

SUBSTUDY 4

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

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

April 2001



National Evaluation of the Cost-Effectiveness of Home Care



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

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April 2001



National Evaluation of the Cost-Effectiveness of Home Care



PREFACE

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

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

This study, *Substudy 4: Pilot Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services*, was designed as a small pilot study for a second, larger study focusing on the costs and outcomes of care in the community and in long term care facilities. The purpose of the pilot study was to test instrumentation and determine the feasibility of data collection strategies. Information was collected on both clients and informal caregivers through interviews. Information regarding formal and informal service provision was collected by means of a series of diaries maintained by clients, informal caregivers, and service providers.

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EXECUTIVE SUMMARY

Substudy 4, a *Pilot Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services*, is part of the National Evaluation of the Cost-Effectiveness of Home Care. The National Evaluation of the Cost-Effectiveness of Home Care is a major program of research that will provide critical new information to policy makers about the cost-effectiveness of home care in Canada. It has a budget of \$1.5 million and is comprised of 15 interrelated studies, six on the cost-effectiveness of home care compared to care in long term care facilities and nine on the cost-effectiveness of home care as an alternative to care in acute care hospitals. The Co-Directors for the National Evaluation of Home Care are Neena Chappell, PhD, Director, Centre on Aging, University of Victoria, and Marcus Hollander, PhD, President, Hollander Analytical Services Ltd., Victoria, British Columbia.

Substudy 4 was a pilot for a second, larger-scale study, Substudy 5. Both studies focus on seniors. The main goal of the studies is to document the typical costs and outcomes of care for clients in home care compared to similar clients in residential care. These studies examine whether there are differences in the formal costs of services and in the health outcomes of clients living in the community versus in long term care facilities. They also measure the informal costs of care by identifying the psychological, social, and financial burdens shouldered by family, friends, and volunteers looking after clients in the community and in facilities. Thus, Substudies 4 and 5 address the impact of home care and residential care services on both clients and their families. The principal investigators for these two substudies are Dr. Neena Chappell, Dr. Marcus Hollander, Dr. Betty Havens, Professor and Senior Scholar, Department of Community Health Sciences, University of Manitoba, and Dr. Carol McWilliam, Professor, School of Nursing, Faculty of Health Sciences, University of Western Ontario.

The primary purpose of Substudy 4 was to test instrumentation and determine the feasibility of data collection strategies in order to identify the final structure of the interview process and the format for the data collection tools for Substudy 5. The pilot study was designed to include more measures than were needed so as to identify those measures that were critical and workable.

The major data collection tools were: a multi-section Client Questionnaire which was used to obtain information about the client directly; a multi-section Caregiver Questionnaire which was used to obtain information from an informal caregiver about his or her experience of providing care to the client; and diaries which assessed health related expenditures for the client as well as assistance and time provided by both informal caregivers and formal service providers. For each tool, information was collected regarding: the amount of time required to complete each instrument; difficulties encountered by clients, informal caregivers, and interviewers with the measurement instruments; and difficulties encountered with obtaining participation. In general, it was noted that both the Client and Caregiver Questionnaires were too long and needed to be revised to be more manageable. As well, the diaries were often incomplete or not completed at all.

Regular teleconferences were held with the investigators and research assistants to

determine which of the measures used in the pilot study would be used in Substudy 5. Instruments were revised based on the results of the interviewing process, the time required to administer the instruments, and the results of the analyses. The instruments for Substudy 5 were gradually refined and included only those items that tapped information relevant to the purposes of the study. In addition, a number of issues which could affect the conduct of Substudy 5 were identified and possible solutions were discussed.

ACKNOWLEDGEMENTS

We would like to acknowledge the work of the research staff and field interviewers. We particularly appreciated the co-operation we received from community and residential service provider organizations and from the individuals who participated in this study.

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1. INTRODUCTION

Concern has been expressed in the media about the cost implications for the health care system of population projections which show a disproportionate increase in the senior population in Canada. The fiscal implications of the “greying” of Canadians (Foot and Stoffman, 1996) have also been seen by health policy makers and planners to pose a significant fiscal challenge for the health care system. Thus, in the past several years, there has been a growing interest by policy makers and planners in the potential use of home care services as a substitute for acute care and long term care residential services in Canada.

There are three major functions of home care:

- The acute care substitution function, where home care meets the needs of people who would otherwise have to remain in, or enter, acute-care facilities;
- The long term care substitution function, where home care meets the needs of people who would otherwise require institutionalization; and
- The maintenance and preventive function which serves people with health and/or functional deficits in the home setting, both maintaining their ability to live independently, and in many cases preventing health and functional breakdowns, and eventual institutionalization (adapted from Federal/Provincial/Territorial Subcommittee on Long Term Care, 1990, p. v).

There is some question about whether or not home care can be a cost-effective alternative to residential care. The work of Hedrick and Inui (1986), Weissert (1985), and others in the United States have contributed to the view that it is not cost-effective to substitute home care for care in an institution. However, more recent work by Canadian researchers such as Hollander (1994, 1999) has challenged this notion. For example, Hollander (1994, 1999) has suggested that home care can, under certain conditions, be a cost-effective alternative to care in long term care facilities.

The cost-effectiveness literature generally only includes cost to payers and does not include the costs to informal care providers. While there is considerable literature on the nature and importance of informal support, little of this literature contains cost-effectiveness data. Logically, however, it would seem that formal support is more likely to be provided where informal support is not available (Chappell, 1992; Chappell & Blanford, 1991; Shapiro & Tate, 1989).

The issue of whether home care is more cost-effective than care in long term care facilities is still unresolved. The interrelation between formal and informal care also requires further study and analysis. Substudies 4 and 5 of the National Evaluation of the Cost-Effectiveness of Home Care focus on the long term care substitution function, that is, on the cost-effectiveness of home care compared to residential care. These substudies also addressed the informal costs of care shouldered by family, friends and volunteers looking after clients living in the community and in long term care facilities.

The primary research question for this study, Substudy 4, was: Is it possible to develop an integrated set of data collection tools for a study of the cost-effectiveness of home care?

2. REVIEW OF INSTRUMENTS

2.1 Introduction

The purpose of Substudy 4 was to test the suitability and acceptability of the instruments selected for both clients and informal caregivers (that is, family, friends, and volunteers who are providing care) as well as to identify issues related to sample selection and response burden. The pilot study was also intended to develop methods for costing services in a consistent manner across community and residential settings.

An extensive review of potential measurement instruments was conducted in 1996 (Hollander, Beebe, & Stark, 1996).¹ Using this review as a starting point, measures were chosen to assess the typical costs and outcomes of care for clients in home care compared to clients in residential care. Measures were also chosen to assess the psychological, social, and financial impacts of care provision on informal caregivers. Information regarding both formal and informal services was collected using diaries completed by clients, caregivers, and formal service providers. Instruments were developed for areas where no acceptable instruments were found.

Except for instruments developed specifically for use in Substudy 4, all of the measures have been extensively used in the literature. A literature review was done for psychometric information on the selected measures. Where such information exists, it is reported below.

The pilot study was purposely designed to include more measures than were needed so as to identify those measures that were critical and workable. Where there were multiple forms for a given topic area which had similar questions, interviewers phrased questions so they could obtain the answers on all similar questions to reduce response burden.

Copies of all the measurement instruments and other data collection forms used in Substudy 4 are included in Appendix A.

2.2 Client Assessment

Two tools were used to assess clients. Client functioning was assessed using either the MDS 2.0 or the Continuing Care Needs Determination Instrument (see below). Additional information regarding clients was collected using a multi-section Client Questionnaire which included: demographic and medical background information; cognitive status information; information related to social relations; information on client satisfaction with services; and information on perceived quality of life.

2.2.1 Comprehensive Assessment and Classification

In order to determine the costs and outcomes of care, it is important to assess the amount of care a client requires. One way to do this is to assess the client's functional abilities.

The "Minimum Data Set" (now the MDS 2.0) is a tool that is often used in long term care

¹ Planning for this study has been ongoing since 1992.

facilities in the United States to assess residents' functioning in a number of areas. The information from the MDS 2.0 is used to establish a reasonable care plan for each resident. Developed by an international consortium, the MDS 2.0 involves assessing a resident's status in the last seven days in several areas. The MDS 2.0 includes clinical and function questions, but not questions on instrumental activities of daily living, informal supports or environmental factors. The MDS 2.0 assesses: cognition; communication; vision; mood and behaviour; psychosocial well-being; physical functioning; continence; disease diagnoses; health conditions; nutritional status; dental status; skin condition; involvement in activities; medications; special treatments and procedures; therapies; and discharge potential. The time required to complete the MDS 2.0 ranges from one to six hours depending on the quality of the information available, the training of the health professional doing the assessment, and the purpose of the assessment (for example, a new admission versus a quarterly review). The MDS 2.0 has been translated and tested for validity and reliability in over 10 countries. It was used in Substudy 4 to assess functioning in facility clients.

In order to assess functioning in community clients, the Continuing Care Needs Determination Instrument (CCNDI) was used. The CCNDI was developed by Alberta Health and Wellness and is based on the MDS 2.0 and the MDS Home Care (MDS-HC) and includes a section on informal supports. Because it is based on the MDS 2.0 and the MDS-HC, the CCNDI assesses many of the same areas: disease diagnoses/disorders; health conditions; communication; vision; nutritional/hydration status; skin condition; continence; physical functioning; cognition; mood and behaviour; involvement in activities; and service utilization (including therapies and special treatments). In addition, an environmental assessment is made.

Although the MDS 2.0 and the CCNDI overlap, they are not identical. In order to obtain the same information on both facility and community clients in Substudy 4, two sets of supplemental questions were developed by the investigators. The CCNDI Supplement included questions which were on the CCNDI, but which were not on the MDS 2.0. This supplement was administered to facility clients, along with the MDS 2.0. The MDS 2.0 Supplement included questions which were on the MDS 2.0, but which were not on the CCNDI. This supplement was administered to community clients along with the CCNDI.

Embedded within the CCNDI is a classification system which allows for the categorization of clients, regardless of whether they live in the community or in facilities.² The Alberta Resident Classification System is a rule based system which classifies clients into seven categories (A-G). The system has been tested for validity and reliability (Charles & Schalm, 1992a, 1992b). An advantage of the Alberta Resident Classification System is that it has been adopted by a number of Canadian provinces and therefore allowed for comparisons among the study sites used in Substudy 4.

² The MDS 2.0 is the basis for a classification system called Resource Utilization Groups (RUG) (Fries, 1990). The recently implemented RUG-III has 44 categories (Fries, Schneider, Foley, Gavazzi, Burke, & Cornelius, 1994). The categories can be collapsed into seven major, but separate domains based on functional need and resource requirements. One advantage of the RUG-III classification system is that it can be used to compare residential clients internationally. A disadvantage, however, is that although it is comprehensive, the RUG-III is clearly linked to long term care facilities and is usually not used in community settings.

2.2.2 Demographic and Medical Background Information

As noted, additional information on clients was collected on the Client Questionnaire. Information was collected on gender, age, marital status, education, ethnic background, medical background, occupational background, and income.

2.2.3 Cognitive Status

It was recognized that the client's *functional* abilities would have a significant impact on both the client and the informal caregiver. It was also recognized that the client's *cognitive* abilities could have an impact on care. Of interest in Substudy 4 was whether the cost(s) of care would differ based on the cognitive status of the clients.

One of the most popular instruments used to assess cognitive status is the Mini-Mental Status Examination (MMSE). The MMSE assesses seven different dimensions of cognitive function: orientation to location and time; registration of information; attention; calculation; short-term memory; written and oral language skills; and visuospatial ability (Folstein, Folstein, & McHugh, 1975). The MMSE has long been used to assess cognition in seniors (Applegate, Blass, & Williams, 1990; Dellasega & Morris, 1993).

The modified MMSE (or 3MS) was developed by adding four more items to the MMSE (Teng & Chui, 1987). These items sample a broader range of cognitive capacity and difficulty levels. The scoring of the items was also changed from a total possible score of 30 on the MMSE to a total possible score of 100 on the 3MS. The test-retest reliability is 0.91 (Teng & Chui, 1987). McDowell, Kristjansson, Hill & Hébert (1997) reported alpha values of .87 and .78 for the 3MS and MMSE, respectively, and split-half reliabilities of .82 and .76, respectively. Because the 3MS allows for more sophisticated scoring than the MMSE, it is more sensitive to subtle losses in cognition than the MMSE (McDowell, et al., 1997). Both the MMSE and the 3MS were used in Substudy 4.

2.2.4 Social Relations

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

Two measures of social relations were included in Substudy 4: the Lubben Social Network Scale and four questions from Seeman and Berkman's Social Support Scale.

The Lubben Social Network Scale was developed specifically for use with elderly populations

(Lubben, 1988). The Social Network Scale consists of ten questions which assess family networks, friends networks, confidant relationships and mutual support resources (such as helping others and cohabitation). The scale takes approximately five to ten minutes to administer and is easily scored. Each of the questions is scored on a five point scale which ranges from 0 to 5. The total score on the scale therefore can range from 0 (no social networks) to 50 (full social networks). Individuals with scores of 20 or less are considered to have limited social networks and may therefore be at risk for social isolation (Lubben, 1988). The internal consistency for the scale is good; Lubben (1988) reported an alpha value of .70.

Seeman and Berkman's (1988) Social Support Scale can be used to examine both instrumental and emotional support. Since the Social Support Scale addresses similar issues to those included on the Lubben Social Network Scale, the entire scale was not used in Substudy 4. However, four questions from the Social Support Scale were thought to be useful to assess social support. Taken together, these four questions address the availability and adequacy of both instrumental and emotional support. The questions can be paraphrased as: 1) When you need some extra help, can you count on anyone to help with daily tasks? 2) Could you have used more help with daily tasks than you received? 3) Can you count on anyone to provide you with emotional support? 4) Could you have used more emotional support than you received?

2.3 Outcome Measures for Clients

In addition to collecting information on functional status, cognitive status and social relations, the Client Questionnaire collected information on several outcome measures including: general health status; beliefs about health; and information regarding perceived quality of life.

2.3.1 Health Status of Clients

The health status of clients was assessed using two instruments: the SF-36 and a measure of the amount of stress clients had experienced in the past year.

The SF-36 is a short, self-report instrument which was constructed for use in the Medical Outcomes Study. The Medical Outcomes Study recorded health data for more than 28,000 adults in three large urban sites in the United States. Consisting of 36 items, the SF-36 is designed to assess a person's perspective on his or her own health status (Ware & Sherbourne, 1992). The items address eight concepts of health: physical functioning; role limitations because of physical health problems; bodily pain; social functioning; general mental health (psychological distress and psychological well being); role limitations because of emotional problems; vitality (energy/fatigue); and general health perceptions. The SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys (Ware & Sherbourne, 1992). The reliability of the eight scales (which correspond to the eight health concepts) have been shown to range from .43 to .96 across 14 studies summarized by Ware, Snow, Kosinski, and Gandek (1997, Table 7.2). The validity of the SF-36 is also reasonably good, (Ware et al., 1997, Table 9-16). The acute version of the SF-36 was used in Substudy 4. This version uses a one week recall period rather than the four week recall period used in the standard version.

The amount of stress clients had experienced in the previous twelve months was assessed using a 20 item scale adapted by the investigators which focused on a variety of stressors including: financial aspects; illnesses and injuries; deaths; and changes in one's personal life.

2.3.2 Beliefs Related to Health

Clients' beliefs about their own health were measured using two instruments: the Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978) and the Self Esteem Scale (Rosenberg, 1965).

The Multidimensional Health Locus of Control Scale developed by Wallston et al. (1978) was used to assess causal beliefs relevant to health. The Multidimensional Health Locus of Control Scale measures three distinct dimensions: internal locus of control; external chance locus of control; and external locus of control by powerful others. The internal locus of control dimension measures the extent to which a person believes health is a function of one's own behaviour. The external chance locus of control measures the extent to which one believes that chance, fate, or luck influences one's health. The external locus of control by powerful others measures the extent to which one's own health status is due to the actions of "powerful" people. Each dimension or subscale consists of six items. Scores on each item are based on a six-point scale which ranges from "Strongly Disagree" (1) to "Strongly Agree" (6). The internal consistency of the subscales is reasonably good; alpha reliabilities range from .67 to .77 (Wallston, et al., 1978).

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

2.3.3 Quality of Life

Three measures of quality of life were included in Substudy 4: Hadorn, Sorensen and Holte's (1995) Health Related Quality of Life Scale; the Terrible-Delightful Scale (Centre on Aging, 1995); and a question on general satisfaction with life.

Hadorn, Sorensen and Holte's (1995) Health Related Quality of Life Scale consists of ten questions which focus on four areas: physical suffering; limits on daily activities; emotional outlook on life; and overall quality of life. The first three areas contain three items each. Each item has a four point response scale with higher scores indicating poorer quality of health. The version of the Health Related Quality of Life Scale used in Substudy 4 was designed to be administered by an interviewer. While nine of the ten questions are addressed to a respondent, the tenth question is the *interviewer's* global estimate of the respondent's quality of life.

The Health Related Quality of Life Scale (which is interviewer administered) correlated well with another measure of quality of life, the Quality of Life and Health Questionnaire (which is self-administered, see Hadorn and Uebersax 1995). Correlations of .48, .72, and .76 were obtained between the two measures at zero, three and six month time intervals, respectively (Hadorn et al., 1995). Test-retest reliabilities for the Health Related Quality of Life Scale were also good. The correlation between scores obtained at time zero and three months was .50. The correlation between scores obtained at time zero and six months was .38 (Hadorn et al., 1995). The correlation between scores at three and six months was .59 (Hadorn et al., 1995).

The Terrible-Delightful Scale (Centre on Aging, 1995) consisted of 10 items which focus on a number of concepts that have been linked to quality of life: health; finances; employment; family relations; friendships; housing; recreation; spirituality; self-esteem; and transportation. For each item, respondents are asked how they would rate their own life with respect to the item using a seven-point scale developed by Andrews and Withey (1976). The scale ranges from “Terrible” (1) to “Mixed” (4) to “Delightful” (7). For this study, two additional categories were included: “Not applicable/no opinion” and “No response”.

Satisfaction with life was assessed using a single item: “How would you describe your satisfaction with life in general at present?” A five-point response scale ranging from “Excellent” to “Bad” was used.

2.4 Use of Services by Clients

In addition to collecting information about the client’s background and various outcome measures, the Client Questionnaire also collected information on the types of assistance the client received, and satisfaction regarding services.

2.4.1 Assistance Related to Health Needs

Assistance related to health needs was assessed using two sets of questions. One set of questions addressed assistance with various tasks provided by informal caregivers. The tasks included household maintenance (meal preparation, housework), personal care (dressing, personal hygiene), physical functioning (moving around the house, getting in and out of bed), and finances (managing finances, shopping).

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

2.4.2 Satisfaction with Services

There are no acceptable existing scales to measure general client satisfaction with services;

questions have to be specific to services. Satisfaction with services was assessed using questions developed by Penning and Chappell (1996). These questions addressed respondents' satisfaction with the services he or she receives, worker characteristics, and care concerns. Respondents' satisfaction with services was assessed using three questions, satisfaction with worker characteristics was assessed using ten questions, and satisfaction with care concerns was assessed using three questions. Responses are scored using a three point scale which ranges from "Rarely" (1) to "Always" (3). Satisfaction with services was also assessed using a number of questions which focused on the cost of services and the ability of the received services to promote client independence.

2.5 Informal Caregivers

Information regarding family members and friends who are providing care to clients was collected using a multi-section Caregiver Questionnaire. This questionnaire included the following: demographic information, information regarding health status; information regarding the type of assistance/care required by the client; information regarding the impact of caregiving; and satisfaction with services. Several of the scales included on the Caregiver Questionnaire were identical to those included on the Client Questionnaire so that comparisons between the client's and caregiver's perceptions on the same aspects of care could be made.

2.5.1 Demographic Information for Caregivers

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

2.5.2 Health Status of Caregivers

The amount of stress caregivers experienced in the past twelve months was assessed using a 20 item scale which was identical to that used on the Client Questionnaire. The items focused on a variety of stressors including: financial aspects; illness and injuries; deaths; and changes in one's personal life.

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

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

The second measure was modified from the Dementia Behaviour Disturbance Scale developed by Baumgarten, Becker and Gauthier (1990). The original scale contained 28 items with a five point response scale which ranged from "Never" (0) to "All the time" (4), with higher scores indicating more behavioural disturbance. The scale was designed to be administered by an interviewer to the primary caregiver. Cronbach's alpha for the 28 item scale was .83 and the test-retest reliability over a two week period was .71 (Baumgarten et al., 1990). The modified scale used in Substudy 4 included 10 items and

the same five point response scale. The items on the modified scale which were taken verbatim from the Dementia Behavior Disturbance Scale all had item to total score correlations of .40 or higher (the average item to total score correlation on the original scale was .42).

2.5.4 Impact of Caregiving

Caregiving can be stressful (burdensome) as well as pleasureable. Two measures were used to assess the impact of the caregiving experience on the informal caregiver: The Montgomery Burden Scale and the Caregiver Reaction Assessment.

The stressful aspects of providing care to a family member or friend was assessed using the Montgomery Burden Scale (Montgomery, Gonyea, & Hooyman, 1985). The Montgomery Burden Scale is a 22 item instrument which measures both objective burden and subjective burden. Objective burden was measured using a nine item inventory and a five point response scale which ranged from “A lot less” to “A lot more”. Objective burden included items such as: amount of time respondent had to him/herself; amount of privacy; and amount of personal freedom. Subjective burden was measured using a thirteen item inventory, and a five point response scale which ranged from “Rarely or never” to “Most of the time”. Subjective burden included items such as: feeling afraid of what the future holds; feeling that one is contributing to the well-being of the person receiving care; and feeling guilty about one’s relationship with the person. Cronbach’s alpha for both inventories was .85 (Montgomery et al., 1985).

The Caregiver Reaction Assessment developed by Given, Given, Stommel, Collins, King, and Franklin (1992) was used to assess both positive and negative aspects of the caregiving experience. This instrument was developed to assess the reactions toward care by family caregivers of elderly individuals with physical impairments, Alzheimer’s disease, and cancer. The tool consists of 24 questions which are scored using a five point scale. Responses on the scale range from “Strongly disagree” (1) to “Strongly agree” (5). The scale includes items such as “My family works together at caring for (the client)”, “I feel privileged to care for (the client)”, and “Caring for (the client) has put a financial strain on my family”. Five of the items are reversed scored. A factor analysis revealed five factors (esteem, support, finance, schedule, and health) All factor loadings were significant. Test-retest correlations for each of the factors at zero, six and twelve months ranged from .78 to .93 (Given et al., 1992).

2.5.5 Caregiver Satisfaction

As with client satisfaction, there are no acceptable existing scales to measure general caregiver satisfaction with services. The caregiver’s satisfaction with the services the client receives was assessed using questions developed by Penning and Chappell (1996). These were similar to the questions used to assess client satisfaction with services. The questions addressed caregivers’ satisfaction with the services clients receive, worker characteristics, and care concerns. Satisfaction with services were assessed with three questions, satisfaction with worker characteristics was assessed with ten questions, and care concerns was assessed with three questions. Responses are scored using a three point scale that ranges from “Rarely” (1) to “Always” (3). Satisfaction with services was also assessed using a number of questions which focused on the cost of services and the ability of the received services to promote client independence.

2.6 Diaries

One of the goals of Substudy 4 was to obtain initial estimates of the costs of formal and informal home care and residential care by examining the use of formal services, unpaid time provided by informal caregivers, and out-of-pocket expenses by both the client and the informal caregivers. There is no existing log book method for collecting these data that has been tested for validity and reliability. Thus, the investigators developed five diaries based on their own experience.³ All diaries were to be kept for a two week period.

Clients were asked to keep a record of their expenditures using the Diary for Care Related Expenditures by the Person Receiving Care (the “Client Expenditures” diary). This diary was used to estimate the cost of caring for the client by adding health-related costs incurred by the clients to the costs of the services provided by the overall health care system. Care-related expenditures which were to be included in the diary included: food for special diets; medical supplies; prescription and non-prescription medications; herbs or other remedies; services of care providers not covered by Medicare, such as herbalists and naturopaths; transportation costs related to care; and other care related expenditures. The diary was intended to be completed by both community and facility clients; facility clients were reminded to include their user and co-payment fees in the diary.

Informal caregivers were asked to keep a similar record of their expenditures related to the care of the client using the Diary for Care Related Expenditures by Family Members or Other Unpaid Helpers for the Person Receiving Care (the “Informal Caregiver Expenditures” diary). This diary was used to estimate the cost of caring for the client incurred by family members or friends. As with the Client Expenditures diary, the Informal Caregiver Expenditures diary was intended to be used for both community and facility clients. Examples of expenditures to be included in the diary were similar to those used for the Client Expenditures diary.

Informal caregivers were also asked to keep a diary of the type of assistance and the amount of time they provided to clients using the Diary of the Assistance Provided by Family Members or Other Unpaid Helpers to the Person Receiving Care (the “Informal Caregiver Time” diary). This diary was used to estimate the costs of unpaid care which is provided by family members or other helpers to the client. It was noted that the diary was to include helping activities which the caregiver would *not* provide to the client if he or she were in good health. Examples of activities which were to be included in the diary included: housekeeping; meal preparation; banking; transportation; giving medication; assistance with medical equipment such as oxygen tanks; assistance with bathing, grooming, and dressing; and supportive help such as visiting and recreational activities.

Health care staff in both the community and the facilities were also asked to keep diaries for a two week period. The assistance and time spent by health care workers and professionals who provided services to community clients were to be recorded in the Diary of Formal Care Services Provided to Persons Receiving Care Services Who Are Living in the Community (the “Formal Services – Community” diary). This diary was to be completed by the client, the informal caregiver, a service provider, or a combination of individuals. The diary was used to record services provided in the home as well as services provided in the community. Examples of activities which could be recorded in this diary

³ The value of diaries as a data collection method in a study of this nature has been discussed by Hollander et al., 1996.

included: visits to the doctor; lab tests; home nursing; home support; physio and occupational therapy; services of mental health staff; and adult day centre.

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

2.7 Summary

In summary, client functioning was assessed using either the MDS 2.0 and the CCNDI Supplement (for facility clients) or the CCNDI and the MDS 2.0 Supplement (for community clients). A variety of measures assessing cognitive functioning, quality of life, and satisfaction with services were included in a multi-section Client Questionnaire. The questionnaire contained the following (in the order in which the measures were included on the questionnaire): additional information (medical background information); Health Related Quality of Life (Hadorn et al.’s Health Related Quality of Life); Life Problems (list of stressors); Terrible/Delightful Scale; General Life Satisfaction (single question); Paid Employment and Income; Demographics; SF-36; Multidimensional Health Locus of Control; Lubben Social Network Scale; Rosenberg Self-Esteem Scale; Seeman and Berkman Social Support Scale; Caregiving (type and amount of assistance provided by informal caregivers); 3MS (and MMSE); Health and Social Service Utilization; and Client Satisfaction (with services).

The impact of caregiving on family members, friends and volunteers was assessed using the Caregiver Questionnaire. This tool also contained several measures. These were (in the order in which they appeared on the questionnaire): Caregiving Questions (type and amount of assistance provided by caregivers); Montgomery Burden Scale; List of Behavioural Problems (modified Dementia Behaviour Disturbance Scale); Caregiver Satisfaction (with services client is receiving); Caregiver Reaction Assessment; Life Problems (list of stressors); Paid Employment and Income; and Demographics.

In addition, four diaries were used to assess expenditures, time, and tasks: Client Expenditures; Informal Caregiver’s Expenditures; Informal Caregiver’s Time; Formal Services – Community *or* Formal Services – Facility.

3. METHODS

3.1 Study Sites

The pilot study was conducted in three sites in order to determine the variations due to differences in service delivery systems among jurisdictions and size of community. The three sites were Winnipeg, Manitoba (urban), London, Ontario (small city), and Charlottetown, Prince Edward Island (rural). Vancouver, British Columbia was originally proposed as a fourth site (which would have provided information about a metropolitan area). However, it was not used due to budget constraints.

3.2 Sample

The intent of Substudy 4 was to obtain data on five clients for each of the highest four care levels using the Alberta Resident Classification System for residential and community based services in each site, that is for Levels D, E, F, and G. Thus, 20 community clients and 20 residential clients were sampled in each site. Data were also collected on the care level classification system in the host province.

Clients were targeted who had been stable at their level and location of care for at least three months. Both cognitively intact and cognitively impaired clients were selected. Clients were chosen so as to have caregivers who were of different ages, different economic statuses and different genders. The selection of clients was also made based on whether or not they were living with their caregiver(s). Sampling grids were used to obtain a variety of clients in terms of level of care and cognitive functioning. When necessary, ten clients for each level of care went through the care level determination process and five of these were selected for inclusion in the pilot study.

Clients were excluded from the study if they: could not speak; could not hear; could not comprehend verbal instructions; did not speak English; had an infectious disease that posed a threat to the interviewer; and/or were physically abusive. Individuals who were mentally challenged (because of Down's syndrome, for example) and those with a mental illness (such as bipolar disorder) were also excluded from the study. However, individuals with a cognitive impairment due to a dementia or a stroke were included.

Staff from both home support agencies and long term care facilities identified a potential pool of clients. Site specific information regarding level of care was then determined from a review of the client's chart. Once potential clients had been identified, agency staff contacted clients and/or families and obtained consent to pass their name onto study personnel. When a potential participant refused, he or she was replaced by someone with similar characteristics.

3.3 Approach

As noted earlier, this study focused mainly on issues related to the ease of administration of instruments, the acceptability of instruments to clients and caregivers, and overall response burden. Data collection involved the use of extensive, multi-faceted instruments for both clients and caregivers. In addition, both clients and informal caregivers maintained diaries tracking care related expenditures. Both

informal caregivers and paid service providers maintained diaries tracking care related time and activities for the clients. Similar instruments were used for both community and facility clients.

Data were gathered between July and November 1999.

4. DESCRIPTION OF THE STUDY SAMPLE

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

This chapter provides descriptive data for both the client and caregiver samples obtained in the pilot study. Chapter 5 provides descriptive data regarding the measures used in Substudy 4, while Chapter 6 provides data regarding the measures selected for use in Substudy 5. Chapter 7 discusses additional issues related to the conduct of Substudy 5.

4.1 Client Sample

Complete data were obtained for 118 clients. In some cases, clients were too ill or cognitively impaired to participate in the study. In these instances, proxies were asked to respond to items regarding factual information, but not those addressing beliefs, feelings, etc.

Table 4-1 provides a description of the client sample in each of the three study sites, that is, Winnipeg, London and Charlottetown. Approximately half of the sample in each site was from the community and overall, half of the clients were receiving home care.

Approximately one third of the clients in the Winnipeg and London sites were male; in the Charlottetown site, slightly less than half of the clients were male. Overall, 37.3% of the sample was male; 62.7% was female. For males, 63.6% were in home care; 36.4% were in residential care. For females, 41.9% were in home care, 58.1% were in facility care. Approximately half (47.5%) of the community clients were male, while only 27.1% of the facility clients were male.

The Winnipeg site had proportionally more elderly clients than the other sites, although the average age was highest in the Charlottetown group. The mean age for the total sample was 82.0 years. Half of the clients in each age group were in the community sample. Over 40% of the clients in both the community and the facility were between 75 and 84 years of age.

The educational level of clients was fairly consistent across study sites with the exception of the “high school graduation” category in Charlottetown. Facility clients tended to have lower educational levels than community clients, but the differences were not significant.

Clients in the Charlottetown site had lower levels of income than clients in the other two sites. Approximately 84% of clients in both the community and the facility samples had incomes of \$20,000 or less.

Table 4-1: Description of Client Sample in the Three Sites

		Site			Total	
		Winnipeg	London	Charlottetown	Number	Percent
		Percent	Percent	Percent		
Type of Care	Community	48.7%	48.6%	52.4%	59	50%
	Facility	51.3%	51.4%	47.6%	59	50%
Gender	Male	33.3%	35.1%	42.9%	44	37.3%
	Female	66.7%	64.9%	57.1%	74	62.7%
Age	< 75 years	12.8%	24.3%	19.5%	22	18.8%
	75 – 84	46.2%	40.5%	41.5%	50	42.7%
	85+	41.0%	35.1%	39.0%	45	38.5%
Education	Grade 8 or less	35.9%	32.4%	38.1%	42	35.6%
	Some high school	17.9%	24.3%	23.8%	26	22.0%
	High school graduation	25.6%	21.6%	2.4%	19	16.1%
	Some technical, trade school or college	20.5%	21.6%	35.7%	31	26.3%
Income	< \$10,000	28.6%	19.2%	47.5%	32	34.0%
	\$10,000 to \$20,000	50.0%	53.8%	50.0%	48	51.1%
	\$20,000 +	21.4%	26.9%	2.5%	14	14.9%
Marital Status of Client	Never Married, Separated or Divorced	7.7%	16.2%	26.2%	20	16.9%
	Married/Common Law	30.8%	40.5%	33.3%	41	34.7%
	Widowed	61.5%	43.2%	40.5%	57	48.3%
Living Arrangement	Lives with Spouse	10.0%	15.8%	22.6%	12	17.1%
	Lives with Other Relatives or Friends	5.0%	5.3%	12.9%	6	8.6%
	Lives with Other Unrelated Individuals	60.0%	52.6%	45.2%	36	51.4%
	Lives Alone	25.0%	26.3%	19.4%	16	22.9%
Number of Medications Used in Last Week	0 to 3	33.3%	31.6%	13.6%	18	26.5%
	4 to 5	25.9%	31.6%	54.5%	25	36.8%
	6 or more	40.7%	36.8%	31.8%	25	36.8%

Overall, just over one-third of the clients in the sample were married. Winnipeg had the highest proportion of widowed clients. Approximately 12% of community clients indicated that they were single, divorced or separated. A further 44.1% of community clients indicated that they were married, and 44.1% indicated they were widowed. In contrast, 22.0% of facility clients indicated they were single, divorced or separated. A further 25.4% indicated they were married and 52.5% indicated they were widowed.

Clients in Charlottetown were less likely to live alone than clients in the other two sites. About half (46.9%) of the community clients lived alone.

The majority of clients in Substudy 4 reported no history of a number of medical conditions (such as mental illness, epilepsy, etc.). Only 16.4% of the clients reported having dental problems, and 29.7% reported having breathing problems.

Some 26.5% of the sample had used less than four medications in the week prior to the study, 36.8% had used four to five medications, and 36.8% had used six or more medications in the previous week. Clients in Winnipeg and London had a similar pattern of medication use; Charlottetown had a relatively higher proportion of clients who used four to five medications. Some 72.9% of community clients had used more than three medications in the week prior to the study. However, only 11.9% of facility clients had used more than three medications in the same time period.

4.2 Caregiver Sample

A total of 78 informal caregivers participated in the study. Table 4-2 presents demographic information for these caregivers for each of the study sites. The table indicates that the majority of caregivers were female. Approximately one third of the caregivers were seniors themselves, and over 18% of the caregivers were over 75 years of age. Over half of the caregivers had some post-secondary school education. Approximately 37% of caregivers indicated that they are currently working and approximately half of these caregivers indicated that they are working 30 to 40 hours a week. Over half of the caregivers had incomes of \$20,000 or less. Over 75% of the caregivers in the London site had incomes of \$20,000 or more. The majority of caregivers were married.

Table 4-2: Description of Caregiver Sample in the Three Sites

		Site			Total	
		Winnipeg	London	Charlottetown	Number	Percent
		Percent	Percent	Percent		
Gender	Male	12.5%	44.4%	22.2%	19	24.4%
	Female	87.5%	55.6%	77.8%	59	75.6%
Age	< 55	45.8%	27.8%	33.3%	28	36.4%
	55 to 64	29.2%	33.3%	27.8%	21	27.3%
	65+	25.0%	33.3%	38.9%	28	36.4%
Education	Grade 8 or less	20.8%	5.6%	11.1%	10	12.8%
	Some high school	8.3%	5.6%	22.2%	11	14.1%
	High school graduation	12.5%	44.4%	16.7%	17	21.8%
	Some technical, trade school or college	58.3%	44.4%	50.0%	40	51.2%
Number of Hours Worked in an Average Week	5-29	30.0%	14.3%	16.7%	6	20.7%
	30 to 40	40.0%	42.9%	66.7%	15	51.7%
	40+	30.0%	42.9%	16.7%	8	27.6%
Income	< \$10,000	29.2%	11.1%	33.3%	21	30.0%
	\$10,000 to \$20,000	16.7%	11.1%	19.5%	13	18.6%
	\$20,000 +	29.2%	77.9%	41.7%	36	51.4%
	\$20,000 +	29.2%	77.9%	41.7%	36	51.4%
Marital Status of Caregivers	Never Married, Separated or Divorced	25.0%	16.7%	27.8%	19	24.4%
	Married/Common Law	70.8%	83.3%	66.7%	56	71.8%
	Widowed	4.2%	0.0%	5.6%	3	3.8%

5. FINDINGS FROM THE INSTRUMENTS USED IN THE PILOT STUDY AND DECISIONS FOR SUBSTUDY 5

5.1 Introduction

The primary purpose of Substudy 4 was to test instrumentation and determine the feasibility of data collection strategies in order to identify the final structure of the interview process and the format for the data collection tools for Substudy 5. Particular attention was paid to information regarding the amount of time required to complete each measurement instrument and difficulties encountered by clients, caregivers, and interviewers with the measurement instruments. Difficulties encountered with obtaining participation were also noted.

Table 5-1 provides a breakdown of the time required to complete each measurement instrument in the pilot study. Table 5-2 provides average times to complete each section of the Client Questionnaire, while Table 5-3 provides average times per section for the Caregiver Questionnaire. In general, it was noted that the questionnaires used in Substudy 4 were too long and needed to be pared down. It was also noted that some sections of the Client Questionnaire were problematic for clients to complete.

Teleconferences were held with the investigators and research assistants to discuss the research findings and the measurement instruments in order to determine which of the measures used in the pilot study would be used in Substudy 5. Instruments were revised based on the results of the interviewing process, the time required to administer the instruments and the results of the analyses. The instruments for Substudy 5 were gradually refined and included only those items that tapped information relevant to the purposes of the study and that were not problematic to administer.

5.2 Assessment of Clients

5.2.1 Comprehensive Assessment and Classification

In Substudy 4, the MDS 2.0 and the CCNDI Supplement were used to collect basic information on facility clients, and the CCNDI and the MDS 2.0 Supplement were used to collect similar information on community clients. On average, it took 193.2 minutes (3.2 hours) to collect the information on facility clients and 161.5 minutes (2.7 hours) to collect the information on community clients. Given the amount of time required to complete these instruments, as well as the fact that much of the data were either not critical to the main purpose of the study or were collected elsewhere, it was decided that the Functional Autonomy Measurement System (SMAF) developed by Hébert, Carrier and Bilodeau (1988) would be used in Substudy 5.

The SMAF obtains the majority of the information that this study requires and takes significantly less time to administer (Hébert et al. noted that, on average, it takes 42 minutes to administer the full instrument). There are a few key questions that the SMAF does not ask; these particular items were retained from the MDS 2.0/CCNDI because they provided additional clinical information. They were added to the end of the Client Questionnaire in a section called Client Chart Review and included information regarding the client's height, weight, weight change, and last influenza vaccination.

Table 5-1: Average Times for Each Measurement Instrument

Measurement Instrument	Average Time In Minutes to Complete Community Clients	Average Time In Minutes to Complete Facility Clients	Average Time In Minutes to Complete All Clients
MDS	--	128.3	128.3
CCNDI Supplement	--	64.9	64.9
CCNDI	74.5	--	74.5
MDS Supplement	87.0	--	87.0
Client Questionnaire	114.8	106.1	111.3
Caregiver Questionnaire	73.7	69.3	71.6
Client Expenditures Diary	30.8	24.3	28.1
Informal Caregiver Expenditures and Time Diaries	40.4	31.4	35.9
Formal Services Diary	37.8	39.0	38.2
Travel Time	116.1	113.3	115.0
“Other” Time (e.g. phone calls, small talk)¹	17.3	17.3	17.3

¹ Estimated figures based on the 41% of the sample for which data were available.

Table 5-2: Average Times to Complete Each Section of the Client Questionnaire

Section Title	Average Time to Complete (in minutes)
Additional Information	13.59
Health Related Quality of Life	7.60
Life Problems	8.32
Terrible/Delightful Scale	11.77
General Life Satisfaction	1.50
Paid Employment and Income	5.95
Demographics	4.64
SF-36	9.14
Multidimensional Health Locus of Control	11.08
Social Network Scale	6.43
Self-Esteem Scale	6.92
Social Support Scale	4.23
Caregiving Questions	9.38
3MS	17.56
Health and Social Service Utilization	14.05
Client Satisfaction	9.15

Table 5-3: Average Times to Complete Each Section of the Caregiver Questionnaire

Section Title	Average Time to Complete (in minutes)
Caregiving Questions	13.82
Montgomery Caregiver Burden Scale	11.94
List of Behavioural Problems	7.03
Caregiver Satisfaction	12.94
Caregiver Reaction Assessment	9.88
Life Problems	7.24
Paid Employment and Income	4.82
Demographics	3.94

5.2.2 Demographic and Medical Background Information

Much of the demographic information was retained for Substudy 5, although most of the medical background information was eliminated as it did not prove to be informative in Substudy 4.

5.2.3 Cognitive Status

Some consideration was given to using the Mental Status Questionnaire rather than the 3MS as the measure of cognitive functioning. The reliability and validity of the Mental Status Questionnaire are quite good and the instrument correlates well with the MMSE. However, the Mental Status Questionnaire has been criticized for not being sensitive in cases where there is mild to moderate dementia since it has been shown to have a significant false positive rate (MacKenzie, Copp, Shaw, & Goodwin, 1996; Nelson, Fogel & Faust, 1986). Nelson et al. (1986) have noted that false positive errors were more common among individuals with less education and lower socioeconomic status. In a study involving community clients, the Mental Status Questionnaire was found to have lower sensitivity and specificity than the MMSE (MacKenzie, et. al., 1996). It was therefore decided that the 3MS would be retained for use in Substudy 5.

5.2.4 Social Relations

The Lubben Social Network Scale appeared to overlap somewhat with the questions from Seeman and Berkman's Social Support Scale. The investigators considered which was more important or useful to have: detailed information regarding clients' social networks (which can provide some information regarding social support) or more limited information that directly assesses clients' perceived levels of social support. Consideration was also given to only including some sections of these two scales.

It was decided that the Social Network Scale would be dropped from the Client Questionnaire, with the exception of one question which would be reworded as "How many people do you live with?" In order to get an idea of the size of the client's social network, it was decided that a question regarding the number of people a client has regular contact with would be included. The four questions from Seeman and Berkman's Social Support Scale were retained for Substudy 5.

5.3 **Outcome Measures for Clients**

5.3.1 Health Status

Much of the information included on the SF-36 was also collected elsewhere (for example, on the SMAF). Therefore, the SF-36 section of the Client Questionnaire was reduced to three questions for Substudy 5. These three questions were taken from the standard version of the SF-36 (as opposed to the acute version of the SF-36 which was used in Substudy 4) as it was felt that the general time frame used for the questions in the standard version was more appropriate for Substudy 5. The three questions were: "In general, would you say your health is..."; "Compared to one year ago, how would you rate your health in general now?"; and "During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?"

The measure assessing the amount of stressors clients had experienced in the past year was not informative as few clients indicated they had experienced any of the situations or events included in this measure. This measure was therefore dropped for Substudy 5.

5.3.2 Beliefs Related to Health

The Multidimensional Health Locus of Control Scale was very problematic for clients as they had difficulty both with the questions and the response scale. This measure, therefore, was not included in Substudy 5 as it was felt that the information obtainable from this instrument would not be critical to the study.

Although clients often found the response scale for the Rosenberg Self-Esteem Scale difficult to use, the investigators felt that self-esteem may be an important intervening variable for quality of life and satisfaction measures. Therefore, this scale was retained for use in Substudy 5.

5.3.3 Quality of Life

The Health Related Quality of Life Scale and the single item addressing life satisfaction were both retained for use in Substudy 5. The Terrible/Delightful Scale was also retained for use in Substudy 5. However, the number of response categories for this instrument was reduced from seven to three (“Dissatisfying”, “Mixed” and “Satisfying”) as many clients found the seven response categories used in the pilot study too confusing.

5.4 Use of Services by Clients

5.4.1 Assistance Related to Health Needs

Some alterations were made to the wording of the questions related to the types of assistance provided by informal caregivers. These changes were made in an effort to capture how much additional help was being provided to clients by informal caregivers as a result of the client’s increased need for care. The investigators felt that the pilot study had not captured this information adequately as the questions used in Substudy 4 did not distinguish between help that is given as part of normal family relationships and additional help that is provided because of the client’s care needs. Given that measuring the informal costs of care (that is, the psychological, social and financial burdens shouldered by family and friends) is a major part of Substudy 5, this distinction was considered to be very important and was incorporated into Substudy 5.

The items on health and social service utilization were retained. A question on large expenditures (defined as \$100 or more), such as the purchase of a walker, special clothing, etc. was added.

5.4.2 Satisfaction with Services

Some of the questions regarding the client’s satisfaction with services were eliminated in order to make this section shorter and more manageable. These were questions 4, 10, 12, 15, 16, 20, 22, 23, 24, 25, and 26.

5.5 Caregiver Instruments

There were three sources of information regarding informal caregivers in the pilot study: informal support questions from the CCNDI; the Caregiver Questionnaire; and the diaries. It was noted that by using the SMAF rather than the CCNDI and MDS 2.0 in Substudy 5, some of the redundancy regarding informal caregivers could be eliminated.

In general, the Caregiver Questionnaire worked well. In some cases, caregivers did not understand certain wording or concepts because of language difficulties. Thus, for the most part, minor changes were made to the Caregiver Questionnaire.

In some cases, such as the section on the provision of assistance, the modifications involved changes in wording or format (for example, categories were included for a question pertaining to the relationship between the caregiver and the client). A question focusing on how much income the caregiver had lost as a result of providing care for the client was added to the section on paid employment and income. As with the Client Questionnaire, the section regarding satisfaction with services was shortened by removing questions 4, 10, 12, 15, 16, 20, 22, 23, 24, 25, 26, and 27.

Some sections were eliminated from the Caregiver Questionnaire in order to make it shorter and more manageable. As with the Client Questionnaire, the section on the number of stressors caregivers had experienced within the past year was not very informative and was therefore removed. Based on the findings of the pilot study, the Caregiver Reaction Assessment seemed to apply mainly to those caregivers who had the client at home. As this scale did not provide crucial information, and because it was felt that the Montgomery Burden Scale was a better measure since it provided information on both objective burden and subjective burden, the Caregiver Reaction Assessment was dropped from Substudy 5.

The final version of the Caregiver Questionnaire contained items related to the provision of assistance to clients and satisfaction with services that were similar to those included on the Client Questionnaire. The Caregiver Questionnaire also asked about the type of assistance provided by caregivers as well as the impact of providing care as measured by the Montgomery Burden Scale.

5.6 Other Changes to the Client and Caregiver Questionnaires

Based on the input from clients, caregivers, and interviewers, other minor changes were made to both the Client and Caregiver Questionnaires, such as altering the wording of certain questions to make them less subjective and/or easier to understand. As well, some of the sections in both instruments were rearranged.

5.7 Diaries

The Client Expenditure diaries were not overly informative as many clients indicated that they did not have many expenditures themselves. They often noted that their informal caregivers or the facility covered their expenditures. It was decided that while it was important to obtain information regarding care-related expenditures for the client, it was not important to identify who was spending the money. Thus, for Substudy 5, it was decided that the expenditures by clients and the expenditures by caregivers would be combined into one diary that could be completed by the client and/or the informal caregiver. In addition, facilities would be asked to provide information

regarding small money items, such as the purchase of hairdressing or foot care services and tuck shop items.

In general, the diaries completed by formal service providers were more complete than those filled out by either clients or their informal caregivers. However, on several occasions, the Formal Services – Facility diaries were filled out in detail for the first few days and then entries tapered off. To address this, the investigators considered several approaches to increase the likelihood of having these diaries completed. For example, the investigators discussed whether both task and time information needed to be included in the Caregiver Time, Formal Services – Community, and Formal Services – Facility diaries. It was noted that as care plans list tasks such as hygiene, mobility, meal assistance, dietary, pastoral and other activities, it might be sufficient to collect information related only to time spent. However, it was decided that task, time, and type of worker were all necessary to determine the costs of services provided. The investigators considered the possibility of keeping the diaries by the client's bedside in an effort to increase completion rates. The investigators also considered hiring someone to speak with service providers at the end of their shifts so as to collect appropriate diary information on a daily basis.

The response rate for all of the diaries was poor in the pilot study. It was therefore decided that clients, informal caregivers, and service providers would be contacted every few days in Substudy 5 to ensure that they were completing the diaries. It was hoped that this process of continuous contact would yield a higher completion rate.

5.8 Summary Regarding Measurement Instruments for Substudy 5

In summary, it was decided that in Substudy 5, information regarding the impact of needed health care services would be addressed using five instruments: the Client Questionnaire, the Caregiver Questionnaire, the Expenditures diary, the Informal Caregiver Time Diary, and either the Formal Services – Community or the Formal Services – Facility diary. With the exception of the Formal Services diaries, it was intended that the same instruments would be used for both community and facility clients and their informal caregivers.

In Substudy 5, the Client Questionnaire will be used to obtain information about the client directly. This multi-section instrument will include the following (in the order in which they appear on the questionnaire): Demographics; Client Satisfaction; 3MS; SMAF; Health and Social Service Utilization; Health Related Quality of Life: Terrible/Delightful Scale; General Life Satisfaction; SF-36 (three questions); Self-Esteem Scale; Social Support; Caregiving; and Paid Employment and Income.

The Caregiver Questionnaire will be used to obtain information from a family member, friend, or other informal caregiver about their experience of providing care to the client. It will also address the psychological, social, and financial impact that providing care to the client has on the informal caregiver. This multi-section instrument will include the following measures in Substudy 5 (again, in the order in which they appear on the questionnaire): Caregiving Questions; Montgomery Caregiver Burden; List of Behavioural Problems; Caregiver Satisfaction; Paid Employment and Income; and Demographics.

The final version of each of the measures to be used in Substudy 5 are presented in Appendix B. Table 5-4 provides an estimate of the time needed to complete each of the Substudy 5

instruments. On average, based on the findings from the pilot study, it is estimated that the Substudy 5 instruments will take approximately 408.2 minutes (or 6.8 hours): 118 minutes (1.97 hours) for the Client Questionnaire; 55 minutes (.92 hours) for the Caregiver Questionnaire; 64 minutes (1.1 hours) for the Client Expenditure and Informal Caregiver’s Time diaries; 38 minutes (.63 hours) for the Formal Services diary; and 133 minutes (2.2 hours) for phone calls and travel time. In contrast, the pilot study took an average of approximately 593 minutes (9.9 hours) for both community and facility clients.

Table 5-4: Estimates of Time Needed to Complete Substudy 5 Survey Instruments

Instrument	Section Title	Estimated Average Time to Complete (in minutes)
Client Questionnaire	Demographics	7.00
	Client Satisfaction	7.00
	3MS	18.00
	SMAF	20.00 ¹
	Health and Social Service Utilization	16.00
	Health Related Quality of Life	7.50
	Terrible/Delightful Scale	8.00
	General Life Satisfaction	1.00
	SF-36 Items	1.50
	Self-Esteem Scale	7.00
	Social Support Scale	4.00
	Caregiving	15.00
	Paid Employment and Income	6.00
	Subtotal for Client Questionnaire	118.00 ²
Caregiver Questionnaire	Caregiving Questions	20.00
	Montgomery Caregiver Burden Scale	8.00
	List of Behavioural Problems	7.00
	Caregiver Satisfaction	8.00
	Paid Employment and Income	8.00
	Demographics	4.00
	Subtotal for Caregiver Questionnaire	55.00 ³
Diaries	Client Expenditures ⁴	28.10 ⁵
	Informal Caregiver’s Time	35.90
	Formal Services ⁶	38.20
	Subtotal for Diaries	102.20
Additional Time	Other (e.g. phone calls, small chat)	18.00 ⁷
	Travel Time	115.00 ⁸
	Subtotal Additional Time	133.00
Grand Total		408.20

¹ Only part of the SMAF will be used in Substudy 5.

² Total time for the Client Questionnaire in Substudy 4 was 111.3 minutes.

³ Total time for the Caregiver Questionnaire in Substudy 4 was 71.6 minutes.

⁴ The Client Expenditures and Informal Caregiver Expenditures diaries were combined into one for Substudy 5.

⁵ The estimated times for the all of the diaries are the same as those obtained in Substudy 4.

⁶ The estimated time is the same for both the Formal Services – Community and the Formal Services – Facility diaries.

⁷ The average time for Substudy 4 was 17.3 minutes.

⁸ The estimated time is the same as for Substudy 4.

6. FINDINGS FROM THE PILOT STUDY FOR THE MEASURES TO BE USED IN SUBSTUDY 5

6.1 Introduction

To provide a basis for sample size calculations for Substudy 5 and to allow for comparisons between Substudies 4 and 5, this chapter reports selected results only for those measures that will be used in the larger study. As the intent of Substudy 5 is to compare and contrast the relative costs and outcomes of service for clients in home care and residential care by level of care, a similar approach was used to analyze the data from Substudy 4.

6.2 Classifying Clients by Level of Care

In order to compare the costs and outcomes of service for community and facility clients, it is important to make comparisons between clients at the same level of care. Initially, the Alberta Resident Classification System was intended to be used in the pilot study as a means of classifying both community and facility clients with regard to their level of care using eight items related to activities of daily living (ADLs). Scores on the ADL items were obtained from either the MDS 2.0/CCNDI Supplement (for facility clients) or the CCNDI/MDS 2.0 Supplement (for community clients). A preliminary analysis of the pilot data revealed that while there was some discrimination using the Alberta Resident Classification System, there was little discrimination in the sample between categories D and E for the London and Charlottetown sites. With regard to the Winnipeg site, level 3 on the Manitoba classification (which was converted to E on the Alberta system) had a lower average score than the E category level in the other two sites. In addition, in the Winnipeg sample, community clients had higher ADL scores than facility clients.

Due to the above problems, it was clear that it would not be possible to have a good comparison within levels of care using the data collected on the classification system in Substudy 4. Therefore, using the ADL data, a three level post hoc classification system was created by one of the investigators (Hollander). Clients who had scored very low and should not have been included in the study were excluded, as were two very heavy or chronic care clients, as most of the samples did not include chronic care clients. In this classification system, clients with scores of 7 to 15 were considered to have “low” care levels, those with scores of 16 to 21 to have “medium” care levels and those with scores of 22 to 30 to have “high” care levels.

The means and standard deviations for the three care levels (low, medium, and high) and the type of care (community, facility) are presented in Table 6-1. It can be seen that, based on the mean scores, there is good separation between the three levels of care. An analysis of variance on level of care was significant, $F(2) = 313.18, p < .001$. The scores are also similar within a level of care for both community and facility clients ($F(1) = .89, p > .05$). Table 6-2 presents the mean scores for each of the care levels for each of the study sites. A two-way analysis of variance revealed a significant interaction between study site and care level, $F(2, 4) = 3.07, p < .05$ as well as a significant main effect for care level, $F(2) = 261.69, p < .001$. The main effect of study site was not significant, $F(2) = 1.41, p > .05$. Therefore, the findings from the pilot study are generally presented in terms of type of care and level of care.

Table 6-1: Group Statistics for Created Classification System

							95% Confidence Interval of the Difference	
Care Level	Type of care	N	Mean	Std. Deviation	St. Error Mean	Sig. (2-tailed)	Lower	Upper
Low	Community	15	11.40	2.47	.64	.856	-2.09	1.75
	Facility	14	11.57	2.56	.69	.856	-2.09	1.75
Medium	Community	10	18.70	1.34	.42	.934	-1.17	1.27
	Facility	20	18.65	1.63	.36	.929	-1.17	1.21
High	Community	16	24.56	2.50	.63	.488	-2.12	1.03
	Facility	19	25.11	2.08	.48	.496	-2.15	1.07

Table 6-2: Mean ADL Scores by Care Level for Each Study Site

Site	Care Level	N	Mean	Std. Deviation
Winnipeg	Low	14	11.14	2.66
	Medium	8	18.88	1.73
	High	6	24.67	1.97
	Total	28	16.25	6.02
London	Low	10	10.70	1.95
	Medium	9	18.33	1.00
	High	10	25.80	2.66
	Total	29	18.28	6.67
Charlottetown	Low	5	14.00	1.22
	Medium	13	18.77	1.74
	High	19	24.42	2.09
	Total	37	21.03	4.26
Total	Low	29	11.48	2.47
	Medium	30	18.67	1.52
	High	35	24.86	2.26
	Total	94	18.76	5.91

For the study site x care level interaction, $F(2, 4) = 3.07, p < .05$.
 For care level, $F(2) = 261.69, p < .001$.

6.3 Measures for Client Assessment

6.3.1 Client Assessment

The cognitive status of clients was assessed in the pilot study using both the MMSE and the 3MS (the MMSE was embedded within the 3MS). For both scales, lower scores are associated with greater cognitive impairment. In general, individuals are considered to be cognitively intact if their MMSE score is 24/30 or greater; for the 3MS, individuals who score higher than 77/100 are considered to be cognitively intact (Tombaugh, McDowell, Kristjansson, & Hubley, 1996).

With regard to the level of cognitive impairment in the various study sites, the clients in Winnipeg had greater levels of cognitive impairment compared to the other two sites on both the MMSE and the 3MS. Some 31.6% of Winnipeg clients scored 15 or less on the MMSE. The comparable rates for London and Charlottetown were 15.8% and 13.3% respectively. For the 3MS, some 30% of Winnipeg clients had a score of 50 or less, compared to an average of 10% for the other two sites. The differences among the study sites were not significant, however.

It is generally believed that dementia is related to placement in a facility. Table 6-3 illustrates that there is a modest relation between cognitive functioning (as measured by the 3MS) and level of care. People with higher care needs were likely to have higher levels of cognitive impairment (that is, lower scores), than individuals with lower care needs in the facilities. The pattern was more mixed for clients in the community. Overall, facility clients had higher levels of cognitive impairment than community clients. An analysis of variance, however, revealed no significant differences for either care level or type of care, nor a significant interaction.

6.3.2 Social Relations

As noted in Chapter 5, the four items from Seeman and Berkman's Social Support Scale were retained for use in Substudy 5.

Similar results were obtained for both community and facility clients. Approximately 52% of clients in both care settings indicated that they received instrumental support and approximately 20% indicated that they needed more. Some 44% of clients in both care settings indicated that they received emotional support and again, 20% of clients indicated that they needed more.

Over half of the low and high care clients indicated that they received instrumental support (65.5% and 54.5% respectively), but only 41.4% of medium care clients indicated that they did so. The results were similar for emotional support. Some 65.5% of clients in the low care level indicated that they received emotional support, while 27.6% and 45.5% of clients in the medium and high care levels, respectively, indicated that they received emotional support. Almost 7% of clients in the low care level indicated that they could use more instrumental support and more emotional support. For clients at the medium care level, 27.5% indicated that they could use more support in both areas. However, 33.4% of clients at the high care level indicated they could use more instrumental support, while 18.2% of clients at this care level indicated they could use more emotional support.

Table 6-3: Mean 3MS Scores by Level of Care and Type of Care

		Type of Care		
Care Level		Community	Facility	Total
Low	N	9	12	21
	Mean	72.43	75.71	74.30
	Std. Deviation	18.98	12.77	15.38
Medium	N	4	10	14
	Mean	86.29	67.92	73.17
	Std. Deviation	9.82	19.41	18.90
High	N	8	12	20
	Mean	69.11	60.56	63.98
	Std. Deviation	22.82	22.09	22.20
Total	N	21	34	55
	Mean	73.81	68.07	70.26
	Std. Deviation	19.54	19.01	19.24

6.4 Outcome Measures for Clients

6.4.1 Health Status of Clients

In Substudy 4, the health status of clients was assessed using the full SF-36. However, only three questions from the SF-36 will be used in Substudy 5. Of these, only one question, the one addressing general health status, is identical to that used in Substudy 4.

In the pilot study, clients' perceptions of their general health were relatively consistent across study sites. Overall, 21.4% of clients rated their general health as "Excellent" or "Very good", 27.1% rated their health as "Good" and 51.4% rated their health as "Fair" or "Poor". These differences were significant, $\chi^2 (2) = 10.66, p < .01$. There were no significant differences among the study sites.

Some 18.8% of community clients and 23.7% of facility clients rated their health as "Excellent" or "Very good"; 28.1% of community clients and 26.3% of facility clients rated their health as "Good"; and 53.1% of community clients and 50.0% of facility clients rated their health as "Fair" or "Poor". These differences were significant for community clients, $\chi^2 (2) = 6.06, p < .05$. The differences were not significant for facility clients.

The percentage of clients rating their general health as "Excellent" or "Very good" was 28.6%, 26.7% and 21.1% for low, medium, and high care levels, respectively. The percentage of clients rating their general health as "Good" was 28.6%, 13.3% and 36.8%, for low, medium, and high care levels, respectively. Finally, the percentage of clients rating their general health as "Fair" or "Poor" was 42.9%, 60.0%, and 42.1% for the low, medium, and high care levels. None of these differences were significant.

6.4.2 Beliefs About Health

The data from the Rosenberg Self-Esteem Scale are presented in Table 6-4. Higher scores represent higher self-esteem. There were no significant differences between study sites. There were also no significant differences for either type of care or level of care.

6.4.3 Quality of Life

Substudy 4 collected data on Hadorn et al.'s (1995) Health Related Quality of Life Scale which assesses quality of life in four areas: physical suffering; limits on daily activities; emotional outlook on life; and overall quality of life. The total score is based on the first three areas (each of which contains three items). Higher scores are indicative of poorer health related quality of life. The data are presented in Table 6-5. Community clients scored significantly lower on the emotional outlook on life subscale (indicative of better health) than facility clients (4.91 versus 6.15, $F(1) = 7.2, p < .01$). There were no significant differences, either between type of care (community versus facility) or among care levels (low, medium, high) for either the physical pain or daily activities subscales. There were also no significant differences for the total score for study site, type of care or level of care.

Table 6-4: Scores on the Rosenberg Self-Esteem Scale

		Type of Care		
Care Level		Community	Facility	Total
Low	N	7	10	17
	Mean	28.71	28.00	28.29
	Std. Deviation	3.68	2.45	2.93
Medium	N	5	8	13
	Mean	28.80	26.63	27.46
	Std. Deviation	1.30	3.11	2.73
High	N	6	9	15
	Mean	28.33	29.00	28.73
	Std. Deviation	3.01	5.22	4.35
Total	N	18	27	45
	Mean	28.61	27.93	28.20
	Std. Deviation	2.81	3.74	3.38

Table 6-5: Mean Scores on the Health Related Quality of Life Scale

		Type of Care		
Care Level		Community	Facility	Total
Low	N	9	11	20
	Mean	23.67	24.91	24.35
	Std. Deviation	4.53	4.83	4.61
Medium	N	6	10	16
	Mean	23.50	27.40	25.94
	Std. Deviation	2.07	4.62	4.25
High	N	5	12	17
	Mean	21.00	22.67	22.18
	Std. Deviation	2.83	3.98	3.68
Total	N	20	33	53
	Mean	22.95	24.85	24.13
	Std. Deviation	3.58	4.75	4.41

The Terrible-Delightful Scale focused on a number of concepts that have been linked to quality of life. Higher scores are indicative of greater satisfaction with these concepts. The data are presented in Table 6-6. There were no significant differences among study sites. As well, there were no significant differences between type of care and level of care.

In Substudy 4, satisfaction with life was assessed using a single item. This same item will be used in the larger study. Overall, 52.9% of clients indicated that their satisfaction with life was “Excellent” or “Good”, 37.1% indicated that it was “Fair”, and 10.0% indicated that it was “Poor” or “Bad”. More of the Winnipeg clients felt that their satisfaction with life was “Poor” or “Bad” than clients in the other two sites (20.0%, 10.5%, and 3.2% of clients in Winnipeg, London, and Charlottetown, respectively, rated their satisfaction with life as “Poor” or “Bad”).

Some 63.6% of community clients indicated that their satisfaction with life was “Excellent” or “Good”, 27.3% indicated it was “Fair”, and 9.1% indicated it was “Poor” or “Bad”. These differences were significant, $\chi^2(2) = 15.27, p < .001$. Facility clients generally rated their satisfaction with life lower: 43.2% rated it as “Excellent” or “Good”; 45.9% rated it as “Fair” and 10.8% rated it as “Poor” or “Bad”. These differences were also significant, $\chi^2(2) = 8.49, p < .01$.

The ratings of satisfaction with life were comparable for all three levels of care, although more clients at the medium care level indicated their satisfaction with life was “Poor” or “Bad”. For clients at the low care level, 57.1% of clients rated their satisfaction with life as “Excellent” or “Good”, 38.1% rated it as “Fair”, and 4.8% rated it as “Poor” or “Bad”. For clients at the medium care level, 46.7% of clients rated their satisfaction with life as “Excellent” or “Good”, 40.0% rated it as “Fair” and 13.3% rated it as “Poor” or “Bad”. For clients at the high care level, 47.4% of clients rated their satisfaction with life as “Excellent” or “Good”, a further 47.4% rated it as “Fair” and 5.3% rated it as “Poor” or “Bad”.

6.5 Service Use by Clients

6.5.1 Assistance Related to Health Needs

Table 6-7 presents data on clients’ estimates of the hours of informal caregiving assistance they receive each week by level of care and type of care. There were no significant differences among the study sites. There was no significant interaction between type of care and level of care, nor was the main effect for level of care significant. However, the main effect of type of care was significant, with community clients estimating that they received more assistance than facility clients ($F(1) = 5.75, p < .05$).

Table 6-8 presents data on the types of health services clients had used in the two weeks prior to the study. Although almost 40% of the clients had seen a primary care physician in the specified time period, 83% had only seen their physician once. Some 22% of clients indicated that they had had a hospital admission in the two weeks preceding the study. Of these, 28% had spent three days or less in hospital and 48% had spent less than a week. Some 24.5% of clients receiving homemaker services reported that they had paid for some or all of the services. Approximately 43% of clients receiving Meals on Wheels indicated that they paid for the service. Some 45.7% of clients indicated that they had no expenditures related to health care supplies in the two weeks prior to the study.

Table 6-6: Mean Scores on the Terrible-Delightful Scale

		Type of Care		
Care Level		Community	Facility	Total
Low	N	9	12	21
	Mean	4.89	4.73	4.80
	Std. Deviation	.52	.69	.61
Medium	N	6	10	16
	Mean	5.02	4.53	4.71
	Std. Deviation	.33	.83	.71
High	N	7	12	19
	Mean	4.91	4.79	4.84
	Std. Deviation	.85	.84	.82
Total	N	22	34	56
	Mean	4.93	4.69	4.79
	Std. Deviation	.58	.77	.71

Table 6-7: Average Number of Hours Per Week of Assistance Provided by Informal Caregivers As Estimated by Both Clients and Caregivers

Care Level	Type of Care	Clients			Caregivers		
		Number	Mean	Standard Deviation	Number	Mean	Standard Deviation
Low	Community	5	23.00	20.51	10	64.15	66.31
	Facility	9	6.31	3.83	3	14.67	15.53
	Total	14	12.27	14.40	13	52.73	61.72
Medium	Community	4	65.25	73.87	9	90.17	60.58
	Facility	7	29.43	61.21	12	10.21	17.71
	Total	11	42.45	64.90	21	44.48	57.31
High	Community	7	56.57	76.24	15	100.87	58.06
	Facility	12	5.92	2.94	15	6.73	5.54
	Total	19	24.58	50.73	30	53.80	62.72
Total	Community	16	48.25	62.05	34	87.24	61.38
	Facility	28	11.92	30.76	30	8.92	12.53
	Total	44	25.13	47.43	64	50.52	59.98

For type of care for clients, $F(1) = 5.75, p < .05$.
 For type of care for caregivers, $F(1) = 31.61, p < .001$.

Table 6-8: Health Services Used in the Previous Two Weeks

Health Service	Number of Clients	Percentage of Clients
Primary Care Physician Visit	47	39.8
Physician Specialist Visit	10	8.5
Emergency Room Visit	2	1.7
Hospital Admission	26	22.0
Community Nurse Visit	32	27.1
Homemaker Visit	49	41.5
Meals on Wheels	7	6.1
Physiotherapist Visit	8	7.0
Occupational Therapist Visit	6	5.3
Social Worker Visit	4	3.5
Nutritionist	8	7.0
Research Nurse	2	1.8
Chiropractors	1	.9
Psychologists	2	1.8
Other Health Care Providers	28	24.8
Laboratory Services at Hospital	18	16.1
Laboratory Services Outside Hospital	16	14.2

Some 33.9% of community clients had seen a primary care physician in the previous two weeks, while 45.8% of facility clients had done so. Some 11.9% of community clients had seen a specialist in the two week prior to the study, although only 5.1% of facility clients had seen one. Only 1.7% of both community and facility clients had gone to emergency in the two weeks prior to the study. More community clients than facility clients had had a hospital admission in the previous two weeks, 30.5% to 13.6%, respectively.

6.5.2 Satisfaction with Services

In Substudy 4, both clients and caregivers were asked several questions regarding satisfaction with the services the client was receiving. Higher scores indicate greater satisfaction. Table 6-9 presents data on three scales related to the amount of choice the client has regarding services, worker characteristics, and care concerns. An analysis of variance revealed that Winnipeg clients were less satisfied with the amount of choice the client had regarding services, $F(2) = 3.23, p < .05$. There were no significant differences among the study sites for either worker characteristics or care concerns.

For the Client Choice subscale, type of care was marginally significant, $F(1) = 3.87, p < .06$. However, community clients rated their satisfaction with worker characteristics significantly higher than facility clients, $F(1) = 5.11, p < .05$. Level of care was significant with respect to the Care Concerns subscale, $F(2) = 3.74, p < .05$.

Clients were asked to rate their satisfaction regarding the cost, quality and effectiveness of the care provided. Overall, 72.7% of the clients were very satisfied with the cost of care. The London site had the lowest proportion of clients who were satisfied with the cost of care. A greater proportion of clients in the Charlottetown site were very satisfied with the services received compared to the other two sites.

Overall, some 51.7% of the clients rated services as “Very Effective”; only 11.7% rated services as “Not Very Effective”. The highest proportion of clients who rated services as “Very Effective” was in Charlottetown (59.3%) and the lowest was in Winnipeg (40.0%). Some 26.7% of the clients in Winnipeg rated services as “Not Very Effective”, while only 3.7% of the clients in Charlottetown rated services as “Not Very Effective”.

6.6 **Findings from Caregiver Measures**

6.6.1 Caregiving Assistance Required as a Result of Client’s Needs

Caregivers’ estimates of the average number of hours of assistance that clients receive each week by level of care is presented in Table 6-7. Overall, informal caregivers estimated that they provided more assistance than clients estimated. There were no significant differences in mean estimates among study sites. However, caregivers of community clients estimated that they provided significantly more assistance than caregivers of facility clients, $F(1) = 31.61, p < .001$. There were no significant differences either for level of care or for the interaction between care level and type of care.

Table 6-9: Client Satisfaction with Services

		Client Choice ¹			Worker Characteristics ²			Care Concerns ³		
		Type of Care			Type of Care			Type of Care		
Care Level		Community	Facility Care	Total	Community	Facility Care	Total	Community	Facility Care	Total
Low	N	9	12	21	8	8	16	5	7	12
	Mean	3.89	4.25	4.10	25.88	26.50	26.19	14.80	14.43	14.58
	Std. Deviation	1.05	1.54	1.34	3.68	3.21	3.35	3.42	2.57	2.81
Medium	N	4	10	14	4	7	11	2	4	6
	Mean	5.75	3.80	4.36	29.25	25.29	26.73	20.00	16.75	17.83
	Std. Deviation	2.06	1.23	1.69	.96	4.15	3.82	.00	1.71	2.14
High	N	6	12	18	3	10	13	3	7	10
	Mean	5.17	4.08	4.44	30.00	25.40	26.46	16.67	13.86	14.70
	Std. Deviation	1.72	1.73	1.76	.00	3.60	3.71	1.53	3.08	2.95
Total	N	19	34	53	15	25	40	10	18	28
	Mean	4.68	4.06	4.28	27.60	25.72	26.43	16.40	14.72	15.32
	Std. Deviation	1.63	1.50	1.56	3.27	3.53	3.51	3.17	2.74	2.96
For Worker Characteristics, type of care was significant, $F(1) = 5.11, p < .05$. For Care Concerns, level of care was significant, $F(2) = 3.74, p < .05$.										

¹ Maximum score is 9.

² Maximum score is 30.

³ Maximum score is 24.

The amount of caregiving assistance required was also assessed using the modified Dementia Behaviour Disturbance Scale (that is, the List of Behavioural Problems). The data are presented in Table 6-10. Higher scores are indicative of more behavioural disturbance. There were no significant differences among the study sites. There were also no significant differences for type of care or level of care.

6.6.2 Impact of Caregiving

The Montgomery Burden Scale was used to assess both objective burden and subjective burden as it relates to the provision of care to clients. The data are presented in Tables 6-11a and 6-11b. Higher scores indicate greater burden.

An analysis of variance on objective burden scores revealed a significant interaction between type of care and care level, $F(1, 2) = 5.81, p < .01$. Type of care was also significant: informal caregivers of community clients reported greater burden than informal caregivers of facility clients, $F(1) = 17.18, p < .001$. There were no significant differences for level of care. An analysis of variance on subjective burden scores revealed no significant differences.

6.6.3 Caregiver Satisfaction with the Services the Client is Receiving

As with the clients, informal caregivers were asked several questions related to satisfaction with the care services the client was receiving. As noted, these questions were similar to those used to address client's satisfaction with services. The data are presented in Table 6-12. It appears that caregivers' satisfaction scores were generally similar to clients' satisfaction scores regardless of level of care or type of care. Winnipeg clients indicated less satisfaction with worker characteristics than clients in the other two study sites ($F(2) = 11.86, p < .001$). No other differences were significant among the study sites.

Caregivers of community clients were significantly more satisfied than caregivers of facility clients with respect to Client Choice, $F(1) = 9.82, p < .01$. No other differences were significant for this subscale. There were no significant differences for the Worker Characteristics or Care Concerns subscales.

Overall, 74.6% of informal caregivers indicated that they were very satisfied with the cost of services. Some 45.3% of informal caregivers felt that services were "Very effective" in promoting the clients' independence; 18.8% felt that services were "Not very effective". Some 67.5% of informal caregivers indicated that they were very satisfied with the ability of the services to meet the needs of the client.

6.7 **Diaries**

The majority of the diaries in Substudy 4 were not completed. When diary information was available, it was often limited and sporadic. It was a rarity to find a diary that had been completed for the full two week period. Because of the poor response rate, it was not possible to use the diaries to do detailed cost estimates for either informal or formal costs of care by level of care.

Table 6-10: Mean Scores on the List of Behavioural Problems

		Type of Care		
Care Level		Community	Facility	Total
Low	N	10	3	13
	Mean	1.23	1.27	1.24
	Std. Deviation	.60	.47	.55
Medium	N	8	12	20
	Mean	.91	1.32	1.16
	Std. Deviation	.75	.64	.70
High	N	14	15	29
	Mean	1.14	1.00	1.07
	Std. Deviation	.52	.51	.51
Total	N	32	30	62
	Mean	1.11	1.12	1.13
	Std. Deviation	.60	.56	.58

Table 6-11a: Mean Scores on the Montgomery Burden Scale (Objective Burden)

		Type of Care		
Care Level		Community	Facility	Total
Low	N	9	3	12
	Mean	29.00	29.67	29.17
	Std. Deviation	5.61	7.37	5.73
Medium	N	9	12	21
	Mean	29.22	22.17	25.19
	Std. Deviation	3.03	5.61	5.81
High	N	15	15	30
	Mean	32.47	20.27	26.37
	Std. Deviation	3.25	6.31	7.92
Total	N	33	30	63
	Mean	30.64	21.97	26.51
	Std. Deviation	4.20	6.52	6.93
For the interaction between type of care and care level, $F(1, 2) = 5.81, p < .01$. For type of care, $F(1) = 17.18, p < .001$.				

Table 6-11b: Mean Scores on the Montgomery Burden Scale (Subjective Burden)

		Type of Care		
Care Level		Community	Facility	Total
Low	N	10	3	13
	Mean	28.30	30.00	28.69
	Std. Deviation	11.30	12.53	11.07
Medium	N	9	12	21
	Mean	24.78	26.67	25.86
	Std. Deviation	5.26	7.16	6.34
High	N	15	15	30
	Mean	27.47	24.60	26.03
	Std. Deviation	7.83	4.79	6.54
Total	N	34	30	64
	Mean	27.00	25.97	26.52
	Std. Deviation	8.34	6.65	7.55

Table 6-12: Caregiver Satisfaction with Services

		Client Choice ¹			Worker Characteristics ²			Care Concerns ³		
		Care Type			Care Type			Care Type		
Care Level		Community	Facility Care	Total	Community	Facility Care	Total	Community	Facility Care	Total
Low	N	9	3	12	6	2	8	4	1	5
	Mean	3.78	4.33	3.92	25.33	27.00	25.75	15.00	16.00	15.20
	Std. Deviation	1.56	1.15	1.44	4.68	.00	4.03	2.16	--	1.92
Medium	N	7	12	19	7	5	12	5	5	10
	Mean	4.71	3.92	4.21	26.43	27.20	26.75	16.00	16.00	16.00
	Std. Deviation	.95	1.38	1.27	5.68	4.21	4.92	2.92	1.87	2.31
High	N	14	14	28	7	3	10	9	6	15
	Mean	5.86	3.14	4.50	26.71	26.00	26.50	15.33	16.17	15.67
	Std. Deviation	.77	.36	1.50	4.42	5.20	4.38	2.40	2.99	2.58
Total	N	30	29	59	20	10	30	18	12	30
	Mean	4.97	3.59	4.29	26.20	26.80	26.40	15.44	16.08	15.70
	Std. Deviation	1.40	1.05	1.41	4.74	3.77	4.38	2.38	2.31	2.34
For Client Choice, type of care was significant, $F(1) = 9.82, p < .01$.										

¹ Maximum score is 9.

² Maximum score is 30.

³ Maximum score is 24.

7. ISSUES AFFECTING THE CONDUCT OF SUBSTUDY 5

In addition to identifying an effective and efficient set of data collection instruments for use in Substudy 5, Substudy 4 also identified several issues which influenced how the larger study would be conducted.

7.1 Selection of Clients

The investigators discussed whether clients should be approached about the study when they first enrolled in home care as opposed to some time period after they had been receiving care services (as in Substudy 4). It was noted that when clients and families first enter the care system, there is a lot of information for them to deal with already. It was also noted that for facility clients, the first few months after placement are often traumatic for both clients and families because of the change in environment. It was also recognized that some of the items on the study instruments, such as those addressing satisfaction with services, only apply when someone has received services for awhile. It was therefore decided that only stable clients would be approached regarding participation in Substudy 5.

As in Substudy 4, it was decided that cognitively impaired clients should be included in Substudy 5, as they comprise a substantial proportion of the seniors' population. The Canadian Study of Health and Aging Working Group (1994) reported that 8% of individuals 65 years of age and older have some form of dementia.

The issue of whether to use client charts/records rather than proxies in order to obtain information about clients who may be unable to provide information directly due to cognitive impairment was considered. It was felt that it was important to include proxies in the design of Substudy 5 since client records may be incomplete or insufficient.

7.2 Accessing Community Clients

For community clients in Substudy 4, a letter was sent to clients from home support agencies requesting permission to forward the client's name on to study personnel. Clients were given a two week window in which to decline. If the same or a similar process is used in Substudy 5, it will have implications for the amount of time required to gain access to community clients.

It was noted that for Substudy 5, supervisors/case coordinators in long term care could be asked to identify and contact clients and families. It was recognized that if each case coordinator was asked to contact two or three participants, the study would not be too burdensome for them. It was decided that agencies should be asked to get permission to release the client's name to study personnel. It was also decided that a short, clear description of the study should be made available to anyone being asked to recruit potential participants.

7.3 Accessing Facility Clients

It was noted that minimal problems were encountered in accessing facility clients in Substudy 4. For the most part, the interviewers were able to interview the clients where the clients wished (for example, in their room or in a lounge in the facility). Sometimes multiple visits were required to complete the study instruments due to the client's health. Facilities generally gave permission to use the nursing station to review the clients' charts.

Some of the long term care facilities in Substudy 4 went through their own ethics/access review before they granted permission for clients in the facility to be approached regarding the study. It is important to recognize that some of the facilities participating in Substudy 5 may also wish to conduct their own ethics/access reviews. This has implications for how the facilities should be approached as well as the amount of time required to gain access to facility clients.

7.4 Accessing Informal Caregivers

It was noted in the pilot study that accessing caregivers was often difficult. While making contact with caregivers by phone was relatively easy, finding a time which was convenient for them to be interviewed was often difficult as they tended to be very busy. It was recognized that this may also be a problem in Substudy 5.

7.5 Accessing Formal Service Providers

In the pilot study, it was sometimes necessary for the interviewers to access formal service providers in order to obtain additional information about the clients. Accessing service providers in the facilities was difficult as they are overworked. Evenings and weekends were often better for staff, although it was noted that sometimes only the day staff knew the relevant information. Interviewers often did not get to meet home care staff. Even when they tried to meet, schedule changes made it difficult. However, it was noted that in-person contact, particularly regarding the diaries, increased formal service providers' participation in the study.

7.6 Difficulty Communicating in English

In the pilot study, clients, caregivers, and formal service providers who did not speak English fluently often lacked the confidence to write down items in the diaries. This was also true of individuals who were illiterate. In some cases, the study participants preferred to dictate the relevant information to the interviewers for transcription. This problem could also arise in Substudy 5 for both informal caregivers and formal service providers.

7.7 Selection of Study Sites and Determination of Number of Participants

As noted earlier, Substudy 4 was conducted in three locations in Canada. Substudy 5 was originally conceived of as a multi-site study as well. However, based on costs associated with data collection for the pilot study, it was determined that given the amount of funding available for the larger study, only two study sites would be possible. Victoria, British Columbia and Winnipeg, Manitoba were

chosen as the two sites because three out of the four investigators lived in one of these cities. As Victoria is a small city and Winnipeg is an urban centre, it was felt that comparisons could be made both between jurisdictions and between size of community.

The cost of data collection also had an impact on the determination of the number of clients to be included in Substudy 5. Initially, it was thought that data would be collected on 1200 participants. However, it was determined that 800 clients would be a more reasonable number. The sample size for Substudy 5 was therefore 400 clients in each of the two study sites, and within each of the sites, 200 clients would be in community care, 200 would be in facility care. It was further intended that the sample would be broken down into four levels of care. Thus, for each care level in each site, it was determined that there would be a minimum of 50 community and 50 facility clients.

Using data from a related study conducted by Hollander (1999) in British Columbia, sample size calculations were conducted for the top two (of five) levels of care. A two group (community versus facility) t-test with a 0.05 one-sided significance level and 80% power was calculated. The estimated sample size was under 50 for clients at each level of care. Thus, the sample size of 50 cases in each type of care, for each care level, was considered sufficient to provide adequate power for the analyses to be conducted in Substudy 5.

8. CONCLUSIONS

The primary purpose of Substudy 4 was to test instrumentation to determine the feasibility of data collection strategies in order to identify the final format of the data collection tools as well as the final structure of the interview process to be used in Substudy 5. Using several sources of information, the investigators gradually identified a set of instruments which could be used to measure the costs and outcomes of care for clients living in the community as well as in facilities. Several issues which could affect the conduct of Substudy 5 were also identified and potential solutions were discussed.

The decisions made based on the findings of Substudy 4 will be assessed in Substudy 5 of the National Evaluation of Home Care. This latter study will involve 400 community and 400 facility clients in two jurisdictions (British Columbia and Manitoba) and two different sized communities (small city and urban centre).

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