

# **Veterans Affairs Canada and the Government of Ontario**

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## **The Continuing Care Research Project for Veterans Affairs Canada and the Government of Ontario**

### **Synthesis Report**

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## **EXECUTIVE SUMMARY**

### **1. Introduction**

Veterans Affairs Canada (VAC) supports a wide range of health and supportive services for veterans. It also provides funding to “top up” existing provincial services, as needed, and provides funding for services that are not funded by provincial Ministries of Health. There are numerous categories of veterans and benefits, within three main health programs: the Health Benefits Program; the Veterans Independence Program (VIP); and Long Term Care.

In 1999, in response to a growing number of clients on waiting lists for beds in long term care facilities, VAC implemented the Overseas Service Veterans At Home Pilot Project. This pilot project offered certain clients, on waiting lists, who met nursing level care and military service requirements (i.e., Overseas Veterans, OSVs), access to some VIP services. Previously, the OSVs had not been eligible for these services. In 2003, VAC implemented the OSV/VIP Program nationally. In 2005, a Frail policy was introduced which provided a new gateway to VIP services and Health Care Benefits for clients with a pensioned condition who satisfied the frail criteria. Given the results of an OSV/VIP pilot study, and the establishment of VIP services as a new benefit for OSVs, VAC was interested in conducting a more rigorous study of the OSV/VIP initiative, both for internal planning and policy development and as a means of obtaining information that could contribute to broader health policy discussions in Canada.

It is recognized that some individuals may be admitted to long term care facilities because they can no longer function on their own in their homes. However, some of these individuals may be able to function in a lower cost residential setting with appropriate, structured support services. Both VAC and the Government of Ontario (GO) had an interest in learning about the potential benefits of long term care and whether supportive housing could be an appropriate alternative to facility care.

### **2. The Continuing Care Research Project**

The interest in conducting a study of the OSV/VIP initiative and examining the potential role of supportive housing as an alternative to community and facility care resulted in the development of the Continuing Care Research Project. The goals of the Continuing Care Research Project were to:

- obtain information on the relative success of the OSV/VIP initiative;
- determine the relative costs and outcomes (i.e., cost-effectiveness) of long term home care, supportive housing, and facility care;
- examine the contributions of long term home care and home support services with respect to the care of the elderly; and
- obtain information which can contribute to the broader policy debate in Canada about health services for the elderly.

The project involved two studies. Study 1 involved an independent evaluation of the costs and outcomes of the OSV/VIP initiative. It was conducted in the same three sites as the initial pilot project (i.e., Halifax, Ottawa and Victoria), and involved four components: interviews with VAC personnel; a historical review of service utilization and costs both before and after the implementation of the OSV/VIP Program; interviews with veterans and their informal caregivers regarding their use of care and support services funded by VAC; and diaries completed by clients and caregivers regarding out-of-pocket expenses and time spent on care services. Study 2 examined the relative costs and outcomes of long term home care, supportive housing and long term facility care. It was conducted in Toronto and in the Peel, York and Durham Regions, and involved two components: interviews with veterans and their informal caregivers regarding their use of care and support services funded by VAC; and diaries completed by clients and caregivers regarding out-of-pocket expenses and time spent on care services.

### **3. Participants**

The focus of both Studies 1 and 2 was on veterans who had served in World War II and/or the Korean War. The supportive housing sample in Study 2 also included spouses of veterans who were receiving benefits and services funded by VAC.<sup>1</sup> Where possible, informal caregivers of clients were identified in order to obtain information regarding the caregivers' experience of providing care and/or support to the clients. For the purposes of this study, informal caregivers were family members, friends, volunteers, members of a service organization, or other individuals who provided the client with unpaid care and/or support.

In Study 1, 355 clients (177 community clients and 178 facility clients) were included in the study. Overall: 94% of the clients were male; 55% were 85 years of age or older; and 58% were married, 36% were widowed. Study 1 also involved 300 informal caregivers; 48% were caring for a client in the community and 52% were caring for a client in a facility. Overall: 84% of caregivers were female; 51% were spouses and 43% were adult children of the client; 53% were 65 years of age or older (40% were 75 years of age or older); and 89% were married.

In Study 2, there were 682 clients (313 community clients, 256 facility clients, and 113 supportive housing clients). Overall: 88% of the clients were male; 55% were 85 years of age or older; and 47% were married, 43% were widowed. There were also 411 informal caregivers in Study 2. Some 45% of the sample were caring for a client in the community, 45% were caring for a client in a facility, and 10% were caring for a client in supportive housing. Overall: 82% of the sample were female; 47% were spouses and 40% were adult children of the client; 54% were 65 years of age or older (45% were 75 years of age or older); and 83% were married.

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<sup>1</sup>In both Studies 1 and 2, the term "client" refers to the veteran, regardless of whether the individual was physically and/or cognitively capable of providing informed consent and participating in the study on his/her own behalf. The non-veterans who participated in the supportive housing sample in Study 2 are also referred to as clients. The term "proxy" refers to an individual who provided informed consent and participated in either study on behalf of a client when the client was unable to participate him/her self. Proxies were often spouses, adult children, or other family members.

#### **4. Findings Related to Key Research Questions**

The Continuing Care Research Project addressed 11 specific research questions. Some questions related to Study 1 only, some related to Study 2 only, and some related to both studies. Key findings related to the research questions are summarized below.

##### **4.1 How do VAC staff and managers see the OSV/VIP Program?**

This question only applied to Study 1. All of the VAC personnel interviewed as part of this component of the Continuing Care Research Project indicated that they were either very or somewhat satisfied with the OSV/VIP Program. In addition, 93% of the respondents felt that the program had been very or somewhat successful. Respondents noted that, over time, the focus of the program had changed from how to ease facility waitlists to how to keep a person at home longer and ease the burden of care. They also noted that while the program has generally been successful for those who had been helped, there were other veterans who could potentially benefit from the program.

##### **4.2 To what extent have people embraced the OSV/VIP Program?**

In order to answer this question (which only applied to Study 1), an analytical database was created using historical utilization data. The findings indicated that as the OSV/VIP Program became available in both the initial and national pilot sites, people who had been ineligible for services and benefits, or who had not sought services and benefits were able to take advantage of the new program (there was a 604% to 659% increase in the use of VIP services by OSVs).

##### **4.3 What are the comparative costs for OSV clients before and after the introduction of the OSV/VIP Program?**

In order to answer this question (which only applied to Study 1), historical expenditure data were obtained. However, because of unresolvable anomalies and incomplete data, estimated costs were based on utilization rates. It was estimated that about seven to eight times as many people could be cared for in the community compared to a long term care facility, for the same amount of money.

##### **4.4 How satisfied are comparable clients in different care settings and how do they rate their quality of life?**

These questions applied to both Studies 1 and 2. Cognitively capable clients<sup>2</sup> in all three care settings (i.e., community, facility and supportive housing) showed high levels of satisfaction with the paid services they were receiving. When all cognitively capable clients were compared, community clients were more satisfied than facility clients. When cognitively capable clients at similar care levels<sup>3</sup> were compared, community clients perceived that their satisfaction was the

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<sup>2</sup> In this study, the term “cognitively capable client” was used to refer to individuals who were considered cognitively competent enough to participate in the study on their own behalf.

<sup>3</sup> Clients were grouped into care levels based on their scores on a functional status measure. Cognitively capable clients at comparable care levels are a subset of all cognitively capable clients.

same or better than facility clients; supportive housing clients fell between the other two groups. There were no differences among clients at different care levels in either study. When asked how satisfied or dissatisfied they were overall with the services they received, 78% of cognitively capable clients in both studies indicated they were very satisfied.

When all cognitively capable clients were compared, facility clients perceived that their physical health-related quality of life was the same or better than community clients; supportive housing clients perceived their physical health-related quality of life to be similar to that of both community and facility clients. Community, facility and supportive housing clients perceived their mental health-related quality of life similarly. When cognitively capable clients at similar care levels were compared: perceptions of physical health-related quality of life decreased as clients' care needs increased; perceptions of mental health-related quality of life remained the same, regardless of an individual's care needs; and facility clients felt that both their physical and mental health-related quality of life was better than community clients. This latter finding may, at least in part, be attributable to the additional services VAC funds for veterans in long term care facilities.

#### 4.5 What proportion of home care services are provided by home support services?

In both Studies 1 and 2, the services used most frequently by community clients were housekeeping, home adaptations and grounds maintenance. These were also the services used most frequently by supportive housing clients in Study 2. In both studies, home support services (i.e., housekeeping services) accounted for 25% of the services used by community clients. By comparison, home adaptations and grounds maintenance both accounted for about 17%. For supportive housing clients, home support services accounted for 16%, home adaptations for 15% and grounds keeping for 18%. Taken together, the findings indicate that home support services play an important role in keeping individuals in the community and that a combination of services are important for individuals living in supportive housing.

#### 4.6 Which home care and home support services are the most instrumental in keeping people out of facility care?

In both Studies 1 and 2, clients and proxies were asked what factors were enabling community clients to remain at home. Clients were able to remain at home because: they received assistance and support from informal caregivers; their health was good; and they were able to care for themselves (perhaps with some assistance for housekeeping, home adaptations and grounds maintenance). Over 70% of caregivers in both studies indicated that they assisted clients with preparing meals and shopping for food and household items. Over 70% of caregivers in Study 1 also indicated that they assisted with laundry, housework and managing finances. Thus, while the findings do not clearly identify specific home care services that are instrumental in keeping people out of facility care, they do identify the important role that informal caregivers play, and highlight the household maintenance functions that the informal caregivers provide.

#### 4.7 Which factors contributed to clients entering a long term care facility?

In both Studies 1 and 2, respondents were asked what factors affected the client's decision to move into a long term care facility. Clients went into facilities primarily because their health needs increased and/or because their informal caregivers were unable to provide the necessary care and/or support. Across the two studies, approximately 31% of respondents indicated that no additional resources would have enabled the client to remain at home, and approximately 46% indicated that the client required 24 hour care. The findings indicate that a substantial proportion of clients were placed in long term care facilities because it was no longer feasible to try to care for them at home.

#### 4.8 What have been the positive and negative impacts on family caregivers?

Caregivers in both Studies 1 and 2 were asked a number of questions regarding the impacts care provision had had on them. The findings indicated that 80% of caregivers rated their health as "Good" or better. Over half of the caregivers had decreased the amount of time they spent on social and leisure activities and approximately one-third of the caregivers had decreased the amount of time they spent working in order to care for the client. Caregivers of community clients experienced more objective burden than caregivers of either facility or supportive housing clients. Caregivers of community, facility and supportive housing clients did not appear to differ with respect to perceptions of subjective burden.<sup>4</sup> Caregivers also noted that caregiving provides both benefits and challenges. On the one hand, it provides caregivers with the opportunity to show care and love to the client, to ensure the client's needs are being met, and so on. On the other hand, it is emotionally draining and restricts the caregiver's activities.

#### 4.9 What is the cost-effectiveness of home care compared to long term facility care?

There are several ways this question can be addressed. For example, one can consider only formal care costs (i.e., costs to government, where caregiver time is valued at zero). Or, one can consider societal costs, and take into account both costs to government and costs to clients and families. Within this latter perspective, caregiver time can be valued at a minimum wage or replacement wage. In both Studies 1 and 2, regardless of how caregiver time was valued, home care was substantially less costly than long term facility care.

In Study 1, for clients at similar care levels, when only formal care costs were considered, facility costs were approximately four to five times the cost of community care. When societal costs with caregiver time valued at minimum wage and out-of-pocket expenses were considered, facility costs were about two to three times the cost of community care. When societal costs with caregiver time valued at replacement wages and out-of-pocket expenses were considered, facility costs were approximately one and one-half times the cost of community care. In Study 2, the costs to government were lower for supportive housing clients than for community clients. In addition, the cost to government for facility care was higher in Study 2 than in Study 1. Considering costs to government, out-of-pocket expenses and caregiver time costed at

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<sup>4</sup> Objective burden refers to the extent to which a caregiver's life or household are disrupted. Subjective burden refers to the caregiver's attitude or emotional reaction regarding providing care.

replacement wages, for clients at similar care levels, overall costs for facility clients were about twice as much as for community clients.

4.10 To what extent is supportive housing an appropriate alternative to home care and long term facility care?

This question only applied to clients and caregivers in Study 2. Respondents indicated that the clients were living in a supportive housing setting because they preferred it, felt they were better off financially, their health care needs had increased and/or they did not have support from an informal caregiver. Respondents also indicated that in many cases, clients did not require additional resources (except perhaps financial assistance) to keep them at home.<sup>5</sup> When asked what kind of housing situation they would prefer for the client, 81% of supportive housing clients and 77% of caregivers of supportive housing clients indicated that they would prefer the client was living in a supportive housing setting. Finally, caregivers in Study 2 were asked if they thought assisted living/supportive housing was an appropriate alternative to home care and/or facility care both in general, and for their client. Approximately 78% of caregivers felt it was an appropriate alternative in general. In addition, 97% of caregivers of supportive housing clients felt it was an appropriate alternative for their client (the comparable figures for caregivers of community and facility clients were 40% and 13%, respectively). Taken together, the findings indicate that supportive housing may be an appropriate alternative to home care and facility care, at least for some clients. They also indicate that, at least for the majority of supportive housing clients in this study, it may be the most appropriate housing/care setting.

4.11 To what extent would adding supportive housing contribute to an enhanced, and cost-effective continuum of care for VAC clients?

This question only applied to Study 2. There were relatively few supportive housing clients in this study. This may be due, in part, to the VIP Program which provides a range of home care and home support services, and is designed to keep people living in their homes for as long as it is both feasible and reasonable to do so. Nevertheless, it appears that supportive housing could contribute to a more fully developed, and cost-effective, continuum of care. Supportive housing fills a potential need for single individuals, is a desirable option for low income families, enables a spouse to remain in familiar and supportive surroundings when a veteran dies, and provides a lower cost alternative to facility care.

## **5. Implications of Key Findings from the Continuing Care Research Project**

The key findings from the Continuing Care Research Project have several implications for VAC as well as the national level.

### **5.1 Comparative Costs and Outcomes of Care**

The findings from the Continuing Care Research project indicate that there is the potential for VAC to obtain systems level efficiencies by, where it is feasible, substituting lower cost home care or supportive housing services for long term care facility services. The extent to

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<sup>5</sup> It is noted that over half of the supportive housing sample were female.

which such possible substitutions can also be made in other jurisdictions will vary in accordance with the policies and practices in these other jurisdictions.

## 5.2 Supportive Housing

The findings from the Continuing Care Research Project indicate that supportive housing can fill a need for veterans who live on their own and require a more structured environment. It is also an option for low or medium income veterans who are married, as it can benefit both the veteran and his/her spouse. More broadly, supportive housing is one of several options, including assisted living, which combine both a residential and a care component. While supportive housing is generally less costly than long term facility care, it is intended to provide a different type of care, and thus, should not be seen as a direct alternative to facility care. Nevertheless, it is certainly worthy of further policy consideration by VAC, and is an area of interest and activity in many jurisdictions in Canada.

## 5.3 The Contribution of Spouses and Family Members

The Continuing Care Research Project documented the substantial role played by spouses, family members and other informal caregivers in allowing veterans to continue to be cared for in their homes. It is noted, however, that many of the caregivers were also elderly and may have had health problems or functional limitations of their own. Given what is currently known about services to spouses in other jurisdictions, and the call for more support for informal caregivers, it is quite likely that this may be a topic of interest not only for VAC but other jurisdictions as well.

## 5.4 Moving to a Health Services Delivery Model

Research has indicated that integrated systems of care delivery, where services are provided in response to care needs, may provide better care, at a lower cost, than non-integrated or stovepipe, models. VAC is moving towards a needs-based care system. This change is strongly supported, based on the empirical evidence in the Continuing Care Research Project and similar studies.

At present, VAC has two main health services, the Health Benefits Program and the Veterans Independence Program. While the Veterans Independence Program is clearly a health services program, the Health Benefits Program has a mixture of health services (such as nursing), and what in most other jurisdictions would be considered non-insured, or extended, health benefits. Given that VAC is moving towards a new health services delivery model, it may wish to rationalize its existing health services into a health services module and a non-insured or extended health care module, in order to be more congruent with arrangements made in other jurisdictions. It may also wish to consider whether it should continue to provide non-insured type benefits or subsidize costs for veterans to obtain services directly from insurance companies.

With regard to facility services, it is believed that there is variability in the amount of care provided to people in long term care facilities. In general, VAC sets a single rate that it will pay for a contract bed in a given facility. It is not clear to what extent VAC can move to a more

comprehensive case-mix classification system, based on a wider range of categories than is currently used. However, there may be some merit in exploring case-mix funding options with facilities to see if such an approach would be feasible and acceptable. In general terms, lack of a case-mix funding system means that the funder may be paying too much for a low care needs client and not enough for a high care needs client. At the clinical level, it may mean that lower care needs clients receive more services than they need and higher care needs clients may not receive all of the services they need. Most jurisdictions in Canada now use some form of case-mix funding to pay for facility services.

### 5.5 Broader Issues Regarding the Nature of VAC Health Services

VAC basically provides a “top up” health care system (except for needed treatment and care provided through VAC in relation to a health condition recognized through a VAC disability pension or disability award). As a result, VAC only has partial data on the health and supportive services used by veterans and, currently, it is not possible to plan health care services for veterans on a system wide basis. It may be useful for VAC to set up data sharing agreements with the provinces and territories to obtain data on health care utilization by veterans, subject to obtaining informed consent for data linkages from the veterans themselves. Such arrangements could provide a better picture of the overall impact on veterans of VAC health services nationally, and the contribution made by VAC to provincial and territorial health care systems.

The VIP Program enables veterans to remain at home and maintain their independence for as long as it is possible and feasible to do so. But the program is also important at the national level. Over the past 10 to 15 years, several provincial health systems have cut lower care needs individuals from service. This has effectively raised the “need” bar for people to be eligible for home care services nationally. The VIP Program appears to be the only major program that still provides maintenance and preventive care for its clients. As such, it represents a key opportunity for research to inform policy at the national level.

### 5.6 Data Integrity and Knowledge as a Key Corporate Resource

New knowledge is a key corporate resource. One cannot engage in evidence based decision-making if the evidence is not readily available, accurate, and/or collected in a consistent manner. VAC is aware of this as evidenced by its desire to develop new knowledge through projects such as the Continuing Care Research Project, by expanding its research capacity, and by having a very high level Gerontological Advisory Council to ensure a regular stream of information about new findings, and ready access to expert advice on complex issues.

In the Continuing Care Research Project, it was difficult to extract accurate, longitudinal data which cut across several generations of information systems from the VAC data systems. It is noted that similar situations exist in numerous other organizations. It is also noted that VAC seems to be able to use its existing data to adequately meet its operational and administrative requirements. The critical broader issue is the extent to which VAC wishes to place a higher priority on information and analysis and obtain data for strategic, as well as operational, purposes. VAC has a real opportunity to be a national leader in terms of health care services. What is required to complement VAC’s existing resources and provide it with the information it

needs to make substantial national contributions is an upgraded capacity to ensure the integrity of its information systems and to conduct sophisticated analyses based on its existing administrative data. With the right informatics and analytical infrastructure, VAC could substantially enhance its ability to create new and relevant knowledge for a wide range of clinical, administrative, policy, planning, and program development purposes.

## **6. Methodological Limitations**

While it is believed that the findings presented in the Continuing Care Research Project are fairly robust, there are, as with any study, some methodological limitations.

First, given the cognitive and/or physical status of the clients in both Studies 1 and 2, there were limits to the number of clients who could be interviewed and who provided data directly. The use of proxies provided more complete data, but only in areas concerned with objective information. With respect to subjective information, it is not possible to determine how generalizable the opinions expressed by cognitively capable clients are to clients with cognitive or other limitations.

Second, fewer diaries were completed than in other, similar studies conducted by the researchers. It is thought that this may have been due largely to the age, and health status, of the main caregiver. Nevertheless, it is thought that the diary data contained the most accurate information regarding time and assistance, and thus, these data were used in estimating costs, even though the sample size was smaller than anticipated.

Third, few people were admitted to hospital or visited family physicians in both Studies 1 and 2. In other studies conducted by the researchers, the use of in-patient hospital services and physician services have been substantial cost factors. However, it is now harder to be admitted to hospital, and hospital stays are shorter than in the past. In addition, the services provided by VAC are designed to maintain client independence. Thus, there may in fact be less use of hospital and physician services by the clients in this study than in previous studies.

Fourth, the development of accurate unit costs is always challenging. As VAC provided most of the services to clients in the Continuing Care Research Project, it seemed reasonable to use rates paid by VAC for community and facility services. It is recognized, however, that rates for providers paid by clients and families directly, or by provincial and/or regional home care systems, may differ somewhat from the rates paid by VAC.

## **7. Final Comments**

The findings from the Continuing Care Research project clearly point out the importance, and potential cost-effectiveness, of home care services and the critical role played by informal caregivers, home support workers, and other non-professional care providers. They also build on the base of evidence from earlier Canadian studies that demonstrate the benefits of long term home care and home support services.

The finding that home care is a lower cost alternative to facility care does not automatically imply that investments in home care will be cost-effective. Investments in home and community care can only increase the overall cost-effectiveness of the continuing care sector, and the broader health care system, if they are made in the context of a broader, integrated system of care in which proactive substitutions of home care for facility care can actually be made. For the past several years, there has been an ongoing call for federal policy to focus on broader, integrated systems of continuing care rather than on separate services (such as home care), or partial services which further segment care delivery (such as short term hospital replacement home care). The federal policy focus has, however, been on the provision of short term, professional, acute care replacement and specialty home care, where home care is seen as a separate service and not as part of a broader, integrated service delivery system.

With the findings from the Continuing Care Research project, there is now a reasonably substantial weight of evidence to indicate that long term home care, home support services, and integrated systems of care delivery with a broad range of primary, secondary, and tertiary services, are deserving of a renewed policy focus in Canada. In order to shift the current policy focus, however, policy makers will first have to determine if they accept the notion that continuing care should be recognized as one of the cornerstones of the Canadian health care system along with hospital care, primary care, population and public health, and drugs. There is currently a tremendous opportunity to move to a new way of thinking about how services for the elderly, and other people with ongoing care needs, could be structured and delivered. Many of the components for a re-invigorated focus on continuing care are already in place. What is required is a shift in the policy focus, and concrete steps to move the notion of an integrated continuing care system to reality.

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## **1. INTRODUCTION**

### **1.1 Overview of Veterans Affairs Canada**

Veterans Affairs Canada (VAC) supports a wide range of health and supportive services for veterans. It also provides funding to “top up” existing provincial services, as needed, and provides funding for services that are not funded by provincial Ministries of Health.

There are numerous categories of veterans and benefits, within three main health programs: the Health Benefits Program; the Veterans Independence Program; and Long Term Care. Under the Health Benefits Program, VAC offers a range of health benefits such as: medical, surgical or dental examinations; surgical or prosthetic devices; home adaptation to accommodate the use of devices or aids; preventive health care; and prescribed medications. The Veterans Independence Program (VIP) is a national home care program that assists clients to remain independent in their own homes. VIP home care benefits include: grounds maintenance; housekeeping; personal care; home adaptations; nutrition services; health and support services provided by health care professionals; ambulatory health care; and social transportation. Under Long Term Care, VAC covers the costs of facility beds.

### **1.2 Overview of the Continuing Care Research Project**

In 1999, in response to a growing number of clients on waiting lists for beds in long term care facilities, VAC implemented the Overseas Service Veterans At Home Pilot Project. This pilot project offered certain clients, on waiting lists, who met nursing level care and military service requirements (i.e., Overseas Veterans, OSVs), access to some VIP services. Previously, the OSVs had not been eligible for these services. An internal review of the pilot project showed that a large majority of clients preferred to remain at home, with support, rather than accept placement in a long term care facility even when a bed became available. In 2003, VAC implemented the OSV/VIP Program nationally. In 2005, the Frail policy was introduced. This provided a new gateway to VIP services and Health Care Benefits for clients with a pensioned condition who satisfied the frail criteria. Given the results of the OSV/VIP pilot study and the establishment of VIP services as a new benefit for OSVs, VAC was interested in conducting a more rigorous study of the OSV/VIP initiative both for internal planning and policy development and as a means of obtaining information that can contribute to broader health policy discussions in Canada.

It is recognized that some individuals may be admitted to long term care facilities because they can no longer function on their own in their home. However, some of these individuals may be able to function in a lower cost residential setting with appropriate, structured support services. Both VAC and the Government of Ontario (GO) had an interest in learning about the potential benefits of long term care and whether supportive housing could be an appropriate alternative to long term facility care. Thus, VAC and the Government of Ontario decided to work together to conduct a detailed study of the relative costs and outcomes of long term care (including home support), supportive housing, and long term facility care.

### 1.3 Goals and Research Questions

The goals of the Continuing Care Research Project were to

- obtain information on the relative success of the OSV/VIP initiative;
- determine the relative costs and outcomes (i.e., cost-effectiveness) of long term home care, supportive housing, and facility care;
- examine the contributions of long term home care and home support services with respect to the care of the elderly; and
- obtain information which can contribute to the broader policy debate in Canada about health services for the elderly.

The Continuing Care Research Project involved two studies. Study 1 was intended to provide a rigorous and independent evaluation of the costs and outcomes of the OSV/VIP initiative. It was conducted in the same three sites as the initial pilot project (i.e., Halifax, Ottawa and Victoria). Study 2 was intended to obtain information regarding the relative costs and outcomes of long term home care, supportive housing, and long term facility care. It was conducted in Toronto and in the Peel, York and Durham Regions.

The Continuing Care Research Project addressed 11 specific research questions. As shown in Table 1-1, some of the questions related to Study 1 only, some related to Study 2 only, and some related to both studies.

**Table 1-1: Research Questions for the Continuing Care Research Project**

Research Question	Applied to	
	Study 1	Study 2
How satisfied are VAC staff and managers with the OSV/VIP Program, what do they see as its strengths and weaknesses, and how would they rate the success of the program?	X	
To what extent have people, who originally would have only received facility care, embraced the VIP home option?	X	
What are the comparative systems costs (i.e. overall costs) for OSV clients before and after introducing the VIP home option, on a cost standardized basis?	X	
How satisfied are comparable clients in VIP, supportive housing (if applicable) and long term facility care and how do they rate their quality of life?	X	X
What proportion of home care services (VIP and health services) are provided by home support services?	X	X
Which home care and home support services are the most instrumental in keeping people out of facility care?	X	X
Which factors contributed to community clients and supportive housing clients (if applicable) entering a long term care facility?	X	X
What have been the positive and negative impacts on family caregivers?	X	X
What is the cost-effectiveness of home care compared to long term facility care?	X	X
To what extent is supportive housing an appropriate alternative to home care and long term facility care?		X
To what extent would adding supportive housing contribute to an enhanced, and cost-effective continuum of care for VAC clients?		X

## **2. METHODOLOGY**

### **2.1 Introduction**

This chapter describes the study sites, samples, data collection tools, and procedures used in both Studies 1 and 2.

Study 1 involved four components:

- interviews with VAC personnel in the national office, in the three district offices involved in the initial pilot study, and in other regional and district offices regarding their experiences with the national pilot project and the subsequent implementation of the OSV/VIP Program;
- a historical review of service utilization and costs both before and after the implementation of the OSV/VIP Program;
- interviews with veterans and their informal caregivers regarding their use of care and support services funded by VAC; and
- diaries completed by clients and caregivers regarding out-of-pocket expenses and time spent on care services.

Study 2 involved two components:

- interviews with veterans and their informal caregivers regarding their use of care and support services funded by VAC; and
- diaries completed by clients and caregivers regarding out-of-pocket expenses and time spent on care services.

In Study 1, the veterans lived in their own or a family member's home or in a long term care facility. In Study 2, the veterans lived in a private home, in supportive housing, or in a long term care facility. Spouses who received services and benefits funded by VAC were also included in the supportive housing sample; these individuals were referred to as non-veterans.

### **2.2 Care Locations**

Data for Study 1 were gathered between July 2006 and January 2007 in three study sites: Halifax, Ottawa and Victoria. These were the same sites that had been used for the OSV/VIP Pilot Project in 1999, specifically because they had long waiting lists for contract facility beds. Each of these sites has a major long term care facility which provides contract beds designated for veterans and paid for by VAC. In Halifax, the Camp Hill Veterans Memorial Building has 175 beds, in Ottawa, the Perley Rideau Veterans' Health Centre has 250 beds, and in Victoria, The Lodge at Broadmead has 115 beds. In addition, a second facility in Victoria (Oak Bay Lodge) had 20 veterans in community beds at the time of the study who met the initial inclusion criteria (see below).

Data for Study 2 were gathered between July 2006 and June 2007 in the City of Toronto<sup>2</sup> for the home and facility samples and in the Greater Toronto Area (Toronto and the Peel, York and Durham Regions) for the supportive housing sample.

As in Study 1, clients in the community sample were living either in their own or a family member's home. Clients in the supportive housing sample were living in buildings served by not-for-profit organizations which received funding for supportive housing services through the Community Services Program of the Ontario Ministry of Health and Long Term Care. Organizations which did not receive supportive housing funding through the Ministry, whether run by non-profit organizations or by for-profit agencies, were excluded. A total of 88 buildings were considered for the study (73 for Toronto, 6 for the York Region, 2 for the Durham Region, and 7 for the Peel Region). Both the veterans and the non-veterans included in the supportive housing sample were residing in one of these buildings.<sup>3</sup> Clients in the facility sample were living either at Sunnybrook Health Sciences Centre or at Tony Stacey Centre for Veterans Care. Sunnybrook Health Sciences Centre has 480 beds that are designated for veterans only. The facility includes physical, cognitive, psychiatric and palliative units; only veterans residing on the physical and cognitive units were considered for the study. The Tony Stacey Centre for Veterans Care provides housing for veterans as well as married spouses of veterans and Silver Cross Mothers. The facility has 100 beds. At the time of the study, the Centre housed 35 veterans.

### 2.3 Sample

The focus of both Studies 1 and 2 was on veterans who had served in World War II and/or the Korean War. The supportive housing sample in Study 2 also included spouses of veterans who were receiving benefits and services funded by VAC. In both Studies 1 and 2, the term "client" was used to refer to the veteran, regardless of whether the individual was physically and/or cognitively capable of providing informed consent and participating in the study on his/her own behalf. The non-veterans who participated in the supportive housing sample in Study 2 were also referred to as clients. The term "proxy" was used to refer to an individual who provided informed consent and participated in either Study 1 or Study 2 on behalf of a client when the client was unable to participate him/her self.<sup>4</sup>

In order to identify the sample, initial lists of veterans (and non-veterans, if applicable) were drawn from VAC's national Reporting Database using a limited number of inclusion criteria. The lists were then forwarded to the VAC Liaison in the appropriate study site. The VAC Liaison reviewed each list and removed any individuals who were no longer receiving

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<sup>2</sup> The City of Toronto includes the former cities of Toronto, Etobicoke, Scarborough, North York, East York and York.

<sup>3</sup> Although 88 potential supportive housing buildings were identified for the study, the veterans and non-veterans who participated in the study lived in 52 buildings.

<sup>4</sup> Proxies were often spouses, adult children, or other family members. In some cases, close friends served as proxies. Proxies generally knew the client quite well, and often had Power of Attorney for the client. The need for a proxy, and the name of one or more proxies (when required) was usually noted in the client's file held in the VAC District Office. When proxies were used, only certain questions on the Client Questionnaire were asked. An individual could have served as both a proxy and an informal caregiver with respect to the study. Alternatively, one individual could have served as a proxy while another individual served as the informal caregiver.

services or benefits from VAC, had died, moved into a location that was not included in the study, or were otherwise unable to be contacted based on information available in the client's file in the District Office. Staff at the study facilities were also asked to review the lists and identify anyone who should be excluded. This preliminary review resulted in a potential sample of veterans (and non-veterans, if applicable) who were then contacted by the VAC Liaison regarding participation in the study.

Once the potential sample had been created, the VAC Liaison contacted each individual (and/or proxy, if applicable), briefly explained the purpose of the study, and asked if he/she would be willing to have the VAC Liaison pass the veteran's name and contact information (and that of the proxy, if relevant) onto the research team.<sup>5</sup> If an individual chose not to have the relevant information passed onto the research team, the VAC Liaison replaced him/her with someone else from the potential sample, until either the list of potential participants was exhausted or the target sample was obtained. At this stage, the VAC Liaison used several exclusion criteria to remove individuals from the potential sample (see Appendix A).

Individuals who agreed to have their name and contact information passed onto the research team were then contacted by a trained interviewer who explained the study in more detail and asked the client/proxy if he/she would be willing to participate in the study. If the individual chose not to participate, no further contact was made. If the individual agreed, arrangements were made to conduct an in-person interview with the client (and/or proxy, if appropriate).

Where possible, informal caregivers of clients were identified in order to obtain information regarding the caregivers' experience of providing care and/or support to the clients. For the purposes of this project, informal caregivers were family members, friends, volunteers, members of a service organization or other individuals who provided the client with unpaid care and/or support. Clients who participated in the study on their own behalf were asked to identify an individual who provided them with unpaid care and support and who could be approached regarding the study. Similarly, proxies were asked to identify an individual who provided unpaid care and/or support to the client. In this case, an individual could identify him/her self as both a proxy and an informal caregiver.

Thus, informal caregivers were "linked" to the client. An individual could only participate as an informal caregiver if the client to whom he/she "belonged" also participated in the study. However, informal caregivers could choose to participate or not participate in the study depending on their own wishes. When an informal caregiver chose to participate in the study, arrangements were made to conduct an in-person or phone interview. A summary of the steps involved in obtaining the client and caregiver samples is provided in Appendix A.

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<sup>5</sup> The VAC Liaison was responsible for obtaining consent to pass the name and contact information onto the research team and for identifying any relevant information regarding contacting the veteran and/or his/her proxy. The VAC Liaison was not responsible for getting the veteran and/or his/her proxy to agree to participate in the study.

## **2.4 Data Collection Tools**

As shown in Table 2-1, five data collection tools were used to examine the impact of care for each client. The same data collection tools were used in both studies. A multi-section Client Questionnaire was used to obtain information about the client directly. A multi-section Caregiver Questionnaire was used to obtain information from an informal caregiver regarding his/her experience of providing care and/or support to the client. Both the Client and Caregiver Questionnaires included existing measurement instruments as well as questions developed for areas where no acceptable measurement instruments could be identified.<sup>6</sup> Detailed information regarding the Client and Caregiver Questionnaires is provided in Appendix B. In addition, three diaries were used to collect information regarding out-of-pocket expenses and time and assistance provided by both informal and formal caregivers.

## **2.5 Procedure**

Study interviewers contacted those individuals (clients and/or proxies) who had indicated that they were willing to be referred to the research team. Contact with community clients, supportive housing clients, and proxies (of community, supportive housing and facility clients) was generally by phone. Contact with facility clients who were considered capable of making an informed decision was generally in person. When clients and proxies agreed to participate in the study, interviewers arranged a mutually convenient time for the interview to be conducted at a location that was convenient for the client (or proxy). Similar arrangements were made with informal caregivers who chose to participate in the study.

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<sup>6</sup> The measurement instruments included on both the Client and Caregiver Questionnaires were selected based on a review of existing measurement instruments in the published and grey literature, input from members of the research team, and the results of a pilot study on the data collection tools.

**Table 2-1: Data Collection Tools**

<b>Tool</b>	<b>Purpose</b>	<b>Content</b>	<b>Comments</b>
Client Questionnaire	To obtain information about the client directly.	<p>Questions regarding the client's:</p> <ul style="list-style-type: none"> <li>• Sociodemographic background</li> <li>• Functional and cognitive status</li> <li>• Health status</li> <li>• Health-related quality of life</li> <li>• Social relations</li> <li>• Use of, and satisfaction with, health related services</li> </ul>	A trained interviewer administered the questionnaire during an in-person interview, which was generally conducted at the client's normal residence. The interview required approximately one hour to complete, and was usually completed in one session.
Caregiver Questionnaire	To obtain information from an informal caregiver regarding his/her experience of providing care and/or support to the client.	<p>Questions regarding the caregiver's:</p> <ul style="list-style-type: none"> <li>• Sociodemographic background</li> <li>• Provision of care and support</li> <li>• Satisfaction with the provision of health related services to the client</li> <li>• Perceptions of the impact providing care has had on him/her</li> </ul>	A trained interviewer administered the questionnaire during an in-person or phone interview, which was generally conducted at the caregiver's normal residence. The interview required approximately 45 minutes to complete, and was usually completed in one session.
Diary of Care Related Expenditures	To obtain information regarding out-of-pocket expenditures incurred by the clients and/or their informal caregivers.	<p>No formal questions. Care-related expenditures could include, but were not limited to:</p> <ul style="list-style-type: none"> <li>• Food for special diets</li> <li>• Medical supplies</li> <li>• Prescription and non-prescription medications</li> <li>• Services provided by home support workers, physiotherapists, etc.</li> </ul>	Clients and/or informal caregivers completed the diaries over a 2 week period. The diary required about 5 minutes per day (or less) to complete. Interviewers contacted clients/caregivers regularly over the 2 week period. In some cases, clients/caregivers dictated the relevant information and interviewers completed the diaries on their behalf.
Diary of Time and Assistance Provided by Informal Caregivers	To obtain information regarding the amount of unpaid care provided by family members or other informal caregivers.	<p>No formal questions. Activities could include, but were not limited to:</p> <ul style="list-style-type: none"> <li>• Housekeeping assistance</li> <li>• Assistance with paying bills</li> <li>• Accompanying the client to doctor's appointments</li> <li>• Giving medications or assisting with medical equipment</li> </ul>	Informal caregivers completed the diaries over a 2 week period. The diary required approximately 5 minutes per day (or less) to complete. Interviewers contacted caregivers regularly over the 2 week period. In some cases, caregivers dictated the relevant information and interviewers completed the diaries on their behalf.
Diary of Time and Assistance Provided by Formal Care Providers	To obtain information regarding the amount of care and support provided by formal care providers and paid for by government.	<p>No formal questions. Activities could include, but were not limited to:</p> <ul style="list-style-type: none"> <li>• Home support</li> <li>• Home nursing</li> <li>• Respite care</li> <li>• Physiotherapy/Occupational Therapy</li> </ul>	For facility clients, this diary was tailored to meet the specific conditions of each of the facilities in the study by staff in the facilities. The diary was completed by paid care staff at each facility (for facility clients), or by clients/informal caregivers (for community and supportive housing clients). The diaries were completed for a 2 week period.

### **3. HIGHLIGHTS OF FINDINGS FROM STUDY 1**

#### **3.1 Introduction**

This chapter provides a summary of the findings from Study 1. Chapter 4 provides a summary of the findings from Study 2. As noted earlier, Study 1 involved four components: interviews with VAC personnel regarding their experiences with the pilot project and the subsequent implementation of the OSV/VIP Program; a historical review of service utilization and costs both before and after the implementation of the OSV/VIP Program; interviews with veterans and their informal caregivers regarding their use of care and support services funded by Veterans Affairs Canada; and completion of diaries by clients and caregivers regarding out-of-pocket expenses and time spent on care.

#### **3.2 Interviews with VAC Personnel**

Interviews were conducted with representatives from Veterans Affairs Canada in order to gain an understanding of how the OSV/VIP pilot project had been implemented nationally as well as within each of the pilot sites, how the initiative had evolved over time, and the perceived strengths and weaknesses of the initiative. During the conduct of these interviews, it became clear that there were three phases to the development and national roll-out of the OSV/VIP Program: an initial pilot project conducted in Halifax, Ottawa and Victoria between July 1999 and the fall of 2001; a national pilot conducted in all of the VAC sites between the fall of 2001 and the fall of 2003; and a national roll-out of the OSV/VIP Program (once legislative authority for the program was provided) beginning in the fall of 2003. A total of 13 representatives from VAC were interviewed – 3 from the national headquarters, 6 from the District Offices involved in the pilot project, and 4 from two other District Offices. They included representatives of residential care services, nursing officers, client service managers, and area counselors. All of the respondents from the national headquarters and the district offices were actively involved in the initial pilot project. All but one of the remaining individuals was involved in the national pilot.

Respondents who were involved in the initial pilot project were asked to describe how the project had been implemented within their catchment area as well as the benefits and challenges of implementing the project. Overall, respondents felt that the implementation of the pilot project had gone well. They noted the following benefits of the initiative:

- The OSV/VIP initiative enabled VAC to provide a specific group of veterans (OSVs) with services and benefits that enabled them to stay at home longer.
- The program was well received by veterans and their families.
- The initiative was seen as being economically good for VAC.

Respondents also noted the following challenges for the initiative:

- Developing guidelines, standards, and an evaluation framework were challenging as was disseminating information to field staff.
- In some cases, it was difficult to help all of the veterans who may have benefited from the initiative as people needed to qualify for long term facility care before they

were eligible for the services. In other cases, veterans may have received services at home when they should have been in a long term care facility, either because of their own needs or because of the impact caregiving was having on their primary caregiver.

- The initiative was resource intense from VAC's perspective.

Respondents who were involved in the initial pilot were also asked how the OSV/VIP Program had evolved over time. Respondents noted the following:

- The program became more acceptable to front line staff within VAC as they recognized its strength and flexibility.
- The program has evolved over time to better meet the needs of clients and continues to be an avenue of choice for many people.
- In some cases, it may be easier for veterans to obtain services through a "Frail Policy" as they do not need to be put on a facility waitlist in order to be eligible for services. It was felt that together, the OSV/VIP Program and the Frail policy enable VAC personnel to look at what will benefit the client the most.

All respondents were asked about the strengths and weaknesses of the OSV/VIP Program. With respect to strengths, respondents noted the following:

- Since it is necessary to put veterans on a waitlist in order for them to receive OSV/VIP services and benefits, waitlists may have been falsely increased. Several respondents noted that they are trying to keep separate lists – one for those individuals who only want the OSV/VIP Program and one for those who really need to be waitlisted for facility placement. While there is still a demand for facilities, the waitlists for facility placement do not seem to be as long as they were before the OSV/VIP initiative as veterans generally choose to stay at home for as long as it is appropriate to do so.
- An individual may need assistance or supervision but not 24 hour nursing care. The OSV/VIP Program has enabled unmet health needs to be addressed, which may be particularly important for veterans who are alone.
- The program has provided tangible recognition to a group of veterans who previously were not able to access programs and services from VAC, by providing them with the option to remain at home should they so desire. The program is generally seen as preventive and designed to keep people out of long term care, if possible. However, it is not intended to take the place of long term facility care, especially if the veteran's health, the informal caregiver's health and/or the home environment make it inadvisable for the client to stay at home.
- The OSV/VIP Program may reduce the stress on veterans (and their informal caregivers), provide them with a better quality of life, delay facility placement, and increase life expectancy. The program may not delay facility placement for those with dementia or severe physical conditions, although it may provide the informal caregiver with better support.

With respect to weaknesses, respondents noted the following:

- The OSV/VIP Program may result in some people remaining at home when they should really be placed in a long term care facility. Respondents noted that there is an inability to closely monitor individuals who are potentially at risk.<sup>7</sup>
- Frailer veterans are being placed in long term care facilities. This may be difficult for both staff and families as clients may not live long after they have been placed.
- In order to be eligible for the OSV/VIP Program, clients must be assessed as requiring federal Level 2 care.<sup>8</sup> However, the eligibility criteria for the program may not truly address clients' needs. Respondents noted that the program should involve a needs based model rather than a gateway model.
- Differences between provincial systems and VAC may result in some eligible veterans "falling through the cracks" if they are not aware of what VAC is able to offer them. Provincial assessment forms do not always ask if an individual is a veteran and publicity regarding the program has been low.

Overall, 62% of respondents indicated they were very satisfied with the OSV/VIP Program; another 39% indicated they were somewhat satisfied.<sup>9</sup> Respondents noted that the OSV/VIP Program is an "excellent" initiative that provides extra choice for veterans, addresses "a lot of unmet care needs" and has helped "immeasurably" with waitlists. They also noted that the program "bridges the gap between community care and premature institutionalization."

Overall 62% of respondents indicated that the program had been very successful; another 31% felt it had been somewhat successful. Respondents noted that the focus of the program had changed from how to ease facility waitlists to how to keep a person at home longer and ease the burden of care. Respondents also noted that while the program has generally been successful for those who have been helped, there is another group of veterans who could potentially benefit from it. This group is made up of a combination of individuals who are not known to VAC as well as those who have applied to VAC but have not been assessed as being at federal Level 2.

### **3.3 Historical Review of Service Utilization and Costs**

In order to conduct a historical review of service utilization and costs both before and after implementation of the OSV/VIP Program, an analytical database was created.<sup>10</sup> As shown in Table 3-1, the database covered the two and a half years prior to the OSV/VIP pilot project, the four and a half years during the initial and national pilot phases, and the two years following

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<sup>7</sup> This point was noted for individuals who did not meet the eligibility criteria for the program, as well as for those who were on the program and currently in need of facility services.

<sup>8</sup> Federal Level 2 care is for individuals requiring the availability of personal care on a 24 hour basis under medical and nursing supervision.

<sup>9</sup> To facilitate reading, all percentages have been rounded to the nearest whole number in this document. Because of rounding, percentages may not sum to 100%. Any discrepancies between this document and the technical documents for the two studies are due to rounding.

<sup>10</sup> An analytical database is a single data repository that contains information regarding a number of key areas. The database is composed of extracts from existing administrative databases that exist together in one electronic space. The extracts are designed to identify key variables, from each existing database, for analysis in the specific project.

the implementation of the OSV/VIP Program (as a national program), once appropriate legislative authority had been obtained.

**Table 3-1: Phases for the Analytical Database**

Phase	Time Frame	Initial Pilot Sites <sup>11</sup>	National Pilot Sites <sup>12</sup>	All Other Sites <sup>13</sup>
I	Jan. 1997 - Jun. 1999	Pre-initial pilot phase	Pre-initial pilot phase	Pre-initial pilot phase
II	Jul. 1999 - Dec. 2001	Initial pilot phase	Pre-national pilot phase	Pre-national pilot phase
III	Jan. 2002 - Dec. 2003	National pilot phase	National pilot phase	Pre-national program phase
IV	Jan. 2004 – Dec. 2005	National program	National program	National program

The data required for the analyses reported in this section were obtained from currently implemented systems or were archived data from systems that have since been replaced. These data have been/are collected and held in disparate systems, and stored/held in different departments within VAC. The data are not routinely merged to provide insights into the interrelationships between community and facility service provision, nor shifts between these two care settings over time.

In order to address the extent to which the OSV/VIP initiative has been embraced, both the number of claimants (i.e., OSVs) and the number of claims were examined for each of the four time periods of interest. There was a substantial increase in the number of facility beds utilized between late 2001 and mid 2004 in both the pilot sites and the non-pilot sites.<sup>14</sup> The number of beds (facility claimants) in the pilot sites increased from 459 in the July to December 2001 period to 1,132 in the January to June 2004 period (an increase of 147%). The comparable increase in the non-pilot sites was 2,133 to 5,258 (also an increase of 147%). These increases were the result of the OSV Wait List Management Initiative, introduced in 2000, which resulted in 2,600 new contract beds. The initiative also allowed veterans (such as OSVs) who were only eligible for contract beds to use community beds at VAC’s expense until they could move into a new contract bed.

In addition to the increase in facility beds, there was also an increase in the number of OSV/VIP community claimants in the pilot sites from the beginning of the pilot project in July 1999 to December 2005. In contrast, in the non-pilot sites, the uptake essentially started at the beginning of the national pilot phase in January 2002 and gradually continued to increase to December 2005. Overall, the increase for community claimants from the pilot sites was from 121 in the January to June 1999 period (the period just prior to implementation of the initial pilot) to 918 in the July to December 2005 period (the last six months of the period of interest). This represents an increase of 659%. The comparable numbers for the non-pilot sites were 126 and 887, respectively (an increase of 604%), but most of the actual increase occurred after the beginning of the national pilot phase in January 2002.

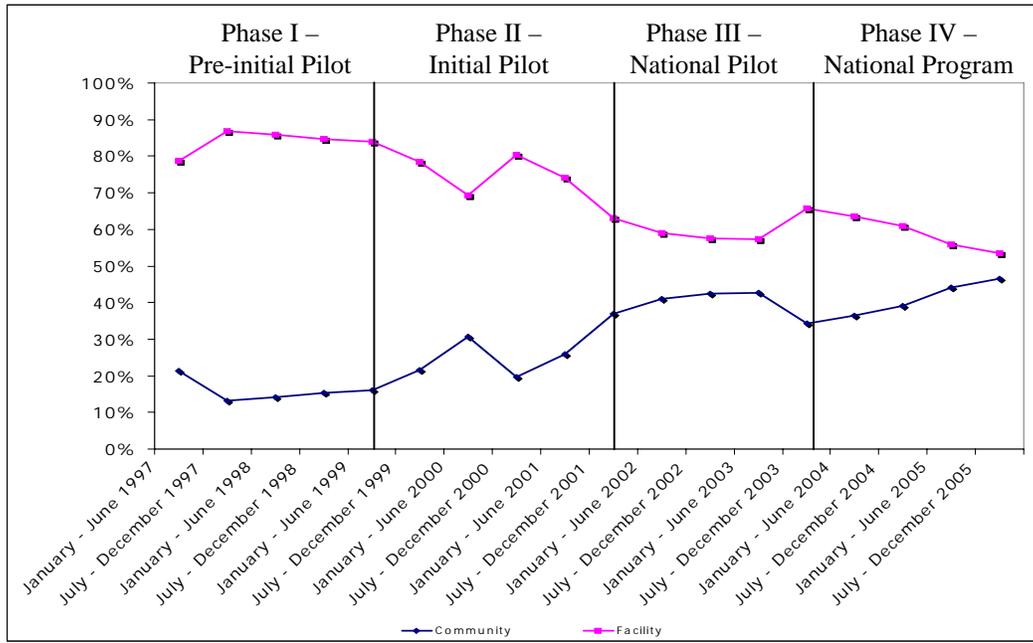
<sup>11</sup> These were Halifax, Ottawa, and Victoria.

<sup>12</sup> These were all sites which chose to participate in the national pilot phase (not including Halifax, Ottawa and Victoria).

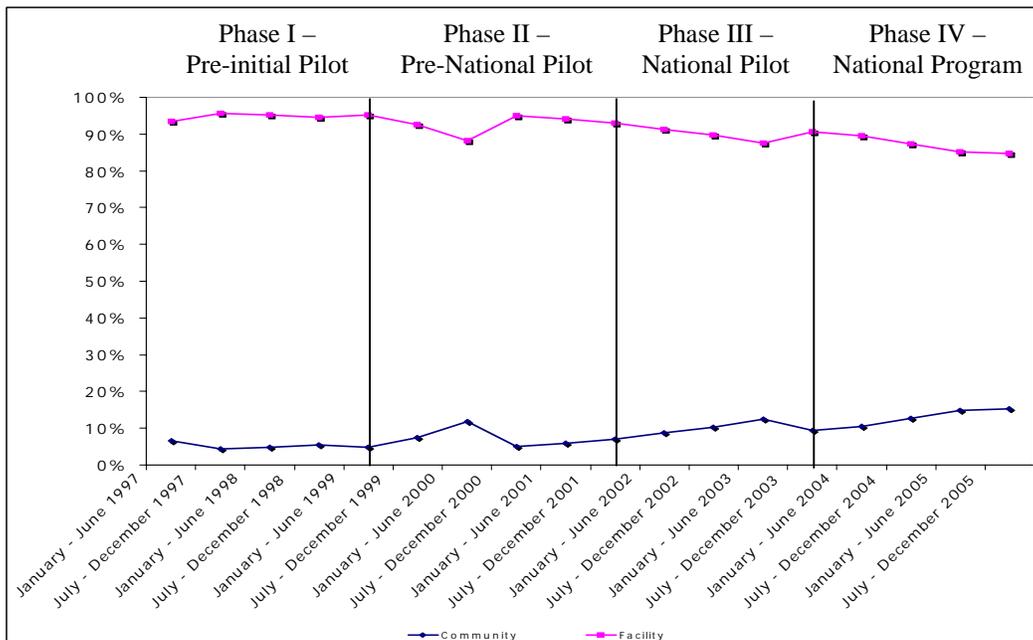
<sup>13</sup> These were all sites who chose not to participate in the pilot phases, but have been using the OSV/VIP option since it became a legislated program.

<sup>14</sup> The non-pilot sites included all of the sites (except Halifax, Ottawa and Victoria) that participated in the national pilot and national program phases (i.e., the National Pilot Sites and All Other Sites identified in Table 3-1).

While the increases were similar for community claimants in the pilot and non-pilot sites, the relative uptake was considerably higher in the pilot sites. On a proportional basis, community claimants in the pilot sites constituted 16% of all claimants in the January to June 1999 period; this increased to 47% in the July to December 2005 period (see Figure 3-1). The comparable percentages for the non-pilot sites were 5% and 15% (see Figure 3-2).



**Figure 3-1: Percentage of Total Claimants – Pilot Sites**



**Figure 3-2: Percentage of Total Claimants – Non-Pilot Sites**

Thus, proportionally, there was a substantially greater uptake of the OSV/VIP initiative in the pilot sites compared to the non-pilot sites. These findings indicate that, as the OSV/VIP Program became available, people who had previously not sought benefits and services from VAC, or who had been ineligible for services and benefits, were able to take advantage of the new program.

In order to conduct a historical cost analysis, expenditure data were obtained for the four time periods of interest. However, unresolvable anomalies and incomplete data limited the extent to which the data could be analyzed with confidence. Thus, a decision was made not to use the data, but to estimate costs based on utilization rates.

As noted earlier, in the pilot sites, the number of community claimants increased by 659% between the January to June 1999 period and the July to December 2005 period. In contrast, the number of facility claimants increased by 67%. The natural increase of community clients at the facility increase of 67% would have been 202 individuals.

The introduction of the OSV/VIP Program resulted in added costs for 716 (918-202) claimants. If all of the 716 claimants had claims at the maximum allowable amount of \$8,000 per year for VIP, the cost would be \$5,728,000. At an estimated average cost of \$62,576 per bed,<sup>15</sup> this is equivalent to 92 new beds. If some proportion of the 716 individuals (e.g., 400 individuals) actually required a bed and their annual community cost was \$4,000 per year (still a relatively high amount for community claimants), the cost of care in the community would be \$1,600,000 or the equivalent of 26 beds. Thus, to the extent that 400 to 716 clients really needed to be cared for in a facility, providing care in the community would be a better cost option.

### **3.4 Interviews with Clients and Informal Caregivers**

#### **3.4.1 Description of the Client Sample in Study 1**

The target sample for Study 1 was 360 clients, 120 from each of the three study sites (i.e., Halifax, Ottawa and Victoria), and within each study site, 60 community clients and 60 facility clients. The final client sample for Study 1 consisted of 355 clients, 177 community clients and 178 facility clients.

In Study 1:

- Approximately 94% of the clients were male.
- Approximately 55% of the clients were 85 years of age or older. Facility clients were older than community clients.
- Approximately 58% of the clients were married and 36% were widowed. Community clients were more likely to be married; facility clients were more likely to be widowed.

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<sup>15</sup> This is an estimated cost based on the facilities included in this study (see Section 3.5.4).

- Approximately 98% of clients indicated that English was their primary language. The ability to communicate in English was one of the selection criteria for participation in the study.
- Overall, the clients were well educated – 52% had some post-secondary education at the technical/trade school, college or university level. Community and facility clients were similar with respect to education level.
- Over 90% of clients received income from Old Age Pension and/or the Canada Pension Plan; 82% received income from a retirement pension.
- Proxies were used for 19% of the community clients and 71% of the facility clients.

### 3.4.2 Functional Health of Clients

The Functional Autonomy Measurement System (SMAF) was used to assess clients' functioning. Study personnel completed the SMAF using information provided by the client, a caregiver, a health care professional, or a combination of individuals as well as their own observations.

Nine “care level” categories were created using total SMAF scores. As shown in Table 3-2, community clients generally had lower care needs than facility clients. However, there was a group of community and facility clients with comparable care needs in the middle range (i.e., at levels 4, 5 and, to some extent, 6).<sup>16</sup> An analysis of clients based on total SMAF scores indicated that clients in the various care levels differed from one another but community and facility clients were similar to one another.

**Table 3-2: Number of Clients in Each Care Level in Study 1**

Care Level	Community		Facility		Total	
	N	%	N	%	N	%
Level 1 (0 – 5.0) <sup>17</sup>	12	7	0	0	12	3
Level 2 (5.5 – 10.0)	36	21	0	0	36	10
Level 3 (10.5 – 18.0)	47	27	0	0	47	13
Level 4 (18.5 – 28.0)	39	23	22	12	61	17
Level 5 (28.5 – 38.0)	29	17	25	14	54	15
Level 6 (38.5 – 48.0)	10	6	33	19	43	12
Level 7 (48.5 – 58.0)	0	0	39	22	39	11
Level 8 (58.5 – 68.0)	0	0	36	20	36	10
Level 9 (68.5 – 87.0)	0	0	22	12	22	6
<b>Total</b>	<b>173</b>	<b>100</b>	<b>177</b>	<b>100</b>	<b>350</b>	<b>100</b>

<sup>16</sup> Five clients were eliminated from Table 3-2 and analyses involving the SMAF care levels due to small cell sizes. The clients included three community clients in Level 7, one community client in Level 8 and one facility client in Level 3.

<sup>17</sup> Numbers in parentheses are total SMAF scores. SMAF scores can range from 0 to 87. Higher scores are indicative of greater care needs.

### 3.4.3 Cognitive Status of Clients

The cognitive status of clients was assessed using the Modified Mini-Mental State Examination (MMSE). The following findings apply only to those clients who were considered to be capable of providing informed consent:

- MMSE scores were obtained for 75% of community clients and 25% of facility clients.
- Of the 177 individuals for whom MMSE scores were obtained, 77% were considered to have no cognitive impairment and 23% were considered to have mild cognitive impairment.<sup>18, 19</sup>
- In general, community clients scored significantly higher than facility clients on the MMSE, indicating that they had less cognitive impairment. This finding is not surprising given that cognitive impairment may be one of the reasons individuals go into a facility.

### 3.4.4 Health Status of Clients

Perceived health status was assessed using a single item that asked cognitively capable clients to compare themselves to other people their own age. The findings indicated that:

- Approximately 56% of cognitively capable community clients and 78% of cognitively capable facility clients rated their health as good or better, despite the fact that they were receiving care and/or support services to meet their needs.
- Facility clients perceived that their health was better than community clients.<sup>20</sup>
- Cognitively capable clients generally perceived that their health status declined as their functional status declined.<sup>21</sup>

The psychological health status of cognitively capable clients was assessed using a 15 item version of the Geriatric Depression Scale (GDS-15). The findings indicated that overall, 30% of cognitively capable clients were considered to have mild depression and 7% were considered to have moderate to severe depression. The findings were similar for both community and facility clients when all cognitively capable clients were compared.

### 3.4.5 Health-Related Quality of Life

The health-related quality of life of cognitively capable clients was assessed using the SF-8. The findings indicated that:

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<sup>18</sup> MMSE scores were not obtained for 175 individuals (or about half of the sample) who required proxy consent. It was presumed that these clients had severe cognitive impairment, but this may be a slight overestimation if proxies were used because clients were considered too physically frail rather than too cognitively frail.

<sup>19</sup> These individuals, plus three additional individuals who chose not to complete the MMSE but were considered to be cognitively competent, are referred to as “cognitively capable clients” in the following sections.

<sup>20</sup> This was also observed by Hollander, Chappell, Havens, McWilliam, & Miller (2002).

<sup>21</sup> However, an analysis examining the relation between health status and care level was not significant.

- When all cognitively capable clients were compared, facility clients perceived that their physical health-related quality of life was better than community clients. Community and facility clients did not differ with respect to their perceptions of their mental health-related quality of life.
- When cognitively capable clients at comparable care levels (based on the SMAF) were compared, clients with lower care needs perceived that their physical health-related quality of life was better than clients with higher care needs, clients at different care levels perceived that their mental health-related quality of life was similar, and facility clients perceived that both their physical and mental health-related quality of life was better than community clients. This latter finding may, in part, be due to additional services VAC funds for facility clients.

### 3.4.6 Social Relations

Both social networks and social supports were considered components of a client's social relations in this study.<sup>22</sup> The findings indicated that:

- Some 64% of community clients lived with one other person, usually their spouse, while 93% of facility clients lived in a single room.
- On average, community clients interacted with 25 people and facility clients interacted with 18 people over the course of a month; this difference was significant.
- Over 95% of clients indicated that they received help with daily activities from someone. Of these, 79% indicated that they received help from an informal caregiver.<sup>23</sup> Community and facility clients did not differ with respect to who provided them with assistance with daily activities.
- Overall, 92% of clients indicated that they received emotional support from someone. Of these, 83% received emotional support from an informal caregiver.<sup>24</sup> Community clients were more likely to receive emotional support from informal caregivers than were facility clients (although informal caregivers provided support to both groups of clients).

### 3.4.7 Service Utilization

Respondents were asked if community clients currently received a variety of care and/or support services (many of which are included in the VIP Program). Because the VIP Program is primarily intended to assist individuals to stay in the community, clients living in a facility were not asked these questions. Table 3-3 presents the number of clients who used each type of

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<sup>22</sup> The term "social networks" applies to all of an individual's social contacts. The term "social supports" refers to a subset of people within a social network which an individual can rely on for assistance with personal and household responsibilities and/or emotional support.

<sup>23</sup> This figure is based on those clients who indicated that they received help and indicated that an informal caregiver (either alone or in combination with a formal caregiver) provided the assistance.

<sup>24</sup> This figure is based on those clients who indicated that they received emotional support and indicated that an informal caregiver (either alone or in combination with a formal caregiver) provided the assistance.

service.<sup>25</sup> As can be seen, the services used most frequently were housekeeping, home adaptations, and grounds maintenance.

**Table 3-3: Use of Care and Support Services by Community Clients**

<b>Client Receives Assistance With...</b>	<b>N</b>	<b>%</b>
Grounds Maintenance (e.g. lawn mowing, snow removal)	93	53
Housekeeping (e.g., laundry, cleaning floors)	154	87
Personal Care (e.g., dressing, washing)	61	35
Home Adaptations (e.g., handrails)	107	61
Nutrition Services (e.g., Meals on Wheels)	46	26
Health and Support Services Provided by Professionals (e.g., home nursing)	42	24
Ambulatory Health Care (e.g., adult day care)	17	10
Social Transportation (e.g., to church services)	50	29
Other (e.g., handyman services, socialization activities, transportation to medical appointments)	56	32

Respondents were asked whether clients received assistance from an unpaid (i.e., informal) caregiver, who provided the assistance (if applicable), and approximately how much time the individual(s) provided in an average week. The findings indicated that:

- Approximately 93% of community clients and 97% of facility clients received assistance from an informal caregiver.
- The majority of individuals who provided care and support to clients were close family members. With respect to community clients, 60% were cared for by their spouse, 36% were cared for by a daughter or daughter-in-law and 30% were cared for by a son or son-in-law.<sup>26</sup> With respect to facility clients, 35% were cared for by their spouse, 55% were cared for by a daughter or daughter-in-law, and 44% were cared for by a son or son-in-law.
- Overall, community clients received more assistance (in terms of hours per week) from informal caregivers than facility clients. Community clients received an average of 57 hours of care per week, while facility clients received an average of 10 hours per week.

### 3.4.8 Clients' Satisfaction with Services

Clients' satisfaction with the paid services they were receiving was assessed using a set of questions which asked them how much choice they felt they had regarding the provision of services, the characteristics of their workers, and how involved the same workers and family members were in their care. Only cognitively capable clients were asked these questions. The findings indicated that:

- Both community and facility clients showed high levels of satisfaction with the services they received.

<sup>25</sup> Clients could indicate that they received assistance with more than one activity. The percentages in the table are based on the total number of community clients (i.e., 177).

<sup>26</sup> Clients could indicate that they received support from more than one individual. Thus, the percentages can sum to more than 100%.

- When all cognitively capable clients were compared, community clients were more satisfied than facility clients with the services they received.
- When cognitively capable clients at comparable care levels (as assessed by the SMAF) were compared, there were no differences among clients at different care levels or between community and facility clients.

Cognitively capable clients were also asked to indicate how satisfied or dissatisfied they were overall with the services they received. In addition, they were asked an open ended question regarding the reasons for their satisfaction or dissatisfaction. The findings indicated that:

- Approximately 79% of clients were very satisfied with the services they received; another 21% were somewhat satisfied.
- Approximately 46% of community clients but only 19% of facility clients indicated they were satisfied because of worker attributes (e.g., workers are punctual, courteous and cooperative).
- Approximately 12% of community clients and 11% of facility clients were satisfied because they felt the services met their needs.
- Some 9% of community clients and 19% of facility clients were dissatisfied with services because of system attributes (e.g., staff shortages, lack of consistent workers).
- In addition, 7% of community clients and 4% of facility clients were dissatisfied because of the quality of service (e.g., poor service, unsatisfactory work).

For community clients, clients and proxies were asked an open ended question regarding the factors that were enabling the client to remain at home. Respondents could provide more than one response. As shown in Table 3-4, the primary reasons clients were able to remain at home were: they received assistance and support from informal caregivers; their health was good; and they were able to care for themselves (perhaps with some assistance from others).

For facility clients, clients and proxies were asked an open ended question regarding the factors that had affected the client's decision to move into a long term care facility. As shown in Table 3-4, clients went into facilities primarily because their health needs increased and/or because their informal caregivers were unable to provide the necessary care and/or support. Respondents were also asked an open ended question regarding whether there were any resources which were not available to them which may have enabled the client to stay at home instead of moving into a long term care facility. Some 39% of respondents indicated that no additional services would have enabled the client to remain at home. Another 39% indicated that the client required 24 hour care.

Cognitively capable clients were asked what kind of housing situation they would prefer if they had complete choice of their living situation. The findings indicated that:

- Some 93% of community clients would prefer to be living in their own or a family member’s home with appropriate care and support, 5% would prefer an assisted living/supportive housing setting, and 2% would prefer a facility.
- In contrast, 72% of facility clients would prefer to be living in a facility, 26% would prefer to be living in their own or a family member’s home and 2% would prefer an assisted living/supportive housing setting.

**Table 3-4: Factors Affecting Where the Client Lives (Study 1)**

		N	% <sup>27</sup>
Factors Enabling Client To Remain At Home	Client Choice (e.g., client likes own home)	20	11
	Client Health (e.g., client is in good health, has good mobility)	56	32
	Client Control (e.g., client capable of managing on his/her own)	40	23
	Informal Care Available (e.g., assistance from family members)	101	57
	Formal Care Available (e.g., formal care services are provided)	35	20
	Environment (e.g., home is close to shopping, transportation routes)	16	9
	Supportive Services Are Available (e.g., housekeeping)	28	16
	Financial Independence (e.g., client is financially independent)	18	10
	Support from VAC (e.g., client receives services paid for by VAC)	24	14
Factors Affecting Decision To Have Client Move Into Long Term Care Facility	Client’s Overall Health Care Needs Increased	55	31
	Client’s Physical Health Care Needs Increased	68	38
	Client’s Cognitive Health Care Needs Increased	71	40
	Concerns Regarding Client’s Safety (e.g., night wandering, falls)	36	20
	Informal Caregiver Unable To Provide Care And/Or Support	60	34
	Appropriate Formal Care Services Not Available	8	5
	Physician Recommended Facility Placement	17	10
	Client Ready To Go Into Facility	7	4

Clients and proxies were asked an open ended question regarding what suggestions (if any) they had for Veterans Affairs Canada to improve services to veterans. Approximately 25% of respondents did not have any suggestions for improvements, implying that VAC is doing a good job. Another 16% indicated that the clients’ needs were being met. However, 19% of respondents commented on communication issues with VAC, particularly that VAC should contact veterans and their families regarding possible benefits.

### 3.4.9 Description of the Caregiver Sample in Study 1

As noted previously, clients and proxies were asked to identify a family member or friend who provided the client with care and support. In some cases, clients did not have anyone, or the client/proxy may have chosen not to identify someone. In addition, the identified individuals could choose not to participate in the study. The findings regarding informal caregivers are thus based only on the 300 individuals who chose to participate in the study. The findings indicated that:

<sup>27</sup> Percentages for community clients are based on the total number of community clients (i.e., 177). Percentages for facility clients are based on the total number of facility clients (i.e., 178). Respondents could provide more than one response; thus, the percentages sum to more than 100%.

- Some 48% of the sample were caring for a client in the community and 52% were caring for a client in a facility.
- Overall, 84% of caregivers were female and 16% were male. Female caregivers were more likely to be caring for community clients than for facility clients.
- Approximately 51% of the caregivers were spouses, another 43% were adult children of the client. Spouses were more likely to be caregivers of community clients while adult children were more likely to be caregivers of facility clients.
- Approximately 53% of the caregivers were 65 years of age or older; 40% were 75 years of age or older. On average, caregivers of community clients were older than caregivers of facility clients (71 years vs. 64 years, respectively; this difference was significant).
- Approximately 89% of caregivers were married. Caregivers of community and facility clients did not differ with respect to their marital status.
- Almost all of the caregivers (97%) indicated that their primary language was English.
- Some 66% of caregivers had some post-secondary education. Caregivers of facility clients were more likely than caregivers of community clients to have some post-secondary education.
- Caregivers could indicate that they received income from more than one source. Some 51% of caregivers received an Old Age Pension, 49% received Canada Pension Plan Benefits and 38% received income from paid or self employment.
- Approximately 21% of caregivers of community clients and 46% of caregivers of facility clients indicated that they were currently working for pay. Of the caregivers that were working, 70% worked more than 30 hours per week.

#### 3.4.10 Provision of Assistance by Informal Caregivers

Informal caregivers were asked several questions regarding the care and support they provided to clients. The findings indicated that:

- Approximately 48% of caregivers had been providing care and support for more than five years. There was no difference between caregivers of community clients and caregivers of facility clients with respect to the amount of time they had been providing care.
- Some 73% of caregivers of community clients lived with the client.<sup>28</sup>
- Overall, 19% of caregivers provided unpaid care to someone in addition to the client. Caregivers of community and facility clients did not differ.
- Some 74% of caregivers indicated that they received assistance in providing care and/or support to the client; there was no difference between caregivers of community

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<sup>28</sup> While 64% of community *clients* indicated that they lived with one other person, 73% of *caregivers* of community clients indicated that they lived with the client. This seeming discrepancy is due to the fact that the sample of all clients is bigger than the sample of clients who had caregivers that participated in the study.

and facility clients. Overall, 65% of caregivers received assistance from the clients' children.

- Approximately 60% of caregivers of community clients and 11% of caregivers of facility clients spent 21 hours or more a week providing care and/or support to the client.<sup>29</sup> Caregivers of community clients spent significantly more time providing care and/or support than caregivers of facility clients. On average, caregivers of community clients provided 54 hours of care and/or support per week while caregivers of facility clients provided 11 hours of care and/or support per week.
- Approximately 51% of primary caregivers of community clients and 9% of primary caregivers of facility clients spent 21 hours or more per week providing care and/or support to the client *because of his/her condition*.<sup>30</sup> Primary caregivers of community clients provided significantly more care and/or support per week because of the client's condition than primary caregivers of facility clients (47 hours vs. 9 hours, respectively).
- Over 70% of caregivers of community clients assisted clients with managing finances, doing housework, doing laundry, preparing meals, shopping for food and household items, and providing emotional support. Over 80% of caregivers of facility clients assisted with managing finances and providing emotional support.

#### 3.4.11 Caregivers' Satisfaction with Services the Client is Receiving

Caregivers' satisfaction with the paid services clients received was assessed using questions similar to those used with clients (see Section 3.4.8 above). The findings indicated that caregivers of community clients were more satisfied than caregivers of facility clients.

Caregivers were also asked to indicate how satisfied or dissatisfied they were overall with the services the client received. In addition, they were asked an open ended question regarding the reasons for their satisfaction or dissatisfaction. The findings indicated that:

- Approximately 77% of caregivers of community clients were very satisfied; another 22% were somewhat satisfied. The comparable figures for caregivers of facility clients were 90% and 9%, respectively.
- Approximately 34% of caregivers of community clients and 42% of caregivers of facility clients indicated they were satisfied because of worker attributes (e.g., workers are dedicated).
- Approximately 37% of caregivers of community clients and 33% of caregivers of facility clients indicated they were satisfied because of service attributes (e.g., services meet the client's needs, the client is receiving the best care available).

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<sup>29</sup> These findings relate to time provided by the primary caregiver and other unpaid caregivers, and may include time spent with the client because the caregiver(s) wanted to as well as time spent because of the client's condition. Informal caregiver time used in estimating costs (see Section 3.5.3) was based only on time spent because of the client's condition.

<sup>30</sup> Primary caregivers, particularly spouses, often provide care and/or support as part of their relationship with the client, independent of the client's health. The question related to this finding asked how much care and/or support was provided *because of* the client's health.

- Approximately 17% of caregivers of facility clients also indicated that they were satisfied because of the facility's attributes (e.g., what the facility had to offer) and 10% indicated they were satisfied because of communication between staff and family members. (These areas were not commented on by caregivers of community clients.)
- Approximately 9% of caregivers of both community and facility clients expressed dissatisfaction primarily because of issues related to staffing (e.g., staff shortages, lack of continuity of staff).

Caregivers were asked what kind of housing situation they would prefer for the client if they had complete choice of where he/she lived. The findings indicated that:

- Some 79% of caregivers of community clients would prefer that clients were living in their own or a family member's home with appropriate care and support, 12% would prefer that they were living in an assisted living/supportive housing setting and 9% would prefer that they were in a facility.
- Some 91% of caregivers of facility clients would prefer that clients were living in a facility, 7% would prefer that they were living in their own or a family member's home and 3% would prefer that they were in an assisted living/supportive housing setting.

#### 3.4.12 Services and Supports Caregivers Are Receiving

Caregivers were asked an open ended question regarding what types of assistance they were currently receiving to help them care for the client. The findings indicated that:

- Some 47% of caregivers do not receive any assistance.
- Some 46% of caregivers of community clients receive assistance with housekeeping and similar supportive services inside the home and 26% receive assistance with grounds keeping and similar supportive services outside the home. The comparable figures for caregivers of facility clients were 12% and 14%, respectively.

Caregivers were also asked an open ended question regarding what additional services they would like to receive to assist them in providing care and/or support to the client. The findings indicated that:

- Some 40% of caregivers of community clients and 55% of caregivers of facility clients felt that they did not require assistance.
- Some 19% of caregivers of community clients would like assistance with socialization (especially respite), 15% would like assistance with supportive services inside the home (e.g., house cleaning) and 12% would like more care services (e.g., more hours).
- In addition, 8% of caregivers of facility clients indicated they would like assistance with transportation and 7% indicated they would like assistance with socialization.

Caregivers were asked if they currently received financial assistance to help them care for the client. Overall 22% of caregivers indicated that they received financial assistance. Caregivers of community clients were more likely to receive financial assistance than caregivers of facility clients. Some 82% of caregivers indicated VAC provided financial assistance. Caregivers who were not currently receiving financial assistance were asked if they would like to receive financial assistance to help them care for the client. Some 46% of caregivers of community clients and 67% of caregivers of facility clients indicated that they did not require financial assistance, at least at this time. However, 16% of community caregivers indicated that they would like financial assistance to help them cover the client's care related expenses; another 11% indicated that they would like some general assistance. The comparable figures for caregivers of facility clients were less than 1% and 5%, respectively.

Caregivers were asked how satisfied they were with the services and supports they received from Veterans Affairs Canada. Of the caregivers who answered this question, 81% indicated that they were very satisfied with the services and supports they received.<sup>31</sup>

### 3.4.13 Effects of Caregiving

Caregivers were asked to rate their health relative to other people their own age. Overall, 80% of caregivers rated their health as good or better. Caregivers of community and facility clients rated their health similarly.

Caregivers were asked if they had changed their social or leisure activities and/or the amount of time they spent working because of caring for the client. The findings indicated that:

- Overall, 36% of caregivers had not changed their social or leisure activities because of providing care.
- Approximately 11% of caregivers of facility clients indicated that they had *increased* their social or leisure activities; none of the caregivers of community clients indicated that this was the case.
- Some 69% of caregivers of community clients and 48% of caregivers of facility clients *decreased* their social or leisure activities. Of these, 38% had reduced the amount of time they spent in social or leisure activities by more than 10.5 hours a week.
- Approximately 65% of caregivers indicated they had not changed the amount of time they spent working and 35% decreased the amount of time they spent working in order to care for the client.
- Of the caregivers who had reduced the amount of time they spent working, 44% had reduced the amount of time by more than 10.5 hours a week. Approximately 73% of caregivers had made the change within the last five years.

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<sup>31</sup> The findings should be interpreted with caution, however, as 26% of caregivers did not provide a response to this question primarily because they felt that the client, rather than themselves, received the services and supports from VAC.

The objective and subjective burden of providing care and/or support to clients was assessed using a modified version of the Montgomery Burden Scale. Objective burden refers to the extent to which a caregiver’s life or household are disrupted. Subjective burden refers to the caregiver’s attitude or emotional reaction regarding providing care. The findings indicated that caregivers of community clients experienced more objective and subjective burden than caregivers of facility clients. Neither objective nor subjective burden increased as clients’ care needs increased.

Caregivers were asked open ended questions about the benefits and disadvantages of providing care. As shown in Table 3-5, overall, 54% of caregivers felt that caregiving provided them with an opportunity to show care and love to the client; another 21% felt that it enabled them to make sure that the client was well looked after. However, 47% of caregivers commented on the emotional aspects of caregiving (e.g., that caregiving is emotionally draining) and 26% commented on the sense of commitment and responsibility (e.g., being under time constraints).

**Table 3-5: Benefits and Disadvantages of Providing Care (Study 1)**

		Community		Facility		Total	
		N	%	N	%	N	%
<b>Benefits of Caregiving<sup>32</sup></b>	Opportunity to Show Care and Love	89	62	72	46	161	54
	Satisfaction from Providing Care	9	6	8	5	17	6
	Caregiver Has Learned From Experience	7	5	27	17	34	11
	Client is Well Looked After	17	12	47	30	64	21
	Caregiver Has Peace of Mind	5	4	41	26	46	15
	Client is in Own Home	34	24	0	0	34	11
	Caregiver’s Situation Has Improved	0	0	17	11	17	6
	Caregiver Doing “Duty”	17	12	12	8	29	10
	No Benefits	16	11	10	6	26	9
<b>Disadvantages of Caregiving</b>	No Disadvantages	26	18	50	32	76	25
	Coping with Client’s Condition	7	5	15	10	22	7
	Emotional Aspects	71	49	71	46	142	47
	Commitment and Responsibility	42	29	36	23	78	26
	Caregiver Feels Tied Down	85	59	10	6	95	32
	Caregiver Away From Own Home	8	6	10	6	18	6
	Caregiver’s Role Has Changed	7	5	9	6	16	5

Caregivers were asked open ended questions regarding what suggestions they had for improving quality of life, both for the client and for themselves. The findings indicated that:

- Approximately 40% of caregivers did not provide any suggestions for improving the client’s quality of life, noting that the client’s needs were being met.
- Some 25% of caregivers commented on the need to increase socialization opportunities (e.g., outings, walks, visitors).
- Over 10% of caregivers of facility clients (but not community clients) commented on the need to respect clients and to address staffing issues.

<sup>32</sup> Caregivers could provide more than one response for both benefits and disadvantages. The percentages in the table are based on the total possible number of respondents (144 caregivers of community clients, 156 caregivers of facility clients, 300 caregivers in total).

- Some 33% of caregivers of community clients and 54% of caregivers of facility clients did not have any suggestions for improving their own quality of life, implying that their needs were being met.
- Some 32% of caregivers of community clients and 9% of caregivers of facility clients indicated that they would like some respite.
- In addition, 17% of caregivers of community clients indicated that they would like more help, particularly with respect to housekeeping and meal preparation.

### **3.5 Costing**

#### **3.5.1 Introduction**

Estimated costs associated with caring for clients were based primarily on data collected through the various diaries (see Table 2-1). The diaries were kept by clients, informal caregivers and formal care providers for a two week period. The quality of the information provided in the diaries varied from very detailed and complete records to little information. For “Good” diaries, the information in the diary appeared complete for the two week period and was coded without amendment or interpretation. For “Mediocre” diaries, partial information was provided in the diaries, and the data had to be manipulated and/or retrieved from other sources (such as the Client Interview). For “Poor” diaries, the information provided in the diaries was so poor or so incomplete that it was impossible to obtain any meaningful information. Only good and mediocre diaries were used in the analyses discussed in the following sections.

The response rate for the diaries was not as high as anticipated. It is believed that this may be due, at least in part, to the age of the clients and their caregivers and the time involved in caring for the client. As a result, some of the cells in the tables in the following sections are based on relatively small numbers, and the average score may have been affected by one or more outliers. A check of the data indicated that for most outliers, the scores represented relatively accurate findings. Nevertheless, it is not clear to what extent similar outliers would be found in other samples of clients and it is not clear how representative the proportion of outliers in this sample is of all clients. In order to strike a balance between data accuracy and data anomalies, a small set of fairly extreme outliers (those more than three standard deviations away from the average score) were excluded to try to obtain more representative data. For Study 1, a total of 31 outliers were excluded from the various cost estimates discussed in Sections 3.5.2 to 3.5.6.

Not all of the people who completed diaries completed each type of diary. In fact, only a relatively small number of respondents completed all diaries. The data regarding each type of diary are based on the set of people who provided data for that particular diary (not including outliers). The costs were estimated based on group averages. While this approach introduced some lack of precision in the data, it is believed that the data presented are reasonably representative of the clients in the study.

### 3.5.2 Out-of-Pocket Expenses

Information on out-of-pocket expenses incurred by clients and/or their informal caregivers was obtained through the Diary of Care Related Expenditures. All of these diaries (i.e., 100%) were considered “Good” or “Mediocre”.

Table 3-6 presents average costs for different types of expenditures for all clients for whom diary data regarding expenditures were available.<sup>33</sup> The overall average expenditure for community clients for a two week period was \$197. The comparable figure for facility clients was \$512; this is primarily due to facility user fees.<sup>34</sup> Overall, out-of-pocket expenditures were estimated to be \$2,144 per year for community clients and \$12,495 per year for facility clients.

**Table 3-6: Average Costs For Out of Pocket Expenditures Incurred by Clients and Informal Caregivers Over a Two Week Period**

Type of Expenditures	Community	Facility
Medical Supply/Equipment (e.g., medications; incontinence products)	\$100	\$ 19
Care Related Home & Personal Maintenance (e.g., paid housekeeping, Meals on Wheels)	\$ 60	\$ 50
Medically Related Care Services (e.g., podiatry/chiropractic, massage therapy)	\$ 15	\$ 10
Long Term Care Facility Co-payment	N/A	\$393
Other Services/Costs	\$ 22	\$ 40
<b>Average Total</b>	<b>\$197</b>	<b>\$512</b>

### 3.5.3 Costing of Time and Assistance Provided by Informal Caregivers

The Diary of Time and Assistance Provided by Informal Caregivers was used to examine how much time informal caregivers spent providing care and support to clients. Approximately 93% of these diaries were considered “Good” or “Mediocre”. Two averages were calculated regarding the amount of time informal caregivers spent providing care and support to clients. The first was the average amount of time spent for all clients (for whom diary data were available). This is a measure of how much time is spent providing care, regardless of whether the service is provided to a specific client. The second was the average amount of time spent for those clients who received the service (for whom diary data were available). The first average can be used for general planning purposes, the second can be used for planning care requirements for clients with specific needs.

As shown in Table 3-7, the average amount of time provided by caregivers of community clients over a two week period for all clients, was 35 hours; the comparable figure for caregivers of facility clients was 14 hours.<sup>35</sup> The majority of services provided by caregivers of community clients were home and personal maintenance services. For all clients, caregivers spent an average of 27 hours (77% of all hours) on these types of activities. The majority of services provided by caregivers of facility clients were psychosocial activities. For all clients, caregivers spent an average of 9 hours (64% of all hours) on these activities.

<sup>33</sup> Definitions of each of the categories in Table 3-6 are provided in Appendix C.

<sup>34</sup> At the time of the study, the facility co-pay for most clients was \$835 per month.

<sup>35</sup> Definitions of each of the categories in Table 3-7 are provided in Appendix C.

Informal caregiver time can be costed using a number of different approaches. One approach is to use minimum wage; a minimum wage of \$7.83 per hour was used (the average minimum wage in 2007 for British Columbia, Ontario and Nova Scotia). A second approach is to use replacement costs based on the type of service provided. A value of \$60.00 per hour was used for professional services and a value of \$27.00 per hour was used for all other services. These are average estimates based on rates paid by VAC for nurses and other professional care providers and individuals providing housekeeping services; they may differ somewhat from overall, national rates for similar services.

**Table 3-7: Average Number of Hours Spent on Various Activities Over a Two Week Period by Informal Caregivers Due to the Client’s Condition**

Type of Activity	Community		Facility	
	All Clients <sup>36</sup>	Clients Who Received the Services	All Clients <sup>37</sup>	Clients Who Received the Services
Professional Care Type (e.g., assisting with foot care)	1	4	0.2	1
Hands-on Supportive Care (e.g., bathing)	3	8	1	6
Home & Personal Maintenance (e.g., housekeeping)	27	28	3	4
Psychosocial (e.g., providing emotional support)	4	8	9	10
Other	0	8	0.3	4
<b>Total</b>	<b>35</b>	<b>N/A</b>	<b>14</b>	<b>N/A</b>

When caregiver time was valued at minimum wage, the contributions of informal caregivers ranged from \$3,703 to \$12,877 per year for community clients and from \$1,812 to \$3,495 per year for facility clients. When caregiver time was valued at replacement wage, the contributions of informal caregivers ranged from \$13,371 to \$46,449 per year for community clients and from \$6,322 to \$12,249 per year for facility clients.

#### 3.5.4 Costing of Paid Care Funded by Government

The Diary of Time and Assistance Provided by Formal Care Providers was used to estimate costs to government for paid care services provided to clients. All of these diaries were considered “Good” or “Mediocre”.

Table 3-8 provides rates, by type of worker, used in calculating the cost of paid care services. The estimated unit costs are based on rates paid by VAC. The table also provides the average hours provided for a two week period based on all clients (for whom diary data were available), and the percentage of hours provided by each type of worker. The average amount of time provided by paid care workers to community clients was 10 hours for a two week period. Care Aides/Care Workers provided 51% of these hours, while homemakers/home maintenance staff provided 33% of these workers. The average annual cost to government for community clients (based on the diary data) was estimated to be \$7,963.

<sup>36</sup> Refers to all clients for whom diary data were available, not all clients in the study.

<sup>37</sup> Refers to all clients for whom diary data were available, not all clients in the study.

With regard to facility rates, VAC payments may range from fairly modest payments to the full cost of a contract bed. Given this variability, the full cost of a contract bed was used as this study looked at overall societal costs. A standard rate of \$62,576 per year was used for all facility clients.<sup>38</sup> The standard facility rate represents the cost of a facility bed if VAC were to pay 100% of the cost.

**Table 3-8: Rates and Average Hours for Paid Care Providers of Community Clients Over a Two Week Period**

Provider	Rate Per Hour	Average Hours Across All Clients <sup>39</sup>	% of Hours Provided by Worker
Physician	\$150.00	0.1	1
Registered Nurse	\$ 66.50	0.3	3
Licensed/Registered Practical Nurse	\$34.80	0.2	2
General Nurse	\$37.20	0.0	0
Physiotherapist	\$44.56	0.0	0
Occupational Therapist	\$37.58	0.0	0
Other Medical Professional	\$100.02	0.1	1
Care Aide/Care Worker	\$27.00	5.1	51
Homemaker/Home Maintenance	\$27.00	3.3	33
Complementary Health Care Provider	\$100.00	0.0	0
Other Providers	\$30.00	0.5	5
<b>Total</b>		<b>10</b>	<b>100</b>

### 3.5.5 Costs to VAC

VAC makes a wide range of payments, through 15 broad payment categories called Programs of Choice (POCs; see Appendix D). The POCs can be divided into two main categories. One, which includes nursing services, related health services, and VIP, is quite similar to what would be provided through most provincial home care programs. The other category is similar to extended health care services, and includes services such as prescription drugs, dental services, aids to daily living and special equipment. In order to develop as complete costing estimates as possible, home care equivalent costs and other health related costs were estimated based on costing data provided by VAC.

### 3.5.6 Comparative Cost Analysis in Terms of Cost to Government and Societal Costs for Community and Facility Clients

Table 3-9 shows comparative costs for community and facility clients based on care levels created from total SMAF scores. The table indicates that caring for community clients costs less per year than caring for facility clients.

<sup>38</sup> The annual figure for facility clients was based on an estimated average of the rates negotiated by VAC and the facilities in this study. The negotiated rate is not based on any specific breakdown, but is intended to cover all aspects of care (including registered and non-registered staff time, activation, food, etc.). Thus, VAC pays facilities a standard per diem and does not pay on a case mix adjusted basis. Separate analyses, based on facility budget/expenditures data, indicated that the average facility rate (total dollars divided by total beds) was very similar to the VAC rate for the facilities in this study.

<sup>39</sup> Refers to all clients for whom diary data were available, not all clients in the study.

**Table 3-9: Costs to Government, Clients and/or Caregivers, and Total Societal Costs, for Community and Facility Clients<sup>40</sup>**

	Care Levels (based on SMAF scores)	Costs to Government <sup>41</sup>	Other Health Related Costs <sup>42</sup>	Total Costs to Government <sup>43</sup>	Out of Pocket Expenses for Clients and/or Caregivers	Imputed Caregiver Costs		Total Costs to Clients and/or Caregivers <sup>44</sup>	Total Societal Costs <sup>45</sup>
						Caregiver Time at Minimum Wage	Caregiver Time at Replacement Wage		
Community	Levels 1 & 2	3,800	1,037	4,837	1,040	3,703	13,371	14,411	19,248
	Level 3	5,388	743	5,905	2,493	5,000	17,701	20,194	26,099
	Level 4	11,122	1,661	12,783	1,915	7,985	29,168	31,083	43,866
	Level 5	14,120	755	14,875	3,848	12,877	46,449	50,297	65,172
	Level 6 & Higher	11,878 <sup>46</sup>	2,702	14,581	1,289	11,207	40,974	42,263	56,844
	Overall Average	7,963	1,209	9,104	2,144	7,134	25,760	27,904	37,008
Facility	Level 4	62,576	432	63,008	12,443	3,400	11,796	24,239	87,247
	Level 5	62,576	5,099	67,675	14,536	2,620	9,081	23,617	91,292
	Level 6	62,576	2,018	64,594	12,630	3,347	11,833	24,463	89,057
	Level 7	62,576	2,235	64,811	11,726	3,495	12,249	23,975	88,786
	Level 8	62,576	2,720	65,296	12,731	1,812	6,322	19,053	84,349
	Level 9	62,576	1,627	64,203	11,395	2,196	7,725	19,120	83,323
Overall Average	62,576	2,599	65,175	12,495	2,772	9,706	22,201	87,376	

<sup>40</sup> Study 1 was conducted between July 2006 and January 2007. Thus, the costs are primarily 2006 costs.

<sup>41</sup> For community clients, Costs to Government are for paid care based on diary data. For facility clients, Costs to Government are a standard rate based on an estimated average for the facilities in this study.

<sup>42</sup> Other Health Related Costs for both community and facility clients were estimated based on costing data provided by VAC. For facility clients, costs for all health services were included in this category.

<sup>43</sup> Sum of Costs to Government and Other Health Related Costs.

<sup>44</sup> Sum of Out-of-Pocket Expenses and Caregiver Time at Replacement Wage.

<sup>45</sup> Sum of Total Costs to Government and Total Costs to Clients and/or Caregivers.

<sup>46</sup> Estimates for costs to VAC were higher than estimates based on diary data; thus the cost to VAC was used for this group.

## **4. HIGHLIGHTS OF FINDINGS FROM STUDY 2**

### **4.1 Introduction**

This chapter provides a summary of the findings from Study 2. As noted earlier, Study 2 involved two components: interviews with veterans and their informal caregivers regarding their use of care and support services funded by Veterans Affairs Canada; and completion of diaries by clients and caregivers regarding out-of-pocket expenses and time spent on care. In this study, the veterans lived in their own or a family member's home, in supportive housing, or in a long term care facility. Non-veterans were also included in the supportive housing sample.<sup>47</sup>

### **4.2 Interviews with Clients and Informal Caregivers**

#### **4.2.1 Description of the Client Sample for Study 2**

The target sample for Study 2 was 960 clients, 320 in each of the three groups (community, facility and supportive housing). The final client sample for this study consisted of 313 community clients (98% of the target sample), 256 facility clients (80% of the target sample), and 113 supportive housing clients (35% of the target sample), for a total sample of 682 clients. The overall sample thus consisted of 46% community clients, 38% facility clients, and 17% supportive housing clients. Given these relative proportions, the supportive housing component of Study 2 was considered more exploratory than initially anticipated.

In Study 2:

- Approximately 88% of the clients were male and 12% were female. These findings are likely due to the fact that the community sample only contained males, while the facility and supportive housing samples contained both males and females. Many of the females in the supportive housing sample were non-veterans.
- Approximately 55% of the clients were 85 years of age or older. Facility clients were significantly older than community clients and supportive housing clients were significantly younger than both community and facility clients. On average, community clients were 86 years of age, facility clients were 85 years of age, and supportive housing clients were 83 years of age.
- Overall, 47% of clients were married and 43% were widowed. Community clients were more likely to be married than facility clients. Supportive housing clients were more likely to be widowed than either community or facility clients.
- Approximately 98% of clients indicated that English was their primary language.<sup>48</sup>
- Overall, 39% of clients had some post-secondary education; another 41% had not completed high school. Community clients were more likely than facility clients to have some college or university education. Supportive housing clients were less likely to have finished high school than either community or facility clients.

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<sup>47</sup> Both veterans and non-veterans are referred to as clients in this study.

<sup>48</sup> The ability to communicate in English was one of the selection criteria for participation in the study.

- Over 90% of clients received income from Old Age Pension and/or the Canada Pension Plan. Compared to community and facility clients, fewer supportive housing clients received income from trusts and investments and/or retirement pensions and more supportive housing clients received the Guaranteed Income Supplement. These findings suggest that, in general, supportive housing clients may have lower incomes than either community or facility clients. This is consistent with the fact that, in order to receive supportive housing funding, agencies in this study need to ensure that at least 40% of their clients are low income.
- Proxies were used for 6% of the community clients, 58% of the facility clients, and 4% of the supportive housing clients.

#### 4.2.2 Functional Health of Clients

As in Study 1, the SMAF was used to assess clients' functioning and nine "care level" categories were created using total SMAF scores. As shown in Table 4-1, community and supportive housing clients generally had lower care needs than facility clients. However, there was a group of community, facility and supportive housing clients with comparable care needs in the middle range (i.e., at levels 3, 4, 5).<sup>49</sup> An analysis of clients based on total SMAF scores indicated that: clients in the various care levels differed from one another; community clients had lower care needs than facility clients; and supportive housing clients had lower care needs overall than both community and facility clients.

**Table 4-1: Number of Clients in Each Care Level in Study 2**

Care Level	Community		Facility		Supportive Housing		Total	
	N	%	N	%	N	%	N	%
Level 1 (0 – 5.0) <sup>50</sup>	76	25	0	0	40	36	116	17
Level 2 (5.5 – 10.0)	82	27	0	0	27	24	109	16
Level 3 (10.5 – 18.0)	85	28	9	4	24	22	118	17
Level 4 (18.5 – 28.0)	38	12	27	11	13	12	78	12
Level 5 (28.5 – 38.0)	14	5	47	18	7	6	68	9
Level 6 (38.5 – 48.0)	14	5	42	16	0	0	56	8
Level 7 (48.5 – 58.0)	0	0	41	16	0	0	41	6
Level 8 (58.5 – 68.0)	0	0	47	18	0	0	47	7
Level 9 (68.5 – 87.0)	0	0	43	17	0	0	43	6
<b>Total</b>	<b>309</b>	<b>100</b>	<b>256</b>	<b>100</b>	<b>111</b>	<b>100</b>	<b>676</b>	<b>100</b>

<sup>49</sup> Six clients were eliminated from Table 4-1 and analyses involving the SMAF care levels due to small cell sizes. The clients included one supportive housing client from Level 6, two community clients and one supportive housing client from Level 7 and two community clients from Level 9.

<sup>50</sup> Numbers in parentheses are total SMAF scores. SMAF scores can range from 0 to 87. Higher scores are indicative of greater care needs.

#### 4.2.3 Cognitive Status of Clients

As in Study 1, the cognitive status of clients was assessed using the MMSE. The following findings apply only to those clients who were considered to be capable of providing informed consent:

- MMSE scores were obtained for 91% of community clients, 39% of facility clients and 96% of supportive housing clients.
- Of the 490 clients for whom MMSE scores were obtained, 83% were considered to have no cognitive impairment and 17% were considered to have mild cognitive impairment.<sup>51, 52</sup>
- In general, community and supportive housing clients scored significantly higher than facility clients on the MMSE, indicating that they had less cognitive impairment than the facility clients. Supportive housing clients were similar to community clients.

#### 4.2.4 Health Status of Clients

Perceived health status was assessed using a single item that asked cognitively capable clients to compare themselves to other people their own age. The findings indicated that:

- Approximately 67% of cognitively capable community clients, 59% of cognitively capable facility clients and 63% of cognitively capable supportive housing clients rated their health as good or better, despite the fact that they were often receiving care and/or support services to meet their needs.
- Community, facility and supportive housing clients rated their health similarly.
- Cognitively capable clients generally perceived that their health status declined as their functional status declined.

The psychological health status of cognitively capable clients was assessed using the GDS-15. The findings indicated that overall, 22% of cognitively capable clients were considered to have mild depression and 4% were considered to have moderate to severe depression. The findings were similar for community, facility and supportive housing clients when all cognitively capable clients were compared.

#### 4.2.5 Health-Related Quality of Life

The health-related quality of life of cognitively capable clients was assessed using the SF-8. The findings indicated that:

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<sup>51</sup> MMSE scores were not obtained for 189 individuals (about 28% of the total sample) who required proxy consent. It was presumed that these clients had severe cognitive impairment, but this may be a slight overestimation if proxies were used because clients were considered too physically frail rather than too cognitively frail.

<sup>52</sup> These individuals, plus three additional individuals who did not complete the MMSE but were considered to be cognitively competent, are referred to as “cognitively capable clients” in the following sections.

- When all cognitively capable clients were compared, community, facility and supportive housing clients did not differ with respect to their perceptions of either their physical or their mental health-related quality of life.
- When cognitively capable clients at comparable care levels (based on the SMAF) were compared, clients with lower care needs perceived that their physical health-related quality of life was better than clients with higher care needs. However, clients at different care levels perceived that their mental health-related quality of life was similar. Compared to both community and supportive housing clients, facility clients perceived that their physical health-related quality of life was better. Compared to community clients (but not supportive housing clients), facility clients perceived that their mental health-related quality of life was better. This may be due, at least in part, to the additional services VAC funds for facility clients.

#### 4.2.6 Social Relations

Both social networks and social supports were considered components of a client's social relations. The findings indicated that:

- Some 59% of community clients lived with one other person (usually their spouse) while 85% of the supportive housing clients lived alone. The facility sample was fairly evenly divided with approximately one third of the sample being in single rooms, approximately one third sharing a room with one other person, and approximately one third sharing a room with two or more people.
- On average, community clients interacted with 43 people over the course of the month, facility clients interacted with 29 people and supportive housing clients interacted with 36 people. Both community and supportive housing clients interacted with significantly more people than facility clients.
- Overall, 90% of clients indicated that they received assistance with daily activities from someone. Of these, 83% received the assistance from an informal caregiver.<sup>53</sup> Community and facility clients were most likely to receive assistance with daily activities from an informal caregiver. Supportive housing clients were most likely to receive assistance from both informal and formal caregivers.
- Overall, 86% of clients indicated that they received emotional support from someone. Of these, 91% received emotional support from an informal caregiver.<sup>54</sup> While all three groups of clients received emotional support from informal caregivers, supportive housing clients were more likely to receive emotional support from formal caregivers than were community or facility clients.

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<sup>53</sup> This figure is based on those clients who indicated that they received help with daily activities and that an informal caregiver (either alone or in combination with a formal caregiver) provided the assistance.

<sup>54</sup> This figure is based on those clients who indicated that they received emotional support and that an informal caregiver (either alone or in combination with a formal caregiver) provided the support.

#### 4.2.7 Service Utilization

Respondents were asked if community and supportive housing clients currently received a variety of care and/or support services (many of which are included in the VIP Program). As the VIP Program is primarily intended to assist individuals to stay in the community, clients living in a facility were not asked these questions. Table 4-2 presents the number of clients who used each type of service.<sup>55</sup>

Overall, the services used most frequently by both community and supportive housing clients were housekeeping, grounds maintenance, and home adaptations. For clients living in supportive housing settings, grounds maintenance and home adaptations may have been provided as part of the building services; housekeeping services may or may not have been included as part of the client’s “rent”.<sup>56</sup>

**Table 4-2: Use of Care and Support Services by Community and Supportive Housing Clients**

Client Receives Assistance With....	Community		Supportive Housing		Total	
	N	%	N	%	N	%
Grounds Maintenance (e.g., lawn mowing, snow removal)	217	69	113	100	330	78
Housekeeping (e.g., laundry, cleaning floors)	307	98	102	90	409	96
Personal Care (e.g., dressing, washing)	45	15	23	20	68	16
Home Adaptations (e.g., handrails)	197	63	95	84	292	69
Nutrition Services (e.g., Meals on Wheels)	54	17	52	46	106	25
Health & Support Services Provided By Professionals (e.g., nursing)	69	22	48	44	117	28
Ambulatory Health Care (e.g., adult day care)	8	3	0	0	8	2
Transportation For Medically Related Issues (e.g., dialysis)	138	44	61	54	199	47
Social Transportation (e.g., to church services)	51	16	56	50	107	25
Case Management (e.g., service assessment, planning and review)	88	30	29	27	117	29
Service Coordination (e.g., referrals to other agencies for assistance)	39	13	23	21	62	15
Other (e.g., heavy housework, socialization, financial management)	22	7	30	27	52	12

Respondents were asked whether clients received assistance from an unpaid (i.e., informal) caregiver, who provided the assistance (if applicable), and approximately how much time the individual(s) provided in an average week. The findings indicated that:

- Some 85% of community clients, 96% of facility clients and 71% of supportive housing clients received assistance from an informal caregiver.
- The majority of individuals who provided care and support to clients were close family members. With respect to community clients, approximately 51% were cared for by a spouse, 39% were cared for by a daughter or daughter-in-law, and 39% were

<sup>55</sup> Clients could indicate that they received assistance with more than one activity. The percentages in the table are based on the total potential number of clients (313 for community clients, 113 for supportive housing clients, 426 clients in total).

<sup>56</sup> It is noted that in Ontario, the term “rent” only covers direct housing costs, not services. Thus, housekeeping services may not have been part of the client’s rent *per se*, but may have been seen as part of the rent if they were provided by the supportive housing building.

cared for by a son or son-in-law. The comparable figures for facility clients were 35%, 50% and 42%, respectively. The comparable figures for supportive housing clients were 11%, 32% and 32%, respectively.

- Overall, community clients received more assistance (in terms of hours per week) from informal caregivers than facility clients. Community clients also received more assistance than supportive housing clients. Community clients received an average of 27 hours of care and/or support per week, facility clients received an average of 12 hours per week, and supportive housing clients received an average of 10 hours per week.

#### 4.2.8 Clients' Satisfaction with Services

As in Study 1, clients' satisfaction with the paid services they were receiving was assessed using a set of questions regarding various aspects of care provision. Only cognitively capable clients were asked these questions. The findings indicated that:

- Community, facility and supportive housing clients showed high levels of satisfaction with the services they received.
- When all cognitively capable clients were compared, community clients were more satisfied than facility clients with the care services they were receiving. Supportive housing clients were less satisfied than community clients, but more satisfied than facility clients.
- When cognitively capable clients at comparable care levels (as assessed by the SMAF) were compared, similar findings were obtained. There were no differences among clients at different care levels.

Cognitively capable clients were also asked to indicate how satisfied or dissatisfied they were overall with the services they received. In addition, they were asked an open ended question regarding the reasons for their satisfaction or dissatisfaction. The findings indicated that:

- Overall, 76% of clients indicated they were very satisfied with the services they received; another 23% indicated they were somewhat satisfied. Community clients were more satisfied than facility clients; supportive housing clients were more satisfied than facility clients, but very similar to community clients.
- Approximately 75% of community clients, 57% of facility clients, and 95% of supportive housing clients indicated that they were satisfied because of worker attributes (e.g., workers are punctual, courteous, efficient).
- Approximately 9% of community clients, 5% of facility clients and 16% of supportive housing clients were satisfied because they felt the services met their needs.
- Approximately 6% of community clients, 16% of facility clients and 4% of supportive housing clients indicated they were dissatisfied with the quality of services they received (e.g., poor service, unsatisfactory work).

- Approximately 3% of community clients, 12% of facility clients and 4% of supportive housing clients expressed dissatisfaction because of system attributes (e.g., staff shortages).
- In addition, less than 1% of community clients, 13% of facility clients and 6% of supportive housing clients expressed dissatisfaction because of worker attributes (e.g., unfriendly staff, staff do not listen).

For community clients, clients and proxies were asked an open ended question regarding the factors that were enabling the clients to remain at home. Respondents could provide more than one response. As shown in Table 4-3, the primary reasons clients were able to remain at home were: they received assistance from informal caregivers; their health was good; they were able to care for themselves; they were financially independent; and/or they chose to remain at home.

**Table 4-3: Factors Affecting Where the Client Lives (Study 2)**

		N	% <sup>57</sup>
Factors Enabling Client To Remain At Home	Client Choice (e.g., client likes own home)	89	28
	Client Health (e.g., client is in good health, has good mobility)	139	44
	Client Control (e.g., client able to care for him/her self)	81	26
	Informal Care Is Available (e.g., assistance from family members)	138	44
	Formal Care Is Available (e.g., formal care services are provided)	37	12
	Environment (e.g., home is close to shopping, transportation)	16	5
	Supportive Services Are Available (e.g., housekeeping)	24	8
	Financial Independence (e.g., client is financially independent)	79	25
	Support From VAC (e.g., client receives services paid for by VAC)	45	14
Factors Affecting Decision To Have Client Move Into Supportive Housing	Client's Overall Health And/Or Physical Health Needs Increased <sup>58</sup>	28	25
	No Support From An Informal Caregiver	22	20
	Client And Family Wanted To Be Closer Together	21	19
	Client Preferred To Be In Supportive Housing (e.g., location)	55	49
	Client Better Off Financially	50	44
	Client May Need Supportive Housing Services In The Future	7	6
Factors Affecting Decision To Have Client Move Into A Long Term Care Facility	Client's Overall Health Care Needs Increased	53	21
	Client's Physical Health Care Needs Increased	95	37
	Client's Cognitive Health Care Needs Increased	69	27
	Concerns Regarding Client's Safety (e.g., night wandering, falls)	43	17
	Informal Caregiver Unable To Provide Care And/Or Support	88	34
	Appropriate Formal Care Services Not Available	13	5
	Physician Recommended Facility Placement	13	5
	Client Ready To Go Into Facility	68	27

For supportive housing clients, clients and proxies were asked an open ended question regarding the factors that affected the client's decision to move into supportive housing. Respondents could provide more than one response. As shown in Table 4-3 (above), respondents

<sup>57</sup> The percentages in the table are based on the total number of possible respondents (i.e. 313 for community clients, 113 for supportive housing clients, and 256 for facility clients).

<sup>58</sup> None of the respondents noted that the client went into supportive housing because his/her cognitive health care needs increased.

indicated that the clients were living in a supportive housing setting because they preferred it, felt they were better off financially, their health care needs had increased and/or they did not have support from an informal caregiver (either because they did not have one or because the caregiver lived too far away). Respondents were also asked if there were any resources that were not available to them which may have enabled the client to stay at home instead of moving into a supportive housing setting. In many cases, clients did not require additional resources *per se*. Some 35% of respondents indicated that the client had moved into supportive housing because that is where he/she preferred to be, 29% indicated that the client's home environment was no longer appropriate (e.g., the house was too big) and 25% indicated that the client required financial assistance to remain in his/her home.<sup>59</sup>

For facility clients, clients and proxies were asked an open ended question regarding the factors that had affected the client's decision to move into a long term care facility. As shown in Table 4-3 (above), clients went into a long term care facility primarily because their health needs increased, their informal caregivers were unable to provide the necessary care and/or support and/or the client was ready for a facility. Respondents were also asked if there were any resources which were not available to them which may have enabled the client to stay at home instead of moving into a long term care facility. Approximately 23% of respondents indicated that no additional resources would have enabled the client to remain at home, 53% indicated that the client required 24 hour care, and 13% indicated that the informal caregiver was unable to provide appropriate care and/or support.

Cognitively capable clients were asked what kind of housing situation they would prefer if they had complete choice of their living situation. The findings indicated that:

- Approximately 98% of community clients would prefer to be living in their own home or a family member's home with appropriate care and support and 2% would prefer to be living in supportive housing.
- Some 75% of facility clients would prefer to be living in a facility, 22% would prefer to be in their own or a family member's home, and 3% would prefer to be in supportive housing.
- Some 81% of supportive housing clients would prefer to be in a supportive housing setting, and 19% would prefer to be in their own or a family member's home.

Clients and proxies were asked an open ended question regarding what suggestions (if any) they had for Veterans Affairs Canada to improve services to veterans. Respondents could provide more than one suggestion. Some 15% of respondents did not have any suggestions for improvements, implying that VAC is doing a good job. Approximately 32% of respondents indicated that the clients' needs are being met. However, respondents also made several suggestions for improvements, particularly regarding communication issues with VAC and when and how much service is provided. Approximately 58% of the respondents who commented on communication issues indicated that VAC should contact veterans and their families regarding the benefits and/or services that may be available to them. An additional 30% of these respondents indicated that they would like to be able to contact personnel in their local VAC

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<sup>59</sup> It is noted that about half of the clients in the supportive housing sample were female.

office directly. Some 33% of the respondents who commented on improving when and how much service is provided noted that veterans need to be assessed more frequently (this was particularly the case for veterans in the community). An additional 17% of these respondents noted that clients needed to have more hours of service (again, this may be more relevant to veterans in the community than in either supportive housing or a long term care facility).

#### 4.2.9 Description of the Caregiver Sample in Study 2

As in Study 1, clients and proxies were asked to identify a family member or friend who provided the client with care and/or support. The identified individuals could choose to participate in the study or not. The findings regarding informal caregivers in this and the following sections are based on the 411 informal caregivers who chose to participate in the study. The findings indicated that:

- Some 45% of the sample were caring for a client in the community, 45% were caring for a client in a facility, and 10% were caring for a client in supportive housing.
- Overall, 82% of the sample were female and 18% were male. Males were more likely to be caregivers for facility and supportive housing clients than for community clients.
- Approximately 47% of the caregivers were spouses,<sup>60</sup> another 40% were adult children of the client. While spouses were likely to be caregivers for community clients, adult children were more likely to be caregivers for facility and supportive housing clients.
- Approximately 54% of the caregivers were 65 years of age or older; 45% were 75 years of age or older. Caregivers of community clients were significantly older than caregivers of facility clients; caregivers of supportive housing clients were not significantly different from caregivers of either community or facility clients. On average, caregivers of community clients were 71 years of age, caregivers of facility clients were 66 years of age and caregivers of supportive housing clients were 67 years of age.
- Some 83% of the caregivers were married. Caregivers of community and facility clients were more likely to be married than were caregivers of supportive housing clients.
- Approximately 95% of the caregivers indicated that their primary language was English.
- Some 54% of caregivers had some post-secondary education. Caregivers of facility clients were more likely to have some post-secondary education than were caregivers of either community clients or supportive housing clients.
- Caregivers could indicate that they received income from multiple sources. Half of the caregivers received an Old Age Pension, 46% received Canada Pension Plan Benefits and 36% received income from paid or self-employment.

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<sup>60</sup> All of the spousal caregivers were wives.

- Some 26% of caregivers of community clients, 43% of caregivers of facility clients, and 45% of caregivers of supportive housing clients were currently working for pay. Caregivers of community clients were less likely to be working than were caregivers of facility or supportive housing clients. Approximately 68% of caregivers indicated that they worked more than 30 hours per week. Caregivers of community, facility and supportive housing clients did not differ with respect to the amount of time they spent working each week.

#### 4.2.10 Provision of Assistance by Informal Caregivers

Informal caregivers were asked several questions regarding the care and/or support they provided to clients. The findings indicated that:

- Over half (53%) of the caregivers had been providing care and/or support for more than five years. Caregivers of community clients had spent more time providing care than caregivers of facility clients. The amount of time spent by caregivers of supportive housing clients did not differ from that spent by caregivers of either community or facility clients.
- Approximately 74% of caregivers of community clients and 33% of caregivers of supportive housing clients lived with the client.<sup>61</sup>
- Overall, 20% of caregivers provided care to someone in addition to the client; in most cases, this was unpaid care.
- Some 69% of caregivers indicated that they received assistance in providing care and/or support to the client. Caregivers of facility clients were more likely to receive assistance than caregivers of either community or supportive housing clients. Overall, 81% of caregivers received assistance from the clients' children.
- Approximately 44% of caregivers of community clients, 23% of caregivers of facility clients and 23% of caregivers of supportive housing clients spent 21 hours or more a week providing care and/or support to the client.<sup>62</sup> Caregivers of community clients spent significantly more time providing care and/or support than caregivers of either facility or supportive housing clients. On average, caregivers of community clients provided 37 hours of care and/or support per week, while caregivers of facility clients provided 16 hours per week and caregivers of supportive housing clients provided 17 hours per week.
- Some 32% of primary caregivers of community clients, 13% of primary caregivers of facility clients and 8% of primary caregivers of supportive housing clients spent 21 hours or more a week providing care and/or support to the client *because of his/her*

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<sup>61</sup> While 85% of supportive housing *clients* indicated that they lived alone (suggesting that 15% of clients lived with another individual), 33% of *caregivers* of supportive housing clients lived with the client. This seeming discrepancy is due to the fact that not all of the clients had caregivers and thus, the sample of all clients is bigger than the sample of clients who had caregivers that participated in the study. This also applies to the caregivers of community clients.

<sup>62</sup> These findings relate to time provided by the primary caregiver and other unpaid caregivers, and may include time spent with the client because the caregiver(s) wanted to as well as time spent because of the client's condition. Informal caregiver time used in estimating costs (see Section 4.3.3) was based only on time spent *because of the client's condition*.

condition. Primary caregivers of community clients spent significantly more time providing care and/or support per week than primary caregivers of either facility or supportive housing clients (27 hours vs. 13 hours and 9 hours for community, facility and supportive housing clients, respectively).

- Over 70% of caregivers of community clients assisted clients with meal preparation and shopping for food and household items. Over 70% of caregivers of facility clients assisted the client with his/her finances, decision making and shopping for food and household items. Over 70% of caregivers of supportive housing clients assisted with shopping for food and household items. In addition, over 70% of caregivers of community, facility and supportive housing clients indicated that they provided emotional support.

#### 4.2.11 Caregivers' Satisfaction with Services the Client is Receiving

Caregivers' satisfaction with the paid services clients were receiving was assessed using questions similar to those used with clients in both Studies 1 and 2 (see Section 3.4.8 above). The findings indicated that caregivers of community clients were significantly more satisfied than caregivers of facility clients; caregivers of community and supportive housing clients did not differ.

Caregivers were also asked to indicate how satisfied or dissatisfied they were overall with the services the client received. In addition, they were asked an open ended question regarding the reasons for their satisfaction or dissatisfaction. The findings indicated that:

- Approximately 73% of caregivers of community clients were very satisfied; another 25% were somewhat satisfied. The comparable figures for caregivers of facility clients were 75% and 22%, respectively. The comparable figures for caregivers of supportive housing clients were 78% and 22%, respectively.
- Overall, 9% of caregivers indicated they were satisfied because they were not experiencing any major problems; another 8% indicated they were satisfied because the client was satisfied.
- Approximately 36% of caregivers of community clients, 25% of caregivers of facility clients and 33% of caregivers of supportive housing clients indicated they were satisfied because of worker attributes (e.g., excellent, dedicated workers).
- In addition, 23% of caregivers of community clients, 42% of caregivers of facility clients and 22% of caregivers of supportive housing clients indicated they were satisfied because of service attributes (e.g., services meet the client's needs).
- Finally, 10% of caregivers of facility clients and 7% of caregivers of supportive housing clients were satisfied because staff communicated with the family regarding the client's needs (no caregivers of community clients commented on this).
- Caregivers expressed dissatisfaction because of worker attributes (e.g., workers are not punctual, are inefficient), facility attributes (e.g., poor quality of food, lack of stimulation/activities), staff issues (e.g., lack of continuity of workers and staff shortages, particularly in facilities) and communication issues (e.g., among staff

members, between staff and clients/families); overall percentages ranged from 5% to 9%.

Caregivers were asked what kind of housing situation they would prefer for the client if they had complete choice of where he/she lived. The findings indicated that, in general, caregivers feel the clients are living where they should be:

- Approximately 94% of caregivers of community clients would prefer that clients were living in their own or a family member's home with appropriate care and support, 4% would prefer that they were living in an assisted living/supportive housing setting and 2% would prefer they were in a facility.
- Approximately 84% of caregivers of facility clients would prefer that clients were living in a facility, 14% would prefer they were living in their own or a family member's home and 2% would prefer that they were in an assisted living/supportive housing setting.
- Approximately 77% of caregivers of supportive housing clients would prefer that clients were living in an assisted living/supportive housing setting, 18% would prefer that they were living in their own or a family member's home and 5% would prefer that they were living in a facility.

Caregivers were asked if they thought assisted living/supportive housing was an appropriate alternative to home care and/or facility care in general. They were also asked if they thought it was an appropriate alternative for their client. Overall, 78% of the caregivers felt that assisted living/supportive housing was an appropriate alternative in general. Approximately 40% of caregivers of community clients, 13% of caregivers of facility clients, and 97% of caregivers of supportive housing clients felt it was an appropriate option for their client. The findings indicate that supportive housing clients are probably living in the best environment at this time, that some of the community clients could benefit from an environment with more formal supports, and that some of the facility clients may need formal supports, but not necessarily formal health care services.

#### 4.2.12 Services and Supports Caregivers Are Receiving

Caregivers were asked an open ended question regarding the types of assistance they were currently receiving to help them care for the client. The findings indicated that:

- Approximately 47% of caregivers do not receive any assistance.
- Approximately 51% of caregivers of community clients receive assistance with housekeeping and similar supportive services inside the home and 34% receive assistance with grounds keeping and similar supportive services outside the home. The comparable figures for caregivers of facility clients were 11% for supportive services both inside and outside the home. For caregivers of supportive housing clients, 18% indicated that they received assistance with supportive services inside the home; none of these caregivers mentioned supportive services outside the home.

- Overall, 13% of caregivers received financial assistance from VAC (e.g., through VIP) and other sources, 8% received assistance with professional health care services (e.g., personal care) and 5% received support from family members.

Caregivers were also asked an open ended question regarding what additional services they would like to receive to assist them in providing care and/or support to the client. The findings indicated that:

- Approximately 37% of caregivers of community clients, 48% of caregivers of facility clients, and 63% of caregivers of supportive housing clients felt they did not require assistance, at least at the time of the study (some anticipated needing assistance in the future).
- Overall, 16% of caregivers indicated they would like assistance with transportation (e.g., access to transportation, assistance with gas and parking expenses) and 12% would like assistance with socialization (e.g., respite services). In addition, 10% of caregivers of community clients indicated they would like (more) assistance with housekeeping and similar supportive services inside the home (this was not as important for caregivers of either facility or supportive housing clients).

Caregivers were asked if they currently received financial assistance to help them care for the client. Overall, 27% of caregivers indicated that they received financial assistance. Caregivers of community clients were more likely to receive financial assistance than caregivers of either facility or supportive housing clients. Over 75% of caregivers of community and facility clients indicated VAC provided financial assistance. Caregivers of supportive housing clients tended not to receive financial assistance, but when they did, family members played an important role.<sup>63</sup> Caregivers who were not currently receiving financial assistance were asked if they would like to receive financial assistance to help them care for the client. Some 39% of caregivers of community clients, 64% of caregivers of facility clients and 50% of caregivers of supportive housing clients indicated that they did not require financial assistance, at least at this time. However, approximately 15% of caregivers of both community and supportive housing clients indicated that they would like financial assistance in general (only 6% of caregivers of facility clients indicated this). Financial assistance with socialization was important for 9% of caregivers of facility clients (but 3% and 6%, respectively, of caregivers of community and supportive housing clients). Financial assistance with transportation was important for 7% of caregivers of community clients, 9% of caregivers of facility clients and 6% of caregivers of supportive housing clients.<sup>64</sup>

Caregivers were asked how satisfied they were with the services and supports they received from VAC. Of the caregivers who answered this question, 70% indicated that they were very satisfied with the services and supports they received.<sup>65</sup>

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<sup>63</sup> The data from the supportive housing sample needs to be interpreted with caution, however, due to small numbers.

<sup>64</sup> The findings regarding assistance with socialization and transportation for the supportive housing sample need to be interpreted with caution due to small numbers.

<sup>65</sup> The findings should be interpreted with caution, however, as 27% of caregivers did not provide a response to this question, primarily because they felt that the client, rather than themselves, received the services and supports from VAC.

#### 4.2.13 Effects of Caregiving

Caregivers were asked to rate their health relative to people their own age. Overall, 80% of caregivers rated their health as good or better. Caregivers of community, facility and supportive housing clients rated their health similarly.

Caregivers were asked if they had changed their social or leisure activities and/or the amount of time they spent working because of caring for the client. The findings indicated that:

- Overall, 42% of caregivers had not changed their social or leisure activities because of providing care.
- Overall, 1% of caregivers indicated that they had *increased* their social or leisure activities, but 58% indicated that they had *decreased* their activities. Caregivers of community and facility clients were more likely to have decreased their social or leisure activities than caregivers of supportive housing clients.
- Of the caregivers who had reduced the amount of time they spent in social or leisure activities, 35% had reduced that time by more than 10.5 hours per week. Caregivers of community, facility and supportive housing clients were similar with respect to the changes they had made in their social or leisure activities.
- Approximately 67% of caregivers indicated they had not changed the amount of time they spent working and 33% decreased the amount of time they spent working in order to care for the client.
- Of the caregivers who had reduced the amount of time they spent working, 46% had reduced the amount of time by more than 10.5 hours per week. Approximately 66% of caregivers had made the change within the last five years.

The objective and subjective burden of providing care and/or support to clients was assessed using a modified version of the Montgomery Burden Scale. Caregivers of community clients experienced more objective burden than caregivers of either facility or supportive housing clients. Caregivers of community, facility and supportive housing clients did not differ with respect to subjective burden. Neither objective nor subjective burden increased as clients' care needs increased.

Caregivers were asked open ended questions about the benefits and disadvantages of providing care. As shown in Table 4-4, overall, approximately 73% of caregivers felt that caregiving provided them with an opportunity to show care and love to the client; another 12% received satisfaction from providing care. However, 44% of caregivers commented on the emotional aspects of caregiving (e.g., caregiving is emotionally draining) and 28% commented on the sense of commitment and responsibility (e.g., time constraints).

**Table 4-4: Benefits and Disadvantages of Providing Care (Study 2)**

		Community		Facility		Supportive Housing		Total	
		N	%	N	%	N	%	N	%
<b>Benefits of Caregiving<sup>66</sup></b>	Opportunity to Show Care and Love	130	70	134	72	35	88	299	73
	Satisfaction from Providing Care	25	14	16	9	7	18	48	12
	Caregiver Has Learned from Experience	9	5	30	16	3	8	42	10
	Client is Well Looked After	20	11	26	14	2	5	48	12
	Caregiver Has Peace of Mind	11	6	33	18	6	15	50	12
	Client is in Own Home	21	11	0	0	0	0	21	5
	Caregiver Doing “Duty”	28	15	5	3	7	18	40	10
	No Benefits	23	12	40	22	1	3	64	16
<b>Disadvantages of Caregiving</b>	No Disadvantages	75	41	21	11	20	50	116	28
	Coping with Client’s Condition	10	5	19	10	5	13	34	8
	Emotional Aspects	53	29	114	61	12	30	179	44
	Commitment and Responsibility	29	16	74	40	13	33	116	28
	Caregiver Feels Tied Down	56	30	33	18	4	10	93	23
	Employment Issues	9	5	11	6	2	5	22	5
	Distance Caregiver Lives from Client	2	1	18	10	1	3	21	5
	Caregiver’s Own Health	12	7	16	9	0	0	28	7

Caregivers were asked open ended questions regarding what suggestions they had for improving quality of life, both for the client and for themselves. The findings indicated that:

- Approximately 35% of caregivers did not provide any suggestions for improving the client’s quality of life, noting that the client’s needs were currently being met.
- Overall 21% of caregivers commented on the need to increase socialization opportunities.
- Approximately 10% of caregivers of both community and supportive housing clients commented on the need for more services in the home. Approximately 12% of caregivers of facility clients commented on the need for companionship (either from paid companions or volunteers), and another 12% commented on the need to address staffing issues (e.g., consistency in workers).
- Overall, 47% of caregivers did not have any suggestions for improving their own quality of life, implying that their needs were currently being met.
- However, 16% of caregivers of community clients, 15% of caregivers of facility clients and 8% of caregivers of supportive housing clients indicated that they would like some respite.
- Some 13% of caregivers of community clients and 7% of caregivers of facility clients indicated they would like more help in general, and 7% of caregivers of facility clients indicated they would like assistance with transportation.

<sup>66</sup> Caregivers could provide more than one response for both benefits and challenges. The percentages in the table are based on the total possible number of respondents (185 caregivers of community clients, 186 caregivers of facility clients, 40 caregivers of supportive housing clients, 411 caregivers in total.)

### 4.3 Costing

#### 4.3.1 Introduction

The findings in this section are based on data collected through the various diaries (see Table 2-1). As in Study 1, the diaries were kept by clients, informal caregivers and formal care providers for a two week period. As in the first study, the quality of the information provided in the diaries varied from very detailed and complete records to little information. Only “Good” and “Mediocre” diaries (see Section 3.5.1) were used in the analyses presented in the following sections. Further, as in the first study, the response rate for the diaries was lower than anticipated. Again, extreme outliers (those more than three standard deviations away from the average score) were excluded in an effort to obtain more representative data. For Study 2, a total of 53 outliers were excluded from the various cost estimates discussed in Sections 4.3.2 to 4.3.6. The data regarding each type of diary were based on the set of people who provided data for that particular diary (not including outliers) and costs were estimated based on group averages.

#### 4.3.2 Out-of-Pocket Expenses

Information on out-of-pocket expenses incurred by clients and/or their informal caregivers was obtained through the Diary of Care Related Expenditures. All of these diaries were considered “Good” or “Mediocre”.

Table 4-5 presents average costs for different types of expenditures for all clients for whom diary data regarding expenditures were available. The overall average expenditure for community clients for a two week period was \$207. The comparable figure for facility clients was \$552; this is primarily due to facility user fees.<sup>67</sup> The comparable figure for supportive housing clients was \$141. Overall, out-of-pocket expenditures were estimated to be \$5,372 per year for community clients, \$14,340 per year for facility clients, and \$3,654 per year for supportive housing clients.<sup>68</sup>

**Table 4-5: Average Cost For Out of Pocket Expenditures Incurred by All Clients and Informal Caregivers Over a Two Week Period**

Type of Expenditures	Community	Facility	Supportive Housing
Medical Supply/Equipment (e.g., medications; incontinence products)	\$ 24	\$ 2	\$ 15
Care Related Home & Personal Maintenance (e.g., paid housekeeping)	\$145	\$126	\$ 44
Medically Related Care Services (e.g., massage therapy)	\$ 7	\$ 1	\$ 3
Long Term Care Facility Co-payments	N/A	\$393	\$ 57
Other Services/Costs	\$ 31	\$ 29	\$ 21
<b>Average Total</b>	<b>\$207</b>	<b>\$552</b>	<b>\$141</b>

<sup>67</sup> At the time of the study, the facility co-pay for most clients was \$835 per month.

<sup>68</sup> The costs for supportive housing clients include costs for health and supportive care but do not include the rent paid. Some respondents recorded a rent factor, but it was not clear to what extent this included rent alone, or rent and a package of related services. Thus, this factor was not included in the cost calculations.

### 4.3.3 Costing of Time and Assistance Provided by Informal Caregivers

The Diary of Time and Assistance Provided by Informal Caregivers was used to examine how much time informal caregivers spent providing care and support to clients. Approximately 98% of these diaries were considered “Good” or “Mediocre”.

As in Study 1, two averages were calculated regarding the amount of time informal caregivers spent providing care and/or support to clients – the average amount of time spent for all clients (for whom diary data were available) and the average amount of time spent for those clients who received the service (for whom diary data were available). As shown in Table 4-6, the average amount of time provided by caregivers of community clients over a two week period for all clients, was 24 hours. The comparable figures for caregivers of facility and supportive housing clients were 17 and 13 hours, respectively. The majority of services provided by caregivers of community clients were for home and personal maintenance. For all clients, caregivers spent an average of 17 hours (71% of all hours) on these types of tasks. The majority of services provided by caregivers of facility clients were for psychosocial services. For all clients, caregivers spent an average of 13 hours (76% of all hours) on these activities. The majority of services provided by caregivers of supportive housing clients were also for home and personal maintenance. For all clients, caregivers spent an average of 7 hours (54% of all hours) on these activities.

**Table 4-6: Average Number of Hours Spent on Various Activities Over a Two Week Period by Informal Caregivers Due to the Client’s Condition**

Type of Activity	Community		Facility		Supportive Housing	
	All Clients <sup>69</sup>	Clients Who Received the Services	All Clients	Clients Who Received the Services	All Clients	Clients Who Received the Services
Professional Care Type (e.g., assisting with foot care)	1	4	0	2	0	3
Hands-on Supportive Care (e.g., bathing)	3	27	1	8	0	1
Home & Personal Maintenance (e.g., housekeeping)	17	19	3	5	7	9
Psychosocial (e.g., providing emotional support)	3	7	13	13	6	8
Other	0	5	0	3	0	0
<b>Total</b>	<b>24</b>	<b>N/A</b>	<b>17</b>	<b>N/A</b>	<b>13</b>	<b>N/A</b>

As in Study 1, informal caregiver time was costed using both minimum wage and replacement wage. A minimum wage of \$8.00 per hour was used. For replacement wage, a value of \$60.00 per hour was used for professional services and a value of \$27.00 per hour was used for all other services. When caregiver time was valued at minimum wage, the contributions of informal caregivers ranged from \$2,430 to \$16,231 per year for community clients, \$905 to

<sup>69</sup> The term “All Clients” refers to all clients for whom diary data were available, not all clients in the study.

\$4,905 per year for facility clients and \$1,970 to \$4,238 per year for supportive housing clients. When caregiver time was valued at replacement wage, the contributions of informal caregivers ranged from \$8,218 to \$56,988 per year for community clients, \$3,054 to \$16,556 per year for facility clients, and \$6,647 to \$14,519 per year for supportive housing clients.

#### 4.3.4 Costing of Paid Care Funded by Government

The Diary of Time and Assistance Provided by Formal Care Providers was used to estimate costs to government for paid care services provided to community and supportive housing clients. Approximately 94% of these diaries were considered “Good” or “Mediocre”.

Table 4-7 provides rates by type of worker (based on rates paid by VAC), the average hours provided for a two week period based on all clients, and the percentage of hours provided by each type of worker. The average amount of time provided by paid care workers to community clients was 8 hours for a two week period. The comparable figure for supportive housing clients was 6 hours for a two week period. For community clients, Care Aides/Care Workers provided 10% of these hours and Homemaker/Home maintenance staff provided 75% of these hours. The comparable figures for supportive housing clients were 22% and 55%, respectively. Overall, costs to government were estimated to be \$7,028 per year for community clients and \$5,860 per year for supportive housing clients. As in Study 1, the full cost to VAC of a contract bed was used as a cost estimate for facility clients. For Study 2, a standard rate of \$80,143 per year was used for all facility clients.<sup>70</sup>

**Table 4-7: Rates and Average Hours for Paid Care Providers of Community and Supportive Housing Clients Over a Two Week Period**

Provider	Rate Per Hour	Community		Supportive Housing	
		Average Hours for All Clients <sup>71</sup>	% of Hours Provided by Worker	Average Hours for All Clients	% of Hours Provided by Worker
Physician	\$150.00	0.2	2	0.2	3
Registered Nurse	\$66.50	0.1	1	0.0	0
Licensed/Registered Practical Nurse	\$34.80	0.0	0	0.0	0
General Nurse	\$37.20	0.0	0	0.2	3
Physiotherapist	\$44.60	0.1	1	0.2	3
Occupational Therapist	\$37.60	0.0	0	0.0	0
Other Medical Professional	\$100.00	0.2	2	0.2	3
Care Aide/Care Worker	\$27.00	0.8	10	1.3	22
Homemaker/Home Maintenance	\$27.00	6.2	75	3.3	55
Complementary Health Care Provider	\$100.00	0.0	0	0.1	2
Other Providers	\$30.00	0.7	8	0.8	13
<b>Total</b>		<b>8</b>	<b>100</b>	<b>6</b>	<b>100</b>

<sup>70</sup> The annual figure for facility clients was based on an estimated average of the rates negotiated by VAC and the facilities in this study. The negotiated rate is not based on any specific breakdown, but is intended to cover all aspects of care (including registered and non-registered staff time, activation, food, etc.). Separate analyses, based on facility budget/expenditure data, indicated that the average facility rate (total dollars divided by total beds) was very similar to the VAC rate for the facilities in this study.

<sup>71</sup> The term “All Clients” refers to all clients for whom diary data were available, not all clients in the study.

#### 4.3.5 Costs to VAC

As noted previously, VAC makes a wide range of payments through 15 POCs (see Appendix D). In order to develop as complete costing estimates as possible, home care equivalent costs and other health related costs were estimated based on costing data provided by VAC for these 15 POCs.

#### 4.3.6 Comparative Cost Analysis in Terms of Cost to Government and Societal Costs for Community, Facility and Supportive Housing Clients

Table 4-8 shows comparative costs for community, facility and supportive housing clients based on care levels created from total SMAF scores. The table indicates that caring for both community and supportive housing clients costs less per year than caring for facility clients. While caring for supportive housing clients costs less than caring for community clients, the costs were generally higher if the rent factor was included for supportive housing.

**Table 4-8: Costs to Government, Clients and/or Caregivers, and Total Societal Costs, for Community, Facility and Supportive Housing Clients<sup>72</sup>**

	Care Levels (based on SMAF scores)	Costs to Government <sup>73</sup>	Other Health Related Costs <sup>74</sup>	Total Costs to Government <sup>75</sup>	Out of Pocket Expenses for Clients and/or Caregivers	Imputed Caregiver Costs		Total Costs to Clients and/or Caregivers <sup>76</sup>	Total Societal Costs <sup>77</sup>
						Caregiver Time at Minimum Wage	Caregiver Time at Replacement Wage		
Community	Level 1	5,926	1,164	7,090	3,376	2,379	8,218	11,594	18,684
	Level 2	5,982	1,051	7,033	4,377	2,790	9,798	14,175	21,208
	Level 3	6,458	671	7,129	5,678	3,580	12,457	18,135	25,264
	Level 4	8,089	3,325	11,414	3,501	5,099	18,610	22,111	33,525
	Level 5	15,723	1,036	16,759	17,151	15,348	56,988	74,139	90,898
	Level 6 & Higher	12,379	525	12,904	8,574	15,886	56,986	65,560	78,464
	Overall Average	7,028	1,202	8,230	5,372	4,873	17,381	22,753	30,983
Facility	Level 3	80,143	3,005	83,148	11,192	886	3,054	14,246	97,394
	Level 4	80,143	7,435	87,578	12,126	1,704	6,162	18,288	105,866
	Level 5	80,143	5,412	85,555	12,869	1,861	6,463	19,332	104,887
	Level 6	80,143	2,430	82,573	12,405	2,963	10,374	22,779	105,352
	Level 7	80,143	3,611	83,754	16,289	4,220	14,664	30,953	114,707
	Level 8	80,143	3,228	83,371	16,928	4,493	15,902	32,830	116,201
	Level 9	80,143	3,267	83,410	13,846	4,800	16,556	30,402	113,812
	Overall Average	80,143	4,025	84,168	14,340	3,531	12,342	26,682	110,850
Supportive Housing	Level 1	4,108	845	4,953	2,189	2,314	8,103	10,292	15,245
	Level 2	4,441 <sup>78</sup>	3,369	7,810	2,229	2,105	7,394	9,623	17,433
	Level 3	6,878	1,164	8,042	4,071	4,148	14,519	18,590	26,632
	Level 4	10,442	350	10,792	10,214	1,928	6,647	16,861	27,653
	Level 5 or Higher	8,295	2,018	10,313	4,046	3,408	12,244	16,290	26,603
	Overall Average	5,860	1,703	7,563	3,654	2,647	9,281	12,935	20,498

<sup>72</sup> The study was conducted between July 2006 and June 2007. Thus, the costs reflect both 2006 and 2007 costs.

<sup>73</sup> For community and supportive housing clients, Costs to Government are for paid care based on diary data. For facility clients, Costs to Government are a standard rate based on an estimated average for the facilities in this study.

<sup>74</sup> Other Health Related Costs for community, facility and supportive housing clients were estimated based on costing data provided by VAC. For facility clients, costs for all health services were included in this category.

<sup>75</sup> Sum of Costs to Government and Other Health Related Costs.

<sup>76</sup> Sum of Out-of-Pocket Expenses and Caregiver Time at Replacement Wage.

<sup>77</sup> Sum of Total Costs to Government and Total Costs to Clients and/or Caregivers.

<sup>78</sup> Estimates for costs to VAC were higher than estimates based on diaries; thus the cost for VAC was used for this group.

## **5. THE RESEARCH QUESTIONS REVISITED**

### **5.1 Introduction**

This chapter relooks at the various research questions and discusses the findings presented in Chapters 3 and 4 with respect to these questions. As noted in Section 1.3, many of the research questions related to both studies, although a few related to only one or the other.

### **5.2 How do VAC staff and managers see the OSV/VIP Program?**

This question only applied to Study 1. All of the VAC personnel interviewed as part of this component of the Continuing Care Research Project indicated that they were either very or somewhat satisfied with the OSV/VIP Program. In addition, 93% of the respondents felt that the program had been very or somewhat successful.

Respondents noted the following benefits of the program:

- Waitlists for facility placement do not seem to be as long as they were prior to the introduction of the OSV/VIP Program.
- The OSV/VIP Program has enabled unmet health needs to be addressed, particularly for veterans who may require assistance or supervision, but not 24 hour nursing care.
- The program enables OSVs to remain at home as long as possible, by providing them with preventive home care.
- The program may also reduce stress on veterans and their informal caregivers, provide them with a better quality of life, delay facility placement, and increase life expectancy.

Respondents noted the following weaknesses of the program:

- The OSV/VIP Program may result in some people remaining at home when they should really be placed in a long term care facility.
- Frailer veterans are being placed in long term care facilities; this may be difficult for both staff and families to cope with.
- Eligibility for the OSV/VIP Program is based on a gateway model (i.e., clients must be assessed as requiring federal Level 2 care), rather than on a needs based model.
- Differences between provincial systems and VAC may result in some eligible veterans “falling through the cracks.”

In summary, respondents noted that the focus of the OSV/VIP Program had changed from how to ease facility waitlists to how to keep a person at home longer and ease the burden of care. They also noted that while the program has generally been successful for those who have been helped, there are other veterans who could potentially benefit from the program.

### **5.3 To what extent have people embraced the OSV/VIP Program?**

In order to answer this question (which only applied to Study 1), an analytical database was created using historical utilization data. The findings indicated that the number of community claimants in the pilot study sites increased by 659% during the period of interest. The comparable percentage increase in the non-pilot sites was 604%, most of which occurred during the national pilot phase. While the increases were similar for community claimants in the pilot and non-pilot sites, the relative proportion of community to facility clients was higher in the pilot sites compared to the non-pilot sites. In parallel to the OSV/VIP initiative, there was a substantial increase in bed supply. This increase was the result of a policy introduced in 2000 which resulted in 2,600 new contract beds. The number of facility beds utilized increased, primarily during the national pilot phase, by 147% in both the pilot and non-pilot sites. Taken together, the findings indicated that as the OSV/VIP Program became available, people who had been ineligible for services and benefits or who had not sought benefits and services, were able to take advantage of the new program.

### **5.4 What are the comparative costs for OSV clients before and after the introduction of the OSV/VIP Program?**

In order to answer this question (which only applied to Study 1), historical expenditure data were obtained. However, unresolvable anomalies and incomplete data limited the reliability of the data. Thus, a decision was made not to use the existing expenditure data, but to estimate costs based on utilization rates. It was calculated that, based on facility rates, the number of community clients would have been expected to increase by 202 individuals between January 1999 and December 2005. However, the introduction of the OSV/VIP Program resulted in added costs for 716 claimants. It was estimated that, at the maximum allowable amount of \$8,000 per year for VIP services, the cost for these 716 individuals was equivalent to 92 new facility beds. If the annual costs for VIP services were lower, the cost of community care would be lower and equivalent to fewer beds, but overall, providing care in the community would still be less expensive than providing care in a long term care facility.

### **5.5 How satisfied are comparable clients in different care settings and how do they rate their quality of life?**

These questions applied only to cognitively capable clients in both Studies 1 and 2. The SMAF was used in this study to identify clients at comparable care levels.

With respect to satisfaction, the findings indicated that for cognitively capable clients in all three care settings (i.e., community, facility and supportive housing) satisfaction with paid services was quite high. When all cognitively capable clients were compared, community clients perceived that their satisfaction was better than facility clients; supportive housing fell between the other two groups (that is, they were not as satisfied as community clients, but were more satisfied than facility clients). When clients at similar care levels were compared, community clients perceived that their satisfaction was the same or better than facility clients. In Study 2, supportive housing clients fell between the other two groups. There were no differences among clients at different care levels in either study. When asked to indicate how satisfied or dissatisfied

they were overall with the services they received, 78% of cognitively capable clients in both studies indicated they were very satisfied.

With respect to health-related quality of life, the findings from all cognitively capable clients in both studies indicated that facility clients perceived their physical health-related quality of life to be the same or better than community clients. Community, facility and supportive housing clients perceived their mental health-related quality of life similarly. When clients at comparable care levels were compared: perceptions of physical health-related quality of life decreased as clients' care needs increased; perceptions of mental health-related quality of life remained the same, regardless of an individual's care needs; and facility clients felt that both their physical and mental health-related quality of life was better than community clients. This latter finding may, at least in part, be attributable to the additional services VAC funds for veterans in long term care facilities.

## **5.6 What proportion of home care services are provided by home support services?**

In both Studies 1 and 2, the services used most frequently by community clients were housekeeping, home adaptations and ground maintenance. These were also the services used most frequently by supportive housing clients in Study 2. In Study 1, 87% of community clients used housekeeping services. By comparison, 61% of clients used home adaptations, and 53% used grounds maintenance. In Study 2, 98% of community clients and 90% of supportive housing clients used home support services. By comparison, 63% of community clients and 84% of supportive housing clients used home adaptations, and 69% of community clients and 100% of supportive housing clients used grounds maintenance. For supportive housing clients, home support, home adaptations and grounds maintenance may all have been provided by the supportive housing building. In both Studies 1 and 2, home support services (i.e., housekeeping services) accounted for 25% of the services used by community clients. By comparison, home adaptations and grounds maintenance both accounted for about 17%. For supportive housing clients, home support services accounted for 16%, home adaptations for 15% and grounds keeping for 18%.<sup>79</sup> Taken together, the findings indicate that home support services play an important role in keeping individuals in the community and that a combination of services are important for individuals living in supportive housing.

## **5.7 Which home care and home support services are the most instrumental in keeping people out of facility care?**

In both Studies 1 and 2, clients and proxies were asked what factors were enabling community clients to remain at home. Clients were able to remain at home because: they received assistance and support from informal caregivers; their health was good; and they were able to care for themselves (perhaps with some assistance from others for housekeeping, home adaptations and grounds maintenance). In Study 2, clients also noted that they were able to stay

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<sup>79</sup> Data from the Diary of Time and Assistance Provided by Formal Caregivers indicated that, in Study 1, approximately 33% of the paid care hours provided to community clients were provided by homemakers/home maintenance staff. In Study 2, 75% of the paid care hours provided to community clients and 55% of the paid hours provided to supportive housing clients were provided by homemakers/home maintenance staff. These figures combine services provided by home support workers, grounds keepers, and others.

at home because they were financially independent (e.g., their house was paid for) and/or they chose to do so. Over 70% of caregivers of clients in both studies indicated that they assisted clients with preparing meals and shopping for food and household items; over 70% of caregivers in Study 1 also indicated that they assisted with laundry, housework and managing finances. Thus, while the findings do not clearly identify specific home care services that are instrumental in keeping people out of facility care, they do identify the important role that informal caregivers play, and highlight the household maintenance functions that the informal caregivers provide.

### **5.8 Which factors contributed to clients entering a long term care facility?**

In both Studies 1 and 2, respondents were asked what factors affected the client's decision to move into a long term care facility. Clients went into facilities primarily because their health needs increased and/or because their informal caregivers were unable to provide the necessary care and/or support. Across the two studies, approximately 31% of respondents indicated that no additional resources would have enabled the client to remain at home, and approximately 46% indicated that the client required 24 hour care. In addition, in Study 2, 13% of respondents indicated that the informal caregiver was unable to provide appropriate care and support. Taken together, the findings indicate that a substantial proportion of clients were placed in long term care facilities because it was no longer feasible to try to care for them at home.

### **5.9 What have been the positive and negative impacts on family caregivers?**

Caregivers in both Studies 1 and 2 were asked a number of questions regarding the impacts care provision had had on them. Some 80% of caregivers rated their health as good or better. While approximately 39% of caregivers across the two studies indicated that they had not changed their social or leisure activities because of providing care, another 58% indicated that they had decreased the amount of time they spent on these activities. Of these, approximately 37% had reduced the time by more than 10.5 hours a week. Approximately 66% of caregivers across the two studies indicated that they had not changed the amount of time they spent working, but another 34% indicated that they had decreased the amount of time they spent working. Of these latter individuals, 45% had reduced the amount of time they spent working by more than 10.5 hours per week, and 70% had made the change within the last five years.

Caregivers were also asked about the objective and subjective burden of providing care. In both studies, caregivers of community clients experienced more objective burden than caregivers of facility clients. In Study 2, caregivers of community clients also experienced more objective burden than caregivers of supportive housing clients. In Study 1, caregivers of community clients experienced more subjective burden than caregivers of facility clients. However, in Study 2, caregivers of community, facility and supportive housing clients did not differ with respect to their perceptions of subjective burden.

Finally, caregivers were asked about the benefits and disadvantages of providing care. Across both studies, approximately 64% of caregivers indicated that caregiving provided them with an opportunity to show care and love to the client. In Study 1, caregivers also noted that caregiving enabled them to make sure the client was well looked after and in Study 2, caregivers also noted that they received satisfaction from providing care. In both studies, approximately

46% of caregivers commented on the negative emotional aspects of caregiving and a further 27% commented on the sense of commitment and responsibility.

Taken together, the findings indicate that the majority of caregivers felt they were reasonably healthy. Over half of the caregivers had reduced the amount of time they spent on social and leisure activities and approximately one-third had reduced the amount of time they spent working. Caregivers of community clients experienced more objective burden than caregivers of either facility or supportive housing clients. Caregivers of clients in all three types of care settings did not differ with respect to perceptions of subjective burden. Caregiving also provides both benefits and challenges. On the one hand, it provides caregivers with the opportunity to show care and love to the client, to ensure the client's needs are being met, and so on. On the other hand, it is emotionally draining and restricts the caregiver's activities.

### **5.10 What is the cost-effectiveness of home care compared to long term facility care?**

There are several ways this question can be addressed. For example, one can consider only formal care costs (i.e., costs to government, where caregiver time is valued at zero). Or, one can consider societal costs, and take into account both costs to government and costs to clients and families. Within this latter perspective, caregiver time can be valued at minimum wage or replacement wage. In both Studies 1 and 2, regardless of how caregiver time was valued, home care was substantially less costly than long term facility care.

In Study 1, for clients at similar care levels, when only formal care costs were considered, facility costs were approximately four to five times the cost of community care. When societal costs with caregiver time valued at minimum wage and out-of-pocket expenses were considered, facility costs were about two to three times the cost of community care. When societal costs with caregiver time valued at replacement wages and out-of-pocket expenses were considered, facility costs were approximately one and one-half times the cost of community care. In Study 2, the costs to government were lower for supportive housing clients than for community clients. In addition, the cost to government for facility care was higher in Study 2 than in Study 1. Considering costs to government, out-of-pocket expenses and caregiver time costed at replacement wages, for clients at similar care levels, overall costs for facility clients were about twice as much as for community clients.

### **5.11 To what extent is supportive housing an appropriate alternative to home care and long term facility care?**

In Study 2 (but not Study 1), respondents were asked what factors affected the client's decision to move into supportive housing. Respondents indicated that the clients were living in a supportive housing setting because they preferred it, felt they were better off financially, their health care needs had increased and/or they did not have support from an informal caregiver. Respondents also indicated that, in many cases, clients did not require additional resources (except perhaps financial assistance) to keep them at home.<sup>80</sup>

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<sup>80</sup> It is noted that over half of the supportive housing sample were female.

Clients and caregivers were also asked what kind of housing situation they would prefer for the client, if they had complete choice of the client's living situation. Some 81% of supportive housing clients and 77% of caregivers of supportive housing clients indicated that they would prefer that the client was living in a supportive housing setting. By comparison, 2% of community clients and 3% of facility clients indicated that they would prefer to be in a supportive housing setting. Some 4% of caregivers of community clients and 2% of caregivers of facility clients indicated that they would prefer that the client was in a supportive housing setting.

Caregivers in Study 2 were also asked if they thought assisted living/supportive housing was an appropriate alternative to home care and/or facility care both in general, and for their client. While 78% of all caregivers felt supportive housing was an appropriate alternative in general, 40% of caregivers of community clients, 13% of caregivers of facility clients and 97% of caregivers of supportive housing clients felt it was an appropriate alternative for their client.

Taken together, the findings indicate that supportive housing may be an appropriate alternative to home care and facility care, at least for some clients. They also indicate that, at least for the majority of supportive housing clients in this study, it may be the most appropriate housing/care setting. While some clients indicated that they went into supportive housing because their care needs increased, many went into it because that is where they wanted to be.

#### **5.12 To what extent would adding supportive housing contribute to an enhanced, and cost-effective continuum of care for VAC clients?**

This question only applied to Study 2. There were relatively few supportive housing clients in this study. This may be due, at least in part, to the VIP Program which provides a range of home care and home support services, and is designed to keep people living in their homes for as long as it is both feasible and reasonable to do so. Nevertheless, it appears that supportive housing could contribute to a more fully developed, and cost-effective continuum of care. Supportive housing fills a potential need for single individuals, is a desirable option for low income families, enables a spouse to remain in familiar and supportive surroundings when a veteran dies, and provides a lower cost alternative to facility care.

## **6. IMPLICATIONS OF KEY FINDINGS FROM THE CONTINUING CARE RESEARCH PROJECT**

### **6.1 Introduction**

While both Studies 1 and 2 involved a comparison of costs and outcomes of clients living in different care settings, the policy and program implications of the research process, and the findings, go beyond a simple comparison of costs and outcomes. The findings from the Continuing Care Research Project have a wide range of implications for national policy, VAC policy and practice, and the provision of VAC services to veterans.

### **6.2 Comparative Costs and Outcomes of Care**

The Continuing Care Research Project found that community clients have greater or equal satisfaction with care compared to facility clients.<sup>81</sup> In both Studies 1 and 2, there was also a considerable cost difference, for people at the same level of care need, between care provided in facilities and care provided in the community or in supportive housing. In fact, the differences in costs were greater in this project than in other studies.<sup>82</sup> This difference points out that there is a considerable potential for overall systems efficiencies by providing care in the community, at lower cost, and limiting as appropriate, future bed growth. Over time, such adjustments will not only allow more veterans to be cared for at home for longer periods of time, but will also increase overall systems efficiencies as more people will be able to be cared for at the same, or lower cost. It is also noted that, in other similar studies, a substantial proportion of community clients were at higher levels of care need than the people in this study.<sup>83</sup> This again reinforces the argument that, with the right supports, more veterans with higher level care needs could be looked after in the community. Thus,

- Given the evidence on the comparative costs and outcomes of care in this study, VAC may wish to consider enhancing its home care program so home/community based clients at medium and high levels of care need can continue to be cared for in their homes. VAC may also wish to consider potential efficiencies which could be obtained through supportive housing.
- In order to take advantage of potential efficiencies, VAC may wish to consider eliminating current dollar based ceilings for community clients to ensure that adequate services can be provided in the community, based on client need.

The findings from the Continuing Care Research Project indicate that there continues to be a potential for obtaining systems level efficiencies by, where it is feasible, substituting lower cost home care or supportive housing services for long term care facility services. The extent to which such possible substitutions can also be made in other jurisdictions will vary in accordance

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<sup>81</sup> Facility clients reported somewhat better quality of life than community clients which was a surprising finding. This may be attributable to the additional services funded by VAC for facility clients which are generally not available to non-VAC clients. It may also be due to stresses in the community related to current funding limitations for VIP services.

<sup>82</sup> See for example, Chappell, Havens, Hollander, Miller, & McWilliam (2004).

<sup>83</sup> Chappell et al. (2004).

with the policies and practices in these other jurisdictions. However, in order to analyze the existing potential for cost-effective substitutions, a classification system which is the same, irrespective of the site of care, is required.

### **6.3 Supportive Housing**

Doing research on supportive housing is complex, and this was certainly the case in this study. Conceptually, it is not clear if the rental portion of supportive housing costs should be considered a health related cost, as is the case with the residential portion of facility care, or whether it should be treated like rent or a mortgage paid for community clients (although even in facilities, co-payments are sometimes seen to be room and board related costs). This matter was further exacerbated because of the wide range of options regarding what services may, or may not, be bundled with rent to constitute the supportive housing monthly allocation paid by clients. Another factor that complicated matters was that there were different bundles of services among the supportive housing buildings included in this study. Thus, unlike facility care where most clients in the study were in one location, and where one could look at facility budgets and care time by staff in a fairly consistent manner, this was not possible for the supportive housing providers. A further layer of complexity was introduced into this study due to the requirement that 40% of the units in the supportive housing buildings funded by the Community Services Program of the Ontario Ministry of Health and Long Term Care must be for low income individuals. A substantial proportion of the supportive housing clients in this study appeared to be in supportive housing for financial reasons and had relatively modest care needs. This is reasonable given the nature of the supportive housing options funded by the Ontario Ministry of Health and Long Term Care.

Despite these constraints, and given that the study involved a relatively modest number of veterans in supportive housing, there were still several findings of relevance for the Continuing Care Research Project. Clearly, supportive housing can fill a need for veterans who may be living on their own and who need a more structured environment. Supportive housing is also an option for low or medium income veterans who are married as the supportive nature of this environment can assist both the veteran and his/her spouse. Furthermore, if the veteran dies, widows are able to remain in a familiar and supportive setting as they age, one that can assist them with their potentially increasing health care needs over time.

More broadly, supportive housing is one of several options, including assisted living, which combine both a residential and a care component. It is certainly worthy of further policy consideration by VAC, particularly as this is an increasing area of interest and activity in many jurisdictions in Canada. Thus:

- VAC may wish to further explore whether or not supportive housing and/or assisted living options would provide an appropriate additional component of the care continuum for veterans.
- VAC may wish to conduct additional research into a range of supportive housing/assisted living options.

While supportive housing is generally less costly than long term facility care, it is intended to provide a different type of care, and thus, should not be seen as a direct alternative to facility care.

#### **6.4 The Contribution of Spouses and Family Members**

The Continuing Care Research Project has documented the substantial role played by spouses, family members and other informal caregivers in enabling veterans to be cared for in their homes. It is noted, however, that many of the spouses were also elderly and may have had health problems or functional limitations of their own. Even children could have been elderly (e.g., a 75 year old daughter assisting a 95 year old veteran). Given the limitations on financial support for community clients in current VAC policy, caring for veterans living at home can be quite demanding. This may be particularly true for spouses.

There are other issues related to spouses. The complex web of eligibility required means that some widows receive ongoing benefits while others do not. Furthermore, spouses face particularly difficult conditions once a veteran is placed in a facility. Many have been married for over 50 years. In addition to the emotional strain of living alone after 50 or more years of living with one's marriage partner, there are difficulties coping with all of the day to day issues which would arise for an elderly person, often in diminished health, living alone. There are also financial considerations related to travel costs for visiting one's spouse in a facility and, in some cases, the financial burden of maintaining a household plus paying the facility user fee, facility charges for some services, and the costs of incidentals. Thus, it is suggested that VAC consider what additional services and benefits could be provided to spouses and widows as follows:

- Consider providing additional services to support spouses and other family caregivers through respite care and by providing fully adequate resources to support not only the veteran but the family unit, to allow the veteran to remain at home with appropriate supports for as long as it is feasible and/or desirable to do so.
- Consider providing continuing benefits for widows in recognition of their contribution to the veteran, and to the reduced costs to VAC which come from the contribution of family caregivers.
- Explore possible funding to build new types of care facilities which would allow veterans and spouses to live together in a long term care setting, or, for people with somewhat lower care needs, in assisted living/supportive housing arrangements.

Given what is currently known about services to spouses in other jurisdictions and the call for more support for informal caregivers,<sup>84</sup> it is quite likely that this may also be a topic of interest for other jurisdictions.

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<sup>84</sup> See Hollander, Chappell, Prince, & Shapiro, 2007.

## **6.5 Moving to a Health Services Delivery Model**

### **6.5.1 A Comprehensive Health Services Delivery Model**

VAC is moving towards a needs-based health care system. This change is strongly supported based on the empirical evidence in this, and similar, studies. Research has indicated that integrated systems of care delivery where services are provided in response to care needs, provide better care and are less costly.<sup>85</sup> In an entitlement model, people have rights to certain benefits and may choose to exercise such rights even if the benefits may not be fully required. Furthermore, entitlement approaches set up stovepipes with different eligibility requirements, co-payments and so on. This results in administrative inefficiencies as each stovepipe needs a separate administrative component, and clinical inefficiencies may arise because people may not receive the full range of needed services due to eligibility restrictions for some services. Thus, given the current configuration of VAC health services:

- VAC is strongly encouraged to restructure its services from an eligibility model, to a health services model, as outlined in the report entitled “Keeping the Promise: The Future of Health Benefits for Canada’s War Veterans” which was prepared by VAC’s Gerontological Advisory Council.

### **6.5.2 Continuing Care Services and Non-Insured Benefits**

At present, VAC has two main health services, the Health Benefits Program and the Veterans Independence Program (see Appendix D). While the Veterans Independence Program is clearly a health services program, the Health Benefits Program has a mixture of health services (such as nursing), and what in most other jurisdictions would be considered non-insured, or extended, health benefits. Thus, VAC is currently providing “non-insured” health benefits, while in many other jurisdictions, non-insured health services are often provided through insurance companies. Thus:

- Given that VAC is moving towards a new health services delivery model, it may wish to rationalize its existing health services into a health services module and a non-insured or extended health care module, in order to be more congruent with arrangements made in other jurisdictions. It may also wish to consider whether it should continue to provide non-insured type benefits or subsidize insurance costs for veterans to obtain such services directly from currently existing providers.

### **6.5.3 Case-Mix Funding for Facility Clients**

It is believed that there is variability in the amount of care provided to people in long term care facilities. However, in general, VAC sets a single rate that it will pay for a contract bed in a given facility. While most clients are at federal care levels 2 or 3,<sup>86</sup> there can still be a considerable range of care needs across facility clients.

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<sup>85</sup> See Hollander & Chappell, (2002).

<sup>86</sup> Federal Level 3 care is chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care.

It may be desirable for VAC to move to a more comprehensive case-mix classification system, based on a wider range of categories than is currently used. There may be some merit in exploring case-mix funding options with facilities to see if such an approach would be feasible and acceptable. In general terms, lack of a case-mix funding system means that the funder may be paying too much for a low care needs client and not enough for a high care needs client. At the clinical level, it may mean that lower care needs clients receive more services than they need and higher care needs clients may not receive all of the services they need. Most jurisdictions in Canada now use some form of case-mix funding to pay for facility services.

- VAC may wish to consider the need for, and feasibility of, adopting a more sophisticated classification system for its long term care facility clients. They may also wish to consider whether case-mix funding would be a desirable approach to funding long term care facilities.

## **6.6 Broader Issues Regarding the Nature of VAC Health Services**

### **6.6.1 Data for Policy, Planning and Resource Allocation Purposes**

VAC basically provides a “top up” health care system (except for needed treatment and care provided through VAC in relation to a health condition recognized through a VAC disability pension or disability award). As a result, VAC only has partial data on the health and supportive services used by veterans. It is not currently possible to plan health care services for veterans on a system wide basis. It is also not possible to conduct longitudinal studies on the cost-effectiveness of VAC services with respect to the overall health care system. Further, it is not easy to document the possible cost savings to provincial health care systems from the VAC health system, particularly VIP and its focus on a maintenance and preventive function of home care. Thus, it may be useful for VAC to set up data sharing agreements with the provinces and territories to obtain data on health care utilization by veterans, subject to obtaining informed consent for data linkages from the veterans themselves. Such arrangements could provide a better picture of the overall impact on veterans of VAC health services nationally, and the contribution made by VAC to provincial and territorial health care systems. If there is an interest in this type of initiative, VAC may wish to conduct an initial pilot with a province which has well documented, and accessible, databases such as British Columbia or Saskatchewan. Thus:

- It is suggested that VAC may wish to consider the feasibility of obtaining administrative health data from provincial and territorial governments, to add to its own administrative data, in order to develop new, and more comprehensive information about health services for veterans, and how such services could be improved, *and* to better document the contribution of VAC health services nationally and VAC’s contribution in regard to provincial and territorial health care systems.

### **6.6.2 The Maintenance and Preventive Function of Home Care**

The Veterans Independence Program is making an important, and increasingly unique, contribution at several levels. It allows veterans to remain at home and maintain their independence for as long as it is possible and feasible to do so. VIP is also increasingly important at the national level. There has, over the past 10 to 15 years, been a move across provincial

health systems to cut lower care needs individuals from service. This has effectively raised the “need” bar for people to be eligible for home care services nationally. While some services are still provided for low level care needs clients, this is less and less the case. The VIP Program appears to be the only major program that still provides maintenance and preventive care for its clients. As such, it represents a key opportunity for research to inform policy at the national level. This is important as the policy pendulum may be swinging back to an emphasis on long term home care and home support as evidenced by recent, major initiatives in British Columbia and Ontario that focus on these topics. Thus:

- In recognition of the unique and important aspects of the VIP Program, and the revived recognition of the importance of long term home care and home support, VAC may wish to place a priority on conducting further research on the maintenance and preventive function of home care.

Given the move away from active support for the maintenance and preventive model of home care in most jurisdictions, VAC has a unique opportunity to contribute to the national policy agenda by conducting longitudinal studies in collaboration with one or more provinces on this topic, particularly because of the potential increases in efficiencies to the overall health care system from preventive home care.

## **6.7 Data Integrity and Knowledge as a Key Corporate Resource**

### **6.7.1 The Integrity of Clinical Data: The Tension Between Policy and Practice**

New knowledge is a key corporate resource. One cannot engage in evidence based decision-making if the evidence is not readily available, accurate, and/or collected in a consistent manner. VAC is aware of this as evidenced by its desire to develop new knowledge through projects such as the Continuing Care Research Project, by expanding its research capacity, and by having a very high level Gerontological Advisory Council to ensure a regular stream of information about new findings, and ready access to expert advice on complex issues.

The tension between policy and practice has meant that the data that are collected on a regular basis are not always as robust as they could be. Furthermore, information is primarily collected for operational purposes, or at least more so than for analytical purposes. For example, a review of some of VAC’s assessment data indicated that assessments were not collected consistently. In some cases, data were recorded for client need. In other cases, the data were adjusted to reflect residual need after the contribution of other resources, such as family members, were considered; this “net” need underestimates actual need. It is important to collect data currently, and in the future, which assesses the direct needs of the client as well as the “net” needs of the client (i.e., the level of need discounted for services which can be provided by others). Actual client need data is required for research, planning and program development purposes when one wants to compare the resources used across different sites of care in the care continuum (e.g., community care and facility care) on a standardized basis of actual client need. The “net” need is important for operational client care purposes as it is the “net” need which would be used to determine the extent of services which VAC should provide, after discounting the care which can be provided by others. Thus:

- It is suggested that VAC consider adjusting its assessment processes so that it has accurate data on client needs *per se*, and on the “net” need after other resources have been considered. This determination should be made using an assessment tool that has an embedded client classification system which applies across all sites of care. Actual need and “net” need should also be collected in any future assessment tools which are adopted. Actual need data will be critical for planning, program development, and research and evaluation purposes, while “net” need will be important for determining the resources provided to clients. “Net” need will also be critical in projections of future resource needs, as such projections should focus on future resource requirements for VAC, recognizing that some services will be provided by others.

Another example of the tension between policy and practice focuses on the OSV/VIP Program. In the OSV/VIP Program, veterans should only be provided with community services if they are at a level of care need that is equivalent to the care needs of veterans who are admitted to facilities. Thus, the official policy is that veterans need to be at federal Level 2 to qualify for home and community based services under the OSV/VIP Program. The reality at the front lines has been that there are OSVs who come to the attention of VAC who need care but may be borderline Level 2. Front line staff are committed to doing their best for veterans and would typically authorize services for such clients. The result of the tension between official policy and responding to the care needs of veterans has resulted in a considerable proportion of OSV/VIP community clients having lower care needs, as measured by the SMAF, than facility clients, even though both are deemed to be Level 2 clients. Again, it is very important to collect data that are accurate and not put front line staff into a position where they have to navigate between the potentially competing priorities of collecting accurate data, conforming to policy, and doing what is best for the veteran. Thus:

- It is suggested that VAC review its internal policies and make appropriate adjustments to ensure that there is a congruence between the data to be collected, existing policies, and the needs of the veterans. It is believed that a shift from the current system of care entitlements to a new health care delivery approach, which links the services provided by VAC to the needs of clients, has the potential to go a long way in promoting congruence between data collection, policy and client needs.

#### 6.7.2 Existing Administrative Data and Knowledge as a Key Corporate Resource

In the Continuing Care Research Project, it was difficult to extract accurate, longitudinal data which cut across several generations of information systems from the VAC data systems. It is noted that similar situations exist in numerous other organizations. It is also noted that VAC seems to be able to use its existing data to adequately meet its operational and administrative requirements.

The critical, broader, question is: to what extent does VAC wish to place a higher priority on information and analysis and obtain data for strategic, as well as operational, purposes? Good quality data, and data integrity, can be extremely important resources for any organization in terms of evidence-based policy, program formulation, strategic planning, and so on. VAC has a real opportunity to be a national leader in terms of health care services. What is required to give

VAC the information it needs to make substantial national contributions is an upgraded capacity to ensure the integrity of its information systems and to conduct sophisticated analyses based on its existing administrative data. With the right informatics and analytical infrastructure, VAC could substantially enhance its ability to create new and relevant knowledge for a wide range of clinical, administrative, policy, planning, and program development purposes.

Once one starts to use data it raises questions that lead to improvements in both data quality and policy. In many health care organizations, administrators and clinicians do not fully realize just how much useful data they actually have, and/or what can be done with the data. This often results in using data primarily for operational purposes and not making adequate investments at the strategic level in analysis, and analysts. Analysis is the process by which the treasure chest of new knowledge is opened, and through which important, complex and strategic issues can be informed based on the development and provision of sophisticated analysis. Thus:

- It is suggested that VAC may wish to consider enhancing its capacity to use its existing administrative data by taking steps to ensure that information systems are well documented, and that the necessary work is done at transition points to ensure valid and reliable data over time. In addition, as new systems are developed, the proposed data elements should be reviewed by administrators and analysts to ensure that the kind of data needed for new knowledge development for strategic purposes, as well as for operational purposes, are incorporated into these information systems. Furthermore, given the range of useful data which already exists, VAC may wish to develop an analytical database as a corporate resource which would extract data from all key information systems on a regular basis. The prime function of the analytical database would be to generate new, strategic knowledge for all aspects of the organization. There should also be opportunities to combine administrative data with other research type data, such as satisfaction surveys, to fully round out the knowledge development capacity at VAC.

The development of an analytical database and additional resources for analysis is of relevance to most health care organizations, including Ministries of Health. An analytical database can be used to provide more sophisticated analyses of complex problems and to add significantly to new knowledge development which, in turn, can be used as an input into informed policy formulation and decision-making.

## **6.8 Methodological Limitations**

While it is believed that the findings presented in the Continuing Care Research Project are fairly robust, there are, as with any study, some methodological limitations.

Given the cognitive and/or physical status of the actual clients in Studies 1 and 2, there were limits to the number of clients who could be interviewed and who provided data directly.<sup>87</sup> The use of proxies provided more complete data, but only in areas concerned with objective information. With respect to subjective information, it is not possible to determine how

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<sup>87</sup> This is a limitation of all studies which use an approach similar to that used in the Continuing Care Research Project.

generalizeable the opinions expressed by cognitively capable clients are to clients with cognitive or other limitations. However, there was a reasonable congruence between clients and caregivers, when both responded.

In the Continuing Care Research Project, fewer diaries were completed than in other, similar studies conducted by the researchers. Thus, the diary data were less complete than anticipated. It is thought that the refusal rate was largely due to the age, and health status, of the main caregiver (who was often a spouse). This is an important factor to consider in future studies. A comparison of time for care provision by family caregivers between the diaries and single point-in-time estimates from the Caregiver Interview indicated that the time estimates were lower when diaries were used and people were asked to record actual time on a daily basis. It is thought that the diary data contain the most accurate time estimates and thus, these estimates were used in estimating costs, even though the sample size was smaller than anticipated. However, this raises questions for other studies about using time estimates from interview data to obtain estimates of hours of unpaid care provided.

In the Continuing Care Research Project, few people were admitted to hospital during the period of data collection. Similarly, while there were visits to family physicians, there were fewer such visits than expected. In other studies conducted by the researchers, the use of in-patient hospital services and physician services were substantial cost factors. It is also known that facility clients are less likely to use hospital services. Thus, the overall health care costs for home care and supportive housing clients may be underestimates. However, it is now harder to be admitted to hospital, and hospital stays are shorter than in the past. In addition, the services provided by VAC are designed to maintain client independence. Thus, there may, in fact, be less use of hospital and physician services by the clients in this study than in previous studies.

The development of accurate unit costs is always challenging. However, as VAC provides a range of health and social services, and provides most of the services to clients, it seemed reasonable to use rates paid by VAC for community and facility services. It is recognized that rates for providers paid by clients and families directly, or by provincial and/or regional home care systems, may differ somewhat from the rates paid by VAC.

## **6.9 Final Comments**

It is interesting to note that the findings in this project, that home care has the potential – through appropriate substitutions – to be a cost-effective alternative to facility care, are similar to the findings from studies conducted across three provinces in Western Canada (Chappell et al., 2004; Hollander Analytical Services Ltd., 2006). The finding that home care is a lower cost alternative to facility care does not automatically imply that investments in home care will be cost-effective. Investments in home and community care can only increase the overall cost-effectiveness of the continuing care sector, and the broader health care system, if these investments are made in the context of a broader, integrated system of care in which proactive substitutions of home care for facility care can actually be made.

There has been an ongoing call over the past several years for federal policy to focus on broader, integrated systems of continuing care rather than on separate services (such as home

care), or partial services which further segment care delivery (such as short term hospital replacement home care (see Chappell, et al., 2004; Hollander, 2001: Hollander & Chappell, 2002; Hollander et al., 2007). Long term home care and home support services are critical elements of an appropriate response to the health care needs of Canadian seniors. Furthermore, there is a tremendous potential for making the continuing care system, and the overall health care system, more efficient and effective if one shifts the policy focus to broader, integrated systems of care delivery in which one can make actual substitutions of lower cost care for higher cost care (in a planned and pro-active manner), while providing an equivalent, or even higher, quality of care.

Another finding from the Continuing Care Research Project, which is comparable to other studies, is the critical role that home support services, and unpaid caregivers, play in allowing people to remain in the community and maximize their independence for as long as possible. This study also builds on the base of evidence from earlier studies which support the benefits of long term home care and home support services. The federal policy focus has been on the provision of short term, professional, acute care replacement and specialty home care, where home care is seen as a separate service and not as part of a broader, integrated service delivery system. With the findings from this study, there is now a reasonably substantial weight of evidence to indicate that long term home care, home support services, and integrated systems of care delivery with a broad range of primary, secondary, and tertiary services (including supportive housing), are deserving of a renewed policy focus in Canada.

In order to shift the current policy focus, however, policy makers will first have to determine if they accept the notion that continuing care should be recognized as one of the cornerstones of the Canadian health care system along with hospital care, primary care, population and public health, and drugs. There is currently a tremendous opportunity to move to a new way of thinking about how services for the elderly, and other people with ongoing care needs, could be structured and delivered. Many of the components for a re-invigorated focus on continuing care are already in place. What is required is a shift in the policy focus, and concrete steps to move the notion of an integrated continuing care system to reality. Integrated systems of continuing care were in place, or in development, across Canada in the early 1990s and were, and it is believed would be again, the third largest component of the Canadian health care system in terms of public expenditures. Given the size and scale of these services, they are clearly worthy of a renewed policy focus by senior decision makers across Canada.

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**Appendix A:**  
**Identifying the Client and  
Informal Caregiver Samples**

## 1. Identification of the Client Samples

As noted in the Synthesis Report, the focus of both Studies 1 and 2 was on veterans who had served in World War II and/or the Korean War. The supportive housing sample in Study 2 also included spouses of veterans who were receiving benefits and services funded by VAC.

In order to identify the client sample, initial lists of veterans (and non-veterans, if applicable) were drawn from VAC's national Reporting Database. The lists were then forwarded to the VAC Liaison in the appropriate study site.

The VAC Liaison reviewed each list and removed any individuals who were no longer receiving services or benefits from VAC, had died, moved into a location (e.g., supportive housing building, long term care facility) that was not included in the study, or could not be contacted based on information available in the client's file in the District Office. This preliminary review resulted in a potential sample of veterans (and non-veterans, if applicable) who were then contacted by the VAC Liaison regarding participation in the study.

The VAC Liaison then contacted each individual (and/or proxy, if applicable) in the potential sample, briefly explained the purpose of the study, and asked if he/she would be willing to have the VAC Liaison pass the veteran's name and contact information (and that of the proxy, if relevant) onto the research team. If an individual chose not to have the relevant information passed onto the research team, the VAC Liaison replaced him/her with someone else from the potential sample, until either the list of potential participants was exhausted or the target sample was obtained.

At this stage, the VAC Liaison used the following exclusion criteria to remove individuals from the potential sample:

- The potential participant (i.e., veteran) had died.
- The potential community participant was due to be placed in supportive housing or a facility within the next two weeks.
- (In Study 2 only) the potential supportive housing participant was due to be placed in a facility within the next two weeks.
- The potential participant had recently been placed in a facility. In Study 2, potential participants were also excluded if they had recently gone into supportive housing.<sup>1</sup>
- The potential participant was palliative.

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<sup>1</sup> In both Studies 1 and 2, if the person had been placed in a facility in the last month, they were not included in the community or facility sample. If the person had been in a facility for one month or more, he/she was considered (but not necessarily included) as part of the facility sample. In Study 2, if the person had gone into supportive housing in the last month, he/she was not included in the community or supportive housing samples. If the person had been in supportive housing for one month or more, he/she may have been considered but not necessarily included as part of the supportive housing sample.

- The potential participant was in hospital and was not expected to return to his/her previous living arrangement.<sup>2</sup>
- The potential participant or the potential participant's immediate family was under considerable stress (e.g., due to a death in the family in the last three months, or someone in the family was currently palliative).
- The potential participant was under a Public Trustee *and* there was no one who could provide proxy consent.<sup>3</sup>
- The potential participant was cognitively impaired, required proxy consent *and* there was no one who could, or was willing to, provide proxy consent.<sup>4</sup>
- There was evidence that the potential participant and/or a family member posed a substantial risk to the interviewer.
- The potential participant (or his/her proxy, if required) could not communicate in English.<sup>5</sup>
- The potential participant (or his/her proxy, if required) was going to be unavailable for an extended period of time.<sup>6</sup>
- The potential participant (and/or his/her proxy, if required) could not be reached after five attempts on different days and at different times of day.

The VAC Liaison was responsible for obtaining consent to pass the name and contact information onto the research team, and for identifying any relevant information regarding contacting the veteran and/or his/her proxy (e.g., who should be contacted, what time of day the person should be contacted, etc.). The VAC Liaison was not responsible for getting the veteran and/or his/her proxy to agree to participate in the study.

Individuals who agreed to have their name and contact information passed onto the research team were then contacted by a trained interviewer who explained the study in more detail and asked the client/proxy if he/she would be willing to participate in the study. If the individual chose not to participate, no further contact was made. If the individual agreed, arrangements were made to conduct the interview.

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<sup>2</sup> If the person was temporarily in the hospital (e.g., for a cataract operation, hip replacement) but was expected to return to his/her previous living arrangement, he/she *could* be included in the study depending on when the person was expected to return home.

<sup>3</sup> This exclusion criterion was only used in Study 2 as no Public Trustees were identified in Study 1. However, it would have been applicable in Study 1 as well.

<sup>4</sup> Potential participants were not excluded simply because they had cognitive impairment or dementia.

<sup>5</sup> All interview materials were available only in English. Given the nature of some of the questions on the interview tools, particularly those from standardized measurement instruments which may not be available in other languages (see Appendix B), all interviews were conducted in English. Although a participant or proxy did not have to have English as their primary language, they did have to be relatively fluent in English to be included in the study.

<sup>6</sup> This exclusion criterion was only used in Study 2 as the issue did not arise in Study 1. However, it would have been applicable in Study 1 as well.

## **2. Identification of the Informal Caregiver Samples**

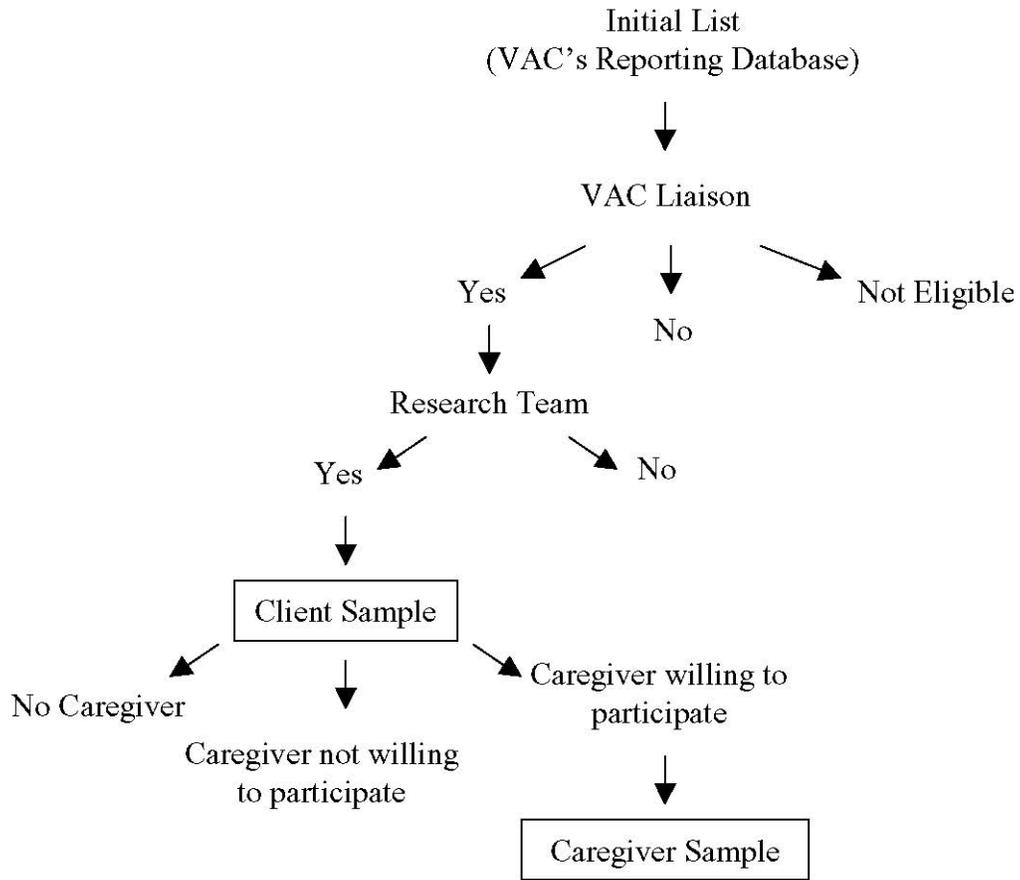
Where possible, informal caregivers of clients were identified in order to obtain information regarding the caregivers' experience of providing care to the clients. For the purposes of this study, informal caregivers were family members, friends, volunteers, members of a service organization or other individuals that were considered by the clients or proxies to provide the client with unpaid care and/or support.

Clients who participated in the study on their own behalf were asked to identify an individual who provided them with unpaid care and support and who could be approached regarding the study. Similarly, proxies were asked to identify an individual who provided unpaid care and/or support to the client. In this case, an individual could identify him/her self as both a proxy and an informal caregiver. Thus, informal caregivers were "linked" to the client.

An individual could only participate as an informal caregiver if the client to whom he/she "belonged" also participated in the study. Although they were linked to the clients, informal caregivers could choose to participate or not participate in the study, depending on their own wishes. This approach resulted in several possible outcomes regarding the availability of data from informal caregivers. First, a client may not have had an informal caregiver. Second, a client may have had an informal caregiver, but may have chosen not to identify the person. Third, a client may have had an informal caregiver and identified the person, but the caregiver him/her self chose not to participate in the study. Fourth, the client may have had an informal caregiver, identified the person and the caregiver agreed to participate. Fifth, a proxy may have participated in the study on behalf of the client but chosen not to participate as the informal caregiver as well, did not identify someone else as an informal caregiver, or identified someone else as an informal caregiver but that person subsequently refused to participate. Sixth, a proxy may have participated in the study on behalf of the client and either chosen to participate as the informal caregiver as well, or identified someone else as the informal caregiver where the second person agreed to participate. In the first, second, third, and fifth cases, the client was included in the study, but no informal caregiver data were available. In the fourth and sixth cases, data were available for both the client and the informal caregiver.

## **3. Summary**

A summary of the steps involved in obtaining the client and caregiver samples is provided in Figure 1.



**Figure 1: Summary of Steps Involved in Identifying and Selecting the Client and Informal Caregiver Samples**

## **Appendix B:**

### **Detailed Information Regarding the Client and Caregiver Questionnaires**

## 1. Introduction

As noted in the Synthesis Report, five data collection tools were used to examine the impact of care for each client in both Studies 1 and 2. The same data collection tools were used in both studies (with minor additions to the Client and Caregiver Questionnaires in Study 2 to address issues related to supportive housing). A multi-section Client Questionnaire was used to obtain information about the client directly. A multi-section Caregiver Questionnaire was used to obtain information from an informal caregiver regarding his/her experience of providing care to the client. In addition, three diaries were used to collect information about: out-of-pocket expenses incurred by clients and/or informal caregivers; time and assistance provided by informal caregivers; and time and assistance provided by formal care providers either in the community or in long term care facilities.

Both the Client and Caregiver Questionnaires included existing measurement instruments as well as questions that were developed for areas where no acceptable measurement instrument could be identified. The measurement instruments included on both the Client and Caregiver Questionnaires were selected based on a review of existing measurement instruments in the published and grey literature, input from members of the research team, and the results of a pilot study on the data collection tools. Concern was expressed, both by VAC and by members of the research team, that the interviews not be too lengthy. A decision was made to keep the total interview time to about 1 to 1.25 hours. The choice of measurement instruments, the number of measurement instruments and questions overall, and the amount of detailed information obtained in the interview, were guided by this decision. In some cases, compromises needed to be made in order to stay within the target timeframe.

## 2. Client Questionnaire

### 2.1 Demographic Information

The demographic information collected on clients included: gender, age, marital status, primary language, education, and income sources.<sup>1</sup>

### 2.2 Functional Status

Functional status was assessed using the Functional Autonomy Measurement System (Système de mesure de l'autonomie fonctionnelle, SMAF). This tool is based on the World Health Organization's (1980) classification of disabilities. The SMAF was designed to assess an individual's functional abilities and service requirements (Hébert, Carrier, & Bilodeau, 1988; Hébert, Guilbault, Desrosiers, & Dubuc, 2001).

The SMAF consists of 29 items that measure functional abilities in five areas: activities of daily living (e.g., washing, dressing); mobility (e.g., walking, negotiating stairs); communication (e.g., vision, hearing); mental functions (e.g., memory, orientation); and

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<sup>1</sup> Income source(s), rather than income *per se*, were included as a proxy for income. Previous work by Hollander, Chappell, Havens, McWilliam & Miller (2002) indicated that 26% of clients/proxies refused to provide information regarding the client's income. It was felt that clients/proxies may be more willing to provide information regarding income *sources* than the *amount* of their income.

instrumental activities of daily living (e.g., meal preparation, laundry). Each item is scored on a five point scale that ranges from 0 (independent) to -3 (dependent).<sup>2</sup> The scoring is based on the individual's actual performance, not his or her potential.<sup>3</sup> For each item, a determination is also made regarding the resources the individual has available to assist him/her to address the disability. The maximum total score (using absolute values) is 87; subscale scores can also be calculated. Higher scores are indicative of poorer functional ability. A case-mix classification system is embedded in the instrument (Tousignant, Hébert, Dubuc, Simoneau, & Dieleman, 2003).

Desrosiers, Bravo, Hébert and Dubuc (1995) reported test-retest and inter-rater reliabilities of 0.95 and 0.96, respectively, for the total SMAF score.<sup>4</sup> The correlation coefficients were over 0.74 for all five subscale scores (which correspond to the five areas of functioning) for both types of reliability (Desrosiers et al., 1995). Hébert, Guilbault, et al. (2001) reported that the SMAF total score correlated 0.92 with nursing care time and accounted for 85% of the variance in required nursing-care time (see also Hébert, et al., 1988; Hébert, Dubuc, Buteau, Desrosiers, Bravo, Trottier, St-Hilaire, & Roy, C. 2001).

### 2.3 Cognitive Status

Cognitive status was assessed using the Mini-Mental State Examination (MMSE). The MMSE is one of the most popular instruments used to assess cognitive functioning in clinical settings, community surveys and epidemiological studies (Tombaugh, McDowell, Kristjansson, & Hubley, 1996; Tombaugh & McIntyre, 1992). It has been used extensively to measure cognitive functioning in elderly individuals (Molloy, Alemaychu, & Roberts, 1991).

The MMSE assesses seven different dimensions of cognitive function: registration of information; attention and calculation; short-term memory; orientation to time; orientation to place; written and oral language skills; and visuospatial ability (Folstein, Folstein & McHugh, 1975; Tombaugh & McIntyre, 1992). The total possible score is 30. Lower scores are indicative of greater cognitive impairment. Questions that are not answered because the client refuses to answer are treated as errors. Questions that are not answered due to blindness, physical disabilities or illiteracy can be prorated (see McDowell, Kristjansson, Hill & Hébert, 1997; McDowell, 2006). Individuals scoring 24 to 30 are generally considered to have no cognitive impairment, those scoring 18 to 23 are considered to have mild cognitive impairment, and those

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<sup>2</sup> Most questions include a rating of 0.5 if the individual can do the task relatively independently, but with some difficulty.

<sup>3</sup> As noted by Hébert, Guilbault, et al. (2001), it could be argued that the SMAF introduces a bias, particularly with respect to some household functions where men of the current generation of elders do not do some functions because their wives do them. The disabilities are cultural, but a man who loses his wife may be institutionalized if the loss is not compensated.

<sup>4</sup> Test-retest reliability is a measure of the stability or repeatability of a measurement applied to a sample of people at one point in time and the same measurement repeated at a second point in time (e.g., two weeks later). Inter-rater reliability or inter-rater correlation is a measure of the extent to which results obtained by different interviewers or raters using the same measurement method agree.

scoring 0 to 17 are considered to have severe cognitive impairment (Tombaugh & McIntyre, 1992).<sup>5</sup>

Tombaugh and McIntyre (1992; see also McDowell, 2006) reported alpha coefficients for the MMSE ranging from 0.68 to 0.96.<sup>6</sup> McDowell et al. (1997) reported a Cronbach's alpha of 0.78 and a split-half reliability of 0.76 in a study involving a community (rather than a clinical) sample.<sup>7, 8</sup>

## 2.4 Health Status

Perceived health status was assessed using a single item: "Compared to other people your own age would you say your health is..." A five point scale, ranging from Excellent to Poor, was used. Lower scores are indicative of better perceived health.

Clients' psychological health was assessed using a 15 item version of the Geriatric Depression Scale (GDS-15). The Geriatric Depression Scale was designed as a screening test for depression in elderly individuals (Yesavage, Brink, Rose, Lum, Huang, Adey & Leirer, 1983).

The scale originally consisted of 30 items. However, a 15 item version was developed to reduce respondent fatigue, particularly in individuals who have a physical illness or dementia (Sheikh & Yesavage, 1986).<sup>9</sup> A yes/no response format is used. Non-depressive answers are given a score of 0 and depressive answers are given a score of 1. The total score can be prorated to compensate for missing items.<sup>10</sup> Scores can range between 0 and 15. Scores between 0 and 4 are considered normal, scores between 5 and 9 are indicative of mild depression and scores between 10 and 15 are indicative of moderate to severe depression (McDowell, 2006).

D'Ath, Katona, Mullan, Evans and Katona (1994) reported a Cronbach's alpha of 0.80 for the 15 item version. They also reported a sensitivity of 91% and a specificity of 72% in a study involving attendees at a health centre (approximately one-third of the sample had depressive symptoms).<sup>11</sup> Alden, Austin and Sturgeon (1989) reported correlations ranging from 0.57 to 0.66 between the 30 and 15 item versions in a study involving older individuals living in

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<sup>5</sup> The modified MMSE (or 3MS) is similar to the MMSE, samples a broader range of cognitive capacity and difficulty levels than the MMSE, and allows for more sophisticated scoring (McDowell, et al., 1997). The 3MS was not used in the current study as it requires more time to administer and score than the MMSE. The MMSE and the 3MS appear to be highly correlated. For example, Grace, Nadler, White, Guilmette, Giuliano, Monsch, & Snow (1995) reported a correlation of 0.84 between the two measures.

<sup>6</sup> Coefficient alpha (Cronbach's alpha) is a measure of the internal consistency of a test.

<sup>7</sup> A split-half reliability is a measure of the extent to which the two halves of a tool appear to be measuring the same concept. It is a measure of the internal consistency of the tool.

<sup>8</sup> Higher alpha values are generally reported for clinical samples as they tend to be more homogenous than community samples (McDowell et al., 1997).

<sup>9</sup> The 15 items are a subset of the 30 items and were selected based on their correlation with depressive symptoms in validation studies (Sheikh & Yesavage, 1986).

<sup>10</sup> The total score can be prorated by multiplying the total score by 15 and dividing by the number of questions that were answered.

<sup>11</sup> Sensitivity refers to the ability of a measurement instrument to identify those individuals who have a condition of interest (in the case of the GDS, depression). It is calculated as the percentage of all individuals with the condition who are judged by the test to have the condition. Specificity refers to the ability of a measurement instrument to correctly identify those individuals who *do not* have the condition of interest.

the community or in a long term care facility. Sheikh and Yesavage (1986) reported a correlation of 0.84 between the 30 and 15 item versions in a study involving elderly individuals living in the community and elderly individuals in various treatment settings for complaints of depression.

## 2.5 Health-Related Quality of Life

Guyatt, Feeny and Patrick (1993) have argued that health related quality of life may be more important than overall quality of life in assessing the impact of chronic conditions. They also noted, however, that in the health/medical literature, the terms “health status”, “functional status” and “quality of life” are often used interchangeably. Because the SMAF was chosen to measure functional status, the health-related quality of life tool selected for the current study was designed to focus on quality of life *per se*.

The Short Form-8 (SF-8) contains eight questions, one for each of the following concepts: physical functioning; role limitations due to physical health problems; bodily pain; social functioning; general mental health; role limitations due to emotional problems; vitality; and general health perceptions.<sup>12</sup> The standard version of the SF-8 (which uses a four-week recall period) was used.<sup>13</sup>

Turner-Bowker et al. (2003) reported test-retest reliabilities for the eight scales in the SF-36 (corresponding to each of the eight questions in the SF-8) ranging from 0.59 to 0.70. Correlations between the eight scales on the SF-36 and the comparable scales on the SF-8 ranged from 0.67 to 0.84, with all but one of the correlations being 0.73 or higher (Turner-Bowker et al., 2003).

## 2.6 Social Relations

The concept of social relations involves two components: social networks and social supports. 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 socioemotional and/or instrumental support.<sup>14</sup>

Clients were asked two questions related to social networks: how many people they lived with, and how many people they usually interacted with over the course of a month. Both questions were adapted from the Lubben Social Network Scale (Lubben, 1988).<sup>15</sup> They were also asked two questions related to social supports: whether they had anyone they could count on for

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<sup>12</sup> These concepts are the same as those covered by the Short Form-36 (SF-36), an instrument used in population surveys and evaluative studies of health policy (Ware & Sherbourne, 1992). Each item on the SF-8 is linked to a comprehensive pool of questionnaire items (which includes, but is not limited to, the SF-36), which have been shown to measure the same health concept (Quality Metric, 2005).

<sup>13</sup> There is also a one-week acute form and a 24-hour acute form of the SF-8 (Turner-Bowker, Bayliss, Ware & Kosinski, 2003).

<sup>14</sup> Socioemotional support includes affection, sympathy and understanding, and talking over issues and concerns. Instrumental support includes help with family, personal and household responsibilities and financial aid (Lubben, 1988; Thoits, 1982).

<sup>15</sup> The Lubben Social Network Scale was developed specifically for use with elderly populations (Lubben, 1988). The scale consists of 10 questions that assess family networks, friends networks and interdependent social supports (e.g., confidant relations).

instrumental support, and whether they had anyone they could count on for emotional support. Both questions were adapted from the EPESE Social Relations Scale (Seeman and Berkman, 1988).<sup>16</sup>

## 2.7 Service Utilization

The Client Questionnaire included four sets of questions regarding the types of health care and support services clients receive. The first set of questions was developed by the research team and was used to determine the types of VIP, transportation, and case management services clients received.<sup>17</sup> The second set of questions was developed by the research team and was designed to identify the types of formal care services clients received in general (that is, this list was not limited to the types of services available through the VIP program). The third set of questions was adapted from Browne, Gafni, Roberts and Hoxby's (1992) Health and Social Services Utilization Tool. The questions asked about clients' use of several categories of health services (such as physicians, occupational therapists, social workers and dentists). They also assessed out-of-pocket expenditures by addressing clients' need for health related supplies (such as mobility aids, dressings, and special foods) and services (such as household help and transportation). The fourth set of questions focused on assistance provided by informal caregivers and examined both who provided assistance as well as how much assistance was provided in an average week.

## 2.8 Satisfaction with Services

The Satisfaction with Care Related Services instrument developed by Penning and Chappell (1996) was used to assess clients' satisfaction with the services he or she receives. The tool consists of 15 questions. Responses are scored using a three point scale that ranges from Rarely to Always. Scores for three subscales as well as a total score can be obtained. The total possible score for the subscales are 9, 24 and 12 for Client Choice, Worker Characteristics, and Care Concerns, respectively. Total scores can range from 15 to 45. Higher scores (on both the subscales and the full instrument) are indicative of greater satisfaction with care related services. Hollander et al. (2002) reported Cronbach's alphas of 0.70 and 0.80 for the total scale based on two samples of elderly individuals.

Clients were also asked to indicate how satisfied or dissatisfied they were with the services they received in general, as well as provide an explanation for their rating.

Clients were asked what factors were influencing where they were currently living (that is, in the community, in supportive housing (if applicable) or in a long term care facility). They were also asked to indicate where they would prefer to live, if they had a choice.

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<sup>16</sup> EPESE is an acronym for Establishment of Populations for Epidemiologic Study of the Elderly. The EPESE Social Relations Scale was developed for use with elderly individuals living in the community. The scale consists of 20 questions which address network structure as well as emotional and social support.

<sup>17</sup> The list included services provided through the VIP program. Although a client may have used a service (such as housekeeping) that is available through the VIP program, VAC may not have covered the cost of the service. In some cases, the service may have been covered under the provincial health program, by another organization, or by the client directly.

Finally, clients were asked how Veterans Affairs Canada could improve services to them directly and/or to veterans more generally.

### **3. Caregiver Questionnaire**

#### **3.1 Demographic Information**

Demographic information was collected regarding the caregiver's gender, age, marital status, primary language, education, income sources,<sup>18</sup> and current employment status.

#### **3.2 Provision of Assistance**

Caregivers were asked several questions regarding their provision of assistance to the clients, for example, how long they had been providing assistance, whether they were living with the client, whether they considered themselves to be the client's primary caregiver, and whether they received help from others. Caregivers were also asked if they provided care to anyone else in addition to the client. Finally, caregivers were asked about the types of tasks they, and others, assisted the client with, as well as the amount of time required to provide that assistance in an average week.

#### **3.3 Service Utilization by Clients**

Caregivers were asked about the client's use of several categories of health services (such as physicians, occupational therapists, social workers and dentists). They were also asked about out-of-pocket expenditures related to the client's need for health related supplies (such as mobility aids, dressings, and special foods) and services (such as household help and transportation). These questions were similar to those included on the Client Questionnaire and were adapted from Browne et al. (1992).

#### **3.4 Caregivers' Satisfaction with Services Received by Clients**

Caregivers' satisfaction with the services clients received was assessed using an adapted version of the Satisfaction with Care Related Services instrument developed by Penning and Chappell (1996). The tool consisted of 16 questions that were similar to those used to examine client satisfaction with services. Caregivers' satisfaction with caregiver choice, worker characteristics and care concerns were assessed using a three point scale that ranged from Rarely to Always. As with the Client Questionnaire, scores for three subscales as well as a total score can be obtained. The total possible score for the subscales are 9, 27 and 12 for Client Choice, Worker Characteristics, and Care Concerns, respectively. Total scores can range from 16 to 48. Higher scores are indicative of greater satisfaction with care related services. Hollander et al. (2002) reported Cronbach's alphas of 0.73 and 0.81 for a 14 item version of the scale based on two samples of elderly individuals.

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<sup>18</sup> Income source(s), rather than income *per se*, were included as a proxy for income. Previous work by Hollander et al. (2002) indicated that 21% of caregivers refused to provide information regarding their income. It was felt that caregivers may be less likely to refuse to provide information regarding income sources.

Caregivers were also asked to indicate how satisfied or dissatisfied they were with the services clients received in general, as well as provide an explanation for their rating. They were also asked to indicate how satisfied or dissatisfied they were with the services and supports specifically provided by Veterans Affairs Canada.

Caregivers were asked to indicate where they would prefer the client lived, if they had a choice. They were also asked whether they thought assisted living/supportive housing was an appropriate alternative to home care and/or facility care, both in general and for their client in particular.

### 3.5 Impact of Providing Care

Caregivers were asked several questions regarding the impact providing care to the client had had on them. These questions included: the impact on the caregiver's social activities; the impact on the caregiver's work/employment; and the perceived benefits and challenges of providing care. Caregivers were also asked what types of assistance (including financial assistance) they received to help them in providing care to the client, and whether they would like to receive additional assistance. In addition, caregivers were asked for suggestions for improving both their own and the clients' quality of life. All of these questions were developed by the research team for this project.

Caregiver burden was examined using a 14 item version of the Montgomery Burden Scale developed by Hollander et al. (2002).<sup>19</sup> The instrument contains six items that assess objective burden and eight items that assess subjective burden. Responses are scored using a five point scale that ranges from A Lot Less to A Lot More. For objective burden, the maximum score is 30 with higher scores reflecting less burden. For subjective burden, the maximum score is 40 with higher scores reflecting greater burden. Hollander et al. (2002) reported Cronbach's alphas ranging from 0.87 to 0.92 for the 14 item scale.

As with the clients, caregivers' perceived health status was assessed using a single item: "Compared to other people your own age would you say your health is..." A five point scale, ranging from Excellent to Poor, was used. Lower scores are indicative of better perceived health.

## **4. Diary of Care Related Expenditures**

The *Diary of Care Related Expenditures by Client, Family Members and Other Unpaid Helpers* was developed by Hollander, Chappell, Haven, McWilliam, Walker, Shaver and Miller (2001; see also Hollander et al., 2002). The diary was used to estimate the costs of caring for the client by adding health-related costs incurred by the clients and/or their informal caregivers to the costs of services provided by the health care system. Care-related expenditures that could be identified in the diary included, but were not limited to: food for special diets; medical supplies; prescription and non-prescription drugs; herbs or other remedies; services provided by herbalists,

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<sup>19</sup> The Montgomery Burden Scale is designed to assess both objective and subjective burden experienced by informal caregivers (Montgomery, Gonyea & Hooymann, 1985). Objective burden is defined as the "extent of disruptions or changes in various aspects of the caregivers' life and household (Montgomery et al., 1985, p. 21). Subjective burden is defined as the caregiver's "attitudes toward or emotional reactions to the caregiving experience" (Mongomery et al., 1985, p. 21).

acupuncturists, naturopaths, or other providers not covered by medicare; health care services provided by homemakers, adult day centers, physiotherapists, or facilities (these may be full costs or co-payments); transportation costs such as buses, taxis, and wheelchair equipped vans; and other expenditures related to the care of the individual requiring continuing care services.

## **5. Time and Assistance Provided by Informal Caregivers**

The *Diary of Time and Assistance Provided by Family Members and Other Unpaid Individuals* was developed by Hollander et al. (2001, 2002). The diary was used to estimate the costs of unpaid care which is provided by family members or other informal caregivers. The diary was intended to collect data regarding the additional assistance informal caregivers provided *because of* the client's health condition. It was not intended to collect information regarding assistance the caregiver normally provided (e.g., a distinction was made between the time required to make a meal and the time required to make a meal for someone with diet and/or nutritional concerns). Activities that could be identified in the diary included, but were not limited to: housekeeping for the person who is receiving continuing care services; banking, bill payments, etc. for the person who is receiving continuing care services; accompanying the person to doctor's appointments and other offices; giving medications, changing bandages, or helping with medical equipment (such as oxygen tanks, testing strips, etc); bathing, dressing or grooming assistance; and visiting and recreational activities.

## **6. Time and Assistance Provided by Formal Care Providers**

The *Diary for Paid Care Providers in the Community* was developed by Hollander et al. (2001, 2002). The diary was used to estimate the costs of care provided by formal care providers providing services in the home or in the broader community (i.e., for both community and supportive housing clients). The provider could be paid either from public or private (e.g., insurance) money. Activities which could be identified in the diary included, but were not limited to: home support; home nursing; adult day centre; respite care; physician visits; physiotherapy; occupational therapy, laboratory tests; and mental health services.

The *Diary for Formal Care Services Provided to Persons Living in Facilities* was developed by Hollander et al. (2001, 2002). The diary was used to estimate the costs of care provided by formal care providers providing health care and/or support services to individuals living in a long term care facility. The diary was used to record information regarding a range of care and support activities (e.g., wound care, administration of medications, redirection and emotional support, spiritual care) as well as who provided the activities (e.g., nurses, care aides, recreational staff).

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## **Appendix C:**

### **Definitions Used in Coding the Diaries**

## **1. Introduction**

As noted in the Synthesis Report and Appendix B, three diaries were used to collect information regarding out-of-pocket expenses incurred by clients and informal caregivers, time and assistance provided by informal caregivers, and time and assistance provided by formal caregivers. The categories used in coding these diaries are defined in the following sections.

## **2. Diary of Care Related Expenditures**

### **2.1 Medical Supply and Equipment Costs**

This category was used for expenditures such as: medications; dressings; incontinence products; vitamins; frames for glasses; batteries for hearing aids or other medical devices; alternative medicine supplies; testing supplies (for diabetics, for example); first aid kits; specialized food; specialized clothing; specialized footwear; bath seats; walkers; wheelchairs; canes; motorized scooters; therapy supplies and materials; and dentures.

### **2.2 Care Related Home and Personal Maintenance Costs**

This category was used for expenditures that were care related, such as: housekeeping in general (paid); laundry (facility only); Meals on Wheels; getting a haircut (facility only); travel costs for informal caregivers; meal preparation and cleanup; toiletries (facility only); respite for the client or informal caregiver; transportation costs (such as Handi-Dart/Wheeltrans); grounds maintenance; and costs for care aids, homemakers and other home support services.

### **2.3 Medically Related Care Service Costs**

This category was used for expenditures such as: podiatry/chiropractic, physiotherapy; massage therapy; medical laboratory services; addictions treatment centres; doctor's appointments; optometrist visits; orthodontist appointments; professional home care services; counseling; short term hospital visits; emergency department visits; hospital stays; ambulance trips; services from complementary health care providers; and services from other, traditional, health service professions.

### **2.4 Long Term Care Facility Co-Payments**

This category was used for long term care facility co-payments.

### **2.5 Other Services/Costs**

This category was used for expenditures that would usually not be perceived as care related but a part of life, such as: laundry (community only); going out for a meal; getting a haircut (community only); recreational activities; shopping; clothing; electronics; gym costs, etc.

### **3. Diary of Time and Assistance Provided by Informal Caregivers**

#### **3.1 Professional Care Type Activities**

This category was used for activities that are often provided by nurses. It included: monitoring and/or administering medications; assisting with machines, devices and monitors; changing bandages; assisting with foot care; providing ordered physical activity or therapy; and case management services such as activities related to the organization of services, particularly the organization of both health and social services.

#### **3.2 Hands-on Supportive Care Activities**

This category was used for activities often provided by a Care Aide, such as toileting, bathing, feeding, positioning and dressing.

#### **3.3 Home and Personal Maintenance Activities**

This category was used for activities done for the client that make it possible to live, and function, in a normal, clean living environment. It included: general housekeeping; vacuuming, dusting; bringing water; garden work (including cutting grass); laundry; house maintenance inside; house maintenance outside (including shoveling snow); activities related to shopping, meal preparation and associated clean up (such as dishes); paying bills, banking and working with lawyers; driving to medical appointments and social programs such as adult day centres; taking the client for a haircut; taking the client to church (church services); maintaining contact with the client, or on the client's behalf, by writing letters or making phone calls; other communications related activities; and making decisions or assisting the client to make decisions.

#### **3.4 Psychosocial Activities**

This category was used for activities done with the client that relate to the social, recreational, and non-medical needs of the client. It included: visiting the client; providing or participating in recreational activities with the client; and providing emotional support, comfort and companionship.

#### **3.5 Other Activities**

This category was used for the provision of other services. Examples included caregiver travel time related to visiting the client and caregiver education sessions.

### **4. Diary of Time and Assistance Provided by Formal Caregivers**

Coding of this diary involved the same categories used in coding the time and assistance provided by informal caregivers.

## **Appendix D:**

# **Description of VAC's Health Benefits and Veterans Independence Programs**

## **HEALTH BENEFITS PROGRAM**

Health benefits are available to eligible veterans (the majority are living at home) through 15 Programs of Choice:

### **POC 1: Aids for Daily Living**

This program provides devices and accessories (including repairs) designed to assist an individual with his/her activities of daily living. Examples include: canes; self-help aids for dressing or feeding; foot boards; and raised toilet seats.

### **POC 2: Ambulance/Medical Travel Services**

This program provides use of ambulance services to or from a medical facility when it is needed because of an emergency or medical condition. It also provides coverage for health related travel costs that are incurred in order to receive a benefit/service.

### **POC 3: Audio (Hearing) Services**

This program provides benefits to help with hearing impairments. Examples include: hearing aids and accessories (e.g., batteries); dispensing and fitting fees; and telephone amplifiers.

### **POC 4: Dental Services**

This program provides basic dental care and some (pre-authorized) comprehensive dental services. Examples include: cleanings; exams; fillings; and fluoride treatments.

### **POC 5: Hospital Services**

This program provides benefits for both inpatient and outpatient treatment services provided in an accredited provincial acute care, chronic care, or rehabilitative care hospital, or a health facility.

### **POC 6: Medical Services**

This program offers medical services provided by a licensed physician. The program also covers the cost of medical examinations, treatments or reports specifically requested by VAC.

### **POC 7: Medical Supplies**

This program provides medical and surgical equipment and supplies normally used by an individual in a non-hospital setting. Examples include bandages and incontinence supplies.

### **POC 8: Nursing Services**

This program provides services for nursing assessments and basic or advanced foot care. Examples include: administering medications; applying dressings; counselling clients or caregivers in the use of medical supplies; and foot care.

### **POC 9: Oxygen Therapy**

This program provides oxygen and accessories. Examples include: oxygen concentrators; compressors; and oxygen gas.

### **POC 10: Prescription Drugs**

This program provides drug products and other benefits dispensed by a pharmacist. Examples include: prescription drugs; over-the counter medications; and medical supplies.

### **POC 11: Prosthetics and Orthotics**

This program provides necessary prosthetics or orthotics and includes accessories and repairs for these benefits.

### **POC 12: Related Health Services**

This program provides alternative benefits and services provided by licensed health professionals. Examples include: occupational therapy; physiotherapy; massage therapy; and psychological counselling.

### **POC 13: Special Equipment**

This program provides special equipment required for the care and treatment of VAC clients. Examples include: hospital beds; walkers; lifts; and wheelchairs.

### **POC 14: Vision (Eye) Care**

This program provides lenses, frames and accessories to correct sight impairments.

### **POC 15: Veterans Independence Program**

This program is described in more detail below.

## **VETERANS INDEPENDENCE PROGRAM**

Several categories of benefits are available under the Veterans Independence Program. The categories are as follows:

### **Grounds Maintenance**

This category includes activities regularly required to maintain the grounds immediately surrounding the client's principal residence. Examples include: snow removal from steps, walkways, and driveways; snow and ice removal from roofs and eaves troughs; lawn mowing; and raking.

### **Housekeeping**

This category includes routine tasks or domestic chores required to support the client in remaining self-sufficient at his/her principal residence. Examples include: laundry (including ironing and mending); vacuuming; cleaning floors (e.g., sweeping, washing, waxing, etc.); and meal preparation.

### **Personal Care**

This category includes services provided by approved health care providers to assist the client with his/her activities of daily living. Examples include: assistance with eating; assistance with dressing; adjusting prosthetic devices; attending to toileting; and assistance with ambulation.

### **Home Adaptations**

This category includes modifications made to the client's principal residence to provide access for basic everyday activities such as food preparation, personal hygiene and sleep. Examples include handrails on stairways and ramps.

### **Access to Nutrition**

This category includes access to nutritional food, regardless of whether it is delivered to the client's home, offered in the community, or served at a local restaurant. Examples include the cost of delivering food to the home, and transportation costs (e.g., taxi) to bring the client to a local restaurant or community facility to obtain meals.

### **Health and Support Services Provided by Health Professionals**

This category includes health assessments and diagnostic services, care, and maintenance not available to clients as a provincially covered service.

### **Ambulatory Health Care**

This category includes health and social services provided by health professionals outside the home. Examples include adult day care and travel costs to access these services.

### **Social Transportation**

This category includes transportation services to enable clients to participate in social activities, in response to their basic social, recreational or personal needs. Examples include: church services; occasional visits to friends/relatives; community centres; banks; and grocery stores.

### **Intermediate Care Services**

This benefit is included in VIP, but is not a home care service. Intermediate care services may be provided when living at home is no longer practical and a greater level of nursing and personal assistance is needed in a long term care facility.

Source: Veterans Affairs Canada and Blue Cross. (2006). *A guide to access VAC Health Benefits and the Veterans Independence Program*. Available on-line at [www.vac-acc.gc.ca](http://www.vac-acc.gc.ca).