

FACTORS INFLUENCING THE UTILIZATION OF  
COMMUNITY LONG-TERM CARE SERVICES

CENTRE FOR NEWFOUNDLAND STUDIES

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PABLO NAVARRO







# **Factors Influencing the Utilization of Community Long-Term Care Services**

by  
© Pablo Navarro

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in partial fulfilment of the requirements  
for the degree of Master of Science

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## **Abstract**

**Background:** Community Long-Term Care Services (CLTCS) are intended to support caregivers and delay institutionalization of care recipients. Evidence suggests CLTCS are under-utilized in Newfoundland by caregivers of people with dementia. **Objectives:** To explore the meaning of caregiving among caregivers in Newfoundland; to investigate a range of factors that may influence CLTCS utilization; and to assess CLTCS capacity in the region. **Methods:** Survey and interview of a sample of caregivers from the Canadian Study on Health and Aging, and a historical survey of homecare agencies. **Results:** Despite an apparent need for services, caregivers did not want CLTCS delivered in the home by strangers. Caregivers were more accepting of out-of-home services. Too few homecare agencies responded to the survey to carry out an analysis. **Conclusions:** The meaning of caregiving for caregivers affects the acceptability and utilization of CLTCS. Currently used quantitative instruments may benefit from supplementary qualitative data.

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## **List of Abbreviations**

AD: Alzheimer's Disease

CIND: Cognitive Impairment No Dementia

CLTCS: Community Long-Term Care Service

CSHA: Canadian Study on Health and Aging

LTC: Long-Term Care (Institutional Care)

VD: Vascular Dementia

## **List of Appendices**

Appendix A: Community Long-Term Care Services in Newfoundland (Eastern Avalon Peninsula)

Appendix B: Homecare Capacity Survey Instruments

Appendix C: Caregiving Experience Interview Questions

Appendix D: CSHA Caregiver Study Follow-Up Instruments

## **Chapter 1: Introduction**

The inspiration for this study originated while I was working in homecare in St. John's, Newfoundland. I had moved from Ottawa, Ontario, where I had been trained as a homecare worker and had been employed for the previous year. In St. John's, my placements were most often with people with dementia who were living in the community. My responsibilities centered on assisting the primary caregiver by assuming some or all of the care activities for the person with dementia. The beneficiary of my services was intended to be the caregiver as much as the person with dementia. In the course of my employment, I frequently noticed that formal homecare services were engaged later than they could have been. The need for formal help appeared to exist and had been recognized by the caregiver's family and friends some time before any attempt was made to engage a homecare worker.

My first-hand experiences were reflected in the findings of the Canadian Study on Health and Aging (CSHA). The CSHA Caregiver Study (Canadian Study of Health and Aging Workgroup, 1994bb) showed that caregivers in Atlantic Canada of people with dementia under-utilized available Community Long-Term Care Services (CLTCS) compared to caregivers in the rest of the country. The under-utilization of services was expected to contribute to higher levels of caregiver strain and higher rates of institutionalization of people with dementia. The current study originated with the objective of identifying and

interpreting the factors that contributed to the under-utilization of CLTCS in Atlantic Canada reported in the CSHA.

The following sections of the Introduction provide an overview of dementia community care and Community Long-Term Care Services and a conceptual framework for their utilization. The remainder of this thesis is divided into four chapters. The Literature Review chapter provides a review of relevant research findings addressing dementia community care, followed by a description of the research objectives of the current study. The Methods chapter describes the experimental design, the instruments used in the study and the analytical methods used in the study. The Results chapter gives a comprehensive review of the study findings. The Discussion chapter addresses the major findings of the study in relation to previous research. The Discussion chapter also addresses: the limitations of the study, recommendations for future research and considerations for dementia community care policy and caregiver programs.

## **1.1 Dementia and Community Care: Overview**

A person with dementia will experience a progressive loss of intellectual function and will become increasingly mentally and physically disabled. The clinical symptoms of dementia include impairments of memory, cognition, reasoning, learning, comprehension, orientation, calculation, emotional control and social behaviour (Burns, 2002; Henderson, 1994). The underlying diseases which cause dementia and their estimated percentage of cases in Canada are: Alzheimer's Disease (66.4%), vascular

dementia (18.1%), Parkinson's Disease (2.4%), other known causes (4.6%), and unknown causes (8.5%) (Canadian Study of Health and Aging Workgroup, 1994a). There is presently no treatment that will reverse or stop any of the underlying causes of dementia, and what treatments do exist may slow the progression of the disease but do not stop the progression or reverse the effects.

The terms “community caregiver” and “primary caregiver” are used interchangeably in this study to refer to the person in the community that is most responsible for someone with dementia. This responsibility is invested with values, expectations and judgements that come from within the caregiver and the community. Community caregiving is embedded with positive cultural valuation. Community caregiving is expected to provide a better quality of life for a person with dementia. It is considered economically beneficial for the health-care system by transferring a part of the financial burden of care to the person with dementia, their community caregiver and their family (Grunfeld, Glossop, McDowell, & Danbrook, 1997). At the same time, community cultures may impose negative value judgements on a potential caregiver who decides not to provide care. Potential caregivers who decide not to take on the role of community caregiver may feel guilt and remorse, and these feelings play a role in influencing their decisions. The alternative to community care is institutionalization, which itself is embedded with many negative connotations. In the Canadian cultural context, community caregiving is generally considered preferable to institutionalization.



Taking on the responsibility to be a caregiver, voluntarily or not, has a central importance for a person (CARP, 1999). The motivations and experiences of people who are caregivers may be diverse and contradictory. Caregivers may welcome or dread their role, and may love or hate their experience. Accepting the role of caregiver is a major decision. The prognosis of dementia is always fatal and the duration of morbidity is measured in years. The progression of disease severity may vary, with periods of lucidity and functionality, but it is ultimately in the direction of total physical disability and complete mental incapacity (Burns, 2002; Henderson, 1994). Caregivers who decide to end community care will most often place a person with dementia in a long-term care facility. While the role of caregiver changes with the institutionalization of the person with dementia it does not end: the caregiver often remains a key provider of care activities (Gold, Reis, Markiewicz, & Andres, 1995). The decision to institutionalize is as important to the caregiver as the decision to accept the community caregiving role, and is often emotionally stressful (Rudd, Viney, & Preston, 1999). Central to the decision to institutionalize is the interplay between the needs of the care recipient and the ability of the caregiver to meet those needs.

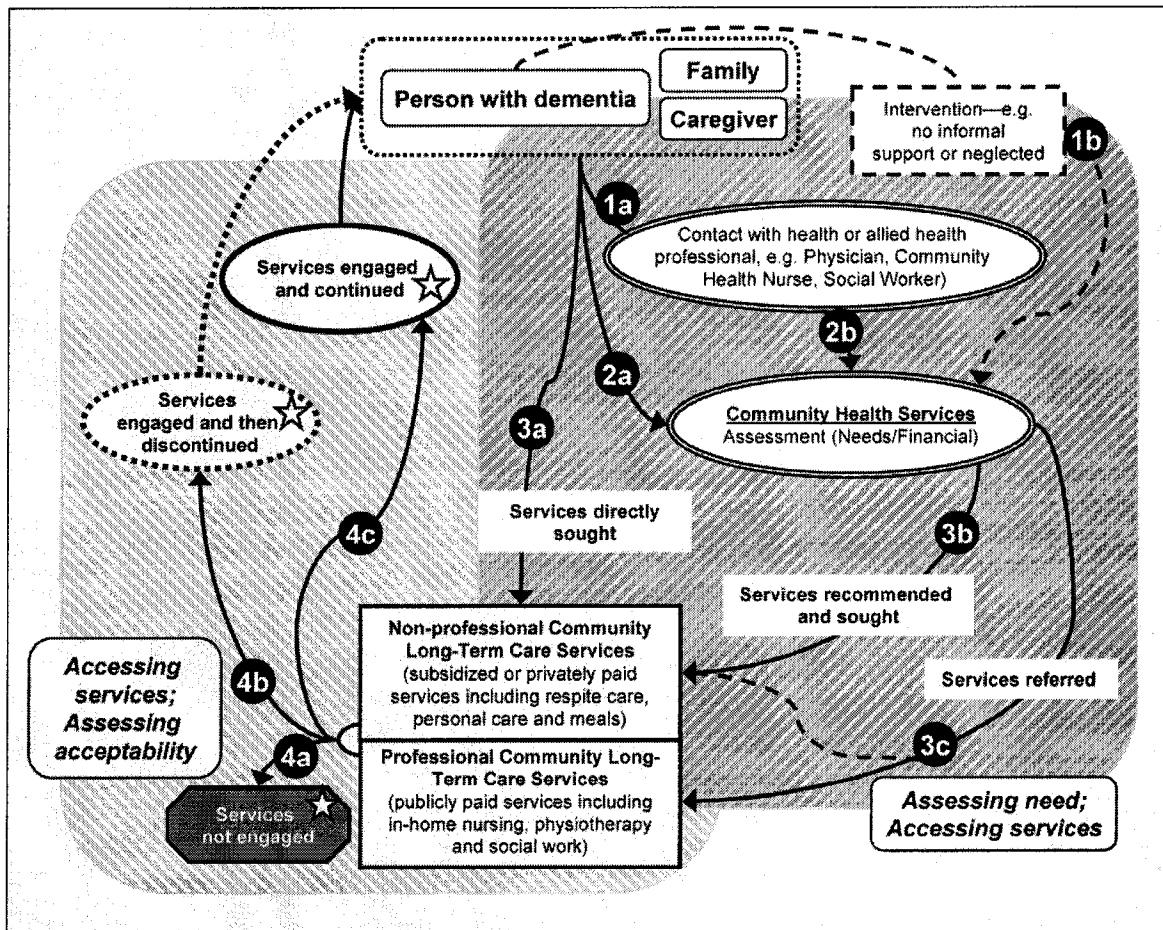
In situations where a caregiver cannot reasonably meet the needs of a person with dementia, Community Long-Term Care Services (CLTCS) may provide relief that will extend that person's residence in the community. CLTCS are services that are designed for community-residing individuals with long-term care needs, and are also designed to help community caregivers in meeting their responsibilities.

## **1.2 Community Long-Term Care Services: Overview**

Community Long-Term Care Services (CLTCS) encompass a range of paid services intended to assist community-dwelling care recipients and their caregivers. CLTCS consist of services that support the caregiver, that substitute for the caregiver during limited periods of time, or that provide services for a community-dwelling care recipient. Where the care recipient has dementia, the objectives of CLTCS are to maximize his or her stay in the community, and to enhance the quality of life for both care recipient and caregiver. A well-known example of CLTCS is personal care. Typically, a personal care attendant will come to the residence to help with bathing, dressing, personal grooming and transferring the care recipient. The attendant enables the care recipient to carry out basic activities of living and at the same time reduces the burden of care on the caregiver.

Community Long-Term Care Services are provided by personnel who have a wide range of qualifications and training, from professional nurses with university education to largely untrained homecare workers who work for minimum wage (CARP, 1999). In Newfoundland, CLTCS are delivered by a range of institutions that include publicly funded healthcare institutions, private companies and non-profit organizations. The payment systems for these services are also varied and have changed over the past fifteen years (CARP, 1999). Presently, CLTCS in the Eastern Avalon region of Newfoundland include services that are fully covered by healthcare, services that are publicly subsidized based on income and need, and private services that are paid for in full by the caregiver

or the family of the person with dementia. Appendix A provides a summary of CLTCS in the Eastern Avalon region of Newfoundland.



**Figure 1: Access routes and outcomes to community-based services.**

On the Eastern Avalon Peninsula of Newfoundland, caregivers and their families may engage community-based services through several routes (see Figure 1). Health professionals and allied health professionals are key figures in accessing services (1a). Acting as gatekeepers, they will most often refer caregivers to Community Health Services or provide the caregiver with information on services that are available in their region (2b). Caregivers and family may also visit Community Health Services without

referral (2a). One of the key roles of Community Health Services is to provide needs and financial assessments for CLTCS to caregivers and their families.

In some cases where a person does not have a caregiver, or if the caregiver is considered negligent, the provincial Department of Health and Community Services may intervene and assume responsibility for the care of the person with dementia (1b). In so doing, they also assume full financial responsibility for the provision of services. These cases are rare and in this study utilization of services is taken to mean the voluntary use of services by the informal community caregiver and the family of the person with dementia.

The financial assessment carried out by Community Health Services determines whether a person with dementia is eligible for coverage based on having less than five thousand dollars in savings. The needs assessment results in either referrals for publicly-paid professional services (3b; for example physiotherapy or in-home nursing) or recommendations for non-professional services (3c; for example, personal care or meal preparation). Non-professional services are paid for privately or, in cases of financial need, with public funds (3c, hatched line). Caregivers and family may also approach CLTCS agencies directly (3a) or may hire individuals who do not work for an agency to carry out community-based services.

Caregivers and family that need, and are aware of, services then begin the process of accessing those services. A service may be engaged by a caregiver and family and

retained for the duration of the community-care of the person with dementia (4c). A service may also be engaged and discontinued (4b) or not engaged at all (4a).

A key measure of the ability of CLTCS to meet their goals is their utilization. In the context of this study, utilization occurs when the caregiver engages a service to help him or her in providing community care to a person with dementia. A great number of factors influence the ability and choice of caregivers to use a Community Long-Term Care Service. These factors may be grouped together and in its simplest form CLTCS utilization may be understood as the result of a need for services that are accessible and acceptable to the caregiver and person with dementia. These three groups of factors are described below.

### ***Need for CLTCS***

Service utilization is initiated by a need for services. A need for services is determined by the care requirements of the person with dementia and the capacity of his or her informal community caregiver to provide care. When informal caregivers can meet the requirements of care with a reasonable amount of effort, then there is little need for CLTCS. If the requirements of care are too much for the caregiver to provide, or if the caregiver is compromised in their ability to provide care, then CLTCS are considered appropriate. A need for services may be realized by the caregiver and family of the person with dementia, may be determined by a health or allied health professional, or in some cases, determined by an intervention on the part of social services (indicated by 1b in Figure 1 above).

Once a need for services has been established, the services may be sought out by the caregiver and family themselves or they may be recommended or referred. In order for CLTCS to be used, they must be accessible to the informal caregiver and the person with dementia. CLTCS accessibility is determined by the freedom and ability of the caregiver to make use of those services.

### ***CLTCS Accessibility***

The second set of factors that influence the utilization of CLTCS involves the accessibility of services. First and foremost services must be available in order to be accessible. The different delivery modes of CLTCS, public and private, mean that there are separate features that govern their availability. Services that are publicly administered will depend on government policy and funding, while services that are delivered by private-sector third parties will depend on market forces. With few exceptions, availability is highest in urban centres and lowest in rural and remote regions; for example, some rural areas have a greater placement to population ratio for personal care homes than the larger urban centres (Wheeler, 2004).

If services are available, their accessibility will then depend on a wide range of factors (see Figure 1 above). In order to access needed services, caregivers must be aware that they exist and know that the services are available to them. In the case of services that are delivered by the private sector, accessibility is strongly influenced by the ability of the caregiver to pay for them. The location of the community residence may also play a critical role in the accessibility of a service. People with dementia who live in rural or

remote areas may have to travel farther to access a service or they may find that they live outside of the service area for those CLTCS designed to be delivered in the home.

Accessibility of services is further affected by their ease of use and waiting times.

Caregivers of people with dementia typically do not have a lot of time and energy to dedicate towards accessing a CLTCS. As such, complicated procedures and delays will also have the effect of decreasing the accessibility and utilization of a service.

These factors represent some of the more important aspects of accessibility. The utilization of a service that is needed and accessible also depends on a set of factors related to what may be called the acceptability of that service.

### ***CLTCS Acceptability***

In order for a Community Long-Term Care Service to be engaged and continued, the service must be needed and accessible. However, the utilization of a service that is needed and is accessible is not guaranteed. A third set of factors that influence the utilization of CLTCS may be described as those affecting its acceptability. The decision to use a service is most often made by the caregiver and family of the care recipient, and may also be recommended by a physician or social worker. The person or people involved in making that decision will have criteria and conditions that will need to be satisfied in order to engage and continue using a service. Acceptability refers to those factors that affect a person's choice to use a service that is both needed and accessible.

The acceptability of a service depends on many key factors including payment structure (public or private), professionalism, effectiveness, and cultural appropriateness. For example, a caregiver may be accepting of a service if it is publicly funded, but may choose not to engage the same service if it must be paid for out of pocket.

The acceptability of professional services, for example physiotherapy, is more commonly referred to as compliance, since the service has been deemed necessary by a qualified health professional. In the case of non-professional services, which may be paid for in part or in whole by the caregiver or family of the care recipient, acceptability may be referred to as customer satisfaction (Dello Buono et al., 1999). From the perspective of the family, the perceived effectiveness of a CLTCS will also play a large part in its acceptability<sup>1</sup>. Caregivers may be non-compliant with services that they do not perceive as being effective, and can be expected to be less likely to use a privately paid for service.

The specific criteria and conditions for making the choice to use a service, and their relative importance, will be as unique as the people making the decision to use a CLTCS. They will be influenced by the individual's beliefs, attitudes and values, all of which are deeply influenced by culture. People with similar cultural backgrounds will tend to have

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<sup>1</sup> The effectiveness of a service may also be considered from the perspective of the service provider. Services that are assessed as not effective by the provider may be restructured or discontinued.



more criteria in common for what they find acceptable and unacceptable in terms of CLTCS.

### **1.3 Summary**

A person with dementia is characterized by a progressive deterioration of his or her mental capacities. The resulting functional disability requires an increasingly intense level of care that is traditionally provided through informal care from family and friends until the death or institutionalization of the person with dementia.

Community Long-Term Care Services are intended to maximize the time a person with dementia may remain in the community. Many, if not most, of CLTCS are designed to assist the primary caregiver with the duties and demands of dementia community care. The successful utilization, i.e., the engagement and continuation, of CLTCS may be interpreted using the framework described above. The framework describes three sets of factors that are necessary for CLTCS utilization: need, accessibility and acceptability. The factors that influence the utilization of CLTCS will be interpreted as having an impact on one or more of these sets of factors.

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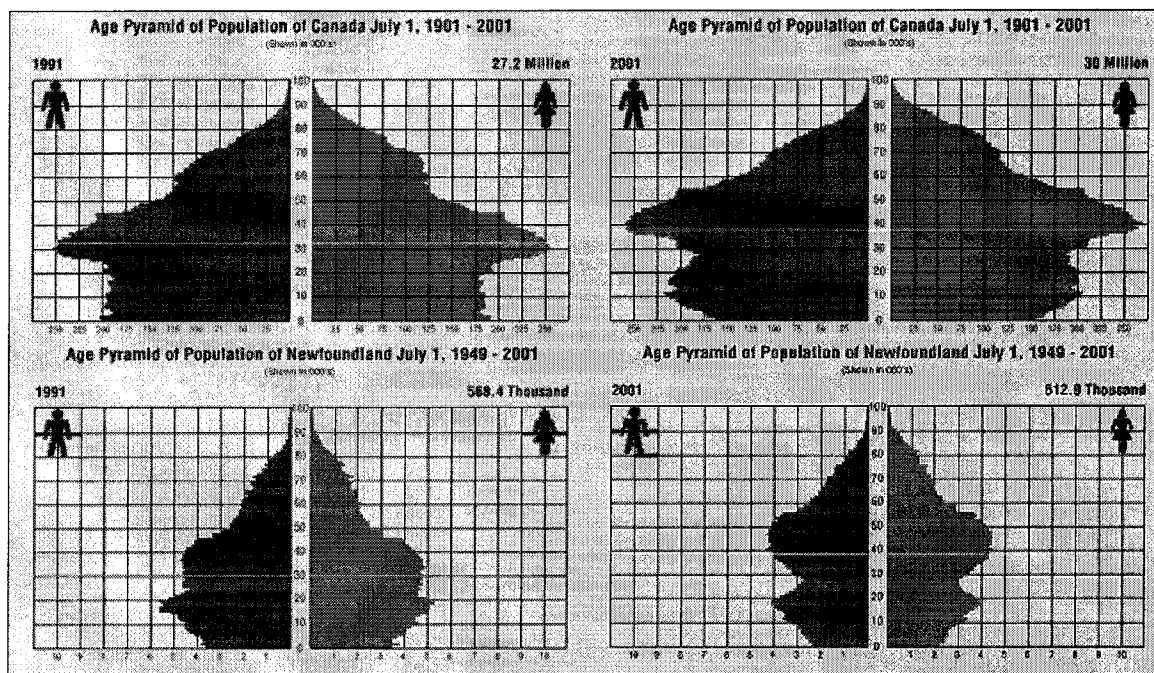
## **Chapter 2: Literature Review**

This chapter provides a review of research findings relevant to the present study. The literature review addresses several aspects of the impact of dementia in Canada at the population level in terms of the prevalence, costs, and effects of dementia care on caregivers. It then considers previous research on the institutionalization and community care of people with dementia. The chapter continues with a review of the research concerning the utilization of Community Long-Term Care Services in general and in dementia community care. The chapter concludes with a description of the present study and its objectives.

### **2.1 Dementia in the Population**

The Canadian population has been getting older since the end of the baby boom in 1960. In the last decade, the aging of the Canadian population has seen two trends: an increasing life span and a proportional upward shift in the age of the population as a whole. Canadians are now living longer than before, especially in the 80 and over (80+) portion of the population that has grown 41% in the past ten years to 932,000 (see Figure 2 below). This trend is expected to continue over the next ten years, with the 80+ section of the population growing another 43% to an estimated 1.3 million by 2011. The age distribution of Canadians is also changing, with a greater proportion of the population

being older than before. In the past ten years, the median age for the country rose 4.1 years from 33.5 to 37.6 years (Statistics Canada, 2002).



*Figure 2: Population distribution for Canada and Newfoundland (1991 and 2001).*

The same trends are evident in the Newfoundland and Labrador population. The largest growth for any age group in the province was 41% for the 80+ group, rising from 10,595 to 14,970 in the past decade. The median age has increased from 30.8 in 1991 to 38.4 years, an increase of 7.6 years (Statistics Canada, 2002). These measures underscore the proportionately greater shift in aging for Newfoundland and Labrador compared to the rest of the country. From 1991 to 2001 the median age of the province went from below to above the national average. The principal factors in the aging shift of the population of the Province have been a decreasing birth rate and out-migration, especially among young adults (Statistics Canada, 2002).

One consequence of the Canadian population's getting older is an increase in the number of cases of dementia. Dementia is predominantly a disease of "old-age", and so there is an increase in the number of cases of dementia with an increase in the number of older (65+) people. Approximately 8% of Canadians over the age of 65 have dementia, and in 1991 this resulted in an Estimated Number of cases in the Population (ENP) of 252,600. In 2001, there will be an ENP of 319,136 with dementia (Canadian Study of Health and Aging Workgroup, 1994a).

<i>Age-adjusted rates of dementia per 1,000 non-demented persons in Canada; 95% confidence intervals indicated in brackets.</i>			
<b>Age group</b>	<b>Women</b>	<b>Men</b>	<b>Total</b>
65-69	7.1 (2.4-11.8)	3.7 (0.7-7.3)	5.5 (2.3-8.8)
70-74	7.9 (4.4-11.5)	14.7 (9.4-20.1)	10.9 (7.2-14.6)
75-79	19.3 (13.3-25.3)	26.5 (18.4-34.6)	22.3 (16.3-28.2)
80-84	44.0 (33.2-54.8)	38.6 (27.5-49.7)	42.0 (32.2-51.7)
85+	110.2 (86.0-134.3)	99.0 (74.0-124.0)	106.5 (83.8-129.2)
All ages	21.8 (16.5-27.0)	19.1 (14.1-24.0)	20.6 (15.8-25.4)

*Table 1: Incident rates of dementia in Canada.*

Furthermore, the risk for developing dementia increases with age after 65. Among otherwise non-demented Canadians, the incidence of dementia dramatically increases with age (see Table 1). The incidence rates translate into 60,150 new cases of dementia each year, with approximately three women for every two men diagnosed. Twenty-two percent of the cases will arise in institutions, but the remaining 78% will be diagnosed among community dwellers (Canadian Study of Health and Aging Workgroup, 2000). There are an estimated 7,981 people with dementia in Newfoundland and Labrador, with approximately 1,326 new cases diagnosed in 2002 (Canadian Study of Health and Aging, unpublished data). These findings taken together with trends of increased life expectancy

indicate that there will be a greater number of dementia cases in Canada as well as in Newfoundland and Labrador (Wolfson et al., 2001).

## **2.2 Costs of Dementia Care**

The costs of providing care for people with dementia are substantial. The data from the Canadian Study of Health and Aging provided the first national assessment of the direct and indirect costs of dementia in Canada. The net cost of dementia for 1991 was estimated to be \$3.9 billion. The care of patients in long-term care facilities accounted for \$2.18 billion (56%) while the cost related to community dwellers was estimated to be \$1.25 billion (32%)<sup>2</sup>. Of the latter amount 51% (\$636 million) was "conservatively estimated" to be lost wages for unpaid, or informal, services. The remaining 49% went towards paid or formal Community Long-Term Care services, paid for privately and with public funds (Ostbye & Crosse, 1994).

Institutionalized care is more expensive than community-based care for two reasons. First, disease severity increases both the risk of institutionalization and the costs associated with dementia-care, resulting in a concentration of the more severe and more expensive cases of dementia in long-term care facilities. (Andersen, Lauridsen, Andersen,

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<sup>2</sup> The remainder of the costs were associated with: drugs, hospitalization and diagnosis of people with dementia over 65 years (\$74 million); research (\$10 million); and all costs related to people with dementia who were under 65 years (\$389 million).

& Kragh Sorensen, 2003; Hux et al., 1998). Second, community-based care reduces the measurable costs of dementia through unpaid informal services by members of the community (Ostbye & Crosse, 1994). This underscores the importance of community caregiving in a fiscally sustainable health care system. The correlation of risk of institutionalization with increased disease severity is directly linked to the progression of dementia severity and the related changes in dementia community caregiving.

## **2.3 Effects of Dementia**

The progression of dementia, in terms of disease symptoms and severity, depends on the underlying disease and is difficult to predict (Agüero-Torres, Qiu, Winblad, & Fratiglioni, 2002). Although the progression of dementia is variable, people with dementia from all causes in all age groups have higher mortality rates. Results from the CSHA estimate a median survival time of 3.3 years for all forms of dementia (90% confidence interval: 2.7, 4.0) with a median survival time of 3.1 years for probable Alzheimer's Disease and 3.3 years for vascular dementia (Wolfson et al., 2001). While other studies have found higher estimates, for example (Aevarsson, Svanborg, & Skoog, 1998; Claus, Walstra, Bossuyt, Teunisse, & Van Gool, 1999), research consistently describes the duration of dementia in years, not months.

From the time of the onset of symptoms until death or institutionalization, a person with dementia will become progressively more physically and mentally disabled. As disease severity worsens, a person with dementia will require assistance with their Activities of Daily Living (ADL) (bathing or showering, dressing, getting in or out of bed or a chair,

using the toilet, and eating) and Instrumental Activities of Daily Living (IADL) (preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone) (Kempen & Suurmeijer, 1991; Kemper, 1992). In the absence of death from another illness, a person with dementia will ultimately lose all functional ability including continence and swallowing. Consequently, the progression of dementia results in the need for increasingly greater and more intense amounts of care (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000; Zarit, Reever, & Bach-Peterson, 1980).

People with dementia develop a greater degree of disability compared to other types of care recipients. The CSHA Caregiver Study found that the functional ability of care recipients, with and without dementia respectively, was: 23.4% and 86.0% with mild or no disability; 30.8% and 12.1% with moderate disability; 47.7% and 1.9% with severe or total disability (Canadian Study of Health and Aging Workgroup, 1994b). Other research findings are consistent with these (Canadian Study of Health and Aging Working Group, 2002; Rockwood, Awalt, MacKnight, & McDowell, 2000).

Compounding the reduction in functional ability, behavioural disturbances are also a common and distinctive feature of dementia (Baumgarten, Becker, & Gauthier, 1990). They can range from the frustrating, for example, repeating questions, losing things or a general loss of interest, to the threatening, including making unwarranted accusations, cursing and physical attacks. Caregivers may not realize the extent to which these behavioural disturbances are due to the dementia resulting in stress (Paton, Johnston,



Katona, & Livingston, 2004). This is often compounded by the caregiver's need to be vigilant over the care recipient, e.g. to prevent the care recipient from wandering or leaving electrical appliances turned on. Furthermore, since people with dementia frequently have unusual sleep patterns, monitoring may be required through the night and this can leave caregivers exhausted and sleep deprived (Wilcox & King, 1999).

There is clear evidence that people with dementia require substantial care. An increasing number of cases in the population of Newfoundland and Labrador will be expected unless cures or effective treatments are found for the underlying causes. The proportional aging of the population, in addition to the effects of out-migration among young adults, will also mean that there will be fewer people in the population to assume the key role of informal community caregiver.

## **2.4 Community Caregivers of People with Dementia**

For the majority of newly diagnosed cases of dementia (78%) (Canadian Study of Health and Aging Workgroup, 2000), care delivery begins in a community setting. The predominant mode of care in these cases is through an informal community caregiver. The CSHA Caregiver Study found that 93.7% of caregivers of persons with dementia living in the community were informal (Canadian Study of Health and Aging Workgroup, 1994b). It is not surprising then, that informal caregiving has been described as "the bedrock of community care" for older persons with dementia (Strong, Martins, & Rollings, 2000). Though most caregivers have social support networks that allow them to

distribute caring responsibilities, the majority of care remains the responsibility of a single individual who becomes the primary caregiver (Brodaty, Griffin, & Hadzi Pavlovic, 1990; Canadian Study of Health and Aging Working Group, 2002).

The Canadian Study of Health and Aging Caregiver Study provided a description of the informal community caregivers who play the principal role in care delivery in the early stages of dementia. The CSHA Caregiver Study sampled 327 informal community caregivers of people with dementia throughout Canada (Canadian Study of Health and Aging Workgroup, 1994b). Most caregivers were female (75.4%) and married (70.6%). Over half of informal community caregivers were either wives (24.1%) or daughters (28.9%) of the person with dementia, outweighing their male counterparts of husbands (13.3%) and sons (9.5%). The remaining 24.1% of caregivers who were "other family/friends" were mostly other female relatives or in-laws.

The mean age of informal community caregivers of a person with dementia was 61.9 years, with 36% over the age of 70 and 11% over the age of 80. They were older than their counterparts who were caring for someone in an institution (mean age 59.1 years). This may be due in part to situations where a spouse, who would have been the informal caregiver, has died and the person with dementia was subsequently institutionalized. In these cases a younger relative, most often a daughter, becomes the informal caregiver. Informal community caregivers of a person with dementia were also older than caregivers of someone without dementia living in the community (mean age 58.2 years). Informal community caregivers of a person with dementia were also less likely to be employed

(29.3%) compared to caregivers of people in institutions (41.4%) or of people without dementia living in the community (36.0%) (Canadian Study of Health and Aging Workgroup, 1994b).

Informal community caregivers of people with dementia are called upon to perform a wide range of duties to mitigate the functional disability of the care recipient. As the amount and intensity of care increase with disease severity, dementia caregiving develops in step. In cases of mild dementia, when symptoms may be mild enough to escape detection or diagnosis, caregiving duties are often light. The deterioration of functional ability as the dementia progresses results in a concomitant increase in dependence on the caregiver (Grunfeld, Glossop, McDowell, & Danbrook, 1997).

Despite these challenges, informal community caregiving is beneficial for a person with dementia. A person with dementia who is living in the community with informal care can also expect a greater amount of direct care and supervision than someone in an institution (Hux et al., 1998; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Similarly, the health-care system benefits economically from informal community care. The presence of an informal community caregiver prolongs the time a person with dementia can remain in the community (Glazebrook, Rockwood, Stolee, Fisk, & Gray, 1994). However, the financial benefits to the system provided by dementia community care are in contrast to the personal costs to the dementia community-caregivers themselves.

## **2.5 Effects of Dementia Caregiving on Caregivers**

The experience of informal community caring for people with dementia is characterized by several differentiated negative effects on the caregiver. However, a balanced review of the literature must recognize that some effects of dementia community care are positive. Caregivers may feel a sense of satisfaction or reward from providing care to a loved-one (Cohen, Colantonio, & Vernich, 2002), and caregiver gain is considered an important facet of community caring (Kramer, 1997a, 1997b). That being said, the dominant reaction of dementia community caregivers is one of feeling overwhelmed by their situation (Canadian Study of Health and Aging Workgroup, 1994b; Gold, Reis, Markiewicz, & Andres, 1995).

It is well documented that the responsibilities and difficulties of caring for a person with dementia result in stresses rarely matched in kind or severity in other types of caregiving. Population-based research has confirmed that psychological and emotional stress are higher among informal community caregivers of people with dementia compared to informal community caregivers of people without dementia or of people with dementia in institutions (Grafström, Fratiglioni, Sandman, & Winblad, 1992; Ory et al., 1999).

'Caregiver burden' is a multi-dimensional measure of the stress of caregiving that has been formalized with instruments like the Zarit Burden Inventory (ZBI), designed specifically for informal community caregivers of people with dementia (Zarit et al., 1980). The ZBI measures the frequency of caregiver feelings towards their health,

psychological-well being, social life and relationship with the care recipient. The result of the ZBI is a global score for burden ranging from a minimum of zero (no burden) to a maximum of 84.

Population-based research using the ZBI has found consistently that informal community caregivers of people with dementia have higher scores (mean score 21.7) on global psychological stress than caregivers of people with dementia in institutions (mean score 14.1; CSHA Working Group, 1994b). The level of caregiver burden has also been shown to increase over the course of caregiving, and to remain higher, among caregivers of people with dementia who remain in the community compared to those of people with dementia who were institutionalized (Canadian Study of Health and Aging Working Group, 2002). Chappell and Penning (1996) used the CSHA dataset to identify variables that predicted the level of burden among 327 informal community caregivers of people with dementia. They found that being a spouse or child of the person with dementia were significant predictors of higher levels of burden among caregivers ( $p < 0.001$ ). Care recipient variables that were associated with higher levels of burden were behavioural disturbances (aimlessness, aggressiveness, forgetfulness, restlessness, and apathy;  $p < 0.001$ ) and impairment of Instrumental Activities of Daily Living (IADL;  $p < 0.001$ ). Additional research with the CSHA dataset has shown that female caregivers are at a higher risk than male caregivers having a high level of burden (defined as a ZBI score of 33 or higher; OR=2.6; 95% CI 1.0, 6.7) (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002).

The most prominent and consistent clinical effect of caring for a person with dementia is depression. (Baumgarten, 1989; Covinsky et al., 2003; Pinquart & Sorensen, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990). Rates of depressive disorders among informal community caregivers of people with dementia are higher compared to non-caregivers (32% vs. 6% after 13 months) (Kiecolt Glaser, Dura, Speicher, Trask, & Glaser, 1991) or compared to caregivers of people without dementia (20% vs. 7% after 18 months) (Russo, Vitaliano, Brewer, Katon, & Becker, 1995). Non-specific depressive symptoms follow the same trends and are higher among informal community caregivers of people with dementia compared to control groups (Baumgarten et al., 1994; Schulz & Williamson, 1991). The CSHA administered the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) to measure twenty non-specific depressive symptoms. CES-D scores range from a minimum of 0 to 60, and a score of 16 or above on the CES-D indicates clinical depression. Their results are consistent with previous findings; informal community caregivers of people with dementia had higher mean scores (9.3) and a greater percentage of caregivers scoring 16+ (25.9%) than either caregivers of people without dementia (mean score 6.4, percentage 16+ 13.8%) or caregivers of people with dementia in institutions (mean score 7.3, percentage 16+ 13.7%)(Canadian Study of Health and Aging Workgroup, 1994b). Although the CSHA results were consistent with regard to the relative levels of depression, scores were lower than expected based on previous research that used samples of convenience that were not representative of the population; the authors did not provide an explanation for this finding, but note that population studies of

caregivers have yielded similar inconsistencies in the past (Canadian Study of Health and Aging Workgroup, 1994b).

Potential causes of caregiver depression have been investigated with cross-sectional studies that cannot determine causation, but may establish correlations between depression and other variables. Depression and caregiver burden are strongly correlated ( $r=0.63$ ,  $p<0.0001$ ); not surprisingly, they share several associated factors (Chappell & Penning, 1996). Results from the CSHA have shown that depression is associated with the caregiver's being a spouse or child of the care recipient, and functional impairment and behavioural disturbance in the care recipient (Chappell & Penning, 1996; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998).

Informal community caregivers of people with dementia are also at higher risk for other types of psychological morbidity. Anxiety disorders are more frequent among caregivers of people with dementia after they began their caregiving roles than they are among non-caregivers (16% vs. 5%) (Russo et al., 1995). Self-rated health scores are consistently lower for informal community caregivers of people with dementia than for control groups (Baumgarten et al., 1992). The negative effects on the mental health of informal community caregivers of people with dementia are reflected in higher rates of psychotropic drug use (Baumgarten et al., 1992; Grafström et al., 1992), and in higher rates of visits to mental health professionals (Clipp & George, 1990).

The evidence for negative physical health effects is more equivocal than that for mental health effects. Several studies have reported finding indicators of a decrease in the physical health of caregivers of people with dementia. These indicators include increases in the number of chronic physical health conditions (Gold et al., 1995; Grunfeld et al., 1997), increases in the rates of drug prescriptions for physical health problems and decreases in self-reported health scores (SRHS) (Dura, Stukenberg, & Kiecolt Glaser, 1991). However, many research studies have not been able to duplicate these results (Baumgarten et al., 1992) or have shown that the physical health of caregivers improves after ceasing to provide care (Grasel, 2002).

The CSHA Caregiver Study studied physical health problems among different types of caregivers and found that informal caregivers of people with dementia, living both in the community and institutions, to be equal with a mean number of 2.6 chronic conditions. These results were higher than for caregivers of people without dementia, who had a mean number of 1.9 chronic conditions for community caregivers and 2.2 for caregivers of people in institutions (Canadian Study of Health and Aging Workgroup, 1994b). Longitudinal data from the 1996 CSHA Caregiver Study follow-up found that caregivers of a person with dementia (53% for incident cases of dementia and 49% for prevalent cases) were more likely to report three or more chronic conditions than caregivers of a person without dementia (39%,  $z=3.52$ ,  $p<0.001$ ) (Canadian Study of Health and Aging Working Group, 2002). Self-rated health scores (SRHS) were more likely to be fair or poor among informal community caregivers of a person with dementia (18% for incident cases and 11% for prevalent cases) than for caregivers of a person without dementia (7%,



$z=4.66$ ,  $p<0.01$ ). The authors suggest that, while chronic health conditions may increase over time, SRHS may decrease during the initial transition to providing care. They also note that the results from the CSHA Caregiver Study are confounded by the increasing age of the caregivers themselves. Taken together, these results suggest that community caregivers of people with dementia are at least, if not more, likely to experience a decrease in their physical health compared to other caregivers.

Hooker and colleagues (2002) carried out a longitudinal survey of sixty-four caregivers of people with dementia and concluded that stress was the key mediating factor explaining decreases in physical health. Their findings are consistent with a growing body of research that has studied the cellular and physiological responses to stress among informal community-caregivers of a person with dementia, for example Keicolt-Glaser et al (1991). Recent studies have demonstrated a biological mechanism responsible for the physical health effects due to caregiving, based on the production of pro-inflammatory cytokines, in particular interleukin-6, that result in a decrease in immune-system function and effectiveness (Hadjiconstantinou et al., 2001; Kiecolt Glaser et al., 2003)

In summary, informal community caregiving is associated with more negative than positive effects on the caregivers. Caregiver burden is characteristically higher among community caregivers of people with dementia than among other types of caregivers. Community caregivers of people with dementia experience greater levels of depression than caregivers of people without dementia. Research suggests that the levels of stress and depression may vary with the progression of dementia and the associated changes in

caring, including institutionalization. The ability of caregivers to cope with the stress of providing community care is compromised by these negative emotional and psychological effects of dementia care. Research has not conclusively shown that caregivers are more likely to have physical health problems because of their role in dementia community care. However, the physical health of caregivers does decrease naturally with age, and only compounds the difficulties of meeting the care requirements of people with dementia.

## **2.6 Institutionalization**

One option for a caregiver who can no longer provide the required level of care is to institutionalize the care recipient. In effect, this is the transferring of responsibility for the delivery of care to a long-term care (LTC) facility. Research has consistently confirmed that people with dementia have a much higher risk for institutionalization than other older people (Canadian Study of Health and Aging Workgroup, 1994b; Glazebrook et al., 1994; Rockwood, Stolee, & McDowell, 1996; Scott, Edwards, Davis, Cornman, & Macera, 1997). In 1991, approximately half of the people with dementia were living in institutional residences (Canadian Study of Health and Aging Workgroup, 1994b).

The risk factors for institutional placement of a person with dementia are often related to those that produce negative effects for informal caregivers. People with dementia are more likely to be in LTC if they are older (Canadian Study of Health and Aging Workgroup, 1994a, 1994b; Glazebrook et al., 1994), exhibit behavioural disturbances

(Cohen et al., 1993; Gold et al., 1995; Pruchno, Michaels, & Potashnik, 1990; Thomas et al., 2004) have increased impairments in Activities of Daily Living (Cohen et al., 1993; Pruchno, Michaels et al., 1990; Scott et al., 1997; Thomas et al., 2004) or Instrumental Activities of Daily Living (Glazebrook et al., 1994; Rockwood et al., 1996), and are not married (Kristjansson, Helliwell, Forbes, & Hill, 1999).

Risk factors for institutionalization may also include characteristics of informal community caregivers. Certainly, caregiver burden, depression, psychological distress and physical health are risk factors for institutionalization (Cohen et al., 1993; Gold et al., 1995; Lieberman & Kramer, 1991; Pruchno, Kleban, Michaels, & Dempsey, 1990).

Caregivers who are spouses are less likely to institutionalize a care recipient with dementia than a child, and both are less likely to institutionalize than a caregiver who is not a direct family relation (Glazebrook et al., 1994; Kristjansson et al., 1999; Scott et al., 1997). Other factors associated with caregivers that have been found to increase the risk of institutionalization are: caregiver financial problems in providing care for the care recipient (Lieberman & Kramer, 1991), increased medication use by the care recipient (Pruchno, Kleban et al., 1990), a decrease in health (Cohen et al., 1993), and a shorter duration of caregiving (Pruchno, Kleban et al., 1990).

The wide range of risk factors for institutionalization of a person with dementia underscores the many challenges and risks of informal community caregiving. The costs of institutionalization, over 50% of the estimated net costs of dementia in Canada (Ostbye & Crosse, 1994), have caused genuine concern about the feasibility of long-term care

placement in the context of an already stretched public health care system (Morris et al., 1999; Parr, Brossart, & Thompson, 1996). The costs are not negligible to caregivers and their family in a financial sense when the lost wages and out-of-pocket expenses associated with informal dementia community-care are taken into consideration. These costs, in addition to the negative psychological, emotional and physical effects to caregivers, underscore the need to provide services that can bridge the time between purely informal care and institutionalization.

## **2.7 CLTCS in Dementia Community Care**

Community Long-Term Care Services (CLTCS) describe a wide variety of services provided to caregivers and care recipients who are living in the community instead of an institution. CLTCS are not specific for dementia-care, but will be discussed in that context here. They are often referred to as homecare although CLTCS also includes services that may be provided outside of the home setting, for example, day-care. The Federal/Provincial/Territorial Working Group on Home Care (Principles of the National Framework on Aging: A Policy Guide, 1998) has described CLTCS as "an array of services that enables clients incapacitated in whole or in part to live at home, often with the effect of [delaying, substituting or preventing] long-term care or acute care alternatives". The intended effects of CLTCS may be used to group services into three categories: supportive, substitutive and preventive.

Supportive services are those CLTCS that provide assistance to informal community caregivers with the daily tasks of caregiving. Supportive services represent traditional "homecare" services such as homemaking, meal preparation and personal care for the person with dementia. Paid personnel who work with the informal caregiver deliver Supportive services. They are delivered in the home, although meal preparation may be carried out at a centralized location, for example "Meals-On-Wheels". Supportive services are intended to help delay institutionalization through shifting some of the responsibilities of dementia caregiving from the informal community caregiver to formal caregivers.

Substitutive services provide a replacement for the informal caregiver for a finite period of time. In-home respite care consists of paid personnel who come to the home and trade places with the community caregiver. Respite day care programs provide the same function except that the care recipient spends the day outside of the home, usually in an institutional facility. Both of these services allow the caregiver some time to him or herself during the day without the care recipient. Caregivers may use this time to run errands, to do chores, to participate in social activities or to simply have a break from the responsibilities of caring. Substitutive services also include overnight programs that may be delivered in the home or outside. These services also allow the caregiver to have personal time, and, just as importantly, the opportunity to have a less interrupted sleep.

Preventive services describe services directed at both the caregiver and the care recipient. Preventive services for care recipients include in-home nursing, physiotherapy,

occupational therapy, chiropractic treatments and podiatry. A professional allied health worker comes to the home to deliver a skilled service in the same manner as a traditional “house call”. For example, community nurses may make weekly visits to a bed-ridden person with dementia to check them for bedsores and dehydration and to advise the caregiver on medications for the care recipient. Preventive services for the person with dementia aim to minimize the potential for him or her to develop acute health conditions. Preventive services for caregivers include formal counselling and caregiver support groups. They are intended to provide therapeutic and/or educational support for caregivers, with the intention of mitigating the deleterious effects of caregiving and to prevent additional health problems or complications.

Thus, Community Long-Term Care Services may be provided for the benefit of the care recipient, the caregiver or both. The primary objective of CLTCS is to maximize the duration of community residence of the care recipient. The different types of services may be classified into three categories according to how they contribute to that objective. Supportive services assist with the basic tasks and responsibilities of community care, reducing the overall burden of care on caregivers and, hopefully, increasing the stay of the care recipient in the community. Substitutive services provide a replacement for the caregiver who in turn can then do things without the care recipient; even if that thing is simply to sleep. Preventive services attempt to minimize the potential need for acute care of the care recipient, as well as to minimize the potential for caregiver burnout.

### ***CLTCS Utilization***

The evaluation of CLTCS utilization in dementia care is complicated by the private nature of the services. With no centralized source of utilization data, as there is for hospital admissions or institutionalization, research has relied on surveys of samples of caregivers. Although this research has been vital in contributing to understanding CLTCS utilization, there remain concerns with the majority of studies. Dementia caregiving research is most often conducted with samples of convenience solicited from clinics, support groups, and public announcements. Potential sample bias and the consequent lack of a representative sample have called into question the ability to generalize the research findings (Canadian Study of Health and Aging Workgroup, 1994a; Dura & Kiecolt Glaser, 1990; Heun, Hardt, Muller, & Maier, 1997).

The most representative sampling of dementia caregivers in Canada was in the Canadian Study of Health and Aging (CSHA) Caregiver Study. This population-based sample minimized sampling bias and provided the most robust caregiver sample available in Canadian-based research. Research findings from the first phase of the CSHA Caregiver Study have shown that community caregivers of people with dementia used one or more CLTCS more frequently than caregivers of people without dementia (56% vs. 41%) (Canadian Study of Health and Aging Workgroup, 1994b).

<b>Caregiver Group</b>	<b>CSHA Phase</b>	<b>Used at least one CLTCS</b>
Dementia Caregivers	1 (1991)	56%
	2 (1996)	77%
Non-dementia Caregivers	1 (1991)	41%
	2 (1996)	58%

*Table 2: CLTCS utilization among CSHA caregiver groups.*

Caregivers of people with dementia were more likely than caregivers of people without dementia to use homemaking services (41.3% vs. 21.4%), in-home nursing (20.2% vs. 6.1%), personal care (18.8% vs. 7.4%), home-delivered meals (8.0% vs. 1.9%), day centres (8.0% vs. 0.6%), respite care (3.1% vs. 0.3%) and support groups (3.4% vs. 0.3%). Only physiotherapy was used more often by non-dementia caregivers (15.3% vs. 26.2%) (Canadian Study of Health and Aging Workgroup, 1994a). An analysis of CSHA Caregiver Study data from Newfoundland has shown similar patterns of service utilization, although service use was on the whole lower than the national rates. Caregivers of people with dementia were more likely than caregivers of people without dementia to use one or more CLTCS (38% vs. 8%) (Crowell et al., 1996).

These findings are consistent with other research that has been carried out in Canada and abroad that show that caregivers of people with dementia have higher needs and utilization rates of community-based services than caregivers of people without dementia (Beattie, Tuokko, & Hertzman, 1994; Biegel, Bass, Schulz, & Morycz, 1993; Cox, 1997; Ganguli, Seaberg, Belle, Fischer, & Kuller, 1993; Grabbe et al., 1995; Hawranik & Strain, 2001; Houde, 1998; Penning, 1995).



The follow up to the CSHA Caregiver Study (CSHA 2) found a consistent and increased utilization of CLTCS. Caregivers of people with dementia used at least one service more often in the second phase of the CSHA than they did in the first phase (77% vs. 56%). Caregivers of people without dementia also had an increase in the use of at least one service (58% vs. 41%) (Canadian Study of Health and Aging Working Group, 2002). Both groups of caregivers showed an increased rate of CLTCS utilization. These results may be explained in part by an increase in the need for these services due to the aging of the caregivers and the care recipients. However, it is also likely that an increase in the accessibility of CLTCS, particularly in terms of the availability and awareness of services, contributed to the increase in utilization. Much research has attempted to identify and interpret the predictors of CLTCS utilization. Although there have been advances in identifying individual predictors, the complex interaction among the people involved in dementia caregiving and the available services has complicated understanding the interaction of those predictors.

### ***Predictors of CLTCS Utilization***

The research described above shows that dementia is itself a predictor for CLTCS utilization: similar caregivers of people without dementia are less likely to use a service. Disease severity is also a predictor of service utilization. The level of care-recipient disability, a measure of disease severity, was a consistent predictor of CLTCS utilization in the second phase of the CSHA Caregiver Study. At lower levels of disability, caregivers of people with dementia used fewer services than caregivers of people without

dementia (25% vs. 50%). At low levels of disability, care recipients require less supervision and less assistance with their daily activities. The levels of CLTCS utilization were higher for caregivers of people with dementia with moderate disability (71%) and approximately the same for caregivers of people without dementia with moderate disability (69%). A disturbing result in CSHA-1 was that caregivers of people with dementia with high levels of disability received fewer services than the comparison group. In the follow-up study, this trend was reversed, and 88% of caregivers of people with dementia were using at least one CLTCS compared to 75% of caregivers of people without dementia (Canadian Study of Health and Aging Working Group, unpublished manuscript).

In addition to disability, research has shown other variables affect CLTCS utilization. Using data from the CSHA Caregiver Study, researchers have found that living alone or in a non-urban setting was a significant predictor of service use. Caregiver burden was not found to be associated with CLTCS utilization, indicating that caregiver levels of stress do not directly predict the utilization of services (Canadian Study of Health and Aging Working Group, 2002). However, the perceived health of the caregiver was found to be a predictor of service use. Other research has suggested that some caregivers wait until a point of crisis before accessing services, and that they then access services only because the crisis has brought them to a physician. Several studies have indicated that lack of information plays a key role in lower service utilization (Dello Buono et al., 1999; Vetter et al., 1998).

There are some predictors that have a broad effect and will influence directly or indirectly a wide range of criteria involved in CLTCS utilization. Demographic, geographic, relationship to the caregiver, and ethnicity variables are broad predictors. For example, a consistent trend shown in both CSHA 1 and 2 was that the type of family relation between caregiver and care recipient affected the use of CLTCS. Wives were the least likely to employ services (47%) compared to children (70%) and other caregivers (77%). Both disability and filial relation independently predicted service use (CSHA Working Group, in press).

### ***Effectiveness of CLTCS***

Early research investigating the effectiveness of CLTCS has produced mixed results. One major problem was the high variability among third-party service providers in terms of workforce training and service development, delivery and evaluation (Brodaty, Green, & Koschera, 2003; CARP, 1999). The second major difficulty for these studies was the use of caregiver samples of convenience that may have introduced a selection bias. One exception is a study of 327 caregivers drawn from the Canadian Study of Health and Aging that used structural equation modeling to demonstrate that informal supports are more effective than formal CLTCS in reducing caregiver burden and depression, but that CLTCS did have a positive marginal effect (Raina et al., 2003).

Existing research studying the effectiveness of CLTCS is equivocal. Several studies have reported that community-based services did not reduce the likelihood of

institutionalization (Thompson et al., 2000). Lieberman & Kramer (1991) found that overall CLTCS utilization did not significantly decrease the risk of institutionalization. However, the authors did find that caregiver counselling, homemaking services, and access to a medical clinic lowered the risk of institutionalization. Other studies have reported that higher community services utilization may be a risk factor for institutionalization (Cohen et al., 1993; Pruchno, Kleban et al., 1990); however, an alternative interpretation suggests that the increase in community services was more likely a result of temporary measures implemented once Long-Term Care (LTC) placement had been already decided (Cohen et al., 1993).

Other studies have successfully employed standardized CLTCS interventions in field trials (Hepburn, Lewis, Sherman, & Tornatore, 2003) and randomized controlled trials (Eloniemi Sulkava et al., 2001). Mittelman and colleagues have shown that caregivers who received only six sessions of counselling were two-thirds as likely to place the care recipient in long-term care over a period of three and a half years (Mittelman et al., 1996). Similar research has shown that more comprehensive support to caregivers may also significantly decrease symptoms of depression (Mittelman et al., 1995; Mittelman, Roth, Coon, & Haley, 2004). Teaching caregivers management strategies has been shown to decrease the behavioural disturbances and alleviate burden (de Vugt et al., 2004). A meta-analysis of 30 studies that incorporated randomization and standardized interventions has shown benefits to the caregiver in terms of psychological distress but not in terms of the formalized measure of caregiver burden (Brodaty, Green, & Koschera, 2003; Zarit et al., 1980).

In Canada, the lack of national or provincial standards for third-party CLTCS most likely contributes to the variability of outcomes among caregivers and care recipients. Other contributors to the variability of outcomes, as well as to the variability of the effects of dementia community care on caregivers, may involve cultural background of the caregivers and their families. For example, the Canadian Study on Health and Aging found that being non-English or non-French speaking was associated with a lower use of services (Durand, Krueger, Chambers, Grek, & Charles, 1995). However, in using only three categories, the results of this study understate the socio-cultural variability within Canada that has developed from early settlement and regional cultural differences and from later multi-cultural immigration patterns.

### ***Socio-cultural Factors in Dementia Community Care***

A growing body of research is acknowledging the influence of socio-cultural factors on the community care of dementia. However, research in this field is complicated by difficulties in defining culturally-based variables to differentiate groups of people (Chater, 1996). Accordingly, variables like race and ethnic background have been used despite their complex conceptual constructs, and both have been found to play important roles in a person's perceptions and attitudes towards old age and dementia (Pollitt, 1996, 1997; Pollitt et al., 1997). One study has shown ethnicity to have a gradient-like effect on the time to institutionalization of community care recipients with dementia: less-accultured Latina caregivers in California delayed institutionalization the most

compared to their more acculturated Latina or Caucasian counterparts (Mausbach et al., 2004).

Race and ethnic background have also been shown to have an influence on the effects of dementia community care on caregivers and their utilization of Community Long-Term Care Services. Korean community caregivers living in Korea were shown to have higher rates of depression than Korean community caregivers living in the United States, who themselves were more depressed than Caucasian caregivers (Lee & Farran, 2004).

Hispanic American daughter caregivers of people with dementia have been shown to have higher levels of depression than non-Hispanic daughter caregivers (Harwood et al., 1998; Mintzer et al., 1992). African-American caregivers of a person with dementia have been shown to have lower levels of burden than their white counterparts, and to find caring activities less stressful (Macera et al., 1992). Comparisons between African-American and Hispanic American caregivers of a person with dementia have further corroborated these findings; Hispanic American caregivers demonstrated a greater vulnerability to all forms of strain from caregiving than African American caregivers (Cox & Monk, 1996). White caregivers of a person with dementia, despite having higher socio-economic status and greater access to services, have been shown to be more likely than African-Americans to have greater burden, depression, and rates of institutionalization (Connell & Gibson, 1997; Haley et al., 1996; Wood & Parham, 1990).

Socio-cultural factors may also contribute to differences in the patterns of community care for a person with dementia. A meta-analysis studying twenty years of research

(1980-2000) in cultural aspects of caregiving has shown that: “ethnic minority caregivers have more diverse informal networks than their White counterparts and, in general, minority caregivers use informal services similarly and formal services less than non-minority caregivers” (Dilworth-Anderson, Williams, & Gibson, 2002). Black Americans were found to rely on informal support structures more frequently (Connell & Gibson, 1997; Haley et al., 1996; Haley et al., 1995), view caregiving as a traditional family value and an act of love (Sterritt & Pokorny, 1998), and to use religious faith as an effective coping mechanism (Haley et al., 1996; Wood & Parham, 1990). Among minority caregivers with higher levels of caregiver strain, lower rates of CLTCS utilization have been attributed, in part, to a lack of culturally sensitive services and out-reach programs (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Rait & Burns, 1997). The CSHA provided data that showed that minorities in Canada (neither English Canadian nor French-Canadian nor British/Scottish/Irish) were more likely to be dissatisfied with CLTCS (Durand et al., 1995). The authors do not suggest an explanation for these findings.

Ethnicity has been shown to have broad effects on the caregiver's understanding of dementia and community care, caregiver strain and the utilization of services. However, ethnicity is only one of many cultural factors that may influence caregivers of a person with dementia. In Canada, cultural factors may also include social culture based on language, for example, French and English speaking Canadians. Socio-cultural differences may also be the result of an independent historical development. Newfoundland and Labrador was the last province to enter into Canada in 1949. Its

social, economic and demographic history prior to confederation is largely distinct from the rest of Canada (Perlin, 1959). While the "rest of Canada" is neither culturally homogenous nor historically undifferentiated, the population of Newfoundland may be reasonably considered to have socio-cultural differences from the majority Canadian population. For example, while the people of Newfoundland share English, and to a much lesser extent French, as common languages, it has a history of social divisions based on place of origin and religion: Protestants, mainly from Wales and south-western England, and Catholics from south-eastern Ireland. The religious divide in Newfoundland has played key roles in politics, education and the social economy of the province (Rollman, 1988). A conspicuous example of the Protestant-Catholic divide between Newfoundlanders of English and Irish decent was the denominational school system, in which the virtually all schools in the province were associated to a church.

Existing research on dementia community care in Newfoundland is relatively sparse, and has focused on historical traditions of elder care in the Province. The care of older persons in Newfoundland is characterized by informal community-based care delivered by family (Lewis, 1997). An older parent may have moved in with a daughter to be cared for; alternatively the older parent may have had a child, most often an older married son, move into and take responsibility for the family home. Institutional care has existed in Newfoundland for over a hundred years and has generally been perceived as a place for older persons who do not have family or family support (Lewis, 1997). Research has indicated that Newfoundlanders value independence, kinship ties and community, and have a preference for community-based care where possible (Andersen, Crellin, &



O'Dwyer, 1998). Historically, women have provided the vast majority of community care in Newfoundland unpaid, a tradition that continues today (Morris et al., 1999).

## **2.8 Summary and the Present Study**

Dementia is an increasing health concern in Canada. The responsibility of care for people with dementia has traditionally resided with family and other informal community caregivers. Informal care has been shown to be preferable to institutionalization in terms of the amount of care a person with dementia may receive and in terms of the costs to the health care system. However, community caregivers have also been shown to experience negative effects from their role. These effects not only compromise their ability to provide care, they also contribute to increased mental and physical morbidity among caregivers.

As an alternative to institutionalization, Community Long-Term Care Services are intended to provide additional support to community caregivers. The effectiveness of CLTCS remains in dispute, but they are hoped to at the least mitigate the negative effects of community care on informal caregivers. Similarly, CLTCS are expected to increase the length of stay in the community of people with dementia. Evidence from the Canadian Study of Health and Aging suggests that CLTCS are under-utilized in Atlantic Canada. The lower rates of utilization may be due to factors associated with accessibility, for example cost or availability. Previous research from the United States indicates that caregiving and the use of services may also be influenced by cultural factors. The

regional difference in CLTCS utilization between the Atlantic and other provinces raises the possibility that cultural factors may play a role.

This study will seek to identify and interpret the factors that influence the utilization of Community Long-Term Care Services for dementia community care on the Eastern Avalon Peninsula of Newfoundland. The study will address variables that have been previously acknowledged to predict the utilization of CLTCS. It will expand on previous research to include an assessment of the accessibility of services as a potential cause for lower utilization rates. The study will also explore the meaning of community care among Newfoundland caregivers and relate their conceptualization of community care to their utilization of CLTCS.

## **2.9 Objectives**

The objectives of this study are:

1. To conduct a follow-up to the CSHA Caregiver Study.
2. To assess the accessibility of Community Long-Term Care Services to caregivers of people with dementia. The accessibility of services will be considered in terms of the human resources available for service delivery, the training of personnel and the geographic coverage of services.
3. To explore the meaning of dementia community care among a sample of Newfoundland caregivers.
4. To use these findings to investigate the factors that may influence the utilization of Community Long-Term Care Services by Newfoundland caregivers and people with dementia

## 2.10 References

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## **Chapter 3: Methods**

The study is made up of three components: the Homecare Capacity component, the Caregiving Experience component and the Canadian Study on Health and Aging (CSHA) Caregiver Study Follow-Up. The Homecare Capacity component is an assessment of the Community Long-Term Care Services (CLTCS) capacity in the region encompassing the study sample from the year before the CSHA began to the time this study was carried out (1989-1999). This component will assess the availability of both general and specialized services for persons with dementia. The second component is an exploration of the community caregiving experiences of the research participants and their acceptance of CLTCS. The last component is a modified follow-up of the Canadian Study on Health and Aging (CSHA) Caregiver Study. This component consists of a survey that provides a description of caregivers and care recipients with dementia and their utilization of CLTCS. This component will investigate several factors that are recognized as predictors of service utilization and are indicative of the need for services.

This chapter describes the experimental design, research instruments and methodologies of each component. It also includes a description of the analyses that were carried out on the research results.

### **3.1 Homecare Agency Capacity (HAC)**

The Homecare Agency Capacity (HAC) component is intended to provide an assessment of the traditional home-based CLTCS for caregivers of persons with dementia. It focuses on the services commonly referred to as "homecare": homemaking, preparing meals, personal care and respite care. The HAC is a historical assessment of homecare capacity from 1989 to 1999 for the region of the Avalon Peninsula included in Phases I (1991) and II (1996) of the CSHA.

Homecare agencies were identified using editions of the Eastern Newfoundland/St. John's Yellow Pages (Newtel Communications, 1989—1999) and Polk's Business Directory from 1989-90 to 1999-2000 (Polk's Directory, 1989—1999). Businesses that were listed under "Home Health Services & Supplies" were considered potential homecare agencies. Homecare agencies that were still in operation were contacted by phone and given a preliminary screening survey to establish that they did provide one or more homecare services and to document the agency's years of operation during the study period. Eligible homecare agencies were asked to participate in the survey, and agencies that gave consent over the phone were mailed a survey to determine capacity.

The survey was a customized form with a table that was to be filled out by the homecare agency manager or owner. The survey consisted of variables that referred to operating status and ownership, service area, service capacity, costing and training (Appendix B). A table format was used in an effort to make it easy and quick to fill out, with the intent of

maximizing the number of respondents. Instructions and a self-addressed stamped envelope were included with the survey for return post.

The survey asked for information regarding general homecare capacity as well as for the capacity for services specialized for persons with dementia. General capacity would be estimated by considering the annual reports and generating estimates of service area, the number of employees, the number of hours billed by the homecare agency and the approximate cost per hour for homecare services. Specialized services were estimated based on the number of the agency's clients with dementia, the number of workers serving clients with dementia and the implementation of any specialized training for caring for someone with dementia.

In addition to the survey, participating homecare agencies were also queried with regards to previously operating agencies and their staff. Contact names given for previous agencies were recorded and followed up by phone calls; contacts that were reached were administered the screening questionnaire and survey by phone. Since these contacts had worked for agencies no longer in operation, estimates were taken for the survey.

### **3.2 Caregiver Components—Research Participants**

The Caregiving Experience and CSHA Caregiver Study Follow-Up components of the study were carried out together. Both components drew on the Newfoundland sample of the CSHA Prevalence and Caregiver studies. Consequently, the sampling methodology and eligibility criteria for this study are based on these CSHA studies. These are

described below in addition to the sub-sampling and eligibility criteria for the present study. The data collection for both components took place during the same face-to-face interview. The interview instruments and format are described below.

### ***CSHA Research Participant Sampling Method***

The research participants of the current study were identified through their connection to the research participants in the first phase of the CSHA Prevalence Study. Research participants in the CSHA Prevalence Study are referred to as Index Subjects. They were randomly selected persons who were 65 years or older, living in institutions or the community and fluent in either English or French. Index subjects lived in 36 study areas, consisting of urban centres and their surrounding rural areas, spread over the ten Canadian provinces divided into five geographic regions. Two initial samples of Index Subjects were drawn to represent community and institutional dwellers.

The community and institutional samples were stratified into three age groups (65-74 years, 75-84 years and 85 years or over). The second and third oldest age groups were over-sampled by a factor of 2 and 2.5 in order to provide a sufficient number of research participants for the CSHA study design. Index Subjects who refused to participate or who were unreachable were replaced by somebody of the same sex, age, and geographic regions. Each of the five geographic regions began with an initial community sample of 1800 Index Subjects.

The institutional sample was obtained from comprehensive lists of institutions in the sample areas. The institutions were stratified according to the size of the patient population: small (up to 25 beds), medium (26 to 100 beds), and large (more than 100 beds). Each geographic region randomly selected 17 institutions from a list of institutions that was stratified by size. Index Subjects were then randomly selected from the resident lists of the 17 randomly selected institutions.

Community Index Subjects who gave consent to participate in the study were interviewed and given a screening test for dementia that consisted the Modified Mini-Mental State (3MS). Index subjects who tested positive on the screening test (scoring 78 or below), those for whom the 3MS could not be administered for scheduling or health reasons, and a random sample of subjects who tested negative for the screening test were asked to undergo a clinical assessment (Canadian Study of Health and Aging Workgroup, 1994). Institutional Index Subjects with consent to participate in the CSHA were administered the clinical assessment directly. The rates of dementia were expected to be much higher among the institutional population, and, as a result, the screening test was not administered to this group (Canadian Study of Health and Aging Workgroup, 1994). The clinical assessment was a multi-disciplinary series of tests, which provided detailed information on the medical condition and cognitive capacities of the Index Subject. Upon completion of the clinical assessment, Index Subjects were classified as no cognitive impairment, cognitively impaired with no dementia (CIND), or as having dementia.



Community and Institutional Index Subjects with dementia and their families were invited to participate in the Caregiver Study. A random sample of geographically- and age- matched community Index Subjects with negative screening tests and their families were invited to participate in the Caregiver Study as a community control sample.

Community Index Subjects and their families were designated eligible for either of the studies but could not participate in both. Institutional Index Subjects with a normal clinical assessment and their families were invited to participate as an institutional control sample. Institutional Index Subjects and their families could participate in both studies.

In the Caregiver Study, Index Subjects were grouped by residential status (community or institution) and diagnostic status (dementia or non-dementia). The Caregiver Study sampling unit consisted of a pair of people referred to as a dyad: the Index Subject and his or her primary caregiver. The pairing system applied to Index Subjects with either a dementia or a normal diagnostic status. Primary caregivers were identified by the Index Subject in the screening interview as well as by their family. For the purposes of the CSHA studies, the definition of a primary caregiver was: "the person perceived by the subject or the family as the person who was or would be most responsible for the day-to-day decision making and provision of care to the index subject".

The Caregiver Study included both formal and informal caregivers, with the intention of providing as complete a picture of caregiving in Canada as possible. The Caregiver Study was followed up in the second and third phases of the CSHA. The objective of the CSHA-2 Caregiver Study was to measure the effects of informal caregiving over time; as

such, only informal community caregivers were revisited. Furthermore, informal community caregivers remained eligible only if they had continued providing care. If they had not, or if an Index Subject experienced a change in their primary caregiver, then that pair was not included in the CSHA-2 Caregiver Study.

### ***Sampling Method for the Current Study***

The research participant sample for the current study was developed from the Canadian Study of Health Aging sample of Index Subjects. The sample consists of two sets of research participants. The first set consists of persons who were enrolled in the second phase of the CSHA Caregiver Study as informal community caregivers of persons with dementia. This group of caregivers were eligible to participate provided they lived on the Avalon Peninsula of Newfoundland. Informal community caregivers of Index Subjects living in institutions were not eligible, nor were formal caregivers, as the focus of this study was on informal community caregivers.

The second set of research participants consists of informal community caregivers of Index Subjects who had developed dementia between the time of the first and second phase of the CSHA. This group of caregivers was eligible if they lived on the Avalon Peninsula. They were ineligible if they had been a part of the control group for the CSHA Risk Factor Study, in order to maintain the division between the two CSHA sub-studies. The second set was developed because the number of eligible research participants in the

first set was too small to provide the power necessary for a quantitative analysis of the CSHA Caregiver Study Follow-Up component.

The eligible caregivers for the second sampling round were identified through files compiled during the Canadian Study of Health and Aging. The CSHA files contained information on the primary caregiver of the Index Subject that included name, address and telephone number.

### ***Recruitment Method***

An interviewer who had worked on Phase 1 and 2 of the CSHA Caregiver Study made first contact with all eligible caregivers. She reminded the caregiver of their involvement in the CSHA Caregiver Study and explained that a new study was underway. The CSHA interviewer established verbal consent from the caregivers to be contacted by phone for recruitment in this study.

I carried out the research participant recruitment for this study by phone. I called caregivers, introduced myself and restated the purpose of the study. I also explained the interview format and the confidential and voluntary nature of participation in the project. During this phone call, if possible, we scheduled a time and place to have the interview.

In some cases, the CSHA interviewer was not able to reach a potential research participant. I used phone books and internet-based directories to seek out those research participants. If that strategy did not work, I would call the person who was listed as the

third-party contact in the CSHA Caregiver Study file. If contact information for the caregiver was obtained, the CSHA interviewer would then call the caregiver and begin the process of establishing verbal consent for me to call him or her.

Several techniques were employed to maximize the likelihood of caregiver participation in the current study. The caregivers were reminded of their previous participation and thanked for their contributions. The importance of understanding cultural and regional distinctions in informal caregiving was emphasized. In situations where the potential research participant was very busy, a flexible interview scheduling system was used. The interview time frame remained open over one or more days, and the interview was confirmed a few hours before. Many of the caregivers lived outside the city, and were unable or unwilling to travel for the interview to the university. A vehicle was obtained to enable the interviewer to visit these caregivers at home.

A research participant sample was also developed for a pilot test. This sample consisted of people who had been caregivers and/or who were older Newfoundlanders. The pilot study sample was a sample of convenience of persons who were either known to the interviewer or who volunteered in response to a poster placed at a local gym that held fitness classes for older persons.

### **3.3 Caregiver Components: Interview Instruments**

The interviews were based on the last year during which the caregiver was providing care in the community or the current year if the caregiver was still providing care in the

community. This is termed the study window. The time between the study window and the interview is the Elapsed Time.

### ***Caregiver Childhood***

The first section of the CSHA Caregiver Study Follow-Up addressed the caregiver's childhood. Childhood was considered the time from birth until the caregiver had moved out of the family house or until they had reached their twenty-first birthday. The items in this section were asked in a semi-structured interview. Caregivers were asked about family composition, that is, who lived in the home during their childhood. Caregivers were asked to recount their places of residence and the approximate dates and reasons for changing communities or neighbourhoods. In the last part of this section, caregivers were asked to recount any occurrences of community caregiving experiences that took place in the home.

### ***Caregiving Experience***

The second component of the current study explored the caregiving experience of informal community caregivers of persons with dementia. This component consisted of seven open-ended questions that explored the meaning of caregiving on the part of the caregivers (see Appendix C). The Caregiving Experience component was tape recorded with the permission of the research participants.

The Caregiving Experience component provided the only opportunity in the study to collect qualitative data. The questions were an adapted version of those used by Sterritt and Pokorny (1998). They were designed with the objective of exploring the meaning of caregiving among a group of African-American caregivers. The study was intended to see how "cultural attitudes, beliefs, and values influenced" the caregiving experience of a socio-cultural minority with a long, and to a large degree segregated, history in the United States. These questions were selected with the view that Newfoundlanders also consisted of a socio-cultural minority that had a long history and largely separate history from Canada. These questions were also selected because they were general in nature while covering a broad scope of the caregiving experience. In the present study, a seventh question was added that addressed the informal primary caregiver's attitudes towards the utilization of external Community Long-Term Care Services.

### ***CSHA Caregiver Study Follow-up***

The third component of this study was a modified version of the follow-up to the Canadian Study on Health and Aging (CSHA) Caregiver Study for the Newfoundland sample. This component consisted of a survey that was administered during face-to-face interviews with caregivers in their homes or in the Health Sciences Centre in St. John's, Newfoundland. The survey asked for information on the primary caregiver, the index subject, and service utilization. The survey was modified to include items relating to caregiver childhood experiences and to remove items directly relating to caregiver and

care recipient income. The income-related items were removed because of the sensitive nature of these questions.

### ***Section 1: Caregiver Background Information***

The first section of the CSHA Caregiver Study Follow-Up determined the caregiver status of the research participant as the primary caregiver. If the research participant was the person most responsible for the Index Subject, they were considered as the primary caregiver. The survey then determined who provided informal support to the caregiver, with a coding system for the responses. Most of the codes were for different kinds of family relations, for example: daughter, nephew, granddaughter, and so on. The first section ended with an assessment of the work status of the caregiver and any work disturbances they had experienced that were due to the Index Subject or their caregiving role.

### ***Section 2: Measures of Index Subject & Caregiver***

The second section of the CSHA Caregiver Study Follow-Up measured aspects of the Index Subject's disease severity and the caregiver's state of well-being. The survey incorporated standardized and validated scale-type questionnaires for this section.

Index Subject disease severity was measured in terms of behavioural pathology and functional ability. Index Subject behavioural pathology was measured using the Dementia Behaviour Disturbance Scale (DBD) (Baumgarten, Becker, & Gauthier, 1990).

It assesses the number and frequency of behavioural disturbances exhibited by the Index Subject. The caregiver is asked to indicate the frequency of 28 behaviours using a standard five-point scale ranging from "Never" to "All of the time".

The functional ability of Index Subjects was measured using the Older Americans Resources and Services (OARS) Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) questionnaires (Fillenbaum, 1988). The ADL assesses functional ability by asking how Index Subjects carry out basic daily activities: eating, dressing, personal care, walking, getting in and out of bed, using the bathroom. The IADL assesses the ability of Index Subjects to carry out activities necessary for independent living, including: using the telephone, getting to places out of walking distance, shopping, preparing meals, doing housework, taking medications, managing money. The focus of the questions is to determine what degree of assistance is required by the Index Subject to carry out an activity if he/or she needs to. Index Subjects are graded on a three-point scale: "without any help", "with some help" or "completely unable". For questions where Index Subjects required help, the caregiver was asked who provided assistance. Up to three people were recorded.

Caregiver well-being was measured in terms of caregiver burden and depression. The Zarit Burden Inventory (ZBI) was used to assess the level of caregiver distress and strain (Zarit, Reever, & Bach-Peterson, 1980). It consists of twenty-one items consisting of statements that describe a way of feeling. Caregivers responded to each item in terms of how often they felt that way. The ZBI uses a five-point scale ranging from "Never" to



"All of the time" to rate each item. Caregiver depression was measured using the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D lists twenty items describing behaviours and feelings. Caregivers responded to each item in terms of how often they did or felt that way. The CES-D uses a four-point scale that ranges from "Rarely" to "Most of the time" each item.

Approximately ten years had elapsed between the initiation of the CSHA and the current study. It was expected that several caregivers would no longer be providing care, either because of institutionalization or the death of the index subject. Since the four scale questionnaires are intended to be asked of people in existent caregiving situations, a time frame was established for caregivers who were no longer providing community care. If the caregiver was no longer providing care, the scale-type questions (ADL, DBD, CES-D and ZBI) were set in the last two months that the care recipient was in the community and being cared for by the research participant. Responses from the CSHA-1 and CSHA-2 Caregiver Studies provided comparisons in responses over time. The remainder of the questions were not time-specific in the same way, and asked questions regarding either the general experience of caregiving or events in the past.

### ***Section 3: Community Long-Term Care Services***

The third section of the CSHA Caregiver Study Follow-Up addressed CLTCS utilization. A series of items taken from the Caregiver Study covered the utilization of seven different categories of community long term care services (CLTCS): homemaker support

(cleaning, laundry, meal preparation and other), home delivered meals, personal care services (bathing, grooming, dressing, etc.), in-home nursing care, additional professional services (physiotherapy, occupational therapy, podiatry and chiropractic treatments), day care (day centre or day hospital), in-home respite care, and services used by the caregiver to help care for the index subject.

	<b>Code: Reason for not utilizing or terminating service (as listed in the CSHA Caregiver Study questionnaire)</b>
<b>Reasons related to Need</b>	I wanted to provide this service myself
	Subject and family did not need the service
<b>Reasons related to Accessibility</b> (includes reasons related to: <ul style="list-style-type: none"> <li>• availability</li> <li>• awareness</li> <li>• affordability</li> <li>• timeliness</li> </ul>	Caregiver found using service too complicated, or waiting list too long. Includes problems with transportation
	Caregiver thought the service was too expensive
	Subject thought the service was too expensive
	Subject unable to get out to use the service
	Subject was not eligible to receive this service
	This service was not available in our area
	We were not aware that this service was available
<b>Reasons related to Acceptability</b>	Caregiver tried and did not like the service
	I did not want strangers in my house
	It upsets subject to have someone else care for him/her
	Subject did not want strangers in the home
	Subject did not want the service
	Subject tried and did not like the service
<b>Other reasons</b>	Other
	We plan to use this service soon

*Table 3: Reasons for not utilizing a service (CSHA Caregiver Study).*

For each service, one question asked if the service had been used. If the service had been used, the subsequent questions addressed the frequency, provision, payment, consistency, reliability, and effectiveness of the service. If the service had been used and stopped or not used at all, the subsequent questions addressed the reasons for non-utilization. In cases where the service had never been used, caregivers were first asked if they were

aware that the service existed and whether or not it was available in their area. If caregivers were aware of an available service, they were then asked what their reasons were for non-utilization. Up to three responses were recorded and coded during the interview. There were sixteen codes that described the reasons and an "Other" category.

The criteria for service utilization described above applied to the responses for service non-utilization. The sixteen codes included reasons that related to the need for services, the accessibility to services and the acceptability of services. The reasons are listed and grouped in Table 3.

The CSHA Caregiver Study Follow-Up survey items are summarized below:

**Caregiver information:**

- Demographic characteristics, living arrangements, employment status of the caregiver;
- Caregiver childhood experiences of informal caregiving and residential history in Newfoundland and Labrador;
- Caregiver depression, evaluated with the Centre for Epidemiologic Studies Depression (CES-D) scale;
- Caregiver burden, determined with the Zarit Burden Inventory;
- Caregiver support, indicated by contact with children and close friends, and including questions relating to the extent to which there were other people to potentially share in the caregiving role.

**Care recipient information:**

- Care recipient functional status, evaluated with the Older Americans Resources and Services Activities (OARS) of Daily Living (ADL), which also includes items used to evaluate Instrumental Activities of Daily Living (IADL);
- Help received by the care recipient, on tasks addressed by the OARS and ADL questionnaire, the people who helped, and the amount of time devoted to helping;
- Care recipient behavioural problems evaluated with the Dementia Behaviour Disturbance scale;

### **Service utilization information:**

#### ***Information was sought for the following Community Long-Term Care Services:***

- ***Supportive services:*** Homemaking, Meals (delivered or prepared in home), Personal Care
- ***Substitutive services:*** Day Care (out of home), Respite Care (In-home)
- ***Preventive services:*** In-home Nursing, Professional Services (caregivers chose the most frequently used service from: Physiotherapy, Occupational Therapy, Chiropractic Treatments or Podiatry), Caregiver Services (caregivers chose the most frequently used service from: Social Worker, Psychologist, Psychiatrist, Clergy, Self-Help Group, Support Group (including Alzheimer's Society), Phone Help Lines, Other)

#### ***For each service, the following information was sought:***

- Utilization of the service, awareness that the service was available, frequency of use, service provider, method of payment, estimate of payment per month, continuity of the provider of the service, reliability of service availability, satisfaction with the service (meeting needs, quantity, quality), reasons for discontinuation, reasons for non-utilization.

### **3.4 Interview format**

The interviews took place in the caregiver's place of residence or in a classroom at the university medical school. At the beginning of the interview, an informed consent form was read by the caregiver and discussed with the interviewer. The caregiver's signature on the form indicated informed consent. The duration of the interview ranged from 45 minutes to three hours and was completed in one visit. The interview followed the guidelines established by the Canadian Study on Health and Aging and documented in their interviewer manual. The guidelines outlined a semi-structured interview format that allowed for some open-ended questions but that remained closely tied to the interview schedule.

Interviews were intended to take place with the primary caregiver and interviewer alone. This was considered important to maintain confidentiality and to encourage the caregiver

to speak freely without concern of others being aware of their responses. On several occasions a third party was present, either a spouse or a relative. Their presence was most often explained as emotional support, to help with remembering details, or as a caregiver to the interviewee. The preference for privacy was always explained, but was waived if both the caregiver and the third party agreed. During the questions, the third party was encouraged not to comment before the caregiver answered and not to challenge caregiver answers.

The interview format for the Caregiver Experience section followed the guidelines outlined in the CSHA Interviewer Handbook (Canadian Study of Health and Aging Workgroup, 1989) and the principles described in Berg's Qualitative Research Methods for the Social Sciences (Berg, 1995). The interview format was a semi-structured series of questions adapted from a study carried out by Sterritt and Pokorny (1998) that studied the experience of caregiving among different ethnic groups in the Southern United States. The questions were open-ended and asked in order and the respondent was given wide latitude for interpretation. There were two types of prompts prepared for respondents. One set of prompts were intended to help caregivers to elucidate when they had difficulty with description, for example "could you tell me more about that?" or "how do you mean?" A second set of prompts were prepared to provide clarification to the questions in cases where they were not understood, for example, explaining that a "homecare worker" was someone who was paid to provide community-based services and who was not related to the care recipient.

Throughout the Caregiver Experience section, respondents were allowed to follow their trains of thought wherever they led them. In cases where the responses diverged substantially from the spirit of the question, the interviewer would bring the respondent back to the question after he or she had finished. In cases where a response to an earlier question touched on issues addressed by subsequent questions, the interviewer acknowledged that some issues had been mentioned and then inquired if there were other aspects that the caregiver wanted to discuss or if there was further elaboration the caregiver wanted to provide. This section was placed before the CSHA Caregiver Study follow-up survey in order to minimize the potential for caregivers to limit their responses because of fatigue or concerns over the amount of time that the full interview took.

Each interview began with an introduction and a short conversation with the research participant. In the introduction, the interviewer explained the project, his role and interest in the project. The introduction also included a brief explanation of how the interviewer came to be living in Newfoundland, where the interviewer originally lived and where the interviewer's family came from. This explanation was offered in an attempt to minimize any discomforts on the part of the research participants and to initiate an open interview environment for a personal and often difficult subject. Feedback from the pilot study phase of the project strongly recommended this approach since the interviewer was not from Newfoundland and had a noticeably foreign name and appearance, and the research participants were often older persons for whom comfort might be strongly related to commonality of personal background. The conversation that followed the introduction

established a comfortable environment and usually involved the making and sharing of tea.

Immediately prior to administering the interview instruments, the caregiver was asked to recount a synopsis of his or her caregiving experience. This was done for two reasons. The first was that it provided a frame of reference for the interviewer in terms of time, place, people and events. The second was that it helped to establish a rapport between the caregiver and the interviewer. On some occasions, it appeared that the caregiver felt nervous about the interview, often believing that they were being tested or evaluated. Recounting a brief history of their caregiving seemed to help them relax and gain a sense of control over the interviewing situation. At other times, caregivers did not appear to feel completely at ease with the interviewer, but in the telling of their caregiving histories may have felt that there was nonetheless an understanding on the part of the interviewer of their experience.

Care was taken to ensure effective communication for both the interviewer and the interviewee. High-contrast and large-lettered laminated answer cards were designed for questions that involved scales. The interviewer verified any dialectal expressions with the caregiver at the time or with other sources after the interview. In the section of the interview where open-ended questions were asked, permission was asked to record the participant on audiotape. In the event where the caregiver did not give permission for a tape recording, detailed notes were taken on paper. Prompts were devised prior to interviewing for any open-ended questions that may have been difficult to understand,

and accessible definitions had been prepared for many of the terms in the closed questions.

The order of the interview components was the same for all research participants. The first part of the interview consisted of survey items relating to the research participant's childhood. This was used as a warm-up for the rest of the interview and helped establish a rapport with the interviewer and comfort with the interview equipment. The second part of the interview consisted of the Caregiving Experience component. This part of the interview consisted of open-ended questions that were elaborated if the research participant had difficulty understanding. The research participant was asked to elaborate if their response was brief by means of prompter questions such as "could you tell me more about that" or "in what way do you mean that". Research participants were not reminded of previous responses if there were contradictions in what they were saying. This was considered important as a way to record the conflicting feelings and perceptions of their caregiving experience and also to avoid any perception that the interviewer was challenging the research participant's honesty. The interviewer took notes on the content and manner of the responses for each research participant. This part of the interview was taped with permission, using a microphone that was either placed in front of the research participant or pinned on the participant's clothing. . If the research participant permitted the taping of the interview, a "warm-up" period of conversation was used to adjust to the microphone and to distract attention away from the recording.



The interview concluded with the modified CSHA Caregiver Study questionnaire. The questionnaire was delivered in the same order for all research participants. Laminated large-print cards were used for items that required the research participant to select a response from a list of options. The interviewer took notes on the survey during the interview. The interviewer prompted research participants with reminders of previously given information for items that the research participant did not recall.

### **3.5 Pilot study**

The study instruments were piloted on a sample of convenience of eight subjects. The pilot study familiarized the interviewer with the instruments and provided an opportunity for feedback to the interviewer about the instruments and the delivery of the interview.

### **3.6 Ethics**

The current study received approval from the Human Investigations Committee (HIC) of Memorial University of Newfoundland. The HIC is the research ethics board from which approval is required for any research projects involving human participants that are carried out under the auspices of the Faculty of Medicine, Memorial University.

All procedures conducted during the course of the study abided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2003). The researcher and staff with access to the participants' identifying information signed confidentiality agreements. The anonymity and confidentiality of research participants was ensured by

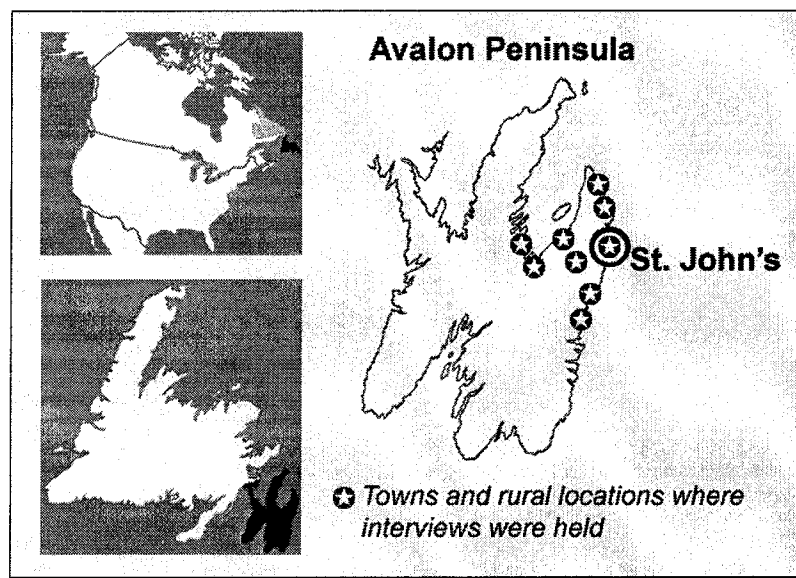
the use of serial numbers for identification, and the segregation of identifying information and study data in separate, secured physical locations or in separate encrypted and password-secured computer files. Upon completion of the study, all data was returned to the Division of Community Health, Faculty of Medicine, Memorial University of Newfoundland.

The first contact with research participants was made by a research assistant who had previously worked on the CSHA and was familiar with the research participants. Informed consent was required for any subsequent stage of contact or participation in the study. At all stages, research participants were clearly informed that participation was voluntary, confidential and anonymous, and would have no effect on any current or future receipt of health care services.

Research participants who agreed to an interview were given the choice of having the interview in their home or in a classroom in the university medical school. Since many of the interviews took place in the research participants' homes, and since the interviewer was unknown to the research participants, identification was presented upon arrival and phone numbers provided should the research participants wish to verify the interviewer's identity.

Since a major theme of this study was the utilization of community services and the care of people with dementia, an information package was offered to all research participants. The package included information on a local senior's resource centre, health care

services, Alzheimer Disease, and support groups. No solicitations, advertising or promotions were included in the package. Care was taken to draw attention to any services that the interviewer thought would be beneficial to the participant.



*Figure 3: Study setting and interview locations.*

### **3.7 Setting**

The current study was set in the Newfoundland study area for the CSHA (see Figure 3). The study area consisted of the Eastern portion of the Avalon Peninsula, bordered by the coast on the North, East, and South. The study area encompassed the rural area bound by St Mary's Bay, Route 90 (Salmonier Line), the Trans-Canada Highway, and Route 70. The study area included the urban area of St John's.

### **3.8 Data management**

Research participant personal information was organized in paper information files and a Microsoft Access 2000 database. The information files were stored in a locked container in a monitored and locked room. The database information included: caregiver name, address and phone number, key data from the previous CSHA Caregiver Studies, contact history, interview time, directions to their home and reasons for refusal.

Responses to the first and third sections of the interview were recorded on paper versions of the interview script. The second section of the interview consisted of open-ended questions and was recorded on audiotape, except in a few instances where detailed notes were taken. All data from the interview were entered into a second Microsoft Access 2000 database (Microsoft, 2001), including transcriptions from the second section of the interview. Copies of all computer files were archived on a network drive in the medical school. Both the main work computer and the network drive employ several layers of security to prevent unauthorized access.

Several procedures were employed for data quality control. Notes were taken directly after the interview to record the interviewer's impression of the quality of data, any potential problems in the collection of information, and to highlight any questions which the participant had difficulty answering. Fields, i.e., variables, in the database used to store interview information were programmed to reduce potential data entry errors. Fields that stored numeric data were set to accept values that fell within the range of potential

responses. If data were missing from requisite fields an error message would prevent further data entry. The data entry sequence paralleled the order in which questions were asked in the interview. Variables that were contingent on previous responses were appropriately skipped or required. After each set of interview data, a query was run to search for outliers that were then verified to be either accurate responses or data entry errors. A field was also included in the database for any potential coding difficulties or missing responses as an indicator of data quality.

### **3.9 Analysis**

#### ***Caregiving Experience***

The data from the Caregiving Experience component of the study consisted of notes taken during the session (the interview notes), audio recordings of the interview itself and notes made immediately after the session (post-interview notes). The interview notes included point-form notes on the responses and the interview dynamics. These dynamics included body language, perceived comfort, tone of voice and expressivity. The audio recordings were transcribed word-for-word, with each interview transcribed in a single sitting. Expressions that were unfamiliar to the interviewer were clarified and noted on the transcription page. The post-interview notes included a self-evaluation, reflections on and points of interest of the interview. The interview notes, post-interview notes and transcriptions formed a data package.

The goals of the qualitative analysis of the Caregiving Experience interview were to search for the meanings of community care among this sample of caregivers and to explore their feelings and attitudes about using paid, non-family assistance. The analysis of the Caregiving Experience follows the methods for content analysis described by Berg in "Qualitative Research Methods for the Social Sciences" (1995) and by Patton "How to Use Qualitative Methods in Evaluation" (1987). Additional resources were used in different stages in the analysis, including "The Content Analysis Guidebook" (Neuendorf, 2002) and "Qualitative Data Analysis: an Expanded Sourcebook" (Miles, 1994).

The first stage of the analysis was an open exploration of the transcripts. In this stage, manifest and latent meanings were identified in the transcripts. The manifest meanings were considered the explicit meanings of a response. They were identified exclusively from the transcriptions. For example, one caregiver said the following in response to "what does caring for the [care recipient] mean to you?":

*Caregiver: "What it means of course is that I want to see that she had the best of care. We want her to be looked after."*

In this example, the caregiver clearly articulates that caregiving means his mother will receive the highest quality of care, the "best of care".

The latent meanings were considered the implicit or indirect meanings of a response to an individual question. They were identified and interpreted using the full data package, and

may have drawn on responses to other questions. For example, the caregiver cited above also said:

*Caregiver: " But I think this year [staying at the cottage is] going to change. It actually has changed; we're not going to ever go anywhere unless there's somebody with her. So we're hoping to have somebody with her constantly, I don't know what it's going to be. Got to make some plans. Because I'm sure not getting younger either, so we've got to try to have a life. "*

The caregiver has described how he wants to be able to participate in activities without being responsible for his mother. Throughout the interview, he made references to not having time and to feeling burnt out. These statements and his demeanour throughout the interview indicated that he was stressed by the constant attention required to provide care.

The latent and manifest meanings were organized for each individual research participant at the question, or item, level. In the second level of the analysis, the meanings were then integrated into themes across participants at the item level. The initial identification of themes was weighted towards inclusiveness, the inclusion of all meanings, with a high tolerance for overlap and redundancy. The themes were then refined in iterative steps whereby themes were redefined and consolidated or divided with the intention of reducing overlap and redundancy. The final iteration produced a parsimonious and inclusive list of themes.

### ***CSHA Caregiver Study Follow-Up***

The results from the CSHA Caregiver Study Follow-Up were analysed in three stages with quantitative methods appropriate to the survey items. First, the survey data were

used to generate descriptive statistics that summarized the data on both individual and group levels. Second, the data were tested to see if they were appropriate for use in higher-level statistical analyses. Third, the raw data were either used in higher-level statistical tests or subjected to a transformation that would make them appropriate for the tests.

Descriptive statistics for demographic data were generated for the sample as a whole. This included standard measures such as mean, median, skewness and kurtosis. Cross-tabulations of the research participants on demographic variables were also calculated. Frequencies were calculated and distribution patterns were assessed for multiple-response items. The scale items made up of four standardized questionnaires were used to calculate scores for the research participants.

The data were tested for use in higher-level statistical treatments. Power and degrees of freedom were established for planned tests. Data from the scale items were standardized for use in regression analyses. Multiple regressions were carried out using service utilization as the predicted variable. Models were developed using an interactive selection of dependent or predictor variables. Tests of regression residuals were used to evaluate the appropriateness of the multiple regression treatments. However, ultimately the number of caregivers in the current study was too small to carry out a reliable regression analysis, and the results of the analysis are not included in this study.



### 3.10 References

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## **Chapter 4: Results**

This chapter presents the results of this study, organized according to the study components. Each section includes a description of the eligible participants and participation rates. The Caregiving Experience component includes the major themes that emerged from the interview questions. The results are presented in the same order as the questions were asked. The themes are not ranked in any particular manner. A summary of the CSHA Caregiver Study follow up results is presented last.

### **4.1 Homecare Capacity Component**

The Homecare Capacity component surveyed Community Long-Term Care Services (CLTCS) agencies that provided homecare-type services and were operating from 1989 to 2001. Homecare-type services were homemaking, meal preparation, personal care and respite care. Forty-six eligible agencies were identified (see Table 4). Thirty agencies were no longer operational and no former representatives could be identified or contacted. Representatives, either managers or owners, were successfully contacted for the remaining sixteen agencies. Fifteen of these agencies were still open and providing services and one had been closed for two years. Representatives from thirteen of the sixteen agencies gave consent to participate in the study; three declined citing a lack of resources. Two of the agencies were subsidiaries. The mean number of years that the homecare agencies were open and providing services was 6.3 years (standard deviation = 3.3 years).

<b>Description of CLTCS Agencies (1989-2001, Avalon Peninsula)</b>	<b>Number</b>
Were operating during study period	46
No longer operating at the time of the survey	30
Able to contact an agency representative	16
Representative agreed to participate in study	13
Representative returned completed survey	1

*Table 4: Summary of homecare agencies.*

Of the thirteen participating homecare agencies, one returned the Homecare Capacity Assessment survey. Follow-up calls to the homecare agencies were made in an attempt to increase participation or determine the reason for non-compliance. All twelve of these cited a lack of the resources and/or documentation needed to complete the survey as their reasons for not participating.

## **4.2 Caregiver Components—Participants**

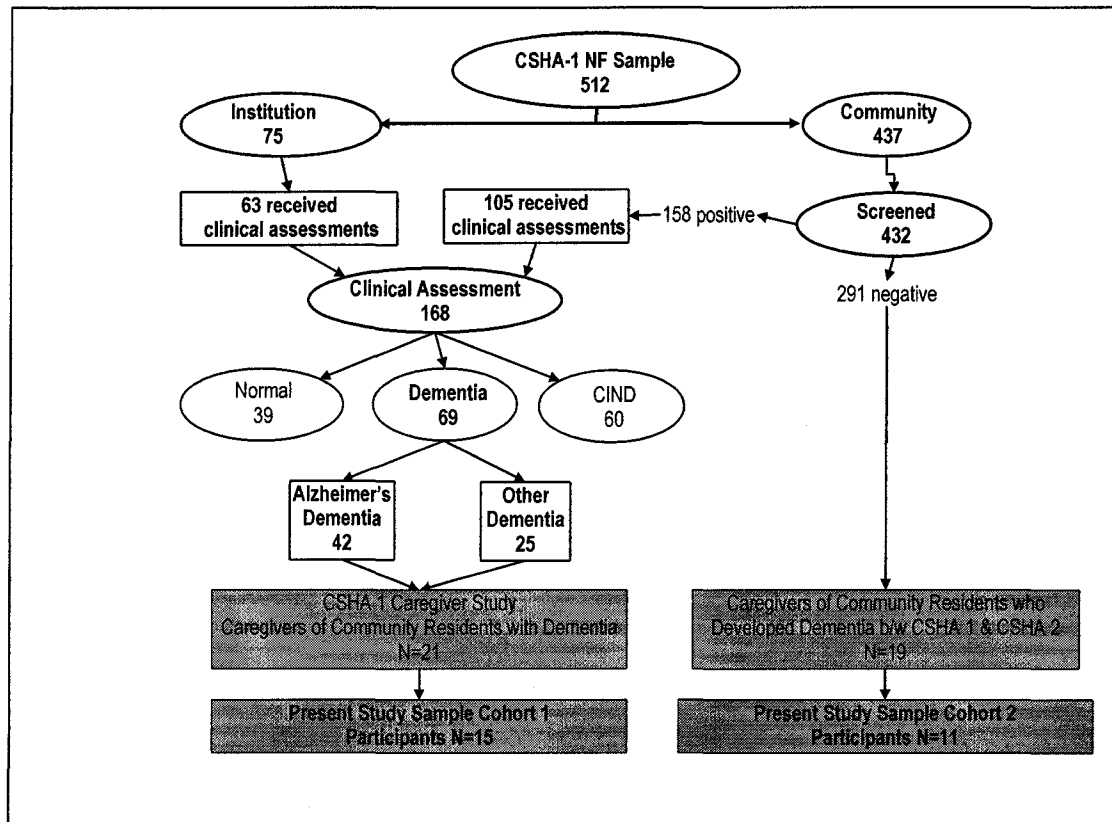
There were 51 Newfoundland caregivers who took part in the Canadian Study of Health and Aging (CSHA) Caregiver Study in 1990 (Table 5, page 94). Forty-four caregivers were contacted from this cohort. Four of the caregivers were confirmed to have died, three caregivers were not confirmed to have died, but their whereabouts could not be determined.

Eight caregivers refused to participate: three due to illness, two because they felt emotionally unprepared to discuss the care recipient and three because they were not interested in participating. Seven caregivers were unable to give interviews because they were not living in the province (4), were unable to schedule an interview time (2) or were incapable of carrying out the interview because of memory loss (1). The remaining

twenty-nine of the contacted caregivers agreed to participate in the study and were interviewed.

Fourteen of the interviewed caregivers were from the CSHA Caregiver Study control group (7) or the institutional group (7). These two groups were interviewed for a proposed research component that consisted of a longitudinal analysis of all of the participants in the Newfoundland part of the CSHA Caregiver Study. The longitudinal component was cancelled because of the small number of research participants available for follow-up. These data from the control group and institutional group were not used in the present study. Although the 14 caregivers were initially included for the longitudinal component, they were later excluded to retain the focus on informal community caregivers of a person with dementia. The other 15 community caregivers from the original CSHA Caregiver Study made up one part of this study's sample (Figure 4).

The primary caregivers of 19 care recipients who had developed dementia between the first and second phases of the CSHA made up the sample pool for the second cohort. Five of the caregivers refused to participate and three were deceased. Eleven caregivers from this cohort agreed to participate and were interviewed; these caregivers make up the remaining part of the current study sample. The flow of participants in both cohorts is described in Figure 4. For clarity, the flowchart describes only the flow of participants in the current study only; numbers for participants who refused to take part or were deemed ineligible, participants in the CSHA Caregiver Study control group and participants in the CSHA Risk Factor Study are not included.



**Figure 4: Participant flow in CSHA 1 Newfoundland cohort and in this study.**

Most of the caregivers interviewed were no longer caring for the care recipient in the community. The study window, the time on which the caregivers reported, depended on their status as active community caregivers. Of the caregivers in this sample, five were still providing care in the community at the time of the interview (19%). The study window for these caregivers was the two weeks prior to the interview. The majority of care recipients had either been placed in a long-term care facility or had died (n=21, 81%) at the time of the interview. The study window for these caregivers was the last three to six months that the care recipient was in still living in the community. The average recall time for these caregivers was 4.2 years.

The study sample was predominantly female. Eighty-five percent of the caregivers were women. The most common relationship between the caregiver and the care recipient was being a daughter.

	<b>Status (Current study participants in bold)</b>	<b>CSHA Caregiver Study</b>	<b>CSHA</b>	<b>Total</b>
Contacted	<b>Interviewed—Informal community caregiver of a person with dementia</b>	<b>15</b>	<b>11</b>	<b>26</b>
	<i>Interviewed but excluded from this study—Not informal community caregiver of a person with dementia</i>	14	0	14
	Refused to participate	8	5	13
	Unable to participate	7	0	7
Not contacted	Deceased	4	3	7
	Not found	3	0	3
Total		51	19	70

*Table 5: Caregiver participation.*

<b>Relationship to Index Subject</b>	<b>Frequency</b>	<b>Percent</b>
Wife	2	7.7
Daughter	16	61.5
Son	3	11.5
Friend	1	3.8
Daughter-in-Law	1	3.8
Granddaughter	1	3.8
Nephew's Wife	1	3.8
Niece's Daughter	1	3.8
<b>Total</b>	<b>26</b>	<b>100%</b>

*Table 6: Index Subject—Caregiver relationship.*

The mean age of the caregivers during the study window was 57.8 years (delta=2.0). More than half of the care recipients, the CSHA Index Subjects, were women (n=18, 69%; men n=8, 31). The mean age of care recipients during the study window is 91.4 years (delta=7.7).

### **4.3 Caregiving Experience Component**

The results of the analysis of the Caregiving Experience component are a series of themes that represent the meanings of the responses from the research participants to seven open-ended questions. These themes are described below and grouped according to the questions. In the process of carrying out the analysis of the Caregiving Experience component, a pattern emerged that provided an interpretative structure for the themes themselves. This structure is explained after the themes. Presented first are some general results from the interviews taken as a whole.

The rapport between the caregiver and me, the interviewer, was important for establishing effective communication and having a successful interview. The introduction and warm-up phases of the interview, described above in the methods section, were intended to set a tone that would encourage a good rapport. It provided an intended counter-balance to my status as a "CFA" (meaning "come from away"). The admission of foreignness was also used as an implicit explanation for why additional explanations and clarifications may be required. It was not possible to measure the success of this approach, but the intended effect was for caregivers to feel empowered as the authority on the topic at hand, that is to say, on their own caregiving experience.

Many interviews could be described as having a collaborative dynamic, where the caregiver and interviewer worked together to reach a mutual understanding of the caregiver's experience. Most interviews went well; caregivers appeared to feel

comfortable and the dynamic of the interview was conversational. In some cases, a caregiver seemed at times inhibited or unsure of how to answer a question. The interviewer made use of appropriate prompts and silence to try to facilitate communication.

Below and on the following pages are two examples from two separate interviews. This example was taken from an interview that went well:

*Interviewer: What are your main sources of help, strength, or support?*

*Caregiver: We haven't...*

*[Pause] maybe the wrong thing to say, but there's no support except for my two sons, of course, but they are sometimes...*

*[Pause] first I'll tell them what misery is getting to me. And this is something they have readily consented to come in and baby sit on holidays and that kind of thing...*

*Interviewer: Mmm-hmm.*

*[Pause] But other than that, I know there's sources available.*

*[Pause] Through the Alzheimer's Society and things of that nature, but we haven't accessed these services at all. The only thing we have done is talk to a social worker and community services.*

*Interviewer: So, I understand what aren't your sources of strength and support, but in terms of what are, you mentioned your sons, your family—*

*Caregiver: My wife and two sons, really, are the only two sources of support that we have—that I have. Just because of the fact that I'm the only child, and there's nobody else I can trade places with. No one else.*

*Interviewer: Do you have any hobbies or pastimes that you may use to blow off steam or relax?*

*Caregiver: Well, yes and no. I found that since this is really getting to me, and I don't know how personal you want to get into this, or how much information that you want, but I found that the last nine months, I retired a year ago, up until that point and a few months after that I was pretty active. I have a workshop out in the garden that I mentioned earlier. I'd spend a lot of time out there, building or whatever, but the last six to eight months I've lost total interest in all of it. I don't even go*



*out there anymore. And I don't really know why I'm feeling that way. It just goes back to the stress of the mother again.*

*Caregiver: I think. I don't know. Sometimes I think I should go and see somebody, you know, just to see if this is really the cause of it. I just lost total interest. I've got a place in the country that I built myself. We started in 1973, we spent a lot of time up there the past 25 years, and the last six months I've probably been up there twice. Lost interest in that. I often sit down and wonder if the root problem of this is because of the problem I have at home? Could be.*

With the above caregiver, a son caring for his mother, communication was often stilted and difficult. With this and other questions in the Caregiver Experience component, he seemed to have things to say but was apprehensive in speaking freely or without a sense of restraint. The caregiver began most answers with several pauses and hesitant speech that would then speed up very quickly as he finished a sentence. With my responses, tone of voice and body language, I tried to give him some space and convey that I acknowledged what he was saying without judgement or pity. At the same time, in prompting for clarifications I sensed that he may have had difficulties talking about his emotions and spoke in a fairly cut-and-dry manner to allow him to respond in kind if he wanted to without feeling that he was failing to answer the question.

However, some interviews were marked by an atmosphere of discomfort and were not as successful. In these cases, talking about the care recipient produced feelings of distress or sadness that resulted in brief and limited answers. The interviewer attempted to solicit more detailed explanations, while trying to avoid having the caregiver think or feel that his or her given responses were not "right" or satisfactory. This strategy and its execution were not always successful. One particular interview provides an example. This interview was the second of three scheduled for that day. I had been feeling rushed which may have

had an effect on my demeanour. The interview started clumsily and despite my attempts to recover, it never seemed to reach a level of comfort conducive to open communication with the caregiver, the daughter of the care recipient:

*Interviewer: First of all, let me ask you what does caring for [the caregiver's mother] mean to you?*

*Caregiver: I loved her. [very hesitant]*

*[pause]*

*Caregiver: See, I was working. And I couldn't take care of her, I used to take her here in the nights, she used to come up here. She was staying down there [next door]. She would come up in the nights and she'd sleep, you know, stay with me the nights.*

*[pause]*

*Interviewer: Did she have somebody else living in the house with her?*

*Caregiver: No. She had a boyfriend. He used to be down a lot at supper and times like that. And that's OK for going for a while. Then she started getting stressful.*

*[pause]*

*Interviewer: When did she start getting stressful?*

*Caregiver: About two, three years ago. No more, I guess she's in a home three years. I would say later. (note: her mother had stayed in the community for six years)*

*[pause]*

*Interviewer: So for now, she was living here, rather she's living there and coming to sleep here, and you are basically taking care of her.*

*Caregiver: Yes. [becoming visibly upset]*

*[pause]*

*Interviewer: And what did that mean to you. Why were you taking care of her?*

*Caregiver: Because I loved her, OK? That's it. [visibly agitated]*

*[pause]*

*[we moved onto the next question]*

The main problem with the beginning of this interview was that my attention was not fully centred on the caregiver, but rather on being efficient, getting the information and completing the interview within a reasonable amount of time. My attempt to recover a better tone for the interview was to move on to discussing more of the history of her caring experience. As a consequence, I feel I did not pay sufficient attention or respect to the significance of the caregiver's love for her mother and how that related to her community care experience. My efforts to coax the caregiver to elaborate, with a soft tone of voice, did not work. Instead, I sensed that the caregiver was feeling badgered or judged on her responses.

Having a clear focus on the caregiver, by being calm and empathising with him or her, was central to a successful interview. In this case, I think that I should have stepped back from the interview and re-focussed on her first answer.

***Caregiving Experience: What does caring for \_\_\_\_\_ mean to you?***

**Themes: Payback, Best of Care, Stress, One of Life's Tasks**

The first question of the Caregiving Experience interview asked about the meaning of dementia community care. This question allowed for an open interpretation of "meaning" and left the context to be decided by the caregiver. The question was intended to elicit the caregiver's beliefs and attitudes towards the informal community care of the care recipient. Most caregivers interpreted the question in the context of the personal significance of caring. Many caregivers also interpreted the question in the context of

how caregiving fit into their life experiences. A small number of caregivers initially understood the question to mean "what does caring for the care recipient consist of in terms of your tasks and duties"; most often, their responses would naturally change towards a more personal meaning. In a few rare cases, the interviewer would acknowledge the caregiver's responses and follow-up with the prompt: "and what does caring for the care recipient mean to you, personally?"

**Theme: Payback**

A major theme found in the responses to this question is named "Payback". This theme pertains to children caregivers of a parent, and its predominance may be said to be largely a product of the high number of daughter caregivers. It describes the desire of caregivers to return the care they received as children when the parent enters the final stage of life. The disabling effects of dementia, in which the parent becomes as dependent as a child, also define it. The importance of this theme cannot be understated, as it was often a key element in the research participant's decision to be a caregiver, as illustrated by the caregiver who coined the term:

*Caregiver: ... Probably a lot of people wouldn't [provide community care]. I don't know. I just do it because I figured I needed to, that's all.*

*Interviewer: Why?*

*Caregiver: I just do it because I figured I needed to, that's all.*

*Interviewer: Why?*

*Caregiver: I guess for the fact that she had me and reared me and looked after me when I needed her... it's like payback.*

Payback highlights how caregiving was, for many, the essence of showing love. It was an opportunity to express the love a caregiver had for his or her parent. This was particularly evident in responses from caregivers who had deep feelings of attachment and affection for the care recipient. These two examples indicate this belief well:

*Caregiver: Well, I guess really it meant, it was a role reversal I guess it meant giving back to Mom a lot of what she had given me in terms of caring, it was definitely a task, a labour of love.*

and,

*Caregiver: Well, I guess, it's something, how could I say, it's your mother, and caring for her made me feel good, made me feel I was doing something for her, for all the things she had done for me. That's the way I felt about it myself personally.*

#### **Theme: Best of Care**

Another major theme is named "Best of Care". It was more evenly distributed over caregivers and less dependent on caregiver relationship to the care recipient. The Best of Care theme encompasses meanings of caring for someone as an imperative on the part of the caregiver to ensure or safeguard the quality of care for the care recipient. The Best of Care theme describes the feeling of, and belief in, the personal responsibility to have the most suitable and effective caregiving. It was not surprising then that among many community caregivers, the highest standard of care was expected to come from them and to come in a community setting. There was a palpable sense of pride among some caregivers who volunteered responses that expressed this theme:

*Interviewer: First of all, let me ask you what does caring for [caregiver's mother] mean to you?*

*Caregiver: In what way?*

*Interviewer: In any way you want to interpret it.*

*Caregiver: I wouldn't have anyone else to care for her.*

*Interviewer: Why is that?*

*Caregiver: Because I think I can do a better job. Now, unless she got, unless she got to where I couldn't handle it. Then I would put her in professional care. And if the same thing happens to me, put me in professional care.*

This is not to say that pride was the only motivator for the caregiver described above, or the only source of the Best of Care theme. The Best of Care theme also includes responses that indicated a humble and thoughtful consideration in caregiving. Caregivers were much attuned to the needs and wants of the care recipient:

*Caregiver: Making sure that she was being looked after the way that she looked after herself. My mom, she was the type of lady, she always wanted to be dressed nice, hair done nice, that sort of thing, so those were things that were important for me to know that she was well looked after. Making sure she was kept clean, fed properly, ate properly, got all of her vitamins and things like this.*

### **Theme: Stress**

Stress adequately describes the theme that incorporates the vast majority of the reported negative effects of dementia community care. Independent of whether or not a caregiver enjoyed their experience, he or she may have found caring for the care recipient a source of mental, physical or emotional tension. The theme of Stress was expressed as a result of the adaptation to the intensity required for caring and the changes to the caregiver's life that came with it:

*Interviewer: First of all, let me ask you what does caring for [caregiver's mother] mean to you?*

*Caregiver: ... It's means that it's a strain on both of us, me and my wife obviously, it's a strain to the point where we just can't go anywhere anymore. We certainly can't stay overnight anymore. Up to last year we could go up to the country and stay overnight, we probably stay two nights, but we had to telephone, in constant contact with her.*

The theme of Stress also emerged in situations where the care recipient exhibited behavioural disturbances. The behavioural disturbances included behaviour that embarrassed the caregiver, that risked physical injury to the care recipient, or that was accusatory or harassing in nature:

*Caregiver: ...Basically it come pretty hard, it was hard to do it. One night, especially, I met this girl. She was a nurse up at the Grace Hospital. Very nice girl. I said 'Mom, don't cook supper for me tomorrow', I'll never forget this, 'because I'm going out to supper' and she said to me 'Oh, you're taking that whore out to supper again'. You know? Then I just dropped her and stayed home.*

The constituent responses of the Stress theme also included reflections on having dealt with those aspects of caregiving that produced mental, physical and emotional tension. The caregiver who provided the above quotation seemed to be able to manage the stress of his situation and didn't reflect much on how it had affected him personally. In other cases, caregivers gave responses that indicated that the stress had come and gone and left a mark, and that the meaning of their caring experience was stress-induced exhaustion:

*Caregiver: ...I guess I was getting tired of being the responsible person, tired of having to be strong, tired of having to give and I thought 'One day, my god, is there going to be something in this for me in terms of me and my time'.*

### **Theme: One of Life's Tasks**

Caregiving was also understood in a pragmatic sense to be a series of tasks, and while they were demanding, they were nothing particularly out of the ordinary. The theme One

of Life's Task describes the caregivers' meanings of dementia community care in an operational sense. It is made up most often of lists of duties and chores that the caregiver carried out. In some cases, the intensity of the caring was in marked contrast to the detached tone of the caregiver:

*Interviewer: First of all, let me ask you what does caring for [caregiver's mother] mean to you?*

*Caregiver: It means taking care of her, and getting her something to eat and washing her hair, and helping with her personal care, and make sure she takes her medications on time, and getting her medications and everything like that. That's what I basically done...*

The theme of One of Life's Tasks is more than a theme of lists. It also describes the integration of the caregiver role into the daily life of the caregiver. The responses that inform this theme indicate that the caregiving role was accepted as a part of life among many caregivers, and not a complete change in their life.

*Interviewer: So what did caring for your mother mean to you?*

*Caregiver: I don't know. In regards to saying it was a duty or a chore no it wasn't, it was just something you automatically did I guess. So... I don't know. I didn't feel it was an imposition, or obligated, I don't know, it was just something that was automatically done because she was your Mom and you did what you could for her I guess. I guess everybody's like that, I don't know.*

### **Caregiver Experience: Why did you decide to care for \_\_\_\_ at home?**

**Themes: Continuity of Place, Caregiver Primacy, Protection, Respect**

This question may be seen as problematic since it is a leading question that presumes the caregiver had a choice in making the decision to provide care in the home. The responses of the caregivers in this sample indicated that they did in fact prefer to care for the care



recipient in the community. The preference for community care was strong enough to sometimes be an obstacle to long-term care placement in situations where it was necessary. In one case, the care recipient had become confined to a wheelchair in a non-adapted home, had had a stroke and was in the end-stages of dementia. Nonetheless, the caregiver (his wife) was opposed to long-term care and continued as the primary caregiver in most regards:

*Caregiver: The reason I wanted him in the home is because I wanted to see how he was treated, how he was fed, how he was kept clean, and his clean clothes. We did all them even though we didn't have to. We would bring home his clothes and wash them. We'd put him here to sleep, gave him his medication.*

**Theme: Continuity of Place**

There was a very strong belief among caregivers that the care recipient should be as close as possible to where they had been living previous to developing dementia. This belief forms the core of the Continuity of Place theme. It incorporates a range of responses that provide, in the examples given, variations on the common theme that continuity is a primary objective.

*Interviewer: Why did you want to keep your Mom at home as long as possible?*

*Caregiver: Because I just figured that's where she belonged to.*

*Interviewer: Tell me why.*

*Caregiver: Because... I don't know, you pick up the phone and you want to call your Mom and see how to make a pastry you would put over wild game, or you just want to chat with her a few minutes... Mom belongs in a home.*

In the above quotation, continuity of place appears to be symbolic for continuity of the relationship between the caregiver and Index subject. It also appears to be symbolic of

the desired continuity of the person with dementia themselves. The attachment of the caregiver to the care recipient is also an attachment to where he or she is living:

*Caregiver: When you live with someone for fifty-five years, it's hard to let them go. I would want him to be here.*

### **Theme: Caregiver Primacy**

Caregiver Primacy describes a caregiver-centred theme. This theme arose from responses that indicated that the caregiver wanted to maintain the primary position for providing care. It is closely linked to the meaning of caregiving as Payback. Having the care recipient in the home was the strongest expression of the caregivers' desires to reciprocate the care they had received earlier in life.

*Interviewer: Why did you decide to care for \_\_\_ at home?*

*Caregiver: Because I wanted to. Well, she's my mother. And I didn't want strangers looking after her at that point; I was going to do what I could for her.*

*Interviewer: OK. Explain?*

*Caregiver: Well, she always there for me, so why couldn't I do the same for her. There isn't much else to say.*

### **Theme: Protection**

The other caregiver-centred theme that emerged is named Protection. Many caregivers appeared to perceive long-term care as a form of abandonment of the care recipient. Responses that contributed to the Protection theme were those that indicated that the caregiver was acting as a protector for the care recipient, specifically from the possibility of long-term care placement. The emotional ramifications of long-term care placement

would be hurtful for the care recipient and an admission of a lack of love or caring on the part of the caregiver. The two following quotations illustrate this theme:

*Caregiver: She, the mother, was a good woman and the caregiver didn't know why she should be hurt by being put into a home. CG thought that her mother was not a problem to handle, that she never hurt no one.*

and,

*Caregiver: ...he was part of the family, and you know, I mean at that time like I said, I would never have been able kind of say 'gee, great thanks, nice knowing you and you're on your own', you know?*

### **Theme: Respect**

Caregivers did not hesitate to explain that a part of the reason for choosing community caring was that it would fulfill the wishes of the care recipient. These kinds of responses provided the substance of the Respect theme. This theme is so named because it appeared that the wishes of the care recipient were important specifically because the caregiver wanted to show that he or she respected the care recipient.

*Caregiver: Mother and father did not want to go into a home, and tried their best to do what they wanted to do. It was their lives, why should they be unhappy?*

Often, it was not obvious that the caregiver knew for a fact the wishes of the care recipient. The gradual development of dementia may compromise the mental capacities of a person in an equally gradual manner. Without having discussed the possibility of dementia care prior to developing the syndrome, it would be difficult to know what the care recipient may or may not have wanted in the way of care. Nonetheless, the caregiver's perceptions of the wishes of the care recipient were just as important as any

concrete knowledge. The caregiver's perceptions may have also been influenced by other motivations, in this case, a desire to be the primary caregiver and a preference for continuity:

*Caregiver: I don't think that she would ever want to go in a home. When she was in good health, she never did, and as her mind, she got Alzheimer's and got sick that way, knowing that she wouldn't know where she was at, I still felt I wanted her here where I could do and care for her. Familiar surrounding, she would be in her own environment. That's how I knew that she would have wanted me to keep it that way.*

***Caregiver Experience: What were the greatest difficulties in caring for \_\_?***

**Themes: Loss of the Individual, Behavioural Difficulties & Frustration, Constant Attention**

**Theme: Loss of the Individual**

A theme articulated by caregivers in response to their difficulties was witnessing the Loss of the Individual with dementia. This theme is better understood in the context of the relationship between care recipient and caregiver, most often a daughter. The responses of this theme indicated that the loss of the individual occurred through the deterioration of his or her memory and recognition. This sense of loss is particularly noticeable in the absence of other difficulties typical to dementia:

*Interviewer: What are the greatest difficulties in caring for [caregiver's mother]?*

*Caregiver: Probably when she was going through the stage of not knowing who the family members were. As for looking after her, doing things for her, she wasn't difficult to work with or anything like that.*

**Theme: Behavioural Difficulties & Frustration**

The caregivers in this sample also found behavioural difficulties to be a source of difficulty in their care. There was a wide range of behaviours that posed difficulties for caregivers, including wandering, hoarding, flashing, aggression, repetition and delusions. The strongest theme that ties the responses together was that they were frustrating:

*Caregiver: She kept thinking there was a stranger outside her door, and would ask over and over again who was there. It became very frustrating telling her there was no one there.*

The most common aspect of the frustration appeared to be from caregivers trying to reconcile their emotional reaction to the behaviours of the care recipients. Caregivers reported feeling that the care recipient's behavioural disturbance was intentional instead of a product of the dementia. Essentially, caregivers had a difficult time not taking the care recipient seriously. Caregivers may have been aware that the behaviour disturbance was not intentional, and yet it still left the caregiver with feelings of anger and frustration. The tone of voice of one caregiver sounded as though he had revived a feeling of frustration in the recounting of an occurrence involving the care recipient's laundry:

*Caregiver: We came home and the ironing board was down in the basement. It's usually upstairs. So my mother obviously came upstairs and got the ironing board, brought it down, and there were four shirts belonging to me, rolled up in a ball waiting to be ironed. And when my wife got home, she went down and the four shirts were hung up nice and neat on coat hangers. They weren't ironed. She thought she ironed them, hung them up nice and neat on a coat hanger, but they weren't done, she just hung them up. So it almost seems like she's playing games with you, that she's trying to fool you, but that's her mind. Because I don't think she's bad enough to try fool us, by doing that, but that's just the way she's thinking. She figures she's ironed them, hung them up nice and neat, but they weren't done*

**Theme: Constant Attention**

A prevalent theme in the difficulties experienced by caregivers was the demand for constant attention. Caregivers reported a range of symptoms that they felt may be dangerous or otherwise warranted invigilation, essentially the behavioural disturbances listed above. The result was that caregivers felt drained by allocating part or all of their attention to the care recipient and the subsequent lack of time free of the caregiver role. Caregiving starts to feel like confinement:

*Caregiver: The hardest part was, basically, me. I couldn't go nowhere, I had to stick around the house all the time. If I didn't go to work, in the day time, wasn't bad. I was down cutting wood, cleaning up the yard, or shovelling snow, in the day time wasn't bad. But in the night time she used to kill me. Because, I couldn't go nowhere.*

Compounding the situation were the erratic sleep patterns of the care recipients that meant that the caregiver often did not get an uninterrupted night's sleep. Poor sleep hygiene was one of the main components of the Constant Attention theme:

*Caregiver: And being up with him all night, in the sense that you don't get that break, you don't get to go to bed at 10:00 and sleep all night because 9 times out of 10 you're going to be up all night with something.*

*I stayed up with him most often until probably we'd be all gone to sleep and he would try to get up and he'd fall down on the floor, so I would have to get up and get out and get him back in the bed.*

*That was tough on me personally. I felt tired, like I said it took the good out of me.*

**Caregiver Experience: What kinds of satisfaction, or rewards, do you/did you receive in caring for \_\_\_\_?**

**Themes: Fulfillment of Duty, Sense of Accomplishment**

**Theme: Fulfillment of Duty**

Many caregivers did not immediately identify any satisfactions or rewards from their caregiver experience. In such cases, caregivers were prompted to reflect on their experience. The response was frequently that their only reward was the knowledge that they had fulfilled the duties of a caregiver. In some cases, this meant that they also understood that they had played an important role in the care recipient's life:

*Interviewer: What kinds of satisfaction, or rewards, do you receive in caring for [caregiver's mother]?*

*Caregiver: Actually I didn't get any satisfaction or rewards. I done it because it had to be done. I didn't even think about satisfaction or rewards then.*

*Interviewer: But now--looking back now.*

*Caregiver: Oh, what I mean is that she got to stay home until she got bedridden, if I hadn't done it, she would have been down there a lot sooner.*

A caregiver's fulfillment of a chosen or imposed duty is the accomplishment of something he or she *felt* they should do. There is an element of a person's conscience involved with any tasks that a person feels they should do, as there is with any perceived duty. The fulfillment of a duty was treated as being distinct from a research participant's sense of personal accomplishment in their role as a caregiver (see below). This distinction was articulated by one caregiver who provided a clarification of the meanings to the interviewer:

*Interviewer: So how are those things, how do those things give you the satisfaction or rewards that you were looking after her in the home?*

*Caregiver: Just feeling that I'm still able to do it. Just the satisfaction in my own mind, that I was able to do it.*

*Interviewer: A sense of achievement?*

*Caregiver: I don't know about achievement. I guess just the fact that I feel it is something I should do.*

The Fulfillment of Duty theme necessarily logically includes the assumption of the caregiver role, in the sense that a person would have to have started being a caregiver in order to have the opportunity to fulfill the duties of a caregiver. This theme also shows itself in how caregivers felt when they relinquished their duties as a caregiver. Some caregivers articulated their sense of personal satisfaction in the context of having fulfilled their duties up until it was no longer within their capacity to do so (on next page):

*Caregiver: So I guess, that I got some satisfaction out of that feeling, that I felt I did what I could at the time that I could do it, but then when it got to the point I felt I just couldn't do anymore, I guess maybe after a while I had the sense to realize that I just couldn't deal with it anymore*

### **Theme: Sense of Accomplishment**

In contrast with the Fulfillment of Duties theme, the Sense of Accomplishment theme represents responses from caregivers who had a more positive outlook on their experience. Some caregivers felt a sense of gratification from more than fulfilling the duties. Rather, they felt a sense of accomplishment that was related to their objectives in providing community care. In many cases, caregivers felt proud that they had provided the means for the care recipient to be cared for as he or she had wanted.



**Caregiver:** *The good things was, I knew what Mom loved, because she always lived with us. I knew what she expected out of life, and I knew how she wanted to be treated. And being here with us, I knew she would always get the best of care, and that was all I could ask for.*

In the above quotation, the wishes of the care recipient are not the sole objective of the caregiver. She also communicates her desire to provide the best of care, and she felt that she had accomplished this as well. This made her feel good, as it did other caregivers for whom that was the primary objective and the primary reason they felt a sense of satisfaction from their caregiving experience:

**Interviewer:** *What kinds of satisfaction, or rewards, do you receive in caring for [caregiver's husband]?*

**Caregiver:** *I felt good about it that I was keeping him at home. Because I just didn't want him gone out of my sight. He couldn't be cared for but only by me. Uh huh.*

It was clear that the Sense of Accomplishment felt by caregivers was intimately linked to their motivations for providing community care. Another caregiver had begun to answer the question with an explanation that they had not received any material benefits from their experience. Instead, the satisfaction came from being able to realize a continuity of place for the care recipient, an objective that figured in their choice of community care:

**Interviewer:** *So, I think you were just saying that it made you feel good, gave you a sense of satisfaction.*

**Caregiver:** *Satisfaction, yes.*

**Interviewer:** *Why?*

**Caregiver:** *Like I said, the satisfaction of just seeing her still at home in her own home. She was still up and knitting and crocheting. The last going off it didn't look the best, but she still liked to do it. You could take something that she was knitting, probably supposed to be square like this, and you'd hold it up and it would be all on an angle or there would be holes through it. And she always had her special chair that she sat in the corner and looked through the window.*

***Caregiver Experience: What are/were your main sources of help, strength and support?***

**Themes: Family, Distractions, Self-Reliance**

**Theme: Family**

The predominant theme of the sources of help to caregivers was Family. Informal community caregivers turned to their families first for help and support in caring for the care recipient. The most common family members to provide help were immediate, for example, spouses or children. Daughters were especially identified as being supportive to parents who were caregivers. In some cases, the integration of support from daughters was almost total (on next page):

*Interviewer: What are your main sources of help, strength, or support?*

*Caregiver: My daughter, she was excellent. She bathed her or do her hair, same things for her that I would do. She was always there when I wasn't there. We could share things with each other. Whether it was during the day or the evening, she knew same as I did, what was going on.*

Support from family members was not always forthcoming. Some caregivers were reluctant to impose on their relatives and described situations where family support was obtained only after hints or indirect requests for help. In other cases support from immediate family did not materialize even when requests were made, but support from extended family networks did. In general, any family relation seemed preferable to non-family relations as a source of support. One caregiver spoke of going to her mother's house to care for her. Earlier in the interview she made mention of other friends and

volunteers that she may have asked. She appeared to feel that potential sources of support should have been related in some way

*Caregiver: I can't look up and say like some religious people do, that I believe in god and god gave me this strength and everything like that to do these things and so on, but I just felt that it was just an inner feeling, something that I had to and to know that I did it up to the end.*

*Interviewer: Did any friends or family support you during that time?*

*Caregiver: Friends? No. They're not for that. [pause]*

*Interviewer: How about family?*

*Caregiver: It didn't seem like anybody else wanted to go with me anytime, except for a niece, I had one niece and my mother was her grandmother, she used to go with me once in a while. Nobody else that I know of.*

### **Theme: Distractions**

Planned distractions, in the form of hobbies, exercise, or social outings constitute a theme among caregivers as a way to deal with the stresses of caregiving. The distractions are described as being designed or chosen to offer the caregiver a window of time during which their activities and responsibilities are not of a caregiving nature. Hobbies and personal interests were one form of distraction that provided an alternative activity to caregiving:

*Caregiver: ...hobbies, yeah, I'm crafty and that sort of thing, I sew, do all kinds of crafts and knit and stuff"*

*Interviewer: Do you think you used those to--*

*Caregiver: Oh yes, definitely, definitely yes, did wonders. And I would always take the time, whereas probably I don't do it now, but to visit, friends. We would make a special point to go out of the house and say well I'm going to go see such and such tonight now, and would do things like that, and was involved in... various things, school too, do courses and things like that, so I find that kind of takes your mind away from some of the things.*

The distraction was not always simply an alternative, but may also have been chosen for its ability to act as an outlet for frustration. One caregiver described the importance of "blowing off steam" earlier in the interview, and when reminded of this replied:

*Caregiver: Oh my god, oh my god the treadmill! I almost got the motor burned out. You know, just fitness, fitness really was, fitness and reading. And there wasn't a whole lot of time for either really because it was full time work and Mom, you know, and sleep.*

At the core of this theme is the caregiver's need to have respite from their caregiving duties. It appeared that it was easier for caregivers to take a break from their duties if they substituted them with other activities. While some distractions involved friends or family, the Distractions theme describes caregivers finding strength in alternatives. Depending on the caregiver's personality, these alternatives may have also been solitary in nature (on next page):

*Caregiver: Just me. Just trying to keep my sanity. I didn't go to church, I didn't have no hobbies... Basically it was getting out, during the day time, just getting out. Down to the garden, walk around the garden, clean up this, rake that, just as long as I wasn't in the house. I'm still the same today. So long as I'm not in the house I'm alright. If I can get out and do something, rake the lawn, do anything at all outdoors, I feel great. Ask me to set up some curtains or wash the dishes, I'd just as soon pick them up and throw them out.*

### **Theme: Self-Reliance**

A striking feature among the responses of caregivers to this question was that they were their own source of strength and support. These negative responses form what may be considered a theme in its own right, a theme of Self-Reliance. Although caregivers may have actually received help or support from other sources, their perception is that they

either did not or did not want to. For example, there are elements of the Self-Reliance theme in the last quotation of the Distractions theme above, in which a caregiver begins with "just me" and continues with a list of solitary distractions which do not involve anyone else. This tone was not uncommon among many caregivers. It seemed to indicate that they felt or believed that their role was theirs alone, and that while they weren't averse to asking for help, they chose not to do so:

*Caregiver: Well, I guess I've got a lot of my strength from my mother, maybe that's going to turn into stubbornness, too, or something, that's what my kids tell me, but not that I don't like to rely on other people but I figure everyone got their plate full kind of thing*

There appears to be reluctance to ask for assistance, in this case explained as a consideration for "everyone" having his or her own responsibilities. The stubbornness alluded by the previous caregiver is also a facet of self-reliance, a determination to persevere on one's own if no other help is forthcoming. In some cases, caregivers reflected back on their experience and identified this trait with second thoughts:

*Caregiver: When she got really bad at the end, they got me some homecare. The homecare woman used to come in about 12:00 in the night and stay with her all night, so I got some sleep then. Other than that, I took care of her myself. Now if I had my time back, I would have done that a lot sooner than what I did. Because whereas I was doing all this, I didn't have no time phoning this one and phoning that one. Jesus, no good phoning Dr. B\_\_\_, like you know, he'd be saying 'she's alright boy, that's alright', that you know.*

*Interviewer: Did you have any other sources of strength or support?*

*Caregiver: No, actually I done most all of it...*

This caregiver was one of few to use homecare services, and in her case it was brought in by a social worker instead of by request. The realization that things could have been

different is evidence that the belief in shouldering alone the responsibilities of caregiving was real at the time.

***Caregiver Experience: What kinds of assistance do you feel would help/would have helped you?***

**Themes: Respite Care, Individualized Support**

**Theme: Respite Care**

One major theme was found in the responses to this question, and that was Respite Care. The need to have relief from the stress of caregiving was clearly articulated by many caregivers:

*Interviewer: What kinds of assistance do you feel would help you?*

*Caregiver: The only assistance I would like to have is somebody who could stay with her for periods of time, give us a break in a way*

Respite Care solutions were considered helpful for two reasons. First and foremost, they would provide a pause in the caregiving routine for the caregiver. The immediate benefits would be a break from the stress of providing care and a chance to relax. However, the break provided with respite care would also be long enough for the caregiver to spend time with family that would not be dominated by the care recipient. Small, unscheduled breaks were not considered sufficient in order to get a break:

*Caregiver: [referring to a sleep-over respite care program] ...where they take the parent for a couple of weeks, just to give the family a break to be able to go or do things like that, cause even if we went anywhere for a day, I always had to make sure I had to come back, make sure I was back for supertime or make previous arrangements before I left or things like that.*

The second reason respite care was thought to be helpful was for the care recipient.

Caregivers were aware that they could not always spend as much time or pay as much attention to the care recipient as they wanted to. Respite care was thought to be able to provide supervision that would protect the care recipient. It was also thought to be able to provide some human contact that would benefit the care recipient, especially in the initial stages of dementia:

*Interviewer: What kinds of assistance do you feel would help/would have helped you?*

*Caregiver: Someone to be with her. I used to come home at lunch hour a bit, and then when I think about it now, I wish that if I had recognized that, yes, she is getting Alzheimer's, and she needs someone to talk to sort of thing, I would have had someone with her at that time.*

Caregivers usually talked about Respite Care either without reference to the mode of delivery, or in the context of a formal service. However, sometimes caregivers would have liked respite care to be delivered from other family members. In one case, out-migration had resulted in most of the caregiver's siblings living a substantial distance from his home where he cared for his mother. His feeling was that the assistance he wanted was for respite care, but he wanted it to be delivered by other family members.

*Caregiver: I don't know. More of the family coming home and taking her out. I used to have her brother home every now and then, he lives in New Brunswick, he'd come probably once a year, take her out to supper. That was it. Big deal. My sister come from away- you take care of her, I'm off this week. Little did they know it wasn't that easy. It wasn't as easy as just sitting down and taking care of her. Little did they know, after taking two-week holidays, they were damned glad to get back home.*

**Theme: Individualized Support**

No other theme was as predominant as the Respite Care theme. Given that this sample of caregivers drew on the support of family members and had a strong sense of self-reliance, this may not be surprising. Caregivers did give responses that indicated they felt that other kinds of assistance would have been beneficial. However, the responses were highly individual and reflected the particular circumstances of the caregiver. For example, one caregiver had had great difficulty with her mother's oxygen tank; another no longer had access to transportation since the care recipient had developed dementia; while another cited the need for greater access to social occasions where she could meet people and develop friendships. Some of the difficulties that were addressed by the caregivers in their suggestions for assistance might have been helped by respite care. The remainder were more specialized, with the majority of needs presumably having been managed by the caregiver and their family. A theme emerged of Individualized Support that would provide assistance that was relatively minor in terms of the resources involved, but that would have a significant impact for the caregiver.

***Caregiver Experience: What are your feelings about having a homecare worker for \_\_\_\_?***

**Themes: Good for the Care Recipient, Quality Concern, Distress**

**Theme: Good for the Care Recipient**

Of the caregivers who had used a homecare worker, many had positive feelings about the experience. The main theme among these caregivers was that it had been Good for the



Care Recipient. An important factor in caregivers' feelings was whether or not the new person was readily integrated into the care situation. The most important ingredient for the integration was that the care recipient to react well to the homecare worker.

Caregivers, who felt good about their homecare history, cited a bonding between the care recipient and the homecare worker as evidence of how it had been a good experience.

*Caregiver: That was great, mother loved it, oh my goodness, yes. She loved seeing her once a week so she could sit down and have a cup of tea with her. She didn't care about any work being done, she wanted the company. There were two girls who used to come in, and they would clean this table here spotless. And as soon as they left, mother would get up and clean it again. That is true.*

Bonding was not the only way that caregivers judged if the homecare worker had been beneficial to the care recipient. In another case, the caregiver explained that having a homecare worker made certain personal care duties easier for the care recipient. In particular, the care recipient did not want to get naked in front of his daughter, the caregiver:

*Caregiver: Great. The only thing we had now was the person that came in to kind of, took care of his baths and things like that. We didn't have any one to come in to cook meals or clean house or anything like that, but I thought it was great because it was one thing I didn't have to worry about doing. You know, it was easier because of the emotional connection, for this person to encourage my father to get in to the bath than for me because he would say, you know, then of course I'd be all upset, and he would probably say something to hurt my feelings*

### **Theme: Stranger Concern**

The dominant theme among caregivers who had negative feelings about homecare workers may be called Stranger Concern. This theme incorporates feelings of concern, discomfort or anxiety about the ability of a stranger to provide care for the care recipient.

There was concern that, without knowing the care recipient, a homecare worker would be unable to provide care in an appropriate and effective way. The caregiver in turn would either have to settle for inappropriate care, or would have to supervise the homecare worker himself/herself:

*Caregiver: I would have to be there to see that she did it, or that she was doing it, or... say know my mother, get her to know my mother, you know because certain things probably the girl or man, or the girl or lady I guess would come in here for, would explain to her, and it would still be my responsibility, it would be just as well for me to be there, unless I couldn't do it myself. Right?*

Furthermore, since the homecare worker did not have the pre-existing attachment, their commitment was suspected to be less than adequate. Continuing from the previous quotation:

*Caregiver: And this is why I felt the home was better, because [the family is] there for that reason, they're all there, and that's their work everyday. Where the caregiver comes in, it's their work, but they're only there for their eight hours or something*

Stranger Concern also affected caregivers who were not as assertive as the one quoted above. In one case, a caregiver remembered how she felt about homecare prior to using the service. It provides an example of how the feelings towards having strangers in the house were a powerful motivator among the caregivers:

*Caregiver: I didn't mind at all. I was realizing then that, you know, I wouldn't have been able to do it much longer anyway.*

*Interviewer: You didn't mind having a stranger come in?*

*Caregiver: I did, but there's nothing you can do about that. A stranger, like you know what I mean, coming in your house and invading your privacy and stuff, you know. But when you got no other choice, you got no other choice.*

**Theme: Quality Concern**

In addition to caregivers feeling weary of entrusting the care of a family member to someone they did not know they also had concerns about the quality of service. The Quality Concern theme encompasses a range of feelings that may or may not prevent a caregiver from using a homecare worker but that all share a concern about the quality of care they can expect to receive. In one case, a caregiver was motivated to secure care and at the same time aware that finding someone appropriate would be difficult:

*Interviewer: What are your feelings about hiring somebody to come in?*

*Caregiver: I've got no problems with it, provided I know it's the kind of person I want. I know that's not an easy task. I was reading the article in the paper, about daycare services and how much of a short supply there is and so on. So, finding the right person...*

Caregivers who had utilized homecare services corroborated the Quality Concern theme. Generally negative perceptions of the quality of care related to a lack of training. Homecare workers were perceived as unskilled and unprepared for the task. In one case, the caregiver provided an assessment of the service she received:

*Caregiver: They would just sit there, without doing anything, not trying to exercise their [mother and father's] abilities.*

In communicating their concerns about the quality of service, caregivers sometimes expressed themselves by comparing homecare workers to other health professionals. One caregiver's concerns over quality extended beyond training and preparation to include professionalism as well:

**Caregiver:** *I think that's what you need to take when a person is going to make a career of that, it's like a nursing... nursing assistants we used to call them years ago in the hospitals, you don't have them anymore, I don't know if they do, they assist the nurses in the hospitals. They wouldn't give the needles or medications, but they feed the patients and wash the patients, and do things like that. What they would almost be doing if they were a caregiver. And these people were trained for that, they had training for it. So I think it would be nice if they had more people trained for the program.*

**Theme: Distress**

The last theme among caregivers' feelings towards homecare workers had more to do with someone else's feelings than their own. This may have been due to the distress experienced by the care recipient by having someone else care for him or her. The distress may be out of a fear of being alone or being threatened by the stranger. In either case, and even in cases of advanced dementia, the reaction of the care recipient is clear:

**Caregiver:** *No, I'd rather do it myself. And Nanny gets... even when the nurse comes in, she gets really agitated. She wants me. As long as she can see me, she's OK. But if there's someone strange, she gets really upset.*

In other, more complicated cases, the care recipient was living with a spouse who was not the primary caregiver. In these cases, it was possible for the spouse to become distressed with the homecare worker. For caregivers with a non-demented parent who felt strongly against outside help, it was very difficult to initiate or continue the homecare services. The distress in these cases was primarily from the invasion of privacy that a homecare worker represented.

**Caregiver:** *Neither one of them [care recipient and husband] were satisfied. That was my biggest stumbling block. I wanted help to come in, but they weren't satisfied. My Dad said he didn't want a stranger living in his house. Mom said the same thing, but at that stage in the game she was probably just repeating what my Dad said. Or that's what I used to discover a lot. He wasn't satisfied, he wasn't big on strangers.*

#### **4.4 CSHA Caregiver Study Follow-Up**

The two rounds of caregiver recruitment provided 26 research participants for the CSHA Caregiver Study Follow-Up. Data from the sample was used to derive descriptive statistics that are presented below.

##### ***Caregiver Childhood Variables***

The interview survey contained several variables that describe the caregivers' childhood and formative years, and provided an informal assessment of the caregiver's cultural background and history in relation to Newfoundland and Labrador. Most of the caregivers (n=25, 96%) were born in Newfoundland. They self-reported having grown up in the province without interruption, although one caregiver did spend his secondary school years at a boarding school. The single caregiver not born in the province was born in Germany in 1913. She and her husband moved to Newfoundland and Labrador shortly after the Second World War

Caregivers were asked about where they grew up. The time frame was from birth to their 21st birthday or until they had moved out of their parents' house, whichever came first.

Caregivers and their families changed communities a mean number of 1.62 times.

Caregivers were described as growing up in urban (population >10,000) or rural (population <10,000) communities. Fourteen caregivers reported growing up in urban communities (54%), nine in rural communities (35%), and one in both (4%). The two remaining caregivers were considered as "other", and included the caregiver who was not

born in Newfoundland and the caregiver who spent the school year abroad at boarding school.

Caregivers were asked about any caregiving experiences they may have had in their childhood. Specifically, caregivers were queried about the number of community caregiving experiences that took place in their own home as a child. Caregivers reported, on average, a single community caregiving experience (0.62) in their home as a child, with a minimum of 0 and maximum of three caregiving experiences.

### ***Caregiver Burden and Depression***

The interview survey contained two scale questionnaires that measured negative effects to caregivers associated with dementia caregiving. The Zarit Burden Inventory (ZBI) was administered to measure caregiver burden. The scores range from zero (no burden) to a maximum of 84. Caregivers in the study sample had a mean ZBI score of 28.12. This result was higher than the mean score from the first phase of the CSHA Caregiver Study of 21.7, and slightly less than the mean score from the second phase of 30.2 for caregivers who had remained in the community (Canadian Study of Health and Aging Workgroup, 1994; Canadian Study of Health and Aging Working Group, 2002).

The Centre for Epidemiologic Studies Depression scale (CES-D) was administered to measure caregiver depression. CES-D scores range from zero (no depressive symptoms or behaviours) to a maximum of 60. A score of 16 or over indicates a clinically significant level of distress and the likelihood of depression. Caregivers in the study

sample had a mean CES-D score of 12.81. This result was higher than the mean score of 9.3 from the first phase of the CSHA Caregiver Study, and higher than the mean scores from the second phase of the Caregiver Study (8.6 for prevalent cases of dementia, 8.2 for incident cases of dementia and 8.3 for cases where the care recipient had dementia during the first phase and had died before the second phase) (Canadian Study of Health and Aging Workgroup, 1994; Canadian Study of Health and Aging Working Group, 2002). The percentage of caregivers who scored over 16 on the CES-D was 31%, and was higher than the percentage from CSHA-1 of 25.9% or from any of the groups of dementia community caregivers in CSHA-2: 17% for prevalent cases, 16% for incident cases and 17% for cases where the care recipient had died before the second phase.

### ***Care Recipient Functionality and Disturbances***

The interview included three scale questionnaires that evaluated the functional abilities of care recipients and their degree of behavioural disturbance. All three scales were administered to the caregiver, who reported on the care recipient's abilities and behaviours.

Functional ability was evaluated with two scale questionnaires: the Activities of Daily Living scale (ADL) and the Independent Activities of Daily Living scale (IADL). ADL scores range from zero (no functional ability) to 14 (functionally able). Care recipients had a mean ADL score of 8.60. This score was higher than the mean score of 6.1 from the first phase of the Caregiver Study. IADL scores have the same range as ADL scores, from zero to fourteen. Care recipients had a mean score of 5.32, which was lower than

the mean score of 6.12/14 from the first phase of the Caregiver Study (Penning, 1995).

The combined ADL/IADL scores for caregivers in this study was 6.9/14, compared to the CSHA-2 mean scores of 11.7/14 for prevalent cases, 10.1 for incident cases and 12.3 for the care recipients with dementia at CSHA-1 who died before CSHA-2 (Canadian Study of Health and Aging Working Group, 2002). In this study, caregivers reported that they were the main source of assistance to care recipients on both ADL (72%) or IADL (84%). These results are higher than those found in the CSHA-2 study that found that caregivers helped with 56% of ADL/IADL tasks (Canadian Study of Health and Aging Working Group, 2002).

The Dementia Behaviour Disturbance (DBD) scale asked caregivers for the frequency of a set of actions and modes of conduct. DBD scores range from zero (no behaviour disturbance) to a maximum of 84. Care recipients in the study group had a mean score of 50.85, which was much higher than the results from the CSHA-1 Caregiver Study of 16.9 (Chappell & Penning, 1996). The results from the second phase of the Caregiver Study were higher than the first phase, with mean DBD scores of 24.7 for care recipients with dementia who had moved into an institution, and 15.7 for those care recipients who had stayed in the community.

### ***Caregiver Work Disturbances***

The effects of dementia community caregiving on work activity were evaluated with two items in the CSHA Caregiver Study Follow-Up questionnaire. The first item asked caregivers who had worked for pay in any capacity (n=20, 76%) about the occurrence of



13 types of disturbances they may have experienced due to their responsibilities as a community caregiver. The mean number of types of work disturbances among working caregivers was 2.92. The most common work disturbances were having to leave work for an appointment with a physician (80%) and having to miss work (55%). Other disturbances included: come late for work (40%), decrease hours worked (15%), change shift (15%), and frequent interruptions on the phone (15%). None of the caregivers declined advancement, changed jobs or increased hours because they were caring for someone with dementia. The second item referred to whether or not caregivers had stopped working because of caregiving. Three caregivers (15%) responded that they had.

### ***Informal Caregiver Support***

Caregivers may have received formal or informal support. Informal support was defined as any unpaid help and included assistance with homemaking responsibilities, personal care, meal preparation, respite care and transportation. Each of the 26 caregivers in the study sample had received some form of informal support. Informal support from immediate family members, i.e., spouses and children, was the most common at 85% (n=22). A majority of caregivers also received support from extended family members (n=19, 73%), while many fewer had unpaid help from non-family members (n=5, 19%).

### ***Formal Caregiver Support—CLTCS Utilization***

Formal supports for community caregivers are termed Community Long-Term Care Services (CLTCS). CLTCS describe a wide variety of services that are intended to aide informal caregivers. For the purposes of this thesis, CLTCS are grouped into three types

of services: supportive, substitutive and preventive. Supportive services provide assistance to informal community caregivers with the daily tasks of caregiving. They include Homemaker Services, Meals and Personal Care. Substitutive services provide a replacement for the informal caregiver for a finite period of time. They include Day-Care and Respite Care. The third type, Preventive Services, are intended to provide monitoring and specialized support with the goal of minimizing co-morbidity and caregiver burnout. They may be directed at the caregiver or the care recipient, and include In-home Nursing, Physiotherapy, Occupational Therapy, Podiatry, Chiropractic Treatments, Other caregiver related services (for example, Social Work, Counselling).

Nearly all the caregivers used one or more of the full range of CLTCS (n=24, 92%) during the study window. The rates of utilization differed among the three classes of services. The least accessed services were the Supportive services, with 38% (n=10) of caregivers using at least one service. The most accessed services were Substitutive services, used by 69% of caregivers (n=18). Preventive services were used by half of the caregivers (n=13, 50%). The mean number of individual services ever used by caregivers was 2.0. A summary of the rates of utilization for individual services is described in Table 7.

CLTCS	#Caregivers
Supportive (one or more service)	10 (38%)
<i><b>Homemaker</b></i>	<b>2 (8%)</b>
<i><b>Delivered Meals</b></i>	<b>3 (12%)</b>
<i><b>Personal Care</b></i>	<b>9 (35%)</b>
Preventive (one or more service)	13 (50%)

<b><i>In-home Nursing</i></b>	<b>12 (46%)</b>
<b><i>Other Professional Services</i> <i>(one of physiotherapy, occupational therapy, chiropractic treatments, podiatry)</i></b>	<b>4 (15%)</b>
<b><i>Caregiver Services</i></b>	<b>14 (54%)</b>
Substitutive (one or more service)	18 (69%)
<b><i>Day Care</i></b>	<b>6 (23%)</b>
<b><i>Respite Care (in-home)</i></b>	<b>5 (19%)</b>
All CLTCS (one or more services)	24 (92%)

*Table 7: Utilization of Community Long-Term Care Services.*

Caregivers who utilized any CLTCS were asked to rate the service in terms of personnel consistency, reliability, fulfilling needs, quantity and quality. There were relatively few caregivers who utilized services, and their results are summarized in Table 8. The rating questions (in the rows) and the mean scores are provided for each service (in the columns).

For the most part, caregivers rated the CLTCS consistent, reliable and meeting their needs. Respite Care was singled out for having a higher turnover rate, lower reliability and lesser ability to meet the needs of caregivers. The quantity of the service, which was the amount of time or number of visits, was rated as Mostly Satisfactory or better for Personal Care, In-home Nursing and Day-Care. Homemaker and Meals services were rated Mostly Satisfied to Not Satisfied. Respite Care had the worst ratings (3.2) for satisfaction with regard to the amount of services that were available, meaning that caregivers wanted more of this service.

### **Supportive & Substitutive CLTCS Utilization**

<b>Quality of Supportive and Substitutive Community Long-Term Care Service</b>	<b>Homemaker (n=2)</b>	<b>Meals (n=3)</b>	<b>Personal Care (n=9)</b>	<b>In-home Nursing (n=12)</b>	<b>Day Care (n=6)</b>	<b>Respite Care, in-home (n=5)</b>
—better quality is indicated by a lower score —mean values of scores indicated on the right for each CLTCS						
<b>Over the past few months, has the service always been provided by the same individual?</b> 1= Always the same person      2= Usually the same person 3= Rarely/never the same person	1	2	1.7	1.9	1.7	2.8
<b>Would you say the service is reliable? That is, is the meal delivered at the appointed time?</b> 1= Very reliable                      2= Usually reliable 3= Not very reliable	1	1.3	1.3	1.1	1	1.6
<b>To what extent has the service met the family's needs?</b> 1= Almost all needs met      2= Most needs met, 3= Only a few needs met      4= None of their needs met	1	1.3	1.6	1.1	1.1	2
<b>How satisfied are you with the quantity of help received?</b> 1= Very satisfied                      2= Mostly satisfied, 3= Not satisfied                      4= Quite dissatisfied	2.5	2.3	1.8	1.3	1.4	3.2
<b>How satisfied are you with the quality of help received?</b> 1= Very satisfied                      2= Mostly satisfied, 3= Not satisfied                      4= Quite dissatisfied	2	1.7	1.7	1.3	1.7	1.8

*Table 8: Caregiver ratings of individual CLTCS.*

### **Formal Caregiver Support—CLTCS Non-Utilization**

For any individual Community Long-Term Care Services, there were more caregivers who did not utilize the service than those who did (see Tables 9-11 below). The CSHA Caregiver Study Follow-Up survey asked caregivers to cite up to three reasons for why they did not utilize a particular service. Caregiver responses were coded according to sixteen reasons or as "Other". Two of the codes were related to the need for services: "Subject and family did not need the service" and "I wanted to provide this service myself".

The results are summarized in Tables 9-11. The tables group Substitutive, Supportive and Preventive services together, and indicate the percentage of caregivers who cited a specific reason (in the rows) for their not utilizing a particular service (in the columns).

### ***Supportive CLTCS Non-Utilization***

<b>Supportive Services Caregivers who did not use the service</b>	<b>n=24 92.3%</b>	<b>n=24 92.3%</b>	<b>n=17 65.4%</b>
<b>Reason for not utilizing service</b> <i>Caregivers could cite up to three reasons. Values represent percentage of caregivers citing that reason.</i>	<b>Homemaker</b>	<b>Meals</b>	<b>Personal Care</b>
<b><i>Reasons related to Need</i></b>			
I wanted to provide this service myself	34.6 %	38.5 %	23.1 %
Subject and family did not need the service	50.0 %	50.0 %	38.5 %
<b><i>Reasons related to Accessibility</i></b>			
Caregiver found using service too complicated, or waiting list too long. Includes problems with transportation			
Caregiver thought the service was too expensive	11.5 %	3.8 %	
Subject thought the service was too expensive		3.8 %	
Subject unable to get out to use the service			
Subject was not eligible to receive this service			
This service was not available in our area	3.8 %	11.5 %	
We were not aware that this service was available	7.7 %	3.8 %	3.8 %
<b><i>Reasons related to Acceptability</i></b>			
Caregiver tried and did not like the service			
I did not want strangers in my house	3.8 %		
It upsets subject to have someone else care for him/her	7.7 %		3.8 %
Subject did not want strangers in the home	7.7 %	3.8 %	7.7 %
Subject did not want the service	3.8 %		15.4 %
Subject tried and did not like the service			
<b><i>Other reasons</i></b>			
Other	3.8 %	7.7 %	3.8 %
We plan to use this service soon			

***Table 9: Reasons for not using Supportive CLTCS.***

Most caregivers had not utilized a Supportive CLTCS during the study window, 92% for Homemaker and Meals services and 65% for Personal Care. Need-related reasons accounted for a majority of the reasons that caregivers gave for not utilizing Supportive

services (see Table 9 above). The most frequent reason for not utilizing a supportive service was that the care recipient and family did not need the service (Homemaker, 50%; Meals, 50%; Personal Care, 38%). The second most frequent reason was that caregivers wanted to provide the services themselves (Homemaker, 34%; Meals, 38%; Personal Care, 23%).

Accessibility- and acceptability-related reasons were comparable in terms of their frequency in being cited as reasons for non-utilization. The accessibility-related reasons were similar across the three services. For Homemaker services, caregivers cited cost (11%), not knowing the service was available (7.7%) and one caregiver cited a lack of availability (3.8%). Meals services were cited as not available (11%), too expensive (7.7%), or unknown to the caregiver (3.8%). Only one caregiver was not aware of Personal Care services, which was the only accessibility reason cited.

In terms of the acceptability-related reasons, some of care recipients did not want the service or did not want strangers in the home for Homemaker services (11%), Meals (3.8%) or Personal Care (23%). A small number of care recipients were reported to be upset to have someone other than the caregiver providing care (Homemaker, 7.7%; Personal Care 3.8%).

#### ***Substitutive CLTCS Non-Utilization***

<b>Substitutive Services</b>		
<b>Caregivers who did not use the service</b>	<b>n=23 88.5%</b>	<b>n=23 88.5%</b>
<b>Reason for not utilizing service</b>	<b>Day Care</b>	<b>Respite Care</b>
<i>Caregivers could cite up to three reasons.</i>		
<i>Values represent percentage of caregivers citing that reason.</i>		

<b>Reasons related to Need</b>		
I wanted to provide this service myself	3.8 %	19.2 %
Subject and family did not need the service	23.1 %	42.3 %
<b>Reasons related to Accessibility</b>		
Caregiver found using service too complicated, or waiting list too long. Includes problems with transportation	7.7 %	3.8 %
Caregiver thought the service was too expensive		
Subject thought the service was too expensive		
Subject unable to get out to use the service	3.8 %	
Subject was not eligible to receive this service	7.7 %	
This service was no available in our area	3.8 %	3.8 %
We were not aware that this service was available	15.4 %	11.5 %
<b>Reasons related to Acceptability</b>		
Caregiver tried and did not like the service		
I did not want strangers in my house		7.7 %
It upsets subject to have someone else care for him/her	11.5 %	15.4 %
Subject did not want the service		15.4 %
Subject did not want/like strangers	42.3 %	19.2 %
Subject tried and did not like the service		3.8 %
<b>Other reasons</b>		
Other	7.7 %	15.4 %
We plan to use this service soon		

*Table 10: Reasons for not using Substitutive CLTCS.*

None of the caregivers said they had been planning on using the service. One or two caregivers cited individual reasons that did not have codes (see Table 9 above).

Most caregivers (88.5%) did not utilize a Substitutive CLTCS during the study window. Compared to Supportive services, need-related options were cited less often as reasons for non-utilization (see Table 7 above). Caregivers reported that care recipients and their families did not need Day Care in 23.1% of cases, and did not need Respite Care in 42.3% of cases. Caregivers cited wanting to provide Respite Care (19.2%) and Day Care (3.8%) themselves; when the nature of the service was explained, the respondents answered that they understood how the service worked and that they “wanted to provide

the service themselves”. These answers were interpreted as the caregivers not needing the service.

Caregivers cited reasons that related to accessibility for not utilizing Day Care services that included: the service not being available (3.8%), not being aware of the service (15.4%), not being eligible for the service (7.7%), complications in using the service (7.7%) and the care recipient not being able to access the service (3.8%). In addition, 11.5% of caregivers were not aware that Respite Care was available, while one caregiver found the service too complicated and one reported that it was not available during the study window. Cost was not given as a reason for not using Day Care or Respite Care services.

Compared to their responses concerning Supportive Services, caregivers were more likely to cite a reason for not using Substitutive Services that was related to the acceptability of services. Two caregivers cited not wanting to have a stranger in the house as a reason for not using Respite Care. The trend, however, was not with the caregiver's wishes but with the care recipients. Caregivers reported that the care recipient became upset with someone else caring for them in Day Care (11.5%) and Respite Care (15.4%), not wanting Respite Care (15.4%), and having tried it and not liked it (3.8%). The main acceptability-related reason for not using Substitutive services was that the care recipient did not want or like strangers, which was cited by 42.3% of caregivers for Day Care and 19.2% of caregivers for Respite Care.



None of the caregivers said they had been planning on using the service. Two caregivers cited individual reasons that did not have codes (see Table 9 above).

***Preventive CLTCS non-utilization***

<b>Preventive Services Caregivers who did not use the service</b>	<b>n=19 73.1%</b>	<b>n=17 66.6%</b>
<b>Reason for not utilizing service</b>	<b>In-home Nursing</b>	<b>Caregiver Services</b>
<b><i>Reasons related to Need</i></b>		
I wanted to provide this service myself	11.5	
Subject and family did not need the service	61.5	50.0
<b><i>Reasons related to Accessibility</i></b>		
Caregiver found using service too complicated, or waiting list too long. Includes problems with transportation		4.2
Caregiver thought the service was too expensive		4.2
Subject thought the service was too expensive		
Subject unable to get out to use the service		
Subject was not eligible to receive this service	3.8	
This service was no available in our area	3.8	
We were not aware that this service was available		8.3
<b><i>Reasons related to Acceptability</i></b>		
Caregiver tried and did not like the service		
I did not want strangers in my house		
It upsets subject to have someone else care for him/her		
Subject did not want strangers in the home	3.8	
Subject did not want the service		4.2
Subject tried and did not like the service		
<b><i>Other reasons</i></b>		
Other		33.3
We plan to use this service soon		

***Table 11: Reasons for not using Preventive CLTCS.***

In-Home Nursing was not used by 73.1% of caregivers. They cited not needing the service (61.5%), wanting to provide the service themselves, as in the case of insulin injections (11.5%), not being eligible (3.8%), lack of availability (3.8%) and in one case, the care recipient not wanting to have a stranger in the home. Caregiver-services encompassed a range of services meant for the caregiver, including social work,

psychologist, support group and spiritual support. They were not used by two thirds of the caregivers. They were reported as not needed by half of the caregivers. Some found the services too complicated to use (4.2%), too expensive (4.2%), or were unaware of the available services (8.3%). In one case, it was the care recipient who felt uncomfortable with the caregiver receiving services in the home for herself, and the service was not used.

#### **4.5 References**

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## **Chapter 5: Discussion**

This study had the objective of investigating the factors that may account for the comparatively lower rates of utilization of Community Long-Term Care Services (CLTCS) by community caregivers of persons with dementia in Newfoundland. The study was based on the premise that CLTCS utilization was determined by the need for, accessibility to, and acceptability of those services. These three sets of criteria formed a conceptual model for the interpretation of the utilization of CLTCS.

The study design was intended to assess the factors that influence CLTCS utilization in the context of these three sets of criteria. The need for services was assessed with traditional questionnaires measuring the conditions of caregiver and care recipient, and explored with open-ended questions to the caregiver. The accessibility of services was assessed through the Homecare Capacity component, and survey questions that addressed individual services. The acceptability of services was also assessed with specific survey questions as well as open-ended questions that explored the meaning of community care.

The following discussion covers four areas. First, changes to the original study design are described and the reasons for these changes. Second, the main limitations of the study are addressed. Third, the results of the study are described and discussed. Fourth, recommendations are presented that may contribute to an increase in the successful utilization of Community Long-Term Care Services.

## **5.1 Experimental Design Changes**

The original design for this study was to conduct a follow-up to the Canadian Study of Health and Aging (CSHA) Caregiver Study Phase II. The data from the follow-up study and the first two phases of the CSHA would have been used in a three-stage longitudinal analysis.

The proposed design also included two other components intended to investigate some of the potential reasons that lower CLTCS utilization had been observed in Newfoundland (CHSA Working Group, 1994b). First, the Homecare Capacity assessment would have supplemented the Caregiver Study data with information on homecare-type services, including home making, meal preparation, personal care and respite care, available during the CSHA study period. The Homecare Capacity component was designed to provide historical data on the human resources available for dementia community care, the level of training of local homecare agency employees, and the amount of services that had been utilized. These results would then have been linked to the Caregiver Study data on a yearly and geographic basis, and provided an indicator of the availability of services to the caregivers in the sample.

The second component was the Caregiving Experience component. This component was added with the intention of exploring the meanings of dementia community care to informal caregivers. The Caregiving Experience component consisted of a series of open-ended questions that would provide first-person, qualitative data. These findings would

be used to inform the interpretation of the longitudinal analysis and to suggest potential factors influencing CLTCS utilization that may have been neglected by the CSHA Caregiver Study.

The original design encountered two major obstacles. First, the number of community caregivers remaining in the Newfoundland study region from the CSHA Caregiver Study was too small to carry out a longitudinal analysis. Second, the Homecare Capacity component did not yield a sufficient amount of data: a representative was found for less than a third of the identified homecare agencies and only one representative participated despite repeated follow-up.

As a result, the experimental design was modified. The research sample was expanded to include the caregivers of care recipients who had developed dementia during the period between the first and second phases of the CSHA Caregiver Studies (1990-1 and 1995-6). The modification in the experimental design changed the study from a longitudinal analysis to a follow-up study. The Homecare Capacity component was not pursued any further. The Caregiving Experience component was retained unchanged. The consequences of the changes in experimental design are addressed below in the section that addresses the limitations of the current study.

## **5.2 Limitations of the Current Study**

This study had several limitations associated with the experimental design. The expansion of the study sample to include caregivers who had not been in the original

CSHA Caregiver Study sample introduced a selection bias. The original CSHA and CSHA Caregiver samples were both random samples. By expanding the study sample, it became a sample of convenience drawn from a larger random sample. The result was that the results from this study cannot be generalized to the population as a whole which includes a higher proportion of males and older caregivers than the study sample. The design for this study was based, initially, on carrying out a quantitative survey to be used in a longitudinal analysis. The survey instruments for the follow-up component were intended to be used with caregivers who were providing community care to the care recipient at the time of the study. The inclusion of caregivers who were no longer providing community care introduced recall bias due to the variable lengths of time that had passed between the interview date and the end of community care due to death or institutionalization. The results of this study are also skewed in terms of the disease severity. Caregivers who were no longer providing care reported on the last six months of community care for the care recipient, which would have been the period of time when the care recipient had the most severe disability.

A second limitation of the study sample was its heterogeneity in terms of when the caregivers were engaged in dementia community care. Only five caregivers were providing community care at the time of the study while the remainder had stopped providing community care, on average, 4.2 years before ( $\delta=2.8$  years). Although caregivers rarely felt uncertain about their responses, the large variability in recall time (0 to 7 years) may be assumed to have had an effect on the results.

The design of the interview in the Caregiving Experience component, in retrospect, had two main limitations. The omission of survey items related to physical health conditions was unfortunate in light of the findings from the Caregiver Experience described below. The first and second phases of the CSHA Caregiver Study included questionnaires for self-rated health and chronic health conditions but these were not included in this study. There was concern that the predominantly female participants may not have felt comfortable discussing their health status with a stranger who was male and from 'away'. Consideration was also given to the fact that the interview would be so long that it would discourage participation. In retrospect, the decision to exclude self-reported physical health indicators was an unfortunate one. Population-based research has shown that Newfoundlanders over-estimate their physical health more than in any other region in the country (Craig & Cameron, 2004; Federal Provincial and Territorial Advisory Committee on Population Health, 1999). Data on self-rated health would have been useful since this tendency may account for some of the findings that will be discussed further on. The second limitation of the interview design was that the potential to further develop the qualitative Caregiver Experience component. Had it initially been the central focus of this study, caregivers would have been contacted again to review their responses and to further comment and refine their answers, as suggested by Neuendorf (2002).

The query concerning childhood community care experiences likely did not elicit the full caregiving experience. The question was phrased in such a way that it limited community care experiences to those that took place in the home of the respondent. It did not allow for cases where the study participant, as a child, was involved in caregiving experiences

for a care recipient living in his or her own home. This was important because many of the caregivers that were interviewed grew up with extended family close by who were potential care recipients, and travelling was not a major obstacle to providing community care. Having the care recipient remain in their own home could have been preferable for a number of potential reasons, including a lack of space in the home of potential caregivers or a belief in the importance of continuity of place.

The Homecare Capacity component of the study confronted unexpected problems. Some agencies had simply disappeared without any record of their operations even, for example, the number of employees. Agencies that were replaced or taken over appear to have left little or no documentation related to their work activity or training. Alternative sources for these data have not been found and do not appear to exist for the time period of this study. The main difficulty in collecting data from those agencies that were still operational seemed to be that they did not have the resources necessary, or perhaps the motivation, to complete the survey. However, several contacts from operating agencies confided "off the record" that they doubted the documentation still existed. While private homecare agencies have a reason to maintain financial records, there is little incentive to preserve records of client profiles, employees or employee training. This lack of documentation poses an obstacle to any research on Community Long-Term Care Services since it makes the assessment of the availability and capacity of private services virtually impossible.



### **5.3 Discussion of Study Results**

#### ***Caregivers and Care Recipients***

The research sample for this study consisted of informal community caregivers of people with dementia who had participated in the Newfoundland component of the Canadian Study on Health and Aging. The CSHA sample was a stratified random sample of people living in rural and urban parts of the Eastern Avalon Peninsula. The CSHA Caregiver Study consisted of a sub-sample of CSHA participants that included people with and without dementia, and who were living in both the community and institutions (Canadian Study of Health and Aging Workgroup, 1994).

This study was carried out in 1999-2000, eight years after the first phase of the CSHA, and drew on the original CSHA Caregiver Study cohort as well as other CSHA participants who were not in the initial CSHA Caregiver Study. As mentioned above, these factors introduced bias into the study sample. During the interval, older, mostly spousal caregivers were more likely to become ill, be institutionalized or to have died. As a result, there was a smaller proportion of spousal caregivers in this study (7.7%) compared to the CSHA Caregiver Study (37.4%) and the sample was younger (57.8 years old during the study window) than in the original study (61.9 years old; Canadian Study of Health and Aging Workgroup, 1994).

Several other important characteristics of the study sample differed from those used in previous research. Women made up more of the caregiver sample in this study than in the

CSHA Caregiver Study (84.4% female compared to 75.4%). Caregivers in this study were more likely to be daughters than in the CSHA Caregiver Study (61.5% compared to 28.9%). Spousal caregivers were under-represented because of the elapsed time since the beginning of the study and subsequent aging-related factors, for example, an increased likelihood to develop a physical health condition that may contribute to discontinuing caregiving or not participating in the study. There were also fewer caregivers who were not immediate family relatives (parent or child), with 19% in the current study compared to 24.1% in the first phase of the CSHA Caregiver Study (Canadian Study of Health and Aging Workgroup, 1994). The sample from this study under-represents spousal and male caregivers while over-representing daughters and exaggerates their admittedly predominant position as the most common informal caregivers in the Province (Canadian Study of Health and Aging Workgroup, 1994; Morris et al., 1999).

The caregivers in this study reported higher levels of burden, with a mean score of 28.1, than the CSHA Caregiver Study (mean score of 21.7) (Canadian Study of Health and Aging Workgroup, 1994). Caregivers who were providing care at the time of the study had a mean score that was lower than caregivers who were no longer providing care (25.2 vs. 28.8). They also had a higher mean number of depressive symptoms (12.8 compared to 9.3), Canadian Study of Health and Aging Workgroup, 1994). Caregivers who were providing care at the time of the interview had lower scores for depressive symptoms than those who were no longer providing care (11.1 vs. 13.2). The higher scores for the latter group of caregivers suggest a bias due to the fact that caregivers who were no longer caring for the care recipient were asked to report on the last six months of their

caregiving experience; previous research has shown that this is the most demanding period for dementia community caregivers (Glazebrook, Rockwood, Stolee, Fisk, & Gray, 1994; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998).

Caregivers also reported much higher rates of behavioural disturbances in this study (50.85) compared to the CSHA Caregiver Study (mean score 16.9). This finding, though much higher than anticipated, is consistent with the higher burden and depressive symptoms scores. Previous research has shown that burden and depression are strongly correlated to behavioural disturbances (Baumgarten et al., 1994; Chappell & Penning, 1996; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Penning, 1995). However, other research has found that increases in behavioural disturbances were not accompanied by a change in the number of depressive symptoms (Canadian Study of Health and Aging Working Group, 2002).

### ***CLTCS Utilization***

The findings from the first phase of the CSHA Caregivers Study raised concerns that community caregivers of people with dementia were not accessing services: 64% of caregivers in Atlantic Canada used no services compared to 58% nationally. The second phase of the CSHA Caregiver Study reported an increase in service use, with 77% of caregivers in Canada using at least one service (Canadian Study of Health and Aging Workgroup, 1994; Canadian Study of Health and Aging Working Group, 2002). The current study found that 98% of caregivers had used at least one Community Long-Term

Care Service, suggesting a trend of increased service use. However, this finding should be interpreted with caution, since the majority of this study sample was made up of daughters who have been shown to be more likely to use services than spousal caregivers. Furthermore, although 98% of caregivers reported using at least one service, this does not mean that they continued using the service for any length of time.

Despite the relatively low use of community services, care recipients had substantial care requirements as indicated by their reported levels of disability. They required assistance carrying out many of their daily activities according to their scores on the Activities of Daily Living (ADL; 8.60/14) and Independent Activities of Daily Living (IADL; 5.32/14) scales. The mean of their total scores (13.92) was slightly higher than those from the second phase of the CSHA Caregiver Study that found a mean total score of 11.7 for all prevalent care recipients and 10.0 for incident subjects (Canadian Study of Health and Aging Working Group, 2002). The care recipients' needs for assistance were fulfilled primarily by the informal community caregivers in the study sample. The caregivers were the main source of help for most of the activities (86%). These findings are consistent with other research that has shown that dementia community care has high care requirements and that the informal community caregiver carries out the majority of the care duties (Grunfeld, Glossop, McDowell, & Danbrook, 1997; Morris et al., 1999). The care recipients were also reported to have a high frequency of behavioural disturbances that may confound efforts to provide care. A person with dementia who exhibits behavioural disturbances will require additional attention, may threaten the caregiver and

may interfere in the carrying out of care activities (Chappell & Penning, 1996; Teri, 1997).

As discussed above, the results from the survey indicated that caregivers experienced levels of psychological strain typical in dementia community care (O'Rourke & Tuokko, 2000; Pruchno, Kleban, Michaels, & Dempsey, 1990). The high levels of care requirements and caregiver strain indicated a disparity between the caregivers' capacity to reasonably provide care and the care requirements of the care recipients. This disparity was acknowledged and articulated by caregivers during the interviews. The caregivers considered stress to be a fundamental aspect of dementia community care. Stress was attributed in part to the reorientation of the lives of caregivers and their families. Caregivers also identified behavioural disturbances as particularly stressful. Moreover, the need for constant vigilance, even in the absence of behavioural difficulties, was exhausting and reduced caregivers' coping abilities. The constant demands of dementia community care inevitably left caregivers feeling depleted and weary:

**"... I guess I was getting tired of being the responsible person, tired of having to be strong, tired of having to give and I thought 'One day, my god, is there going to be something in this for me in terms of me and my time'".**

The results suggest that the community care demands appeared to exceed what caregivers could reasonably provide. This disparity suggests that there was a need for additional support and that the utilization of CLTCS would have been appropriate. However survey results show that the majority of caregivers did not fully engage the services that were

available. These findings are consistent with the second phase of the CSHA Caregiver Study that show that services were being under-utilized in the Atlantic Provinces despite evidence that caregivers would have benefited from them (CSHA Working Group, 1994b).

### ***CLTCS Utilization and Constructs of Need***

It was assumed that where a need for services existed, utilization would be determined by the accessibility to, and the acceptability of, Community Long-Term Care Services. However, when caregivers were asked to explain why they did not utilize CLTCS, reasons related to accessibility and acceptability were infrequent. In the case of professional-type services, for example, Physiotherapy or In-home Nursing, it was often the case that the care recipient did not have any health needs that warranted that type of service.

The most interesting results of this study were that caregivers also reported a lack of need for Supportive and Substitutive services. These services are designed to mitigate the cumulative demands and stress of dementia community care. The Supportive services surveyed in this study were Homemaker, Meals Preparation and Personal Care. They divide the responsibilities of dementia community care between the primary caregiver and a paid, or formal, support worker. The Substitutive services included in-home Respite Care and out-of-home Day Care. Substitutive services relieve caregivers of the responsibility of the care recipient for a short-term duration. The study results suggested

that these two sorts of CLTCS would have been appropriate and beneficial for the caregivers in this sample. The caregivers indicated that they had difficulty in reasonably meeting the requirements of care of the care recipients. They reported feeling that the constant demands of dementia community care were stressful and draining. These findings are consistent with their scores on conventional measures of caregiver strain. In summary, caregivers could quite reasonably have been expected to perceive a need for both Supportive and Substitutive services.

Contrary to this expectation, caregivers reported a lack of need more often than any other reason to explain their non-utilization of Supportive services: half of the caregivers (50%) in the case of Homemaker and Meals, and 38.5% in the case of Personal Care. This trend was split within the Substitutive services. A lack of need was the most common reason for not utilizing in-home Respite Care (42% of caregivers) and the second-most common for off-site Day Care (23.1%). Caregivers were more likely to report a lack of need for the Supportive services and in-home Respite Care than they were to report reasons related to accessibility and acceptability combined. The caregivers' predominant perception of not needing Supportive services and in-home Respite Care contradicts other results that indicate they had a need for those types of assistance.

### ***Contradiction between Measured and Perceived Need***

The most striking finding of this study is this apparent contradiction between measured and perceived need. How can this contradiction be explained? One line of explanation

can be found by comparing the answers of the respondents concerning two related types of Substitutive Services. Respite Care and Day Care services have similar functions for the caregiver. Both replace the primary caregiver with formal care for a limited period of time. The only substantive difference between the two is the location of service delivery. Respite Care usually takes place at the community residence, while Day Care involves the care recipient spending time at a location that is not the home. Both services can provide the caregiver with a full break from their caring responsibilities. This "full break", or "respite", emerged as the main theme among the responses of caregivers as to what forms of assistance they would have found helpful. Caregivers had, and were aware of, a need for respite from dementia community care. However, the place of service delivery appeared to influence the perception of that need. The results suggest that caregivers were more willing to acknowledge a need for respite care provided outside of the home, i.e. Day Care. Caregivers seemed to find it more acceptable to have respite care provided when it was done outside of the home.

The same issue of location of service delivery may also help explain the perceived lack of need for Supportive services. The Supportive services (Homemaker, Meals and Personal Care) are intended to divide the duties of community care and to reduce the demands placed on the caregiver. Caregivers acknowledged that the demands of community care, including household duties, were stressful and exhausting. They were made complicated by the need to invigilate the Care recipient, indicated by the Constant Attention theme in Caregiving Experience component of the study. Thus, caregivers appeared to have a need for help that could have been met by one or more Supportive services, and yet they were



most likely to report not needing the service as the reason for non-utilization. Since all three services are delivered in the home, this apparent contradiction is consistent with the interpretation that the home setting appeared to influence the perception of need, and thus the utilization of CLTCS.

Looking further to the study results, the relationship between location of service-delivery and perceptions of need may be seen in the context of how caregivers thought about community-based care. In this study, research participants were caregivers for whom caring meant ensuring the highest standard of care for the Care recipient. This is illustrated by the "Best of Care" theme in the results of the Caregiving Experience component. The caregivers believed that the best care would be delivered in the home. This belief may have been strongly embedded, as the results from the Childhood Experience portion of the survey showed that most caregivers rarely moved and experienced a strong continuity with their home setting and their family. More importantly, caregivers felt that the home gave them control over the care of the care recipient. This was indicated in both the Best of Care and Caregiver Primacy themes from the Caregiving Experience component. The caregivers thought that their shared history, most often as a spouse or child, made them the best suited to make decisions regarding the care of the care recipient.

### ***Need and Gender***

Research from nursing and women's studies provides valuable insights for the interpretation of the findings described above. Existing research has shown that social expectations of women as caregivers foster a strong belief that women are the gender that is both responsible and the best suited to provide informal care (Aronson, 1998). These results are parallel the findings from this study that show caregivers, who were mostly women, wanted to provide the Best of Care and wanted to maintain Caregiver Primacy in the home. Research has also shown that when women seek formal care support, they may be vulnerable to feelings of failure and a wish to prove themselves as able and loving caregivers (Heinrich, Neufeld, & Harrison, 2003). This may partly account for the reason why the caregivers in this study did not associate their psychological and physical stress with a need for formal services. Such services would not provide a solution to their goals or expectations.

The same study indicated that caregiver women in Canada employ strategies based on mutuality when seeking support (Heinrich et al., 2003). Caregivers in the sample reported attempting to form relationships with formal support workers that were intended to be collaborative, and were increasingly dissatisfied with formal support as the level of collaboration decreased. The caregivers in this study had a mistrust of strangers participating in their community care settings (Distrust of Strangers theme). It is reasonable to expect that a lack of trust would decrease the potential to form collaborative relationships and, consequently, increase dissatisfaction with the formal services. The

lack of trust may also impede seeking services if caregivers assume that mutuality will not be possible. Furthermore, one study showed that caregivers who do seek formal support may be trading some of the duties involved in the direct care of the person with dementia for the less rewarding but also stressful duties of coordination and supervision (Aronson, 1998). The result is that caregivers may be gaining a new set of stressors from overseeing formal care in an attempt to manage the burden of directly providing care. Day Care effectively frees the caregiver from both sets of duties and may facilitate collaborative relationships by distancing the formal support worker from the home.

### ***Estimation of Need***

An alternative interpretation of the gap between reported and perceived need for services may come from previous research showing that Newfoundlanders tend to over-estimate the status of their own health. Newfoundlanders consistently score very high on self-assessed health status while, at the same time, their rates of such key health problems as cardiovascular disease, heart disease and obesity are among the highest in the country (Federal Provincial and Territorial Advisory Committee on Population Health, 1999). It is possible that the caregivers' disparate assessment of their needs for CLTCS is another aspect of a general tendency to over-estimate functional ability. The interpretation of this trend by the Department of Health and Community Services (who also help administer CLTCS for people with dementia) was that:

"[t]his says a lot for the make-up of people in our province. In spite of the challenges we face as individuals, we feel good about ourselves overall and we feel that life is meaningful. Even on our physical health, we ranked our functional status as the highest in the country, meaning we didn't feel restricted in our daily lives by any physical problem." (Health and Community Services, 1999)

This is an optimistic interpretation, in that it presupposes that having a positive outlook will benefit the individual in accomplishing his/her goals and objectives. However, in the case of community caregivers such as those interviewed in this study this optimistic perception may be inappropriate. Admitting the stress and negative effects of caregiving earlier, rather than later, might serve them better in their ultimate objectives of prolonging the community residence of the care recipient.

The original framework for this study placed the utilization of services in the context of a three-fold model involving the need for services, their accessibility and their acceptability. What our interviews have revealed is that the first and the third factors are not independent. The framework did not take into consideration that caregivers might not have felt their own need to be an acceptable part of community care. Nor did the framework adequately recognize that "objective" measures of need may not be fulfilled by formal services. In either case, caregivers may not have accessed services until after they had reached a state of burnout. Vetter et al. (1998) found that caregivers in Germany often waited until their stress levels were extremely high before they sought CLTCS or were "strongly recommended" to seek them by a health professional. The authors' interpretation was that caregivers were unaware of the services available to them and thus

did not consider their utilization. However, most caregivers in our Newfoundland sample were aware that services existed and were available in their region. As mentioned above, the services that were the most acceptable to caregivers were those that would take the care recipient out of the home.

### ***Caring as Labour and Love***

The caregivers in this study also thought of community-based caring as an opportunity to reciprocate the love and care that they received from a parent or spouse care recipient. This meaning of community care is at the core of the "Payback" theme that emerged from the Caregiving Experience component. It shows how caring is both a labour and a love of caregivers. The survey results showed that caregivers were indeed the main persons responsible for carrying out community care tasks and assisting the care recipients in their daily activities. After "not needing the service", caregivers were most likely to report wanting to provide the service themselves as a reason for not utilizing Homemaker (34.6%), Meals (38.5%) and Personal Care (23.1%) services. Nearly a fifth (19.2%) of caregivers said they wanted to provide in-home Respite Care themselves, saying that they would rather stay with the care recipient than to have a break and leave them at home with someone else.

These findings are similar to those of Sterritt and Pokorny (1998). They found that African-American caregivers saw caregiving as an act of love: "Well, I do it out of love. And the reward is that I do have her, even though she has this (disease)"; and as a

traditional family value caregivers in their study preferred to provide care themselves over someone else: “It’s been rough, but as for me taking care of her, it is the way I was brought up” (Sterritt & Pokorny, 1998). The intertwining of love and obligation is not a universal characteristic of women caregivers, or caregivers in general, but rather a socio-cultural construct. Chee and Levkoff (2001) found that filial responsibility superseded love as the most important reason for providing care among Korean women caregivers. Feminist researchers of informal caregiving stress the importance of distinguishing between a woman caregiver caring about a person and a woman caregiver caring for the person, particularly in contemporary mainstream North American culture (Baines, Evans, & Neysmith, 1998). Thus, the Payback theme that integrates caring about and caring for a relative may be related to a socio-cultural trait that is stronger in Newfoundland and African-American cultural contexts.

### ***Self-Reliance in Caring***

Interestingly, there were other similarities in coping between this study sample and that of Sterritt and Pokorny's research. The caregivers in this study drew on their self-reliance and coping mechanisms for strength (Self-Reliance and Distractions themes) as much or more than they did on their family for assistance or help (Family Theme). Formal services did not constitute a main theme and were hardly mentioned. This shares some similarities to the findings of Sterritt and Pokorny (1998), who found that African-American caregivers relied most on solitary prayer and more on social supports than on formal supports.

The importance of self-reliance and family among the caregivers in this study is consistent with ethnographic research on Newfoundland elders and elder care that stresses the importance of self-reliance in Newfoundland culture and the role of the family in taking care of older persons. Self-reliance was viewed as a key survival trait, necessary for coping with limited employment opportunities, scant resources and few available services (Andersen, Crellin & O'Dwyer, 1998). The family was the principal provider of care for older persons, and it followed that the family should be able to provide that care on their own. If they could not, a long-term care placement was the traditional, albeit rare, alternative preferred over formal services introduced into the home (Lewis, 1997).

### ***CLTCS Utilization and the Accessibility***

Contrary to what might have been expected, the non-utilization of services among caregivers did not appear to be heavily influenced by factors related to accessibility. Of the Supportive services, small numbers of caregivers felt that Homemaker services were too expensive (11.5%) and that Meals preparation was not available in their area (11.5%). Lack of awareness was the most frequent reason cited for caregivers not engaging Day Care (15.4%) or Respite Care (11.5%). Accessibility played hardly any role in caregivers not using Preventive services.

### ***Care Recipient Acceptability***

Factors affecting acceptability appeared to play a greater role in the non-utilization of Supportive services. In particular, the reactions of care recipients to being left with a formal care worker were strong enough to persuade the caregivers to not engage either Respite care or Day Care. In the case of the latter, the care recipient's aversion to being with strangers was the most common reason reported for non-utilization of the service (42.3%). The care recipients were also unlikely to accept Respite care services, mainly because they became upset (15.4%), did not want the service (15.4%) or did not like strangers (19.2%).

The preferences of the care recipient had a noticeable effect on the caregivers. They appeared to maintain a high degree of deference towards the care recipients, even into the later stages of dementia. A major theme in the decision to provide care in the home was respect for the care recipient's preferences (Respect Theme). The reticence of caregivers to use Day Care or Respite care indicates that many caregivers maintained respect for the wishes of the care recipient even when that respect ended up sacrificing their own need for respite.

This may be indicative of a more general reluctance to accept the deterioration of the mental capacities of the care recipient. Other results provide evidence to support this interpretation. For example, some caregivers who reported that behavioural disturbance was a major source of stress added that they sometimes perceived the disturbances as



being deliberate. The caregivers would become all the more upset, suspecting the care recipient of tormenting them.

The deterioration of the care recipient's competency places an increasing responsibility on the caregiver to make decisions on the care recipient's behalf. The accepting of responsibility for a person with dementia is significant precisely because it will involve, at times, making decisions for the care recipient without his or her consent. When dementia reaches end-stages, the caregiver will be making all decisions on the care recipient's behalf. Thus, it is important for the caregiver to navigate the transition from peer to guardian with a maximum of consideration for the care recipient's different competencies. Caregivers who have difficulty taking responsibility for the care recipient, in particular, in situations where there is a trade-off between the caregiver's and care recipient's unhappiness, may be influenced by the mood swings, desires and dislikes of a care recipient who is dependent on the caregiver for making those decisions. In terms of CLTCS utilization, this means that the caregivers may be not utilizing available services that they need and find acceptable.

### ***Socio-Cultural Characteristics and Influences***

The caregivers who participated in this study had deep roots in Newfoundland. With few exceptions, they were born and raised on the island and shared family histories that included at least three generations of Newfoundlanders. They tended not to move very much or very far, with a mean number of fewer than two (1.62) changes of childhood

residence. As with most Newfoundlanders, the caregivers in this study grew up and continued to live near extended family members (Andersen, Crellin, & O'Dwyer, 1998). Caregivers would refer to their families by the town that they came from, for example, "Placentia Bay Hickeys", which would differentiate them from "Outer Cove Hickeys" (Hickey is a common last name). Caregivers that had had unstable residential experiences as children tended to move more than once, but stayed within the island portion of the Province. Economic conditions were the main reason that families had major changes of residence. Caregivers from those families often volunteered descriptions of how the family stayed close despite the changes in residence.

Caregivers' strong attachment to their family and place of residence was reflected in many of the themes that emerged from the Caregiver Experience component. Family ties were at the core of the meaning of community care. Caregivers wanted to "Pay back" a parent for having raised them and considered caregiving as "One of Life's Tasks". In other words, taking care of a parent at the end of their life was as natural as a parent raising a child. To entrust this care to someone else was generally looked down upon. As one caregiver put it: "a daughter ought to take care of her mother, it's a part of life isn't it? I mean, she took care of me, when I was little. It's only right". The strength of the family ties was also reflected in the support that caregivers received. Caregivers expected, and largely received, most of their help from other family members. They were more likely to report distractions or self-reliance as a source of support than formal caregiving, further exemplifying the private and family nature of caregiving. The caregivers' attachment to place was reflected in the importance for them to preserve continuity in the

residence of the care recipient. The strong attachment to family and place appears to be a cultural phenomenon of Newfoundlanders and may explain, in part, why the caregivers in this study appeared so reluctant to allow formal services into their homes.

Previous research has suggested that minority groups may develop their own patterns of community caregiving by virtue of their socio-economic status and distinct cultural heritage (Connell & Gibson, 1997; Janevic & Connell, 2001; Kosloski, Schaefer, Allwardt, Montgomery, & Karner, 2002; Sterritt & Pokorny, 1998). In this respect, the caregivers of this study shared some similarities with minority groups of caregivers in North America. The sample from this study showed lower utilization rates, stronger reliance on informal networks, a dominance of female and daughter caregivers, and caregiving as a traditional family value and an act of love. Newfoundlanders differ from most of ethnic groups that have been studied, for example, Latinos (Kosloski et al., 2002) and East Asians (Braun, Takamura, Forman, Sasaki, & Meininger, 1995), in that they have long history of settlement that is relatively homogeneous in an ethno-cultural sense.

Although we are suggesting that cultural traits play a significant role in explaining patterns of service utilization for CLTCS in Newfoundland, there is another cultural variable that is typically used in discussions of Newfoundland political and social behaviour that doesn't appear to be confirmed by our data. This is the distinction drawn by Newfoundlanders themselves between those "from town", meaning the city of St. John's, and those from "around the bay" "Around the bay" is an expression that refers to an outport community on the coast but, by extension it has come to refer to any place in

Newfoundland that is not St. John's. These terms closely match the urban and rural classification of the CSHA study, and may be considered as the equivalent to how caregivers perceive urban and rural places of residence. Contrary to expectations, the results from this study did not show any substantive differences between rural and urban caregivers in terms of their understanding of dementia or caregiving. There was also no major difference in the rate of their utilization of Community Long-Term Care Services. The lack of differences is likely due to low across-the-board rates of service utilization. However, it is expected that the availability of services in rural areas during the study period was lower than in St. John's and the surrounding suburban areas. In developing the Homecare Capacity component, the Principal Investigator identified only a handful of homecare agencies (8 out of 50) that appeared to be serving rural areas outside of St. John's in 1989-1999.

### ***Recommendations***

The key findings from this study suggest two kinds of recommendations that may enhance the utilization of Community Long-Term Care Services. The first is for service facilitators, for example, Health and Community Services, to take into account the potential for primary caregivers to under-estimate their needs for services. This tendency may be balanced through assessment tools that do not rely solely on self-rated questions regarding the need for services. For example, assessment tools that are being developed by Graham Worrall in Newfoundland provide a comparison of self-assessed and externally assessed levels of need. While it is important not to force or appear to force

services, caregivers may be more open to trying services if they feel that it is validated by a test or objective measure.

The second kind of recommendation is to allow for the development of alternative forms of support for informal community caregivers that are more appropriate to Newfoundland caregivers. Health system reforms that have increased standardization and a market place approach at the expense of flexibility and financial accessibility do little to help the majority of caregivers who are women (Gustafson, 2000; Neysmith, 1998).

Greater access to Day Care programs may provide the kind of respite care that caregivers called for in this study. The financial obstacles to operating large institutions for Day Care programs may be mediated by creating or adapting Personal Care homes for respite care services that are much more cost effective.

Increased financial support programs for informal caregivers would also be an effective means of increasing community care capacity, given the preference of caregivers for family participation in community care, and the government's acknowledgement of both the cost-effectiveness and quality of service of community care (Federal Provincial and Territorial Advisory Committee on Population Health, 1999; Parent & Anderson, 2001). The current amount of Employment Insurance available for caregiving support is only six weeks, which is clearly inappropriate for any chronic condition requiring intensive care.

Last, the promotion and subsidizing of limited and individualized formal support services, such as transportation and home modifications, may fill relatively small gaps in

support that presently may have large consequences. The lack of transportation services in Newfoundland is a serious problem for older people who are living in rural communities, who have to take costly taxis or even more expensive ambulances in order to reach a hospital for even the simplest tests. Simple modifications to homes would enable care recipients, and often caregivers themselves, to remain safely in the community for longer periods of time. For example, hand grips and bathing seats in bathrooms, ramps for wheelchairs and banister supports for staircases are inexpensive and largely reusable accessibility aids that increase the safety of the community residence and may prolong the community stay of a person with dementia.

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## Appendix A: Community Long-Term Care Services in Newfoundland (Eastern Avalon Peninsula)

Service	Site of delivery		Payment method			Administration	
	At home	Out of home	Public	Subsidized	Private	Public	Private
Chiropractic Services	X	X			X		X
Day Care		X	X	X	X	X	X
Driver	X				X		X
Homemaker	X			X	X		X
Home repair and gardening	X				X		X
In-Home Nursing	X		X	X	X	X	X
Meal Preparation	X			X	X	X	X
Occupational Therapy	X	X	X		X	X	X
Personal Care Attendant	X			X	X		X
Physiotherapy	X	X	X		X	X	X
Podiatry	X	X	X		X	X	X
Respite Care	X			X	X		X
Social Worker	X	X	X			X	

## Appendix B: Homecare Capacity Survey Instruments

### Instructions

This sheet provides instructions for filling out the homecare agency form.

Please make any changes directly on the form.

**Year**  
Each row on the chart represents one year, as of April 1<sup>st</sup> for example: 89-90 would be the year from April 1<sup>st</sup> 1989 to March 31<sup>st</sup> 1990.

**Status**  
Please indicate if your agency was open for business. If your agency was open for only a part of a year, indicate the months it was open.

**Owner**  
Please indicate the owner of your agency for that year.

**Service Area**  
Please include the geographic area that your agency served, for example: "Downtown Central St John's" or "Brigus and surrounding communities".

**#Emp**  
Please include the average number of homecare worker positions in your agency for that year. Indicate full and part time positions separately.

**Name**  
*Please verify that the name of your agency is correct, and indicate any name changes that may have occurred since 1989.*

**Address & Phone**  
*Please verify that the current street address, town, postal code, and phone number are correctly included.*

**Dementia—Clients**  
*Please indicate the number of clients your agency had who had dementia.*

**Dementia—Workers**  
*Please indicate the number of homecare workers your agency provided to clients with dementia.*

**Dementia—Training**  
*Please indicate with Yes or No whether your agency provided homecare workers with any specialised training for working with clients with dementia.*

**Cost**  
*Please include the average cost for a homecare worker, on a per hour basis.*

**# Hours**  
*Please include the total number of homecare hours billed by your agency for that year.*

Year	Status	Owner	Service Area	# Emp. (Full Time)	# Emp. (Part Time)	Cost (per hour)	Dementia Clients	Dementia Workers	Dementia Training	Cost	# Hours
89-90											
90-91											
91-92											
92-93											
93-94											
94-95											
95-96											
96-97											
97-98											
98-99											
99-00											

Homecare Capacity assessment survey instructions.

Name: <input type="text" value="MCR Name"/>		Address: <input type="text" value="Street Address 1"/> <input type="text" value="Street Address 2"/>		Phone: <input type="text" value="Phone"/>						
+	Year	Status (open/closed)	Owner (person/corporation)	Service Area (range of clients)	# Emp. (full & part time)	#Hours (total billed)	Cost (per hour)	Dementia		
								Training (yh)	Workers (#)	Clients (#)
	89-90									
	90-91									
	91-92									
	92-93									
	93-94									
	94-95									
	95-96									
	96-97									
	97-98									
	98-99									
99-00										

Homecare Capacity assessment survey.

## **Appendix C: Caregiving Experience Interview Questions**

- 2.01 First of all, let me ask you what does caring for \_\_\_\_\_ mean to you?
- 2.02 Why did you decide to care for \_\_\_\_\_ at home?
- 2.03 What are the greatest difficulties in caring for \_\_\_\_\_?
- 2.04 What kinds of satisfaction, or rewards, do you receive in caring for \_\_\_\_\_?
- 2.05 What are your main sources of help, strength, or support?
- 2.06 What kinds of assistance do you feel would help you?
- 2.07 What are your feelings about having a homecare worker for \_\_\_\_\_?

## Appendix D: CSHA Caregiver Study Follow-Up Instruments

### 1. Zarit Burden Inventory (ZBI)

Here is a list of the ways that people sometimes feel when caring for another person. After I read each question, please indicate how often you have felt that way:

Never (1), Rarely (2), Sometimes (3), Frequently (4), or All of the Time (5)

Remember, there are no right or wrong answers.

	1	2	3	4	5
-Asks for more help than needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Not enough time for yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Stressed by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel embarrassed over behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel angry around _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-_____ affects relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Afraid what future holds for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel _____ is dependent upon you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel strained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel your health has suffered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel don't have privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Social life has suffered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Uncomfortable inviting friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-_____ expects you to care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Haven't enough money to care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Unable to care much longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Lost control of your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Wish to transfer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Uncertain what to do about _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel should do more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel could do better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-How burdened you feel in caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 2. Centre for Epidemiologic Studies Depression Scale (CES-D)

Now, I would like to ask you about how you have been feeling. I will read you a list of ways you might have felt or behaved. As I read you each statement, please tell me how often you felt this way during the past week:

Rarely (1), Some of the time (2), a Moderate amount of the time (3), Most of the time (4).

Remember, there are no right or wrong answers.

	1	2	3	4
-Bothered by things that don't usually bother me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Didn't feel like eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Could not shake off the blues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel as good as other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Trouble keeping my mind on things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Feel depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Everything I did was an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Hopeful about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Thought my life a failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Felt fearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Sleep was restless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I was happy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I talked less than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I felt lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-People were unfriendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I enjoyed life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I had crying spells	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I felt sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-I felt people dislike me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Could not 'get going'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 3. Dementia Behavior Disturbance Scale (DBD )

I am going to read you a list of common problems. Please tell me if \_\_\_\_\_ has had any of these problems generally these days (e.g., in the past week). If so, how often have they occurred:  
Never (1), Rarely (2), Sometimes (3), Frequently (4), or All of the Time (5)

Remember, there are no right or wrong answers.

	1	2	3	4	5
-Lack of interest in daily activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Unwarranted accusations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Verbally abusive, curses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Empties drawers or closets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Dresses inappropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Exposes himself indecently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Screams for no reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Physical attacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Inappropriate sexual advances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Paces up and down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Moves arms in restless way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Lost outside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Incontinent of urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Incontinent of stool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Wakes up at night for no reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Wanders in the house at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Sleeps excessively during the day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Overeats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Refuses to eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Cries or laughs inappropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Refuses to be helped	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Throws food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Wanders aimlessly outside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Hoards things for no reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Destroys property, breaks things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Loses, misplaces, or hides things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Asks same question again	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-Repeat the same action	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



#### 4. Activities of Daily Living and Independent Activities of Daily Living

Now, I want to ask you about how \_\_\_\_\_ manages (*his/her*) daily life. I will mention a number of common, daily activities, and for each I want you to say if \_\_\_\_\_ can manage this without help, or with some help, or whether (*he/she*) cannot do it at all, that is, you or someone has to do this for them.

without any help (2) with some help (1) completely unable do that (0)  
refused (7) don't know (8) missing (9)

**NB:** If response is "with some help" or "completely unable" ask who helped

**NB:** The questions test capacity, not performance. Therefore, if the respondent says that the subject did not do an activity (e.g. I always do the cooking), the respondent would be prompted with "Could she/he do it if she/he needed to?"

	2	1	0	Helper
-can _____ eat...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ dress and undress...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ take care of own appearance, for example combing hair and shaving...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ walk...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ get in and out of bed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ take a bath or shower...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ use the bathroom or toilet...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ use the telephone...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ get to places out of walking distance...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ go shopping for groceries or clothes... (assuming he/she has transportation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ prepare his/her own meals...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ do housework...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ take his/her own medicine...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
-can _____ manage his/her own money...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____









