Adult Day Centre Respite Care:
Research Design of a Study to Assess the Efficacy of Caregiver Respite

Ashley Stoppler
B.Sc., University of Northern British Columbia, 2003

Project Submitted in Partial Fulfillment of
The Requirements for the Degree of
Master of Business Administration

© Ashley Stoppler, 2009
Abstract

Persons diagnosed with dementia have been recognized as a client group within Northern Health that requires specialized care. Care is currently provided through Long Term Care Case Management, residential Complex Care and Assisted Living, Home Support, Adult Day Centres, in-home and facility respite, and in the client’s home by family members and private caregivers. With an aging population predictive of an increased number of dementia clients, Northern Health recognizes that the current methods of providing care may not be sufficient to sustain clients and caregivers in the future. This project designs a study that examines the effects of respite care for dementia clients on the burden felt by their caregivers. It is hypothesized that mean scores of caregiver burden reported by primary informal caregivers of dementia clients, as measured by the Zarit Burden Interview, will be lower for members of the treatment group (consisting of caregivers utilizing the respite services of the Rainbow Adult Day Centre) than for members of the control group (consisting of caregivers who are not utilizing the respite services of the Rainbow Adult Day Centre).
Table of Contents

Abstract .......................................................................................................................... ii
Acknowledgements ........................................................................................................ iv
Introduction ....................................................................................................................... 1
Organizational Background ............................................................................................... 4
  Northern Health ............................................................................................................. 4
  Prince George Regional Hospital ................................................................................ 5
  Dementia Clients in Prince George ............................................................................... 6
Literature Review ............................................................................................................. 8
  Caring for Clients with Dementia ................................................................................ 8
  Measuring Caregiver Burden ...................................................................................... 11
  Adult Day Care as a Respite Service .......................................................................... 14
  Research Methodology .............................................................................................. 18
  Conclusion ................................................................................................................. 22
Research Design and Study Implementation Prospects ................................................ 24
  Research Project Rationale ....................................................................................... 24
  Rainbow Adult Day Centre as a Respite Provider ................................................. 25
  Research Question ................................................................................................... 26
  Intended Use of Research Results ........................................................................... 27
  Research Design Methodology .................................................................................. 27
    Setting .................................................................................................................... 30
    Procedure ............................................................................................................... 31
    Measures ................................................................................................................. 31
  Operational Considerations ....................................................................................... 34
    Caregiver Interest .................................................................................................. 34
    Human Resources ................................................................................................ 36
    Support Services ................................................................................................... 37
    Special Considerations ......................................................................................... 38
Research Dissemination ................................................................................................ 39
  Discussion ................................................................................................................ 41
Appendices ..................................................................................................................... 43
  Appendix A - Effect Sizes for Respite Interventions: Burden .................................... 43
  Appendix B - Characteristics of Selected Studies Measuring the Effects of Psychosocial
    Interventions on Caregiver Burden ........................................................................ 44
  Appendix C – Rainbow Adult Day Centre Survey (2008) ........................................ 46
  Appendix D – Program Satisfaction Survey ............................................................ 47
  Appendix E – Zarit Burden Interview ...................................................................... 49
  Appendix G – Consent Form (Control Group) .......................................................... 54
  Appendix H – Consent Form (Treatment Group) ..................................................... 57
  Selected Bibliography ............................................................................................... 61
Acknowledgements

Acknowledgment is extended for the support of my supervisor, Dr. Steven Cronshaw, whose patience and guidance has allowed me to complete this project. My thanks are also extended to my colleagues at Northern Health for their advice and support throughout this project, and in particular to the Home and Community Care managers who offered their insight and expertise in the field of dementia care. Your dedication to the people of the North is truly appreciated.

To my friends and family that have talked me “off the ledge,” let me cry on their shoulders, then gave the kick that was needed to motivate me - thank you! Your understanding and encouragement played a significant role in allowing me to complete this project and the MBA program overall with my sanity still intact.

Finally, to my classmates in the MBA graduating class of 2009, I can not imagine having completed this program without you. I wish you all the best of luck in your future endeavors.
Introduction

Dementia, defined by *The Diagnostic and Statistical Manual of Mental Disorders* (4th Edition) as “multiple cognitive deficits that include impairment in memory” (American Psychological Association, 1994, p. 135), is a condition that exists in many forms, most of which are chronic and progressive. Symptoms become apparent slowly, often taking months or years to progress. According to the Northern Health Clinical Practice Guidelines, an individual’s functional ability and physical health deteriorate until the client requires constant care (Northern Health, 2005, p. 2). Clinical features include a global impairment of intellect and memory, changes in personality, and often a progressive impairment of language, insight and judgment (American Psychological Association, 1994).

With such a complex condition, the care required by dementia clients is quite specialized and the provision of client-centred care is key, as each individual’s symptoms, abilities and impairments are different. Individuals with dementia reportedly receive more care from family members than do any other illness or disability-based client group (Wimo, et al., 2002 as cited in Mavall and Thorslund, 2006), thus the importance of supporting these caregivers. It has been reported that caregivers of clients with dementia experience a more substantial burden than those caring for clients with other conditions, and that these caregivers of clients with dementia are especially vulnerable to burnout (Derence, 50). The Family Caregiver Alliance (as cited in Derence, 2005) reports that the levels of stress and fatigue encountered by dementia caregivers place “both the caregiver and the person with dementia at risk and is one of the most cited reasons for early institutionalization” (p. 50-51).
Respite services, defined as “services or programs that provide short- or medium-term substitute care of the person being cared for” (Shanley, 2006, p. 234) have been one form of intervention offered to caregivers of dementia clients for several decades. In Prince George, Northern Health currently offers respite as an intervention to caregivers of clients with a range of illnesses via overnight in-home care through the services of a Community Health Worker, in a facility through three short-stay facility beds, and on a regular part-time basis at the Rainbow Adult Day Centre (RADC). As Northern Health currently does not have the capacity to expand the in-home and residential respite care services, this project focuses on the use of the RADC in respite provision.

Of particular interest is the determination of the impact of a respite program on levels of caregiver distress. With a waitlist already in place, Northern Health is exploring the option of expanding the hours offered by the RADC to provide respite specifically to caregivers of dementia clients who are not already RADC clients. It is anticipated by the managers of the Home & Community Care programs that oversee the RADC and Home Care that the provision of this service would offer appropriate and economical support to the primary informal caregivers of dementia clients, allowing them to maintain the client in the community for a longer period of time, as well as providing a more seamless transition to facility care when the client can no longer be supported at home.

The outcome of the resulting research study is thus of significance in two primary aspects: supporting families, many of whom want to maintain their relative in the home for as long as possible (Collins, King, and Kokinakis, 1994), which is in alignment with the wish of most elderly people to age in place, avoiding institutionalization and remaining in their
homes (Zank and Schacke, 2002); and, providing a cost-effective model of care, as an American study estimated that a one-month delay in Complex Care admission for dementia clients could save the healthcare system $1 billion a year (2001 National Alzheimer’s Association Study, as cited in Derence, 2005). According to a leading researcher in this field, Steven Zarit (1994), “the willingness and ability of families to continue providing assistance is critical, both from the perspective of giving personalized care to the elder and for keeping the costs of long-term care within manageable limits” (p. 351). As such, it will also be of interest to examine whether the provision of respite will assist caregivers in supporting dementia clients in the community for a longer period of time rather than those who do not utilize the respite services.
Organizational Background

Northern Health

Northern Health is an organization under British Columbia’s Ministry of Health which is responsible for delivering healthcare (acute care, mental health, public health, addictions, home & community care services) to the 310,000 residents in Northern British Columbia. As displayed in Figure 1, Northern Health is responsible for the delivery of care across almost two-thirds of British Columbia, with boundaries set as the Northwest and Yukon Territories to the North, the BC Interior to the South, Alberta to the East, and Alaska and the Pacific Ocean to the West.

Figure 1. Map of Northern Health

Within Prince George, Northern Health receives provincial funding for 200 inpatient acute care beds (Prince George Regional Hospital) as well as 282 complex care beds and 52
assisted living beds within the city’s Home & Community Care (H&CC) facilities. In addition, as of March 2009, Northern Health has opened 36 un-funded complex care beds to cope with the high need for residential care within Prince George. In the summer of 2009, the Gateway Project, a 94 bed complex care facility and 50 assisted living beds is expected to open in Prince George.

Prince George Regional Hospital

Prince George Regional Hospital (PGRH) is at the centre of Northern Health, directly serving a community of over 83,000 individuals, while also supports the care of the population of the rest of the region. For the last several years, PGRH has been faced with serious congestion in the flow of patients throughout the hospital. On a regular (sometimes daily) basis, the demand for hospital care exceeds the capacity at PGRH. One of the primary factors contributing to the bottleneck is the high volume of clients residing in the hospital who are awaiting placement in a long term care facility (either Assisted Living or Complex Care). These clients are deemed Alternate Level of Care (ALC), as they do not require the hours, nor acuity of care typically provided by staff in a hospital environment, but are unable to be placed in an appropriate facility due to a lack of available beds in long term care facilities. As such, they are forced to reside in an acute care ward at PGRH until an appropriate bed becomes available. The typical ALC client is an elderly individual who has been cared for at home by a primary informal caregiver, but has been admitted to PGRH for an acute episode. Upon recovery from the acute incident, a patient would normally be discharged home, but the ALC client is unable to return to his or her home for any number of reasons including increased level of care required and caregiver burnout. As of March 19,
2009, 16% of acute care beds at PGRH were being occupied by ALC clients, with 12 of the
32 ALC clients (37.5%) having a diagnosis of dementia. Not only are the ALC clients
utilizing beds and nursing care that could be redirected to acute care patients, but they may
be unable to receive the specialized care that dementia patients require.

Even after placement on the ALC list for placement in residential care, clients are not
guaranteed the next available bed, as there are also clients on the Emergency Community
Waitlist seeking long term care. This list consists of clients currently being cared for in the
community, but by caregivers who are approaching the point of being unable to manage the
client in the home. As of March 19, 2009, there were 7 clients on the Emergency
Community Waitlist, with 6 of them having been diagnosed with dementia. Clients on this
list are at risk for admission to PGRH at any given moment, should a crisis occur at home or
the caregiver reaches the breaking point and can no longer provide care.

Dementia Clients in Prince George

Though only 9.44% of Prince George’s current population is comprised of individuals
65 years of age or over (the age range during which dementia beings to become apparent),
Northern Health’s Environmental Scan: 2006-2009 indicates that the growth rate of this
population, at 20%, is double that of the population as a whole (Northern Health, 2006, p.
39). The Canadian Study of Health and Aging Working Group reported that an estimated
252,600 Canadians had dementia in 1991, with an anticipated 60,150 new cases being
diagnosed each year (p.10). Combined with the prediction that all other age groups will see a
slow decline in population, or at best, very slow growth, it can be anticipated that there will
be more dementia clients requiring care, fewer caregivers available, and thus greater demand
placed upon healthcare’s already overtaxed programs and services. With fewer caregivers likely to be available, Northern Health must examine the methods in which care is and can be provided most effectively and efficiently to this key demographic.

The primary deliverable for this project is to formulate a research study through which Northern Health can pilot a respite program at the RADC specifically targeting dementia clients and their primary informal caregivers. This study will allow for the collection of empirical evidence surrounding the impact of respite on the level of burden felt by the caregiver and thus provide data for decisions to be made by Northern Health with respect to care for clients with dementia.
Literature Review

In order to develop a well-rounded study of the impacts of respite via the RADC on the level of burden felt by informal caregivers, it was important to thoroughly review the research which has been conducted throughout the world. The literature review begins with an overview of who is providing care to dementia clients in the community and a description of the levels of effort and time committed to their caregiving duties. This data provides readers with an understanding of how significant an undertaking the commitment to caregiving is. In order to focus the review more narrowly, caregiver burden is then discussed, with specific focus on the research that has been performed over the last 30 years to measure the effects of interventions on levels of self-reported caregiver burden. As the intended research study focuses on the use of respite as an intervention, further literature is reviewed to examine the impact this particular intervention has on primary informal caregivers. Finally, the research methodology of the reviewed studies is reflected on to formulate an effective methodology for the Northern Health research study, in order to avoid the pitfalls of previous work that has been inconclusive, as well as to ensure that the new study’s results can be compared to the body of research currently in existence.

Caring for Clients with Dementia

Substantial research has been performed on the best practices for the provision of care for clients with dementia. Of specific note are Northern Health’s Clinical Practice Guidelines (2005), with information collected from leading names in dementia research, and Duffin’s (2007) best practice recommendations. Articles such as “Nonpharmacological
Interventions for Persons with Dementia” (Cohen-Mansfield, 2005), which identify proven methods of intervention are also abundant, as dementia research is a key focus of gerontological study. Works such as these provide an understanding of the care needs of dementia clients, which is imperative in determining the benefits and/or costs of alternative models of care to the client.

A literature review focused on measuring the cost effectiveness of respite (Keefe and Manning, 2005) revealed that approximately 50% of people with dementia continue to reside at home, and 97% of this group have caregivers, most of which are likely informal (unpaid). Of the caregivers, 70% are female, with approximately half being either daughters or wives of the dementia client. 30% of the caregivers remain in the workforce. 50% of caregivers are at least 65 years old, with 36% of them aged 71 or over. Brodhead (as cited in Keefe and Manning, 2005) is quoted as saying that the primary informal caregivers who assume the responsibilities of caring for dementia clients in Canada are “the invisible back-up that allows our health care system to keep functioning as it continues to shift away from institutionalized care” (p. 4). Without friends and family members who are dedicated to providing safe and compassionate care in the home, our health care system would collapse under the pressure for more residential services.

The primary informal caregivers who look after dementia clients in the home devote extensive time to the client. A 2004 survey by the National Alliance for Caregiving and AARP, cited in Derence (2005), reported that caregivers of dementia clients face a disproportionately heavy burden compared to those looking after clients with other diagnoses. Derence also states that, compared to their caregiving peers, dementia caregivers
are especially vulnerable to reaching the point of severe burnout. At this point, levels of
caregiver stress and fatigue place both the caregiver and the care recipient at risk of harm or
early institutionalization.

As reported in Gottlieb and Johnson (2000), Cox’s 1997 research reported that 121
hours of caregiving are provided per week by informal caregivers, and Zarit, Stevens,
Townsend, and Greene’s 1998 study further broke down the time commitment to include: 4.9
hours per day assisting with Instrumental Activities of Daily Living (i.e. preparing food,
cleaning house, managing medications), 5.5 hours per day managing behavioural issues, 5.5
hours per day handling cognitive problems, and 3.3 hours per day of general supervision. In
addition to the time commitments made by caregivers, personal costs associated with caring
for a family member with dementia are significant. Arno et al. (1999, as cited in Gaugler,
Jarrot, Zarit, Parris Stephens, and Townsend, 2003) report that the informal care costs (i.e.
lost employment opportunities, increased healthcare utilization, opportunity costs) associated
with an informal caregiver may be more than double the financial expenditures of formal
long-term care services.

Unfortunately, demographic trends examined by Jarrott, Zarit, Berg, and Johansson
(2000) indicate that the number of potential informal caregivers will not grow at the same
rate as the population requiring care. Trends affecting the pool of informal caregivers
include higher divorce rates and the resultant rise in single-parent homes, as well as the
increase in female labour force participation. With many adults now raising children alone
and more women working outside the home, the ability or willingness to take on care
responsibility for elderly relatives may be diminished. Not only will these trends affect the
number of available caregivers, but also the amount of time that the caregivers may have to devote to the client. Informal caregivers who work outside of the home often make alterations to their work schedules (i.e. reducing hours, changing shifts, rejecting promotions) to accommodate their caregiving responsibilities. Scharlach and Boyd (as cited in Jarrot et al. 2000) reported that employed informal caregivers miss 50% more work days than non-caregivers and that 40% of these caregivers report that their caregiving duties interfere with their employment.

Measuring Caregiver Burden

The need for caregivers to maintain their own physical and mental well-being is paramount to their continued support of the clients they care for. As quoted in Lund, Wright, Caserta, and Utz (2006):

Looking out for your own well-being is similar to being a passenger on an airplane and being told that in case of an emergency you should place the oxygen mask on yourself first before caring for someone else. Why? Because you can be a more effective caregiver if you are healthy, happy and alive (p.3).

Empirical research on the topic of caregiver burnout began with Zarit, Reever & Bach-Peterson’s 1980 study, which described the development and initial use of the Zarit Burden Interview to measure the burden felt by caregivers of the impaired elderly (Knight, Lutzky, and Macofsky-Urban, 1993). In the decades since that time, substantial research has been performed on the effects of interventions in reducing caregiver stress and burden (e.g.,
Though research has been plentiful, the findings have been contradictory. Early research, conducted using subjective rating methodology, reported positive findings with high levels of satisfaction and improved ability to cope among the caregivers (Barnes, et al., 1981, Aronson, et al., 1984, Glosser & Wexler, 1985 as cited in Carradice, Beail, and Shankland, 2003). Later studies found that interventions have a very small impact on the caregivers’ perceived burden or stress (Gaugler and Zarit, 2001, Gottlieb and Johnson, 2000).

Knight et al. (1993) recognized the contradictions in findings pertaining to caregiver distress and conducted a meta-analytic review of the associated research from 1980-1990, with a focus on the use of data to provide recommendations to aid in future research pertaining to the subject of caregiver distress. Upon review of 18 peer-reviewed published studies, 10 of the studies were found to have had sufficient data to calculate the size of the intervention effect. Effect size is defined by Knight et al. as “the difference between the change in the intervention group and the change in the comparison group divided by the standard deviation. An effect size of 0 would indicate no difference. In general, an effect size of 1 is considered strong, .5 moderate, and .3 is small” (p. 241). One area specifically examined in the meta-analysis was the impact of respite on caregiver burden, the findings of which are detailed in Appendix A. Of the studies which measured burden specifically, the average effect size is calculated at only 0.15. However, the range of effect sizes between the studies is large, which may be due to factors including, but not limited to, the significant difference in interventions studied and differing moderator effects. To compare results
better, Knight et al. removed the studies which compared interdisciplinary assessment and case management in the hospital setting on post-discharge outcomes, as well as those which examined home health services. They were left with six studies and then removed the two studies in which the participant groups could have differed on respite received, but did not because the comparison group was also receiving high levels of respite. The four groups from the three studies that remained in the analysis (see bolded entries in Appendix A) showed an average effect size of 0.63, which would indicate that there was a moderate to strong impact of respite on caregiver burden.

Thompson and Spilsbury (2004), as reported in Pinquart and Sorensen (2006), completed a narrative review of six studies of the effects of interventions on caregivers of clients with Alzheimer’s Disease. Their conclusion was that there was “little or no evidence for a quantifiable effect of interventions” (p. 578). Similarly, Brodaty et al. (2003), in a meta-analysis of 30 studies, found that while there were positive intervention effects on the aspects of psychological morbidity, caregiver knowledge and patient mood, there was not a positive effect on caregiver burden.

Pinquart and Sorensen (2006) sought to bring some clarity to the subject by performing a meta-analytic review of 127 studies in which:

- The client had been diagnosed with dementia
- There was a comparison between an intervention condition and a control condition not receiving the intervention
• At least one of the following was measured and reported: caregiver burden, depression, self-reported well-being, knowledge and/or coping abilities of the caregiver, client symptoms, institutionalization
• Statistics could be converted into effect size
• Studies were written in either English or German, or could be translated to either language

Of the 127 applicable studies, caregiver burden was measured in 85 studies (32 using the Zarit Burden Interview and 53 using other scales). Statistical analysis of these studies indicated that the interventions examined did have “statistically significant immediate effects on caregiver burden…” (p. 584).

*Adult Day Care as a Respite Service*

Of particular interest in this review of the literature is study of the provision of respite services through adult day care programs. Originally developed in the United Kingdom during World War II, adult day centres were utilized in the rehabilitation of the elderly, and became widely used during the de-institutionalization movement in the United States during the 1960s (Weissert, 1976 as cited in Gaugler et al., 2003). Adult day care, though offered throughout the world, is a diverse concept with many differences between the care offered, activities provided, operating hours, admission requirements, staff training, etc. However, many adult day care centers share the same goals: to create a meaningful day for the participant; to offer respite to family caregivers; and, to provide care for the client (Samuelsson et al., 1998 as cited in Mavall & Malmberg, 2007).
The use of adult day centres in the provision of respite allows informal caregivers (often family members) the opportunity to give up their caregiving duties for a specified period of time, easing their responsibilities on a temporary basis. While caregivers do use respite to allow themselves a break from care provision, it may also be utilized so that the caregiver can work outside of the home, travel, or preserve a high quality family life. As such, the hypothesis exists that the use of adult day care centres “should reduce the emotional and psychological distress of caregiving” (Gaugler et al. 2003, p. 39).

The literature regarding the care of dementia clients in adult day centres is abundant and researchers have studied both the centres’ impact on the client as well as the effect on the caregiver. Gaugler et al. (2003) examined the effect of adult day centre usage on the time caregivers spent managing behavioural problems, Activities of Daily Living, Instrumental Activities of Daily Living, as well as the caregivers’ general perceptions of the care recipient’s impairment. The results from this study indicate that this method of respite moderates the time spent coping with behaviour problems and that use of the service over a three month period “may exert potential positive psychosocial and behavioral effects not only on the caregivers, but on their community residing elderly relatives who have dementia as well” (p. 52).

Måvall and Thorslund (2006) examined whether day care provided an effective form of respite for 90 caregivers of dementia clients. 51 of the caregivers met the inclusion criteria of the study and were asked to assess their feelings of worry, depression, over load and role captivity prior to the client commencing day care and again after four months of usage. The findings show that day care may be an effective method of respite provision, but
that it is most beneficial to the caregivers of clients in the early stages of dementia, and who have not yet had enough time to reach high exhaustion levels.

Using the theory that maintaining enrollment in a day care centre for a long period indicates that the respite services are beneficial to the client, and that short periods of enrollment indicate no benefit to the client, Måvall and Thorslund (2007) also looked at the reasons why day care was discontinued. Findings from this study showed that only the caregivers whose clients discontinued service within four months found no benefit for either themselves or the care recipients. It should be noted that all of the clients who discontinued day care services had severe behavioural problems, and it is thus theorized that day care centres were unable to meet the specialized needs of those clients.

Gottlieb and Johnson (2000) discussed whether day care is an effective method of respite for dementia caregivers, recognizing that “respite ranks among the most urgently desired community services” (p. 119), but that the demand for respite outweighs the actual utilization. Their literature review indicated that, for many caregivers, adult day centre-based respite may actually act as a conduit between in-home and residential care. With residential care placement rates of 26% within 6 months of respite commencement and 44% within 12 months of commencement, it appears that the day centre services may ease caregivers out of their full-time role as caregiver and cause them to be more willing to find a permanent residential facility placement for the dementia client. However, for caregivers who do not seek placement for the care recipient, the authors recognize that respite does provide an opportunity for caregivers to exert some control over their exposure to the stressors they
encounter during care provision. Given how much care provision constrains the daily lives of caregivers, this opportunity to exercise control may be especially beneficial.

Personal reports of caregiver experiences with community services such as adult day cares are discussed in the work by Collins et al. (1994), Beisecker, Wright, Kasal Chrisman and Ashworth (1996), and Cotrell (1996). Collins et al. found that, of 68 dementia caregivers who admitted clients to residential care, 20% felt that adult day care would have been very important in terms of delaying institutionalization, and another 32% felt that it would have been somewhat important. Study participants also indicated that night care, either provided in-home or at a facility, would be a potentially useful service in delaying admission into residential care.

Beisecker et al. (1996) report that caregivers who use out-of-home respite services, such as adult day centres, show lower levels of emotional stress and less strain between themselves and their care recipients. Similar to Collins et al. (1994), they also indicate that there is demand for overnight care. Unlike care recipients with purely physical problems, dementia clients require 24 hour care, as most do not sleep through the night and require constant monitoring.

Studies conducted using randomized experimental designs with both treatment and control groups which examined if the use of adult day care programs impacted caregiver adaptation found that such respite programs had little impact on the levels of stress or depression felt by caregivers. According to Gaugler et al. (2003), these studies had strong experimental designs which likely did not skew results. However, they noted that caregivers
in the treatment groups often utilized low levels of the respite service, which made it unclear as to what effect the respite intervention could have had on caregiver outcomes.

Research Methodology

Part of the discrepancy in findings when studying caregiver intervention is likely related to the inconsistency in research composition. Studies have often been comprised of small sample sizes, may or may not have contained a control group, been both quantitative and qualitative, consist of case studies and program reports, and often have little theory guiding the intervention (Knight et al., 1993, Carradice, Beail, and Shankland, 2003). The combination of these factors limits the comparability of the currently available research. The examination of meta-analytic reviews of studies which sought to reduce caregiver burden are especially enlightening in that they both summarize the findings from numerous studies on this topic, as well as provide suggestions as to how to examine interventions in a more scientific fashion, allowing for replication in future studies and comparability of results (e.g., Knight et al., 1993; Pinquart, Sorenson, 2006).

Appendix B, adapted from Brodaty et al.’s 2003 meta-analytical study provides an overview of research from the last two decades which examined psychosocial interventions on caregiver burden. During their review of past research, the authors developed criteria for rating the quality of the studies. This criteria assigned numeric values to: design format; subjects; validity of outcomes; statistical significance; results (see Table 1). Of the 16 studies detailed in this chart, three were classified by the researchers as having been of poor quality, two as having been of good quality, and the other 11 falling somewhere in between. Such
low quality scores for the research indicate that there is significant room for improvement in the research methodology being employed in the study of the impact on caregiver burden.

Table 1

Criteria for Rating Quality of Studies

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td></td>
</tr>
<tr>
<td>Randomized</td>
<td>1</td>
</tr>
<tr>
<td>Controlled (or comparison group used)</td>
<td>1</td>
</tr>
<tr>
<td>Subjects</td>
<td></td>
</tr>
<tr>
<td>Use of standardized diagnostic criteria</td>
<td>1</td>
</tr>
<tr>
<td>All subjects accounted for/withdrawals noted</td>
<td>1</td>
</tr>
<tr>
<td>Outcomes</td>
<td></td>
</tr>
<tr>
<td>Well-validated, reliable measures (caregiver and/or patient)</td>
<td>1</td>
</tr>
<tr>
<td>Objective outcome (e.g., institutionalization or death)</td>
<td>1</td>
</tr>
<tr>
<td>Questionable/unreliable outcome measure</td>
<td>0</td>
</tr>
<tr>
<td>Statistics</td>
<td></td>
</tr>
<tr>
<td>Statistical significance considered</td>
<td>1</td>
</tr>
<tr>
<td>Adjustment for multiple comparisons</td>
<td>1</td>
</tr>
<tr>
<td>Evidence of sufficient power</td>
<td>1</td>
</tr>
<tr>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>Blind ratings</td>
<td>1</td>
</tr>
<tr>
<td>Follow-up assessment 6 months or beyond</td>
<td>1</td>
</tr>
</tbody>
</table>

Good quality: >7
Poor quality: <5

One of the key factors in creating a study with strong research methodology is the selection of a measurement tool, a fact that Knight et al. identify in their 1993 meta-analysis of caregiver distress. There is a wide array of tools available to study the levels of caregiver burden: Brief Symptom Inventory; Caregiver Hassles Scale; Ranking Scale; Screen for Caregiver Burden; Minimum Data Set Home Care (MDS-HC); Modified Caregiver Strain

---

Index (CSI); Montgomery Subjective Burden Measure; Zarit Burden Interview (ZBI); etc. Unfortunately many researchers who use these tools do not report validity or reliability measures in their studies, leaving readers to question the measurements. As noted by Knight et al. (1993), if measures with relatively low test-rest reliability are used, the effects of the studied interventions can be underestimated. Similarly, real effects may be obscured if the measurement is poor, an occurrence known in psychometric theory as attenuation.

In addition to selecting a measurement tool that has strong reliability and validity, it is recommended that the tool selected be one that is commonly used, which would improve the comparability of the research to other studies and enhance the accumulation of scientific knowledge. In order to determine which available tool(s) fit this criteria, the meta-analyses of Brodaty et al. (2003), Knight et al. (1993), and Pinquart and Sorenson (2006) were examined to find the tools which were most frequently used, and would thus provide the most comparability. The most common measurements in these studies were respectively: ZBI (9 of 16 studies); ZBI (5 of 7 studies), Montgomery (2 of 5 studies); ZBI (32 of 85 studies).

With the Zarit Burden Interview (ZBI) appearing to be the most used tool by far, it is important to look further into the properties of this tool. According to The Memory and Behavior Problems Checklist and The Burden Interview by Zarit and Zarit (2000), the Burden Interview was “designed to assess the stresses experienced by family caregivers of elderly and disabled persons” (p. 8). The ZBI combines the measurement of both personal strain and role strain, thus creating a composite measurement tool. Zarit and Zarit (2000) concede that when research calls for a discrete measure of a specific stress process, measures
that more specifically address the topic of interest would be more useful, but that the ZBI is of use when a “single summary measure of caregivers’ appraisal of the impact their involvement has had on their lives is needed” (p. 8).

Consisting of 22 statements that reflect the feelings that the caregiver has in the course of providing care to their family member, the ZBI asks subjects to rate each statement as to how often it applies to them using a Likert scale model with answers ranging from “never” to “nearly always”. The questionnaire can be completed either individually by the caregiver, or as part of an interview process. Each answer on the Likert scale is assigned a value from 0 (never) to 4 (nearly always). Upon completion of the ZBI, the researcher sums the responses for each item, with the greater score indicating greater caregiver distress. Zarit and Zarit are careful to note that the ZBI should not be used alone to measure the emotional state of a caregiver, but that assessment should also include clinical observations and measures of depression.

Zarit and Zarit also provide a detailed review of the psychometric properties of the ZBI. According to their 2000 publication (p. 8), the following holds true for the tool:

- Internal reliability has been estimated with Chronbach’s alpha at 0.88 (Hassinger, 1985) and 0.91 (Gallagher et al., 1985)
- Test-retest reliability is 0.71 (Gallagher et al., 1985)
- Validity has been estimated by correlating the total score with a single global rating of burden ($r = 0.71$) and with subscales of the Brief Symptom Inventory (Anthony-Bergstone, Zarit & Gatz, 1988)
• Alpha measurement for the subscale of Personal Strain, derived using confirmatory factor analysis is 0.80
• Alpha measurement for the subscale of Role Strain, derived using confirmatory factor analysis is 0.81

Designed by a leading researcher in the gerontological study of caregiver distress and burden, and having been in use for over two decades, the Zarit Burden Interview would certainly be considered a reputable measurement device. Combined with its ease of use for both the caregiver and the researcher, the ZBI makes an excellent choice for a tool to measure the impact of interventions on the level of burden expressed by the primary informal caregivers of clients with dementia.

Conclusion

It should be noted that attempts were made to utilize Canadian research, particularly with regards to the use of adult day care in the provision of respite. However, of the over 50 studies reviewed, no Canadian content was located. This is unusual considering that the subject of dementia care is of importance to health authorities worldwide and that Canadian health authorities are keenly interested in the topic. In the province of British Columbia, respite care is offered through adult day care centres in: Fraser Health; Interior Health; Northern Health; Vancouver Coastal Health; Vancouver Island Health Authority. Given the prevalence of such programs, it is disappointing that peer-reviewed literature is not available regarding the effects of the services on the clients that they serve. It is hoped that the research report on the Northern Health pilot project will be part of Canada’s contribution to the international dementia care literature pool.
It had been hoped that a review of the available literature would provide the Northern Health management team with enough evidence regarding the effects of adult day centre-based respite on the levels of caregiver burden to make decisions regarding additional programming at the RADC. The Northern Interior Home & Community Care Management Team intuitively felt that additional programming would reduce burden for the caregivers of dementia clients, and believed that the literature would support this belief. Unfortunately the literature currently available, though plentiful, is inconclusive and thus cannot be used as a basis for making decisions regarding permanent programming changes and significant funding commitments. This fact emphasizes the need for Northern Health to undertake a pilot project with strong research methodology to gain empirical evidence upon which to base funding and programming decisions, as well as to contribute to the research community.
Research Design and Study Implementation Prospects

Research Project Rationale

As is apparent from the literature review, the topics of caregiver burden and the effect of respite have been widely studied, but have not resulted in a consensus regarding whether or not the use of respite is directly linked to reduced levels of caregiver burden. The general opinion, uninformed by the literature, seems to be that respite would reduce caregiver burden and the assumption is then also often made that reduced caregiver burden would lead to delayed client admissions into residential or acute care. In fact, discussions with the H&CC management team prior to conducting the literature review provided just such sentiments, and the suggestion was made that Northern Health add additional programming at the RADC to provide further respite care to dementia clients and their caregivers. However, upon reviewing the available literature, it was apparent that there was not sufficient evidence of the positive effects of respite through adult day centres to warrant the expenditure of Northern Health’s limited operating dollars on further programming.

In order to make informed decisions based on empirical evidence, a pilot project to measure the efficacy of the provision of respite via the RADC in Prince George was suggested. Running a pilot project rooted in strong research methodology for 6-12 months will allow Northern Health to make further programming decisions based on strong data, as well as to contribute further data to the research on centre-based respite and caregiver burden.
Rainbow Adult Day Centre as a Respite Provider

The RADC currently operates 5 days a week from 8:00 am – 5:00 pm and serves clients with a wide variety of needs, including those with dementia. Through the respite program at the RADC, clients enjoy nutritious meals, recreation and exercise programs, bathing in a specially designed tub if needed, hairdressing services, personalized healthcare (i.e. vital signs monitoring, medication administration, etc.), and mobility assessments and assistance, to name a few. Caregivers of participating clients receive assurance that the care recipient is in a safe, healthy and friendly environment with trained care staff. In addition, the caregivers receive a break from caregiving duties, obtain information about the health and well-being of the care recipient, receive referrals to other community programs and services, and gain personal support from the expert care staff. Program capacity has been reached and a waitlist of 22 clients currently exists. An informal survey (Appendix C) conducted by the Care Program Manager at an RADC social event in August 2008 indicated that caregivers would be very receptive to program offerings during the evenings, nights and weekends.

Given that the RADC is currently at capacity, the only way to pilot the project is to increase hours of operation and/or days of the week that the program operates. Based upon staff availability and convenience for caregivers and clients, the proposed pilot would see the addition of Sundays from 0900-1500 and Monday through Thursday evenings from 1700-2030.

Of the 22 clients on the RDC waitlist, it is anticipated that the majority will have dementia. 6 of the 7 clients on the Community Emergency Waitlist also have dementia. Having been placed on this Emergency Waitlist indicates that these clients are barely able to
be maintained in the community and that they may present to acute care at any time, often due to caregiver distress. Given the high numbers of dementia clients awaiting services in Prince George and the perceived demand for the expansion of hours of service at the RADC, there should be a prime opportunity available to run a pilot project of additional programming at the RADC to determine whether respite of this form impacts the burden felt by the informal caregivers of dementia clients.

Research Question

The primary research question to be answered by this study is: does the provision of respite care via RADC programs have an impact on the levels of burden reported by the primary informal caregivers of dementia clients in Prince George? Further questions that may be explored, but are not the focus of this project, include:

• Does the use of respite care via the RADC affect the rate of admission of dementia clients into residential care?

• Does the use of respite care via the RADC impact the number of home support hours utilized by the dementia clients?

• Is the provision of respite care via the RADC a cost-effective method of providing care to dementia clients, in comparison with other H&CC services?
Intended Use of Research Results

The research results are intended to be used by the Northern Interior H&CC Management Team and the Chief Operating Officer for the Northern Interior Health Service Delivery Area in making decisions surrounding the potential expansion of programming at the RADC. Specifically, the proposal has been made to permanently expand hours to include evenings, nights, and weekends. Both the level of interest in the pilot project and the resultant data may be used either to support or negate empirically the idea of service expansion.

Research Design Methodology

Given the social science-based nature of this research project, a quasi-experimental design methodology is necessary. Though deemed unscientific and unreliable by physical and biological scientists, it is not always possible, as in this case, to use a fully quantitative experiment. The study will strongly resemble quantitative research, but will lack the random allocation of participants into the test and control groups and will lack a completely null treatment control group. While the quasi-experimental design may not stand up to rigorous statistical analysis, virtually all of the research available in the research uses the same methodology and therefore comparability still exists.

The treatment group will be composed of primary informal caregivers of dementia clients who utilize the respite services of the RADC. The control group will consist of primary informal caregivers of dementia clients who do not utilize the respite services of the RADC. Randomized assignment to the treatment and control groups may be deemed
unethical, and will therefore be avoided. With numerous caregivers on waitlists for services, it seems inappropriate to deny these individuals services should they be randomly assigned to the control group. As such, this study will give those caregivers who have already demonstrated the interest in and/or need for respite care through RADC services the first opportunity to participate in the control group. This may reduce the validity of the results because the individuals in the control group will likely be caregivers who do not wish to use respite services, perhaps due to lower levels of burden.

When comparing findings between the treatment and control groups, it is important to consider that clients in the control group will most likely already be receiving H&CC services, though not in the form of RADC respite. Having been recruited from the RADC or Community Emergency waitlists, or through the Case Managers, control group clients have already been assessed by a Case Manager, and any services they may be receiving will be included in their H&CC chart. Since the control group is not receiving a placebo treatment, nor are they indicative of a group receiving no intervention, the effects of receiving respite services may be underestimated. Knight et al. (1993) identified that, while it does make sense to compare the introduction of respite services to those already offered, the lack of a true null-intervention control group must be taken into consideration when reviewing research results (particularly those with negative results). Similarly, it is not believed to be ethical to prevent participants in the treatment group from seeking other services during the study timeframe. This may further confound findings, as caregiver burden may be positively or negatively affected by additional services (i.e. home support) obtained during the study.
Participants.

Based upon staffing levels at the RADC, 15 clients per session would achieve the optimal client:staff ratio. As the pilot program will be run with two treatment groups, each attending two to three respite sessions per week, a total of 30 treatment group participants and 30 control group participants are required. It must be noted that, for the purpose of this study, the participants are the primary informal caregivers of the dementia clients attending the RADC pilot project, not the dementia clients themselves.

In order for caregivers to participate in the study, the clients they care for must have a primary diagnosis of dementia and have been assessed by a Case Manager from Northern Health’s H&CC department within 6 months prior to program commencement. Eligibility would be limited to caregivers of clients who are not currently utilizing the services of the RADC, though they may be receiving other supports from H&CC. As there are currently 22 dementia clients on the waiting list for the RADC, the caregivers of these clients will receive the first invitations to participate, along with those caregivers whose clients are on the Community Emergency Waitlist. There are also five dementia clients participating in Northern Health’s Frail Elderly Collaborative. These individuals have been identified as at high risk for admittance to hospital, and the caregivers of these clients will also be invited.

To expand the potential participant pool further, the Case Managers from H&CC will use the interRAI Resident Assessment Instrument – Home Care (RAI) data to identify H&CC clients who meet the diagnosis criteria, and the caregivers of these clients would be approached to participate. Participation in the respite program at the RADC would not preclude clients or caregivers from accessing any other H&CC services. The Case Managers
or research representative will use the script included in Appendix F to ensure a consistent message is given to all potential participants. Should the pilot project still not have enough participants to fill the 30 available spaces at the RADC, media will be employed to attract interest from members of the community who may not currently be in the H&CC system. Should participants from the community wish to participate, they would immediately undergo an interRAI assessment through the H&CC Case Management department.

To form a control group, the Case Managers will do an analysis of the clients cared for by the test group to determine the Cognitive Performance Scale (CPS) and Instrumental Activities of Daily Living (IADL) ratings, both of which are already tracked within the H&CC computer systems. They will then use this data to find the same number of H&CC clients with similar attributes, but who are not using the RADC services, and identify their caregivers. These caregivers will be approached and asked to participate as part of the control group, which would involve no change in services in connection with the study, but would require that they complete the burden measurement tool at the specified times. Any caregivers who decline to participate in the treatment group will also be offered the opportunity to participate as part of the 30 caregiver control group.

Setting.

The pilot project would be based out of the Rainbow Adult Day Centre in Prince George, British Columbia.
Procedure.

Prior to beginning RADC participation, all clients, whether from the test or control group, will complete the ZBI, which measures the degree of burden felt by caregivers. The head nurse at the RADC will complete the general intake process, as she would with any other client. The clients cared for by the test group will then be scheduled to attend the RADC two evenings a week and every other Sunday. Though it is hoped that attendance remains stable, clients and caregivers may withdraw at any time. The services provided to the participating clients will be the same as those generally provided to other RADC clients. The clients cared for by the control group will not see any changes in the services they receive, unless requested through by their care providers. The ZBI will be conducted again on all participants to provide measures of burden at three months, six months, and 12 months (should the pilot project continue for that long).

Measures.

The Zarit Burden Interview (Appendix E) will be used to measure the dependent variable, caregiver burden, at T1 (prior to respite program commencement), T2 (3 months after commencement), T3 (6 months after commencement) and at T4 (at the end of the 12 month pilot project or earlier if the pilot does not run for the entire year). Written consent to use the ZBI for this study was attained by Ashley Stoppler in November 2008, with the caveat that a copy of the research project be sent to Dr. Steven Zarit upon completion.

As mentioned in the literature review, the two reliability scores listed in the ZBI’s psychometric properties were that of Internal Reliability (reported at 0.88 and 0.91) and the
External Reliability measure of Test-Retest Reliability (reported at 0.71). Since the ZBI consists of two internal scales (12 questions measure Personal Strain and 6 measure Role Strain), the measure of Internal Reliability is not overly applicable for the purposes of this study. However, the External Reliability correlation coefficient, as assessed through Test-Retest Reliability, indicates the extent to which the level of reported burden would vary from one administration of the ZBI to another if no variables changed. Since the study compares a group in which a variable will change (the group receiving RADC services) to a group in which the variable remains unchanged, it is important to know that the ZBI has external validity and that the control group’s scores should be consistent. In an ideal situation, the correlation coefficient for external reliability would be 1.0, but this virtually never happens. According to www.statistics.com, a correlation coefficient of 0.7-0.8 is considered satisfactory, though 0.71 is at the low end of the acceptable range. As such, the chance of finding a statistically significant effect on caregiver burden is reduced.

Though not the primary focus of this study, it is recommended that researchers examine the cost-effectiveness of the pilot project, which will assist Northern Health management in determining whether or not to commit permanent funding dollars to such a program. Cost-effectiveness needs to be examined from several different angles, including delayed admissions to residential care and the reduction in Home Support hours. The H&CC Case Managers are able to track, using the client charts, the number of admissions into residential care or acute care for ALC placement for the clients being cared for by both the treatment and control groups. If, during the research period, there is a difference in the number of days that clients from either group spend in the community as opposed to either residential or acute care (awaiting residential placement), the costs of care per day can be
easily calculated. For each client, the Business Analyst can determine the cost of care per day based on H&CC services being received in the community (including home support and RADC respite), as well as the cost of care per day for hospitalization or residential care. As the cost of care is lower if the client remains in the community, researchers will be able to identify the cost savings for each additional day clients are able to remain in the community as a result of respite services.

In addition to costs related to institutionalization, it is important to look at the utilization of other H&CC services, such as home support. Many of the dementia clients cared for by both the treatment and control group caregivers will be receiving home support services. This information will be readily available through the Procura database and will include the number of hours of care received per day or week. Throughout the study, researchers should monitor the number of home support hours utilized for clients affiliated with each group to determine whether the clients cared for by the treatment group utilize fewer hours of home support than those utilized by the control group. As the cost associated with home support is easily quantifiable, the Business Analyst will be able to identify cost reductions associated with reduced utilization. Similarly, due to the high demand for home support, the H&CC program that provides the service currently incurs substantial overtime costs each fiscal period, as well as having to pay a premium to utilize agency nurses when Northern Health cannot provide enough staff to meet client needs. The costs associated with overtime and agency nursing should be monitored throughout the project to determine if the additional respite provision has an impact on the need for these expenditures.
Finally, it is important from a programming point of view to measure the satisfaction of caregivers using the RADC. Though, in the past, this may have been done simply by examining attrition rates, tools exist to give a more empirical evaluation of program satisfaction. For this pilot project, the Program Satisfaction tool developed by Jarrott et al. (1999) will be used (Appendix D). This brief 12-item interview will be used to assess caregiver satisfaction with the RADC as a program and provide data upon which the program managers can base programming and facility decisions. Appendix 4 includes the Program Satisfaction interview and the associated instructions, as provided by Zarit. Written permission to use this measurement tool is not required as long as there are no significant changes are made to the original.

**Operational Considerations**

*Caregiver Interest.*

The survey completed in 2008 indicated that there was demand for these additional hours, however when caregivers from the RADC waitlist and Community Emergency Waitlist were contacted in November 2008 and asked if they wished to participate in an evening and weekend-based program, the response was unequivocally “no”, with only two of the caregivers contacted showing interest at that time.

Many potential explanations exist as to why the initial planned expansion of hours did not receive more interest. The survey that indicated high levels of interest was completed primarily by the caregivers who were already utilizing RADC services, and thus are not the target population of the pilot. Before moving forward, it is recommended that the researchers complete a more specific survey, this time targeting the caregivers who meet the project
eligibility criteria. This would provide a better idea of the actual interest level in the community, and while it is anticipated that there would be significant interest, another negative response from caregivers may indicate to Northern Health that expanded respite services offered through the RADC is not a project that deserves further exploration at this time. Also in regards to the survey, the H&CC managers have questioned whether time of year played a role in the misalignment of responses. The survey was conducted in August, at a time when it stays light out until very late at night and the driving conditions in Prince George are optimal. However, when caregivers were contacted directly, it was with regard to a program starting in early December and running through the winter, when it becomes dark early and the road conditions may be questionable. As many caregivers are elderly themselves, it is perceived that they may be uncomfortable driving in these conditions and therefore not able to transport the dementia clients to and from evening programs. It was suggested by the program manager that offering the program at a different time of year, or else providing transportation options to the caregivers and clients may be methods of solving this dilemma. Questions of this nature would be included in the survey.

Another contributing factor may have been the very short timeline that was proposed. Caregivers were contacted in mid to late November 2008 and asked to participate in a program that began in early December. This did not provide much time for caregivers to think about the available options, discuss the program with the client’s physician or case manager, or provide the opportunity to visit the RADC to become acquainted with the services. It would be very important, when inviting caregivers to be participants in either the treatment or control group, to provide the information about the pilot project and accompanying data collection to the caregivers well in advance of commencement of the
pilot. It is also advisable to provide this information in writing as well as communicating it verbally so that the caregivers have all of the available information upon which to base their decisions.

**Human Resources.**

Several operational considerations need to be addressed prior to undertaking such a research project. In order to begin a new program at the RADC, the management of the program must look at staffing, union issues, support services, to name a few.

The staffing complement required to care for the 15 clients who would attend the RADC each session has been identified as one Care Aide and one Recreation Assistant. These staff would have the support of the Registered Nurse on duty at the adjoining Rainbow Park Lodge long term care facility. In addition to this direct care staff, support services would be impacted in both the Housekeeping and Dietary departments as additional cleaning would be required and an additional meal per day would need to be prepared for the RADC. There are currently no Dietary staff working at Rainbow Park Lodge during the evening and meals are prepared and delivered by another facility. However, with the added 15 meals per night, it would be more efficient to bring in an evening Dietary shift to prepare the meals for both the Lodge and the RADC.

Whenever new programs are put in place or changes are made to scheduling, Northern Health must be in communication with the affected unions. In regards to this pilot, three separate unions require consultation. The British Columbia Nurses Union must be contacted regarding the extension of hours for the Registered Nurse at the Rainbow Park Lodge to provide back-up for the RADC. As per the collective agreement, the Registered
Nurse must also be consulted to see if she is in agreement to the schedule change. The Health Sciences Association must be consulted to see if they would approve increasing the workload for the Recreation Therapist who would oversee the RADC programming. Finally, the Health Employees Union must be contacted about the addition of new positions at the RADC, changes in Housekeeping and Dietary schedules, and provided with the applicable job descriptions. It should be noted that, in November 2008, the Residential Care Program Manager for Prince George contacted all three unions as well as the affected staff members, and all parties agreed to the changes in an effort to support the pilot project.

Support Services.

In addition to the human resource issues that must be addressed, there are support services that need to be considered. As has already been identified, transportation to and from the program is a major concern for many elderly caregivers. The start time of the program (1700) has been set to allow for the Carefree bus to pick up clients at their homes and deliver them to the RADC in time for the program. However, current Carefree hours do not accommodate transportation from the RADC to home later in the evening. Prior to commencing the pilot, it is key that Northern Health arrange for return transportation, either via a special arrangement with Carefree, or perhaps through the NH Connections bus program. Finally, hot meals are a necessity for clients to make the atmosphere as home-like as possible. In order to accommodate arrivals of clients and later evening activities, meals need to be served between 1730-1800.
Special Considerations

The possibility exists that the provision of an “extra” service for dementia clients only may be perceived as unfair by caregivers of clients with other conditions. However, a vast difference in the abilities and care requirements of clients who are cognitive and those who have cognitive impairments such as dementia are very apparent. Cognitive clients and their caregivers have reported to the Residential Care Manager that they do not wish to participate in the same programming as clients with cognitive impairments. Based on this desire to have separate programming and the obvious need for additional methods of support for dementia clients and their caregivers, lead the H&CC Management Team to believe that the issue of an unfair level of service provision will not arise.

As this proposed pilot project would be undertaken as part of a research study, it is imperative that Research and Ethics Board approval be obtained from Northern Health, as well as from the University of Northern British Columbia. It should be noted that both Boards approved the application in November 2008.
Research Dissemination

Northern Health undertakes substantial research each year in a variety of subject matter areas pertaining to the provision of health care to the residents of Northern British Columbia. Unfortunately, the organization has not yet developed a formal means by which to disseminate the findings of its research either throughout the organization or the health care sector overall. As the research project proposed in this paper will not only provide empirical, applicable evidence to assist Northern Health management in making decisions, but also contributes to the international wealth of research on caregiver burden, it is imperative that the research findings be widely disseminated.

Findings from the research performed during the pilot project at the RADC should be compiled into a formal research report that is initially presented to the Northern Interior H&CC Management Team, along with the Chief Operating Officer for the Northern Interior Health Service Delivery Area. As this is the group that spearheaded the introduction of the pilot and makes decisions about which programs operate within Prince George and where operating dollars are spent, it is important that they have a very clear understanding of the findings. As Northern Health is divided into three health service delivery areas, it will then be important to share the findings with the managerial counterparts in the Northeast and the Northwest, which could be done via provision of the written report and/or presentation at their H&CC Management Team meetings. Similarly, the Executive Director of H&CC, though not responsible for operational activities within the department, should also be aware of the findings as they pertain to his role of providing strategic direction.

Finally, in an effort to contribute to the global study of caregiver burden, the researcher should submit the formal research report to peer-reviewed journals in an effort to
have the work published. It is not only an opportunity to share the findings of Northern Health with the greater healthcare field, but also a chance to complete the scientific process, from hypothesis to conclusion.
Discussion

The number of Northern Health residents living with dementia is expected to grow exponentially over the coming years as our population ages. As most individuals with dementia prefer to remain in the community, as opposed to in residential care facilities, it is often family members and friends of the clients who take on the caregiving responsibilities. Not only does this act of providing primary informal care allow the client to remain at home, but it may provide a sense of accomplishment for the caregiver, while at the same time redirecting some of the pressure away from the residential care system. However, as has been identified in the literature, the duty of providing care to clients with dementia is extremely involved and often takes both a physical and emotional toll on the caregiver. As such, it is important to examine models for assisting the primary informal caregivers with maintaining dementia clients in the home. Northern Health currently assists caregivers by providing adult day care, respite, case management and home care nursing. However, with the exception of the Rainbow Adult Day Centre, there is very limited capacity to expand many of these services to provide further assistance.

Given the fact that further programming could be offered at the RADC, a literature review was performed to determine whether or not providing respite to dementia clients in such a setting was an effective method of supporting caregivers. The literature, while plentiful, was contradictory and not concrete enough for Northern Health management to make decisions regarding the expenditure of funding to implement further programming. As such, a research project has been formulated that would allow Northern Health to expand services at the RADC on a temporary basis to measure the impact that respite services at the Centre have on the levels of burden felt by the caregivers of dementia clients. The project
would use strong research methodology and a well known measurement tool to provide accurate data and comparability to prior research. By undertaking such a pilot project, management will be able to measure empirically the effects of respite services and therefore make informed decisions about whether or not it is an area where funding should be directed.

As the population distribution shifts, at the same time that our communities experience an increase in elderly clients with dementia, there will also be a decrease in the number of primary informal caregivers available to provide care in the home. As such, Northern Health recognizes that effective methods of supporting caregivers must be in place and research into the best methods of doing so is the first step in making proactive decisions to support the care of dementia clients within Northern British Columbia.
### Appendices

**Appendix A - Effect Sizes for Respite Interventions: Burden**

<table>
<thead>
<tr>
<th>Study</th>
<th>Details</th>
<th>Duration</th>
<th>Measure</th>
<th>$D$</th>
<th>$N$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Montgomery &amp; Borgatta, 1989</td>
<td>Respite only, Medicare waivers equivalent to choice of in-home, day care or 24-hour care; equal to cost of 14 days inpatient respite</td>
<td>Follow-up after 1 year</td>
<td>Burden - Montgomery</td>
<td>0.74</td>
<td>94</td>
</tr>
<tr>
<td>Mohide et al., 1990</td>
<td>Respite, family consultant, education &amp; support group</td>
<td>6 months</td>
<td>Burden - Montgomery</td>
<td>0.75</td>
<td>89</td>
</tr>
<tr>
<td>Montgomery</td>
<td>4 hours per week in-home respite &amp; family-oriented nursing consults</td>
<td>6 months</td>
<td>CES - Depression</td>
<td>0.28</td>
<td>30</td>
</tr>
<tr>
<td>Burdz, Eaton, &amp; Bond, 1988</td>
<td>2-week respite stay in nursing home</td>
<td>2 weeks respite, 5-week follow-up</td>
<td>Burden - Zarit</td>
<td>0.31</td>
<td>35</td>
</tr>
<tr>
<td>Oktay &amp; Volland, 1990</td>
<td>Post-hospital support; coordinated medical, nursing, social services. No difference in respite between groups</td>
<td>1-year follow-up</td>
<td>General Health Questionnaire</td>
<td>-0.21</td>
<td>61</td>
</tr>
<tr>
<td>Silliman et al., 1990</td>
<td>Interdisciplinary assessment &amp; case planning prior to hospital discharge</td>
<td>1 meeting, 2-month follow-up</td>
<td>General Health Questionnaire</td>
<td>0.02</td>
<td>52</td>
</tr>
<tr>
<td>Hughes et al., 1990</td>
<td>Home-based health care. Treatment group more rehab therapy, social work &amp; dietary visits</td>
<td>6 months</td>
<td>PGC - Morale</td>
<td>-0.11</td>
<td>189</td>
</tr>
<tr>
<td>Lawton, Brody &amp; Saperstein, 1989</td>
<td>Capped respite subsidy; home, daycare or inpatient respite</td>
<td>12 months</td>
<td>Subjective burden CES - Depression</td>
<td>0.08</td>
<td>176</td>
</tr>
</tbody>
</table>

---

Appendix B - Characteristics of Selected Studies Measuring the Effects of Psychosocial Interventions on Caregiver Burden

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Outcome Measure</th>
<th>Instrument</th>
<th># of Subjects Randomized</th>
<th>Intervention Type</th>
<th>Study Quality</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brodaty et al. 1994</td>
<td>NR</td>
<td>Psychological morbidity</td>
<td>GHQ BI Knowledge measure</td>
<td>81 (completed = 33, partially completed = 22, control = 26)</td>
<td>E, S, SM</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Chang et al. 1999</td>
<td>RCT</td>
<td>Psychological morbidity</td>
<td>BSI CAT</td>
<td>87 (completed = 65, treatment = 31, control = 34)</td>
<td>P</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Gendron et al. 1996</td>
<td>RCT</td>
<td>Psychological morbidity</td>
<td>HSC BI</td>
<td>35 (treatment = 53, control = 23), withdrawals = 9</td>
<td>S, T</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Hebert et al. 1994</td>
<td>RCT</td>
<td>Psychological morbidity</td>
<td>BSI BI ADKT</td>
<td>45 (treatment = 24, control = 21), withdrawals = 7</td>
<td>S, SM</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Kahan et al. 1985</td>
<td>NR</td>
<td>Psychological morbidity</td>
<td>SDS BI</td>
<td>40 (treatment = 22, control = 18)</td>
<td>S</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>LoGiudice et al. 1999</td>
<td>RCT</td>
<td>Psychological morbidity</td>
<td>GHQ BI DKT</td>
<td>50 (treatment = 25, control = 25), withdrawals = 5</td>
<td>C, F, P</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>McCallion et al. 1999</td>
<td>RCT</td>
<td>Burden Patient mood</td>
<td>CHS CSDD</td>
<td>66 (treatment = 32, control = 34), withdrawals</td>
<td>E, P</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>

4 Design: NR - nonrandomized (quasi-experimental), RCT - randomized controlled trials
Instrument: ADKT - Alzheimer’s Disease Knowledge Test, BI - Burden Interview, BSI - Brief Symptom Inventory, CES-D - Center for Epidemiological Studies Depression Scale, CDS - Cornell Depression Scale, DKT - Dementia Knowledge Test, HDRS - Hamilton Depression Rating Scale, MBPC-B - Memory and Behavior Problem Checklist (Part B), PANAS - Positive and Negative Affect Scale, SCB - Screen for Caregiver Burden
Intervention Type: P - patient involvement, S - support group/program, SM - stress management, T - training
Study Quality: Good quality > 7, Poor quality < 5
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Type of Interventions</th>
<th>Outcome Measures</th>
<th>N (treatment)</th>
<th>N (control)</th>
<th>Withdrawals</th>
</tr>
</thead>
<tbody>
<tr>
<td>McCurry et al. 1998</td>
<td>RCT</td>
<td>Psychological morbidity Burden</td>
<td>CES-D SCB</td>
<td>36 (treatment 1 = 7, treatment 2 = 15, control = 15)</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Ostwald et al. 1999</td>
<td>RCT</td>
<td>Psychological morbidity Burden</td>
<td>CES-D BI</td>
<td>117 (treatment = 72, control = 45)</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Quayhagen et al. 1989</td>
<td>NR</td>
<td>Psychological morbidity Burden</td>
<td>HSC BI</td>
<td>16 (treatment = 10, control = 6)</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Quayhagen et al. 2000 (Daycare, Dyadic counseling, Cognitive stimulation)</td>
<td>RCT</td>
<td>Psychological morbidity Burden</td>
<td>BSI MBPC-B</td>
<td>103 (group n’s = 21, 29, 22, 16, 15)</td>
<td>7</td>
<td>Day care = 4, Dyad counsel = 3, Cog stim = 3</td>
</tr>
<tr>
<td>Ripich et al. 1998</td>
<td>NR</td>
<td>Psychological morbidity Burden Knowledge</td>
<td>PANAS CHS Knowledge questionnaire</td>
<td>37 (treatment = 19, control = 18)</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Robinson et al. 1999</td>
<td>RCT</td>
<td>Burden Objective burden scale</td>
<td>HDRS CDS</td>
<td>20 (treatment = 11, control = 9)</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Teri et al. 1997 (Problem solving, Pleasant events)</td>
<td>RCT</td>
<td>Psychological morbidity Burden Patient Mood</td>
<td>HDRS CDS</td>
<td>88 (withdrawals = 16)</td>
<td>7</td>
<td>Problem solving = 3, Pleasant events = 3</td>
</tr>
<tr>
<td>Zanetti et al. 1998</td>
<td>NR</td>
<td>Psychological morbidity Burden Knowledge</td>
<td>BSI Rankin Scale ADKT</td>
<td>23 (treatment = 12, control = 11)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Zarit et al. 1987 (Counseling, Support group)</td>
<td>RCT</td>
<td>Psychological morbidity Burden</td>
<td>BSI BI</td>
<td>185 (group n’s = 44, 36, 39)</td>
<td>7</td>
<td>Counseling = 3, Support = 3</td>
</tr>
</tbody>
</table>
Dear Day Centre Client/Family

Due to the ever increasing needs of our elderly population and their families, we are considering extending our current hours of operation.

We are currently open Mon-Fri 8-5pm. We are considering extending our hours of operation to include evenings, nights and weekends.

The nights would be for clients who are up wandering all night. We would not have rooms to sleep in, but, rather recliners for them to rest in. These hours of operation would be aimed at giving the caregiver a good nights sleep.

We would like to hear from you, the client/caregiver what would meet your needs the best. Please fill in section below and return to the Day Centre no later than Aug 15, 2008.

Tick which of the following services you feel would benefit your situation

___ Days 8am-5pm
___ Evenings 5pm-10pm
___ Nights 10pm-8am
___ Weekends 8am-4pm

Preferred nights
___ Monday
___ Tuesday
___ Wednesday
___ Thursday
___ Friday
___ Saturday
___ Sunday

We propose to run a trial of the extended hours and days from September to December, and then review.

Comments or suggestions-

Thank-you

Rainbow Adult Day Centre – Home & Community Care
1000 Liard Drive, Prince George, V2M 3Z3  T: (250) 649-7293  F: (250) 565-7452
Appendix D – Program Satisfaction Survey

BACKGROUND:
This twelve item scale assesses caregivers satisfaction with the adult day care program to which they send their relatives. Caregivers rate items on a five point response scale ranging from VERY SATISFIED (5) to VERY DISSATISFIED (1).

FACTOR ANALYSIS:
Principle components analysis was performed on the 12 item scale of program satisfaction. The unrotated solution revealed 3 components accounting for 58.1% of the total variance. Three components were retained and rotated using varimax rotation.

FORMAT:

Instructions: “Now I’d like to ask you about specific aspects of the day care program. How satisfied are you with the following aspects of the day care program you have been participating in?”

Response:
- 5 = very satisfied
- 4 = somewhat satisfied
- 3 = neither
- 2 = somewhat dissatisfied
- 1 = very dissatisfied

Component 1: Program Characteristics

1. Skill of the staff in caring for your (relative)
2. Ability of the staff in helping your (relative) adjust initially to day care
3. Ability of the staff to handle your (relative’s) behavior (e.g., agitation or aggressiveness)
4. Friendliness and concern of the day care staff
5. Activities provided by the program
6. Meals provided by the program
7. Setting of the day care

Component 1: Program Characteristics

1. Skill of the staff in caring for your (relative)
2. Ability of the staff in helping your (relative) adjust initially to day care
3. Ability of the staff to handle your (relative’s) behavior (e.g., agitation or aggressiveness)
4. Friendliness and concern of the day care staff
5. Activities provided by the program
6. Meals provided by the program
7. Setting of the day care

---

Component 2: Program Logistics

1. Number of hours offered per day
2. Time (open) during the day
3. Number of days offered per week
4. Location of the day care

Component 3: Program Cost

1. Cost of the day care

**RELIABILITY:**

Cronbach’s α (all items) = 0.7632
α (component one) = 0.8036
α (component two) = 0.7101
α (component three) = not applicable - single item

Stability coefficients (correlations):

**Component 1**

<table>
<thead>
<tr>
<th></th>
<th>T2</th>
<th>T3</th>
</tr>
</thead>
<tbody>
<tr>
<td>T2</td>
<td>---</td>
<td>.67</td>
</tr>
<tr>
<td>T3</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>

**Component 2**

<table>
<thead>
<tr>
<th></th>
<th>T2</th>
<th>T3</th>
</tr>
</thead>
<tbody>
<tr>
<td>T2</td>
<td>---</td>
<td>.03</td>
</tr>
<tr>
<td>T3</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>

**Component 3**

<table>
<thead>
<tr>
<th></th>
<th>T2</th>
<th>T3</th>
</tr>
</thead>
<tbody>
<tr>
<td>T2</td>
<td>---</td>
<td>.21</td>
</tr>
<tr>
<td>T3</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>
Appendix E - Zarit Burden Interview

BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: Never, Rarely, Sometimes, Quite Frequently, or Nearly Always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

2. Do you feel that, because of the time you spend with your relative, you don’t have enough time for yourself?

3. Do you feel stressed about caring for your relative and trying to fulfill other responsibilities for your family or work?

4. Do you feel embarrassed about your relative’s behavior?

5. Do you feel angry with your relative when you are around him/her?

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

7. Are you afraid of what the future holds for your relative?

8. Do you feel that your relative is dependent on you?

9. Do you feel stressed when you are around your relative?

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. Never</td>
<td>Rarely</td>
</tr>
<tr>
<td>1. Sometimes</td>
<td>Quite Frequently</td>
</tr>
<tr>
<td>2. Sometimes</td>
<td>Frequently</td>
</tr>
<tr>
<td>3. Quite Frequently</td>
<td></td>
</tr>
<tr>
<td>4. Nearly Always</td>
<td></td>
</tr>
</tbody>
</table>

Review copy
Do not use without permission
10. Do you feel that your health has suffered because of your involvement with your relative?
   Rarely Frequently

11. Do you feel that, because of your relative, you don't have as much privacy as you would like?
   Rarely Frequently

12. Do you feel that your social life has suffered because you are caring for your relative?
   Rarely Frequently

13. Do you feel uncomfortable about having friends over, because of your relative?
   Rarely Frequently

14. Do you feel that your relative now expects you to take care of him/her as if you were the only one he/she could depend on?
   Rarely Frequently

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
   Rarely Frequently

16. Do you feel that you will be unable to take care of your relative for much longer?
   Rarely Frequently

17. Do you feel that you have lost control of your life since your relative's illness began?
   Rarely Frequently

18. Do you wish that you could just leave the care of your relative to someone else?
   Rarely Frequently
19. Do you feel uncertain about what to do about your relative?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Quite</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td>1.</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td></td>
<td></td>
<td>2.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frequently</td>
<td></td>
<td>3.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.</td>
</tr>
</tbody>
</table>

20. Do you feel that you should be doing more for your relative?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Quite</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td>1.</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td></td>
<td></td>
<td>2.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frequently</td>
<td></td>
<td>3.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.</td>
</tr>
</tbody>
</table>
Appendix F - Script for the Invitation to Participate in the Pilot Project

“You are being asked to participate in a joint Northern Health and University of Northern British Columbia research study. This study consists of operating a pilot project within Home & Community Care, estimated to last between 3-12 months. Northern Health is expanding our Rainbow Adult Day Centre hours to see if enhanced hours will provide needed respite for caregivers and provide clients with an appropriate place for socialization. This review of this pilot project is being conducted to study the effects of respite services, as offered through the Rainbow Adult Day Centre (RADC), on levels of burden felt by the informal caregivers of Home & Community Care clients in Prince George. It will also measure whether the use of these respite services affects the rate of admission to acute and/or long term care for the clients in the study. Your participation is voluntary and you may choose to withdraw at any time during the study without penalty of any kind. If you decide to withdraw at any point before the study is complete, the information that you have provided thus far will be destroyed.

Criteria for participation in the pilot project include any primary informal caregiver of a long term care client who has a diagnosis of dementia and would benefit from the services of the RADC.

NH is working to expand Rainbow Adult Day Centre hours to:
Sunday days 0900- 4:30pm.
Monday, Tuesday, Wednesday, Thursday - 5:00 to 9:00pm.

These expanded hours are supported by NH to look at caregiver stress and burden; we ask that participants agree to participate in a series of confidential questionnaires over the next 3-12 months. The first questionnaire will be completed before the client begins attending the Adult Day Centre, the second will be completed after they’ve attended for three months, and then re-done every 3 months until the end of the pilot project. Only the first questionnaire needs to be completed in person – the remaining data can be collected over the phone or via mail.

Research shows that attendance at adult day centers at a minimum of three days a week is significant to decrease caregiver stress and burden - however 2 days may also assist. We suggest that clients attend 2-3 days per week in this project however we may enroll clients for attendance 1-2 days a week depending on availability.

This is the first expansion of the hours of a program that is already in existence. There are no plans to decrease or cancel any of the programs that we presently run at the RADC during the weekdays Monday to Friday. At this point we are inviting only new clients to join into the expanded hours. However if there is space available and people who currently attend the day program Monday through Friday wish to participate in the evening or Sunday programs, the requests will be considered. Clients who agree to attend the Sunday or evening programs that currently are on the waitlist for the Monday to Friday programs will not be removed from that waitlist unless they agree.”
Appendix G – Consent Form (Control Group)

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
FOR THE RAINBOW ADULT DAY CENTRE PILOT PROGRAM – CONTROL GROUP

Title of Study: Adult Day Centre Respite Care: A Study of its Effects on Dementia Caregivers

Principal Investigator: Dr. Steven Cronshaw
University of Northern British Columbia
3333 University Way, Prince George, BC  V2N 4Z9
cronshaw@unbc.ca
(250)960-6785

Researcher: Ashley Stoppler – UNBC, Northern Health
1475 Edmonton Street, Prince George, BC  V2M 1S2
(250) 649-7505
ashley.stoppler@northernhealth.ca

You are being asked to participate in a joint Northern Health and University of Northern British Columbia research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand. This project is being conducted by Ashley Stoppler, who is fulfilling the requirements for the degree of Master of Business Administration at the University of Northern British Columbia under the supervision of Dr. Steven Cronshaw, Professor.

Purpose of Study
This research study is being conducted to study the effects of respite services, as offered through the Rainbow Adult Day Centre (RADC), on levels of burden felt by the informal caregivers of dementia clients in Prince George. It will also measure whether the use of these respite services affects the rate of admission to acute and/or long term care for the dementia clients in the study.

What is Required
As part of this study, you are being asked to complete the 22 question Zarit Burden Interview either in person or over the phone prior to commencement of the pilot program. Upon completion of the pilot program in February 2009, you will be asked to complete the 22 question Zarit Burden Interview either in person or over the phone. It is expected that completion of these interviews should take no longer than 30 minutes.

Follow-Up Contact
You are also being asked for your consent to be contacted to participate in a follow-up component of the study approximately three months from your initial participation. Providing permission to be contacted later is not a commitment to participation in the follow-up interview. If you agree to being contacted, the voluntary and confidential nature of the interview, along with other aspects of ethical research practices, will be explained once contact is made. At that time, your consent to participate in the follow-up interview will be required before the interview can proceed.
Monetary Compensation
You will receive no payment or reimbursement for any expenses related to this study.

Confidentiality
Your responses on the burden interviews will be kept completely confidential and anonymous, and you may decline to respond or withdraw your participation at any time. Code numbers will be used on the burden interviews instead of names in order to protect your identity. Your name will only appear on the consent forms, which will be kept separate from the interviews. The coded interviews will be stored in a locked filing cabinet, located in an alarmed office that is accessible only to Ashley Stoppler. No personal names or identifying information will be entered into electronic files—any data that is entered into a computer will be encrypted, password protected, and stored in a secure alarmed office.

Right to Decline or Withdraw
Your participation is voluntary and you may choose to withdraw at any time during the study without penalty of any kind. If you decide to withdraw at any point before the study is complete, the information that you have provided thus far will be destroyed.

Disposal of Data
All data will be kept in a secure location (with coded interviews kept separate from personal information) for three years after the completion of the study. The data will then be destroyed by shredding the interviews and consent forms and by deleting all computerized data files (including electronic storage devices).

Risks and Discomforts
No risks have been identified for participants of this study.

Benefits
There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other caregivers of dementia clients in the future.

Dissemination of Results
A final report of the findings will be produced with a summary of all participant responses. Participant responses on the interviews will be kept anonymous, with no identifiable information included. The final report will be submitted to the UNBC Library, peer-reviewed journals for publication, and presented at professional conferences. No names or identifying information will be included in the dissemination of the research results. At the end of the study, participants can request a copy of the final research report by contacting Ashley Stoppler.

Other important Information and Contacts
You will be given a copy of the signed informed consent form for your own files. If you have any comments or would like further information about this study, please contact Ashley Stoppler. You may also contact Steven Cronshaw at the University of Northern British Columbia by telephone at (250)960-6785 or by e-mail at cronshaw@unbc.ca

If you would like to verify the ethical approval of this study, or raise any concerns that you may have, please contact the Office of Research at the University of Northern British Columbia at (250) 960-5820.
INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

I have read this consent form. I have had the opportunity to discuss this research study with a member of the study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

This study was explained to me by ___________________________ Date ______________ (day/month/year)

I have received a copy of this consent form and the information sheet, and my signature indicates that I agree to participate in the study.

Participant signature ___________________________ Date ______________ (day/month/year)

Participant printed name: ___________________________

If the information detailed in this form was explained over the telephone and consent was received verbally:
I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant’s legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant’s legally acceptable representative.

Witness signature ___________________________ Date ______________ (day/month/year)

Witness printed name: ___________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator: ___________________________

Printed Name: ___________________________ Date ______________ (day/month/year)
Appendix H – Consent Form (Treatment Group)

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
FOR PARTICIPANTS IN THE RAINBOW ADULT DAY CENTRE PILOT PROGRAM

Title of Study: Adult Day Centre Respite Care: A Study of its Effects on Dementia Caregivers

Principal Investigator: Dr. Steven Cronshaw
University of Northern British Columbia
3333 University Way, Prince George, BC V2N 4Z9
cronshaw@unbc.ca
(250) 960-6785

Researcher: Ashley Stoppler – UNBC, Northern Health
1475 Edmonton Street, Prince George, BC V2M 1S2
(250) 649-7505
ashley.stoppler@northernhealth.ca

You are being asked to participate in a joint Northern Health and University of Northern British Columbia research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand. This project is being conducted by Ashley Stoppler, who is fulfilling the requirements for the degree of Master of Business Administration at the University of Northern British Columbia under the supervision of Dr. Steven Cronshaw, Professor.

Purpose of Study
This research study is being conducted to study the effects of respite services, as offered through the Rainbow Adult Day Centre (RADC), on levels of burden felt by the informal caregivers of dementia clients in Prince George. It will also measure whether the use of these respite services affects the rate of admission to acute and/or long term care for the dementia clients in the study.

What is Required
You are invited to register the client that you care for in the Rainbow Adult Day Centre pilot evening/weekend program. This will involve the client that you care for participating in the program for two evenings per week, along with alternate Sundays. Though it is recognized that it may not always be possible for the client to attend every session, we ask that you please make the effort to have them attend as many registered sessions as possible to achieve the maximum benefits from the program. There is no fee associated with participation in this study, however the fee for attending the Rainbow Adult Day Centre program will be calculated in accordance with Northern Health’s current policy.

As part of this study, you are being asked to complete the 22 question Zarit Burden Interview either in person or over the phone prior to commencement of the pilot program. Upon completion of the pilot program in February 2009, you will be asked to complete the 22 question Zarit Burden Interview either in person or over the phone. It is expected that completion of these interviews should take no longer than 30 minutes.
Follow-Up Contact
You are also being asked for your consent to be contacted to participate in a follow-up component of the study approximately three months from your initial participation. Providing permission to be contacted later is not a commitment to participation in the follow-up interview. If you agree to being contacted, the voluntary and confidential nature of the interview, along with other aspects of ethical research practices, will be explained once contact is made. At that time, your consent to participate in the follow-up interview will be required before the interview can proceed.

Monetary Compensation
You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality
Your responses on the burden interviews will be kept completely confidential and anonymous, and you may decline to respond or withdraw your participation at any time. Code numbers will be used on the burden interviews instead of names in order to protect your identity. Your name will only appear on the consent forms, which will be kept separate from the interviews. The coded interviews will be stored in a locked filing cabinet, located in an alarmed office that is accessible only to Ashley Stoppler. No personal names or identifying information will be entered into electronic files—any data that is entered into a computer will be encrypted, password protected, and stored in a secure alarmed office.

Right to Decline or Withdraw
Your participation is voluntary and you may choose to withdraw at any time during the study without penalty of any kind. If you decide to withdraw at any point before the study is complete, the information that you have provided thus far will be destroyed.

Disposal of Data
All data will be kept in a secure location (with coded interviews kept separate from personal information) for three years after the completion of the study. The data will then be destroyed by shredding the interviews and consent forms and by deleting all computerized data files (including electronic storage devices).

Risks and Discomforts
No risks have been identified for participants of this study.

Benefits
There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other caregivers of dementia clients in the future.
**Dissemination of Results**

A final report of the findings will be produced with a summary of all participant responses. Participant responses on the interviews will be kept anonymous, with no identifiable information included. The final report will be submitted to the UNBC Library, peer-reviewed journals for publication, and presented at professional conferences. *No names or identifying information will be included in the dissemination of the research results.* At the end of the study, participants can request a copy of the final research report by contacting Ashley Stoppler.

**Other important Information and Contacts**

You will be given a copy of the signed informed consent form for your own files. If you have any comments or would like further information about this study, please contact Ashley Stoppler. You may also contact Steven Cronshaw at the University of Northern British Columbia by telephone at (250)960-6785 or by e-mail at cronshaw@unbc.ca

If you would like to verify the ethical approval of this study, or raise any concerns that you may have, please contact the Office of Research at the University of Northern British Columbia at (250) 960-5820.
INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

I have read this consent form. I have had the opportunity to discuss this research study with a member of the study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

This study was explained to me by ___________________________ Date ____________
(day/month/year)

I have received a copy of this consent form and the information sheet, and my signature indicates that I agree to participate in the study.

Participant signature_________________________ Date ____________
(day/month/year)

Participant printed name: ___________________________

If the information detailed in this form was explained over the telephone and consent was received verbally:
I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

Witness signature_________________________ Date ____________
(day/month/year)

Witness printed name: ___________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator: ___________________________

Printed Name: ___________________________ Date ____________
(day/month/year)
Selected Bibliography


Cahill, S., Drury, M., Lawolor, B., O’Connell, M. (2003). They have started to call their ‘club’: A survey of staff views of dementia-specific day care centres in Ireland. Dementia, (2)1: 85-103


