis. That is, the analyses indicated that in both study sites, community and facility clients were comparable and clients at each of the care levels were comparable.

5.8.3 Satisfaction with Life

Satisfaction with life was assessed using a single item: “How would you describe your satisfaction with life in general at present?” In general, clients rated their satisfaction with life as “Good.” A two-factor (type of care by care levels) ANOVA was conducted on each sample. There were no significant effects in either analysis. That is, the analyses indicated that in both study sites, community and facility clients were comparable and clients at each of the care levels were comparable.

5.8.4 Satisfaction with Services

Satisfaction with services was assessed using questions that addressed clients’ satisfaction with services received, worker characteristics, and care concerns (Penning & Chappell, 1996). Cronbach’s alphas for the total scale were .70 and .80 for the Victoria and Winnipeg samples, respectively.

A two-factor (type of care by care levels) ANOVA was conducted on each sample. The pattern of findings was inconsistent in the two analyses. More specifically, the main effect of care levels was significant in the Victoria sample ($F(2, 128) = 3.28, p < .05$), but not in the Winnipeg sample. The main effect of type of care was significant in the Winnipeg sample ($F(1, 56) = 6.03, p < .05$), but not in the Victoria sample. The type of care by care levels interaction was not significant in either sample. The findings indicated that in the Victoria sample, satisfaction with services decreased as the care needs of the client increased, but was similar between community and facility clients. In the Winnipeg sample, clients’ satisfaction with services was similar across care levels, but overall, community clients were more satisfied with services than facility clients.

5.9 **Other Analyses**

As noted earlier, the analyses reported above were based on “care levels” created by reducing the distribution of SMAF total scores into categories. One may question whether findings similar to those reported above would have been obtained if community and facility clients had been compared directly (that is, if clients had not been divided into care levels). Several t-tests were conducted on both samples to address this. The findings supported those reported above.

5.10 **Summary of Findings from the Client Data**

By analyzing the data from the two study sites separately, similarities and differences between the Victoria and Winnipeg samples were highlighted.

In both samples:

- facility clients felt better about their overall health (as measured by General Health) than community clients;
- community clients had higher cognitive functioning (as assessed by the 3MS) than facility clients and cognitive functioning declined as clients' general functioning (as assessed by the SMAF) declined;
- community clients indicated they would like more instrumental support than facility clients but community and facility clients were comparable with respect to their desire for more emotional support (as measured by the Social Support Scale);
- facility clients perceived their health related quality of life (as measured by the Health Related Quality of Life Scale) to be better than community clients; and
- community and facility clients were comparable with respect to their perceptions of overall quality of life (as measured by the Terrible-Delightful and Satisfaction with Life measures).

In the Victoria sample:

- community clients had stronger social networks than facility clients (as measured by three single item indicators);
- clients generally perceived that their health related quality of life (as measured by the Health Related Quality of Life Scale) decreased as their care needs increased; and
- clients' satisfaction with the services they were receiving (as measured by the Satisfaction with Services Scale) decreased as their care needs increased.

In the Winnipeg sample:

- facility clients felt better about their health than community clients (as measured by Health Now Versus One Year Ago and Health Interferes with Activities);
- facility clients had higher perceptions of self-esteem than community clients (as measured by the Rosenberg Self-Esteem Scale); and
- community clients were more satisfied with services than facility clients (as measured by the Satisfaction with Services Scale).

6. DESCRIPTION OF THE SAMPLE AND DISCUSSION OF FINDINGS REGARDING THE OUTCOME MEASURES FOR CAREGIVERS

Vignette: The client and her husband are in their early 90's. She requires constant supervision and care. Her husband also requires some care. The caregivers for both of them are the client's 61 year old step-daughter and her 80 year old sister-in-law. Neither of the caregivers would consider not providing the care, and they do not appear to be stressed by doing so.

6.1 Demographic Information

Table 6-1 provides a description of the caregiver sample in the two study sites. A series of analyses were conducted on the demographic data from the total sample of 501 caregivers to determine if there were any differences between caregivers in Victoria and Winnipeg or between caregivers of community and facility clients.³⁷

Approximately 36.7% of the sample were caring for a client in the community, while 63.3% were caring for a client in a facility. Some 41.2% of the caregivers in the Victoria site and 32.7% of the caregivers in the Winnipeg site were providing care to a client in the community.

Overall, 25.9% of the caregivers were male; 74.1% were female. There were no differences between caregivers in the two study sites or between caregivers of community clients and caregivers of facility clients with respect to gender.

Some 30.4% of the individuals caring for a client in the community were under 55 years of age, while 22.8% were 75 years of age or older. For individuals caring for a client in a facility, 31.3% were under 55 years of age, while 12.1% were 75 years of age or older. There were no differences between study sites or between caregivers of community clients and caregivers of facility clients with respect to the caregivers' age.

Some 22.9% of caregivers had obtained a university degree, while only 2.8% had grade 8 or less. There were no differences between caregivers in the two study sites or between caregivers of community clients and caregivers of facility clients with respect to educational level.

Approximately 21.0% of caregivers refused to provide information regarding their income. Overall, caregivers had higher salaries than the individuals they were caring for: 46.2% of caregivers indicated that their annual income was \$30,000 or more while only 14.4% of clients indicated that they made \$30,000 or more per year. Some 31.3% of caregivers of community clients and 19.5% of caregivers of facility clients indicated that their annual income was less than \$15,000. In contrast, 24.4% of caregivers of community clients and 25.8% of caregivers of facility clients indicated that their annual income was \$45,000 or more. Caregivers in the two study sites did not differ with respect to income. As well, caregivers of community clients and caregivers of facility clients were comparable with respect to income.

³⁷ As in Chapter 5, multiple analyses were done on all of the measures discussed in this chapter. Again, no Bonferroni corrections were made to the probability levels.

Table 6-1: Description of the Caregiver Sample in the Two Study Sites

		Victoria		Winnipeg		Total			
		Community	Facility	Community	Facility	Community		Facility	
		Percent	Percent	Percent	Percent	Number	Percent	Number	Percent
Gender	Male	19.6	27.9	32.9	24.3	47	25.8	82	25.9
	Female	80.4	72.1	67.1	75.7	135	74.2	235	74.1
Age	Less than 45	9.2	4.5	11.6	8.0	19	10.3	20	6.5
	45 to 54	26.5	22.6	12.8	26.4	37	20.1	76	24.8
	55 to 64	32.7	34.6	31.4	31.0	59	32.1	100	32.6
	65 to 74	11.2	24.1	18.6	24.1	27	14.7	74	24.1
	75 and older	20.4	14.3	25.6	10.3	42	22.8	37	12.1
Education	Grade 8 or less	8.2	0.0	3.5	1.7	11	6.0	3	1.0
	Some high school	10.2	14.6	18.6	19.2	26	14.1	54	17.2
	High school graduation	18.4	27.0	20.9	23.7	36	19.6	79	25.2
	Some technical, trade school or college	41.8	35.0	34.9	31.6	71	38.6	104	33.1
	Bachelor or graduate degree	21.4	23.4	22.1	23.7	40	21.7	74	23.6
Income	< \$15,000	33.3	15.2	28.9	22.6	50	31.3	46	19.5
	\$15,000 to \$29,999	27.6	26.3	27.3	34.3	44	27.5	73	31.9
	\$30,000 to \$44,999	13.8	28.3	20.5	20.4	27	16.9	56	23.7
	\$45,000 and over	25.3	30.3	23.3	22.6	39	24.4	61	25.8
Marital Status of Caregiver	Never Married, separated or divorced	19.4	21.7	26.7	15.3	42	22.8	57	18.1
	Married/common law	70.4	72.5	68.6	74.0	128	69.6	231	73.3
	Widowed	10.2	5.8	4.7	10.7	14	7.6	27	8.6
Relationship of Caregiver to Client³⁸	Spouse	14.3	11.4	37.2	9.0	46	25.0	32	10.1
	Child	59.2	61.4	45.3	71.2	97	52.7	212	66.9
	Other Family	13.3	21.4	8.1	17.5	20	10.9	61	19.2
	Non-Family	13.3	5.7	9.3	2.3	21	11.4	12	3.8

³⁸ “Child” was defined as a daughter, son, daughter-in-law, or son-in-law. “Other Family” was defined as a sibling, niece/nephew, cousin, grandchild, great-grandchild, or spouse of any of these family members. “Non-Family” was defined as a friend, neighbour, or volunteer.

Overall, 71.9% of the caregivers were married, 8.2% were widowed, and 19.8% were single (never married, separated, or divorced). There were no differences between caregivers in the two study sites or between caregivers of community clients and caregivers of facility clients with respect to marital status.

The majority (61.7%) of caregivers were children (a daughter, son, daughter-in-law or son-in-law); an additional 15.6% were spouses. Some 16.2% of the caregivers were other family members (such as siblings, nieces/nephews, cousins, grandchildren, great-grandchildren, and spouses of all of these family members). The remaining 6.7% of the caregivers were non-family (such as friends, neighbours, and volunteers). There were no differences between the two study sites with respect to the caregiver's relationship to the client. Compared to caregivers of facility clients, more caregivers of community clients were spouses ($X^2(1) = 16.72, p < .001$) or friends, neighbours, or other non-family ($X^2(1) = 10.34, p < .01$). In contrast, compared to caregivers of community clients, significantly more caregivers of facility clients were other family members, $X^2(1) = 5.00, p < .05$. Approximately the same number of children provided care to community clients as provided care to facility clients.

Overall, 44.7% of caregivers indicated that they were currently working. Some 46.0% of the caregivers in the Victoria site and 43.5% of the caregivers in the Winnipeg site were working. Of the caregivers who were currently working, 62.2% were caring for someone in a facility.³⁹ In addition, 79.2% of the caregivers who were working worked 40 hours or less a week, while 15.4% worked 50 hours or more per week.

Some 16.2% of caregivers indicated that they lived with the client. Not surprisingly, for these caregivers, 92.3% of the clients lived in the community. For 7.4% of the caregivers, however, both the client and the caregiver lived in a facility (often the same one). Some 58.0% of the caregivers who lived with the client were in the Winnipeg site.

The majority (74.4%) of caregivers indicated that they received help from others. Children and children-in-law of the client were most likely to provide assistance to the main caregiver, whether that was the client's spouse or the client's child. Other family members (such as grandchildren) as well as friends and neighbours also provided assistance.

6.2 Caregiver Outcome Measures by Client Care Level

Analyses were conducted using data only from the caregivers of clients discussed in Chapter 5. These analyses focused on comparisons between caregivers of community clients and caregivers of facility clients at each of the care levels described in Table 5-2. For each measure, two ANOVAs were conducted – one looking at data from caregivers in the Victoria sample and one looking at data from caregivers in the Winnipeg site.

³⁹ This is primarily due to the fact that the caregivers of facility clients tended to be adult children and other family members who were still in the work force, while caregivers of community clients tended to be spouses who had never worked or who had retired.

6.2.1 Behaviour Disturbance Scale

The modified Behaviour Disturbance Scale consisted of 11 items. Cronbach's alphas for this scale were .79 and .74 for the Victoria and Winnipeg samples, respectively.

A two-factor (type of care by care levels) ANOVA was conducted on each sample. In each analysis, the main effect of care levels was significant, but neither the main effect of type of care nor the type of care by care levels interaction was significant. For the Victoria sample, the main effect of care levels was $F(3, 206) = 31.81, p < .001$. For the Winnipeg sample, it was $F(3, 205) = 18.92, p < .001$. The findings indicated that in both study sites, caregivers of community and facility clients perceived that the amount of behavioural disturbances experienced increased as the care demands (that is, the care level) of the clients increased. However, caregivers in both sites perceived that the amount of behavioural disturbances experienced by community and facility clients was comparable.

6.2.2 Impact of Caregiving: The Montgomery Burden Scale

Vignette: The client, a widow who is physically frail and has advanced dementia, has been on a facility waiting list for two years. She receives home support daily, but it is insufficient to meet her needs. Her caregiver (a daughter with her own health problems) has a daily routine she follows with the client which includes directing breakfast preparation over the phone, constant cueing, and frequent visits and phone calls which continue right through to bed time. Due to intensive caregiving, the caregiver is burning out. She visits the doctor twice a month and has been on antidepressants.

The impact of providing care to clients was assessed using a modified version of the Montgomery Burden Scale (Montgomery et al., 1985). The modified scale included six items that assessed objective burden and eight items that assessed subjective burden. Cronbach's alphas for the objective burden subscale were .88, and .92, for the Victoria and Winnipeg samples, respectively. Cronbach's alphas for the subjective burden subscale were .87, and .88 for the Victoria and Winnipeg samples, respectively.

A two-factor (type of care by care levels) ANOVA was conducted on the objective burden subscale data for each sample. The findings indicated that the type of care by care levels interaction was significant in the Victoria sample ($F(3, 204) = 6.14, p < .001$), but not in the Winnipeg sample. The main effect of type of care was significant in both samples. For the Victoria sample, the main effect of type of care was $F(1, 204) = 86.52, p < .001$. For the Winnipeg sample, it was $F(1, 202) = 79.86, p < .001$. The main effect of care levels was not significant in either sample.

A two-factor (type of care by care levels) ANOVA was also conducted on the subjective burden subscale data for each sample. The findings indicated that in each analysis, there was a significant main effect of type of care; for the Victoria sample, $F(1, 203) = 83.46, p < .001$, and for the Winnipeg sample, $F(1, 199) = 39.70, p < .001$. Neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample.

Taken together, the findings on the Montgomery Burden Scale indicated that caregivers of facility clients perceived that they had less objective burden (that is, they had more time to do various activities for themselves) than caregivers of community clients. However, caregivers of facility clients also perceived that they had more emotional burden (that is, they felt more stress and anxiety) than caregivers of community clients. Perceptions of both objective and subjective burden were comparable across client care levels in both sites.

6.2.3 Caregiver Satisfaction

Caregivers' satisfaction with the services the client was receiving was assessed using items that were similar to those used to assess clients' satisfaction with services (Penning & Chappell, 1996). These questions addressed caregivers' satisfaction with the services, worker characteristics, and care concerns. One of the items on the Worker Characteristics subscale (which asked about workers' skilfulness in teaching the client to look after himself/herself) was problematic for some of the individuals who provided care to clients who were severely cognitively impaired. For these clients, caregivers often indicated that little could be done for the client regardless of the worker's skill level. The analyses reported below do not include this item. Cronbach's alphas for the 14-item total scale were .73 for the Victoria sample and .81 for the Winnipeg sample.⁴⁰

A two-factor (type of care by care levels) ANOVA was conducted on the total scale score in both samples. The type of care by care levels interaction was significant in the Victoria sample ($F(3, 125) = 4.17, p < .01$), but not in the Winnipeg sample. Neither the main effect of type of care nor the main effect of care levels was significant in either sample. The findings indicated that in the Victoria sample, caregivers' satisfaction with services was affected by the client's living situation (community versus facility) as well as the client's care needs (that is, the care level). With regard to the most functional clients, caregivers of facility clients were generally more satisfied than caregivers of community clients. With respect to the least functional clients, caregivers of community clients were more satisfied than caregivers of facility clients. In the Winnipeg sample, however, caregivers of community clients were generally as satisfied with the services clients were receiving as caregivers of facility clients.

6.3 **Comparisons Between Clients' Satisfaction with Services and Caregivers' Satisfaction with Services**

As noted in Chapter 4, the Satisfaction with Services Scale was included on both the Client Questionnaire and the Caregiver Questionnaire. Therefore, comparisons were made between how satisfied clients were and how satisfied caregivers were with the services clients were receiving.⁴¹ Paired sample t-tests were conducted on the total scale score for both samples. In each sample, caregivers were significantly more satisfied than clients with the services clients

⁴⁰ Cronbach's alphas for the 15-item scale were .74 and .83 for the Victoria and Winnipeg samples, respectively.

⁴¹ The analyses were based only on those clients for whom data were available from both the client and his or her caregiver.

were receiving. For the Victoria sample, $t(67) = 2.39, p < .05$. For the Winnipeg sample, $t(29) = 2.60, p < .05$.

6.4 Summary of Findings from Informal Caregiver Data

Only the data from those caregivers who were caring for clients at the various care levels described in Chapter 5 were analyzed. In both study sites, caregivers indicated that the amount of behavioural disturbances experienced increased as the care level of the clients increased, but there was no difference between community and facility clients. As well, in both study sites, caregivers of facility clients perceived that they had less objective burden but more subjective (emotional) burden than caregivers of community clients. In the Victoria sample, caregivers' satisfaction with the services the clients were receiving was affected by where the clients were living as well as the clients' care requirements. In the Winnipeg sample, caregivers' satisfaction with services was comparable for both community and facility clients and was comparable across care levels. In both study sites, caregivers' satisfaction with the services clients were receiving was higher than clients' satisfaction with the services.

7. COSTS OF RECEIVING AND PROVIDING CARE

One of the goals of Substudy 5 was to obtain estimates of the costs of formal and informal home care and residential care by examining: the amount of time and type of assistance provided by formal service providers; the amount of time and type of assistance provided by informal caregivers; and out-of-pocket expenses of both clients and informal caregivers. Cost estimates were based on information provided in the various diaries and on an analysis of budget and operational cost data provided by regional health authorities in Victoria and Winnipeg.

7.1 Description of the Diaries

The assistance and time provided to community clients by health care workers and professionals were recorded in the Formal Services – Community diary while the assistance and time spent by health care workers and professionals who provided services to facility clients were recorded in the Formal Services – Facility diary. The diaries were completed by community and facility staff, and occasionally by study personnel using information provided by staff or contained in agency records.

The Informal Caregiver diary was used to record activities and time that family members, friends, and volunteers provided *because of* the client's health care needs. The diaries were completed by informal caregivers, and in some cases by study personnel using information provided by the caregivers.

The Client Expenditures diary was used to estimate the cost of caring for the person in care (that is, the client) by adding the health-related costs incurred by the client, family members, or friends of the individual in care to the costs of services provided by the overall health care system. The diaries were completed by clients, family members, friends, and volunteers. In some cases, study personnel completed the diaries using information provided by the clients. On occasion, information from resident expense records was used for facility clients.

Community and facility staff, informal caregivers, and clients were asked to keep the diaries for a two week period (that is, for 14 days). Copies of all diary forms are presented in Appendix B.

7.2 Coding of the Diaries

7.2.1 Quality of the Information Provided in the Diaries

The quality of the information provided in the diaries varied from very detailed and complete records to no information at all. Diaries within each diary type were placed in one of six categories which were defined by the quality of the information provided in the diary.

For diaries placed in Category 1, the information in the diary appeared complete for the two week period and was coded without amendment or interpretation. For the Client Expenditures diary, if the individual completing the diary specifically indicated that there had

been no expenditures during the specified time period, the information was considered to be complete and was reported accordingly.

For diaries placed in Category 2, the information in the diary was mainly complete, but in need of some minimal calculations or interpretations. For example, for the Formal Services – Facility diary, staff may have provided a detailed schedule of a typical day for the client and then recorded only the exceptions to this schedule over the two week period.

For diaries placed in Category 3, partial information was provided and assumptions had to be made at the time of coding. In some cases, a number of gaps remained.

Category 4 “diaries” were not applicable (for example, an Informal Caregiver diary which was not completed because the client did not have a caregiver).

Category 5 “diaries” were considered missing either because they were blank when they should not have been or because the information was so poor that it was impossible to obtain any meaningful information from them.

Category 6 “diaries” represent refusals by identified respondents to complete the diary.

The number of diaries falling into the various categories for the total sample of 580 clients is presented in Table 7-1 (note that diaries in Categories 4, 5 and 6 have been combined). As Categories 1 to 3 show, the response rate for all of the diaries was very good: 94.1% for the Formal Services – Community diaries; 97.5% for the Formal Services – Facility diaries; 83.3% for the Informal Caregiver diaries; and 87.6% for the Client Expenditure diaries. Of all community and facility diaries completed, the majority fell into Category 2 (that is, they were reasonably comprehensive, but needed some minimal calculations or interpretation). Because the best information was contained in diaries from Categories 1 and 2, only these diaries were included in the analyses reported in the following sections.

7.2.2 Coding the Formal Services Diaries

For the Formal Services – Community and Formal Services – Facility diaries entries were coded with respect to the type of task provided, who provided the task, and the amount of time that was spent on the task.

The tasks were divided into seven major categories:

- Clinical Necessities – this category contained activities that provided for basic functions of care, such as monitoring and/or administering medications; assisting with machines, devices and monitors; changing bandages; assisting with foot care, toileting, bathing, feeding, positioning, and dressing; and providing ordered physical activity or therapy.

Table 7-1: Number of Diaries Obtained in Each Site

Type of Diary	Quality of Diary Information		Victoria		Winnipeg	
			Community	Facility	Community	Facility
Formal Services ⁴²	1	Number	1	0	22	31
		Percent	0.8%	0.0%	21.8%	15.7%
	2	Number	110	158	67	144
		Percent	90.9%	98.8%	66.3%	72.7%
	3	Number	4	2	5	14
		Percent	3.3%	1.3%	5.0%	7.1%
	4, 5, & 6	Number	6	0	7	9
		Percent	5.0%	0.0%	6.9%	4.5%
Client Expenditure	1	Number	14	18	23	43
		Percent	11.6%	11.3%	22.8%	21.7%
	2	Number	95	135	64	114
		Percent	78.5%	84.4%	63.4%	57.6%
	3	Number	1	1	0	0
		Percent	0.8%	0.6%	0.0%	0.0%
	4, 5, & 6	Number	11	6	14	41
		Percent	9.1%	3.8%	13.9%	20.7%
Informal Caregiver	1	Number	4	7	28	36
		Percent	3.3%	4.4%	27.7%	18.2%
	2	Number	102	127	56	118
		Percent	84.3%	79.4%	55.4%	59.6%
	3	Number	0	0	0	5
		Percent	0.0%	0.0%	0.0%	2.5%
	4, 5, 6	Number	15	26	17	39
		Percent	12.4%	16.3%	16.8%	19.7%
Total for Each Type of Diary		Number	121	160	101	198

- Housekeeping – this category included activities that made it possible to live in a normal, clean, living environment such as general housekeeping; vacuuming; dusting; garden work; laundry; and routine maintenance of the exterior.
- Meal Preparation – this category included meal preparation and associated clean up (such as dishes).
- Maintenance – this category included activities others could do to make it possible for the client to stay in his or her own home, but which were not critical to the medical/health care of the individual. The category included activities such as: paying bills, banking, and working with lawyers and insurance agents; buying supplies, including food; driving to medical appointments and social programs such as adult day centres; taking the client for a haircut; taking the client to church; and maintaining contact with the client, or on the client’s behalf, by writing letters and making phone calls.

⁴² Diaries in the “Community” column refer to Formal Services – Community diaries. Diaries in the “Facility” column refer to Formal Services – Facility diaries.

- Psychological/social activities – this category included those activities that related to the social, recreational, and non-medical needs of the clients such as: visiting the client; providing or participating in recreational activities with the client; and shopping with the client.
- Respite – this category included activities which enabled the informal caregiver to have time away from direct caregiving.⁴³ Respite could be either unpaid (for example, provided by a friend or other family member) or paid (for example, provided by a health care aide).
- Companionship – this category included activities which were provided by paid or unpaid individuals solely to ensure the safety and well-being of the client (that is, the activities did not include direct care).

The type of workers carrying out the activities were categorized into four categories: care aide (which included home support workers, home care attendants, residential care attendants, and housekeeping, dietary and laundry workers⁴⁴); nurse (which included licensed practical nurses, registered nurses, and psychiatric nurses); physician (which included both primary care physicians and physician specialists); and other health professionals (which included occupational therapists, physiotherapists, massage therapists, and podiatrists/chiropractors).

7.2.3 Coding the Informal Caregiver Diaries

As with the entries in the Formal Services diaries, the entries in the Informal Caregiver diaries were coded with respect to the type of task provided, who provided the task, and the amount of time that was spent on the task. The seven categories used to classify tasks provided by formal service workers were also used to code the type of assistance provided by informal caregivers.

7.2.4 Coding the Expenditure Diaries

Expenditures included on the Client Expenditure diaries were divided into five categories:

- Medical Supply Costs – this category included expenditures such as: dressings; incontinence products; medications; vitamins; batteries for hearing aids or other medical devices; testing supplies (for diabetics, for example); food; and specialized clothing.

⁴³ Informal caregivers often reported using their “respite time” to garden, tend to exterior household maintenance, and prepare meals for the week.

⁴⁴ These latter three categories generally only applied to facility clients. An analysis using other comparative data (Hollander, 1994) indicated severe under-reporting of housekeeping, dietary and laundry. Therefore, these workers were excluded from the “care aide” category in the analyses reported below. However, the costs for this category of worker are included in the cost estimates presented further on in this report.

- Activity Costs – this category included costs associated with various activities such as: housekeeping in general and laundry; going out for a meal; getting a haircut; recreational activities; travel costs for informal caregivers; meal preparation and cleanup; and respite for the client or the informal caregiver.
- Care-Related Service Costs – this category included expenditures related to: podiatry/chiropractic; physiotherapy; massage therapy; medical laboratory services; and other service professions.
- Equipment Costs – this category included expenditures for equipment such as bath seats and walkers; therapy supplies and materials; and incontinence supplies.
- Major Expenditure Costs – this category included expenditures for items such as private home care; ambulance trips; transportation costs (such as Handi-dart/Handi-transit); and dentures.

7.3 Additional Information

Two instruments were included on the Client Questionnaire to collect information regarding the type and amount of assistance required by a client because of his or her care needs. The first measure consisted of a set of questions (developed by the investigators) which focused on the types of assistance (such as household maintenance, personal care, physical functioning, and finances) provided by informal caregivers to the clients. The second measure consisted of a set of questions developed by Browne et al. (1992) to address health and social service utilization. The items related to the respondent's use of formal health services (such as physicians and home support workers), the cost of health related supplies (such as dressings and equipment), and the cost of health related services (such as transportation to and from medical appointments and day programs).

Data from these instruments were used to confirm and further elaborate the information provided in the diaries and to give a more complete picture of the support provided to the client by both formal service workers and informal caregivers. When the same information was provided on the Client Questionnaire and in a diary (for example, the purchase of a wheelchair which may have appeared both as a major expenditure on the Client Questionnaire and as an expenditure during the two-week period covered by the diary), the information was only recorded once.

For a small number of clients (approximately 1%), the combined information from the diaries and the health and social service utilization measure was used to identify costs poorly estimated using either measure alone. For example, for the two week time period covered by the Client Questionnaire, the client may have seen a massage therapist four times. However, for the time period covered by the diary, the client may not have seen a massage therapist at all. The costs of massage therapy for the particular client could have been inaccurately estimated by using one of the two data sources, while combining sources enabled more accurate computation. In

some cases, costs may have been included in either a diary or the Client Questionnaire which were not directly related to the client's health care needs (for example, the purchase of food or clothing which was not related to the client's health). When it was thought that costs may have been poorly estimated, the values were adjusted using the norm for clients who were thought to have reasonably accurate information.

7.4 Time Provided by Formal Service Workers

The costs of formal health care services were estimated using information provided in the Formal Services diaries and on the Client Questionnaire.

An initial analysis of the time data indicated that community clients in Winnipeg were receiving about twice as many hours of formal care service as community clients in Victoria. An inspection of the data indicated that in the Victoria site, a few clients received a substantial number of formal service hours. In the Winnipeg site, however, several community clients received a large number of formal care hours.

Further inspection of the Winnipeg data indicated that clients who had a large number of formal service hours often needed more monitoring time than care time. For example, a client may have received eight hours of paid care time, but the formal service worker(s) (generally a care aide/home support worker) may have only spent one to two hours conducting actual care-related tasks; the rest of the time was spent ensuring that the client was safe and comfortable. It therefore appeared that in Winnipeg, a policy choice had been made to provide additional resources to at-risk clients to allow them to remain in their own homes.

The identification of a subset of clients who received a large number of formal service hours presented a dilemma for the analysis. On the one hand, since they represented valid cases, one could argue that they should be included in the data analysis even though the analysis would be affected by the relative proportion of such cases in a given sample. On the other hand, one could argue that the purpose of the analysis was to compare the costs and outcomes for more typical cases. To avoid having results which were an artefact of the differential proportion of high users of home care services in the two study sites, it was decided that the high users would be excluded from the main analyses but that the data for both high and more typical users would be presented in this report.

A relatively high cut point of 120 hours per month (86,400 minutes per year) of care aide time was used to ensure that the analyses would include almost all typical cases. This cut point was determined using two sources of information. First, in British Columbia, extended care clients are allowed up to 120 hours of home support per month. The actual average hours per month used by clients at this care level is about half of the maximum allowable hours. While none of the Victoria clients were at the extended or chronic level of care, a few clients in the Winnipeg sample approximated this level. Second, the relative proportion of care time versus monitoring time for high users in Winnipeg was examined using a variety of cut points. At 120 hours per month, it seemed that some 40% to 50% of the formal service time was used to provide actual care services. In addition, the costs of care for community clients who received some 120

hours of care aide time were similar to the costs of facility care. The policy in Winnipeg was to provide services for community clients up to the cost of facility care. Thus, the cut point of 120 hours of care aide time per month was deemed to be appropriate based on three different criteria.

When the cut point of 120 hours of care aide time was applied to both community and facility clients, it was found that some facility clients also exceeded this level of care in the Winnipeg site but not in the Victoria site. It therefore appeared, that in Winnipeg, there were also a few exceptional clients in residential care who used disproportionate amounts of resources. This finding has implications for both policy and resource allocation.

Table 7-2 presents data regarding the average number of hours of formal service time provided by care aides and home support workers for clients receiving up to 120 hours per month of care aide time. Table 7-3 presents the same data for clients receiving over 120 hours per month of care aide time. Table 7-3 indicates that there were 4 community and 0 facility clients who were above the 120 hour cut point in the Victoria site, but 26 community and 13 facility clients who were above the cut point in the Winnipeg site.⁴⁵ The remainder of this chapter focuses only on those clients who were receiving 120 hours or less of care aide time per month. As with the analyses reported in Chapters 5 and 6, the Victoria and Winnipeg data were analyzed separately. The data for clients receiving more than 120 hours of care aide time per month were not analyzed, but are presented in Appendix D.

Two-factor (type of care by care levels) ANOVAs were conducted on the care aide and home support worker time data presented in Table 7-2.^{46,47} The results indicated that both the main effect of type of care and the main effect of care levels was significant in the Victoria sample. The main effect of type of care was $F(1, 202) = 7.47, p < .01$. The main effect of care levels was $F(3, 202) = 7.76, p < .001$. Neither of the main effects was significant in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample.

Table 7-4 presents data on services provided by nurses (RNs and LPNs) for clients who were receiving up to 120 hours per month of care aide time. It is interesting to note that relatively few hours of nursing care were provided to clients in the community. Two-factor (type of care by care levels) ANOVAs conducted on the nursing staff time data revealed that the main effect of type of care was significant in both the Victoria and Winnipeg samples. For the Victoria sample, $F(1, 202) = 87.00, p < .001$. For the Winnipeg sample, $F(1, 131) = 14.80, p < .001$. However, neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample.

⁴⁵ Appendix C summarizes why and how many participants were removed from the original sample.

⁴⁶ Because of the small number of community clients in Level E of the Winnipeg sample, these clients were eliminated from the analyses reported in the main body of the text. All analyses were run with and without these clients included. Similar findings were obtained. The data for Level E are included in the various tables for information.

⁴⁷ The data presented in Tables 7-2 to 7-6 only include on-site care related time and do not include non-direct care related time which is also spent by these workers (such as travel time, time for charting and time for discussing the client with colleagues). An adjustment was made to include this time in the cost estimates.

Table 7-2: Mean Annual Hours for Care Aides and Home Support Workers for Clients with 120 Hours per Month or Less of Care Aide Time

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	349.50	209.23		
	Standard Deviation	197.82	114.48		
	Number	37	12		
Level B: Slightly Independent	Mean	510.49	308.98	601.34	554.15
	Standard Deviation	249.99	171.14	308.05	398.83
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	434.85	428.69	752.48	600.21
	Standard Deviation	317.05	302.76	285.86	322.20
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	659.48	541.55	587.40	509.88
	Standard Deviation	416.04	300.78	306.84	302.45
	Number	8	26	13	52
Level E: Largely Dependent	Mean			978.25	583.97
	Standard Deviation			274.62	326.16
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

Table 7-3: Mean Annual Hours for Care Aides and Home Support Workers for Clients with more than 120 Hours per Month of Care Aide Time

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	-	0		
Level B: Slightly Independent	Mean	1805.27	-	-	1863.33
	Standard Deviation	-	-	-	104.18
	Number	1	0	0 ⁴⁸	2
Level C: Slightly Dependent	Mean	3276.00	-	2095.53	1759.33
	Standard Deviation	-	-	540.51	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	2095.17	-	2988.80	2108.17
	Standard Deviation	609.76	-	1922.97	395.28
	Number	2	0	13	7
Level E: Largely Dependent	Mean			2074.15	2239.76
	Standard Deviation			687.90	677.51
	Number			6	3

⁴⁸ There was one extreme outlier in this cell who was deleted from the sample.

Table 7-4: Mean Annual Nursing Hours (for Clients with 120 Hours per Month or Less of Care Aide Time)⁴⁹

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	1.64	95.35		
	Standard Deviation	6.95	60.84		
	Number	37	12		
Level B: Slightly Independent	Mean	0.57	106.84	53.39	123.97
	Standard Deviation	2.71	92.70	114.43	165.95
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	5.42	99.52	18.63	126.50
	Standard Deviation	12.95	90.34	39.40	108.02
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	0.00	150.13	36.07	98.90
	Standard Deviation	0.00	96.79	81.26	86.03
	Number	8	26	13	52
Level E: Largely Dependent	Mean			10.29	137.31
	Standard Deviation			20.58	167.89
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

In order to determine whether the amount of time provided by direct care staff (that is, care aides, home support workers, and nursing staff) differed in the two study sites, 2 (study site) by 3 (care levels)⁵⁰ ANOVAs were conducted on the care aide/home support worker data presented in Table 7-2 and on the nursing data presented in Table 7-4, for the community and facility clients individually.

The analysis of the data from community clients indicated that there was no difference between the two study sites with respect to the amount of time provided by care aide and home support workers. However, the amount of nursing time provided to community clients was significantly higher in Winnipeg than in Victoria, $F(1, 74) = 5.81, p < .05$. The amount of time provided by care aides, home support workers and nursing staff to community clients did not differ as a function of the client's care level. The site by care level interaction was not significant in either the analysis of care aide time or the analysis of nursing time.

The analysis of the data from facility clients indicated that Winnipeg clients received significantly more time from care aides than Victoria clients, $F(1, 212) = 7.98, p < .01$. However, facility clients received the same amount of nursing time in both study sites. The main effect of care levels was not significant for either care aide time or nursing time. The site by care levels interactions were significant for both the analysis of the care aide time and the analysis of nursing time. For care aide time, $F(2, 212) = 3.47, p < .05$. For nursing time, $F(2, 212) = 3.24, p < .05$.

Table 7-5 presents data on the amount of time provided by other health professionals, such as massage therapists and podiatrists/chiropractors. Two-factor (type of care by care levels)

⁴⁹ Includes time from RNs, LPNs, and psychiatric nurses.

⁵⁰ Only three levels of care were common to both sites.

ANOVAs conducted on the data from the two study sites revealed no significant effects. The findings indicated that the amount of time provided by these formal service workers was about the same regardless of where the client was located and irrespective of the client’s level of care.

Table 7-5: Mean Annual Hours for Other Health Professionals (for Clients with 120 Hours per Month or Less of Care Aide Time)⁵¹

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	10.95	8.58		
	Standard Deviation	25.09	8.45		
	Number	37	12		
Level B: Slightly Independent	Mean	10.64	7.56	13.31	43.02
	Standard Deviation	28.50	10.23	37.56	105.94
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	17.51	8.27	4.33	11.14
	Standard Deviation	27.69	11.69	4.57	24.21
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	9.75	6.29	4.67	17.67
	Standard Deviation	12.84	6.64	4.50	69.77
	Number	8	26	13	52
Level E: Largely Dependent	Mean			4.33	21.26
	Standard Deviation			5.00	68.59
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

Table 7-6 presents data on the amount of time provided to clients by physicians. Two-factor (type of care by care levels) ANOVAs were conducted on the data from the two study sites. The main effect of care levels was significant in the Victoria sample ($F(3, 202) = 3.09, p < .05$), but not in the Winnipeg sample, indicating that the amount of time provided by physicians differed as the care needs of the clients varied in Victoria, but not in Winnipeg. The main effect of type of care was not significant in either sample, indicating that physicians spent the same amount of time with community and facility clients in both samples.

Two-factor (2 study sites by 3 care levels) ANOVAs conducted on the time provided by other health professionals, and physicians indicated there were no differences between the study sites for these categories of formal service workers.

Taken together, the findings on the time data indicate that, not surprisingly, clients receive the most assistance from care aides, home support workers and nursing staff. Community clients use more services from care aides and home support workers than do facility clients, but use fewer services from nurses than do facility clients. The amount of time provided by these two groups of workers varied in the two study sites. Specifically, community clients in Winnipeg received more nursing time than community clients in Victoria, and facility clients in Winnipeg received more care aide time than facility clients in Victoria. The amount of time provided by care aides and home support workers increased as the care needs of the client increased in the Victoria site, but remained constant across care levels in the Winnipeg site. The amount of time

⁵¹ Includes time from occupational therapists, physiotherapists, massage therapists, and podiatrists/chiropractors.

provided by nursing staff was about the same regardless of the client’s care needs in both sites.

Table 7-6: Mean Annual Physician Hours (for Clients with 120 Hours per Month or Less of Care Aide Time)⁵²

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	7.26	5.42		
	Standard Deviation	10.92	6.09		
	Number	37	12		
Level B: Slightly Independent	Mean	4.60	2.27	3.71	1.77
	Standard Deviation	6.37	4.03	4.20	4.20
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	2.17	1.99	3.25	2.81
	Standard Deviation	4.23	3.52	3.43	4.48
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	4.06	2.75	3.00	2.63
	Standard Deviation	6.89	4.18	4.29	5.03
	Number	8	26	13	52
Level E: Largely Dependent	Mean			0.00	4.93
	Standard Deviation			0.00	6.18
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

The finding that, in Winnipeg, the time allocated to clients and residents remains relatively constant regardless of care level is, initially, somewhat surprising. However, it is noted that Manitoba does not allocate nor cap hours of care differentially within its levels of care.

7.5 Time Provided by Support Staff in Facilities

When the amount of time provided by non-care related support staff in facilities (such as dietary, housekeeping and laundry) was considered, it was noted that the information regarding the amount of time and the type of tasks provided by these workers was not recorded consistently or adequately. This probably reflects the fact that the individuals who completed the diaries (primarily care staff in the facilities) were not generally aware of the time spent on non-care related activities. It was therefore decided that an estimate of support time would be used to determine the costs of these services. This estimate was based on a national study of long term care facilities which indicated that across types of facilities and over time, there was a consistent ratio of support costs to care costs (support costs were approximately 50% of care costs; see Hollander, 1994).

7.6 Time Provided by Informal Caregivers

Table 7-7 presents data on the amount of time provided by informal caregivers. A two-factor (type of care by care levels) ANOVA conducted on these data for the Victoria site indicated that the type of care by care levels interaction was significant, $F(3, 202) = 6.51, p < .001$. As well, both main effects were significant. The main effect of type of care was $F(1, 202)$

⁵² Includes time from primary care physicians and physician specialists.

= 40.32, $p < .001$. The main effect of care levels was $F(3, 202) = 13.88$, $p < .001$. A similar analysis on the Winnipeg data revealed a significant main effect of type of care, $F(1, 131) = 30.33$, $p < .001$. Neither the main effect of care levels nor the type of care by care levels interaction was significant. Taken together, the findings indicated that informal caregivers provide more time to community clients than to facility clients in both study sites. The amount of time provided increased as the care needs of the clients increased, but only in the Victoria site.

Two-factor (site by care levels) ANOVAs were conducted on the community and facility data individually. For community clients, the amount of time provided by informal caregivers increased as the care needs of the client increased, $F(2, 74) = 4.47$, $p < .05$. The amount of time provided by informal caregivers was comparable in the two study sites. For facility clients, there were no significant differences in the amount of time provided by informal caregivers regardless of where the client was located (Victoria or Winnipeg) or the client's care level.

Table 7-7: Mean Annual Hours for Informal Caregivers (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	222.93	143.98		
	Standard Deviation	277.67	153.23		
	Number	37	12		
Level B: Slightly Independent	Mean	475.67	181.37	643.65	175.82
	Standard Deviation	689.49	198.11	1216.22	208.94
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	580.45	223.87	826.84	241.45
	Standard Deviation	332.07	270.66	869.31	326.92
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	1345.66	350.83	1131.23	268.74
	Standard Deviation	964.73	533.42	663.28	329.15
	Number	8	26	13	52
Level E: Largely Dependent	Mean			722.58	180.85
	Standard Deviation			510.21	245.64
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

7.7 Calculating Costs of Care

7.7.1 Formal Care Costs

In order to determine the costs of formal care services, a number of adjustments and estimates had to be made because of the different types of cost data available. In some cases, only the billing rates from third party care provider agencies were accessible, while in other cases, staff salary rates were provided. Billing rates from external agencies were for actual care time plus all overhead costs. Thus, it was decided to use actual care time from the diaries as the basis for the cost estimates to make them comparable to billing costs.

Estimates also needed to be made for dietary, housekeeping, and laundry workers in facilities for which there were no data. Based on Hollander's (1994) findings, it was estimated

that the cost of these support services was half the cost of care services. Care dollars for facility clients were therefore grossed up by 50% to account for costs associated with these staff.

The monetary cost of formal care services (in salary dollars per hour) was determined for each category of health care worker. The rates used for costing formal services in each of the study sites are presented in Table 7-8. In order to account for all of the time spent by formal service workers in providing care to clients, a non-care time adjustment was made to account for travel time, charting time, meeting time, staff training time, and benefits and administrative overhead. The adjustment allowed comparisons to be made between community and facility clients using identical information. The cost associated with each category of formal service worker was calculated by multiplying the amount of time provided by that type of worker by the adjusted rate for that category of worker.

Table 7-8: Rates Used for Estimating Formal Costs⁵³

Category of Worker or Cost		Base Rate in Victoria ⁵⁴	Adjusted Rate in Victoria	Base Rate in Winnipeg ⁵⁴	Adjusted Rate in Winnipeg
Care Aide	Facility:	\$19.69	\$36.23	\$13.30	\$24.47
	Community:	\$16.00	\$29.44	\$11.80	\$21.71
Home Support Worker (Community)		-	-	\$9.70	\$17.85
Licensed Practical Nurse		\$20.25	\$37.26	\$18.04	\$33.19
Registered Nurse		\$24.73	\$45.50	\$22.68	\$41.73
Therapist (Occupational Therapy, Physiotherapy, Massage Therapy)		\$26.27	\$48.34	\$24.08	\$44.31
Social Worker		\$24.73	\$45.50	\$22.68	\$41.73
Podiatrist/Chiropodist		\$60.00	\$60.00	\$60.00	\$60.00
Physician / Specialist		\$90.00	\$90.00	\$90.00	\$90.00
Laboratory Tests		\$60.00	\$60.00	\$60.00	\$60.00
Emergency Room Visit		\$125.00	\$125.00	\$125.00	\$125.00
Hospital Day		\$550.00	\$550.00	\$550.00	\$550.00
Administration Overhead (at 55 hours per client; applies to facility clients only)		\$25.00	\$25.00	\$22.00	\$22.00
Private Caregiver		\$15.00 to \$25.00	\$15.00 to \$25.00	\$15.00 to \$25.00	\$15.00 to \$25.00
Total Facility Cost (per day)	Level A	\$92.62	\$92.62	-	-
	Level B	\$109.27	\$109.27	\$123.75	\$123.75
	Level C	\$125.82	\$125.82	\$124.12	\$124.12
	Level D	\$151.67	\$151.67	\$111.58	\$111.58
	Level E	-	-	\$125.66	\$125.66

7.7.2 Informal Care Costs

Informal care costs were calculated using direct out-of-pocket expenses and total amount of informal caregiving time as reported in the Client Expenditures and Informal Caregiver diaries, and on the Client Questionnaire.

Recreation activities, attendance at church, and attendance at adult day centres were all

⁵³ Based on per hour, per visit, or per day time periods, as appropriate.

⁵⁴ Base rates for Care Aide to Social Worker in these columns are based on staff salaries. Adjusted rates include adjustments for travel time, charting time, meeting time, staff training time, and benefits and administrative overhead, in order to convert the salary rate (rate per hour paid to the employee) to a fully costed adjusted rate (rate per hour worked on client care).

recorded on the diaries but were not included in the calculations of care costs. Recreation activities were eliminated from the analyses because there was a wide variation in the number of attendees and the cost per program. As well, information regarding attendance at recreation programs was not recorded for most clients. Attendance at church was disregarded in the analyses because the cost of church programs is covered by a large number of donors and it was felt that the small costs incurred by clients would have little impact on the analyses. The cost of adult day centres was included in the cost analyses when it was listed as an expenditure. However, the time in attendance at an adult day program was not converted to a dollar cost as information regarding the specific day program, the number of attendees, the types of activities offered, and the overhead costs was not collected.

7.8 Comparative Cost Analyses

It had initially been anticipated that the data from the two study sites would be combined to obtain a larger sample size and thus increase the robustness of the statistical analyses. Given the differences between the two sites with respect to policy, staffing patterns, unit costs and other factors, however, it was decided that the cost data should be analyzed separately for each study site. Thus, the two study sites were considered to be a replication rather than part of the same study sample.⁵⁵

The main purpose of this study was to analyze the extent to which home care is a cost-effective alternative to residential care when one includes both formal *and* informal costs, that is, when one adopts a societal perspective for analysis. In order to obtain a valid cost comparison, this study included relatively stable clients only.⁵⁶

As noted in Chapter 5, there was relatively little difference between community and facility clients and among clients at the various care levels with respect to quality of life and satisfaction with service measures. Given this, a cost-minimization analysis was conducted which compared the cost of providing care to community clients to the cost of providing care to facility clients, by level of care, within each study site. For both community and facility clients, the costs of care were calculated by determining: (a) the cost of continuing care services (which included home support workers, care aides, nursing staff, therapeutic staff, support staff, and the non-care time adjustment); (b) the cost of other health services (which included physician services and acute care hospital services); (c) purchased services for community clients or user fees for facility clients; (d) direct informal costs (that is, out-of-pocket expenditures provided by clients and/or informal caregivers); and (e) the cost of assistance provided by informal caregivers (using three different approaches to costing informal caregiver time).

⁵⁵ This approach highlighted differences between the two study sites.

⁵⁶ In *Substudy 1: Final Report of the Study on the Comparative Cost Analysis of Home Care and Residential Care Services* (Hollander, 2001) it was found that with regard to costs to government, the costs of stable home care clients were about one-half, or less, of the costs of residential clients, depending on the level of care. It was also noted that the major costs for home care occurred when clients were moving from one care level to another. Thus, the costs for community clients presented for the current study are somewhat lower than they would be if the sample included clients in transition. However, adopting such a sampling frame would have provided a less valid comparison because a portion of home care clients could have moved to another level of care during the study period, thus reducing the accuracy of the within care level cost comparisons we were focusing on.

Table 7-9 presents a breakdown of all costs, by level of care and type of care for the two study sites. Column 1, “Care Staff Costs,” includes costs associated with home support workers, care aides, nursing staff and other health professionals. Column 2, “Support Staff Costs,” includes costs associated with dietary, housekeeping and laundry workers. Column 3, “Administrative Costs,” reflects the adjustment made to account for administrative overhead. Column 4, “Continuing Care Costs,” is the sum of Columns 1 to 3. The values in this column include costs to government as well as purchased services and facility user fees. Column 5, “Physician & Hospital Costs,” includes costs associated with physician services and hospital visits. Since the government pays 100% of these services, the values in this column include costs to government only. Column 6, “Total Formal Care Costs,” is the sum of Columns 4 and 5. Column 7, “Purchased Services/Facility User Fees,” reflects the combined amount community clients and/or caregivers paid for additional services as well as the user fees paid by facility clients and/or their caregivers.⁵⁷ Column 8, “Out-of-Pocket Expenses,” reflects direct costs paid by clients and/or informal caregivers. Column 9, “Informal Caregiver Time at Minimum Wage,” reflects informal caregiver time valued at minimum wage.⁵⁸ Column 10, “Informal Caregiver Time at Replacement Wage,” reflects informal caregiver time valued at the wage rate of the appropriate category of worker(s) who would need to be hired in the absence of a caregiver.⁵⁹ Column 11, “Maximum Costs to Clients and/or Informal Caregivers,” is the sum of Columns 7, 8 and 10. Thus, Table 7-9 indicates how each cost element contributes to the total.

7.8.1 Continuing Care Services

A two-factor (type of care by care levels) ANOVA was conducted using the cost to government for continuing care services data (that is, the data in Column 4 minus the data in Column 7 in Table 7-9)⁶⁰ from each study site separately. The findings indicated that the main effect of type of care was significant in both samples. For the Victoria sample, the main effect of type of care was $F(1, 202) = 81.00, p < .001$. For the Winnipeg sample, it was $F(1, 131) = 37.94, p < .001$.⁶¹ The main effect of care levels was significant in the Victoria sample, ($F(3, 202) = 5.62, p < .001$), but not in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample. Taken together, the findings indicated that the costs of care for community clients was significantly lower than the costs of care for facility clients in both study sites. The costs of care increased as the care needs of the clients increased in the Victoria sample, but not in the Winnipeg sample.

⁵⁷ In both the Victoria and Winnipeg samples, “Purchased Services” reflects the cost to community clients and/or families of obtaining services in addition to those authorized by the health care system. In the Victoria sample, the amount also reflects community clients’ co-payments for authorized services. Community clients in the Winnipeg sample did not have co-payments.

⁵⁸ Minimum wage was calculated at \$8.36 per hour for the Victoria site and \$6.65 for the Winnipeg site. These rates were based on provincial minimum wage rates at the time the study was conducted and include 11% benefits.

⁵⁹ The rates presented in Table 7-8 were used in these calculations.

⁶⁰ The data on total continuing care costs (that is, the data in Column 4 in Table 7-9 which includes both cost to government and client purchased service and facility user fees) were also analyzed. The results were similar to those reported here for cost to government only.

⁶¹ As with the time data, the analyses on the cost data from the Winnipeg site did not include Level E due to the small number of community clients in this level.

**Table 7-9: Mean Annual Costs for Formal and Informal Care Categories
(for Clients with 120 Hours per Month or Less of Care Aide Time)**

Site, Type, and Level of Care	Care Category										
	1	2	3	4	5	6	7	8	9	10	11
	Care Staff Costs ⁶²	Support Staff Costs ⁶³	Administrative Costs ⁶⁴	Continuing Care Costs ⁶⁵	Physician & Hospital Costs ⁶⁶	Total Formal Care Costs ⁶⁷	Purchased Services/Facility User Fees ⁶⁸	Out-of-Pocket Expenses ⁶⁹	Informal Caregiver Time at Minimum Wage ⁷⁰	Informal Caregiver Time at Replacement Wage ⁷¹	Maximum Costs to Client and/or Informal Caregiver ⁷²
Victoria Community											
Level A	\$10,893.25	-	-	\$10,893.25	\$1,970.41	\$12,863.66	\$ 614.46	\$1,673.86	\$ 1,863.72	\$ 5,221.08	\$ 7,509.40
Level B	\$15,568.99	-	-	\$15,568.99	\$2,422.39	\$17,991.38	\$ 803.13	\$1,843.70	\$ 3,976.59	\$11,140.15	\$13,786.98
Level C	\$13,895.06	-	-	\$13,895.06	\$1,020.00	\$14,915.06	\$ 370.50	\$3,338.72	\$ 4,852.56	\$13,594.14	\$17,303.36
Level D	\$19,886.38	-	-	\$19,886.38	\$ 434.38	\$20,320.76	\$ 3,450.00	\$6,783.13	\$11,249.74	\$31,515.42	\$41,748.55
Victoria Facility											
Level A	\$12,333.33	\$ 5,959.37	\$15,512.50	\$33,805.20	\$ 579.17	\$34,384.37	\$10,291.78	\$1,499.18	\$ 1,203.63	\$ 3,371.89	\$15,162.85
Level B	\$16,370.46	\$ 8,002.44	\$15,512.50	\$39,885.40	\$ 256.67	\$40,142.07	\$11,000.58	\$1,574.46	\$ 1,516.26	\$ 4,247.70	\$16,822.74
Level C	\$20,407.08	\$10,003.65	\$15,512.50	\$45,923.23	\$ 958.70	\$46,881.93	\$10,867.00	\$1,722.69	\$ 1,871.54	\$ 5,243.00	\$17,832.69
Level D	\$26,665.02	\$13,180.39	\$15,512.50	\$55,357.91	\$ 379.23	\$55,737.14	\$11,427.59	\$2,356.52	\$ 2,932.97	\$ 8,216.52	\$22,000.63
Winnipeg Community											
Level B	\$15,725.32	-	-	\$15,725.32	\$2,459.29	\$18,184.61	\$ 204.29	\$1,755.42	\$ 4,280.30	\$ 7,372.99	\$ 9,332.70
Level C	\$17,062.81	-	-	\$17,062.81	\$1,062.50	\$18,125.31	\$ 1,566.00	\$1,423.10	\$ 5,498.51	\$ 9,546.05	\$12,535.15
Level D	\$14,423.02	-	-	\$14,423.02	\$1,675.77	\$16,098.79	\$ 570.77	\$2,801.45	\$ 7,522.70	\$13,374.30	\$16,746.52
Level E	\$21,859.29	-	-	\$21,859.29	\$1,956.25	\$23,815.54	\$ 0.00	\$2,628.25	\$ 4,805.18	\$ 8,669.97	\$11,298.22
Winnipeg Facility											
Level B	\$20,406.87	\$ 9,250.37	\$15,512.50	\$45,169.74	\$ 159.55	\$45,329.29	\$11,673.70	\$ 308.57	\$ 1,169.17	\$ 1,980.36	\$13,962.63
Level C	\$20,024.77	\$ 9,765.63	\$15,512.50	\$45,302.90	\$ 255.41	\$45,558.31	\$13,406.55	\$ 903.56	\$ 1,605.63	\$ 2,745.45	\$17,055.56
Level D	\$17,070.94	\$ 8,144.07	\$15,512.50	\$40,727.51	\$ 675.38	\$41,402.89	\$12,807.15	\$1,068.70	\$ 1,787.13	\$ 3,165.17	\$17,041.02
Level E	\$20,550.30	\$ 9,804.06	\$15,512.50	\$45,866.86	\$ 880.00	\$46,746.86	\$13,324.14	\$1,599.14	\$ 1,202.65	\$ 2,214.38	\$17,137.66

⁶² Care Staff Costs include Home Support Workers, Care Aides, Nursing Staff, and Other Health Professionals.

⁶³ Support Staff Costs include Dietary, Housekeeping, and Laundry.

⁶⁴ Administrative Costs reflect an adjustment made for capital costs, equipment, food, administrative staff and other administrative overhead costs for facility clients.

⁶⁵ Continuing Care Costs are the sum of the columns Care Staff Costs, Support Staff Costs and Administrative Costs (includes Purchased Services/Facility User Fees).

⁶⁶ Includes Physician and Hospital Services (Purchased Services/Facility User Fees are not applicable).

⁶⁷ Total Formal Care Costs is the sum of the columns Continuing Care Costs and Physician and Hospital Costs.

⁶⁸ Purchased Services apply only to community clients while User Fees apply only to facility clients.

⁶⁹ Out-of-Pocket Expenses are costs paid directly by the client and/or informal caregiver.

⁷⁰ Using site-specific data.

⁷¹ Using site-specific data.

⁷² Maximum Costs to Client and/or Informal Caregiver is the sum of the columns Purchased Services/Facility User Fees, Out-of-Pocket Expenses and Informal Caregiver Time at Replacement Wage.

7.8.2 Physician and Hospital Costs

As noted in Table 7-9 (Column 5), the costs of physician and hospital services were fairly modest (in contrast to findings reported by Hollander, 2001). A two-factor (type of care by care levels) ANOVA was conducted on the data from each study site. The main effect of type of care was significant in the Winnipeg sample ($F(1, 131) = 7.11, p < .01$), indicating that the cost of physician and hospital services was higher for community clients than for facility clients. The main effect of type of care was not significant in the Victoria sample. Neither the main effect of care levels nor the type of care by care levels interaction was significant in either sample.

7.8.3 Cost to Government of All Health Services

Table 7-10 presents data on the cost to government for all health services for continuing care clients (that is, the data in Column 6 minus the data in Column 7 in Table 7-9). A two-factor (type of care by care levels) ANOVA was conducted on the data from each study site. The findings indicated that the type of care by care levels interaction was significant in the Victoria sample ($F(3, 202) = 2.81, p < .05$), but not in the Winnipeg sample. The main effect of type of care was significant in both samples; in the Victoria sample, $F(1, 202) = 68.08, p < .001$ and in the Winnipeg sample, $F(1, 131) = 30.16, p < .001$. The main effect of care levels was significant in the Victoria sample ($F(3, 202) = 4.55, p < .01$), but not in the Winnipeg sample. Taken together, these findings indicated that when all health services are considered, the cost to government is substantially less for community clients than for facility clients. Moreover, the costs to government increased as the care needs of the client increased in the Victoria site, but not in the Winnipeg site.

Table 7-10: Mean Annual Cost to Government of All Health Services for Continuing Care Clients (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	\$12,249.20	\$24,092.59		
	Standard Deviation	\$8,025.57	\$7,622.32		
	Number	37	12		
Level B: Slightly Independent	Mean	\$17,188.25	\$29,141.49	\$17,989.32	\$33,655.59
	Standard Deviation	\$6,996.46	\$11,898.78	\$10,217.75	\$18,076.34
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	\$14,544.56	\$36,014.93	\$16,559.31	\$32,151.75
	Standard Deviation	\$10,941.38	\$17,894.51	\$6,418.52	\$13,523.96
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	\$16,870.76	\$44,309.55	\$15,528.02	\$28,595.75
	Standard Deviation	\$13,465.77	\$16,940.92	\$7,731.96	\$13,897.39
	Number	8	26	13	52
Level E: Largely Dependent	Mean			\$23,815.54	\$33,422.73
	Standard Deviation			\$4,254.38	\$16,864.30
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

As noted in Chapter 3, British Columbia has a five care level system, while Manitoba uses a four level system. In both the Victoria and Winnipeg samples, clients were chosen primarily from two levels, and the SMAF scores were used to divide clients within these care levels into five, more highly differentiated, categories.

The finding that, in the Victoria sample, the cost to government increases as the care needs of the client increases most likely reflects the case mix funding system used in British Columbia in which differential amounts of funds are allocated by level of care. That is, funding increases as level of care increases.

The finding that, in the Winnipeg sample, the cost to government remains relatively constant regardless of care level for both community and facility clients is, at first glance, a bit more puzzling. However, it is noted that Manitoba uses modified case mix funding. It uses one rate for clients in Care Level 1, another for those in Care Level 2, and yet another for clients in Care Levels 3 and 4. We divided the original Winnipeg sample (which consisted of clients primarily at Levels 3 and 4) into five categories based on SMAF scores. Clients in Levels B, C, and D are believed to be like clients in Level 3 of the Manitoba system, and clients in Level E are thought to be comparable to clients in Level 4 of the Manitoba system. Thus, the above finding is not so surprising. Further examination of Table 7-10 indicates that the cost to government for the facility clients in the Winnipeg sample is consistent across care levels. Cost to government for community clients in the Winnipeg sample is similar for clients in Levels B to D, but increases by approximately one-third for clients in Level E (this may be because there are only four clients in this group). While a one-way ANOVA on the Winnipeg community sample indicated that the differences among the care levels were not statistically significant, the pattern was similar to that obtained in the Victoria sample.⁷³ That is, the cost to government is highest for those with the greatest care needs.

7.8.4 Out-of-Pocket Expenses, Client Purchased Services, and Facility User Fees

As noted in Table 7-9 (Column 8), out-of-pocket expenses were fairly modest for both community and facility clients. The largest expense for clients and/or informal caregivers was the user fee for facility care (Column 7). The difference in care costs between community clients and facility clients became even larger when these private costs of care were considered.

7.8.5 Informal Caregiver Time Valued at Zero Cost

As noted in Chapter 2, there is considerable debate in the cost-effectiveness literature regarding how informal care time should be valued. Informal care time can be valued at zero cost. However, informal caregiver time can also be valued using the caregiver's current income rate, minimum wage, or a replacement approach. Minimum wage is usually at the lower end of the range, while replacement or professional wage is at the high end. In this study, informal caregiver time was valued using three approaches – zero-pricing, minimum wage, and replacement wage. Valuing informal caregiver time at the caregiver's current income level was

⁷³ A similar analysis using the full sample of Winnipeg community clients (that is, those receiving 120 hours of care aide time per month as well as those receiving more than 120 hours) was also not significant.

not appropriate for this sample because less than half of the caregivers reported that they were currently working.

When informal caregiver time is valued at zero, the costs of care only incorporate public costs (cost to government), out-of-pocket expenses for clients and/or caregivers, and client purchased services/facility user fees (that is, the sum of Columns 4, 5, and 8 in Table 7-9; note that Column 4 includes purchased services and facility user fees).

Using informal caregiver time valued at zero, a two-factor (type of care by care levels) ANOVA was conducted on the total costs of care data from each study site. For the Victoria sample, both the main effect of type of care and the main effect of care levels were significant. For type of care, $F(1, 202) = 130.99, p < .001$. For care levels, $F(3, 202) = 8.14, p < .001$. The type of care by care levels interaction was not significant. For the Winnipeg sample, the main effect of type of care was significant, $F(1, 131) = 86.64, p < .001$. However, neither the main effect of care levels nor the type of care by care levels interaction was significant.

7.8.6 Informal Care Time Valued at Minimum Wage

Table 7-11 presents the comparative costs for community and facility clients when one combines all formal costs (both continuing care costs and physician and hospital costs), out-of-pocket expenses and informal caregiver time valued at minimum wage (that is, the sum of Columns 4, 5, 8 and 9 in Table 7-9).

Using informal caregiver time valued at minimum wage, a two-factor (type of care by care levels) ANOVA was conducted on the total costs of care. The main effect of type of care was significant in both samples. In the Victoria sample, $F(1, 202) = 95.97, p < .001$. In the Winnipeg sample, $F(1, 131) = 52.41, p < .001$. The main effect of care levels was significant in the Victoria sample ($F(3, 202) = 13.99, p < .001$), but not in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample.

7.8.7 Informal Care Time Valued at Replacement Wage

Table 7-12 presents the comparative costs for community and facility clients when one combines all formal costs (both continuing care costs and physician and hospital costs), out-of-pocket expenses and informal caregiver time valued at replacement wage (that is, the sum of Columns 4, 5, 8 and 10 in Table 7-9).

Using informal caregiver time valued at replacement wage, a two-factor (type of care by care levels) ANOVA was conducted on the total costs of care. Again, the main effect of type of care was significant in both samples. For the Victoria sample, $F(1, 202) = 36.49, p < .001$. For the Winnipeg sample, $F(1, 131) = 31.85, p < .001$. The main effect of care levels was significant in the Victoria sample, ($F(3, 202) = 21.75, p < .001$), but not in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample.

Table 7-11: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Minimum Wage (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	\$16,401.23	\$37,087.18		
	Standard Deviation	\$ 9,089.56	\$ 7,132.98		
	Number	37	12		
Level B: Slightly Independent	Mean	\$23,811.66	\$43,232.79	\$24,220.33	\$46,807.03
	Standard Deviation	\$ 8,727.69	\$11,849.41	\$16,500.93	\$18,784.29
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	\$23,106.35	\$50,476.16	\$25,046.92	\$48,067.49
	Standard Deviation	\$12,572.59	\$17,540.02	\$ 6,753.90	\$13,798.01
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	\$38,353.62	\$61,026.63	\$26,422.94	\$44,258.73
	Standard Deviation	\$20,780.10	\$17,532.38	\$ 7,193.26	\$14,780.74
	Number	8	26	13	52
Level E: Largely Dependent	Mean			\$31,248.97	\$49,548.65
	Standard Deviation			\$ 3,811.87	\$17,003.11
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

Table 7-12: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Replacement Wage (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	\$19,758.59	\$39,255.44		
	Standard Deviation	\$11,590.57	\$ 7,594.13		
	Number	37	12		
Level B: Slightly Independent	Mean	\$30,975.22	\$45,964.23	\$27,313.02	\$47,618.22
	Standard Deviation	\$16,943.63	\$12,566.70	\$21,219.16	\$19,486.61
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	\$31,847.92	\$53,847.62	\$29,094.46	\$49,207.31
	Standard Deviation	\$13,764.31	\$17,417.82	\$ 8,851.74	\$13,805.44
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	\$58,619.30	\$66,310.18	\$32,274.54	\$45,636.77
	Standard Deviation	\$25,473.65	\$21,491.15	\$ 9,200.12	\$15,735.47
	Number	8	26	13	52
Level E: Largely Dependent	Mean			\$35,113.75	\$50,560.38
	Standard Deviation			\$ 6,302.44	\$17,196.53
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

7.8.8 Costs of Care Minus Facility User Fees

It is important to ensure that in doing cost analysis, the costs for the groups being analyzed are comparable. Thus, we considered whether or not facility user fees should be subtracted from the costs of facility care because we did not include room and board costs in our

calculations for community clients. (An often-used rationale for facility user fees is that they cover the costs of room and board.) This is a complex issue which can be looked at in several different ways. First, one could argue that community clients have to pay for their food and housing and that to include user fees for facility clients but not community clients is inappropriate. Second, one could argue that food and housing costs are borne by clients whether they need care or not and, thus, are not an added cost related to the health care needs of the individual in the community. Third, one could argue that most not-for-profit facilities have paid off their mortgage and thus very little of the facility per diem (that is, client user fee) is actually attributable to food and housing (that is, room and board). Fourth, one could think of this cost as being on a sliding scale from very minimal costs up to the cost of the facility user fee. For example, community clients who have paid off their mortgages may have very low costs for food and shelter while those renting an apartment would have higher costs.

It is our view that the facility user fee is a health related cost which is paid because a client needs to be in a particular care setting as part of their care and, thus, differs from the non-care related costs of food and shelter for which everyone pays. Nevertheless, we recognize that in an analysis using a societal perspective, one could argue that one should have an equivalence for food and shelter costs. Thus, we provide tables in this section in which the facility user fee has been subtracted from facility costs.

Table 7-13 presents data on the total cost of formal and informal care (with informal care time valued at minimum wage) minus the facility user fee. Table 7-14 presents comparable data for informal caregiver time valued at replacement wage.

Two-factor (type of care by care levels) ANOVAs were conducted on the data in Table 7-13. The main effect of type of care was significant in both samples; for the Victoria sample, $F(1, 202) = 25.53$, $p < .001$, and for the Winnipeg sample, $F(1, 131) = 8.50$, $p < .01$. The main effect of care levels was significant in the Victoria sample, ($F(3, 202) = 13.32$, $p < .001$), but not in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample.

Two-factor (type of care by care levels) ANOVAs were also conducted on the data in Table 7-14. The main effect of type of care was almost significant in the Victoria sample ($F(1, 202) = 3.77$, $p < .06$), but was not significant in the Winnipeg sample. The main effect of care levels was significant in the Victoria sample, ($F(3, 202) = 21.15$, $p < .001$), but not in the Winnipeg sample. The type of care by care levels interaction was not significant in either sample.

The results indicated that when facility user fees were not included in care costs, there were slight changes in the overall findings. Community care costs were still significantly lower than facility care costs (even with the facility user fee subtracted out of facility costs) when caregiver time was costed at minimum wage. They were also generally lower, but not significantly so, when caregiver time was costed at replacement wage (see Table 7-14). In the Victoria sample, costs of care increased as the care requirements of clients increased regardless of how informal caregiver time was valued. In the Winnipeg sample, costs of care were relatively constant across care levels, regardless of whether informal caregiver time was valued at minimum wage or at replacement wage.

Table 7-13: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Minimum Wage, Minus Facility User Fees (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	\$16,401.23	\$26,795.40		
	Standard Deviation	\$9,089.56	\$ 7,621.09		
	Number	37	12		
Level B: Slightly Independent	Mean	\$23,811.66	\$32,232.21	\$24,220.33	\$35,133.33
	Standard Deviation	\$8,727.69	\$11,929.92	\$16,500.93	\$19,444.50
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	\$23,106.35	\$39,609.16	\$25,046.92	\$34,660.95
	Standard Deviation	\$12,572.59	\$17,731.60	\$6,753.90	\$13,343.36
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	\$38,353.62	\$49,599.04	\$26,422.94	\$31,451.58
	Standard Deviation	\$20,780.10	\$17,094.61	\$7,193.26	\$14,919.25
	Number	8	26	13	52
Level E: Largely Dependent	Mean			\$31,248.97	\$36,224.51
	Standard Deviation			\$3,811.87	\$17,356.40
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

Table 7-14: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Replacement Wage, Minus Facility User Fees (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	\$19,758.59	\$28,963.66		
	Standard Deviation	\$11,590.57	\$8,033.63		
	Number	37	12		
Level B: Slightly Independent	Mean	\$30,975.22	\$34,963.65	\$27,313.02	\$35,944.52
	Standard Deviation	\$16,943.63	\$12,554.19	\$21,219.16	\$20,165.29
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	\$31,847.92	\$42,980.62	\$29,094.46	\$35,800.76
	Standard Deviation	\$13,764.31	\$17,650.91	\$8,851.74	\$13,324.14
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	\$58,619.30	\$54,882.59	\$32,274.54	\$32,829.62
	Standard Deviation	\$25,473.65	\$20,891.09	\$9,200.12	\$15,863.94
	Number	8	26	13	52
Level E: Largely Dependent	Mean			\$35,113.75	\$37,236.24
	Standard Deviation			\$6,302.44	\$17,564.71
	Number			4*	29

* Due to there being less than five cases in this cell, the reported statistical analysis for Winnipeg was based on Levels B to D only.

7.9 Summary of the Comparative Costs of Community and Facility Care

Taken together, the findings from the comparative cost analyses indicated that in both study sites, costs were generally lower for community clients than for facility clients regardless of whether only formal costs (that is, costs to government) or both formal and informal costs (that is costs to government and costs to clients and/or informal caregivers) were considered. As might be expected, when informal caregiver time was valued at either minimum wage or replacement wage, there was a substantial jump in the average annual cost for both community and facility clients relative to when informal caregiver time was valued at zero. Nevertheless, the overall results still indicated that home care was significantly less costly than residential care, except when facility user fees were not included in the analyses and caregiver time was valued at replacement wage. In the latter case, home care was comparable to residential care. The comparative cost analyses also indicated that in the Victoria site, costs of care increased as the care requirements of the client increased. In the Winnipeg site, however, care costs were relatively constant across care levels, a finding that is consistent with policies and the funding system used in Manitoba.

8. DISCUSSION AND CONCLUSIONS

This study highlighted five points which have major implications for policy makers: competing demands on health care agencies; formal versus informal costs of providing care to both community and residential clients; differences between jurisdictions with respect to health care funding and delivery; the substitutability of home care for residential care; and increasing the efficiency of the health care system.

8.1 Competing Demands on Health Care Agencies

It was difficult to obtain the cooperation of clients and care provider agencies for this study due to three key factors. First, because of a number of unfortunate co-occurrences in the past, many continuing care clients in the Victoria site erroneously came to associate surveys of health care needs with cuts in service. They were, therefore, reluctant to consent to participate in the study no matter how much they were reassured that the study would not be linked to future cuts in service. Second, there is an increasing number of students and researchers who are doing community based research. Thus, the agencies approached for this study had often received multiple requests to participate in research projects during the previous months. While the specific demands on the agencies depended on the nature of the particular study, each project had some impact on the agencies' resources, be that access to clients, staff or records. Third, the lack of cooperation from agencies in this study seemed to stem from a more general climate in which the staff of care provider agencies across Canada have been asked to do more with less, over many years, due to fiscal restraint in the health system. Many agencies indicated that they were unable to participate (or could only provide minimal assistance) because of limited staff resources.

The findings and experiences resulting from this investigation suggest that if policy makers wish to make informed, evidence-based decisions, they need to give care providers adequate resources to both provide care and participate in major research projects. Care provider agencies, in turn, may wish to consider focussing on significant studies conducted by experienced and credible researchers rather than participating in all proposed studies, particularly those which have a limited probability of providing scientifically valid results.

8.2 Formal Versus Informal Costs of Providing Care to Community and Residential Clients

Using a societal approach to examining the costs of home care and residential care, this study has demonstrated that considerable time and money is spent on care by informal caregivers and clients. For community clients, depending on the level of care, families can contribute in purchased services, out-of-pocket expenses, and informal caregiver time (costed at a replacement wage) one half as much of the cost as government, to more than the overall cost to government. For example, the average annual cost to government for home care services in Victoria for Level A clients was \$12,249.20. The cost to clients and families for purchased services and out-of-pocket expenses was \$2,288.32 and the cost of informal caregiver time at replacement wages was \$5,221.08 for a total of \$7,509.40. Figures in Winnipeg for Level D clients were: \$15,528.02 for

the cost to government, \$3,372.22 for out-of-pocket expenses and \$13,374.30 for replacement wages for a total of \$16,746.52. Thus, families and friends can contribute, in time and direct costs, more than government to the cost of care for home care clients. A parallel analysis of the facility data indicated that, using replacement wages to cost the time of informal caregivers, families consistently contribute about half as much as government to the cost of residential care.

These findings raise the following policy questions: Is it reasonable for government to pay fully for short term curative care provided by doctors and hospitals but not pay the same proportion for people with ongoing care needs? What is an appropriate allocation of fiscal responsibilities between the family and the state for people requiring home/community based services or residential services? Should home care and residential care be considered “health” services or “social welfare” services?

8.3 Differences Between Jurisdictions With Respect to Health Care Funding and Delivery

In addition to the differences in formal versus informal costs noted above, the two study sites also appeared to have diverse approaches to policies regarding care provision. For example, in the Victoria site, there were relatively few home care clients who were treated as exceptions and were allowed to stay at home even if the costs of their care were similar to, or exceeded, the cost of residential care. For some time, the tradition in British Columbia has been to allow a small proportion of clients (some five to six percent) to exceed established guidelines for maximum hours per month in order to accommodate special cases on compassionate grounds. In the Winnipeg site, the pattern seemed quite different. In fact, given the number of exceptions in this site, the pattern may reflect a policy and programmatic tendency to allow people to remain at home rather than forcing them into facilities even if they exceed the cost of facility care. It may also reflect the flexibility of funding options available in the Winnipeg site.

This study also demonstrated that the costs of care, particularly in facilities, may not be linked to care level (as measured by the SMAF). In the Victoria site, facility costs increased as care level increased, a finding which is consistent with the case mix approach used in British Columbia. In the Winnipeg site, costs were similar for all facility clients regardless of their SMAF care level. As the Winnipeg clients were all funded at the same provincial funding level, this finding is consistent with the funding approach used in Manitoba.

Findings from this study indicate that further research and clinical investigation is warranted regarding how policy makers in Canada develop and implement policies regarding care provision, and how they determine exceptions to those policies. What policy choices are made and why? Are clients who can continue to be safely cared for at home but whose costs to government exceed that of facility care allowed to remain at home (thus favouring client needs and desires over costs)? Should they be? Is some degree of exception allowed as part of the overall policy? If so, what is considered an acceptable level for these exceptions and what criteria are used to determine who constitutes an exception and who does not?

8.4 The Substitutability of Home Care for Residential Care

As noted in the literature review in Chapter 2, and in the findings of this study, home/community care has the potential to be a cost-effective substitute for residential care while providing an equivalent, or better, quality of care. However, cost-effectiveness can only be achieved by making actual substitutions of home care for residential care. Given the differentials in costs noted in the current study, and given the potential of home care to look after quite heavy care clients, it appears that there is still room to achieve further efficiencies in health care delivery. The easy substitutions and savings have probably already been made. However, further savings and/or increases in the efficiency of the care system may be possible with specific, targeted initiatives which include ongoing monitoring and evaluation. Given that reductions in the utilization rates of facility beds have already resulted in relatively low bed to population ratios, it may now be unwise to simply close more beds without providing additional home care services.

8.5 Increasing the Efficiency of the Health Care System

Most major commissions and reviews of the health system have concluded that there is enough money in the system. Given current fiscal restraints, there is an obligation to make the system more efficient and effective by allocating existing funds more wisely. Reduced costs, and the increased overall cost-effectiveness of the Canadian health care system, will not result from providing more funding to acute care hospitals. Rather, increased efficiency will be obtained by developing and maintaining lower cost alternatives, such as home care and residential care, that reduce the need for hospital-based services.

The Carelinks Program (Simon Fraser Health Region, 2000) in the Simon Fraser Health Region in British Columbia is an initiative in which home care has successfully been used as cost-effective alternative to hospital care. The health region made a conscious, proactive policy choice to close 30 beds in a busy hospital and to re-allocate the funds to home care. They saved \$2 million by closing the beds, re-invested \$1 million in home care and had \$1 million left over to improve services and make other useful investments. The savings of \$1 million per annum continue to accrue as long as the 30 beds stay closed.

8.6 Final Conclusions

In conclusion, this study has demonstrated that across all levels of care, home care is less costly, for stable clients, than residential long term care when only formal costs (that is, costs to government) are considered; home care costs are, on average, about 50% of the costs of residential care. When a societal approach, which considers both formal and informal costs, is used to cost care, it appears that informal costs (that is, purchased services, out-of-pocket expenses and care time) are considerable. Families can contribute one half or more of the overall care costs of home and community care, and about one third of the overall care costs of residential care. Policy makers need to consider whether these proportions are reasonable and appropriate given that the government currently covers 100 percent of the costs of physician and hospital care.

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APPENDIX A

Client and Caregiver Perspectives on Service Provision

1. INTRODUCTION

As noted in the Introduction to this report, a number of clients, caregivers, and study personnel expressed their thoughts on several aspects of the current health care system and their experiences with it. While it is recognized that service providers and others may not agree with the sentiments expressed by these individuals, the investigators felt that it was important to report them as they identify areas for further investigation. These comments also reflect the very personal nature of care provision.

The identified issues fall into seven categories: issues regarding the environment; issues regarding workers; issues regarding client's rights and choices; issues regarding service provision; issues regarding administration; issues related to the characteristics of clients and caregivers; and limitations of the present study.

2. ISSUES REGARDING THE ENVIRONMENT

2.1 Type of Care Environment

It might be expected that community clients would feel better than facility clients about their general health and well-being. However, as noted in Chapter 5, facility clients rated their general health and self-esteem higher than community clients. This may have been because facility clients perceived that their environment was better now compared to when they were living in the community (for example, because staffing was more consistent or because the clients had a more regular routine).

Vignette: The caregiver stated that her stepfather was happier in the facility than he was when he was at home with the caregiver's mother and then on his own after his wife died. In the community, the client was very lonely, and was afraid of dying alone. Since the client has been in a facility, his family has treated him with more love and compassion than when he was in the community. The staff in the facility also provide him with a lot of emotional and spiritual support.

2.2 Physical Environment

Several caregivers commented on physical aspects of the environment within which the client was living. For example, one caregiver noted that "the facility always smells of urine and the hallways are dark." Another noted that: "the design of [the facility] is absolutely prison like – long corridors with steel doors off them. The rooms are very small and the wrong shape for the proper placement of a comfortable chair. The architects of these facilities should be made to live in one of these rooms and the common areas for a week to experience the effect of their work!" A third noted that the "noise disturbances from other patients is upsetting."

2.3 Care Environment

Clients and caregivers also commented about the care environment itself. For example, a community client noted that some home support workers wipe their noses with their hands, and cough and sneeze in the kitchen and around her without using a tissue.

Several facility clients indicated that they would like better food and a wider selection of food. Other facility clients indicated that they would like to get out for fresh air more frequently. Many caregivers echoed these suggestions for improvements.

3. ISSUES REGARDING WORKERS

3.1 Clients' and Caregivers' Perceptions of Staff

Clients and caregivers often made a distinction between formal service providers and the organization the staff worked for. Clients generally spoke very highly of facility staff. They were less positive about home support staff because of the turnover in home support workers.

One caregiver noted that the support of the case manager was very useful in helping the family choose a facility and in helping the client to accept facility placement. Another noted that: "the staff are untiringly cheerful against great odds and do their best to make the best of a resident's stay."

3.2 Staff Turnover and/or Changes in Staff

Clients, caregivers and study personnel all commented on the huge turnover of staff, particularly in home support agencies. It was noted that this creates a problem for clients because care is inconsistent and may increase confusion in individuals who are cognitively impaired. Clients also noted that changing staff means getting used to someone new and spending time (which is already limited) explaining things to the workers. Home care clients want to have a limited number of consistent workers. And, they want to have some input into who is assigned to them.

One caregiver noted that "I would like it if one paid caregiver could do all of the tasks, rather than a nurse doing medications, a home care worker doing cleaning, etc. This would make for more consistent care and a closer relationship [with the client]."

3.3 Shortage of Staff and Existing Staff Overworked

A number of comments indicated that both clients and caregivers felt that staffing levels, particularly in facilities, were insufficient. They also felt that staff shortages directly affected the amount and quality of care provided to the client. However, because insufficient staffing levels have been an issue for a long time, neither clients nor caregivers expect changes to be made in this area.

3.4 Properly Trained Staff

Home care clients often commented on the need to have properly trained staff. A number of clients said that some staff, generally their "usual" care staff person (if they had one), were great and knew what they were doing and how to do it. Other care staff seemed to be inadequate with respect to both knowing what to do, and in doing specific tasks well. Unsatisfactory workers were described as lacking basic hygiene knowledge, social skills, motivation, and "common sense." Some examples of staff not knowing what to do included: doing laundry properly (for example, not separating whites and colours), cooking a meal, and cleaning properly. More effort needs to be made to standardize the level of care provided by formal service providers, particularly those providing care to community clients.

4. ISSUES REGARDING CLIENT'S RIGHTS AND CHOICES

4.1 Amount of Time Staff Spend with Clients

The amount of time staff spend with clients appeared to be problematic for both community and facility clients. Community clients indicated that they want staff to spend more time doing things for them. Facility clients indicated they want staff to spend more time chatting with them and giving them emotional support and friendship.

4.2 Respect for the Client's Possessions

Clients and caregivers both commented on the need for staff to respect the client's belongings. For example, a facility client indicated that she would like the staff to assist her more with keeping track of her possessions. A community client noted that groceries have disappeared from her fridge, especially after "one time people" come. A caregiver of a facility client noted that "losing items of clothing to the laundry is a common occurrence. Even when items are labeled, they go missing."

5. ISSUES REGARDING SERVICE PROVISION

5.1 Including Caregivers in the Care of Clients

Some caregivers of facility clients indicated they would like the staff and administrators to include them more in decision making (for example, including them in care conferences). The caregivers also indicated that staff seemed too busy to talk with them about the client (for example, how he or she had been doing, any new behaviours, or changes in the person's health). Caregivers noted that they want staff to talk to them more when they visit the client.

5.2 Services Not Meeting the Needs of the Client and/or the Caregiver

If clients are to remain in the community (either because of personal choice or because of availability of services), community services such as home support must meet the needs of the clients and their caregivers. For example, services for community clients need to be expanded and extended to include the caregiver's respite needs.

Concerns were also expressed about facility care being "institutionalized." One client noted that "as a resident in a lodge (facility), you're slowly but surely becoming a non-person. [The facility] is very well organized with lots of goodwill, [but it is] rather impersonal." It was also noted that activities for facility clients vary among facilities and in some cases might not meet the range of clients in the facility (they may be either too stimulating or not stimulating enough).

5.3 Service Provision is Inadequate

Staff may fail to provide services, or may provide inadequate service.

For example, a caregiver of a community client noted: "From January 1, 2000 to November 27, 2000, home care missed 36 times." Another caregiver noted: "Home care workers just stand around watching television. They are supposed to be [in the client's home] for two hours, but they

only stay 10 minutes.”

A caregiver of a facility client noted “When visiting, we always fix the clothes closet, clean his razor and his eyeglasses (and teeth if not done). We wipe off the wheelchair, the top of his dresser, the hand guards, and his hands. [There] is no sense in complaining; it does not do any good. Compassion is not there.”

A caregiver of another facility client stated: “We frequently arrive for a visit [with the client] to find her in desperate need to use the washroom. We are no longer able to take her ourselves and are forced to try to locate a staff member to assist her. We have often been told that all available staff are on a break or busy with meals, etc. and that she just has to wait. There is apparently a routine check every so often, but she is left so long that she has frequent ‘accidents’. This is very upsetting to her (and certainly does nothing for her self-esteem). Because of a rigid schedule, staff are unable to respond to individual needs for such basic care as assistance to use the toilet. Human bowels and bladders do not function according to a schedule!”

5.4 Service Provision is Limited

Some caregivers noted that it seemed like they were expected by the “system” to provide care to the client when it was not always possible to do so.

Vignette: The client lives with her son who has substantial health problems himself. The client’s daughter provides the majority of the care, although she also works full time. The client has been denied extra home support hours since it is expected that her son should be able to manage the household tasks. However, his health does not allow for this.

6. ISSUES REGARDING ADMINISTRATION

6.1 Agency Records Not Up to Date

The information provided by both home support agencies and long term care facilities to the study personnel was not always accurate. For example, one home support agency indicated that several clients were able to make their own decisions. However, study personnel found that several clients had moderate to severe cognitive impairment.

In some cases, agency records accessed by study personnel were sketchy, if they were found at all. This seemed to be related to recent changes in the agencies, such as amalgamation.

An interviewer noted that she had been told that a client had dementia when in fact he had slurred speech and slow responses as a result of a stroke. She stated “it concerns me that if this is the information care workers are given, his care will be affected by their lack of understanding of his health situation.”

6.2 Too Much Bureaucracy

In some cases, caregivers felt that there was too much bureaucracy within agencies.

Vignette: The caregiver was caring for two aging parents. One parent (the one receiving home support) needed to go to emergency. The caregiver asked the home support worker to stay with the other parent until another family member arrived. The home support worker called her supervisor who initially said “No.” When the caregiver spoke with the same supervisor, she said she had to contact her supervisor. After speaking with the second supervisor, the caregiver received permission to have the home support worker stay but was charged for the worker’s time.

6.3 Suggestions for Improving Home Care

A community client offered several suggestions for improving home care services:

- Pay home support workers on a bi-weekly or monthly basis rather than on an hourly basis. This will provide the workers with more security. It will also attract better and more qualified people.
- Home support workers should have regular clients every day. If the client goes into hospital, the worker could be assigned to the hospital for those hours or days that the client is unavailable.
- If a client goes into hospital, their home support worker should be re-assigned to them once they are released.
- Clients and home support workers should be comfortable with each other.
- Home support workers should be able to provide a range of services (such as giving a bath, providing cleaning and making a meal).
- Clients should be contacted regularly to ascertain their satisfaction with the services they are receiving. Suggestions for improvements should be solicited.

7. ISSUES RELATED TO THE CHARACTERISTICS OF THE CLIENTS AND CAREGIVERS

7.1 Clients Wishing to Remain at Home

Study personnel noted that being able to remain in their own homes seemed very important to some of the community clients. As noted in the Informal Caregiver diaries, community clients rely on relatives, friends and neighbours and go without a lot in order to remain in their homes. One client noted that she often used ENSURE as she didn’t always have food in the house and wasn’t able to stand long enough to prepare meals.

Vignette: The client lived in an older home with single pane windows. The home was heated by a wood stove. During the colder months, her living area was reduced by the use of heavy curtains to block draughts from other parts of the home. She had a commode by her bed. Although she admitted she was quite frail, she was adamant that she wanted to die at home.

Vignette: The client had experienced a stroke that paralysed one side of his body and affected his speech and mental functioning. His health limitations necessitated complete renovations to his two storey home to accommodate a wheelchair. The renovations were made at great expense and effort to both the client and his wife (who is his caregiver).

7.2 Promotion of Client Independence

Occasionally, clients and caregivers indicated that formal service providers made the client more dependent than the client felt was necessary.

One client suggested that to promote her independence, her home support workers could set up an accessible supply closet or shelf so that she could reach things like toilet paper and kleenex on her own.

A caregiver suggested that for more functional facility clients, a comfort “station” (containing a fridge stocked with snacks, a toaster, a sink and a kettle) that clients could access when desired would make the facility feel more like a “home” than an “institution.”

7.3 Caring for Multiple Individuals

Some caregivers were providing care to several individuals. For example, a caregiver in her 70’s was providing care to her 91 year old mother, her 72 year old mentally challenged brother, and her 75 year old husband.

7.4 Caregiving Stress After the Client Has Been Admitted to a Facility

Caregivers report that their stress levels change once their elderly relative or friend is admitted into a care facility.

Vignette: A daughter had her mother living in a ‘granny suite’ attached to her house. As her mom became older and more forgetful, the daughter was always worried about her. As well, the mom was quite isolated and alone much of the time while the daughter was at work. Now the mom is living in a facility and things are much less stressful for the daughter as she feels that her mom is safe and well looked after.

Vignette: The client had been living in her own apartment with the assistance of home support, monitoring systems, and a daughter who ensured her bills were paid and she was able to get to doctor’s appointments and the hospital when necessary. The client’s health and safety were often compromised as her food and medications were taken erratically. While facility placement has ensured that the client has a safer, more consistent lifestyle, she is miserable.

8. LIMITATIONS OF THE CURRENT STUDY

A few clients and caregivers indicated that while the current study was interesting and they were happy to have participated in it, they also noted that the investigators had not addressed issues they felt were important.

For example, a caregiver noted that since the diaries were only kept for a two-week period, it was difficult to include a complete list of the care related expenses and services that she provided during the year. Another caregiver noted that items on the Caregiver Questionnaire addressed burden and emotional aspects, but did not address the physical impact that caregiving can have. A third caregiver wondered why the investigators did not ask where the client *preferred* to be living.

APPENDIX B

Copies of Measurement Instruments and Data Collection Forms

[Not Available Electronically]

APPENDIX C

Loss of Participants at Various Stages of the Analyses

Table C1: Loss of Participants at Various Stages of the Analyses

	Victoria		Winnipeg	
	Community	Facility	Community	Facility
Initial Sample (Chapter 3)	121	160	101	198
No SMAF Score (Chapter 5)	121	160	101	195
SMAF Scores Divided into 5 Levels (Chapter 5)	96	158	89	166
Using SMAF Scores from 4 Levels (Chapter 5)	96	152	79	164
Have Good Quality Diaries (Chapter 7)	84	130	67	142
Receive 120 Hours of Care Aide Time or Less Per Month (Chapter 7)	80	130	41	129

APPENDIX D

Time and Cost Data for Clients Receiving More Than 120 Hours of Care Aide Time Per Month

Table D-1: Mean Annual Nursing Hours (for Clients with more than 120 Hours per Month of Care Aide Time)¹

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	0.00	-	-	121.33
	Standard Deviation	-	-	-	171.59
	Number	1	0	0 ²	2
Level C: Slightly Dependent	Mean	0.00	-	98.94	0.00
	Standard Deviation	-	-	214.02	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	0.00	-	1.00	165.84
	Standard Deviation	0.00	-	3.61	86.83
	Number	2	0	13	7
Level E: Largely Dependent	Mean			30.33	275.02
	Standard Deviation			74.30	175.55
	Number			6	3

Table D-2: Mean Annual Hours for Other Health Professionals (for Clients with more than 120 Hours per Month of Care Aide Time)³

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	8.67	-	-	6.50
	Standard Deviation	-	-	-	9.19
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	0.00	-	28.89	52.00
	Standard Deviation	-	-	53.89	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	19.50	-	5.38	32.81
	Standard Deviation	27.58	-	4.43	56.71
	Number	2	0	13	7
Level E: Largely Dependent	Mean			7.22	8.67
	Standard Deviation			3.54	0.00
	Number			6	3

¹ Includes time from RNs, LPNs, and psychiatric nurses. The data in this table are comparable to those presented in Table 7-4.

² There was one extreme outlier in this cell which was deleted from this and the following tables.

³ Includes time from occupational therapists, physiotherapists, massage therapists, and podiatrists/chiropractors. The data in this table are comparable to those presented in Table 7-5.

Table D-3: Mean Annual Physician Hours (for Clients with more than 120 Hours per Month of Care Aide Time)⁴

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	0.00	-	-	0.00
	Standard Deviation	-	-	-	0.00
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	0.00	-	5.42	6.50
	Standard Deviation	-	-	8.64	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	9.75	-	2.50	1.86
	Standard Deviation	4.60	-	3.29	3.17
	Number	2	0	13	7
Level E: Largely Dependent	Mean			4.33	2.17
	Standard Deviation			3.36	3.75
	Number			6	3

Table D-4: Mean Annual Hours for Informal Caregivers (for Clients with more than 120 Hours of Care Aide Time)⁵

Care Level		Victoria		Winnipeg	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	292.50	-	-	654.33
	Standard Deviation	-	-	-	686.37
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	268.67	-	932.97	751.83
	Standard Deviation	-	-	717.42	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	1213.33	-	1095.87	249.97
	Standard Deviation	818.12	-	1132.02	291.19
	Number	2	0	13	7
Level E: Largely Dependent	Mean			724.10	143.00
	Standard Deviation			662.80	143.00
	Number			6	3

⁴ Includes time from primary care physicians and physician specialists. The data in this table are comparable to those presented in Table 7-6.

⁵ The data in this table are comparable to those presented in Table 7-7.

Table D-5: Mean Annual Cost to Government of All Health Services for Continuing Care Clients (for Clients with more than 120 Hours per Month of Care Aide Time)⁶

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	\$52,006.00	-	-	\$80,248.87
	Standard Deviation	-	-	-	\$16,532.52
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	\$95,717.44	-	\$54,615.74	\$72,104.60
	Standard Deviation	-	-	\$28,649.97	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	\$42,476.84	-	\$63,924.76	\$91,584.70
	Standard Deviation	\$8,935.96	-	\$37,217.92	\$19,907.91
	Number	2	0	13	7
Level E: Largely Dependent	Mean			\$50,655.62	\$106,127.35
	Standard Deviation			\$16,308.13	\$23,940.90
	Number			6	3

Table D-6: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Minimum Wage (for Clients with more than 120 Hours per Month of Care Aide Time)⁷

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	\$58,052.30	-	-	\$96,929.46
	Standard Deviation	-	-	-	\$20,086.63
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	\$101,088.49	-	\$65,852.44	\$88,021.84
	Standard Deviation	-	-	\$33,566.00	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	\$79,488.30	-	\$77,357.63	\$107,098.19
	Standard Deviation	\$24,628.44	-	\$42,581.33	\$19,473.49
	Number	2	0	13	7
Level E: Largely Dependent	Mean			\$58,107.61	\$121,365.33
	Standard Deviation			\$19,301.01	\$20,184.43
	Number			6	3

⁶ The data in this table are comparable to those presented in Table 7-10.

⁷ The data in this table are comparable to those presented in Table 7-11.

Table D-7: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Replacement Wage (for Clients with more than 120 Hours per Month of Care Aide Time)⁸

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	\$62,457.35	-	-	\$99,880.63
	Standard Deviation	-	-	-	\$23,199.05
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	\$105,134.61	-	\$70,821.10	\$91,865.25
	Standard Deviation	-	-	\$36,333.06	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	\$97,761.10	-	\$83,281.07	\$108,495.48
	Standard Deviation	\$36,949.37	-	\$44,484.79	\$20,074.41
	Number	2	0	13	7
Level E: Largely Dependent	Mean			\$62,363.46	\$122,000.25
	Standard Deviation			\$22,984.06	\$20,466.83
	Number			6	3

Table D-8: Mean Average Cost of Continuing Care Service, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Minimum Wage, Minus Facility User Fees (for Clients with more than 120 Hours per Month of Care Aide Time)⁹

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	\$58,052.30	-	-	\$85,972.16
	Standard Deviation	-	-	-	\$22,471.42
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	\$101,088.49	-	\$65,852.44	\$77,148.49
	Standard Deviation	-	-	\$33,566.00	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	\$79,488.30	-	\$77,357.63	\$94,264.79
	Standard Deviation	\$24,628.44	-	\$42,581.33	\$20,266.36
	Number	2	0	13	7
Level E: Largely Dependent	Mean			\$58,107.61	\$109,668.30
	Standard Deviation			\$19,301.01	\$22,370.68
	Number			6	3

⁸ The data in this table are comparable to those presented in Table 7-12.

⁹ The data in this table are comparable to those presented in Table 7-13.

Table D-9: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Replacement Wage, Minus Facility User Fees (for Clients with more than 120 Hours per Month of Care Aide Time)¹⁰

Care Level		Victoria Sample		Winnipeg Sample	
		Community	Facility	Community	Facility
Level A: Somewhat Independent	Mean	-	-		
	Standard Deviation	-	-		
	Number	0	0		
Level B: Slightly Independent	Mean	\$62,457.35	-	-	\$88,923.33
	Standard Deviation	-	-	-	\$25,583.84
	Number	1	0	0	2
Level C: Slightly Dependent	Mean	\$105,134.61	-	\$70,821.10	\$80,991.90
	Standard Deviation	-	-	\$36,333.06	-
	Number	1	0	6	1
Level D: Somewhat Dependent	Mean	\$97,761.10	-	\$83,281.07	\$95,662.08
	Standard Deviation	\$36,949.37	-	\$44,484.79	\$20,853.05
	Number	2	0	13	7
Level E: Largely Dependent	Mean			\$62,363.46	\$110,303.22
	Standard Deviation			\$22,984.06	\$22,677.01
	Number			6	3

¹⁰ The data in this table are comparable to those presented in Table 7-14.