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Waiting for a Space in an Adult Day Support Program:

Retrospective Caregiver Perspectives

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled “Waiting for a Space in an Adult Day Support Program: Retrospective Caregiver Perspectives” submitted by Clare Rachel Hildebrandt in partial fulfillment of the requirements for the degree of Masters of Science.

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ABSTRACT

Adult Day Support Programs (ADSPs) are designed to give caregivers of individuals with dementia respite; however, there is little empirical evidence into the burden borne by caregivers who wait for community based health services. A cross-sectional, retrospective questionnaire was used to assess the levels of burden, stress, depression, self esteem and the perceived impact of waiting for an ADSP of caregivers of individuals who attended dementia-specific ADSPs in the Calgary Health Region. The response rate for perceived, expected, and acceptable waiting times was insufficient to draw conclusions; however, thirty percent of caregivers found that the waiting period allowed them to adapt to the use of ADSPs, compared with twenty-five percent who found that waiting for ADSP services was associated with an increase in stress level. Waiting time did not have an association with current caregiver burden. These results support further investigation into the effects of waiting for community based health services.

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DEDICATION

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To Larry who taught me to laugh
To Joan who taught me to sing, even in the face of despair
To Les who taught me that alligators are always among us
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To Evelyn who taught me that kind works are remembered, even if nothing else is
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LIST OF ABBREVIATIONS

ADSP	Adult Day Support Program
AMA	Alberta Medical Association
ASC	Alzheimer Society of Calgary
CABG	Coronary Artery Bypass Graft
CHR	Calgary Health Region
CSHA	Canadian Study of Health and Aging
GDS	Geriatric Depression Scale
MAWT	Mean Acceptable Waiting Time
NPI-Q	Neuropsychiatric Inventory
RRIT	Regina Risk Indicator Tool
SD	Standard Deviation
SF-36	Medical Outcomes Study – 36 Item Short Form Health Survey
WOMAC	Western Ontario and McMaster Osteoarthritis Index

EPIGRAPH

You can get so confused
That you'll start in to race
Down long wiggled roads at a break-necking pace
And grind on for miles across weirdish wild space,
Headed, I fear, toward a most useless place.

The Waiting Place ...

... for people just waiting.

Waiting for a train to go
or a bus to come, or a plane to go
or the mail to come, or the rain to go
or the phone to ring, or the snow to snow
or waiting around for a yes or a no
or waiting for their hair to grow.
Everyone is just waiting.

NO!

That's not for you!

Somehow you'll escape
all that waiting and staying.
You'll find the bright places
where Boom Bands are playing.

From: Dr. Seuss (1990), Oh, the Places You'll Go!

CHAPTER ONE: INTRODUCTION

1.1 The Study Problem:

In 1991, it was estimated that there were approximately 250,000 Canadians 65 years of age and older with dementia (eight percent of the total population) (CSHA, 1994b). There were an estimated 1,684 to 2,307 cases of Alzheimer disease in Alberta alone (CSHA, 1994a). If age-specific prevalence estimates persist, the number of seniors affected by dementia is expected to triple over the next 40 years (CSHA, 1994b). The estimated annual economic cost of Alzheimer disease in Canada was 3.9 billion dollars in 1991 (Ostbye & Crosse, 1994). The estimated annual cost of caring increases with dementia severity (Hux et al, 1998). It rises from \$9,451 for mild disease to \$36,794 for severe disease (Hux et al, 1998). The majority of the costs for care of severely affected individuals arise from institutional care. Interventions that prolong the period of time when care can be provided in the community would likely both enhance the quality of life of the person with dementia and help control costs (Bergmann et al, 1978).

Dementia affects not only the individual with the disease, but also their family. Because of the limited availability of spaces in Long Term Care centers, individuals with dementia often reside in the community cared for by their family for long periods of time. Providing family caregivers (if present) with support and relief can ease the stress, strain, and/or burden of caring for someone with dementia (Hoffmann & Kaplan, 1996; Strang & Neufeld, 1990; Stephenson, Wilson & Gladman, 1995; Rogowski & Leadbitter, 1981; Jarrott et al, 1999; Henry & Capitman, 1995; Rothman et al., 1993; Weissert et al, 1990; Cox, 1996; Strain, Chappell & Blandford, 1988; Wimo et al, 1990; Gutman, 1991; Zarit

et al, 1998; Gottlieb & Johnson, 1995; Burch et al, 1999; Graham, 1989; Lawton, Bordy & Saperstein, 1989; Montgomery & Borgatta, 1989; Kosloski & Montgomery, 1993; Cox, 1997). One method of caregiver support is the use of Adult Day Support Programs (ADSPs).

ADSPs are designed to give caregivers one or more days of respite a week to allow them the uninterrupted time necessary, for example, to complete household tasks, to socialize with friends, or spend time on themselves. In 2003, there were twelve such programs funded by the Calgary Health Region, each operating from two to six days a week. Three of these programs were run by the Alzheimer Society of Calgary in partnership with the Calgary Health Region, Carewest and the Bethany Care Society and are considered to be dementia-specific. By the time a family has determined that it is in need of support in the form of community-based health services, such as ADSPs, they are typically stressed and may be in crisis.

When caring for a person with dementia, the caregiver is faced with multiple transitions. Typically this includes the transition from partner (or child, sibling etc...) to caregiver; accepting the need for help and allowing others to assist (e.g., other family members, personal/companion care, ADSPs); and, in the move of their loved one from home to a Long Term Care facility. Each of these transitions comes with its own unique burden; however, the burden of waiting for services can be seen as ‘excess burden’. Because demand exceeds supply for health services, families in need are left waiting for the information, education, support and respite they require. However, there is little empirical evidence on the burden borne by caregivers who wait for community-based health services, in particular ADSPs.

1.2 Purpose of the Study:

This study examined caregivers' levels of burden, stress, depression, self esteem as well as the perceived impact of waiting. This cross-sectional, retrospective design allowed for an analysis of the characteristics of caregivers of individuals who attended dementia-specific ADSP services in Calgary. The research model used (Appendix A), similar to that of Meiland et al (2001a), examined the effects of the caregiver's characteristics, the characteristics of the person with dementia, and the characteristics of the living situation on the caregiving experience.

1.3 Research Questions:

The following research questions were addressed:

- (a) What was the mean waiting time for admission into a dementia-specific ADSP in the Calgary Health Region? *[Assessed in the administrative database analysis.]*
- (b) What were the characteristics of individuals and their caregivers who attend dementia-specific ADSPs? *[Assessed by descriptive statistics.]*
- (c) What was the level of burden of caregivers of individuals who attend dementia-specific ADSPs? *[Assessed by mean of Perceived Primary Stressors Score, by each domain.]*
 - i. Did the duration of waiting time for admission (< 1 month versus > 1 month) correlate with an increased level of caregiver burden?
[Hypothesis: Individuals with longer waiting times would have higher levels of burden]

- ii. Did co-habituating with the care receiver correlate with an increased level of caregiver burden? *[Hypothesis: Caregivers who co-habituated with the individual with dementia would be more burdened].*
 - iii. Did the type of relationship between caregiver and care receiver correlate with level of burden? *[Hypothesis: Spousal caregivers would have a higher level of burden than non-spousal caregivers.]*
 - iv. Did gender influence the level of burden? *[Hypothesis: Female caregivers would be more burdened than male caregivers.]*
 - v. Did the severity of dementia correlate with an increased level of burden? *[Hypothesis: Caregivers caring for an individual with dementia with a higher severity of disease would have higher levels of burden.]*
- (d) What were the caregivers' perceived benefits and drawbacks of waiting for admission to an ADSP? *[Assessed by descriptive statistics.]*
 - (e) What support needs did caregivers have while waiting for admission to an ADSP? *[Assessed by descriptive and qualitative analysis.]*

CHAPTER TWO: LITERATURE REVIEW

2.1 Methods of Literature Review:

Despite the significant number of people waiting to obtain spaces in ADSPs across the country, there are no published studies on the consequences of this waiting time on the system, individuals or caregivers. This literature review focuses on related studies in other populations, such as the population of individuals waiting for a space in Long-Term Care centers. A computerized search of the MEDLINE, CINHAL, and Expanded ASAP databases was conducted to identify relevant articles. The search included various combinations of the following Medical Subject Headings and text words: “waiting lists”, “wait list”, “waiting times”, “accessibility”, “burden”, “Adult Day Support Programs”, “Adult Day Care”, “Day Programs”, and “Community Health Services”. Citations were limited to the English language. The references of each article selected were reviewed to locate further articles. A search using the names of authors known to be involved in wait list research was also conducted. In addition, websites of Canadian and international health care providers were searched for relevant unpublished data. Features of the key studies are included in Appendix B.

This literature review has been organized into three sections. The first section provides an overview of the definitions and measurement of wait lists and waiting times. The second and third sections focus on the effects of waiting for treatment on patients, and the effects on caregivers respectively.

2.2 Definitions and Measurement of Wait Lists and Waiting Times:

This section examines how wait lists are typically defined, formed and measured.

The definition and measurement of waiting times is also discussed.

2.2.1 Definitions of Wait Lists:

There are numerous ways that wait lists have been defined in the literature. At a high level, a wait list is simply a roster of individuals waiting for a service. The management of this roster varies across disciplines and sites. There are both informal lists and formalized systems such as centralized wait lists with priority weighting scales. Doyal (1995) divided these types of wait lists into the following four categories: libertarian; utilitarian; egalitarian; and, ad hoc. A libertarian wait list is defined as a sequential queue for service, with new referrals added to the bottom of the list, and admissions being made from the top of the list. Hadorn and Holmes (1997a,b) proposed a utilitarian option of admitting individuals to the queue if, and only if, it presents a cost-effective option. The egalitarian model is illustrated by Basinski et al. (1993) with prioritization by clinical need, a common method used with cardiac care, for example. The ad hoc method is indicative of the subjective components of wait lists. The time an individual is expected to wait may be affected by seemingly extraneous factors such as race (Eggers, 1995), and employment status (Gaffney & Key, 1995).

Wait lists have been referred to as mortlakes by Frankel (1989) when describing wait lists and their causes:

“The formation of waiting lists corresponds more with the development of an ox-bow lake. The meandering flow succeeds

in taking a short cut, and so leaves an isolated lake. Similarly the flow of acute care finds a way of isolating a selected portion of the demand upon it. The alternative term for an ox-bow lake, mortlake, offers a more graphic metaphor for the pool of demand that is set to one side in this way. In the mortlake of the waiting list, we isolate a proportion of the cases of piles, hernias, varicose veins, cataracts and bad hips to flounder as well as they can, unless they choose, or can afford, to buy their way out.” (Frankel, 1989)

Despite the fact that part of the Canada Health Act’s objective is to facilitate reasonable access for health services, the development of mortlakes may be indicative of the fact that some health care services have become relatively inaccessible to Canadians. These mortlakes, or stagnant ponds of individuals continually waiting for a service, are likely to never have access to services due to the implicit but deliberate method of assigning low priority to their health needs (Frankel 1989). Furthermore, it is unlikely that new resources will provide an increase in the access to treatment for such individuals.

2.2.2 The Formation of Wait Lists – A Way of Rationing Scarce Resources?

The reasons for the formation of wait lists are complex and interlinked. It has been argued that wait lists are a result of social policy attempting to ration scarce resources when excess demand exists for health services. Cullis and Jones (1985) referred to a wait list as a list of people waiting to receive a health care service when the price is insufficiently high enough to balance supply and demand. Kennedy (1975) described wait lists as a buffer between the demand from community and the ability of an institution to provide a medical service; therefore, providing a source of patients to allow resources to be met by admissions. Bloom and Fendrick (1987) indicate that whenever money is not used to purchase services, wait lists will result.

Wait lists are used to allocate health services in the absence of an effective market where resources are perceptibly constrained. This is especially true in the provision of an increasing amount of care to an aging population. “Our various systems may merely be using different means of inhibiting consumption of care by older people – gatekeeping and wait lists in Canada and the U.K., cost control and out-of-pocket expenses in U.S.” (Evans 1996, page 1450). Furthermore, physicians may perceive wait lists as the most equitable method of rationing, ‘From physicians’ perspective, longer waiting may be perceived as the easiest, most equitable and least disruptive way to spread constrained resources, especially for patients not requiring urgent care” (Bloom & Fendrick 1989). Therefore, wait lists, when reliable and valid, can be both an indicator of excess demand and a method of rationing access to constrained health care resources.

In a complex health care system there are multiple reasons for the development of wait lists. Wait lists occur when both the supply and demand sides of the equation are out of balance. On the supply side, shortages of resources and key personnel contribute to waiting time. Resource planning is traditionally based on utilization, rather than on needs and evidence-based methodologies. The decentralized responsibility for health care and the lack of coordination further complicate efficient access to services (Amoko et al., 1992a,b). Poor organization of wait lists and inefficient administrative procedures can also lead to an increase in waiting times (Duncan et al., 1988, Lal, 1990, Pope et al., 1991).

An increase in demand for services can further contribute to the imbalance between supply and demand. Demographics may have an impact on the demand for

services, which, in turn, may result in the creation of wait lists. Typically, people consume increasing amounts of health care as they age, both institutional and community-based. The attributes, characteristics and service needs of the elderly may affect the amount of time spent waiting for services. Those with higher needs are usually seen sooner, leaving those with less acute needs waiting for services; therefore, these individuals are possibly not seen until they develop an acute need themselves. However, the opposite may be true for placement into long-term care or a community based ADSP. Managers of Long Term Care centers or ADSPs are able to choose who to admit to their programs based on case descriptions and assessments. Individuals with increased acuity may wait longer for services due to the current acuity levels of those in the system and available resources to help these individuals.

In addition, patient preference for a particular surgeon or Long-Term Care center may lead to an increase in wait lists for the system (Fishbacher and Robertson, 1986, Turner and Cooke, 1991). Alternatively, physicians themselves may contribute to the inefficiency of the system. The costs of efficiency are borne by physicians, while those of inefficiencies are borne by patients in the form of waiting times (Culyer & Cullis 1978). Physicians are arguably able to induce demand for their services as bargaining chip in negotiations with health care administrators, or to ensure the availability of work and a mix of cases for teaching purposes.

2.2.3 Measuring the Length of Wait Lists:

At first glance, measuring the length of a wait list appears simple; however, there are a number of factors that must be considered when making comparisons among wait lists. A simple quantitative analysis of the number of individuals waiting and the time they have waited is the simplest way of measuring the impact of wait lists. The addition of data such as the severity of the conditions of those waiting as well as the impact of waiting further explains the context of the wait list. Any measure of the size of a wait list should be taken in the context of the size of the population served, the capacity of the system and the turnover rate for the particular health service (McDonald et al., 1998). Donaldson (1989) suggests the use of Standardized Wait List Ratios (SWLRs) to provide context to descriptions of the size of wait lists. The accuracy of the data on any given wait list should be regularly verified through the use of auditing. The number of people waiting for admission of a given health service may be overestimated due to the inclusion of individuals' names on the list who no longer require service due to death, diminished changes in health status, movement to another health region, receipt of service elsewhere, resolution of the symptoms, and inappropriate placement on the list in the first place (Tomlinson & Culyer 1992, Lee et al. 1987, Hochuli 1988, Parmar 1993).

2.2.4 Definition of Waiting Times:

There is no consensus as to what constitutes waiting time (Smith, 1994). The definition of waiting time depends on how the wait list is managed and when individuals are placed on the list. As illustrated in Appendix C, the patients' perception of waiting time varies greatly from the typically recorded waiting time. A typical patient views their

waiting time as starting from the moment they decide to seek medical treatment for symptoms. This includes waiting for an appointment with a primary care practitioner, waiting for an appointment with a specialist, and finally waiting for the procedure or intervention. Data collection in surgery usually records, the start of the waiting time as the date the surgeon places the patients name on a surgical list. However, this may only capture a portion of the total time the patient has spent waiting for treatment (McDonald et al., 1998). There are also differences in when and how patients' names are added to wait lists, especially when these lists are centralized. Some physicians may store up names and add them in bulk; others may continuously add them as they arrive. These issues may raise questions regarding the validity of the data in some studies.

2.2.5 Measuring Waiting Times:

The following five common methods are used to measure waiting times: cross-sectional; retrospective; prospective; time to clear; and, the use of acceptable waiting times.

Cross-Sectional Method: The number of individuals on a wait list and their waiting time to date is assessed at a single point in time. This method is typically used with administrative databases and, when used as a method of estimating the mean waiting time, tends to exaggerate the waiting time. Due to a positively skewed distribution of waiting times, a cross-sectional analysis is more likely to find people on the wait list who have been waiting for a long period of time (Shaw, 1997). Therefore, even if most

individuals are seen before the mean waiting time, this is not represented by this method of data collection.

Retrospective Method: The retrospective method calculates a mean waiting time for those individuals who have already been admitted to the health service. The waiting time of individuals on the wait list or those who have died is not considered. Typically, any retrospective method of calculating waiting time will result in a lower value than a cross-sectional estimate of those currently on the wait list (Don et al., 1987).

Prospective Method: Under the prospective, or cohort method, the total waiting time is calculated for a given cohort of individuals referred to a health service. The results may only be applicable to the cohort. This method is the most valid and reliable measure of waiting time. It is also, however, the most costly and time-consuming.

Time to Clear Method: A composite method of the above methods is the use of a time to clear calculation. The number of patients removed from the list in a given time period is divided by the total number of patients on the wait list. This provides an estimate of the length of time required to provide the given health care service to all individuals currently on a wait list. This method relies on the assumption of unchanged capacity, and does not consider the impact of additional individuals added to the wait list.

Acceptable Waiting Time Method: Several studies have introduced the concept of acceptable waiting times, measured through the Maximal Acceptable Waiting Time (MAWT). Patients are presented with different scenarios including waiting time and some measure of risk (e.g. surgical success rate). Waiting time is varied until the maximal acceptable waiting time switch point is determined.

2.2.6 Summary:

There are five commonly used methods of measuring waiting times. The differences between methods complicate the comparison of these lists and times between various health services. The causes of these wait lists are complex, and interlinked. The study of such lists, and proposed solutions to extensive waiting times for health services likewise requires a complex and integrated approach. In order to fully understand the impact of wait lists on the health care system, various approaches must be utilized.

2.3 Effects of Wait Lists on Patients:

The presence of wait lists affects the individuals waiting for services. The simple act of waiting for a service can affect morbidity, mortality and quality of life. Patients have varying degrees of acceptance of the need to wait for a health care procedure, and varying needs for education and support while waiting.

2.3.1 Morbidity and Mortality:

One of the first studies of the effects of wait lists on patients focused on the morbidity associated with waiting for tonsil surgery (Freeland and Curley, 1987). The researchers studied a group of 83 adults and 42 children under the age of 16 with recurrent tonsillitis who were not on an urgent wait list for medical or social reasons. Individuals with increased severity were given priority and there did not appear to be any adverse effects on morbidity of waiting for surgery. Although a certain amount of patient selection had already occurred in order to be placed on the wait list, 20% of children and 8% of adults did not have the operation due to remission. Freeland and Curley argued

that a longer wait list for tonsillectomies allows for the prevention of unnecessary operations.

Morris et al. (1990) conducted a retrospective chart review of patients waiting for cardiac catheterization in Manitoba from May 1981 to December 1982. Patients were admitted for catheterization through immediate care (n=314) or elective care (n=557). Those who were listed as immediate care were more likely to enter the hospital via the emergency room, to have longer hospital stays, and have a higher risk of mortality. Morris et al. also found that there were rare incidences of adverse events among those who were waiting for elective catheterization. A similar study by Carrier et al. (1993) found that a short waiting time for open-heart surgery for those whose condition is stable, is a safe and acceptable option if rapid access to medical and surgical treatment remains available throughout the waiting period.

One of the most controversial types of wait lists is that of individuals waiting for transplants. These wait lists are typically due to the increasing number of individuals who are considered appropriate for such surgery coupled with a relatively constant supply of available organs (McManus et al. 1993). This situation is in contrast to the provision of other health care services, where the imbalance of supply and demand is based on health care resources, rather than organ supply. However, the effects of such wait lists are similar. There is a high level of mortality associated with waiting for heart transplantation (McManus et al., 1993) especially when the numbers of individuals on wait lists increase. McManus et al. (1993) conducted a retrospective analysis of administrative databases in conjunction with a survey of transplant centers participating in the United Network for Organ Sharing. In 1988, there were 512 individuals waiting

for heart transplantation, this number grew to 650 in 1990. The proportion of individuals on the wait list who were eventual recipients of surgery decreased by 7% from 1988 to 1989. Additionally, the ratio of the number patients who died to the number of patients who underwent surgery increased from 0.07 in 1983 to 0.21 in 1989. McManus et al. suggest that this may be a reflection of the methods for deciding who gains admission to the wait list and when.

Bengston et al. (1994) studied the effects of waiting for coronary revascularization through a cross-sectional questionnaire of 831 patients waiting for surgery and 670 age and sex matched controls. Only 27% of those on the wait list were able to work full time compared with 67% of controls ($p<0.0001$). Patients on the wait list frequently had bouts of chest pain, dyspnoea and tachycardia. In addition to physical symptoms, there was an increase in the degree of psychological symptoms such as anxiety, depression, restlessness and stress among those waiting for surgery. They had an increased rate of use of sedatives ($p<0.0001$) and sleeping pills ($p<0.0001$). Those patients with longer waiting times (>six months) had increasingly more nervous reactions and had an even greater use of sedatives and sleeping pills (Bengston et al., 1994).

Likewise, Bengston et al. (1996), using a similar design of surveying all patients on a wait list for coronary angiography and through comparing the results obtained with administrative databases were able to examine the incidence of adverse effects of wait lists (morbidity and mortality). The mortality rate was 2.1% and a further 1.7% had a myocardial infarction. Bengston et al. speculated that this may be an underestimation of mortality since the time from entering the wait list prior to September 1990 was not included.

Cox et al. (1996) examined 423 patients on wait lists for coronary artery bypass grafting in Nova Scotia and Prince Edward Island in a prospective observational study. 12.4% of the 275 patients not originally identified as urgent required reclassification to a higher priority because of worsening symptoms. Cox et al. also found that 25% waited longer than targeted waiting times, with 73.2% of those classified as elective exceeding targets. Preliminary evidence suggested that improving access might generate savings in direct and indirect societal costs. The additional expense of re-hospitalizing 37 patients with worsening symptoms was \$517,000. This did not include the cost of repeat angiography, hospital stays for urgent patients, outpatient visits, lost productivity and income, or prescribed drugs (Cox et al., 1996).

Rosanio et al. (1999) monitored 381 patients on the wait list for radiologic examination of their coronary arteries in Texas using an observational cohort approach. Of these, 6 died, 4 suffered a non-fatal myocardial infarction, and 26 were hospitalized. Delays lasting longer than two weeks led to an increase in the probability of these adverse events. The authors called for shorter waiting times for coronary angiography and for prioritization of the wait list (Rosanio et al., 1999).

Numerous studies have indicated excess morbidity and mortality due to waiting for surgical procedures. Based on this literature review, it appears that no research to date has examined the effects of waiting for community-based health services or Long Term Care on morbidity or mortality.

2.3.2 Quality of Life:

One possible consequence of a wait list is a negative effect on quality of life. Even if a worsening of symptoms does not occur, those waiting may still be suffering unnecessarily.

Rector et al. (1993) used a case control approach to evaluate the responsiveness of the SF-36 to the effects of heart transplantation. A survey was sent to 48 individuals waiting for heart transplants (responses=42) and 177 recipients of hearts (responses=143) in Minnesota. Recipients of heart transplants had significantly higher (i.e. better) scores in all areas of the SF-36 ($p<0.0001$) with the exception of mental function and the ability to perform roles without emotional problems. This study provided the groundwork for measuring changes in quality of life as a result of the procedure. The difference in the quality of life between the two groups is likely due primarily to the transplant, not necessarily to the effects of waiting for a transplant.

Hall et al. (1996) investigated the quality of life for men on a wait list for transurethral resection of the prostate in Australia. All of the fifty patients on the wait list were assessed with the Health-Related Quality of Life Survey Questionnaire. The average waiting time was eight months (range 2-36 months). Ninety-two percent of the men on the wait list were bothered by disturbed sleep, 40% were worried about cancer, and 56% were worried about decreased sexual function. Fourteen patients were assessed one-year post-surgical intervention, and, of these only 3 indicated any bothersome symptoms. Hall noted that these latter patients might have had co-existing conditions.

A Canadian study by Williams et al. (1997) assessed health-related quality of life in 209 patients before and after hip or knee replacements. This study suggested that

queuing systems based on the burden of symptoms could reduce the overall burden and/or pain experienced by patients waiting for surgery. Patients were interviewed at home with a brief socio-demographic questionnaire, a checklist of chronic health problems, the Medical Outcomes Study – 36 Item Short Form Health Survey (SF-36) and a condition-specific measure (the Western Ontario and McMaster Osteoarthritis Index or WOMAC). There was no difference in the waiting time of patients based on severity of symptoms (WOMAC score) or health-related quality of life (SF 36). There were, however, improvements in these two scores after surgery. Waiting times did not appear to have an effect on the post-surgical outcome. The correlation coefficients between waiting times and WOMAC and SF 36 were between -0.07 and -0.12 which were deemed neither statistically or clinically significant. Williams et al. found that “if more symptomatic or functionally impaired patients can achieve consistently excellent relief of their symptoms, disproportionately long waiting times simply impose an avertable burden of suffering and disability” (Williams et al., 1997). This suggests that shortening queues and ordering them based on severity might reduce the burden of waiting.

Derrett et al. (1999) studied the effects of waiting for either a prostatectomy or hip or knee replacement at a New Zealand hospital on health-related quality of life. They interviewed 102 individuals awaiting prostatectomy and 42 individuals waiting for a joint replacement. The interview consisted of socio-demographic questions, acceptable waiting times, the SF-36 Health Survey, and condition specific severity of illness instruments (American Urological Association Urinary Symptom index or Lequesne Index of Severity for Hip and Knee Disease). The priority rating [A (high) to C (low)] was obtained from patient charts. As expected, those on the wait list had a poorer health-

related quality of life than a general sample of the New Zealand population.

Symptomatic burden and health-related quality of life was not related to length of wait. This may have been due to the study design and its overrepresentation of individuals with longer waiting times (Derrett et al., 1999).

Arthur et al. (2000) conducted a randomized, controlled trial to investigate the effects of a multi-dimensional wait list intervention on quality of life of individuals waiting for coronary artery bypass graft surgery in Ontario. While on the wait list for surgery, the intervention group received exercise training twice a week, education and reinforcement, and monthly nurse-initiated telephone calls. The group who received the intervention spent one day less in the hospital overall ($p=0.002$) and less time in intensive care ($p=0.001$). The quality of life of those in the intervention group was better both while waiting, and up to six months post-surgery. The relative effects of the intervention's components could not be separated. As the trial was only conducted in one site, generalizability of these results is uncertain.

2.3.3 Acceptance of Waiting Times:

A patient's experience while waiting for a health care procedure may be influenced by the degree that they accept the need to wait. This acceptance of waiting time can be dependent upon the patient's anticipated waiting time.

In a retrospective, cross-sectional questionnaire of 127 individuals in Ontario, Ho et al. (1994) determined that the acceptance of waiting by patients waiting for knee surgery was affected by the length of the waiting time. The mean waiting time for a consultation was 4.0 weeks with an associated acceptance level of 93.2%, while the

waiting time for surgery was 9.5 weeks with an associated acceptance level of 88.1%. As would be expected, there was a significant difference between the average acceptable waiting time of 13.2 weeks and that considered unacceptable (average of 34.3 weeks) ($p<0.001$) (Ho et al., 1994).

Like Ho et al., Coyte et al. (1994) found that the length of waiting time affected acceptability. Coyte et al. studied the satisfaction levels and acceptance of waiting times in a retrospective sample of 1623 individuals who had undergone knee replacement in Ontario and the United States. Although waiting times were longer in Ontario (four weeks for consultation and eight weeks for surgery) than the United States (two weeks for consultation and three weeks for surgery), the satisfaction levels were similar between the two areas ($p=0.23$). This satisfaction level was however, associated with the length of waiting time in both nations. As waiting time increased, satisfaction diminished ($p<0.001$). Due to the retrospective nature of this study, there are limitations due to recall bias since patients were asked to recall waiting times for an operation that had occurred two to seven years earlier (Coyte et al., 1994).

Dunn et al. (1997) investigated patients' tolerance of waiting for cataract surgery in a cross-sectional survey in Canada, Denmark and Spain. Five hundred and fifty-five patients were interviewed and asked to categorize the length of time that they would be required to wait as either "shorter than they would like", "reasonable", "longer" or "much longer than they would like" as well as questions about demographics, health and visual status, anticipated personal waiting time and general attitude about a reasonable wait for non-specified non-emergent surgery. The anticipated waiting time was the greatest predictor of patients' tolerance of waiting for cataract surgery (Dunn et al., 1997). As in

previous studies, patients' intolerance increased with waiting time. Acceptance of waiting time was not associated with self-reported difficulty with vision or clinical measures. Of interest, patients accepted waiting times that were longer than those identified as acceptable by specialists (Dunn et al., 1997).

Patients' perceptions of 'maximal acceptable waiting time' (MAWT) for coronary artery bypass grafting (CABG) were assessed by Llewellyn-Thomas et al. (1999). A sample of 72 patients on an elective CABG list were solicited to choose between a one-month wait with a 2% risk of surgical mortality and a six-month wait with a 1% risk of surgical mortality. Waiting time was varied until the MAWT switch point was determined. That is, the point where patients would choose an operation with a higher surgical risk to obtain a shorter waiting time. Patients were also asked their expected waiting time, perceived risk of myocardial infarction while waiting, current function, expected functional improvement and the value of that improvement. The median MAWT was two months with a range from one to twelve months. However, the MAWT only correlated significantly with the expected waiting time. Many patients perceived high cumulative levels of risk for a myocardial infarction. This anchoring bias indicates that an intervention to modify patients' perception of risk is necessary, especially when a scheduled surgical date must be deferred (Llewellyn- Thomas et al., 1999).

Derrett et al. (1999) found similar results to Llewellyn- Thomas et al. (1999) in their study of individuals waiting for prostatectomy or hip or knee replacement (discussed in section 2.3.4). People with more severe symptoms expected surgery more quickly than

those with less severe symptoms. However, there was no relationship between the acceptable waiting time and priority scores assigned by surgeons.

The Romanow Report (2002) indicated that Canadians identified long wait lists as the main, and most times only, reason to consider paying for treatments outside of the public health care system. Waiting times and wait list are perceived to be growing in Canada, meanwhile, patient's acceptance of these waiting times is limited.

2.3.4 Education and Support Needs:

The needs of patients who are waiting for health care services are often not addressed. The assessment and provision of education and support services may help to increase the acceptance of the waiting period for health services.

Martin et al. (1995) were among the first to assess the education, information and support needs of patients waiting for treatment. They conducted 4 focus groups with patients (total of twenty individuals) as well as semi-structured interviews with general practitioners (seven individuals), consultants (five individuals) and their secretaries (six individuals). Patients wanted more information about their clinical condition, their expected waiting time and the wait list procedure. Their main source of information about waiting times and the procedure was through the anecdotes of family and friends. Patients were unsure whom to contact if they had questions about their upcoming surgery or consultation, where the procedure would take place, what the procedure involved, who would conduct the procedure, how to determine if they were actually on a list, and what would happen if they were unavailable when their name was chosen for surgery. As one patient on the wait list explained "it's the not knowing that really is the worst thing..."

General practitioners also wanted to minimize the number of times they contacted a specialist in order to maintain professional credibility (Martin et al., 1995).

Wright and Arthur (1996) assessed the impact of a management system on patients waiting for cardiac surgery. This system consisted of a nurse coordinator contacting patients waiting for surgery and informing them that they were available to help with questions or concerns. Patients were then contacted at a later date to provide information about their place on the wait list, to establish a baseline of their knowledge of their physical and emotional status and to assess their coping ability. The upcoming surgical procedure was reviewed to allow patients time to ask questions. Patients identified as needing further information received educational material to help address their needs. Of the 121 subjects who returned the questionnaire, 60% reported anxiety upon learning that surgery was required and 46% of this group discussed their anxiety with the nurse coordinator. Seventy percent of participants, who discussed concerns with the coordinator felt less anxious, compared with only 25 % of those who did not talk to the coordinator ($p=0.001$). This study was limited by the lack of validated instruments and the retrospective nature of the measurement of anxiety (Wright and Arthur, 1996).

Derrett et al. (1999) found that individuals in New Zealand waiting for prostatectomy and hip or knee replacement identified a lack of knowledge of the wait list process, their place on the list and what their expected waiting time would be. These patients were, however, reluctant to complain or to “be a nuisance” and many were unaware who to call with any questions that they had. Patients were also afraid that if they took a holiday or turned down a space due to illness that they would be placed at the bottom of a long list (Derrett et al., 1999).

Scherrer-Bannerman et al. (2000) investigated the differences in web-based versus manual-based education and support for individuals waiting for cardiac surgery in British Columbia. Patients were assigned to either form of education and support based on their access and ability to use the Internet as an information source. The levels of support, anxiety and knowledge were assessed through the use of questionnaires. The information provided by both methods was found to increase support and decrease the anxiety of waiting for cardiac surgery; however, those in the web-based group had a greater decrease in their level of anxiety. Both groups experienced a high level of stress associated with the wait times and the experience of last-minute cancellations. It is important to note the potential for selection bias in this study as the groups were formed based on access and ability to use the Internet. These patients may have been systematically different at baseline from the other group.

2.3.5 Summary:

Based on the literature review, it appears that patients experience excess morbidity and mortality as well as a decrease in their quality of life while waiting for services. A patient's anticipated waiting time is among the greatest predictors of satisfaction while waiting. These effects may be modified through education and support of individuals who are waiting for health care services.

2.4 Effects of Wait Lists on Caregivers:

There have been relatively few studies on the impact of waiting for admission to a health service on a patient's informal caregiver. This review found a total of five such

studies. One study investigated the effects of waiting for a heart transplant on spouses (Collins et al., 1996). Two studies addressed the education and support needs of caregivers and patients waiting for speech therapy (Lee, 1996) or cardiac surgery (Lindsay et al., 1997). The other two studies focused on the burden of waiting for admission to a long-term care facility (Meiland et al., 2001a, Meiland et al., 2001b).

2.4.1 Quality of Life:

Collins et al. (1996) investigated the impact of waiting for a heart transplant on 85 spouses through a cross-sectional survey (response rate = 80%). Spouses were assessed with the following tools: Spouse Transplant Stressor Scale, Jalowiec Coping Scale, Family Inventory of Resources for Management, Quality of Life Index, a six-item rating scale and a demographic form. Waiting time was correlated with the spouses' classification of the impact that waiting for a transplant had on their life. Those who waited longer were more likely to rate the experience as negative ($p=0.04$). Those who rated the experience as negative also reported higher stressor scores ($p=0.03$), used more negative coping strategies ($p=0.03$) and had a lower quality of life ($p=0.04$).

2.4.2 Education and Support Needs:

Lee (1996) investigated the use of an intervention to provide education and support to families of children under three who were waiting for speech therapy in England. The format used was two groups of ten gathering to: discuss their needs while waiting; to provide education on children's developmental milestones; to provide advice on coping with their children's difficulties; to enable parents to share experiences; and, to

be a source of mutual support. A baseline questionnaire was completed to determine how long the children had been waiting for therapy, and the extent of the children's difficulties. After the end of the facilitated sessions a follow-up questionnaire was completed. Parents understood more about and felt more able to cope with their children's difficulties. In addition, they utilized the sessions as a forum for mutual support. Lee also found that children benefited from improved speech during the waiting period. Although only a basic evaluation of such interventions, the results of this study suggest that low-cost interventions to address education and support needs during a waiting period may improve the experience of waiting for care.

Lindsay et al. (1997) studied 113 patients on a cardiac surgery wait list and 87 of their caregivers. Patients were mailed a questionnaire including a demographic profile, a subjective questionnaire, and the Needs Inventory for Patients Who Wait. The responses for patients and caregivers were highly correlated for both areas where they wanted more information ($r=0.84$) and areas that they were the most concerned about ($r=0.91$). Families were also concerned as to how they would support the person they were caring for after the surgery. These results were unaffected by the number of weeks that individuals had been on the wait list for surgery.

The limited number of studies pertaining to education and support needs of caregivers suggest that the provision of specific education and support initiatives may lead to an increase in the level of satisfaction with the waiting experience for caregivers.

2.4.3 Waiting for Long Term Care:

Meiland et al., (2001a,b) studied the effects on caregivers of individuals with dementia of deciding to apply for placement of the person they were caring for into Long-Term Care. While waiting for placement, 93 informal caregivers were interviewed and the files of the patients on the wait list were analyzed. The data collected included demographic characteristics (age, sex, education, occupation, ethnic group, marital status), the type and quality of the relationship with the person with dementia before the disease and at the time of the study, the severity of dementia (the Interview for Deterioration in Daily Living Activities in Dementia, and the Revised Memory and Behavior Problem Checklist), the Social Support Lists – Interaction, and three sub-scales of the Caregiver Reaction Assessment scale (Meiland et al., 2001a). The burden experience of those on the wait list was heterogeneous. Overall burden was assessed through the answer to the following question: “All things in the caregiving of the patient taken together, how burdened are you feeling at the moment?”. Overall, 9% of the informal caregivers rated themselves as not or hardly burdened, 41% as somewhat burdened, 31% as rather heavily burdened, and 20% as very heavily burdened. Considering that only one-quarter of the caregivers lived with the care receiver, this burden level was quite high. Further evidence of this was that more negative experiences were found when the dyad lived together and when more hours of informal care were provided. The fact that some caregivers were not or were hardly burdened may be an indication that some people are placed on wait list earlier in anticipation of a long wait, or that some people are placed on the wait list by a health professional and not the caregiver. However, this information was not collected in this study. This study is also subject to

selection bias because non-respondents may be more heavily burdened than respondents and the caregivers of the most urgent placements were not addressed in this study (Meiland et al., 2001a).

Wait lists may also have positive effects in that they allow families to prepare for the admission and comfort families in the knowledge that if something happens to the caregiver, the patient is under review and might be placed quickly. Wait lists also allow Long-Term Care centers to plan admissions. It is also important to note that there were positive effects of caring for someone with dementia. Caregivers with lower incomes and those who perceived that they had a better relationship with the individual with dementia experienced more self-esteem derived from caregiving than others in the study. Interestingly, a less severe stage of dementia was correlated with more negative experiences (Meiland et al., 2001a). Perhaps this may be because some behavioral problems tend to decrease in later stages (Haley and Pardo, 1989) or that caregivers may have become accustomed to living with a person with dementia and are better able to cope with its challenges (Meiland et al., 2001a). Another hypothesis is a greater proportion of caregivers who are able to cope with the disease are found to be continuing to care for an individual with dementia in the later stages of the disease.

In a follow-up Meiland et al. (2001b) interviewed caregivers six weeks after placement into Long-Term Care, or for those who were still waiting, an interview was conducted after six months of waiting for a space. For those caregivers whose care receiver had found a place in Long-Term Care, the burden of caregiving declined, but depressive symptoms had not. Those who were still waiting had a relatively stable level of burden and state of health while waiting. It could be concluded that although a decline

in health status and an increase in level of burden did not occur while waiting, it may have been possible to decrease the burden and improve the caregiver's mental health by providing a place in Long-Term Care earlier. This indicates that the negative effects of wait time may better be described as an "undesirable postponement of improvement resulting from admission to a nursing home" (Meiland et al., 2001b).

2.4.4 Summary

The review of the literature suggests that the level and type of burden experienced by caregivers waiting for placement of their care receiver in long-term care is heterogeneous. However, this burden is not obliterated by the eventual placement of this individual. The process of caregiving and the associated burden is expected to continue once placement has occurred.

2.5 Summary of Findings:

Wait lists span across the health care system. Their measurement and investigation are typically concerned with acute care services such as coronary or orthopedic surgeries. In a non-price environment, such as health care provision in Canada, wait lists are seen as a way of rationing scarce health resources. The methods for measuring this rationing through wait lists and waiting times are diverse. The act of waiting for a health procedure has been shown to impact morbidity and mortality of patients and the quality of life of both patients and caregivers. These effects have not been measured in the population of individuals waiting for community based health services, such as ADSPs. However, as Young and Turnock state " 'The hospital is full' is a more palpably

demanding alarm bell than ‘the community is full’ – but both need adequate capacity or mutual effectiveness” (Young and Turnock 2001). The proposed research study will begin to address these community based “alarm bells”.

CHAPTER 3: METHODS

3.1 Introduction:

A cross-sectional, retrospective survey of caregivers of individuals currently attending dementia-specific ADSPs was conducted. The analysis will allow for the testing of the proposed research model where the caregiver and care receiver characteristics, as well as the living situation and the degree of support available, affect the caregiver's experience of waiting (Appendix A). The relative strength of these associations will be examined.

3.2 Conceptual Framework and Definitions:

Caregiver burden refers to the “imbalance that exists between physical and mental resources to care for the recipient and those available within the family unit or community” (Hoffman & Mitchell, 1998). The increase in both physical and emotional demands placed on caregivers produce fatigue, stress, limited social contact, individual and group role adjustment, and altered self-esteem. It is not only the condition of the care recipient, but also the characteristics of the caregiving situation that have a direct relationship on the well being of the caregiver (Zarit, Reever & Back-Peterson, 1980). For this study, Zarit’s Appraisal of Primary Stressors (Zarit et al., 1997) was chosen to assess caregiver burden. This scale is a composite measure of secondary stressors in three domains: overload; worry and strain; and, role captivity. It is useful when research calls for a summary measure of the caregivers' appraisal of the impact their involvement in caring for a relative has had on their lives.

Depression may be an indicator of caregiver burden (Pruchno et al., 1990). However, depression can be any of a wide range of states from feeling sad, helpless, or demoralized to a major depressive episode (McDowell & Newell, 1996). The majority of the study participants are expected to be elderly. Since symptoms which are indicative of depression in young adults such as sleep disturbance, weight loss, and pessimism about the future may occur as normal effects of aging or due to physical illness in the elderly, a scale which does not rely on somatic symptoms is required. In this study, the criteria for a diagnosis of depression were not measured; rather, the presence of depressive symptoms was measured as a potentially confounding variable using the Short Form of the Geriatric Depression Scale (Yesavage et al., 1983).

Similarly, stress increases with caregiver burden (Rabin, Bresslet & Prager, 1993). The stress associated with major life events can also confound impact measures. Likewise, self-esteem is a possible confounder of the relationship under study (Hoffmann & Mitchell, 1998). Caregivers with high self-esteem may suffer less burden than those with low self-esteem. The severity of dementia in the care receiver directly affects the burden of the caregiver, and thus, could confound the relationship between ADSP use and caregiver burden.

3.3 Study Design:

This cross-sectional, retrospective study consists of a survey of caregivers of individuals who were currently attending dementia-specific ADSPs at the point of selection. In this study design, exposures and disease status are assessed simultaneously

in a defined population. This allows for a snapshot of the level of burden in the caregivers; however, a temporal relationship cannot be determined. In addition, there is no understanding as to what the level of burden was prior to attendance at the ADSP. Therefore, one can not infer that the caregiver burden status at the time of the questionnaire is secondary to the effect of attending an ADSP or to the duration of waiting time experienced. The presence of multiple confounders (e.g., caregiver characteristics, care receiver characteristics, access to other services, length of time since admission, the lack of an appropriate comparison group) affect the ability to draw causative inferences with regards to the level of caregiver burden.

3.4 Sample

A non-probability sample of convenience of self-identified caregivers was used for this study.

3.4.1 Target Population:

The target population for this study was caregivers of individuals with dementia attending dementia-specific ADSPs in the Calgary Health Region. These ADSPs include: Club 36 @ Ramsay (Alzheimer Society of Calgary), Club 36 @ Carewest Signal Pointe (Alzheimer Society of Calgary and Carewest), and Club 36 @ Bethany Harvest Hills (Alzheimer Society of Calgary and the Bethany Care Society). Caregivers were identified from participant records, where they self identified.

The Alzheimer Society of Calgary has offered Dementia-Specific ADSPs since 1986. These programs were designed to provide meaningful activities for individuals

with dementia while providing respite for their caregivers. They are referred to as Club 36, named after “The 36 Hour Day” (Mace and Rabbins, 1981), one of the first books written for caregivers of individuals with dementia. The philosophy of Club 36 is to provide activities that maximize independence while focusing on the strengths and abilities of participants. Activities that are meaningful to the person with dementia and fulfill basic personal needs such as inclusion, control, safety and affection are an essential aspect of the program. Examples of activities provided include community outings, gardening, woodworking, music and baking as well as individual hobbies. Family caregivers are encouraged to participate in various celebrations throughout the year, including pot-luck dinners and dances as well as an annual candlelight celebration.

3.4.2 Sample Size:

Ideally, a cross-sectional study of this nature would include responses from all individuals within the target population. However, due to the need for caregivers to voluntarily consent to complete the questionnaire, it was not possible to obtain complete data within this project. Several attempts were made to ensure as high a response rate as possible. All caregivers were contacted directly by the Director of ADSPs and invited to participate. This personal invitation was expected to increase the response rate. Additionally, all participants who agreed to participate in the study were sent two reminders: a thank you letter and reminder after two weeks; and, a second reminder containing an additional copy of the questionnaire to those who did not respond after four weeks.

In order to determine what sample size was sufficient to test the hypotheses regarding level of burden between different groups of caregivers, the following sample size calculation was completed. A previous study of caregiver burden in caregivers of individuals with dementia who were not receiving respite or other support services indicated a baseline score of approximately 22 out of a total 28 on Zarit's Appraisal of Primary Stressors (Overload Domain) with a standard deviation of 3.3 (Zarit et al., 1998). A difference of one standard deviation was hypothesized by the researchers to be a clinically significant difference between the two groups. A significance level 0.05 was chosen, with a power level of 80%. STATA's sample size calculator for the comparison of means (StataCorp, 2003) was used in order to obtain the sample size of 16 participants per group. The mean level of Overload was compared by the duration of waiting time for admission (< one month versus > one month), by living arrangement , by relationship to the care receiver, by gender, and by the severity of dementia in the care receiver. It was hoped that the final sample size would lead to groups of caregivers with at least 16 members per characterization; however, this could not be guaranteed due to the design of this study.

3.5 Measures:

Data was collected through the use of a self- administered questionnaire (Appendices D-N). The questionnaire was divided into the following sections:

- Section I: You, The Caregiver;
- Section II: The Person You are Caring For;
- Section III: Support Services You are Receiving;

- Section IV: The Experience of Waiting for an Adult Day Support Program;
- Section V: Feelings You May Have as a Caregiver;
- Section VI: Severity of Dementia in the Person You are Caring For;
- Section VII: Behaviors Commonly Observed in Individuals with Dementia;
- Section VIII: Further Comments.

The sections were constructed in a way to facilitate the flow of questions for the caregivers. The variables addressed were as follows:

The first and second sections (Appendix E) were used to gather demographic information about the caregiver and the care receiver. Data on age, sex, education level and marital status of the caregiver were gathered along with the caregiver's living arrangement with the person with dementia. The age and marital status of the care receiver was collected along with the date of diagnosis with dementia.

The third section (Appendix F) was used to determine the support services which the caregiver and care receiver were receiving. Attendance at caregiver support groups, frequency of attendance (if applicable), attendance at educational workshops or informational sessions (including frequency), the number of these sessions provided by the Alzheimer Society of Calgary, the use of telephone support (including frequency) and topics discussed as well as the use of informational handouts by the caregiver were determined through the use of simple check boxes. The use of Home Care services (including number of hours per week), the type of Home Care services (if applicable), the use of private in-home support (including frequency), the type of such support (if applicable), the use of respite services (including frequency), and the use of family support (including frequency) by the care receiver were also determined. Space to record

other services was available throughout this section in addition to the final question which asked if additional support services were received by the caregiver or care receiver. Participants were asked to mark all responses that reflected why they chose to use an ADSP (room for an open ended response was available) as well as the length of time the care receiver has attended an ADSP (recorded by site).

The fourth section (Appendix G) assessed the experience of waiting for an ADSP. Participants were asked how long they waited for a space in an ADSP, how long they expected to wait, as well as how long they think people should have to wait for a space in an ADSP. A check box was available if the respondents were unsure of the response to any of these questions. Caregivers were asked to indicate how waiting for an ADSP affected them by marking all responses that reflected their experience in a series of responses derived from the Alberta Medical Association Survey on Waiting Times (AMA, 1999). An opportunity for open ended responses was also provided.

The fifth section included the following survey instruments: Zarit's Appraisal of Primary Stressors (Appendix H), the Short Form of the Geriatric Depression Scale (Appendix I), the Global Assessment of Recent Stress Scale (Appendix J), and the Short form of Rosenberg's Self Esteem Scale (Appendix K). An additional question asking if attendance at an ADSP affected any of the above scales was included with room for open ended responses (Appendix J).

The sixth section assessed the severity of dementia in the care receiver through the use of Katz's Index of Independence in Activities of Daily Living (Appendix L Questions A-F) and Lawton's Instrumental Activities of Daily Living Scale (Appendix L

Questions G-M). The ADL and IADL scales were combined as one instrument in the questionnaire for formatting purposes, but were analyzed separately.

The seventh section consists of Kaufer et al's Neuropsychiatric Inventory Questionnaire (NPI-Q) (Appendix M) in order to measure the severity of behaviors commonly experienced by the individual with dementia, and the level of distress these behaviors cause their caregiver. It consists of twelve behaviors, which are rated as present or absent, and, if present, their severity and the level of distress experienced by the caregiver due to the presence of the symptom is rated. The format of the scale was changed slightly to improve readability (to accommodate increased font size) and maintain consistency of format in the questionnaire. The questions posed and possible responses remain unchanged. An additional question was added to this section to determine if the caregiver felt attendance at an ADSP had affected the progression of the care receiver's dementia.

The final section provided an opportunity for further comments and instructions for returning the questionnaire package.

3.6 Questionnaire Development:

The main outcome variable of interest is the perceived burden of the caregivers. This was assessed by Zarit's Appraisal of Primary Stressors (Appendix H) (Zarit et al., 1997). Other potentially confounding or effect modifying variables include sex of the caregiver, relationship of the caregiver to the care receiver, living arrangement of the caregiver and care receiver, current service use by the caregiver and/or the care receiver, depression, stress, and self-esteem of the caregiver, and severity of dementia in the care

receiver (proxy report). These potential confounders or effect modifiers were assessed with the instruments described in the following sections.

3.6.1 Sociodemographic Background and Current Service Use:

A brief socio-demographic questionnaire was used to determine the sex, age, education level, and marital status of the caregiver and the person with dementia as well as the caregiver's relationship and living arrangement with the person with dementia (Appendix E). A section also identified the current use of available services of the caregiver and of the person with dementia.

3.6.2 The Experience of Waiting:

This section (Appendix G) asked respondents to recall the number of days they waited for a space in an ADSP as well as the length of time they expected to wait for a space. The caregiver's perception of acceptable waiting time was also gathered. In addition, this portion of the questionnaire assessed the caregiver's perception of the effects of waiting on themselves and the person they are caring for. It is based on the waiting time survey used by the Alberta Medical Association (1999).

3.6.3 Primary Stressors :

Zarit's Appraisal of Primary Stressors (Zarit et al., 1997), a 17 item self-report inventory, was used to determine the level of perceived burden in the caregivers (Appendix H). There are three components to this scale: overload, worry and strain, and role captivity. Each component has been shown to have moderate to high internal consistency (Cronbach's alpha =0.74, 0.81, 0.82 respectively). The constructs are relatively stable over a period of three months to a year (stability correlation coefficients ranging from 0.63 to 0.74). Areas that are most frequently identified by caregivers as problematic are covered. The caregiver indicates the frequency that the statements have been true during the past month by choosing the most appropriate phase from "never" to "all of the time". To date, this scale has only been used in populations of caregivers of individuals with dementia (Jarrot et al., 1999, Zarit et al., 1998, and Gaugler et al., 2000).

3.6.4 Depression:

The Short Form of the Geriatric Depression Scale (Yesavage et al., 1983) was used to determine current level of depression in the caregiver (Appendix I). This scale is a self-reporting scale of fifteen depressive symptoms that was designed for use as a screening test for depression in the elderly. It does not rely on somatic symptoms since some of these may occur in the elderly as a normal part of aging. Scores of 0 to 4 are considered within the normal range, 5 to 9 indicate mild depression and 10 to 15 indicate moderate to severe depression. Yesavage et al. (ibid.) reported an alpha coefficient of 0.94 for the long form of the scale in a mixed sample of normal and depressed elderly

people indicating relatively high reliability. There is a correlation of 0.84 to 0.89 between the short and long forms of the scale (Sheikh & Yesavage, 1986 and Lesher & Berryhill, 1994). Several studies have compared the Geriatric Depression Scale to other depression scales and demonstrated moderate to high validity (McDowell & Newell, 1996 and Brink et al., 1982). The sensitivity and specificity of this scale have also been demonstrated to be high among cognitively intact elderly people (McDowell & Newell, 1996). This scale has also been shown to be reliable and valid within other age groups (*ibid.*).

3.6.5 Recent Stress:

The Global Assessment of Recent Stress Scale (Linn, 1985) was used in this study to provide a global rating of stress level. This scale consists of eight items. The first seven relate to particular areas in an individual's life, which may be perceived as stressful. The eighth item gives an overall rating of perceived stress (Appendix J). Each item is rated on a ten-point scale from "none" to "extreme". Test-retest correlations ranged from 0.69 to 0.92 for the eight items with a one-day interval (*ibid.*).

3.6.6 Self-Esteem:

Self-esteem was measured by 10 of the Rosenberg items used in epidemiological research by Pearlin et al (Pearlin & Schooler, 1978) (Appendix K). Each item is rated on a four-point scale from "strongly agree" to "strongly disagree".

3.6.7 Severity of Dementia:

As recommended by Cummings et al (2002), three tools were used to assess dementia severity. Katz's Index of Independence in Activities of Daily Living (ADL) (Katz et al., 1963) (Appendix L, Questions A-F) was used to measure the physical functioning of the care receiver. Six areas of daily living are rated on a three point scale with descriptions ranging from independent to totally dependant. Similarly, Lawton's Instrumental Activities of Daily Living Scale (IADL)(Lawton & Brody, 1969) (Appendix L, Questions G-M), which follows a three point rating scale was used to measure the level of independence in more complex activities of the care receiver. The ADL and IADL scales were combined as one instrument in the questionnaire for formatting purposes, but were analyzed separately. Additionally, Kaufer et al's Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer et al., 2000) (Appendix M) was used to measure the severity of behaviors commonly experienced by individuals with dementia, and the level of distress these behaviors cause their caregivers. It consists of twelve behaviors, which are rated as present or absent, and if present, the severity in the care receiver and the level of distress experienced by the caregiver due to the presence of the symptom are rated. These scales allow for a proxy evaluation without the direct involvement of the person with dementia.

3.7 Participant Recruitment:

Caregivers of individuals attending the above dementia-specific ADSPs were identified by the Director of Adult Day Support Programs at the Alzheimer Society of Calgary (study's research associate). The Director phoned each caregiver and invited

them to participate in the study. The Director explained the purpose of the questionnaires, the nature of voluntary participation, the limits of confidentiality, and the right to withdraw at any time to the interested caregivers. The fact that future health care services provided to caregivers or their care receiver would not be influenced by whether or not the caregiver participated in this study was explained in the initial phone call, and reiterated in the agreement to participate (Appendix O). In addition, the Director explained that the study was conducted under the auspices of the University of Calgary, not by the Alzheimer Society of Calgary or the Calgary Health Region.

3.8 Screening Procedure:

If the caregiver was interested in participating, a short eligibility questionnaire was administered by the Director of ADSPs - Alzheimer Society of Calgary. The inclusion and exclusion criteria can be found in Appendix P and the eligibility questionnaire is found in Appendix Q. All eligible, interested caregivers were mailed the questionnaire package (Appendices D-N, O and R). Between August 15, 2003 until September 30, 2003, there were 109 caregivers of individuals with dementia attending the Club 36 programs.

3.9 Data Collection:

On the day of first contact of the Director with the caregiver, a file containing eligibility assessment and demographics of the caregiver was created. The eligible caregivers were mailed a questionnaire package containing a letter explaining the study (Appendix O), instructions to fill out the questionnaire, and return it. The letter stated

that returning the questionnaire implied consent. Upon their receipt, these documents were immediately placed in the participant's file. The questionnaire package contained a card for the participant to send in if they were interested in a summary report of the results, or information about caring for someone with Alzheimer Disease or another form of dementia, and/or a follow-up call from the investigator (Appendix R). These response cards were returned in a separate self-addressed, stamped envelope in order to prevent linking the respondent with their questionnaires. All requests for information were honored as quickly as possible. A listing of the information provided about caring for someone with Alzheimer Disease or another form of dementia to interested participants can be found in Appendix S.

Questionnaires were numbered, but the name of the caregiver or the care recipient did not appear on the questionnaire. Participants were instructed that they could remove the identification number if they wished. This number was used to provide reminder notices, and/or to follow-up on the questionnaire if required. All participants received a reminder and thank you after two weeks (Appendix T). If after one month, a questionnaire was not returned, the Director contacted the participant with a letter reminding them to return their survey (Appendix U). This letter included another copy of the survey in the event that first one was lost. If individuals failed to return a completed survey after receiving the second reminder, they were considered to have refused to participate and no further efforts were made to contact them.

3.10 Data Handling:

The completed questionnaires were stored in a locked cabinet, accessible only by the research associate and principal investigator. Names were not included in the data set, so that it was not possible to identify individual caregivers. A nominal list with the questionnaire number and the name of the caregiver was maintained in a secure location separate from the completed questionnaires. The research associate entered the results of the questionnaires into an Access database on a non-networked microcomputer located at the Alzheimer Society of Calgary. The computer and Access file were password protected with passwords known only to the primary investigator and the research associate. Both the paper and electronic copies of the data will be destroyed three years after the study's completion date.

3.10.1 Data Entry and Cleaning:

An Access 2002 database was created which included tables to store data, as well as forms to facilitate data entry. In order to control data entry, acceptable values and ranges as well data types (numerical, string, binary, text etc.) were indicated for each variable. Non-responses were universally coded as -9. The data for the background and service use questionnaires were entered as categorical or continuous variables where appropriate. The data was then transformed to provide a total or item specific profile score on a given scale. The data was then transferred to and transformed within STATA SE (StataCorp, 2003) to create categorical variables and summary results for scales based on established cut-points or medians as discussed below.

3.10.2 Data Quality:

The quality of the data being processed was assured by double entry directly from the original questionnaires into separate database tables. The two tables were compared through a simple method of subtracting the duplicate data points. If non-zero numbers were obtained, then a discrepancy existed. Any found discrepancies prompted a closer examination of the hard copies of the questionnaires.

The presence of outliers was assessed through the use of frequency distributions, histograms, scatter plots, and Box and Whisker plots. Outliers were identified and the hard copy of the questionnaire was consulted to determine if a transcription error had occurred.

3.10.3 Missing Data:

For returned surveys, areas with missing data that required re-testing or clarification were identified. Respondents who indicated that they would participate in a follow up interview were contacted for clarification of questions of fact (i.e. not psychological measures or scales).

Individuals who entered a non-numerical response for question 26, 27 or 28 in Section IV were entered as unsure with the exception of those who indicated a response of “as soon as possible” which was entered as 0. The qualitative responses to these questions were studied separately. The responses of individuals who indicated a range as a response (i.e. 8-20 days) for questions 26-28 were entered as the mean of the range.

Frequency distributions were created for each survey item. If more than 25% of caregivers did not respond to a question, it was excluded from analysis as suggested by

Aday et al. (1996) and Downey and King (1998); however, this did not occur. In the case of missing values in multiple-item Likert scales it is thought that fewer biases are introduced by estimating reasonable values, than by excluding them (Downey and King, 1998 and German, 1994); however, if more than 25% of the items on a scale were missing, then the total score for that scale was entered as missing. Results of complete scales were compared with those of missing values and those with imputed scales (Personal Mean Imputation). The Likert scales used in this study included: Zarit's Perceived Primary Stressors; Global Assessment of Recent Stress; Rosenberg's Self Esteem; and the NPI-Q. The three approaches were compared to compensate for missing values. Personal Mean Imputation was chosen as no significant differences were found between the methods for all of the above scales. As an example, a comparison of the values obtained with each approach is found in Table 3.1 for the Overload Domain of Zarit's Primary Stressors.

Table 3.1: Comparison of Methods Addressing Missing Values for the Overload**Domain of Zarit's Perceived Primary Stressors.**

Method	Number of Surveys	Mean – Overload Domain	Standard Deviation
Surveys with complete responses	57	18.58	3.27
Surveys with missing values not imputed	63	18.16	3.59
Surveys with Personal Mean Imputation	63	18.57	3.39

3.10.4 Data Transformation and Scale Construction:

When data was transferred from Access 2002 to Stata SE, binary responses of true and false were globally changed to 1 and 0 respectively to assist with analysis. Four items (A, B, C and G) in Zarit's Appraisal of Primary Stressors were reverse coded using a simple algorithm of taking the absolute value of the response minus five. The same transformation was used for items C, E, H, I and J of the Rosenberg Self Esteem Scale. Algebraic conventions were used to create summary scales as indicated in Table 3.2.

Table 3.2: Construction of Summary Scales

Scale	Scale Construction	Possible Range
Zarit's Appraisal of Primary Stressors		
Overload	Sum of items 30A-G	7-28
Worry and Strain	Sum of items 30F-N	7-28
Role Captivity	Sum of items 30O-Q	3-12
Overall Measure	Sum of items 30A-Q	17-68
Geriatric Depression Scale	31 A-O, One point scored for answering YES: B, C, D, F, H, I, J, L, N, O NO: A, E, G, K, M Sum of total points	0-15
Global Assessment of Recent Stress	32 A-H Mean of values 32A-H, minus 1	0-9
Activities of Daily Living	Sum of the number of items 32 A-F indicated as dependent	0-6
Independent Activities of Daily Living	Sum of the number of items 32 G-M indicated as dependent	0-7
NPI-Q		
Severity	Sum of severity score for items 36-47	0-36
Caregiver Distress	Sum of distress score for items 36-47	0-60

3.10.5 Recoded Variables

Various demographic variables were recoded to simplify analysis. These included caregiver and care receiver year of birth, marital status of the caregiver and care receiver, caregiver/care receiver relationship, and the care receiver's date of diagnosis.

Question 1 asked for the year of birth of the respondent and question 6 asked the same of the care receiver. These responses were recoded to age by subtracting the response from 2003. Ages were further divided into the categorical age groups for non-parametric analyses. The age ranges for these groups were determined based on quartiles of each sample, combined with established cut points to maximize the number of individuals in each group without compromising detail. Caregivers' ages were categorized as: <55 years; 56-65 years; 66-75 years; and >75 years, while care receivers' ages were categorized as: <70 years, 71-75 years; 76-80 years and >80 years. The marital status of the caregivers and care receivers was recoded into categorical variables where 0=married and 1=other. The caregiver/care receiver relationship was recoded into three categories (spouse, child or other).

Question 8 asked when (month and year) the care receiver was diagnosed with Alzheimer Disease or dementia (if applicable). The number of months since diagnosis was calculated by subtracting this date from September 2003. The number of months since diagnosis was positively skewed (Figure 3.1); therefore, a natural logarithm transformation was undertaken. After transformation, the results more closely approximated a normal distribution (Figure 3.2 and Figure 3.3).

Figure 3.1: Distribution of Months Since Diagnosis

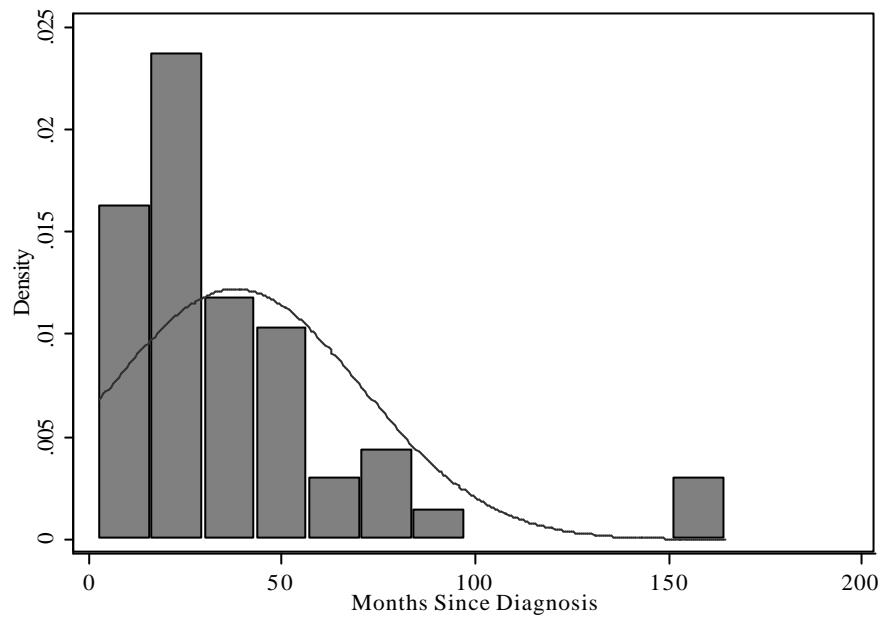


Figure 3.2: Distribution of Natural Logarithm of Months since Diagnosis

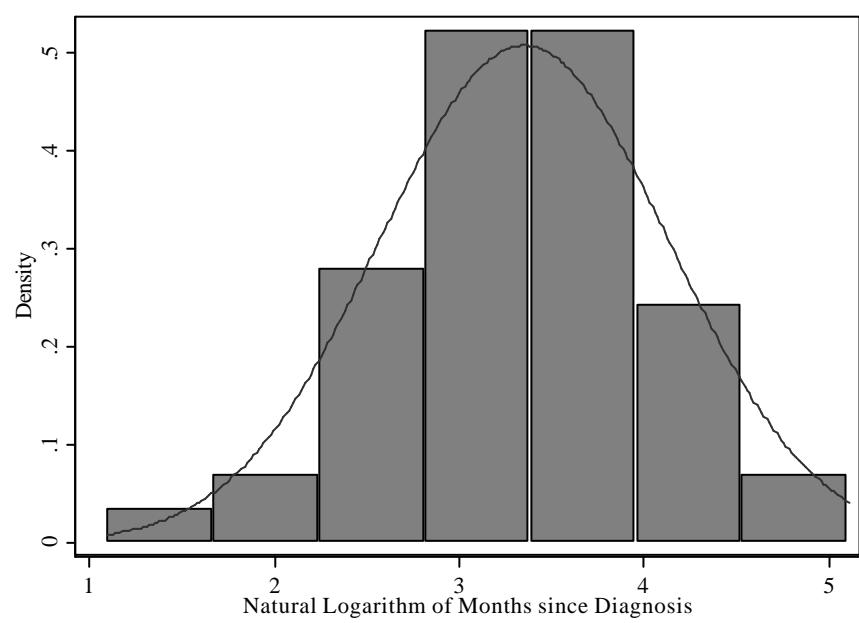
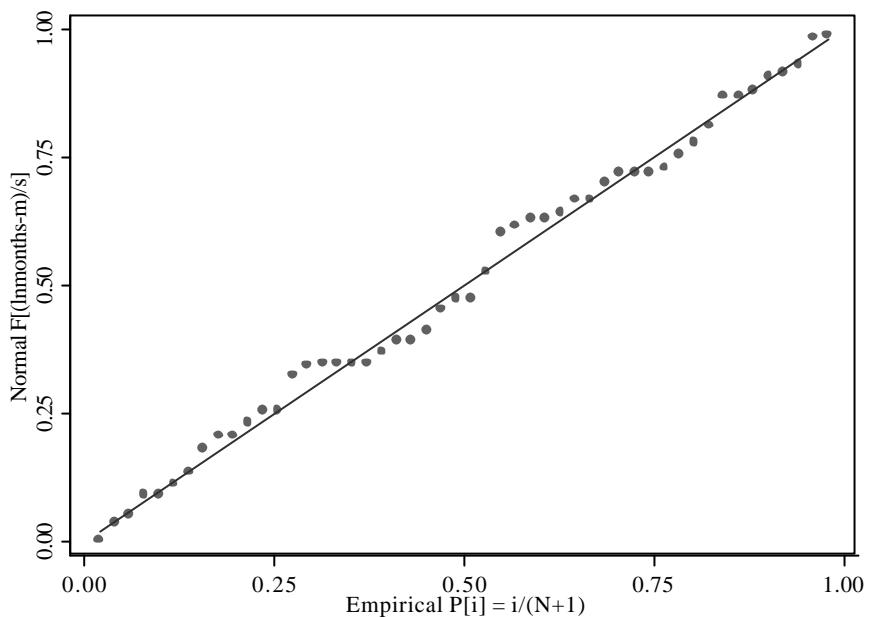


Figure 3.3: Normal Probability Plot of Logarithm of Months since Diagnosis



A new variable was created to reflect the scoring on the Geriatric Depression Scale. Individuals who scored 0-4 were coded as normal, 5-9 as mild depression and 10-15 as screening for moderate to severe depression (Yesavage et al., 1983). This variable was further categorized into a binary variable indicating the presence or absence of the symptoms of depression (presence = score = 5 on the Geriatric Depression Scale).

The use of support services assessed in Section III were further categorized to simplify analysis. Binary variables were created to describe the use of information services, handouts, support services and respite services. Individuals were coded as using information services if they attended information sessions (Question 12) or received telephone support (Question 14). Respondents were considered to have used handouts if they responded with the third option to question 16 (Yes, I have read and understood

them). Caregivers were considered to be users of support if they attended a caregiver support group (Question 10, past or present) and/or received support from family or friends. The use of companion care (Question 18 or 20), or Long Term Care respite (Question 21) were considered to be respite services, above the use of ADSP services.

The total length of time using ADSP services was calculated by taking the larger of the responses found within question 24. For example if an individual attended Club 36 @ Signal Pointe for 12 months, and another ADSP concurrently for 6 months, then the total length of time using ADSP services would be 12 months. The total length of time utilizing ADSP services was categorized into five levels for further analysis: = 3 months; 4-6 months; 7-12 months; 13-24 months; and, >24 months.

Due to the manner in which respondents answered questions 26, 27 and 28 about their perceived, expected and acceptable waiting times, the median responses were equivalent, even though the ranges were quite different. Therefore, these variables were recoded into categorical variables of waiting times less than or equal to 30 days or greater than 30 days.

There was room given for open-ended responses for questions 23, 25, 29, 34 and 49. These responses were coded using the Grounded Theory Approach described in Bernard (2000, pg 443-456). Themes were coded with the use of a code book developed for each question. The number and types of codes are discussed in Chapter 4: Results.

3.11 Data Analysis:

All statistical analysis was completed using STATA SE, a comprehensive statistical package (StataCorp, 2003). The statistical analysis had nine major components:

1. Response rates and requests for further information were studied using frequencies.
2. Descriptive statistics were produced using means, medians, and frequencies for each of the hypothesized outcome and possible confounding or effect modifying variables in each of the caregiver groups.
3. Reasons for ADSP use were assessed using summary statistics.
4. The median perceived, expected and acceptable waiting times and ranges for those currently attending programs were calculated.
5. The perceived benefits and drawbacks of waiting for a space in an ADSP were assessed using summary statistics.
6. Primary stressors were assessed by mean and standard deviation. There is currently no established cut point for the presence or absence of Perceived Primary Stressors in an individual.
7. Predictors of primary stressors were explored. The hypothesized relationships between caregiver burden and duration of time waiting for admission (< 1 month, > 1 month), living arrangement, relationship type, gender and severity of dementia were assessed. These relationships were assessed by either two-sample t-tests or simple linear regression analysis, depending on the continuous or categorical nature of the variables. These results are used to reinforce the theories presented in the conceptual framework. Due to the impact of multiple-significance testing, Bonferroni corrections were employed.
8. Multiple linear regression was used to assess the simultaneous effect of caregiver and care receiver characteristics on primary stressors.

9. The impact of ADSP services for caregivers and care receivers was studied through the use of tables.

3.12 Ethical Considerations:

Because the research instruments used included areas of inquiry dealing with that included mental health concerns, it was imperative that any problem that required intervention be shared with the participant. For example, participants who were found to have significant symptoms of depression (i.e. GDS score > 10 - Moderate to Severe Depression) were contacted by the research associate, and with the caregiver's permission, referred to the participant's family physician and/or the principal investigator. If the participant did not have a family physician, a list of physicians accepting new patients and other available resources (e.g. Canadian Mental Health Association) were made available.

Participation in this research project was entirely voluntary and based upon informed consent (Appendix O). Participants who withdrew their consent would have their records removed from the study and returned to the participant or destroyed. Not including participant names on computer or hard copy files, through locked storage, and reporting in aggregate form, helped to ensure confidentiality. This study did not involve invasive procedures or purposes hidden from the participants. Ethical approval by the Conjoint Health Research Ethics Board of the University of Calgary was obtained before initiation of the study. A copy of these approval letters can be found in Appendices V, W, X, and Y.

CHAPTER 4: RESULTS

The results of the retrospective caregiver survey are presented in this section.

Following a section on response rates, a detailed description of the sample is provided.

The burden of caregiving is explored using t-tests and multivariate regression.

4.1 Response Rates:

At the initiation of this study, August 15, 2003, 95 individuals were enrolled in dementia-specific ADSPs run by the Alzheimer Society of Calgary and an additional 8 individuals enrolled into these programs during the study's recruitment period (August 15, 2003 – September 30, 2003). There were a total of 109 caregivers for these individuals with dementia, seventy-eight (71.6%) of whom agreed to participate in the study. Of the caregivers who did not participate in the study, seventeen (54.8%) were ineligible, seven (22.6%) refused to participate and seven (22.6%) could not be contacted by the researcher. A summary of the reasons for not participating in the study is presented in Table 4.1.

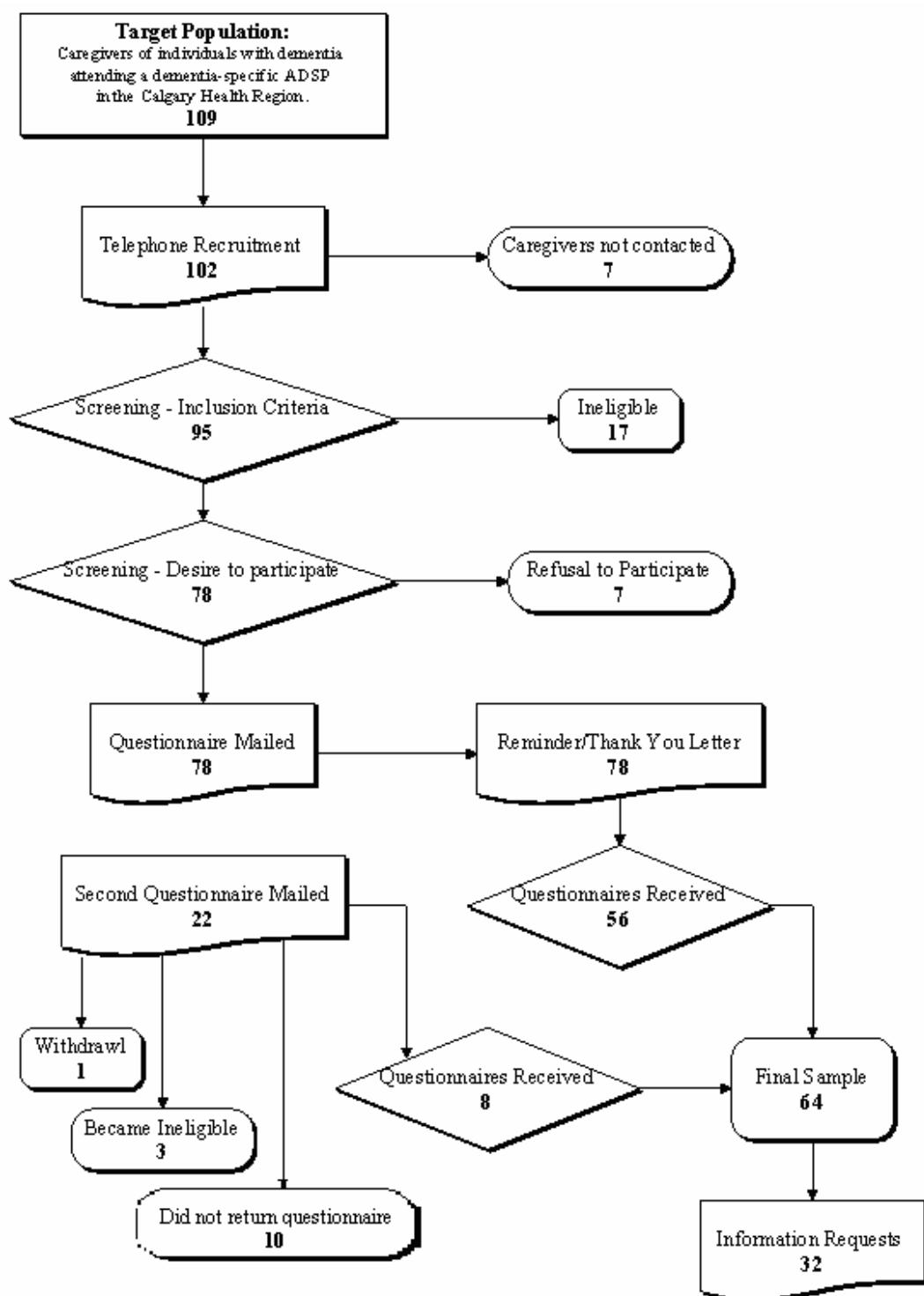
Of the 78 caregiver who agreed to participate in the study, three became ineligible, one withdrew from the study, and ten caregivers did not return their questionnaires after receipt of the two reminders and one additional questionnaire (Table 4.2). A chart describing the flow of caregiver recruitment, and eventual participation is found in Figure 4.1. Although there was the possibility of more than one caregiver for a particular individual with dementia enrolling in the study, this scenario did not materialize in the final sample.

Table 4.1: Caregiver Reason for not Participating in Study

Reason for Not Participating	Number of Observations	Frequency
Ineligible	17	54.8%
Participant not currently attending the ADSP	11	35.5%
Participant illness	2	6.5%
Caregiver illness	3	9.7%
Caregiver language barrier	1	3.2%
Refusal	7	22.6%
Caregiver not contacted	7	22.6%
Total	31	100%

Table 4.2: Reason for Discharge from Study

Reason for Not Participating	Number of Observations	Frequency
Participant discharged from program	1	7.1%
Participant illness	1	7.1%
Caregiver illness	1	7.1%
Caregiver withdrawal - other	1	7.1%
Did not return questionnaire	10	71.4%
Total	14	100%

Figure 4.1: Recruitment of Participants

4.1.1 Requests for Further Information:

Caregivers who participated in the study were sent a results request form (Appendix R) as part of the questionnaire package. This form provided an opportunity for participants to request further information about Alzheimer disease and other dementias, to receive a summary of the study results; and, to indicate if they were available for follow-up questions from the questionnaire. Of the 49 results request forms returned, 32 were interested in an information package, 44 were interested in a summary of the results and 47 were available for a follow-up discussion.

4.2 Description of the Sample:

The final sample consisted of 64 caregivers of individuals who attended the Club 36 dementia-specific ADSPs run by the Alzheimer Society of Calgary during the recruitment period (August 15, 2003 – September 30, 2003). There was a higher proportion of female participants compared to males (62.5% versus 37.5%). The age of respondents ranged from 32 to 86 years, with a mean of about 65 years. No significant difference in the mean age of the two sexes was found ($p=0.105$); however, there was a borderline trend for male respondents to be older (68.7 years versus 62.7 years). The sample was well educated, with only 10 individuals having failed to complete high school. The majority (87.5%) of the sample was married. Please see table 4.3 for further information on the sample.

Table 4.3: Sex, Level of Education and Marital Status of the Caregiver Sample

Variable	Number of Observations	Frequency (%)
Sex		
Male	24	37.5
Female	40	62.5
Total	64	100
Level of Education		
Some Elementary School	4	6.3
Some High School	6	9.4
High School Graduate	6	9.4
Some Commercial College or Technical School	21	32.8
Some University	8	12.5
University Graduate	13	20.3
Post Graduate Studies	6	9.4
Total	64	100
Marital Status		
Single (never married)	0	0
Married	56	87.5
Divorced/separated	4	6.3
Living common-law with partner	0	0
Widowed	3	4.7
Missing Data	1	1.5
Total	64	100

4.3 Description of Care Receivers:

The mean age of the care receivers was 77.4 years (standard deviation = 7.97 years, range of 48-91 years). This was statistically different from the caregivers' mean age ($p<0.0001$). Two care receivers had not yet received a diagnosis of Alzheimer

disease or dementia. Of the rest, only 50 caregivers could remember when the diagnosis was received. The mean length of time (geometric) that the care receivers had been living with a diagnosis of Alzheimer disease or dementia was 28.5 months (about 2.4 years). Sixty-five percent of the care receivers were married, and 25% were widowed. Table 4.4 contains additional information regarding the marital status of care receivers.

Table 4.4: Marital Status of the Care Receiver

Variable	Number of Observations	Frequency
Marital Status		
Single (never married)	3	4.7%
Married	42	65.6%
Divorced/separated	3	4.7%
Living common-law with partner	0	0
Widowed	16	25%
Total	64	100%

Most caregivers were either married to the care receiver (59.4%) or were the children of the care receivers (31.3%) (Table 4.5). The majority (79.7%) of the caregivers lived with the individual who they were caring for (Table 4.5). All of the 38 caregivers in spousal relationships lived with the individual with dementia, and 11 of the 20 children (55%) lived with the care receiver (Table 4.6). Fifty percent of the other caregivers lived together with the care receiver.

Table 4.5: Relationship and Living Arrangement of Caregivers and Care Receivers

Variable	Number of Observations	Frequency
Relationship to Person with Dementia		
Spouse	38	59.4%
Common-law partner	0	0
Child	20	31.3%
Parent	0	0
Sibling	2	3.1%
Friend	2	3.1%
Other	2	3.1%
Total	64	100%
Living Arrangement		
Live together	51	79.7%
Live apart	11	17.2%
Other	2	3.1%
Total	64	100%

Table 4.6: Cross-tabulation of Relationship and Living Arrangement

Relationship	Live Together	Live Apart	Total
Spouse	38	0	38
Child	11	9	20
Other	2	2	4
Total	51	11	62

4.4 The Use of Community Services:

The use of community services by the caregiver and care receiver were assessed in Section III of the survey; the results are presented below.

4.4.1 Information and Support Services:

A greater percentage of caregivers used passive resources, such as informational handouts (read and understood: 84.4%), than educational workshops and information sessions (35.9%), support groups (present: 12.5%, past: 23.4%) and telephone support (48.4%) to gain information and obtain support while caring for someone with dementia (Table 4.7). The most popular areas of discussion of those who received telephone support were disease information (72.0%), accessing a day program (67.7%), the Wandering Registry (45.2%) and information on medications (32.3%) (Table 4.8).

Table 4.7: Use of Community Information and Support Services:

Current Information and Support Service	Number of Observations	Frequency
Support Groups – currently attend	8	12.5%
Support Groups – attended in the past	15	23.4%
Support Groups – ever attended	23	36.0%
Educational Workshops and Information Sessions	23	35.9%
Telephone Support	31	48.4%
Informational Handouts – read and understood	54	84.4%
Informational Handouts –not read or understood	5	7.8%
Total	64	100%

Table 4.8: Frequency of Telephone Support Topics

Topic	Number of Observations	Frequency
Alzheimer Disease or Dementia	22	72.0%
Medications	10	32.3%
Information on Housing Options	4	12.9%
Legal Issues	5	16.1%
Financial Issues	4	12.9%
The Wandering Registry	14	45.2%
Finding a Physician	1	3.2%
Accessing a Day Program	21	67.7%
Accessing Home Care Services	7	22.6%
Accessing Respite	8	25.8%
Placement in a Long Term Care Centre	2	6.5%
Driving Issues	3	9.7%
Total	31	100%

4.4.2 Use of Available Community Support Services:

Support services available in the community range from home care services (both private and publicly funded), respite services, help from family and friends, and the use of other services provided by community agencies.

Although all of the ADSP participants included in this study were required to be Home Care clients and the ADSP program is funded through Home Care, only 79.7% of caregivers indicated that the person they were caring for received Home Care services (Table 4.9). Furthermore, all participants of the dementia-specific ADSPs in the CHR must be referred to the program by a Home Care Coordinator who assessed the participant. Nonetheless, only 14 caregivers (21.9%) indicated that the person they are

caring for attends an ADSP through Home Care (Table 4.9). Similarly, only 20 caregivers (31.3%) indicated that they received professional consultation services though Home Care. Twenty-seven individuals (42.9%) received personal care services through Home Care and 8 individuals (12.5%) through private in-home support (Table 4.9).

Table 4.9: Use of Home Care and Private In-Home Support

Service	Home Care		Private In-Home Support	
	Number of Observations	Frequency	Number of Observations	Frequency
Professional Services	20	31.3%	N/A	N/A
Companion Care	23	35.9%	8	12.5%
Personal Care	27	42.9%	8	12.5%
Housekeeping	7	10.9%	6	9.4%
ADSP	14	21.9%	N/A	N/A
Overnight Respite Care	2	3.1%	N/A	N/A
Other	4	6.3%	2	3.1%
Total	51	79.7%	13	20.3%

Participants and caregivers received a mean of 8.41 hours per week of Home Care services, and 5.23 hours per week of help from family and friends. The use of private in-home support services was positively skewed by two individuals who have purchased 24 hour care for the individual they are caring for. If these two individuals are not considered, the mean amount of private in-home services is 6 hours per week (Standard Deviation = 4.72). Of the individuals who had used Long Term Care respite services, the mean number of admissions (to date, while living in the community) was 2.6 (Standard Deviation = 1.88) (Table 4.10).

Table 4.10: Amount of Home Care and Private In-Home Support Services Used

Service	Number of Observations	Mean	Standard Deviation	Range
Home Care	41	8.41 (hrs/wk)	9.24	0.25-40
Private In-Home Support	10	38.4 (hrs/wk)	68.43	1-168
Private In-Home Support (no 24 hour care)	8	6	4.72	1-14
Long Term Care Respite	15	2.6 (times)	1.88	1-7
Family and Friends	25	5.23 (hrs/wk)	4.29	0.75-20

Respite is the “provision of short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs” (Kagan J, 2001). There are many respite options available to caregivers of individuals with dementia living in the CHR, such as: companion services; help through family and friends, long term care respite; and, ADSPs. Companion care was provided to 23 individuals (35.9%) through Home Care and 8 individuals through private in-home support (12.5%). Caregivers also received respite and support through families and friends (64.1%), short term use of Long Term Care centers (23.4%) and by purchasing services through private in-home support agencies (20.3%). There was evidence of misclassification bias with regards to the use of ADSPs.

Of the caregivers who indicated the use of other support services, four individuals indicated that they used Meal on Wheels services; one caregiver cited the use of Access Calgary (Handi-Bus) services; and, two indicated the use of help with supervision of medications. The remainder of the responses were ones which were previously dealt with

in the survey (i.e. Housekeeping, Home Care, personal care, companion care, help from family and friends).

Table 4.11: Use of Other Community Support Services

Other Support Services	Number of Observations	Frequency
Meals on Wheels	4	6.3%
Access Calgary	1	1.6%
Medication Supervision	2	3.1%
Professional Support	2	3.1%
Home Care	4	6.3%
Personal Care	4	6.3%
Companion Care	5	7.8%
Housekeeping Services	1	1.6%
Support of Family and Friends	3	3.1%
Total	18	28.1%

4.5 The Use of Adult Day Support Programs:

This section outlines the reasons for use and the length of use of ADSPs as indicated by the survey respondents.

4.5.1 Reasons for ADSP Use:

ADSP services were recommended to caregivers by Home Care Coordinators (n=41, 65.1%), physicians (n=24, 38.1%), and others (n=24, 38.1%). Caregivers used ADSP services to obtain a break from caregiving (n= 49, 77.8%). They also believe the care receivers benefit by getting opportunities to meet other people (n=49, 77.8%) to

have something to do (n=48, 76.2%) and to obtain support (n=33, 52.4%). Very few caregivers use ADSP services to monitor the health of the care receiver (n=6, 9.5%) or to obtain bathing services (n=5, 7.9%).

4.5.2 Length of ADSP Use:

The mean length of time a care receiver attended the different ADSPs is broken down in Table 4.12. The average length of ADSP use of all ADSPs combined was 12.60 months.

Table 4.12: Length of ADSP Use

Program	N	Mean	Standard Deviation	Range
Program A	37	12.21	12.68	1-48
Program B	24	12.29	8.25	2-36
Program C	13	6.86	6.71	1-24
Other ADSP	6	12.67	9.67	2-24
Total	62	12.60	11.21	1-48

4.6 The Experience of Waiting for ADSP Services:

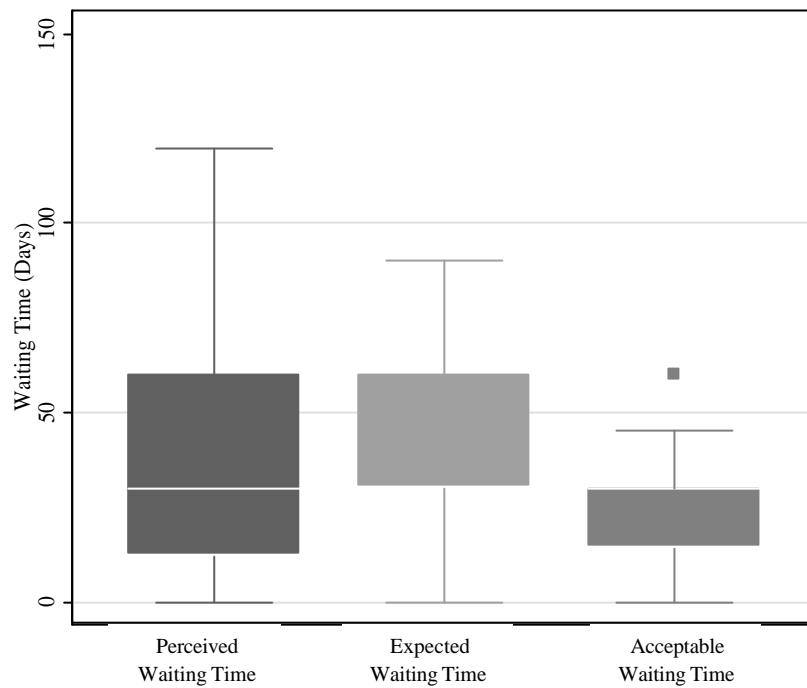
This section examines the perceived, expected and acceptable waiting times for ADSP services, along with the effects of these waiting times on caregivers and individuals with dementia.

4.6.1 Waiting Times:

Caregivers were asked how long they waited for admission to an ADSP, how long they had expected to wait and how long they thought people should have to wait for admission into an ADSP. These survey items were used to measure perceived, expected and acceptable waiting times, respectively. The distributions of these waiting times were highly skewed, and did not respond well to transformation (Figure 4.2). Therefore, these waiting times were categorized as either less than or equal to 30 days, or more than 30 days. The median and mode of all of the waiting times were all equal to 30 days (Table 4.13). One outlier of a perceived waiting time of 1095 days (3 years) existed. If this result was not considered, the range of perceived waiting times was found to be 0-120 days. The proportion of individuals who considered an acceptable waiting time to be more than 30 days was significantly less than the proportion with perceived waiting times ($p=0.0039$) or expected waiting times ($p=0.0029$) of greater than 30 days. There was no significant difference between the perceived and expected waiting times ($p=0.5824$).

Table 4.13: Perceived, Expected and Acceptable Waiting Times for ADSP Services

Waiting Time	N	Median	Range	Proportion >30 days
Perceived Waiting Time (days)	33	30	0-1095	45.5%
Expected Waiting Time (days)	27	30	0-90	48.5%
Acceptable Waiting Time (days)	37	30	0-60	16.2%

Figure 4.2: Comparison of Perceived, Expected and Acceptable Waiting Times**Table 4.14: Proportion of those Unsure of Waiting Times**

Waiting Time	Number of Observations	Percentage
Perceived Waiting Time (days)	30	46.88%
Expected Waiting Time (days)	36	56.25%
Acceptable Waiting Time (days)	25	39.06%

Respondents were given the option of indicating that they were unsure of the time they spent waiting for services. There were no respondents who indicated that they were unsure, yet filled in the number of days waited. The number of individuals who were

unsure of waiting times, presented in Table 4.14, shows that fewer respondents were unsure of an acceptable waiting time than their expected waiting time. This may in part be due to difficulties in recall in this population.

4.6.2 Experience of Waiting for an ADSP:

Caregivers were asked how waiting for a space in an ADSP affected them. The majority of caregivers understood why they needed to wait (69.5%); however, 27.1% were unsure which program the care receiver would be attending. Twenty-five percent indicated that while waiting for ADSP services their stress level increased but only 2 caregivers (3.4%) indicated that they became depressed while waiting. Twenty-seven percent felt that the waiting period allowed time to adapt to the fact that they would be utilizing ADSP services. Ten caregivers (17%) were upset that they had to wait for services, while twenty-one caregivers (33.9%) felt that waiting for services had no impact on themselves or their families (Table 4.15).

4.7 The Experience of Caring for an Individual with Dementia:

The results of the four caregiver rating scales are found in this section. A summary of the results is found in Table 4.16 and discussed below.

Table 4.15: The Experience of Waiting for an ADSP

Experience	Number of Observations	Frequency
Caregiver was upset that they needed to wait	10	17.0%
Caregiver understood why they needed to wait	41	69.5%
Allowed caregiver time to adapt to ADSP use	16	27.1%
Caregiver unsure which program would be attended	16	27.1%
Increased caregiver's stress level	15	25.4%
Caregiver became depressed while waiting	2	3.4%
Decreased caregiver's health level	2	3.4%
Caregiver could not work while waiting	0	0
Decrease in care receiver's health level	3	5.1%
Required paid support while waiting	4	6.8%
No impact on caregiver or family	21	33.9%
Total	59	100%

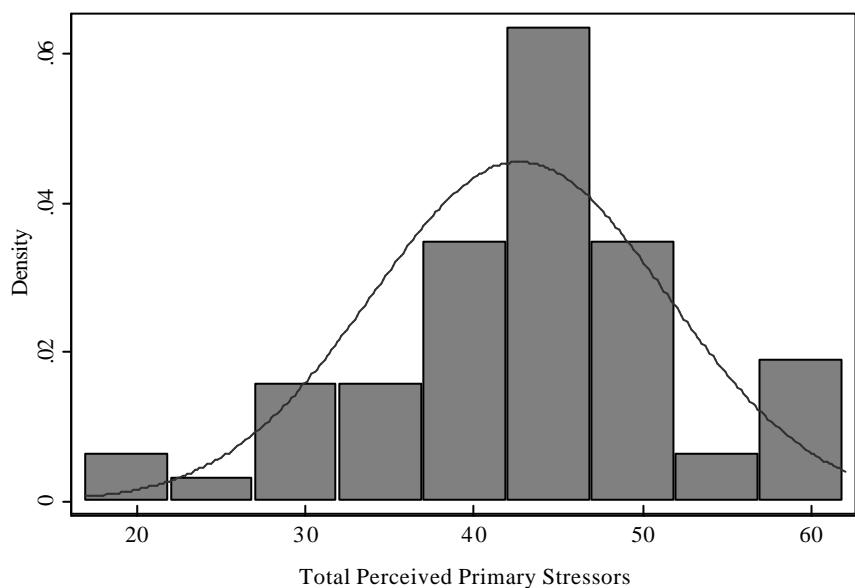
Table 4.16: Mean Scores on the Caregiver Rating Scales

Measure	Number of Observations	Mean	Standard Deviation	Range
Perceived Primary Stressors				
Overload	63	18.57	3.39	10-26
Worry	62	18.03	4.37	7-26
Captivity	63	6.42	2.71	3-12
Total	63	42.72	8.77	20-62
Geriatric Depression Scale	63	4.44	3.61	0-14
Global Assessment of Recent Stress	63	2.72	1.97	0-8.5
Rosenberg's Self Esteem Scale	63	3.24	0.41	2.2-4

4.7.1 Perceived Primary Stressors:

The mean total score on Zarit's Perceived Primary Stressors scale was 42.72 (Standard Deviation = 8.77). The scores were approximately normally distributed, with most clustering around the mean (Figure 4.3). Similar scores were found on the overload and worry components: 18.57 (Standard Deviation = 3.39) and 18.03 (Standard Deviation = 4.37), respectively. A mean score of 6.42 (Standard Deviation = 2.71) was found on the captivity domain (Table 4.16).

Figure 4.3: Distribution of Perceived Primary Stressor Scores



4.7.2 Geriatric Depression Scale:

The distribution of the Geriatric Depression Scale scores was positively skewed (Figure 4.4), with a mean of 4.44 (Standard Deviation = 3.61). Due to the non-normal distribution, and the pre-existence of established cut-off points, the decision was made to

categorize the data, as found in Table 4.17. On examination of the categorized data, it was discovered that just over half (55.56%) of the sample screened as normal, 34.92% screened as mildly depressed and 6 individuals (9.52%) screened as moderately to severely depressed.

Figure 4.4: Distribution of Geriatric Depression Scale Scores

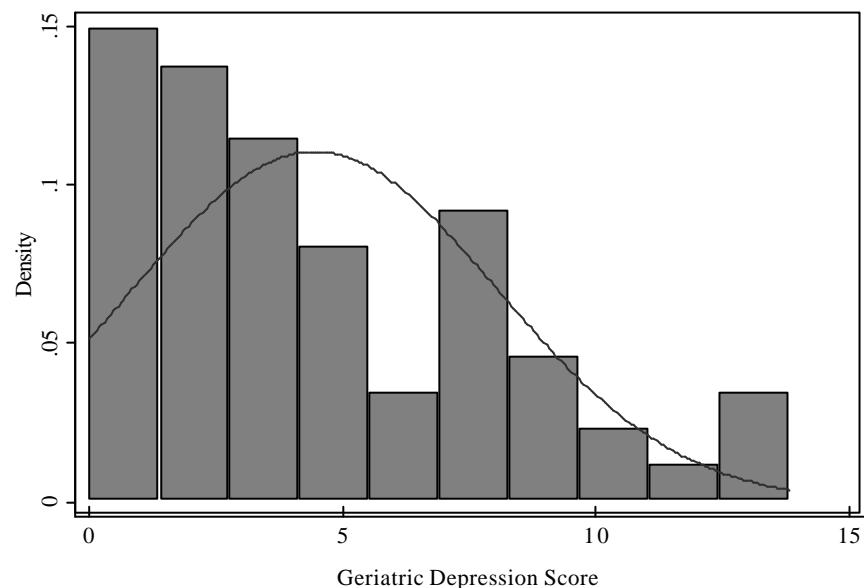


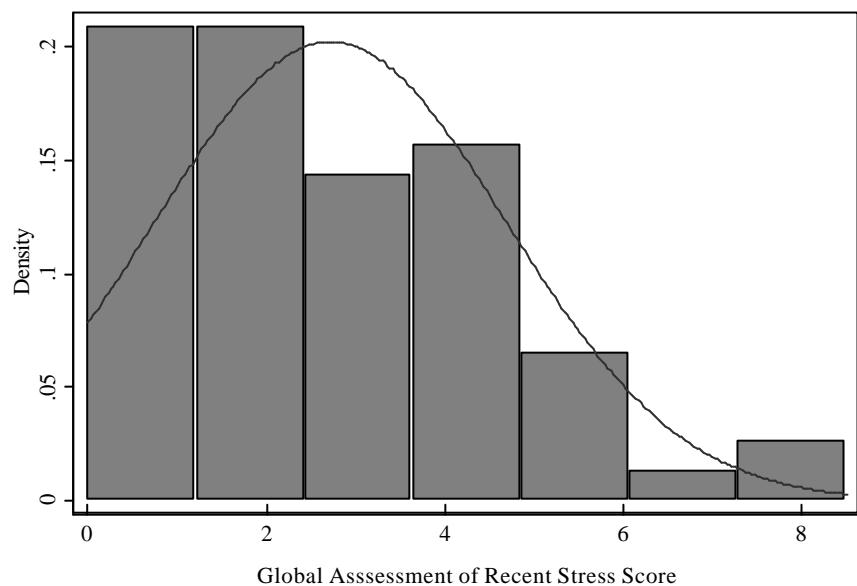
Table 4.17: Categorization of the Geriatric Depression Scale

Geriatric Depression Rating	Number of Observations	Frequency
Normal (0-4)	35	55.6%
Mildly Depressed (5-9)	22	34.9%
Moderate to Severely Depressed (10-15)	6	9.5%
Total	63	100%

4.7.3 Caregiver Stress:

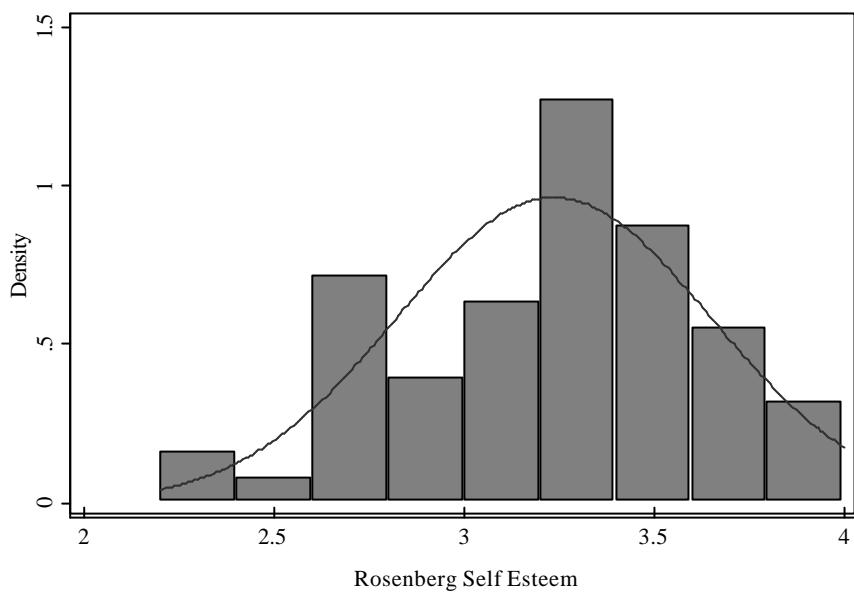
The distribution of the Global Assessment of Recent Stress scores is positively skewed (Figure 4.5), with a median of 2.38 (Table 4.16).

Figure 4.5: Distribution of Global Assessment of Recent Stress Scores



4.7.4 Caregiver Self-Esteem:

The scores on Rosenberg's Self Esteem Scale are skewed slightly to the left (Figure 4.6), with a median of 3.2 (Table 4.16).

Figure 4.6: Distribution of Rosenberg' Self Esteem Scores

4.8 Severity of Dementia:

Several proxy report methods were used to assess the severity of dementia in the care receivers. Caregivers reported more dependence in instrumental activities of daily living (mean = 3.79, Standard Deviation = 2.15) than in activities of daily living (mean = 0.92, Standard Deviation = 0.89). As shown in Table 4.18, the mean scores on the Neuropsychiatric Inventory were 10.46 (Standard Deviation = 6.15) and 12.79 (Standard Deviation = 8.10) for severity of the behavioral problems and the degree of caregiver distress, respectively.

Table 4.18: Summary of Dementia Rating Scales

Measure	N	Mean	Standard Deviation	Range
Activities of Daily Living	62	0.92	0.89	0-3
Instrumental Activities of Daily Living	62	3.79	2.15	0-7
NPI-Q Severity of Behavioral Symptoms	63	10.46	6.15	0-30
NPI-Q Caregiver Distress	63	12.79	8.10	0-36

4.8.1 Activities of Daily Living:

The levels of independence in activities of daily living were examined in order to determine which areas caregivers were giving the most assistance to care receivers.

Bathing and dressing had the highest levels of dependence (33.9% and 51.6% respectively). Continence and toileting were emerging areas of need. Over fifty percent of caregivers (54.7%) were providing assistance with voiding/elimination, while 30.2% were assisting with toileting. Similarly, 32.8% of caregivers were assisting with feeding (Table 4.19).

Table 4.19: Frequency of Dependence in each Area of the ADL Scale

Function	Independent	Assistance Required	Dependent
Bathing	32	9	21
Dressing	27	4	33
Toileting	44	19	0
Transfer	56	8	0
Continence	29	30	5
Feeding	43	21	0

4.8.2 Instrumental Activities of Daily Living:

The same methods used to examine Activities of Daily Living were used to examine instrumental activities of daily living. The majority of care receivers required assistance in IADLs. Ten (15.9%) were still independent in the use of the telephone, and 6 (9.4%) were still able to travel independently. Nearly none were able to shop, do housework, take medications independently, or manage money independently (each less than 5%). No care receivers were able to prepare meals independently (Table 4.20).

Table 4.20: Frequency of Dependence in each Area of the IADL Scale

Function	Independent	Assistance Required	Dependent
Using Telephone	10	23	30
Traveling	6	41	17
Shopping	1	22	41
Preparing Meals	0	22	42
Housework	3	18	43
Taking Medicine	3	48	13
Managing Money	1	14	49

4.8.3 Neuropsychiatric Inventory Questionnaire:

The Neuropsychiatric Inventory Questionnaire (NPI-Q) addresses two areas, the severity of symptoms in the care receiver and the level of distress caused by these symptoms to the caregiver. The symptom severity scores were positively skewed with a mean of 10.46 (Standard Deviation = 6.15) (Figure 4.7). The caregiver distress scores were also positively skewed (Mean = 12.79, Standard Deviation = 8.10) (Figure 4.8).

Table 4.21 summarizes the scores for each domain of the NPI-Q. The most commonly experienced symptoms were nighttime disturbances and apathy/indifference (68.3% each). In contrast, the least common symptoms were hallucinations (20.3%) and euphoria/elation (23.8%). Caregivers were most distressed by the presence of delusions (Mean Distress Score = 2.33) and agitation or aggression (Mean Distress Score = 2.33). Caregivers experienced the least amount of distress with aberrant motor symptoms (Mean Distress Score = 0.78) (Table 4.21).

Table 4.21: NPI-Q Symptom Specific Scores

Symptom	Number (Percentage) with Symptom	Mean Severity of Symptom - if present (SD)	Mean Caregiver Distress Associated with Symptom – if present (SD)
Delusions	21 (32.8%)	1.6 (0.68)	2.33 (1.20)
Hallucinations	13 (20.3%)	1.62 (0.96)	1.63 (1.12)
Agitation/Aggression	39 (60.9%)	1.61 (0.64)	2.33 (1.01)
Dysphoria/Depression	29 (45.3%)	1.39 (0.69)	1.96 (1.13)
Anxiety	40 (63.5%)	1.88 (0.72)	2.31 (1.08)
Euphoria/Elation	15 (23.8%)	1.69 (0.48)	1.40 (0.99)
Apathy/Indifference	43 (68.3%)	1.91 (0.81)	2.08 (1.05)
Disinhibition	30 (47.6%)	1.83 (0.66)	2.17 (1.26)
Irritability/Lability	36 (57.1%)	1.81 (0.75)	2.31 (1.06)
Aberrant Motor	29 (46.8%)	0.56 (0.88)	0.78 (1.20)
Nighttime Disturbances	43 (68.3%)	1.84 (0.72)	1.90 (1.34)
Appetite/Eating Disturbances	32 (50.8%)	1.81 (0.78)	1.87 (1.20)
Total	N/A	10.46 (6.15)	12.79 (8.10)

Figure 4.7: Distribution of NPI-Q Symptom Severity Scores

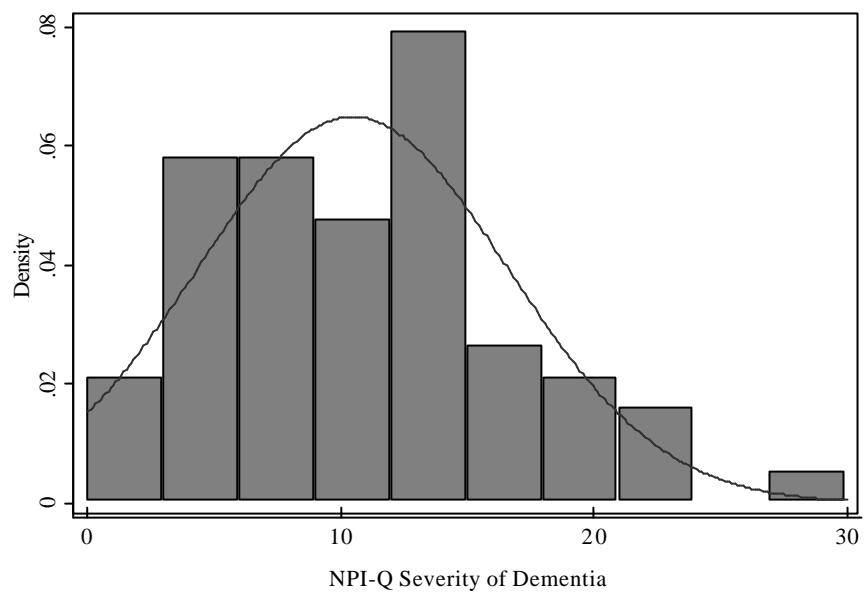
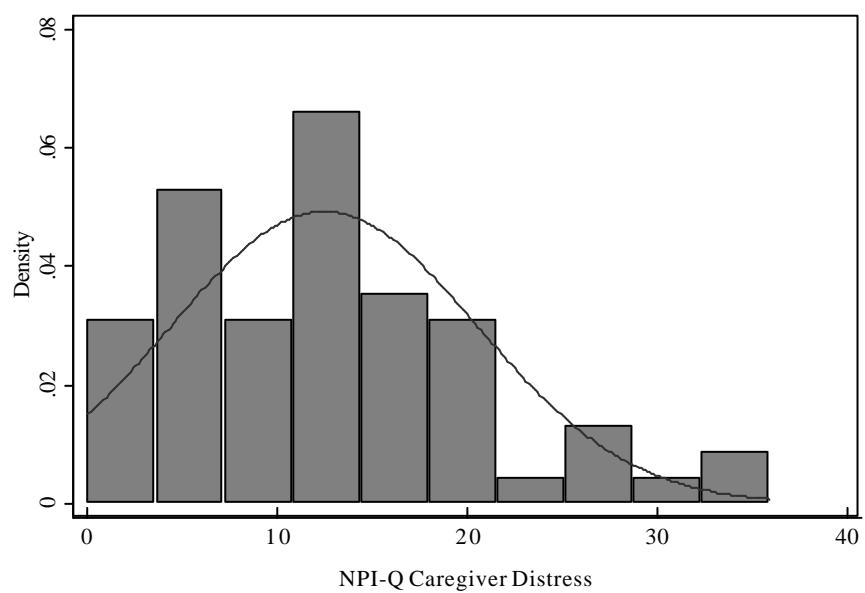


Figure 4.8: Distribution of NPI-Q Caregiver Distress Scores



4.9 The Burden of Caregiving:

This section addresses the secondary analysis of the relationship between Perceived Primary Stressors score and duration of waiting time, living arrangement, relationship, sex, and severity of dementia. The interaction of these predictors on the Perceived Primary Stressors scores are also examined.

4.9.1 Perceived Primary Stressors and Waiting Time:

At the outset of this study, it was hypothesized that waiting time would affect Perceived Primary Stressors score using a t-test. It was found that there was no significant relationship between perceived, expected or acceptable waiting times and the total score (Table 4.22).

Table 4.22: Secondary Analysis of Perceived Primary Stressors and Waiting Times

Characteristic	Category	Number of Observations	Mean Perceived Primary Stressors	Probability ($\alpha = 0.05$)
Perceived Waiting Time	= 30 days	17	42.2 ± 2.16	0.7286
	> 30 days	15	43.15 ± 1.44	
Expected Waiting Time	= 30 days	13	44.16 ± 2.91	0.5333
	> 30 days	13	41.97 ± 1.87	
Acceptable Waiting Time	= 30 days	31	45.78 ± 1.41	0.6106
	> 30 days	6	44.03 ± 2.46	

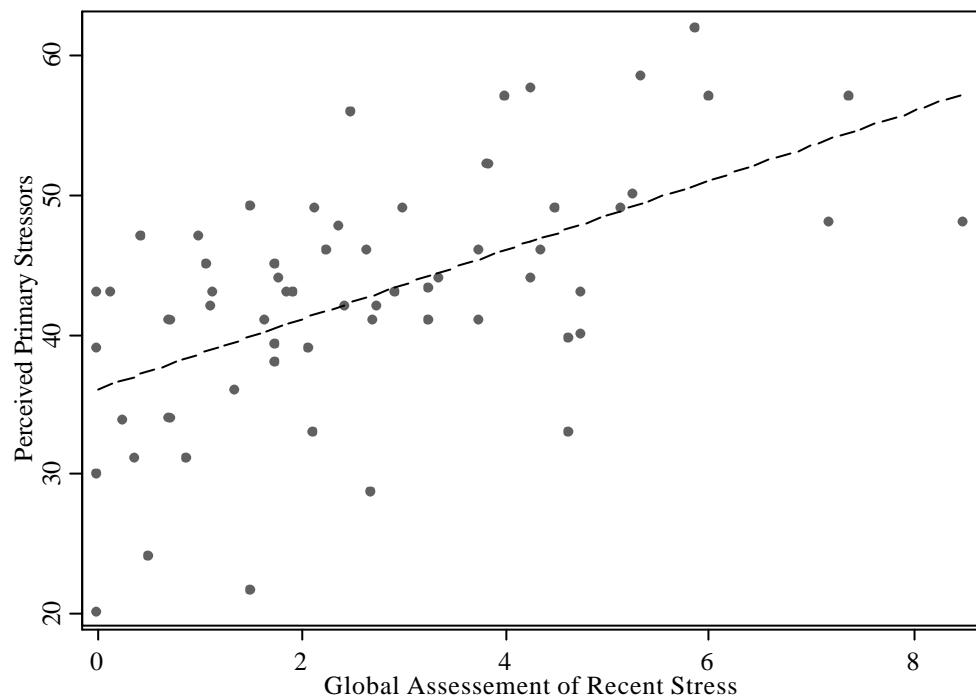
4.9.2 Perceived Primary Stressors Score and Caregiver Characteristics:

Caregiver characteristics (sex, age, education, marital status, relationship to the person with dementia, depression, stress, and self-esteem) were thought to affect the caregiving experience. Both t-tests and simple linear regression were used to assess the relationships (Table 4.23, Table 4.24 and Table 4.25). Statistically significant relationships were found between Perceived Primary Stressors and both caregiver depression and caregiver stress. No significant relationships were found between sex, age, education, marital status, relationship to the person they were caring for (Table 4.23), or self-esteem (Table 4.25, p=0.326, Figure 4.10) and Perceived Primary Stressors score.

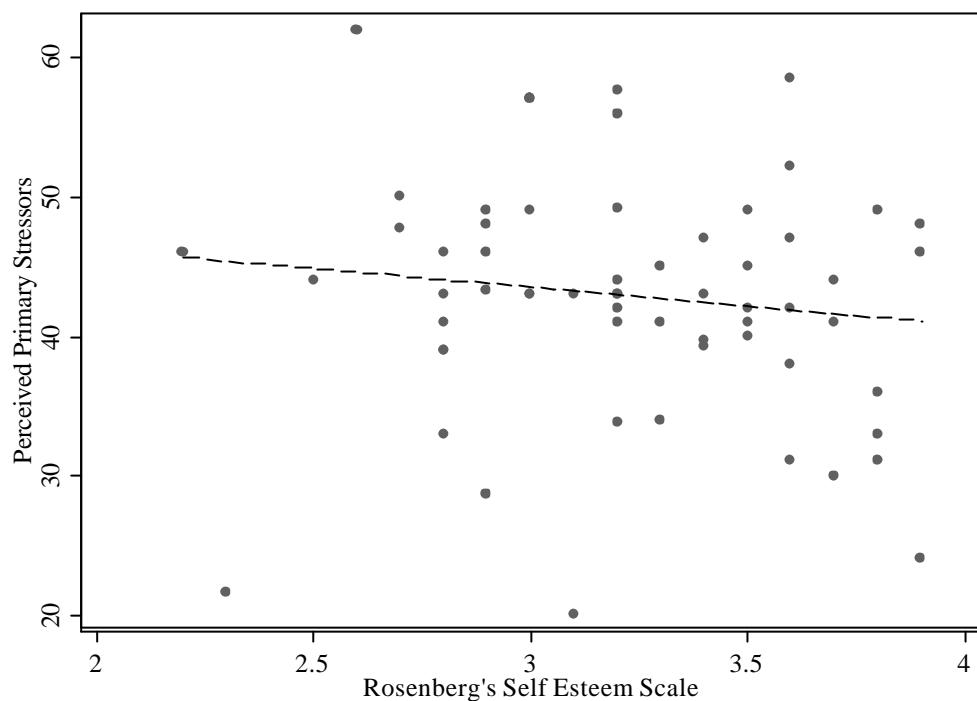
Caregivers with a Geriatric Depression Scale score of five or greater had a greater ($p=0.0064$) Perceived Primary Stressor score (45.92 ± 1.74) than those who scored less than five (39.90 ± 1.30). A significant, positive association between the respondent's scores on the Assessment of Recent Stress and the Perceived Primary Stressors score (<0.001) was found. A scatterplot showing the line of best fit can be found in Figure 4.9 and regression coefficients are found in Table 4.24. A significant association existed between the Perceived Primary Stressors score and the caregiver's rating of their distress level on the NPI-Q ($p<0.001$, Figure 4.11, Table 4.26). These three relationships continued to be significant when multiple-significance testing was taken into account using the Bonferroni method ($p=0.006$ for each).

Table 4.23: Perceived Primary Stressors and Caregiver Characteristics

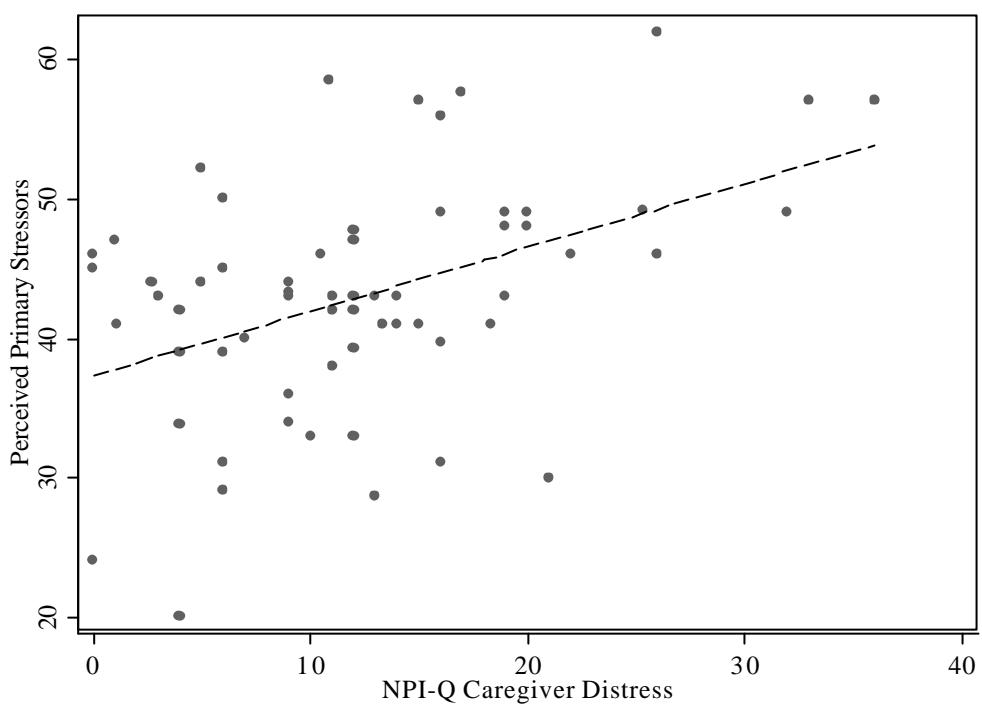
Characteristic	Category	Number of Observations	Mean Perceived Primary Stressors	Probability (α=0.05)
Caregiver Sex	Male	23	41.32±1.73	0.3381
	Female	40	43.54±1.43	
Caregiver Age	= 55 years	15	43.45±7.67	0.4399
	55-65 years	12	46.02±8.72	
	66-75 years	19	41.63±10.07	
	= 76 years	17	40.99±8.19	
Caregiver Education	= High school	16	45.01±2.89	0.2315
	>High school	47	41.95±1.11	
Caregiver Marital Status	Married	55	43.10±1.19	0.3861
	Other	7	40±3.52	
Caregiver/Care Receiver Relationship	Spouse	38	42.38±9.17	0.8916
	Child	19	42.97±8.48	
	Other	6	44.17±8.33	
Geriatric Depression Scale	Normal	34	39.90±1.30	0.0064
	Mild, Moderate or Severe Depression	28	45.92±1.74	

Figure 4.9: Perceived Primary Stressors and Global Assessment of Recent Stress**Table 4.24: Regression Coefficients of Primary Stressors and Recent Stress**

Variable	Coefficient	Standard Error	$P > \frac{1}{2}t^{1/2}$
Constant	36.11861	1.562129	<0.001
Global Assessment of Recent Stress Score	2.494172	0.4634866	<0.001

Figure 4.10: Perceived Primary Stressors and Rosenberg's Self Esteem**Table 4.25: Regression Coefficients of Primary Stressors and Self Esteem**

Variable	Coefficient	Standard Error	P> $\frac{1}{2}t\frac{1}{2}$
Constant	51.6794	8.879884	<0.001
Rosenberg's Self Esteem Score	-2.708469	2.732909	0.326

Figure 4.11: Perceived Primary Stressors and NPI-Q Caregiver Distress Score**Table 4.26: Regression Coefficients of Perceived Primary Stressors and NPI-Q Caregiver Distress Score**

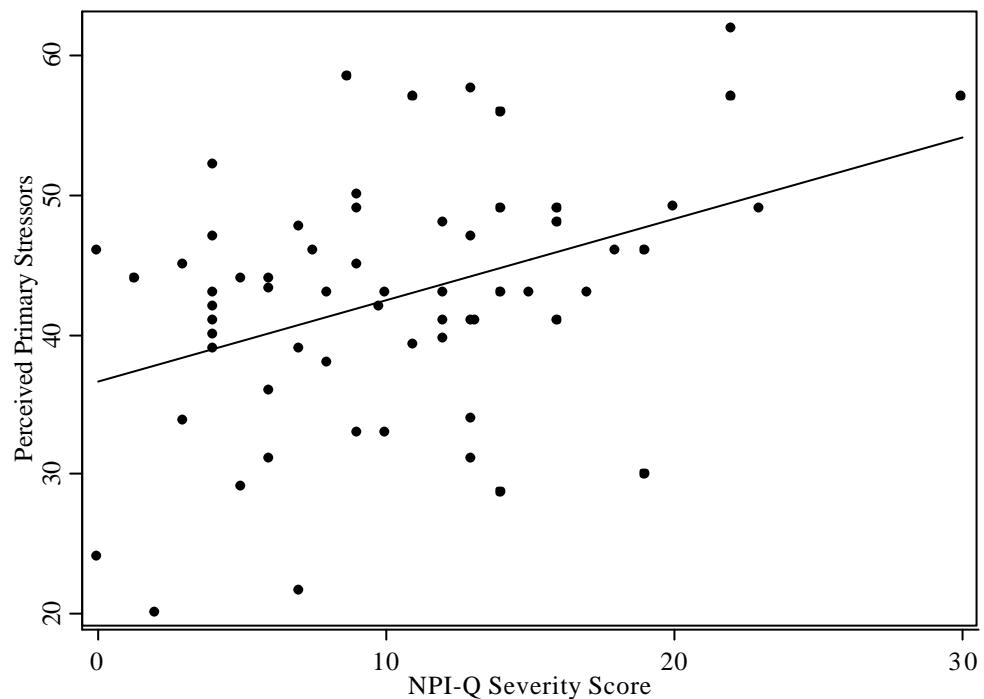
Variable	Coefficient	Standard Error	$P > \frac{1}{2}t^{\frac{1}{2}}$
Constant	37.37784	1.764559	<0.001
NPI-Q Caregiver Distress	0.4597317	0.1194141	<0.001

4.9.3 Perceived Primary Stressors and Care Receiver Characteristics:

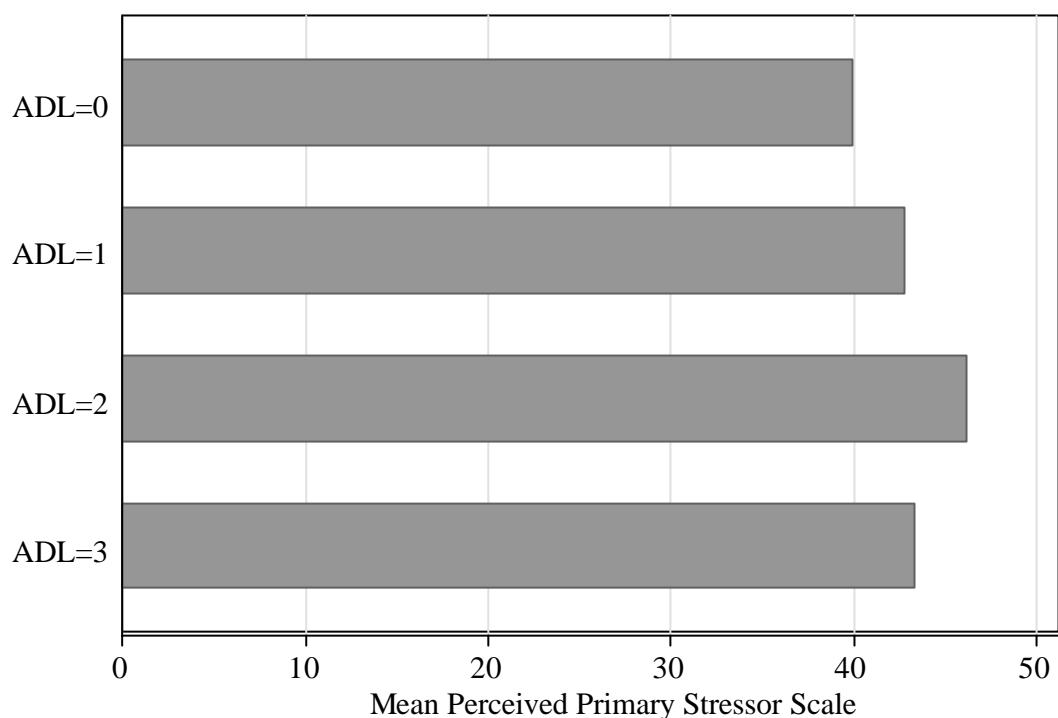
At the outset, the age and marital status of the care receiver along with the severity of dementia were hypothesized to affect the caregiving experience. There was no statistically significant difference found between the age or marital status of the person with dementia and the caregivers' Perceived Primary Stressors score ($p=0.4772$ and $p=0.4845$ respectively) (Table 4.27). Severity of dementia in the care receiver was found to affect the Perceived Primary Stressors. An increase in the NPI-Q symptom severity score ($p=0.001$, Figure 4.12, Table 4.28) and Katz's ADL score ($p=0.032$, Figure 4.13, Table 4.29) were both found to be statistically significantly correlated with an increase in the caregiver's Perceived Primary Stressor score. Although an increase in Lawton's IADL score correlated with an increase in the Perceived Primary Stressor score, the increase was not statistically significant ($p=0.109$, Figure 4.14, Table 4.30).

Table 4.27: Perceived Primary Stressors and Care Receiver Characteristics

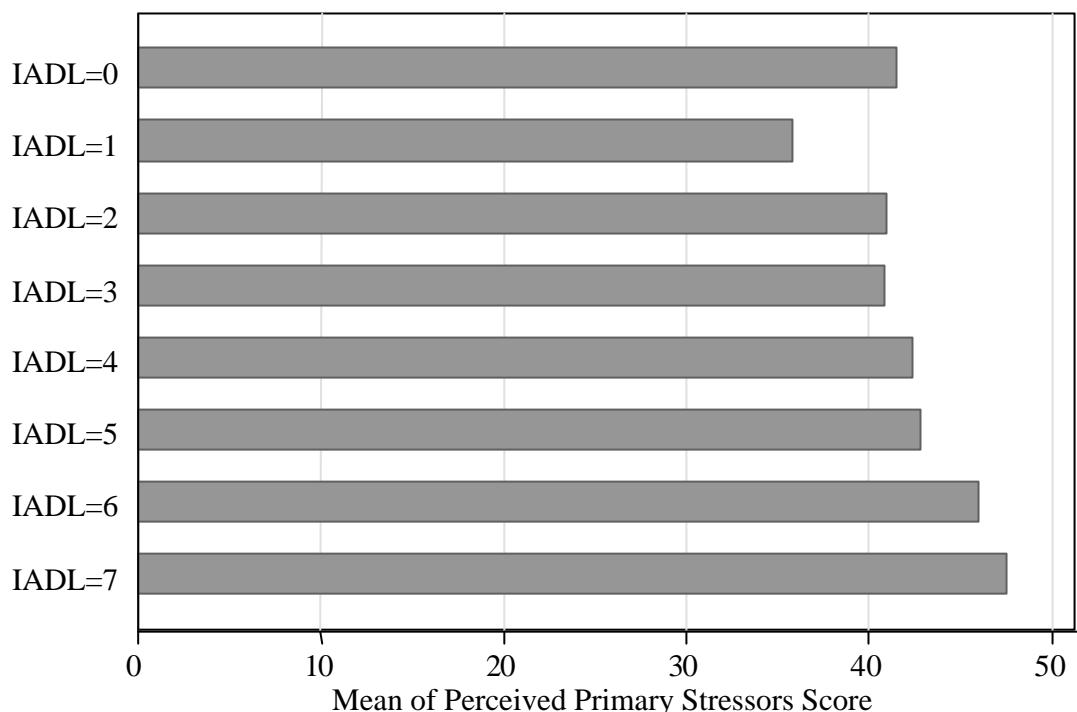
Characteristic	Category	Number of Observations	Mean Perceived Primary Stressors	Probability ($\alpha=0.05$)
Care Receiver Age	=71 years	8	46.81 ± 6.78	0.4772
	71-75 years	17	41.72 ± 11.43	
	76-80 years	12	43.79 ± 6.75	
	= 81 years	26	41.63 ± 8.15	
Care Receiver Marital Status	Married	22	42.15 ± 9.11	0.4845
	Other	41	43.79 ± 8.21	

Figure 4.12: Perceived Primary Stressors and NPI-Q Symptom Severity**Table 4.28: Regression Coefficients of Perceived Primary Stressors and NPI-Q Symptom Severity**

Variable	Coefficient	Standard Error	P> $\frac{1}{2}t^{1/2}$
Constant	36.65733	2.038874	<0.001
NPI-Q Severity Score	0.5822453	0.1682902	0.001

Figure 4.13: Perceived Primary Stressors and ADLs**Table 4.29: Regression Coefficients of Perceived Primary Stressors and ADLs**

Variable	Coefficient	Standard Error	P> $\frac{1}{2}t\frac{1}{2}$
Constant	40.29319	1.487171	<0.001
ADL Score	2.596646	1.179342	0.032

Figure 4.14: Perceived Primary Stressors and IADLs**Table 4.30: Regression Coefficients of Perceived Primary Stressors and IADLs**

Variable	Coefficient	Standard Error	P> $\frac{1}{2}t^{\frac{1}{2}}$
Constant	39.74933	2.218831	<0.001
IADL Score	0.8430029	0.5179321	0.109

4.9.4 Perceived Primary Stressors and the Living Situation:

The caregiving experience was expected to be affected by the living situation and support services used by the caregiver and care receiver. When the living arrangement was categorized by living together and living apart, individuals who lived with the person they were caring for had slightly higher mean Perceived Primary Stressors score than those who lived apart. However, this difference was not statistically significant ($p=0.2163$). Individuals who used information handouts and support services (caregiver support groups, support of family and friends) had lower levels of Perceived Primary Stressors scores; but, these differences were not statistically significant ($p=0.2222$ and $p=0.1653$ respectively). A close to statistically significant difference in the main outcome variable was found for individuals who used respite services ($p=0.0531$). Those who used these services had higher mean scores (Table 4.31).

Table 4.31: Perceived Primary Stressors and Characteristics of the Living Situation

Characteristic	Category	Number of Observations	Mean Perceived Primary Stressors	Probability ($\alpha=0.05$)
Living Arrangement	Together	51	43.39 ± 1.28	0.2163
	Apart	12	39.89 ± 1.87	
Information Handouts	Not Used	10	45.85 ± 2.51	0.2222
	Used	53	42.14 ± 1.22	
Information Services	Not Used	23	42.89 ± 1.74	0.9105
	Used	40	42.63 ± 1.44	
Support Services	Not Used	15	45.48 ± 2.68	0.1653
	Used	48	41.86 ± 1.18	
Respite Services	Not Used	32	40.63 ± 1.73	0.0531
	Used	31	44.89 ± 1.28	

4.9.5 Multivariate Analysis:

As described in Section 3.3.10, multiple linear regression was used to examine the simultaneous relationships of the predictor variables on the Perceived Primary Stressors score of the caregivers. A pair-wise correlation matrix of each of the variables identified as significant in Section 4.3.8 was created (Table 4.32). Additionally, caregiver age, sex and education were maintained as covariates as they are known to affect multiple outcomes in older persons.

Table 4.32 Correlation Matrix of Possible Model Coefficients

	1	2	3	4	5	6	7	8	9	10	11
1. Perceived Stressors	1.0										
2. Caregiver Depression	.34	1.0									
3. Caregiver Stress	.57	.48	1.0								
4. NPI-Q Distress	.45	.20	.48	1.0							
5. NPI-Q Severity	.41	.15	.39	.94	1.0						
6. ADLs	.28	-.03	.13	.25	.22	1.0					
7. IADLs	.21	.24	.21	.39	.31	.50	1.0				
8. Caregiver Sex	-.12	.12	-.02	-.05	-.02	-.15	-.06	1.0			
9. Caregiver Age	-.15	.12	-.08	-.01	.02	.09	.21	.23	1.0		
10. Caregiver Education	-.15	-.13	-.03	.01	-.01	-.18	-.06	.07	-.06	1.0	
11. Caregiver Marital Status	.11	.11	.04	.35	.27	.03	.27	.06	.24	.04	1.0
12. Respite Services	.24	.11	.57	.29	.24	.53	.49	-.17	-.08	-.09	.03

*Correlations with P>0.05 in bold

The two NPI-Q scores (Symptom Severity and Caregiver Distress were found to be highly correlated ($R^2=0.94$), therefore, only one of these was used in the fitting of the model in order to prevent multicollinearity. The Caregiver Distress domain was chosen due to its higher level of correlation with the outcome variable.

The following terms were considered for modeling: caregiver depression (Geriatric Depression Score – categorical = 4, = 5); caregiver stress (Global Assessment of Recent Stress Score – continuous); caregiver distress with symptoms (NPI-Q Caregiver Distress score – continuous); activities of daily living (Katz's ADL score – continuous); caregiver sex; caregiver age (categorical, <55, 55-65, 66-75, >75); caregiver education (categorical, = high school, >high school); caregiver marital status (categorical – married or other); use of respite services (Companion Care or Long Term Care Respite – categorical yes/no). Interaction effects between the terms were evaluated by creating variables by multiplying the caregiver depression, caregiver stress, caregiver distress with symptoms or activities of daily living scores with each other and each of the remaining terms. If these interaction terms were statistically insignificant, they were dropped from the model. Backwards step-wise regression was used to determine the final model. The final model is represented in Table 4.33.

Table 4.33: Multivariate Regression Model

Variable	Coefficient	Standard Error	P>$\frac{1}{2}t\frac{1}{2}$
Constant	33.102	2.497	<0.001
Caregiver Stress	3.744	0.674	<0.001
NPI-Q Caregiver Distress Score	0.267	0.112	0.021
Caregiver Education Level	-3.667	1.793	0.046
Use of Respite Services	8.665	2.71	0.002
Caregiver Stress/Use of Respite Interaction Term	-3.077	0.844	0.001

There was a significant interaction between the Global Assessment of Recent Stress score and the use of respite services ($p=0.001$); therefore, the use of respite services was considered to be an effect modifier of the relationship of recent stress and caregiver burden. This effect is demonstrated graphically in Figure 4.15. Individuals who used respite services had a decreased relationship between recent stress and primary stressors than those who do not use respite services. Due to the study design, the direction of this relationship can not be determined. That is, one can not say whether the use of respite services is a predictor of increased stress, or whether the use of respite services is an outcome of increased stress.

Education was found to be a confounder of the relationship of primary stressors and the caregiver distress domain of the NPI-Q. Caregivers with higher education had

lower levels of perceived primary stressors than those with only high school or less; however, the strength of the relationship is the same for both groups.

Figure 4.15: Effect Modification of the Relationship of Recent Stress and Perceived Primary Stressors by the Use of Respite Services

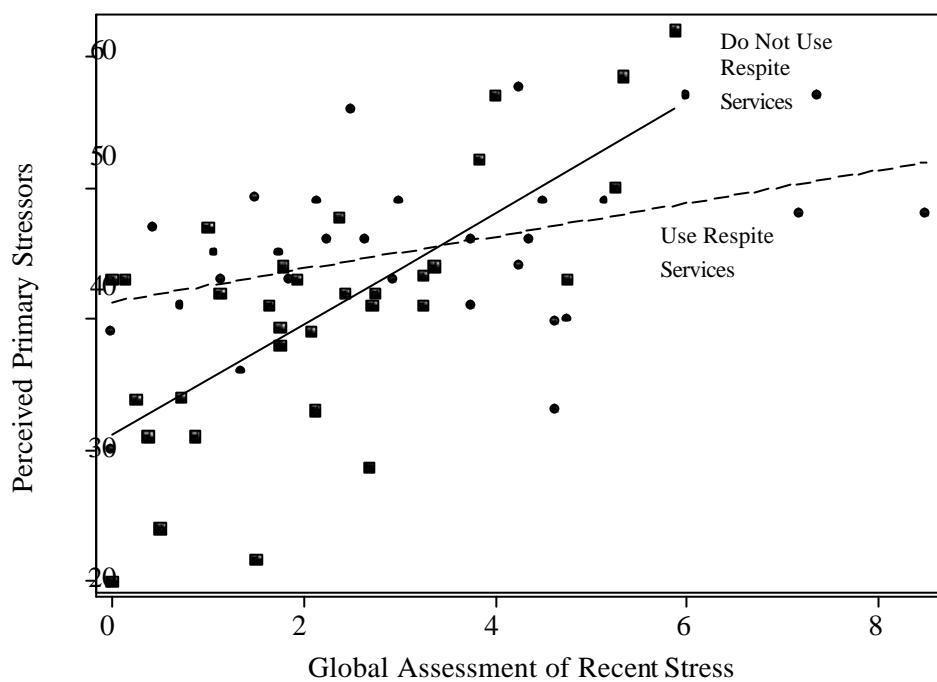
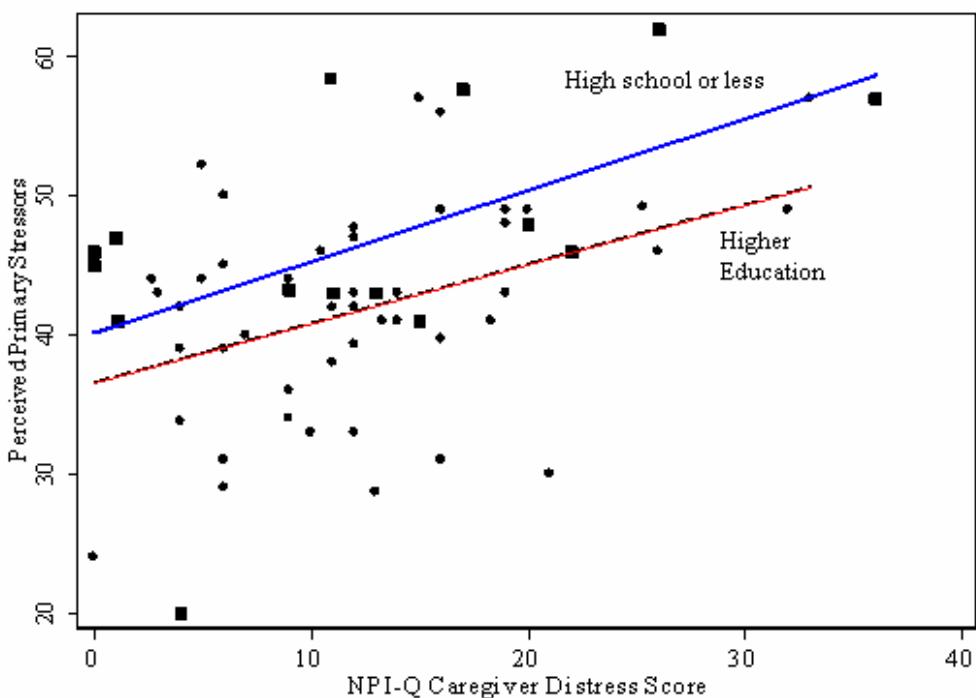


Figure 4.16: Confounding of the Relationship of NPI-Q Caregiver Distress Scores and Perceived Primary Stressors by Caregiver Education Level



4.10 Impact of ADSP Services:

This section addresses the impact of ADSP services on the caregivers' perception of the care receiver's progression of dementia and on the caregiver's quality of life.

4.9.1 Progression of Dementia:

Caregivers were asked whether they felt that the care receiver's disease had become worse, stayed the same, or improved while attending the ADSP. Fifty percent felt that the disease had remained the same (Table 4.34). In order to control the possible impact of length of stay on the results, the progression of the disease was compared by

length of program use (Table 4.35). There was no statistically significant difference in the progression of disease by length of stay ($p=0.572$).

Table 4.34: Progression of Dementia in ADSP Clients

Progression of Dementia	N	Frequency
Become Worse	26	41.27%
Stayed the Same	32	50.79%
Improved	5	7.94%
Total	63	100%

Figure 4.35: Comparison of Disease Progression by Length of ADSP Attendance

ADSP Usage	Gotten Worse	Stayed the Same	Improved	Total
=3 Months	3	6	1	10
4-6 Months	7	10	0	17
7-12 Months	7	3	1	11
13-24 Months	3	6	2	11
=25 Months	6	7	1	14
Total	26	32	5	63

*Pearson chi2(8) = 6.6722 Pr = 0.572

4.10.2 Caregivers:

Caregivers were asked if they felt that attendance at the ADSP had affected their responses in Section V of the questionnaire. Over sixty percent felt that ADSP services had an impact on their experience in caregiving (Table 4.37). Most felt that it was beneficial, but two felt that attendance at the program increased their stress level (as determined from qualitative analysis) (3.5%). The responses to questions 34 (Impact of

ADSP) and 49 (Further comments) were coded for further analysis as explained in Section 3.3.10. The care receivers' attendance at an ADSP allowed caregivers to complete activities and chores (17 responses), to have a break from caregiving (14 responses), and decreased caregivers stress associated with caregiving (7 responses). Some caregivers were concerned with the likely transition to Long Term Care in the future (6 individuals), and had specific concerns about the disease process and problem solving for the person they were caring for (16) (Table 4.36).

Table 4.36: Impact of ADSP Usage – Qualitative Results

Impact of ADSP Usage	Number of Observations
Freedom and break from caregiving	14
Time to complete activities and chores	17
Attendance decreased stress/pressure	7
Attendance increased stress	2
Confident that care receiver is well cared for	6
Concerns about Future and Long Term Care	6
Support received from Club 36 staff	5
Appreciation of Club 36 staff	9
Concerns about disease process, requests for problem solving	16
Stress of Caregiving and feelings of loss	7
Attendance delaying Long Term Care Placement	4
Necessity of the Service	2
Total number of comments	95

Table 4.37: AD SP Attendance and Caregiver Experience

Impact of ADSP Attendance on Caregiver	Number of Observations	Frequency
No	21	36.84%
Yes	36	63.16%
Total	57	100%

The impact of ADSP usage was measured based on the caregiver's perception of the progression of the disease. Caregivers who felt that care receivers' dementia had gotten worse were more likely to express that the use of ADSPs had impacted them ($p=0.013$), (Table 4.38).

Table 4.38: Comparison of Impact of ADSP Usage by Progression of Disease

Progression	No Impact on Caregiver	Impact on Caregiver	Total
Gotten Worse	4	21	25
Stayed the Same	13	14	27
Improved	3	1	4
Total	20	36	56

*Pearson chi2(2) = 8.7390 Pr = 0.013

4.11 Summary of Results:

Caregiver's experiences of waiting for a space in an ADSP as well as the current experience of caring for an individual with Alzheimer disease or dementia were obtained through the use of a questionnaire. The majority of caregivers were living with the care receiver with approximately sixty percent being married to the care receiver. Caregivers were more likely to use informational handouts and telephone support than attend support groups or information sessions. Home Care services and help from family and friends

were frequent methods of receiving assistance. Private in home support and use of Long Term Care respite were both less frequently utilized methods.

Caregivers decided to use ADSP services based on the recommendation of others, generally to have a break from caregiving. In addition, giving the care receiver something to do, opportunities to meet others, and to have opportunities for support were also reasons cited for ADSP use. In contrast, health services such as bathing and health monitoring were not often cited.

The response rate for our questions asking about waiting times was relatively low. The median perceived, expected and acceptable waiting times were all equal to 30 days; however, the proportion who considered an acceptable waiting time to be greater than 30 days was significantly less than those who perceived or expected their waiting time to be greater than 30 days. The majority of caregivers understood why they needed to wait for ADSP services. Almost 30% felt that the waiting period allowed them to adapt to the use of ADSP services, compared with twenty five percent who found that waiting for ADSP services was associated with an increase in stress level. Approximately one third of the sample felt that waiting had no impact on themselves or their family.

Waiting time did not have an association with current caregiver burden. Caregivers' responses to the Perceived Primary Stressor scale were found to be influenced by the presence or absence of depression, the Global Assessment of Recent Stress, the NPI-Q severity of symptoms and caregiver distress, the care receivers' Activities of Daily Living dependency and the use of respite services (borderline). When these relationships were examined simultaneously, the use of respite services was found to be an effect modifier of the relationship between recent stress and primary stressors,

and the caregiver's level of education was found to be a confounder of the relationship between primary stressors and the caregiver distress domain of the NPI-Q.

Caregivers felt that the use of ADSP services had impacted them. Specifically, caregivers who perceived the care receiver's dementia to have worsened since beginning the use of ADSP services were most likely to indicate that ADSP services had an impact on their caregiving experience.

CHAPTER FIVE: DISCUSSION OF RESULTS

In this chapter, key findings of this study are summarized and compared with the findings of other studies described in Chapter Two. An investigation of confounding and effect modification, and the roles of bias and chance is then performed. Following a section on limitations and strengths of the study, the dissemination of results and possible areas of future research are explored.

5.1 Summary of Key Findings:

Caregivers' experiences of waiting for a space in an ADSP as well as their current perceptions about caring for an individual with Alzheimer disease or dementia were assessed through the use of a questionnaire. The majority of caregivers were living with the care receiver. Approximately sixty percent were married to the care receiver. Caregivers were more likely to use informational handouts and telephone support than attend support groups or information sessions. Home Care services and help from family and friends were frequent methods of receiving respite. Private in home support and use of Long Term Care respite were less likely to be used.

Caregivers typically decided to use ADSP services based on the recommendation of others. ADSPs were often accessed as a measure to provide a break from caregiving. Equally important, however, ADSPs were accessed to give the care receiver something positive such as leisure activities, opportunities to meet other people, and opportunities for social support. Health services such as bathing and health monitoring were not often cited as reasons for ADSP use.

The response rate for the specific questions asking for waiting times was low. The median perceived, expected and acceptable waiting times were all equal to 30 days; however, the proportion who considered an acceptable waiting time to be greater than 30 days was significantly less than those who perceived or expected their waiting time to be greater than 30 days. The majority of caregivers understood why they needed to wait for ADSP services. Although almost 30% felt that the waiting period allowed them to adapt to the use of ADSP services, twenty-five percent found that waiting for ADSP services increased their stress level. Approximately one third of the sample felt that waiting had no impact on themselves or their family.

Stated waiting time for ADSPs did not have a long-term relationship with caregiver burden. Caregivers' responses to the Perceived Primary Stressor scale were found to be influenced by the presence or absence of depression, the Global Assessment of Recent Stress, the NPI-Q severity of symptoms and caregiver distress, level of Activities of Daily Living impairment in the care receiver as well as the use of respite services. When these relationships were examined simultaneously, the use of respite services was found to be an effect modifier of the relationship between recent stress and primary stressors, and the caregiver's level of education was found to be a confounder of the relationship between primary stressors and the caregiver distress domain of the NPI-Q.

Caregivers felt that the use of ADSP services had impacted them. Specifically, caregivers who perceived the severity of dementia to have worsened since beginning to use ADSP services were most likely to indicate that ADSP services had an impact on their level of stress, burden, depression and self-esteem.

5.2 Findings in the Context of the Current Literature:

The data in this study contributes to the limited literature currently available on waiting lists for community based health services. The level of burden amongst caregivers of individuals who attend dementia-specific ADSPs was also investigated.

5.2.1 Waiting Times:

A retrospective method was used to estimate the caregiver's perception of waiting time in the cross-sectional survey. This method can be used to calculate a mean waiting time for individuals admitted to the health service (Don et al., 1987). The waiting time of individuals who died while waiting moved into a long term care centre etc... is not considered; therefore, it is expected to lead a lower estimate of waiting time. In this study, the perceived waiting time provided by caregivers was a median of 30 days. This result is much lower than that derived from the administrative databases (51.84 ± 12.49 days), even when the waiting time of only admitted individuals were considered. This may be due to recall bias, or to some caregivers being unaware of the time that the care receiver's name was added to the waiting list.

The use of maximal acceptable waiting time is another method of determining waiting times. It is thought that the patient's experience of waiting for a heath care procedure may be influenced by their acceptance of the need to wait (Ho et al., 1994, Coyte et al., 1994, Dunn et al., 1997, Llewellyn-Thomas et al., 1999). An attempt was made to control for the influence of acceptable waiting time on the caregiver's waiting experience. However, the number of respondents who gave specific responses to waiting

time questions was limited and therefore, there was little power to detect differences in acceptable waiting times on the waiting experience.

There was, however, a significant difference in the proportion who considered an acceptable waiting time that was greater than or equal to 30 days than the proportion who expected waiting times of this length ($p=0.0029$). Simply put, people expected to wait longer than the time they found acceptable. Although not statistically significant, individuals with higher acceptable waiting times had lower perceived primary stressors. This relationship could be explored in further research. In other words, individuals with higher acceptable waiting times might have better coping mechanisms.

5.2.2 The Waiting Experience:

Caregivers were asked to recall their experience of waiting for ADSP services by checking off all applicable responses to a question based on the Alberta Medical Association's (AMA) survey of individuals who waited for health care services (AMA, 1999). The majority of caregivers understood why they needed to wait (69.5%). One third of caregivers felt that waiting had no impact on themselves or their family, compared with 10% of respondents to the AMA survey. Twenty-five percent of caregivers felt they had an increase in their stress level and 3.4% became depressed while waiting. This compared with 57.8% and 40.3% respectively in the AMA sample (*ibid*). Interestingly, 27.1% felt that waiting allowed them to adapt to the use of ADSP services suggesting that caregivers felt that there was some benefit to waiting for services.

ADSPs are often considered the last caregiving transition prior to placement in a Long Term Care centre, and the decision to make this transition can be reportedly quite

stressful (Cotrell, 1996). The results regarding stress levels and waiting were mixed in this study. Although there was some indication of increased stress levels while waiting for services, the waiting process itself appeared to moderate the effects of the transition to a higher level of care. The experience of caregivers waiting for ADSP services is expected to be different from those who responded to the AMA survey while waiting for other health care services such as surgery, as these individuals may be facing more acute needs.

5.2.3 Reasons for Using ADSPs:

Caregivers primarily used ADSP services to have a break from caregiving (77.8%). Caregivers also used ADSP services to benefit the care receiver. Caregivers were interested in providing opportunities for the care receiver to meet others (77.8%); to provide the care receiver with something to do (76.2%); or, to provide the care receiver with support (52.4%). A study by Cotrell (1996) investigated the reasons for initial use of respite services among users and non-users. She found that caregivers often felt that ADSP use was appropriate only for individuals who were quite deteriorated, and that services outside of the home confused the care receiver. The results of this study suggest that caregivers who use ADSP services may have a different understanding of what these services provide. Education to address these misconceptions may be warranted. It is also important to note that ADSP services should market the beneficial effects of programs for care receivers, not just their respite benefits.

The recommendation of a health care professional or friend often played a role in the use of ADSP services. These results point to the importance of the education of

health care professionals in the field around the availability of services. Professionals may have better success in recommending this type of service if they stress the benefits not only to the caregiver but also to the individual with dementia.

5.2.4 Use of Other Community Based Services:

Caregivers were most likely to use informational handouts about Alzheimer disease and other dementias (84.4%) than workshops or information sessions (35.9%). Support groups were used by 35.9% of the sample at one point in time. Almost half of the sample had received telephone support through the Alzheimer Society of Calgary (48.4%). Caregivers received respite through ADSP services, companion care provided through Home Care (35.9%), private arrangements (12.5%), and short-term admissions to Long Term Care centers (23.4%). The use of community based services is much higher among this sample than was found in the CSHA cohort. In the CSHA, caregivers of individuals with dementia used less homemaker service (3.0%), home help for personal tasks (2.0%), in-home nursing care (3.0%), and respite care (25.0%), (CSHA, 1995). Further studies could examine the relative service use of individuals using ADSP services versus non-users of ADSPs.

Interestingly, only 21.9% of the sample indicated that they received ADSP services. An eligibility and selection criterion of the study was being a caregiver of an individual who attended an ADSP funded through Home Care. These findings point to the fact that many caregivers of individuals attending Club 36 may see the service as provided by the Alzheimer Society of Calgary, not as a contracted service of Home Care and the Calgary Health Region. If this survey was being used to determine the number of

individual who used ADSP services, the results would under-estimate use (a measurement error). This does, however, suggest that the other service use estimates derived from the survey may be incorrect.

5.2.5 The Caregiving Experience:

Caregivers who responded to this questionnaire had an overall mean score of 42.7 on Zarit's Perceived Primary Stressors Scale. The mean scores for each domain in our sample were quite comparable with the published results of Zarit et al (1998): Overload (18.6 versus 20.5); Worry and Strain (18.0 versus 17.9); and, Role Captivity (6.4 versus 6.2). Zarit et al found that these levels of Perceived Primary Stressors were lower in caregivers who used ADSP services versus those who did not. Unfortunately, we are unable to compare such results, as this study did not contain an appropriate comparison group.

Almost half of the sample of caregivers (44.4%) were classified as having symptoms of mild or greater depression. Of these individuals, six had an indication of moderate to severe depression. These six individuals were contacted to indicate the possibility of depression. Follow up with their family physician was recommended. The mean overall rating of Global Assessment of Recent Stress was 2.72 and the mean overall rating of Rosenberg's Self Esteem was 3.24. It would be useful to have comparison levels of these scales within other populations of caregivers caring for someone in the community.

Significant relationships between caregiver depression, recent stress, caregiver distress, symptom severity, activities of daily living and the use of respite services were found with the level of perceived primary stressors. Caregivers with a Geriatric

Depression Scale score of five or more had a greater ($p=0.0064$) Perceived Primary Stressor score (45.9 ± 1.7) than those who scored in the normal range (39.9 ± 1.3). There was a direct association between the respondent's scores on the Assessment of Recent Stress and Perceived Primary Stressors (<0.001) and a direct association of Perceived Primary Stressors to the caregiver's rating of their distress level ($p<0.001$) and the symptom severity score ($p=0.001$) on the NPI-Q. The caregiver distress and symptom severity scores were highly correlated ($r^2=0.94$). The ADL score was also significantly correlated with primary stressors ($p=0.032$). The use of respite services was found to be an effect modifier of the relationship between stress and perceived primary stressors (discussed in Section 5.3).

Although the relationships between age, marital status, sex, self esteem, instrumental activities of daily living, living arrangement, service use and Perceived Primary Stressors were not significant, the direction of the relationships were consistent with a published research model (Meiland et al., 2001a). Younger caregivers had a higher score than older caregivers; married caregivers had higher a score than other caregivers ($p=0.38$); caregivers with a lower education level had higher scores ($p=0.23$); female caregivers had higher scores ($p=0.34$); individuals with high self esteem had lower scores ($p=0.326$); individuals caring for persons with higher IADL scores had higher scores ($p=0.11$); and caregivers living with the person whom they were caring for had higher scores ($p=0.22$). There was no significant relationship found between the age of the care receiver ($p=0.48$), the care receivers' marital status (0.49) or the relationship of the care receiver to the caregiver ($p=0.90$). These results support the model of caregiving experience

derived by Meiland et al. (2001a). Some of the lack of statistical significance may be due to Type II errors (discussed below).

With the exception of the use of respite services (found to be an effect modifier) caregivers who used community based information and support services had lower levels of perceived primary stressors; however, these results were not statistically significant. The direction of any relationship cannot be determined in this cross-sectional survey. The number of observations in some of these cells will affect the significance of the results, as a cell number of at least 16 was necessary to detect a significant difference. Only 10 individuals did not use informational handouts. These ten individuals had a mean Perceived Primary Stressor score of 45.9, compared with 42.1 among users. The 15 individuals who did not use support services had a mean score of 45.5 compared with 41.9 for those who used support services. These differences provide some direction for further research on Meiland et al.'s model (Meiland et al., 2001a).

5.3 Investigation of Confounding and Effect Modification:

The simultaneous effect of predictor variables on perceived primary stressors was studied using multiple linear regression analysis. The relationships were found to be affected by both effect modification and confounding.

An effect modifier is “a factor that modifies the effect of a putative causal factor under study. Effect modification is detected by varying the selected effect measure for the factor under study across levels of another factor” (Last, 1995, page 52). There was a significant interaction between the Global Assessment of Recent Stress score and the use of respite services ($p=0.001$); therefore, the use of respite services was considered to be

an effect modifier of the relationship of recent stress and caregiver burden. Individuals who used respite services have a decreased relationship between recent stress and primary stressors than those who do not use respite services. In other words, although users of respite services have a greater score on the Primary Perceived Stressors scale, they have a decreased response to increased recent stress than non-users of respite services.

Confounding is “a situation in which the effects of two processes are not separated. The distortion of the apparent effect of an exposure on risk brought about by the association with other factors that can influence the outcome” (Last, 1995, page 35). In this study, education was found to be a confounder of the relationship of perceived primary stressors and the caregiver distress domain of the NPI-Q. Caregivers with higher education had lower levels of perceived primary stressors than those with only high school or less; however, the strength of the relationship is the same for both groups. It is possible that other variables studied were confounders of the relationships studied, but were missed due to the limited sample size.

5.4 Investigating the Role of Bias:

The investigation of the possibility of bias is important in any scientific investigation. Bias is defined by Last (1995, page 15) as a “deviation of results or inferences from the truth, or processes leading to such deviation. Any trend in the collection, analysis, interpretation, publication, or review of data that can lead to conclusions that are systematically different from the truth.” The following are possible

sources of bias in this study: selection bias, bias due to withdrawal, misclassification and measurement bias, and recall bias.

5.4.1 Selection Bias:

Selection bias is “error due to systematic differences in characteristics between those who are selected for study and those who are not” (Last, 1995, page 153). The studied group of caregivers in the retrospective survey was comprised of volunteers. Volunteers may be systematically different from the whole sample of caregivers of individuals with dementia attending ADSPs in the community. For example, those who participate may have lower level of burden than those who do not, leading to an underestimation of burden. There is also the chance that caregivers experiencing high levels of burden are more likely to receive an ADSP space sooner. This could lead to an overestimation of the level of burden of caregivers of ADSP attendees.

Although the high response rate (82.1%) mediates this particular source of bias, it also indicates that the population who responded might be attempting to please the researcher by participating. Given that the researcher was also the individual responsible for providing the ADSP services, the responses received by respondents might bias the results. For example, if the respondent thought the researcher was attempting to show that wait lists were bad, they may indicate more negative effects of waiting. Conversely, if the respondent wanted to please the researcher, and was pleased with services, they may not indicate any adverse effects of waiting. This potential source of bias could be mediated through the use of a prospective study where the researcher was not the provider of such services.

Despite the possible selection bias, the information gained will nonetheless provide some insight into the experience of caregivers accessing ADSP services. Selection bias could be controlled for through the use of a randomized controlled trial; however, this was not feasible. Provider agencies would not agree to such a study design for ethical reasons.

5.4.2 Bias due to Withdrawals:

Bias due to withdrawals occurs when there is a “difference between the true value and that actually observed in a study due to the characteristics of those subjects who chose to withdraw” (Last, 1995, page 16). The response rate was quite high for this study as 64 of the 78 participants (82.1%) returned completed questionnaires. Fourteen individuals withdrew from participation in the study, either due to no longer meeting the eligibility requirements (four individuals), or through loss to follow-up (ten individuals). If these individuals were systematically different from those who participated, then the results would be susceptible to this type of bias. If, for example, these individuals had a higher level of burden, or recent stress, they may have been less likely to return the questionnaires, leading to an underestimation of these levels in the sample. Since we do not have baseline data on this group, it cannot be determined if they are indeed systematically different from the respondents.

5.4.3 Measurement and Misclassification Bias:

Measurement bias is a “systematic error arising from inaccurate measurements (or classification) of subjects on study variable(s).” (Last, 1995, page 103). If this

misclassification is random, the bias introduced is toward the null. If the misclassification bias is differential, the results may be skewed.

The reliance on self-report could lead to misclassification errors. For example, caregivers were asked if the person they were caring for received Home Care services, and if so, what type. Only fourteen caregivers indicated that the care receiver attended an ADSP through Home Care. An eligibility criteria for this study was that participants be caregivers of individuals attending an ADSP funded through Home Care. All clients of the Alzheimer Society of Calgary's ADSPs must be Home Care clients. Therefore, there is evidence of misclassification. This leads to uncertainty about the responses to other questions dealing with support services received in the community.

Additionally, individuals with certain characteristics may have decided not to respond to specific scales. Very few individuals did not respond to individual scales in their entirety, and of those with incomplete responses, personal mean imputation could be, and was, used to increase the response rate. However, there is some risk with the use of personal mean imputation if the reason participants did not answer questions was directly related to outcomes. This did not appear to be a significant concern in this study.

5.4.4 Recall Bias:

Recall bias is a “systematic error due to differences inaccuracy or completeness of recall to memory of past events or experiences” (Last, 1995, page 141). Due to the retrospective nature of this study, the subjects were asked to recall their experiences while waiting for admission into an ADSP. Therefore, the potential for recall bias is of concern. The use of a retrospective measure of the caregivers' perception of waiting time

is typically lower than a cross-sectional estimate, since it only considers the duration of time waited by individuals who have already been admitted to ADSPs. The accuracy of the waiting time can not be verified using the program statistics as the two datasets are not linked. It is possible that caregivers who are satisfied with services may overestimate the ill-effects of waiting for services. The length of time the person with dementia has been attending the program may affect the accuracy of the caregiver's responses about the duration of waiting time. Additionally, the longer the attendance at an ADSP, the more distant the caregiver's current status would be from that experienced while waiting for admission.

5.5 Investigating the Role of Chance:

Type I and Type II error are two types of error to consider when investigating the role of chance in the interpretation of results. This study is vulnerable to both types of error.

5.5.1 Type I Error:

Type I error is “the error of rejecting a true null hypothesis i.e., declaring that a difference exists when it does not” (Last, 1995, page 57). This study was susceptible to Type I error due to the number of significance tests performed. It is possible that some of the observed statistically significant findings could have been due to the influence of chance. Because of the exploratory nature of our study, we didn’t consistently correct for multiple comparisons, but the possibility of Type I errors was considered when examining the pattern of findings. Our results are useful for generating hypotheses.

5.5.2 Type II Error:

Type II error is “the error of failing to reject a null hypothesis i.e., declaring that a difference does not exist when it in fact does” (Last, 1995, page 57). Due to the small sample size of this study, especially when groups were sub-categorized, the power to detect differences is low. As the power decreases, there is increased opportunity for Type II errors. In some cases, results suggested trends which could be investigated in further studies even though they were not significant in this study.

5.6 Limitations and Strengths of the Study:

This section addresses the strengths and limitations of the study, in particular those of the study design.

5.6.1 Limitations:

Alternative study designs include a cross-sectional survey of caregivers of individuals with dementia waiting for ADSP services or a prospective cohort study. In the past, the wait list for programs was managed by each ADSP independently. Recently, a centralized wait list for ADSP services was introduced for the Calgary Health Region. Along with this change, programs now receive one referral at a time in order to determine the appropriateness of the individual for the available spaces. The Calgary Health Region was approached, but declined the opportunity to provide access to the ADSP wait list for the purposes of this study. Therefore, a retrospective analysis was conducted.

This cross-sectional, retrospective study consists of a survey of caregivers of individuals who were currently attending dementia-specific ADSPs at the point of

selection. In this study design, exposures and disease status were assessed simultaneously in a defined population. This allows for a snapshot of the level of burden in the caregivers; however, a temporal relationship cannot be determined. In addition, there is no accurate assessment of the level of burden prior to ADSP attendance. Therefore, one can not infer that the caregiver burden status at the time of the questionnaire is secondary to the effect of attending an ADSP or to the duration of waiting time experienced. The presence of multiple confounders such as caregiver characteristics, care receiver characteristics, access to other services and length of time since admission in addition to the lack of an appropriate comparison group affect the ability to draw causative inferences with regards to the level of caregiver burden.

Numerous steps were taken to ensure the quality of the data collected. Most of the instruments used had previously been substantiated for reliability and validity, and chosen for their utility with the study's population. However, the reliability and validity of the complete questionnaire package, including the demographics and service use portions were not tested prior to survey administration.

Due to constraints in the health care system, caregivers are being instructed by some care providers to exaggerate their stress levels in order to receive services. While this was a concern, the questionnaire package was administered and analyzed anonymously in order to minimize the possibility of caregivers exaggerating their burden symptoms.

Due to limited sample size, there may have been insufficient power to detect differences when they in fact existed between groups. Additionally, there was limited ability to stratify results by all of the potentially confounding variables. This inability to

control for possible confounders, and the possibility of Type I errors due to multiple tests, affect the strength of the results.

It is possible that the use of self-administered questionnaires led to non-response for some questions. Some individuals may have chosen not to return the questionnaire package. Self-administered questionnaires were used for the following two reasons: to prevent interviewer bias; and, to prevent the exaggeration of burden symptoms by caregivers in the hopes of greater service provision. In addition, participants were assured that their choice to participate in the study would not affect their current health care services.

The results of this study cannot be generalized to all populations of caregivers of individuals with dementia. Results might be generalizable to groups of caregivers who are caring for someone currently attending an ADSP, and have access to a similar set of support services in the community. Ideally, future studies should be conducted on individuals while they are waiting for services. Replication of our results is strongly recommended.

5.6.2 Strengths:

As described in the literature review, there is currently no published research into the burden of waiting for access to ADSPs services and there is very limited research into the burden of waiting for community based services in general. A cross-sectional design is useful in providing a quick and inexpensive assessment of the effect waiting for ADSPs on the caregiver's quality of life. The health status of the target population and the burden of disease can easily be assessed. Another strength of the cross-sectional

design is that it allows for the assessment of multiple exposures and outcomes at a single point in time. This allows for both exploratory analyses and hypotheses generation.

Additionally, the participation rate in the study was quite high. This contributes to confidence in the results. This study provides baseline data on a variety of psychosocial measures that will be of value in future studies of similar populations. The results of this study will also be of use in guiding the development of surveys for these populations.

5.7 Dissemination of Results:

The results of this study are potentially important and as such, attempts will be made to publish the results. Additionally, the results will be shared with agencies, and health policy decision makers in the Calgary region. An increased understanding of what it is like to be caring for an individual with dementia, what it is like to wait for community based health services, and the impact of ADSPs has been developed through this study. These results, in conjunction with the systems perspectives of waiting times may provide a greater context for decision making in Calgary.

5.8 Future Research:

Future research with similar populations should consider the following:

- The effects of waiting for health services would best be assessed while caregivers are waiting for services, not retrospectively.
- These effects while waiting for ADSPs could be compared to the AMA study results.

- A comparison of the effects of waiting for ADSPs and waiting for Long Term Care Admission could further expand the understanding of the caregiving experience.
- Assessing the effect of ADSP attendance on caregiver burden in a cohort study would be useful if a randomized, controlled trial could not be implemented for ethical and/or program reasons.
- Conducting such a trial amongst caregivers waiting for different types of ADSPs (dementia-specific, frail elderly and young adult) could further examine the Calgary experience and provide information regarding access to services.
- Although not statistically significant, individuals with higher acceptable waiting times had lower perceived primary stressors. This relationship could be explored in further research. In other words, individuals with higher acceptable waiting times might have better coping mechanisms or the care receiver was less challenging.
- The results of this study suggest that caregivers who use ADSP services may have a different understanding of what these services provide. Education to address these misconceptions may be warranted. It is also important to note that ADSP services should market the beneficial effects of programs for care receivers, not just their respite benefits. A study examining the effects of these interventions is warranted.
- Further studies could examine the relative service use of individuals using ADSP services versus non-users of ADSPs.

- This study found that waiting allowed caregivers time to adapt to the fact that the care receiver would be attending an ADSP, other benefits of waiting for ADSP services and possible interventions to capitalize on waiting time could be examined.

CHAPTER SIX: STUDY CONCLUSIONS

This cross-sectional, retrospective study was exploratory in nature; however, insight was gained into the experience of caring for an individual with dementia in the Calgary community. Limited information was gained on the experience of waiting for a space in an ADSP due to the study design and limited number of individuals who responded to the questions of perceived, expected, and acceptable waiting times. A trend of caregivers considering their acceptable waiting time to be less than their perceived or expected waiting time was observed. The majority of caregivers understood why they needed to wait for ADSP services. Although almost 30% felt that the waiting period allowed them to adapt to the use of ADSP services, twenty-five percent found that waiting for ADSP services increased their stress level. Approximately one third of the sample felt that waiting had no impact on themselves or their family. Further research examining this waiting experience is warranted.

Caregivers typically decided to use ADSP services based on the recommendation of others. ADSPs were often accessed as a measure to provide a break from caregiving. Equally important, however, ADSPs were accessed to give the care receiver something positive such as leisure activities, opportunities to meet other people, and opportunities for social support. These results should be taken into consideration in the future provision of ADSP services.

Stated waiting time for ADSPs did not have a long-term relationship with caregiver burden. Caregivers' responses to the Perceived Primary Stressor scale were found to be influenced by the presence or absence of depression, the Global Assessment

of Recent Stress, the NPI-Q severity of symptoms and caregiver distress, level of Activities of Daily Living impairment in the care receiver as well as the use of respite services. When these relationships were examined simultaneously, the use of respite services was found to be an effect modifier of the relationship between recent stress and primary stressors, and the caregiver's level of education was found to be a confounder of the relationship between primary stressors and the caregiver distress domain of the NPI-Q. These results support the provision of respite services to help modulate the effects of caring for someone with dementia in the community.

Caregivers felt that the use of ADSP services had impacted them. Specifically, caregivers who perceived the severity of dementia to have worsened since beginning to use ADSP services were most likely to indicate that ADSP services had an impact on their level of stress, burden, depression and self-esteem. Further research into the level of these benefits is encouraged.

This study has helped to provide further evidence to the model proposed by Meiland et al (2001a), and provided insight into the experience of caring for someone with dementia in the community in the Calgary Health Region. Areas for future research were raised by this exploratory study.

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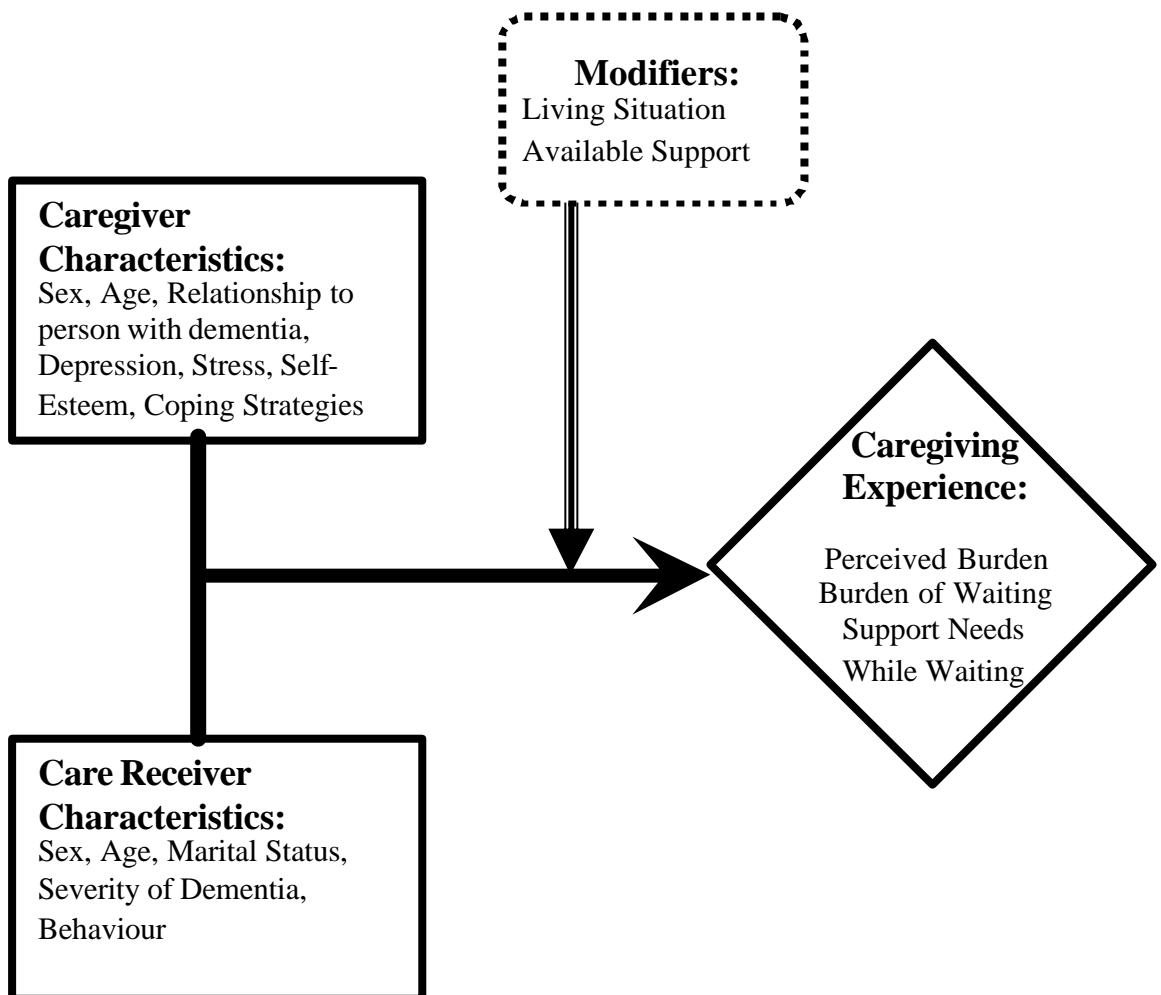
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APPENDIX A: Research Model – Adapted from Meiland et al., 2001a.

APPENDIX B: Overview of Key Studies

Study	Design	Country	Procedure	Data Source	Outcome
Agnew et al., 1994	Retrospective Audit	New Zealand	Coronary Surgery	Charts	Waiting Times
Amoko et al., 1992	Descriptive	Canada	Elective Surgery	Professional Survey	Organization of Waiting List
Arthur et al., 2000	Intervention, Randomized Controlled Trial	Canada	Coronary Surgery	Patient Survey	Post-op Length of Stay
Basinski et al., 1993	Case Scenarios	Canada	Coronary Surgery	Professional Survey	Priority Rating
Bengston et al., 1994	Cross-Sectional	Sweden	Coronary Surgery	Patient Survey	Patient Symptomatic Burden
Bengston et al., 1996	Prospective	Sweden	Coronary Surgery	Patient Survey Databases	Morbidity, Mortality Waiting Times Waiting List Length
Bernstein et al., 1997	Retrospective	Netherlands Sweden U.S.A.	Coronary Surgery	Medical Records	Waiting Times
Bloom & Fendrick, 1987	Cross-Sectional	U.K.	Specialty Clinic	Professional Survey	Waiting Times
Bruce et al., 1998	Cross-Sectional	U.S.A.	Emergency Department	Patient Survey	Satisfaction Waiting Times
Burkell et al., 1996	Audit Computer Modeling	Canada	Long Term Care	Database	Waiting Time
Carrier et al., 1993	Retrospective	Canada	Coronary Surgery	Database	Mortality Morbidity Post-Op Length of Stay

Study	Design	Country	Procedure	Data Source	Outcome
Collins et al., 1996	Cross-Sectional	U.S.A.	Heart Transplant	Caregiver Survey	Waiting Times, Stress, Coping, Quality of Life
Cox, 1996	Prospective	Canada	Coronary Surgery	Patient Survey Charts	Mortality Morbidity
Coyte et al., 1994	Retrospective	Canada & U.S.A.	Orthopedics	Patient Survey	Waiting Times Patient Acceptance of Waiting Time
Derret et al., 1999	Cross-Sectional	New Zealand	Prostate Surgery Orthopedics	Patient Interview	Health Related Quality of Life Acceptable Waiting Times
Devroey et al., 2001	Retrospective	Belgium	Long Term Care	Database	Waiting Times
Don et al., 1987	Cross-Sectional	U.K.	Surgery	Database	Waiting Times
Donaldson et al., 1989	Cross-Sectional	U.K.	Surgery	Surgical Lists	Standardized Waiting List Ratios
Doogue et al., 1997	Consecutive Case Series	New Zealand Canada	Coronary Surgery	Patient Charts	Morbidity and Mortality
Dunn et al., 1997	Cross-Sectional	Canada Denmark Spain	Cataract Surgery	Patient Survey	Acceptance of Waiting Times
Eggers, 1995	Retrospective	U.S.A.	Kidney Transplantation	Database	Waiting Times Access to Transplant WL Access

Study	Design	Country	Procedure	Data Source	Outcome
Fishbacher & Robertson, 1986	Prospective	Scotland	General Practitioner	Clinic Data	Waiting Times
Frankel et al., 1991	Intervention Prospective	U.K.	Elective Surgery	Professional Survey	Waiting Times
Frankel, 1989	Econometric Analysis	U.K.	General Surgery	Database Index	Waiting List Length
Freeland & Curley, 1987	Prospective	U.K.	Tonsil Surgery	Patient Surveys	Morbidity Waiting Times
French et al., 1990	RCT	U.K.	General Practitioner Referrals	Clinic Data	Referral Patterns
Frost, 1980	Econometric Analysis	U.K.	Elective Surgery	Database	Waiting List Length
Gordon et al., 1991	Cross-Sectional	U.S.A.	Transplantation Liver	Database	Waiting Times
Grouden et al., 1998	Prospective	Ireland	Varicose Veins	Clinical Data	Waiting List Length
Gruenberg & Willeman, 1982	Cross-Sectional	U.S.A.	Long Term Care	Database Professional Survey	Waiting Times
Hadorn & Holmes 1997a	Case Scenarios	New Zealand	Elective Surgery	Professional Survey	Priority Rating
Hadorn & Holmes 1997b	Cross-Sectional	New Zealand	Coronary Surgery	Professional Survey	Reasonable Waiting Times
Hall et al., 1996	Cross-Sectional	New Zealand	Prostate Surgery	Patient Survey	Quality of Life
Hanning and Lundstrom., 1998	Time Series	Sweden	Cataract Surgery	Professional Survey Database	Waiting Times Waiting List Length
Hanning, 1996	Prospective	Sweden	Elective Surgery	Database	Waiting Times
Hill, 1988	Descriptive	Australia	Speech Pathology	Utilization Review	N/A

Study	Design	Country	Procedure	Data Source	Outcome
Ho et al., 1994	Retrospective	Canada	Orthopedics	Patient Survey	Acceptance of Waiting Times
Houghton & Brodribb, 1989	Cross-Sectional	U.K.	Elective Surgery	Database	# of Cancellations
Keating et al., 1998	Cross-Sectional	Australia	Speech Pathology	Prospective Survey	Referral Rate
Kee et al., 1997	Cross-Sectional	Ireland	Coronary Surgery	Patient Survey	Priority Rating
Keller, 1997	Intervention Prospective	U.S.A.	Mental Health	Clinic Data	Waiting Times
Kingsley, 1988	Econometric Analysis	U.S.A.	Appointments	Econometrics	Cost to Employer
Lazarus & Gray, 1987	Cross-Sectional	New Zealand	Long Term Care	Database	Waiting List Length
Lee et al., 1987	Retrospective Audit	U.K.	Surgery	Database	Waiting List Length
Lee et al., 1992	Prospective	U.K.	Ophthalmology	Clinical Data	Waiting Time
Lee, 1996	Intervention	U.K.	Speech Therapy	Caregiver Survey	Waiting Times Improvement in Speech
Lindsay et al., 1987	Prospective	Canada	Coronary Surgery	Patient Survey Caregiver Survey	Patient and Caregiver Education and Support Needs
Llewellyn-Thomas et al., 1999	Cross-Sectional	Canada	Coronary Surgery	Patient Survey	Maximal Acceptable Waiting Time
Mackillop et al., 1994	Cross-Sectional	Canada	Radiotherapy	Database	Waiting Times

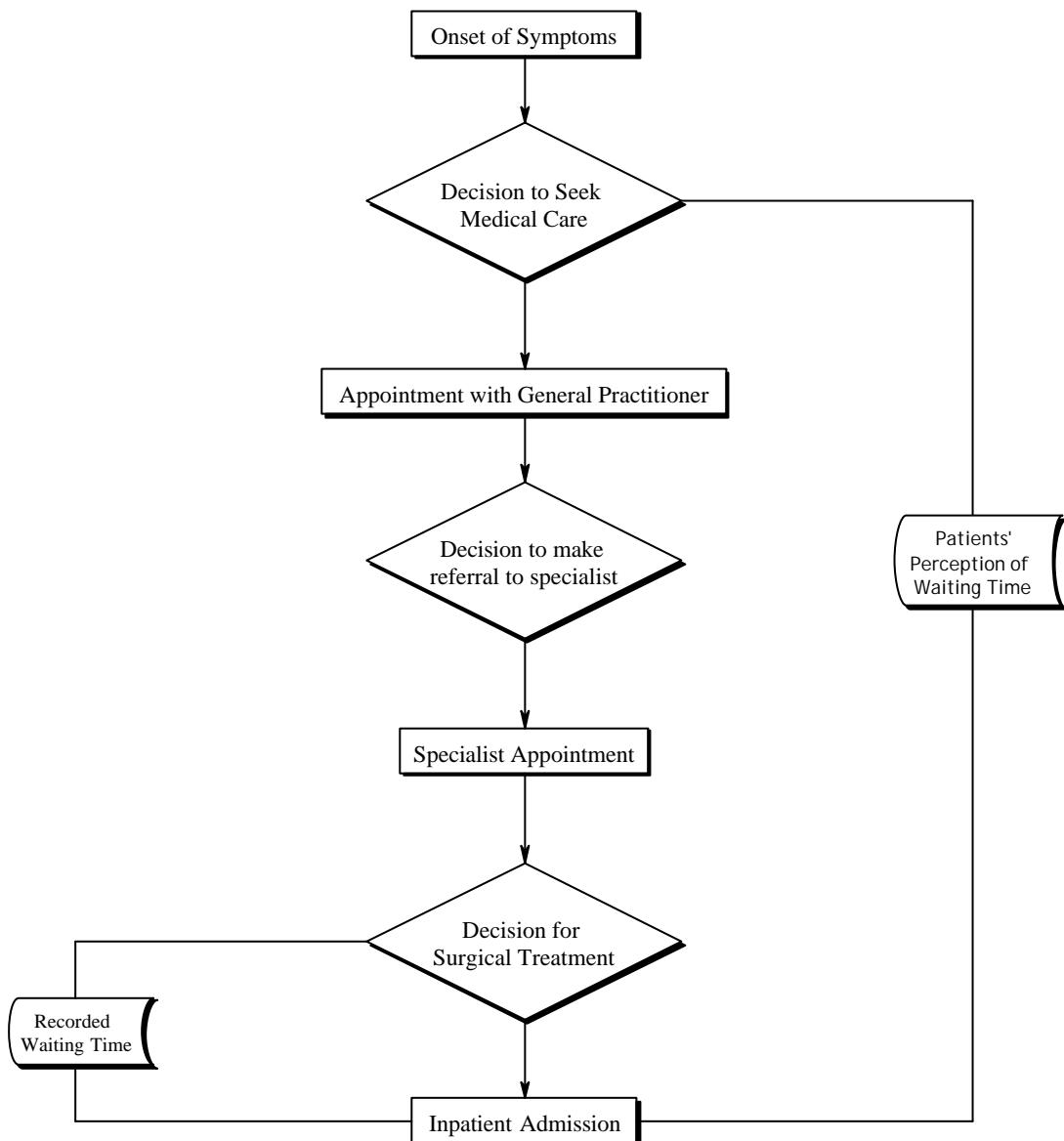
Study	Design	Country	Procedure	Data Source	Outcome
Madhok 1994	Case Review	U.K.	Hernia Surgery Orthopedics	Chart	Waiting Times by consultant
Markson et al., 1983	Retrospective	U.S.A.	Long term care	Professional Survey	Administrati vely Necessary Days
Martin et al., 1995	Descriptive	U.K.	Elective Surgery	Patient Interviews and Focus Groups	Burden of Waiting
Maziak et al., 1996	Prospective	Canada	Coronary Surgery	Charts	Waiting Times
McManus et al., 1993	Retrospective	U.S.A.	Heart Transplant	Professional Survey Database	Waiting Times Mortality
Meiland et al., 2001a	Prospective	Holland	Long Term Care	Caregiver Survey Caregiver Interview	Caregiver Burden
Meiland et al., 2001b	Prospective	Holland	Long Term Care	Caregiver Interview	Caregiver Burden
Mobb et al., 1994	Intervention Prospective	U.K.	Urology	Clinic Data	Waiting List Length
Morgan, 1993	Consumer Access Survey	U.S.A.	MRI	Phone Calls	Access to Care
Morris et al., 1990	Retrospective	Canada	Coronary Surgery	Charts	Waiting Times
Mullen et al., 1996	Cross- Sectional	Canada	Transplantat ion Liver	Prospective Survey	Priority Rating
Natarajan et al., 2002	Prospective	Canada	Coronary Surgery	Database	Waiting Times vs. Requested Waiting Times
Study	Design	Country	Procedure	Data Source	Outcome

Naylor et al., 1990	Case Scenarios	Canada	Coronary Surgery	Professional Survey	Maximal Acceptable Waiting Time
Naylor et al., 1991	Case Scenarios	Canada	Coronary Surgery	Professional Survey	Maximal Acceptable Waiting Time
Naylor et al., 1992a	Case Scenarios	Canada	Coronary Surgery	Prospective Survey	Maximal Acceptable Waiting Time
Naylor et al., 1992b	Cross-sectional	Canada	Coronary Surgery	Professional Survey	Maximal Acceptable Waiting Time
Naylor et al., 1993	Case Series	Canada	Coronary Surgery	Database	Waiting Time
Naylor et al., 1995	Cross-Sectional	Canada	Coronary Surgery	Database	Waiting Times
Parker & Froese, 1992	Intervention Prospective	Canada	Mental Health	Clinic Data	Appointment Kept?
Rector et al., 1993	Case Control	U.S.A.	Heart Transplant	Patient Survey	Quality of life
Rosario et al., 1999	Prospective	U.S.A.	Coronary Surgery	Database	Waiting Times
Ross & Watson., 1988	Retrospective	U.K.	Elective Joint Surgery	Charts	Cancellations
Roy & Hunter, 1996	Prospective	U.K.	Arthritis Surgery	Clinic Data	Morbidity Walking Test
Rubin & Davies., 1975	Cross-Sectional	U.K.	Long Term Care	Professional Survey	Blocked Beds Waiting List Length
Scherrer-Bannerman et al., 2000	Intervention	Canada	Coronary Surgery	Patient Survey	Support, Anxiety

Study	Design	Country	Procedure	Data Source	Outcome
Shapiro et al., 1992	Prospective	Canada	Long Term Care	Charts	Waiting Times Relative Rates of Placement
Sharples et al., 1994	Case Series	U.K.	Heart and Lung Transplant	Charts	Waiting Times
Smith, 1994	Cross-Sectional	U.K.	Cataract Orthopedics	Database	Waiting Times
Suttorp et al., 1992	Case Control	Netherlands	Coronary Surgery	Charts	Mortality
Takala et al., 1997	Intervention	Finland	General Practitioner	Patient Questionnaire	Waiting Times
Tomlinson et al., 1992	Intervention Prospective	New Zealand	Orthopedics	Charts	Waiting List Length
Turner & Cooke, 1991	Retrospective	U.K.	Urology	Charts	Waiting Times
Walker, 1998	Intervention Prospective	U.K.	Mental Health	Database	Waiting List Length
Weston et al., 1997	Intervention	U.K.	Orthopedic	Database	Waiting List Length
Williams et al., 1997	Prospective	Canada	Orthopedic	Patient Interview	Health Related Quality of Life Symptomati c Burden Waiting Times
Wright & Arthur, 1996	Retrospective Intervention	Canada	Coronary Surgery	Patient Survey	Patient perception of assistance

APPENDIX C: Typical Process Map of Waiting for Surgical Treatment

(Adapted from Smith, 1994)



APPENDIX D: Questionnaire Package Cover Page

Number

Waiting for a Space in an Adult Day Support Program:
Retrospective Caregiver Perspectives

QUESTIONNAIRE PACKAGE

Thank you for taking the time to fill out this survey. Please attempt to answer all of the questions. Use the enclosed, stamped, self addressed envelope to return your survey as soon as possible.

The number at the top right of the questionnaire package will be used to contact individuals who have not returned a survey. Please feel free to remove this number.

If you have any questions about how to fill in this questionnaire, please **call Clare Hildebrandt @ 290-0110.**

*Thank you for your help in understanding what it is like
to be waiting for a space in an Adult Day Support Program.*

APPENDIX E: Sociodemographic Background Questionnaire

The following series of questions relate to you, the caregiver of a person with Alzheimer Disease or a related disorder (dementia). You will also be asked questions relating to the person you are caring for. Please answer the questions to the best of your ability.

Section I: You, The Caregiver:

The following are questions about you, the **caregiver** of a person with Alzheimer Disease or a related disorder (dementia).

1. What is the year of **your birth?**

2. Are **you?**

- Male
- Female

3. What is the highest level of education that **you have *completed*?**

- | | |
|--|--|
| <input type="checkbox"/> Some Elementary School | <input type="checkbox"/> Some University |
| <input type="checkbox"/> Some High School | <input type="checkbox"/> University Graduate |
| <input type="checkbox"/> High School Graduate | <input type="checkbox"/> Post Graduate Studies |
| <input type="checkbox"/> Some Commercial College or Technical School | |

4. What is **your present marital status?**

- Single (never married)
- Married
- Divorced/Separated
- Living common-law with partner
- Widowed

5. What is **your relationship to the person you are caring for?**

- | | |
|--|---|
| <input type="checkbox"/> I am his/her spouse | <input type="checkbox"/> I am his/her parent |
| <input type="checkbox"/> I am his/her common-law partner | <input type="checkbox"/> I am his/her sibling |
| <input type="checkbox"/> I am his/her child | <input type="checkbox"/> I am his/her friend |
| <input type="checkbox"/> I am his/her (<i>please indicate</i>) _____ | |

Section II: The Person You are Caring For:

The following are questions about the **person with Alzheimer Disease or a related disorder (dementia) who you are caring for**. Please answer these questions for this individual

6. What is the year of birth of **the person you are caring for?** _____

7. What is the *present* marital status of **the person you are caring for?**

- Single (never married)
- Married
- Divorced/Separated
- Living common-law with partner
- Widowed

8. When was **the person you are caring for** diagnosed with Alzheimer Disease or a related disorder (dementia)?

- They haven't been diagnosed yet
- They were diagnosed in: _____

(Please indicate a month and year if possible)

9. What is **your present** living arrangement with the person you are caring for?

- We live together
- We live apart
- Other (*please indicate*) _____

APPENDIX F: Current Service Use Questionnaire

Section III: Support Services You Are Receiving

The following questions are about the support services you are **currently** receiving. Please place a check mark in the appropriate boxes or fill in the blanks where indicated.

10. Have you attended a caregiver support group?

- No (*please go to question 12*)
- Yes – I attended one in the past (*please go to question 12*)
- Yes – I am currently attending a support group

11. How often do **you regularly** attend support groups?

- | | |
|---|--|
| <input type="checkbox"/> Less than once a month | <input type="checkbox"/> Once a week |
| <input type="checkbox"/> Once a month | <input type="checkbox"/> More than once a week |
| <input type="checkbox"/> Other (<i>please indicate</i>) _____ | |
-

12. Have **you** attended any educational workshops or information sessions about Alzheimer Disease or Dementia?

- No (*please go to question 14*)
 - Yes: Approximate number of events: _____
-

13. How many of these workshops were run by the Alzheimer Society of Calgary?

- | | |
|---|------------------------------|
| <input type="checkbox"/> None | <input type="checkbox"/> One |
| <input type="checkbox"/> Unsure | <input type="checkbox"/> Two |
| <input type="checkbox"/> Other (<i>please indicate</i>) _____ | |
-

14. Have **you** ever received telephone support from staff at the Alzheimer Society of Calgary?

- No (*please go to question 16*)
 - Yes: Approximate number times: _____
-

15. What topics did **you** discuss? (*Please check all that apply*)

- | | |
|---|---|
| <input type="checkbox"/> Alzheimer Disease or Dementia | <input type="checkbox"/> Finding a Physician |
| <input type="checkbox"/> Medications | <input type="checkbox"/> Accessing a Day Program |
| <input type="checkbox"/> Information on Housing Options | <input type="checkbox"/> Accessing Home Care Services |
| <input type="checkbox"/> Legal Issues | <input type="checkbox"/> Accessing Respite |
| <input type="checkbox"/> Financial Issues | <input type="checkbox"/> Placement in a Nursing Home |
| <input type="checkbox"/> The Wandering Registry | <input type="checkbox"/> Driving Issues |
| <input type="checkbox"/> Other (<i>please indicate</i>) _____ | |
-

16. Have **you** ever received information handouts produced by the Alzheimer Society of Calgary?

- No
- Yes, but I have not read or understood them
- Yes, I have read and understood them

17. Does **the person you are caring for** currently receive Home Care services?

- No (*please go to question 19*)
 - Yes: Approximate number of hours per week: _____
-

18. What services does **the person you are caring for** receive from Home Care?
(*please check all that apply*)

- Professional Consultations
 - Companion Care
 - Personal Care
 - Housekeeping
 - Adult Day Support Program
 - Overnight respite care
 - Other: _____
-

19. Does **the person you are caring for** currently receive private in-home support?

- No (*please go to question 21*)
 - Yes: Approximate number of hours per week: _____
-

20. What type of private in-home support does **the person you are caring for** receive?
(please check all that apply)

- Companion Care
- Personal Care
- Housekeeping
- Other: _____

21. Has **the person you are caring for** ever been placed in a long-term care center or a nursing home for a short period of time so that you could have a break from looking after them?

- No
- Yes: Approximate number of times: _____

22. Do **you or the person you are caring for** receive any help from friends or family members?

- No
- Yes: Approximate number of hours per week: _____

23. Why did **you** choose to use an Adult Day Support Program? (*please check all that apply.*)

- It was recommended by my Home Care Coordinator
- It was recommended by my physician
- It was recommended by: _____ *(please indicate)*
- To give the person I am caring for something to do
- To provide the person I am caring for with opportunities to meet other people
- To provide the person I am caring for with support
- To monitor the health of the person I am caring for
- To provide the person I am caring for with bathing services
- To have a break from caregiving
- Other (please explain) _____

24. How long has the person you are caring for been attending the following Adult Day Support Programs? (*please indicate the time in months for all that apply*)

- Club 36 @ Ramsay: _____ months

Club 36 @ Signal Pointe: _____ months

Club 36 @ Harvest Hills: _____ months

Another Adult Day Support Program: _____ months

25. Do you or the person you are caring for receive any other support services?

- No
 Yes (*please list*) e.g. Meals on Wheels _____

APPENDIX G: The Experience of Waiting for an Adult Day Support Program

Section IV: The Experience of Waiting for an Adult Day Support Program

26. How long *did you wait* for a space in an Adult Day Support Program? (*please indicate the approximate number of days*)

- _____ days
 Unsure

27. How long did you *expect* to wait for a space in an Adult Day Support Program? (*please indicate the approximate number of days*)

- _____ days
 Unsure

28. How long *do you think* people should have to wait for a space in an Adult Day Support Program? (*please indicate the approximate number of days*)

- _____ days
 Unsure

29. How did waiting for a space in an Adult Day Support Program affect you? (*please check all that apply*)

- I was upset that I needed to wait.
- I understood why I needed to wait.
- It allowed me time to adapt to the fact that the participant would be attending a day program.
- I was unsure of which program the person I am caring for would be attending.
- It increased my stress level.
- I became depressed while waiting.
- I noticed a decrease in my health level.
- I could not work while waiting.
- I noticed a decrease in the health level of the person I am caring for.
- I needed to purchase in-home support services in the meantime.
- Waiting had no impact on me or my family.

Please indicate any other effects waiting for a space had on you or the person you are caring for: _____

APPENDIX H: Zarit's Appraisal of Primary Stressors

Section V: Feelings you may have as a Caregiver:

	Never	Most of the time	Some of the time	All of the time
30. During <i>the past month</i> , how much of the time have these statements been true for you?				
A. I can get a lot done in the day				
B. I am able to relax				
C. I can count on having a block of time to use as I like				
D. I am exhausted when I go to bed at night				
E. I feel responsible for my relative				
F. I have more things to do than I can handle				
G. I have time just for myself				
H. I worry about my relative				
I. I have difficulty concentrating on activities because of thoughts of my relative				
J. The physical strain on me is more than I can take				
K. I feel more and more tense as the day goes on				
L. I wish I could take more breaks during the day				
M. I don't know what to expect from one hour to the next				
N. I feel if things continue like this, I will not be able to care for my relative at home				
O. I wish I were free to lead a life of my own				
P. I wish I could just run away				
Q. I feel trapped by my relative's illness				

APPENDIX I: The Short Form of the Geriatric Depression Scale

- 31.** The following is a list of ways you may have felt or behaved over the past week.
 Please choose the best answer for how you felt *over the past week* by making a check in the appropriate box:

	Yes	No
A. Are you basically satisfied with your life?		
B. Have you dropped many of your activities and interests?		
C. Do you feel that your life is empty?		
D. Do you often get bored?		
E. Are you in good spirits most of the time?		
F. Are you afraid that something bad is going to happen to you?		
G. Do you feel happy most of the time?		
H. Do you often feel helpless?		
I. Do you prefer to stay at home, rather than go out and do new things?		
J. Do you feel that you have more problems with memory than most?		
K. Do you think it is wonderful to be alive now?		
L. Do you feel pretty worthless the way you are now?		
M. Do you feel full of energy?		
N. Do you feel that your situation is hopeless?		
O. Do you think that most people are better off than you are?		

APPENDIX J: The Global Assessment of Recent Stress Scale

The following is an attempt to evaluate the amount of stress that you have been under in the past week. Several areas where stress could occur are listed below. If no pressure existed, answer 1 ("none"). "Extreme" would mean that you felt very upset, perhaps even noticed physical reactions, such as tension, upset stomach, headache, etc., or that you were mentally distressed, anxious, grieving. Not all stress or pressure comes from bad events that happen, some happy events also cause a lot of pressure. Consider these too.

- 32.** For each of the following please indicate on a scale from 1 to 10 how much “*pressure*” you have been under **IN THE PAST WEEK**.

- A. Pressure related to work/job/school. (Whether self-imposed or not)

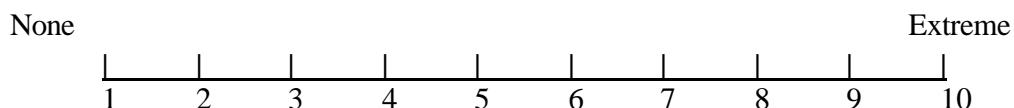


Not applicable

- #### B. Pressure in interpersonal relationships. (Family members and/or significant persons)



- C. Pressure caused by changes in your relationships. (Death, birth, marriage, divorce, etc.)



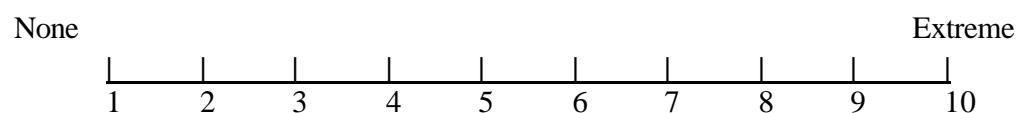
D. Pressure caused by sickness or injury. (Self, others, or both)



E. Pressure caused by financial issues.



F. Pressure from unusual happenings. (Crime, natural disaster, accident, moving, etc.)



G. Pressure from change or lack of change in daily routines.



H. Estimate of overall level of pressure during the past week.



APPENDIX K: Short Form of Rosenberg's Self Esteem Scale

- 33.** The following questions list different ways that people feel about themselves. Please indicate whether you strongly disagree, disagree, agree or strongly agree to the following statements by making an X in the appropriate box.

33. The following questions list different ways that people feel about themselves. Please indicate whether you strongly disagree, disagree, agree or strongly agree to the following statements by making an X in the appropriate box.		Strongly Disagree	Disagree	Agree	Strongly Agree
A.	I feel that I'm a person of worth at least on an equal basis with others				
B.	I feel that I have a number of good qualities				
C.	All in all, I am inclined to feel that I am a failure				
D.	I am able to do things as well as most other people				
E.	I feel I do not have much to be proud of				
F.	I take a positive attitude toward myself				
G.	On the whole, I am satisfied with myself				
H.	I wish I could have more respect for myself				
I.	I certainly feel useless at times				
J.	At times I think I am no good at all				

- 34.** Has the attendance of the person you are caring for at the Adult Day Support Program had an impact on any of the areas identified in questions 28 to 31?

No

Yes (*please explain below*)

APPENDIX L: Katz' Index of Independence in Activities of Daily Living (A-F) and Lawton's Instrumental Activities of Daily Living Scales (G-M)**Section VI: Severity of Dementia in the Person You Are Caring For.**

The following section asks about the person you are caring for. Please answer the questions as best as you can. Remember, although complete answers are best, you can choose not to answer questions.

- 35.** For each area of function listed below, check the description that applies. (The word "assistance" means supervision, direction or personal assistance.)

A. Bathing – Sponge bath, tub bath, or shower.

- Receives no assistance (gets in and out of tub by self, if tub is usual means of bathing)
- Receives assistance in bathing only one part of the body (such as back or a leg)
- Receives assistance in bathing more than one part of the body (or not bathed)

B. Dressing – gets clothes from closets and drawers, including underclothes and outer garments, and uses fasteners (including braces, if worn).

- Gets clothes and gets completely dressed without assistance
- Gets clothes and gets dressed without assistance, except for help in tying shoes
- Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed

C. Toileting – going to the "toilet room" for bowel and urine elimination, cleaning self after elimination, and arranging clothes.

- Goes to the "toilet room", cleans self, and arranges clothes without assistance (may use object for support, such as cane, walker, or wheelchair, and may manage night bedpan or commode, emptying same in morning)
- Receives assistance in going to "toilet room" or in cleaning self or arranging clothes after elimination, or in use of night bedpan or commode
- Does not go to room termed "toilet" for the elimination process.

D. Transfer

- Moves in and out of bed, as well as in and out of chair, without assistance
(may use object for support, such as cane or walker)
- Moves in and out of bed or chair with assistance
- Does not get out of bed

E. Continence

- Controls urination and bowel movements completely by self
- Has occasional accidents
- Supervision helps keep urine or bowel control; catheter is used, or person is incontinent

F. Feeding

- Feeds self without assistance
- Feeds self except for getting assistance in cutting meat or buttering bread
- Receives assistance in feeding or is fed partly or completely by using tubes or intravenous tubes

G. Using Telephone

- Able to look up numbers, dial telephone and receive and make calls without help
- Able to answer telephone or dial operator in an emergency, but needs special telephone or help in getting numbers and/or dialing
- Unable to use telephone

H. Traveling

- Able to drive own car or to travel alone on buses or in taxis
- Able to travel, but needs someone to travel with
- Unable to travel

I. Shopping

- Able to take care of all food and clothes shopping with transportation provided
- Able to shop, but needs someone to shop with
- Unable to shop

J. Preparing Meals

- Able to plan and cook full meals
- Able to prepare light foods, but unable to cook full meals alone
- Unable to prepare any meals

K. Housework

- Able to do heavy housework (i.e. scrub floors)
- Able to do light housework, but needs help with heavy tasks
- Unable to do any housework

L. Taking Medicine

- Able to prepare and take medications in the right dose at the right time
- Able to take medications, but needs reminding, or someone to prepare them
- Unable to take medications

M. Managing Money

- Able to manage buying needs (i.e. write checks, pay bills)
- Able to manage daily buying needs, but needs help managing checkbook and/or paying bills
- Unable to handle money

APPENDIX M: Neuropsychiatric Inventory Questionnaire

SECTION VII: Behaviors Commonly Observed in Individuals with Dementia:

Please answer to following questions based on changes that have occurred since the person you are caring for first began to experience memory problems. Indicate “yes” only if the symptom has been present in the past month. Otherwise, indicate “no”.

For each item marked “yes”:

- Rate the severity of the symptom (how it affects the person you are caring for):
- Rate the distress you experience because of that symptom (how it affects you):

36. Delusions: Does the person you are caring for believe that others are stealing from him or her, or planning to harm him or her in some way?

NO (*continue to question 37*)

YES (*please indicate severity and distress below*)

Severity:

Mild (noticeable, but not a significant change)

Moderate (significant, but not a dramatic change)

Severe (very marked or prominent; a dramatic change)

Distress:

Not distressing at all

Minimal (slightly distressing, not a problem to cope with)

Mild (not very distressing, generally easy to cope with)

Moderate (fairly distressing, not always easy to cope with)

Severe (very distressing, difficult to cope with)

Extreme or very severe (extremely distressing, unable to cope with)

37. Hallucinations: Does the person you are caring for act as if he or she hears voices?

Does he or she talk to people who are not there?

- NO (*continue to question 38*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

38. Agitation or Aggression: Is the person you are caring for stubborn and resistive to help from others?

- NO (*continue to question 39*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

39. Depression or Dysphoria: Does the person you are caring for act as if he or she is sad or in low spirits? Does he or she cry?

- NO (*continue to question 40*)
 YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
 Moderate (significant, but not a dramatic change)
 Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
 Minimal (slightly distressing, not a problem to cope with)
 Mild (not very distressing, generally easy to cope with)
 Moderate (fairly distressing, not always easy to cope with)
 Severe (very distressing, difficult to cope with)
 Extreme or very severe (extremely distressing, unable to cope with)

40. Anxiety: Does the person you are caring for become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

- NO (*continue to question 41*)
 YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
 Moderate (significant, but not a dramatic change)
 Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
 Minimal (slightly distressing, not a problem to cope with)
 Mild (not very distressing, generally easy to cope with)
 Moderate (fairly distressing, not always easy to cope with)
 Severe (very distressing, difficult to cope with)
 Extreme or very severe (extremely distressing, unable to cope with)

41. Elation or Euphoria: Does the person you are caring for appear to feel too good or act excessively happy?

- NO (*continue to question 42*)
 YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
 Moderate (significant, but not a dramatic change)
 Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
 Minimal (slightly distressing, not a problem to cope with)
 Mild (not very distressing, generally easy to cope with)
 Moderate (fairly distressing, not always easy to cope with)
 Severe (very distressing, difficult to cope with)
 Extreme or very severe (extremely distressing, unable to cope with)

42. Apathy or Indifference: Does the person you are caring for seem less interested in his or her usual activities and in the activities and plans of others?

- NO (*continue to question 43*)
 YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
 Moderate (significant, but not a dramatic change)
 Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
 Minimal (slightly distressing, not a problem to cope with)
 Mild (not very distressing, generally easy to cope with)
 Moderate (fairly distressing, not always easy to cope with)
 Severe (very distressing, difficult to cope with)
 Extreme or very severe (extremely distressing, unable to cope with)

43. Disinhibition: Does the person you are caring for seem to act impulsively? For example, does he or she talk to strangers as if he or she knows them or does he or she say things that may hurt people's feelings?

- NO (*continue to question 44*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

44. Irritability or Lability: Is the person you are caring for impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?

- NO (*continue to question 45*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

45. Motor Disturbance: Does the person you are caring for engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

- NO (*continue to question 46*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

46. Nighttime Behaviors: Does the person you are caring for awaken you during the night, rise too early in the morning, or take excessive naps during the day?

- NO (*continue to question 47*)
- YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
- Moderate (significant, but not a dramatic change)
- Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
- Minimal (slightly distressing, not a problem to cope with)
- Mild (not very distressing, generally easy to cope with)
- Moderate (fairly distressing, not always easy to cope with)
- Severe (very distressing, difficult to cope with)
- Extreme or very severe (extremely distressing, unable to cope with)

47. Appetite and Eating: Has the person you are caring for lost or gained weight or had a change in the food he or she likes?

- NO (*continue to question 48*)
 YES (*please indicate severity and distress below*)

Severity:

- Mild (noticeable, but not a significant change)
 Moderate (significant, but not a dramatic change)
 Severe (very marked or prominent; a dramatic change)

Distress:

- Not distressing at all
 Minimal (slightly distressing, not a problem to cope with)
 Mild (not very distressing, generally easy to cope with)
 Moderate (fairly distressing, not always easy to cope with)
 Severe (very distressing, difficult to cope with)
 Extreme or very severe (extremely distressing, unable to cope with)

48. Since the *person you have been caring for* has been attending the Adult Day Support Program, has the progression of their disease:

- Gotten worse?
 Stayed the same?
 Improved?

APPENDIX N: Final Comments and Instructions for Return**Section VIII: Further Comments:**

49. Do you have any further comments?

Section VIII: Instructions for Return

Thank you for taking the time to fill out this questionnaire. Your responses will help us to understand what it is like to wait for a space in an Adult Day Support Program, and what it is like to care for someone with Alzheimer Disease or Dementia. We are grateful for the time you have spent filling this out.

Please return the questionnaire using the enclosed addressed, stamped envelope. If you have misplaced the envelope, please return the questionnaire (marked confidential) to:

**Clare Hildebrandt
Program Evaluation
Alzheimer Society of Calgary
1920 11th Street SE
Calgary, Alberta, T2G 3G2**

If you have any questions, please call Clare Hildebrandt at 290-0110.

APPENDIX O: Agreement to Participate (Consent)

PRINTED ON UNIVERSITY OF CALGARY LETTERHEAD

Research Project: Waiting for a Space in an Adult Day Support Program: *Retrospective Caregiver Perspectives.*

Principal Investigator: Dr. David Hogan

Research Associate: Clare R. Hildebrandt

Sponsor: The Brenda Strafford Chair in Geriatrics

This information is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to examine your experience while you waited for a space in an Adult Day Support Program for the person you are caring for. This summary information, in combination with other systems data, will give health care professionals a better understanding of what it is like to care for someone with dementia while waiting for access into an Adult Day Support Program.

Consent Form, Version #1, May 5th, 2003, Office of Medical Bioethics Grant ID 17242

WHAT WOULD I HAVE TO DO?

Participants in this study are asked to complete a questionnaire. This is included in this package. The questionnaire could take from 30 – 45 minutes to complete. You can answer the questions in one sitting, or if you like, you can take a break in filling out your responses. You will be asked questions about yourself, the person you are caring for and about the support services you are both receiving. Once you are finished filling in the questionnaire, you will be asked to return it in the enclosed, addressed, stamped envelope.

You are under no obligation to answer all questions, but your completion of the questionnaire is important. Only aggregate information about the results of this study will be reported.

WHAT ARE THE RISKS?

There are no known risks from being involved. The Conjoint Health Research Ethics Board of the Calgary Health Region and the University of Calgary have approved this study. All personal information gained in this study will be kept in a locked area and anonymity will be maintained in the reporting of the results.

WILL I BENEFIT IF I TAKE PART?

The results of the research may help us to understand the effects on caregivers waiting for an adult day support program space, and may provide important information on the utility of these programs and help health care administrations in making funding decisions about adult day support programs. The information we get from this study may help us to provide better treatments in the future for patients with dementia.

DO I HAVE TO PARTICIPATE?

The participation in this study is voluntary. You can choose not to complete, or not to return this questionnaire. You may withdraw from the study at anytime by contacting the researchers directly, or by simply not returning the questionnaire. If you wish to withdraw after you have returned the questionnaire, please contact Dr. David Hogan at 220-8474. Your choice of whether or not to participate in this study will not affect health care options (including Adult Day Support Services) available to you.

WILL I BE PAID FOR PARTICIPATING? DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for participating in this study. All postage costs will be covered through the use of stamped envelopes.

WILL MY RECORDS BE KEPT PRIVATE?

Please do not identify yourself on the questionnaire, as all the information you provide is strictly confidential. Although the questionnaires are numbered, you can remove the number if you wish. This number will be used to send one reminder notice to participants. As each questionnaire is returned, the research associate will enter the responses into the computer. No one else will see your questionnaire. The questionnaire will then be placed into a locked cabinet at the Department of Community Health Sciences at the University of Calgary. These questionnaires will be destroyed by shredding three years following the completion of the study.

WHAT IF I WANT MORE INFORMATION?

If you would like to obtain a copy of the results from this study, or an information pamphlet on caring for someone with Alzheimer Disease or another dementia, please fill in the enclosed card and send it to the research associate in a separate envelope from the questionnaire. If you have any questions or concerns about this study, the questions, or the questionnaire, please contact me, Clare Hildebrandt at 290-0110 or Dr. David Hogan at 220-8474. We would be happy to help you.

AGREEMENT TO PARTICIPATE

Your decision to complete and return this questionnaire will be interpreted as an indication of your agreement to participate. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time.

If you have further questions concerning matters related to this research, please contact: Clare Hildebrandt at 290-0110 or Dr, David Hogan at 220-8474.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

Thank you for your assistance,

With Regards,

ORIGINAL SIGNED

Clare Hildebrandt
Research Associate
MSc Candidate
Department of Community Health Sciences
University of Calgary

ORIGINAL SIGNED

Dr. David Hogan
F.A.C.P., F.R.C.P. (C)
Professor
Head, Division of Geriatric Medicine
University of Calgary

APPENDIX P: Inclusion and Exclusion Criteria

Eligibility will be determined using the following inclusion and exclusion criteria:

Inclusion criteria:

- Participant must be a caregiver of a person with dementia for at least six months.

Since dementia is a chronic disease and its effects on caregiver burden may not become apparent during the first months since diagnosis of dementia in the care receiver, a six-month exposure period is used. The diagnosis of dementia will be determined through proxy-report by the caregiver; however, the severity of dementia will be determined with the use of the Activities of Daily Living Scale, the Instrumental Activities of Daily Living, and the Neuropsychiatric Inventory Questionnaire.

- Caregivers must be sufficiently literate in the English language in order to complete the questionnaires, as evaluated by self-report of the participant.
- The person with dementia must be living in the community (an eligibility requirement for ADSP services at the Alzheimer Society of Calgary).

Exclusion criteria:

- Major physical illness of the caregiver in an acute phase preventing the completion of the questionnaires, as evaluated by self-report of the participant.
- Institutionalization or death of the person with dementia after selection into the study and before the questionnaire is administered. This will decrease the influence such life events have on caregiver burden from influencing the results.

APPENDIX Q: Eligibility Questionnaire

This eligibility questionnaire is to be administered by telephone by the Alzheimer Society of Calgary's Director of Adult Day Support Programs (A.K.A. Research Associate/Student). Discussion of the study and consent procedures precedes the following questions.

PARTICIPANT ID : _____

1. Are you able to read and write in English?

- Yes
 No (End interview)

2. How long have you been caring for _____?

- More than 6 months
 Less than 6 months (End interview)

3. Are you interested in participating in the study we discussed earlier?

- Yes
 No (End interview)

4. Discuss mailing of questionnaire package, and return of package.

Date Package Sent: _____

Date Thank You/Reminder Sent: _____

Date Reminder Sent: _____

Date Completed Package Received: _____

APPENDIX R: Request for Further Information

IF YOU ARE INTERESTED IN INFORMATION OR RESULTS FROM THIS STUDY, PLEASE FILL OUT THIS FORM AND RETURN IT IN AN ENVELOPE SEPARATE FROM THE QUESTIONNAIRE TO THE ADDRESS BELOW.

1. I am interested in a summary report of these study results

Yes
 No

2. I am interested in an information pamphlet about caring for someone with Alzheimer Disease or Dementia

Yes
 No

3. May we contact you to follow-up on the questionnaire?

Yes
 No

Name: _____

Address: _____

City: _____ Postal Code: _____

Phone Number:

Please Return to: Clare Hildebrandt
Department of Community Health Sciences
Heritage Medical Building,
3330 Hospital Drive N.W.,
Calgary, Alberta, T2N 4N1

APPENDIX S: Information Package Contents

Information packages mailed to interested study participants included:

- Alzheimer Disease: A Handbook for Care (ASC, 2000);
- What is Alzheimer Disease? (ASC, 2002);
- First Steps: For Families of Those Recently Diagnosed with Alzheimer Disease (ASC, 2002);
- First Steps: For Those Recently Diagnosed with Alzheimer Disease (ASC, 2002);
- Are you Providing Alzheimer Care? 10 Signs of Caregiver Stress (ASC, 2000);
- Reducing Caregiver Stress: Finding Ways to Feel Better (ASC, 2000);
- Ways to Help: Assisting Families Living with Alzheimer Disease (ASC, 2001);
- Research: Alzheimer Disease and Risk Factors (ASC, 2001);
- Research: Alzheimer Disease and Heredity (ASC, 2001);
- Drugs: AriceptTM (also known as donepezil or E2020) (ASC, 2002);
- Drugs: ExcelonTM (also known as rivastigmine) (ASC, 2002);
- Drugs: ReminyTM (also known as galantamine hydrobromide) (ASC, 2002);
- Day to Day: Communication (ASC, 2003);
- Day to Day: Bathing (ASC, 2002);
- Day to Day: Meal Time (ASC, 2003);
- Day to Day: Grooming (ASC, 2002);
- Day to Day: Toileting (ASC, 2002);
- Day to Day: The Progression of Alzheimer Disease (ASC, 2003);
- Day to Day: Caregiving Options: Considering Long-Term Care (ASC, 2003);
- Day to Day: Adjusting to Long-Term Care (ASC, 2003);
- as well as information advertising upcoming workshops and events for caregivers held at the Alzheimer Society of Calgary.

APPENDIX T: Thank You and Reminder Letter (two weeks after entry)

PRINTED ON UNIVERSITY OF CALGARY LETTERHEAD

Research Project: Waiting for a Space in an Adult Day Support Program: *Retrospective Caregiver Perspectives.*

Dear Participant,

Thank you for agreeing to participate in the above study. Your participation will, in combination with other published data, give health care professionals a better understanding of what it is like to care for someone with dementia and what it is like to be waiting for access into an Adult Day Support Program.

If you haven't sent in your completed questionnaire, please attempt to find some time to do so. If you no longer wish to participate in this study, or have misplaced your questionnaire package, please contact me, Clare Hildebrandt at 290-0110.

If a completed questionnaire package is not received two weeks from now, an additional reminder with a new questionnaire package will be mailed to this address. That will be the final reminder that you will receive regarding the questionnaire that was sent to you about caregivers and waiting for access to an Adult Day Support Program.

Participation in the survey is voluntary and responses are confidential.

If you have any questions or concerns, please feel free to contact me at 290-0010. Thank you once again for your contribution to our understanding of what it is like to care for someone with dementia.

Sincerely,

ORIGINAL SIGNED

Clare Hildebrandt,
Director, Adult Day Support Programs, Alzheimer Society of Calgary
Research Associate, Department of Community Health Sciences, University of Calgary

APPENDIX U: Final Reminder Letter (one month after entry)

PRINTED ON UNIVERSITY OF CALGARY LETTERHEAD

Research Project: Waiting for a Space in an Adult Day Support Program: *Retrospective Caregiver Perspectives.*

Dear Participant,

This is a reminder that we have not yet received your completed questionnaire. This is the last reminder that you will receive regarding the questionnaire that was sent to you about caregivers and waiting for access to an Adult Day Support Program. Please find another survey questionnaire enclosed, in the event that you have misplaced yours.

This information, in combination with other published data, will give health care professionals a better understanding of what it is like to care for someone with dementia and what it is like to be waiting for access into an Adult Day Support Program. If you wish only to receive information about caring for someone with Alzheimer Disease or another dementia you are welcome to request this information, and we would be most happy to send it to you.

Participation in the survey is voluntary and responses are anonymous. If you have any questions or concerns, please feel free to contact me at 290-0010. Thank you.

Sincerely,

ORIGINAL SIGNED

Clare Hildebrandt,
Director, Adult Day Support Program, Alzheimer Society of Calgary
Research Associate, Department of Community Health Science, University of Calgary

APPENDIX V: Letter of Support – Alzheimer Society of Calgary

Alzheimer Society
CALGARY

June 20, 2003

To Whom It May Concern:

Re: Letter of support for study by Ms. Clare Hildebrandt

On behalf of the Alzheimer Society of Calgary, I am pleased to provide support to Ms. Hildebrandt in conducting "Waiting for a Space in an Adult Day Support Program: Retrospective Caregiver Perspectives".

The Alzheimer Society of Calgary believes the availability of Adult Day Support programming is vitally important to the quality of life for both the person with dementia and their family caregivers. Ms. Hildebrandt is completing the study as part of her Master's thesis. The study will have value for us in assessing the impact on families waiting to access Adult Day Support Programs.

Ms. Hildebrandt is employed by our organization as the Director, Adult Day Support Programs. She is committed to this project and had designated appropriate time for its successful completion.

Sincerely,

Barbara Ferguson
Executive Director



ALZHEIMER SOCIETY OF CALGARY
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APPENDIX W: Letter of Support – Supervisory Committee

UNIVERSITY OF
CALGARY

FACULTY OF MEDICINE**Professor**

The Brenda Strafford Chair of Geriatrics
Health Sciences Centre
3330 Hospital Drive N.W.
Calgary, Alberta. T2N 4N1
Telephone: (403) 220-4578
Fax: (403) 283-6151
Email: dhogan@ucalgary.ca

June 23, 2003

The Centre for the Advancement of Health

To Whom It May Concern:

RE: THESIS PROPOSAL/CLaire Hildebrandt

I chair the Supervisory Committee of Claire Hildebrandt. On behalf of the Committee I am pleased to state that her thesis proposal has been reviewed and accepted by the Committee.

We will be requesting expedited review as the research protocol involves no more risks than those ordinary encountered in daily life. Also, the protocol does not involve any therapeutic interventions.

Yours truly,

Dr. David B. Hogan, Chair,
Supervisory Committee for Claire Hildebrandt
(MSc Candidate, Department of Community Health Sciences)

APPENDIX X: Ethics Approval – Conjoint Health Research Ethics Board



UNIVERSITY OF
CALGARY

FACULTY OF MEDICINE

Office of Medical Bioethics
 Heritage Medical Research Building/Rm 93
 Telephone: (403) 220-7990
 Fax: (403) 283-8524

2003-07-31

Dr. D.B. Hogan
 Department of Medicine
 University of Calgary
 Calgary, Alberta

Dear Dr. Hogan.

RE: Waiting for a Space in an Adult Day Support Program: Retrospective Caregiver Perspective

Grant-ID: 17242

The above-named research project (dated June 20, 2003) has been granted ethical approval by the Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions. The Board conforms to the Tri-Council Guidelines, ICH Guidelines and amendments to regulations of the Food and Drug Act re clinical trials, including membership and requirements for a quorum.

The study meets the requirements of the Health Information Act.

You and your co-investigators are not members of the CIHREB and did not participate in review or voting on this study.

Please note that this approval is subject to the following conditions:

- (1) you must obtain approval from your appropriate institution where the research project will be conducted (if applicable);
- (2) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (3) a Progress Report must be submitted in one year, 2004-07-31, containing the following information:
 - (i) the number of subjects recruited;
 - (ii) a description of any protocol modification;
 - (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - (iv) a summary of any recent literature, funding, or other relevant information, especially information about risks associated with the research;
 - (v) a copy of the current informed consent form;
 - (vi) the expected date of termination of this project.
- (4) a Final Report must be submitted at the termination of the project.

Please accept the Board's best wishes for success in your research.

Yours sincerely,

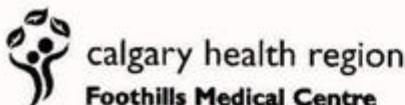
Christopher J. Dolg, MD, MSc, FRCPC
 Chair, Conjoint Health Research Ethics Board

CJD/jd

cc: Adult Research Committee
 Dr. J. Cooley (Information)
 Research Services

APPENDIX Y: Institutional Approval – Adult Research Committee – Calgary Health Region

Foothills Medical Centre
1403 29 Street NW
Calgary, Alberta, Canada T2N 2T9
website www.calgaryhealthregion.ca



05 August 2003

Dr. David Hogan
Department of Medicine
University of Calgary

Dear Dr. Hogan:

Re: #17242 - Waiting for a Space in an Adult Day Support Program: Retrospective Caregiver Perspective

Thank you for submitting an application regarding the above project for review by the Adult Research Committee of the Calgary Health Region (CHR). This will confirm that the committee has granted institutional approval for this project, **contingent on approval by the Conjoint Health Research Ethics Board**.

It is understood from your submission that your study will be entirely funded through external sources and that the CHR will be reimbursed for all research costs associated with this project if applicable. To facilitate a smooth startup of your project, please notify affected departments in the Region well in advance of your intent to initiate this study.

Please note that it is a requirement that you communicate in writing the study results to the CHR Adult Research Committee, and provide any copies of publications arising from the research as well as provide feedback regarding any problems encountered during the course of the study.

Please accept the committee's best wishes for success in your research.

Yours sincerely,

A handwritten signature in black ink, appearing to read "John Jarrell".

John Jarrell, MD
Interim Chair, Adult Research Committee

cc: Dr. T. Noseworthy, Conjoint Health Research Ethics Board