PSYCHOLOGICAL RESILIENCE IN SPOUSAL CAREGIVERS OF MEMORY CLINIC PATIENTS WITH ALZHEIMER DISEASE

by

Anthony L. Kupferschmidt
Bachelor of Arts, McMaster University, 2005
Bachelor of Arts (Honours), Queen’s University, 2003

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

In the
Department of
Gerontology

© Anthony L. Kupferschmidt 2009

SIMON FRASER UNIVERSITY

Summer 2009

All rights reserved. However, in accordance with the Copyright Act of Canada, this work may be reproduced, without authorization, under the conditions for Fair Dealing. Therefore, limited reproduction of this work for the purposes of private study, research, criticism, review and news reporting is likely to be in accordance with the law, particularly if cited appropriately.
**APPROVAL**

<table>
<thead>
<tr>
<th>Name</th>
<th>Anthony L Kupferschmidt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degree</td>
<td>Master of Arts (Gerontology)</td>
</tr>
<tr>
<td>Title of Thesis</td>
<td>PSYCHOLOGICAL RESILIENCE IN SPOUSAL CAREGIVERS OF MEMORY CLINIC PATIENTS WITH ALZHEIMER DISEASE</td>
</tr>
</tbody>
</table>

**Examining Committee:**

<table>
<thead>
<tr>
<th>Chair:</th>
<th>Dr. Barbara Mitchell</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Associate Professor, Gerontology, SFU</td>
</tr>
<tr>
<td>Dr. Norm O’Rourke, R.Psych.</td>
<td>Senior Supervisor</td>
</tr>
<tr>
<td></td>
<td>Associate Professor, Clinical Psychologist</td>
</tr>
<tr>
<td></td>
<td>Department of Gerontology, SFU</td>
</tr>
<tr>
<td>Dr. Andrew Sixsmith</td>
<td>Supervisor</td>
</tr>
<tr>
<td></td>
<td>Professor, Gerontology, SFU</td>
</tr>
<tr>
<td>Dr. Loren Lovegreen</td>
<td>Supervisor</td>
</tr>
<tr>
<td></td>
<td>Assistant Professor, Gerontology, SFU</td>
</tr>
<tr>
<td>Dr. Jean-Francois Kozak</td>
<td>External Examiner</td>
</tr>
<tr>
<td></td>
<td>Director of Research in the Centre for Healthy Aging, Providence Health Care</td>
</tr>
</tbody>
</table>

**Date Defended:** 16-June-2009
Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the “Institutional Repository” link of the SFU Library website <www.lib.sfu.ca> at: <http://ir.lib.sfu.ca/handle/1892/112>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author’s written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library
Burnaby, BC, Canada
STATEMENT OF ETHICS APPROVAL

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library
Simon Fraser University
Burnaby, BC, Canada

Last update: Spring 2010
ABSTRACT

Faced with comparable demands, some caregivers of persons with Alzheimer disease (AD) become overwhelmed early in the course of the illness while others cope for many years under remarkable stress. Psychological resilience may enable clinicians to identify caregivers at risk for stress-induced psychopathology. The current study examined the three facets of psychological resilience (i.e., commitment to living, challenge, perceived control) relative to the well-being of a sample of cohabitating, community-residing spousal caregivers of persons with AD using hierarchical regression. The sample was recruited from a tertiary diagnostic clinic over a period of 21 months ($N = 130$). Challenge and perceived control were inversely associated with depressive symptoms. Perceived control was also significantly related to caregiver burden. None of the psychological resilience constructs uniquely contributed to the prediction of life satisfaction. These findings provide partial support for the hypothesized association between psychological well-being and caregiver well-being indices.

Keywords: psychological resilience; hardiness; caregiving; Alzheimer disease
DEDICATION

For MB and MM
ACKNOWLEDGEMENTS

First and foremost, I wish to extend my most sincere gratitude to the patients of the University of British Columbia Hospital Clinic for Alzheimer Disease and Related Disorders (UBCH CARD) and their spouses, whose responses and circumstances have provided the foundation for this study.

I would like to thank my senior supervisor Dr. Norm O’Rourke for his guidance throughout this process. His insight and attention were instrumental to the success of this research. I also wish to thank Dr. Loren Lovegreen, Dr. Andrew Sixsmith and Dr. Jean-Francois Kozak for their constructive comments and suggestions.

I also offer many thanks to the staff in the SFU Department of Gerontology and Gerontology Research Centre for their assistance during my studies. Thank you also to Penny Simpson for her essential direction.

I have had the immense pleasure of learning with my fellow students in the SFU Department of Gerontology. I hold you all in the highest regard, and your friendship and support throughout my studies have been vital to the realization of this work.

I would also like to convey heartfelt thanks to Dr. Lynn Beattie, Dr. Claudia Jacova, Dr. Sherri Hayden, Dr. Howard Feldman and all of the UBCH CARD staff for their contributions to and facilitation of this research and my learning process. You have provided another strong environment from which to launch my career.

I also want to thank my family for their unwavering encouragement. I am very grateful to my parents for nurturing in me both a passion for working with older adults
and the pursuit of higher learning. Thank you also to my grandparents for your continued countenance.

I would like to gratefully acknowledge the financial support I have received over the course of my graduate training from the Michael Smith Foundation for Health Research, the British Columbia Medical Services Foundation, the Canadian Association on Gerontology - Association Canadienne de Gérontologie, Simon Fraser University and external donors.

Thank you, Tracy, for pointing me westward.

And to Alexis, my dearest friend and partner… your love, inspiration, encouragement and enduring patience have been integral to this experience. Without you I could not have achieved this goal. Thank you for coming to Lotusland with me, and for believing in me.
TABLE OF CONTENTS

Approval ........................................................................................................................ii
Abstract ........................................................................................................................ iii
Dedication .....................................................................................................................iv
Acknowledgements .......................................................................................................v
Table of Contents .........................................................................................................vii
List of Tables ..............................................................................................................viii
List of Abbreviations and Acronyms ..........................................................................ix
Chapter 1: Introduction .................................................................................................1

Chapter 2: Literature Review .......................................................................................5
  Predictors of Caregiving Outcomes ............................................................................5
  Problematic Outcomes ...............................................................................................8
  Positive Outcomes ...................................................................................................11
  Psychological Resilience ..........................................................................................13
  Statement of Hypothesis ..........................................................................................25

Chapter 3: Methodology ..............................................................................................26
  Participants and Recruitment ....................................................................................26
  Study Measures .......................................................................................................28
  Analytic Procedure ..................................................................................................34

Chapter 4: Results .......................................................................................................37
  Descriptive Features of Patient Sample ....................................................................37
  Descriptive Features of Caregiver Sample ................................................................37
  Regression Analyses ................................................................................................42

Chapter 5: Discussion .................................................................................................50
  Limitations and Future Research ..............................................................................54

References ..................................................................................................................59

Appendix A: Covering Memo ....................................................................................82
Appendix B: Information Letter ................................................................................83
Appendix C: Consent Form .......................................................................................85
Appendix D: Study Measures ....................................................................................87
LIST OF TABLES

Table 1: Psychometric Properties of Study Variables………………………………40

Table 2: Correlation Coefficients Between DRS Subscales, Combined Scale Scores, Caregiver Socio-demographic and Patient Variables………………41

Table 3: Regression Analysis of Caregiver Socio-demographic, Patient, and Psychological Resilience Variables on Depressive Symptomatology…..44

Table 4: Regression Analysis of Caregiver Socio-demographic, Patient, and Psychological Resilience Variables on Burden…………………………….46

Table 5: Regression Analysis of Caregiver Socio-demographic, Patient, and Psychological Resilience Variables on Life Satisfaction………………..48
# LIST OF ABBREVIATIONS AND ACRONYMS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>Alzheimer disease</td>
</tr>
<tr>
<td>ADRD</td>
<td>Alzheimer disease and related dementias</td>
</tr>
<tr>
<td>BI</td>
<td>Burden Interview</td>
</tr>
<tr>
<td>CES-D</td>
<td>Center for Epidemiologic Studies Depression</td>
</tr>
<tr>
<td>CSHA</td>
<td>Canadian Study on Health and Aging</td>
</tr>
<tr>
<td>DRS</td>
<td>Dispositional Resilience Scale</td>
</tr>
<tr>
<td>FRS</td>
<td>Functional Rating Scale</td>
</tr>
<tr>
<td>FTD</td>
<td>Frontotemporal dementia</td>
</tr>
<tr>
<td>NINCDS-ADRDA</td>
<td>National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer Disease and Related Disorders Association Criteria for Alzheimer Disease</td>
</tr>
<tr>
<td>PVS</td>
<td>Personal Views Survey</td>
</tr>
<tr>
<td>PWD</td>
<td>Person(s) with dementia</td>
</tr>
<tr>
<td>SLS</td>
<td>Satisfaction With Life Scale</td>
</tr>
</tbody>
</table>
Dementia is a progressive clinical condition distinguished by memory impairment and cognitive dysfunction sufficiently severe to cause impairment in social and occupational functioning (American Psychiatric Association, 2000). Mood, personality and behavioural changes occur; the ability to learn, make decisions and carry out daily activities is eventually lost.

Statistics suggest that 7.9% of all Canadians over 64 years of age meet diagnostic criteria for dementia (Canadian Study on Health and Aging [CSHA] Working Group, 1994a). This study of Alzheimer disease and related dementias (ADRD, including vascular, frontotemporal, Lewy body and other forms of dementia) found that there were approximately 252,500 seniors with dementia in this country (CSHA Working Group, 1994a). Projections indicate that by 2021 there will be 592,000 seniors with dementia (CSHA Working Group, 2000).

The impact of dementia is not limited to those directly afflicted. Caregiving has become one of the most studied topic areas in gerontology (George, 1990). For the most part, this interest has corresponded to increasing dementia prevalence. Provision of informal care at home is very common in the early stages of dementia. Ninety-four percent of caregivers for the more than 80% of persons with dementia (PWD) living in the community are unpaid family members, relatives or friends (CSHA Working Group, 1994b). Spouses constitute 37% of this group, and over a third are at least 70 years of age. Although there is no standard definition utilized across studies, caregiving refers to “…activities and experiences involved in providing help and assistance to relatives or
friends who are unable to provide for themselves” (Pearlin, Mullan, Semple, & Skaff, 1990, p. 583).

Caregiving activities can vary widely according to disease progression, and the potential stressors associated with caring for PWD are numerous (e.g., Gold et al., 1995). Cognitive impairments and behavioural disturbances including wandering, aggression and perseverative behaviours are both common and commonly perceived as stressful by caregivers (Gaugler, Davey, Perlin, & Zarit, 2000).

The provision of physical (e.g., bathing and toileting) and instrumental care (e.g., shopping and meal preparation) can result in restrictions on the caregivers’ time and freedom. PWD caregivers also find that their relationship with their family member changes over time. Caregivers take on new roles and watch irreparable changes occur until PWD cease to remember those around them. Social isolation has been noted in almost half of informal caregivers for persons with ADRD living in the community (CSHA Working Group, 1994a), perhaps as a result of added responsibilities and stigma others may have about interacting with PWD. Friendships and participation in other activities can diminish, existing social support may deteriorate and, as the demands of caregiving increase, energy and motivation to socialize in remaining spare time can dwindle. Caregivers also may have to cease employment as the illness progresses and corresponding care requirements increase.

The demands and complexities of caregiving can also result in problematic health outcomes for PWD caregivers (e.g., Zarit, Orr, & Zarit, 1985) compared to caregivers of physically frail elders with no cognitive impairment (O’Rourke & Tuokko, 2000). For example, role demands can result in physical illness symptoms and chronic health
conditions (CSHA Working Group, 1994a) including cardiovascular problems (Unichio & Kiecolt-Glaser, 1994), poorer self-reported health (Rose-Rego, Strauss, & Smyth, 1998) and increased risk of mortality (Schulz & Beach, 1999).

Providing care for an aging relative or friend with a dementing illness can be burdensome and taxing; feelings of anger, frustration, guilt, worry, sadness, denial, stress and grief are common (Pinquart & Sörenson, 2003; Schulz, O’Brien, Bookwala, & Fleissner,1995). Caregivers of PWD have also been identified as one group at elevated risk for psychiatric illness, including clinical depression (Bookwala, Yee, & Schulz, 2000; O’Rourke, 2003). Whereas depression prevalence is believed to be less than 7% among community-dwelling older adults (Blazer, Hughes, & George, 1987), estimates based on randomly derived Canadian and U.S. samples suggest that the point prevalence among caregivers of PWD is approximately 18% (CSHA Working Group, 1994b; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989).

Although it was first assumed that the strain associated with the care of PWD was directly proportional to patient impairment, this has not been supported by empirical research; instead, variability seems to typify the family caregiving experience. Faced with comparable demands, some caregivers become overwhelmed early in the course of the illness (George, 1994) while others cope under remarkable stress (Stephens & Zarit, 1989) and report higher life satisfaction (Wright, Lund, Caserta, & Pratt, 1991).

Another positive aspect of caregiving, psychological resilience, may be a more common reaction to severe stress and loss than psychopathology (Bonanno, 2004). Psychological resilience (or hardiness) is defined as the process of adaptation in response to adversity, tragedy, threats or significant stress such as the diagnosis and care of a
family member with a debilitating illness (American Psychological Association, 2002). Psychological resilience is not a personality trait or a direct measure of personality, but rather a combination of thoughts and behaviours that can be learned and nurtured over time (Kersting, 2003).

The intent of this research was to examine the potential protective effects of psychological resilience relative to the well-being of spousal caregivers of persons with Alzheimer disease (AD). Does psychological resilience contribute to the prediction of life satisfaction, the absence of depressive symptomatology and caregiver burden over and above that which is determined by demographic variables and illness-related features? Guided by the theoretical conceptualization of psychological resilience proposed by Kobasa (1979), this study examined psychological resilience as a predictor of both positive caregiving outcomes and the absence of negative outcomes among a sample of cohabitating, community-residing spouses of persons with AD.
CHAPTER 2: LITERATURE REVIEW

Predictors of Caregiving Outcomes

Both positive and negative outcomes in caregivers of persons with dementia (PWD) are associated with multiple variables. These predictors are commonly grouped into patient characteristics (e.g., behavioural and functional problems, patient level of cognitive abilities), caregiver characteristics (including sex and health) and the caregiving context (e.g., living arrangements, social support).

Patient-specific variables, including duration and amount of care required and the care receiver’s level of functional and cognitive impairment, have received inconsistent support in the literature as predictors of negative emotional health and psychopathology such as burden and depression in caregivers of persons with Alzheimer disease (AD; Wright, Clipp, & George, 1993). As the clinical features of dementia differ across patients, specific patient behaviours perceived as most stressful also vary across studies. Whereas Gignac and Gottlieb (1996) reported harmful behaviour as most distressing, Pearson, Teri, Wagner, Truax and Lodgson (1993) cited patient withdrawal and apathy as most upsetting.

In contrast, caregiver-related characteristics have demonstrated greater association with psychological distress than patient impairment and duration of caregiving (e.g., O’Rourke, Haverkamp, Tuokko, Hayden, & Beattie, 1996). Caregiver sex, ethnicity, education level, self-rated health and relationship to the care receiver have been identified as associated with the psychological well-being of caregivers (Wright et al., 1993).
The caregiver’s relationship to the care recipient and the quality of that relationship have also been found to moderate the association between stress and outcome variables such as satisfaction with the caregiving role (Meshefedjian, McCusker, Belavance, & Baumgarten, 1998; Kramer, 1993; López, López-Arrieta, & Crespo, 2005). Spouses and female caregivers are most likely to report burden and depressive symptoms (Pinquart & Sörenson, 2003). The experience of caregiving is held to be qualitatively different for spouses as compared to other family members (Abel, 1989). For example, the gradual demise of one’s life partner is generally deemed to be more stressful than the decline of a parent or other family member. Physical components of care provision such as lifting can also prove more challenging for spousal caregivers with age-related health problems.

The context in which care provision occurs also affects caregiving outcomes. For example, the living situation of the caregiver in relation to the care receiver has been identified as an important factor in the literature. Caregivers who live with PWD typically have higher burden and depression scores than those who live elsewhere (Pinquart & Sörenson, 2003). One reason for this is that patients cohabitating with caregivers are generally more severely impaired than those who are able to live independently. Furthermore, cohabitating caregivers persistently experience PWD care requirements (e.g., reversal of sleep patterns) with fewer opportunities for respite (O’Rourke & Tuokko, 2000).

Existing Canadian research has also found burden to be higher for caregivers supporting people with Alzheimer disease and related dementias (ADRD) in the community as compared to caregivers of institutionalized family members (Canadian
Study on Health and Aging [CSHA] Working Group, 2002). This result might suggest that institutional care alleviates a substantial proportion of caregiver distress; however, while the decision to place one’s spouse in a nursing home or long-term care facility may reduce selected stressors, new ones such as guilt (Pratt, Wright, & Schmall, 1987) and financial strain (Monahan, 1995) may arise. Specific tasks performed may also change to supplement care provided by nursing staff. Overall, burden may be a qualitatively distinct construct in caregivers of institutionalized patients vis-à-vis those providing in-home support.

The use of formal support (e.g., adult day care programs, home care services, case management, in-home and institutional respite) and informal support services (i.e., instrumental or socioemotional support from friends, neighbours and other family members) and the relative size of support networks have inconsistently been identified as related to outcomes for caregivers (e.g., O’Rourke & Tuokko, 2000; Thompson & Briggs, 2000). Much ambiguity regarding the utility of social support pertains to the delineation between instrumental assistance and subjective perception. In fact, these facets of social support for family caregivers have emerged as distinct, with the latter being more predictive of health outcomes (Stuckey & Smyth, 1997). Wuest, Ericson, Stern and Irwin (2001) concluded that caregiver perceptions of, and satisfaction with, both formal and informal supports are significantly related to the psychological well-being of spousal caregivers of persons with AD. Generally, the use of informal supports is related more to caregiver characteristics than to the caregiving context (Aneshensel, Mullan, Pearlin, Zarit, & Whitlatch, 1995).
Overall, caregiver variables appear to be more strongly associated with outcomes versus dementia-related factors (e.g., patient impairment, duration of caregiving). For example, caregivers who do not perceive themselves as having adequate or available support from friends and family generally have poor outcomes even if they receive more support another caregivers in equally challenging circumstances. This observation underscores why objective levels of instrumental support are unrelated to caregiving outcomes in contrast to perceived satisfaction with, and perceived continuity of, social support. Furthermore, not all support received from family and friends is necessarily perceived positively (Morgan, 1989).

Caregiver burden, depressive symptomatology, and life satisfaction have been identified as distinct phenomenon, with each worthy of consideration as discrete aspects of caregiver well-being (O’Rourke & Tuokko, 2003). Each of these caregiving outcomes will now be considered in turn.

**Problematic Outcomes**

**Clinical Depression.** The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) categorizes depression as a mood disorder. Diagnosis of a mood disorder (e.g., major depressive disorder, dysthymic disorder, bipolar affective disorder) requires the occurrence of a mood episode (e.g., major depressive episode, manic episode, mixed episode). Depressed mood in a major depressive episode is characterized by sadness, depressed feelings and hopelessness lasting at least two weeks. Often present to some degree is anhedonia or the loss of interest or pleasure in previously enjoyed activities. In addition to pronounced sadness
and/or anhedonia, five or more of the following symptoms must be present to constitute a major depressive disorder diagnosis (in addition to duration and exclusion criteria): decreased energy; feelings of worthlessness or guilt; changes in sleep, psychomotor activity and appetite or weight; repeated thoughts of death or suicidal attempts, planning or ideation; or difficulty with concentrating, thinking or decision-making (American Psychiatric Association, 2000).

Clinical depression among older adults may be recurrent (i.e., chronic course) or of late onset. Aging-related factors such as health conditions, functional impairment and bereavement can contribute to depression onset (Fischer, Wei, Solberg, Rush, & Heinrich, 2003). While epidemiological research suggests that prevalence rates of clinical depression do not markedly differ between younger and older groups (Blazer et al., 1987; King & Markus, 2000), caregivers of PWD are one population with pronounced depressive symptoms (Bookwala et al., 2000). These individuals are commonly elderly themselves (Baumgarten, 1989) and face substantial stressors related to the demands of caregiving such as sleep disruption and social isolation. Much of the outcome literature suggests that caregivers are more likely to suffer an onset of mental illness due to the pronounced demands of the caregiving role. Dura, Stukenberg and Kiecolt-Glaser (1990) compared current and lifetime rates of depression between caregivers and non-caregivers and found that the former experienced more depressive symptoms throughout their caregiving years than did controls at the time of the study.

Studies using screening instruments and structured diagnostic interviews also have shown a consistent pattern of increased depressive symptomatology and depression among PWD caregivers vis-à-vis age- and sex-based norms (Collins & Jones, 1997;
Majerovitz, 1995; Redinbaugh et al., 1995; Haley et al., 1995; 1996). In fact, research utilizing depression self-report inventories and clinical interviews also suggests that an even larger proportion of PWD caregivers exhibit subclinical but substantial psychological distress. For example, Cohen and Eis dorfer (1988) indicated that more than 50% of their sample reported levels of depressive symptomatology within clinical range. These symptoms are nearly twice as prevalent among those caring for someone with dementia as compared to caregivers of other patient groups (Baumgarten et al., 1992; CSHA Working Group, 1994b).

Caregiver Burden. Burden is an outcome specific to caregiving populations. Caregiver burden has commonly been conceptualized as the “…physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults” (George & Gwyther, 1986, p. 253). While seemingly straightforward, this definition encompasses a wide range of experiences that can be further classified into objective and subjective burden. Objective burdens are those events, demands and activities associated with the negative aspects of caregiving and the concrete consequences of the care receiver’s physical and behavioural changes. Subjective burden includes the perceived stressors and individual emotional reactions of the caregiver.

Other researchers have defined caregiver burden as a “context-specific negative affective outcome resulting from one’s idiosyncratic appraisal of objective role demands” (O’Rourke, Haverkamp, Tuokko, Hayden, & Beattie, 1996, p. 584). From this perspective, subjective factors are thought to effect a caregiver’s perceived ability to cope in this capacity. For example, variables such as the caregivers’ past relationship with the
care recipient (Williamson & Schulz, 1990) and history of psychiatric illness (Russo, Vitaliano, Brewer, Katon, & Becker, 1995) have been found to impact both the psychological well-being and caregiver burden. Caregiver-specific variables such as these may help explain variability in expressed burden levels across caregivers facing comparable objective demands (Baumgarten, 1989).

Although it was first assumed that the strain associated with PWD care was directly proportional to patient impairment, this has not been supported by empirical research (Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994); instead, caregiver-specific variables mediate the relationship between patient impairment and burden (Dunkin & Anderson-Hanley, 1998). While some emphasize instrumental aspects of caregiver provision such as physical tasks, the majority regard burden as a subjective experience (Stommel, Given, & Given, 1990) and empirical evidence supports this definition (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000).

Positive Outcomes

Caregiving research has primarily emphasized negative outcomes such as burden and depression (Schulz, 2000). This narrow focus obscures the realization that caregiving can be a rewarding and positive experience (Sherrel, Buckwalter, & Morhardt, 2001). Our understanding of the diverse and rich experience of caregiving is limited despite the fact that positive aspects of this role are commonly reported and emphasized by caregivers (Kramer, 1997; Tarlow et al., 2004). Some of the positive caregiving outcomes considered in the literature include satisfaction with caregiving (López et al., 2005), subjective well-being (Pinquart & Sörensen, 2004), and deriving meaning through
Meaning in caregiving, for example, has been identified as negatively associated with depressive symptomatology (Noonan & Tennstedt, 1997). It is important to elucidate the processes at work in individuals who experience positive caregiving outcomes in order to broaden understanding and potentially encourage adaptation to this role (Kramer, 1997).

**Life Satisfaction.** One positive outcome that has received little attention in the PWD caregiving literature is life satisfaction. Life satisfaction falls under the rubric of subjective well-being, which includes both emotional and cognitive facets (Pavot, Diener, Colvin, & Sandvik, 1991).

While the relationship between the stresses of caregiving and negative outcomes such as depressive symptomatology and burden are generally well understood (see Pinquart & Sörenson, 2003), considerably less is known about the relationship between these stressors and life satisfaction (Pinquart & Sörenson, 2004). We do know, however, that life satisfaction entails more than the absence of burden or depressive symptomatology (O’Rourke & Tuokko, 2003). This distinction is underscored by work by Chappell and Reid (2002) who reported that care receiver cognitive impairments and behavioural problems are correlated with increased caregiver burden but not with decreased life satisfaction.

While meta-analytic research has identified associations between these patient-specific factors and subjective well-being among informal caregivers (Pinquart & Sörenson, 2004), few studies have considered life satisfaction. For example, Roth, Haley, Owen, Clay and Goode (2001) identified racial differences in life satisfaction over time in a large study of family caregivers of community-dwelling PWD, with Caucasian...
participants reporting significant decline compared to African American participants. Harper and Lund (1990) reported a mediating role of life satisfaction between patient functioning and caregiver burden in family caregivers of both institutionalized and noninstitutionalized PWD. Owen and colleagues (2002) also found patient-specific stressors and caregiving-related life event stressors to predict dementia caregiver life satisfaction. Among family caregivers of community-residing PWD, Wright and colleagues (1991) described the use of effective coping strategies as a significant predictor of increased life satisfaction but not decreased caregiver burden.

Despite the fact that depressive symptoms and burden are commonly the primary outcome measures utilized in PWD caregiving research, life satisfaction is a distinct outcome that warrants further attention in this population (Roth et al., 2001). This study examined all three of these outcomes in relation to psychological resilience.

**Psychological Resilience**

Given the salience of person-specific caregiver factors, it is feasible that psychological resilience or hardiness (these terms are employed interchangeably here as they are in the literature) may function as an effective buffer to negative outcomes and emerge as associated with positive outcomes among spousal caregivers. As defined by Kobasa, Maddi and Kahn (1982), psychological resilience reflects a pervasive belief that one can respond effectively under stress. This propensity is thought to be comprised of three interrelated constructs: commitment to living (i.e., a tendency to engage oneself fully in everyday activities); embracing challenge or the belief that change, rather than stability, is normative and; perceived ability to exercise control over life’s circumstances.
According to Kobasa and colleagues (1982), this manifests as a sense of personal autonomy and the belief that one is able to directly affect one’s destiny.

Kobasa and Puccetti (1983) describe resilience “… as facilitating the kind of perception, evaluation, and coping that leads to successful resolution of the situation created by stress events.” Research to date suggests that individuals typifying psychological resilience appraise demanding circumstances as opportunities for personal advancement as opposed to threats to well-being. Stressful conditions are acknowledged and perceived as opportunities for self-development and growth. Given this perspective, psychologically resilient individuals are thought to utilize proactive coping strategies and therefore respond more successfully to taxing events.

**Theoretic Focus**

Maddi and Kobasa (1984) proposed a theory of resilience to explain factors that impact individual health and well-being. This concept is founded upon the existentialist precept that the individual is not simply responsible for, but also the cause of her or his behaviour (Kobasa & Maddi, 1977). Psychological resilience is also rooted strongly in the salutogenic perspective on coping with stressful life events (Antonovsky, 1990). Resilience is hypothesized to serve as an individual resistance resource (Antonovsky, 1979) and a contributing factor to one’s life orientation (Kobasa, 1982).

This theoretical framework suggests that as stressors mount, the signs of strain increase; a stressor may result in tension that can manifest physically or psychologically. Individuals who repeatedly find themselves in such circumstances may experience decreased stress resistance that can result in negative outcomes such as physical or psychological strain. Maddi and Kobasa (1984) specify that resilient individuals confront
stressful circumstances by perceiving events as changeable (control) but meaningful (commitment), and of prospective value for personal development (challenge).

Although resilience has been operationalized differently by other researchers (e.g., Masten & Powell, 2003), this tri-construct framework is the only one founded upon psychological resilience as defined by Kobasa and colleagues (1982). This thesis will draw upon this conceptualization of resilience to examine and elucidate individual differences and their relative impact on PWD caregiving outcomes.

**Mediation versus Moderation**

An understanding of the distinction between mediating and moderating processes is required before reviewing the existing literature on psychological resilience. According to Baron and Kenny (1986), a moderator is a “variable that affects the direction and/or strength of the relation between an independent or predictor variable and a dependent or criterion variable” (p. 1174). In contrast, a mediator variable “accounts for the relation between the predictor and the criterion (variables)” (p. 1176). While a moderator provides information concerning when an effect occurs, a mediational model can elucidate the ‘how’ or ‘why’ of an effect. A moderating effect can be identified through interactions, while regression analyses can elucidate the presence of mediating variables.

Existing research with general adult samples (i.e., younger adults) suggests that psychological resilience is related to the physical health of corporate executives (Kobasa, Maddi, Puccetti, & Zola, 1985), enhanced quality of life among working adults (Manning, Williams, & Wolfe, 1988), the mental and physical health of women with a history or physical and/or sexual abuse (Heckman & Clay, 2005), the success of U.S.
Army Special Forces candidates (Bartone, Roland, Picano, & Williams, 2008), frequency of alcohol and drug use in adolescents (Maddi, Wadhwa, & Haier, 1996), reduced illness among bus drivers (Bartone, 1989), decreased psychological distress in women transitioning from welfare to employment (Gill, 2002), and the psychological well-being of ambulance personnel (Alexander & Klein, 2001).

**Older Adults**

An important emphasis of the gerontological literature is the notion that certain individuals have the capacity to sustain or regain normal functional levels after experiencing adverse life events (e.g., Staudinger, Marsiske, & Baltes, 1993). This notion of resilience could have significant implications in later life given the increased number of stressful life events associated with aging (e.g., retirement, widowhood). While psychological resilience alone will not prevent personal decline or loss, it may define an individual’s ability to cope with adversity. The construct of psychological resilience may expand our understanding of positive outcomes and individual differences in later life (Wallace, Bisconti, & Bergeman, 2001).

Though some studies have applied this three-factor conceptualization to samples of older adults (e.g., McNeil, Kozma, Stones, & Hannah, 1986), comparatively few have examined psychological resilience with this population. Resilience has been found to be a significant negative predictor of depressive symptomatology in retirement village-dwelling older adults (Sharpley & Yardley, 1999). Wallace (2003) reported that hardiness mediated the relationship between quantity of informal support and depressive symptoms, life satisfaction, and self-reported health in a mailed survey of older adults in the rural U.S. Wilder (1996) found that greater resilience was associated with increased
self-reported functional health status and life satisfaction in a convenience sample of seniors. Resilient older adults in India also reported greater life satisfaction (Nathawat & Rathore, 1996). Rhodes (1995) reported both a direct positive significant relationship between resilience and life satisfaction and a significant mediating effect of resilience between demographic variables and life satisfaction in a healthy elderly sample. In a sample of married older adults reporting stressful spousal behaviours, Spradling (2001) reported that resilience moderated the association between marital stress and life satisfaction.

Wallace and colleagues (2001) examined whether resilience functioned as either a mediator or moderator between social support and outcomes including depressive symptoms, life satisfaction, and self-reported health. Their research supported the mediational model by identifying a decreased relationship between social support and all three resilience constructs. It is notable, however, that an unspecified number of Dispositional Resilience Scale items (DRS; Bartone, Ursano, Wright, & Ingraham, 1989), were adapted for this study limiting generalizability of findings.

Widows

Although no research to date has examined resilience among PWD caregivers specific to anticipatory grief, some research on bereavement has noted the important role it may play in coping with stress and grief (e.g., Ong, Bergeman, Bisconti, & Wallace, 2006). For example, Campbell, Swank and Vincent (1991) noted that resilience was a significant predictor of grief resolution over and above time since death. Rossi, Bisconti and Bergeman (2007) reported that resilience both mediated and moderated the relationship between perceived stress and life satisfaction in older adult widows. In a
study of adaptation to widowhood, O’Rourke (2004a) found that psychological resilience, and the commitment facet in particular, were significantly associated with the well-being of widowed women.

Nurses

Psychological resilience has also been examined in samples of formal caregivers. For example, Rodney (2000) found that the constructs of resilience were unrelated to stress in nurses working with PWD with aggressive behaviours in nursing homes. As an explanation for this result, the author suggested that resilience does not generalize to the specific stressors associated with caring for PWD; however, Duquette, Kérouac, Sandhu, Ducharme and Saulnier (1995) identified resilience as the predominant predictor of burnout in geriatric nurses sampled from the register of Quebec nurses. Higher resilience scores were also associated with lower stress levels and greater job satisfaction in home health nurses (Judkins & Rind, 2005). McCranie, Lambert and Lambert (1987) identified a main effect of resilience relative to reduced burnout. These authors did not observe a moderating effect of resilience between job stress and burnout, however.

Other Informal Caregiving Populations

Some research has also used samples of informal caregivers of patients with other illnesses. For example, resilience has been examined in family caregivers of patients with HIV/AIDS (Johns, 1998). A few studies have also considered psychological resilience in mothers of children with intellectual disabilities. Weiss (2002) reported an association between greater control and depressive symptomatology, while Gill and Harris (1991) identified a comparable negative association between the commitment dimension of resilience and number of depressive symptoms. Responses to the full scale
were also found to contribute significantly to mental health in this caregiver sample (Ben-Zur, Duvdevany, & Lury, 2005).

**PWD Caregivers**

To date, a paucity of studies have examined psychological resilience among PWD caregivers. The earliest research in this area is that of Milne, Sacco, Cetinski, Browne and Roberts (1994). These Canadian authors explored the role of resilience in 64 caregivers of mobile patients with moderate to severe cognitive impairment referred to one seniors’ day program over a 1-year period. Results of a stepwise regression analysis suggested that resilience was the strongest predictor of caregiver purpose-in-life in this sample.

L. Clark and Hartman (1996) hypothesized resilience and its facets as predictive of caregiver distress and physical health. Consistent with previous research in non-caregiving samples (Orr & Westman, 1990), greater total resilience score predicted both higher life satisfaction and less depressive symptomatology in family caregivers of older adults. Physical health predicted neither symptoms of depression nor life satisfaction. The main effect for hardiness was significant, accounting for an additional 21% of variance after controlling for caregiving demands. No interactions between resilience and caregiving demand variables attained significance. A parallel multiple regression equation with resilience components, instead of composite score, resulted in nearly identical findings, with commitment emerging as a unique predictor. All three facets were moderately and significantly correlated.

Sussman (2003) examined the relationships between resilience, coping strategies, and emotional distress in caregivers of institutionalized AD patients. Greater caregiver
hardiness predicted lower levels of both reported depressive and anxiety symptoms in this small \( n=42 \) sample.

P. Clark (2002) tested the theoretical model in 67 family caregivers of functionally impaired older adults attending several different adult day care facilities. In doing so, she operationalized stress as care receiver disability. The psychological and physical strain outcomes were operationalized as depressive symptomatology and fatigue, respectively. The author found that psychologically resilient caregivers reported less depressive symptomatology and fatigue; however, the amount of variance explained by the regression analysis was low (5%).

In the most homogeneous caregiver sample to date, Nunley (2002) examined the role of problematic patient behaviours and caregiver resilience vis-à-vis psychological distress among cohabiting spousal PWD caregivers. She tested both the main effect of caregiver resilience and its mediating role vis-à-vis behavioural problems and caregiver burden, quality of life, and depressive symptomatology. Regression analyses suggested that resilience buffers the impact of challenging behaviours on caregiver burden and quality of life. A main effect for resilience also emerged relative to depressive symptoms, with resilient caregivers reporting fewer symptoms regardless of care receiver problematic behaviours. Recruitment for this study included adult day centres, senior centres, home health agencies, churches, and family physicians as well as advertising to support groups, in Alzheimer Association newsletters, and community newspapers. The small sample \( n = 44 \) recruited for this study precluded comparison by means of recruitment.
Problematic Methodology and Sample Size Limitations in Caregiving Research

There are several significant limitations to the existing resilience literature. For instance, use of stepwise regression by Milne and colleagues (1994) among others leads to questionable conclusions. Particularly with correlated independent variables (common in caregiving research), stepwise procedures can lead to erroneous findings (Thompson, 1989). For this reason, top journals automatically reject manuscripts reporting results based on stepwise procedures (Thompson, 1995).

In addition, multiple regression requires samples of sufficient size. A consistent limitation of the existing literature has been the use of unacceptably small sample sizes, raising the spectre of $\beta$ or Type II errors (Cohen, 1992). To date, only Clark (2002) undertook and reported power calculations ($n=67$). With seven independent variables, this author claimed to have derived a sample with adequate power (.92) where $\alpha = .05$. In making this assertion, however, Clark (2002) liberally assumed a large effect size. Sufficient power to detect a medium effect size would have required a sample size of more than 100 participants ($\alpha = .05$; Cohen, 1992). This thesis utilized a sample sufficient to reduce the likelihood of Type II error, while assuming a medium effect size.

Internal versus External Validity in PWD Caregiving Research

The caregiving literature stands as an example of the importance of weighing internal and external validity in study design. By broadening inclusion criteria to capture diverse contextual caregiving experiences and patient samples, externally valid research reduces the applicability of findings to a particular caregiving population. In contrast, internally valid research expands population-specific knowledge via recruitment of homogeneous samples.
While the trade-off between internally versus externally valid research depends on the intent of the study and the research maturity of the specific topic of interest, a primary limitation of the literature on caregivers of PWD is sampling methodology. As the above review of caregiving outcomes highlights, the caregiving context can significantly impact the results of outcome measurement and thereby call into question the generalizability of findings. Inconsistencies may be attributed to sample heterogeneity. The majority of existing research, for instance, combines caregivers of different patient populations, distinct kinship and varied living arrangements relative to the patient. Broad inclusion criteria are further complicated by the dearth of intra-sample analyses of differences between children and spouses, husbands and wives, and daughters and sons.

Conclusions from research utilizing heterogeneous samples must therefore be generalized with caution. More complete understanding can only be ascertained through research with more homogeneous samples or advanced comparative analyses.

In contrast to research with PWD caregivers in general, studies of caregivers of persons with frontotemporal dementia (FTD) provide an example of the consistency of findings with a focused patient population. Limiting study enrollment to FTD caregivers, who face distinct demands such as perseveration, reveals that the level of patient functional impairment is a consistent predictor of depressive symptoms and burden in this caregiver population (e.g., Diehl, Mayer, Förstl, & Kurz, 2003).

Sample Homogeneity in PWD Caregiving Research

The limited research on psychological resilience in this population has not escaped the use of heterogeneous samples. While the results of these studies are similar to those found in other populations, sample heterogeneity precludes full understanding of
this construct among dementia caregivers. For example, L. Clark and Hartman (1996) argued that the effect of resilience on well-being would be comparable across diverse caregiving situations, and therefore did not limit their focus beyond caring for an elderly relative. The authors set out to “indicate a direction for further study within subgroups” (p. 383), but the sample size ($n=53$) and composition precluded subgroup analysis. Only 30% of care receivers in the research by L. Clark and Hartman (1996) were reported to have AD. Similarly, the research by P. Clark (2002) involved caregivers of functionally impaired older adults with primary diagnoses including arthritis, hypertension and cerebrovascular disease in addition to persons with AD. While Milne and colleagues (1994) limited recruitment to caregivers of persons with cognitive impairment, they did not specify patient diagnoses. In contrast, Sussman (2003), Lancer (2007) and Nunley (2002) focused on caregivers of persons with AD, various dementias, and dementia with associated behavioural problems, respectively.

Diversity in the definition and type of caregiver also exists across this limited literature. As a result of variation in sampling methodology, we understand little about psychological resilience in spousal caregivers of PWD. Participants in the P. Clark (2002) study were required to be the “primary family caregiver” (p. 39) without further clarification provided, while recruitment criteria for the L. Clark and Hartman (1996) study required care provision on at least a weekly basis. Lancer (2007) did not limit participation beyond a particularly small sample ($n=18$) of family caregivers in a cognitive-behavioural intervention, whereas Nunley (2002) focused specifically on spouses in the caregiving role for a minimum of six months. Only 21% of participants in the P. Clark (2002) study were spouses, and 29%, 30% and 55% of participating
caregivers in the work by Sussman (2003), L. Clark and Hartman (1996) and Milne and colleagues (1994) were spouses, respectively. Previous research has shown that personality factors may affect who cares for a relative with dementia when a spouse or partner cannot (Hooker, Frazier, & Monahan, 1994). These factors may influence reporting of the caregiving experience and thereby introduce increased variability.

Findings in this area are also confounded by caregiver residence status in relation to the living arrangements of the patients. While Sussman (2003) focused on caregivers of institutionalized persons with AD, L. Clark and Hartman (1996) and Milne and associates (1994) allowed both patients and caregivers to vary by residence status. As a result, less than two-thirds of the participants lived with the care recipient in both instances, and caregivers whose relative resided in a nursing home were also included. The study by Nunley (2002) is the only one to date to recruit spouses exclusively providing primary care at home to partners with dementia.

While the studies reviewed here constitute the foundation of research in this area, there is considerable room for methodological improvement. Apparent contradictory results may be attributable to sample heterogeneity and inadequate sample sizes. Inconsistencies in the literature necessitate an internally consistent and sufficiently powered research methodology in order to clarify associations among constructs. Therefore, a homogeneous sample was recruited for this thesis to examine individual differences and caregiving outcomes without the potential confound of between-group differences or the significant likelihood of Type II error.
Statement of Hypothesis

The literature reveals that both positive and negative dementia caregiving outcomes are influenced by several factors, including caregiver relationship to and cohabitation status with the PWD. In addition, psychological resilience has been demonstrated to play a role in the adaptation of both PWD caregivers and other related populations to aversive circumstances (e.g., L. Clark & Hartman, 1996; Ong et al., 2006). For this study, it was hypothesized that elevated levels of each of the three components of psychological resilience would predict greater caregiver life satisfaction and lower levels of both depressive symptomatology and perceived caregiver burden, controlling for socio-demographic variables and patient illness factors. In other words, psychological resilience was assumed to serve as a protective factor enabling caregivers to assume care demands without significant adverse effects. This study tested this hypothesis in a sample of cohabitating, community-residing spousal caregivers of persons with a diagnosis of either probable or possible AD.
CHAPTER 3: METHODOLOGY

Participants and Recruitment

This study utilized the cross-sectional baseline data of a longitudinal study of psychological resilience among spouses. To facilitate data collection, participants were paid $50 for completing study questionnaires. All research expenses were financed by external funding sources awarded to the senior supervisor.

Spousal caregivers were recruited through systematic chart audits from consecutive patient assessments at the Clinic for Alzheimer Disease and Related Disorders, University of British Columbia Hospital between April 2006 and December 2007 as part of a longitudinal study of psychological resilience among spouses. This tertiary diagnostic clinic receives physician referrals from all regions of British Columbia. Previous research suggests that participants recruited at this site are demographically indistinguishable from the Canadian population of informal caregivers of persons with dementia (PWD; O’Rourke, Haervkamp, Tuokko, Hayden, & Beattie, 1997).

In order to be eligible for inclusion in this study and to ensure sample homogeneity, participants had to meet the following criteria: spouse of a presenting patient; community-dwelling and cohabitating with care recipient; and care recipient has a diagnosis of probable or possible Alzheimer disease (AD).

Subsequent to clinic assessments, each care recipient is discussed during an interdisciplinary team meeting comprised of a neuropsychologist, social worker, geriatric psychiatrist and either a geriatrician or neurologist. At this time, the care recipient
receives a diagnosis or that individual’s previous diagnosis is confirmed or updated based upon disease progression (e.g., from mild cognitive impairment to AD; Petersen et al., 2001).

For a spousal caregiver to be included in this study, the presenting patient had to receive a diagnosis of probable or possible AD according to the criteria outlined by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer Disease and Related Disorders Association Criteria for Alzheimer Disease (NINCDS-ADRDA; McKhann, Drackman, Folstein, Katzman, Price, & Stadlan, 1984). Katzman and Jackson (1991) have reported that the validity of AD diagnoses exceeds 90 percent in interdisciplinary settings. Members of the interdisciplinary team were blind to the hypotheses of the current study.

Caregivers who met inclusion criteria were mailed a covering memo and information letter inviting their participation in this study shortly after the interdisciplinary team meeting in which their spouse was discussed (see Appendices A and B, respectively). Caregivers were then contacted by telephone a minimum of 48 hours after they were likely to have received the study invitation in the mail. If the caregiver agreed to participate, s/he was assigned a 6-digit identifier code and mailed a prepared study package, a consent form (Appendix C), and a postage-paid envelope to return the completed forms. Selected instruments were randomly counter-balanced to ascertain if order effects biased responding to one or more study questionnaires.

Only heterosexual couples were sought for this research. A total of 130 men (n = 63) and women (n = 67) provided responses for this study. The majority of
presenting patients met criteria for probable AD ($n = 119$), while a small proportion had a diagnosis of possible AD ($n = 11$).

**Study Measures**

Existing resilience research has utilized different scales, which has complicated understanding of its role in health outcomes. Later versions of the resilience instruments incorporated theoretical and psychometric refinements that could have an important influence on how resilience relates to other variables. The literature has progressed to the point that only two, ‘third-generation’ measures are commonly used; the Personal Views Survey (PVS; Hardiness Institute, 1985) in one of four revisions to date (PVS, PVS-II, PVS-III and PVS-IIIR) and the Dispositional Resilience Scale (DRS; Bartone et al., 1989).

Alternatives to the DRS and PVS do exist, however. The Cognitive Hardiness Scale (Nowack, 1990), while founded on the 3-part conceptualization of psychological resilience, uses alternative scales to measure hardiness dimensions and has undergone significantly less psychometric examination in the literature. The Health-Related Hardiness Scale (Pollock, 1986) is also founded on a construct with control, commitment and challenge components; however, this construct and its dimensions have circumscribed health-specific definitions (see Pollock & Duffy, 1990) distinct from those of Kobasa and colleagues (1982). Research with adults utilizing other resilience measures without a comparable 3-factor theoretical foundation have not been considered in guiding this research (e.g., Connor-Davidson Resilience Scale: Conner & Davidson, 2003; Family Hardiness Index: McCubbin, McCubbin, & Thompson, 1996;
Psychological Hardiness Scale: Younkin & Betz, 1996; Resilience Scale: Wagnild & Young, 1993; Resilience Scale for Adults: Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003), even where these studies sample caregivers of PWD (e.g., DiBartolo & Soeken, 2003; Garity, 1997; Wilks, 2008) and other relevant populations (e.g., Chappell & Dujela, 2008; Schott-Baer, Fisher, & Gregory, 1995).

In their research on psychological resilience among caregivers of older adults, L. Clark and Hartman (1996) suggest the need for the use of a measure of resilience superior to the PVS. In the most comprehensive review of available instruments to date, Funk (1992) recommends the use of the full, 45-item DRS as the most conceptually and psychometrically sound measure of resilience as compared to the PVS and other measures. The use of the DRS offered an improvement over all existing studies in this area. While the work of P. Clark (2002) utilized an abridged version of this scale, this research utilized the full DRS measure.

*Dispositional Resilience Scale (DRS).* The DRS (Bartone et al., 1989) is comprised of 45 items with responses recorded along 4-point Likert-type scales ranging from *not at all true* (0) to *completely true* (3). The DRS was developed as a measure of hardiness or psychological resilience and is comprised of three interrelated factors or subscales: perceived control; commitment; and challenge. Each subscale includes an equal number of items. One-third of DRS items (five from each subscale) are reverse-scored. Higher scores indicate greater resilience. The DRS is deemed superior to earlier measures of psychological resilience (e.g., sole use of negatively-keyed items and awkward and lengthy phrasing; Funk, 1992).
Internal consistency or responses as measured by Cronbach’s alpha has been reported as $\alpha = .86$ for the total hardiness score and $\alpha = .68$, $\alpha = .72$ and $\alpha = .59$ for the control, commitment and challenge subscales, respectively, in a sample of older married adults (Ong & Bergeman, 2004). The authors of the instrument report comparable internal consistency reliabilities of $\alpha = .85$ for the composite measure and $\alpha = .66$, $\alpha = .82$ and $\alpha = .62$ for the respective subscales in a sample of U.S. Army family assistance workers (Bartone et al., 1989). Pergadia (2002) reported subscale responses of acceptable test-retest reliability over a one-month period ($r = .66$, $r = .82$ and $r = .62$ respectively).

*Center for Epidemiologic Studies Depression (CES-D) Scale.* The CES-D (Radloff, 1977) is a 20-item instrument to which respondents rate the frequency of various depressive symptoms over the past week. Responses are presented along a 4-point scale ranging from *rarely or none of the time* (0) to *most or all of the time* (3). Internal consistency of responses to the CES-D has been estimated to be within optimal parameters for both community and clinical older adult samples (e.g., $\alpha = .85$ to $\alpha = .91$; Himmelfarb & Murrell, 1983). Results of a meta-analysis suggest little variability in the reliability of responses to the CES-D across caregiver populations (O’Rourke, 2004b). The same meta-analysis reported an average internal consistency of $\alpha = .88$ ($SD = .05$; median $\alpha = .89$) and a mean test-retest correlation coefficient of $r = .70$ ($SD = .17$) over an average interval of 24.40 months ($SD = 24.31$). Nor do there appear to be sex differences in the interpretation of CES-D items by PWD caregivers (O’Rourke, 2005).

Lewinsohn, Seeley, Roberts, and Allen (1997) assert that the utility of the CES-D is not negated by age, sex, physical disease, cognitive decline or physical impairment.
Although developed and validated with general adult populations, the CES-D appears to be reliable and valid for use with older adults (Radloff & Teri, 1986).

Response totals greater than 15/60 on the CES-D are deemed suggestive of clinically significant depressive symptomatology (Radloff & Teri, 1986). If a participant scored within this range, this information was relayed to a clinic physician. Referral information for treatment and community resources was provided to caregivers as required in accord with IRB requirements.

**Burden Interview (BI).** The BI is believed to be the most commonly utilized measure of caregiver burden (Knight, Fox, & Chou, 2000) and consistent with the operational definition of O’Rourke and colleagues (1997), the BI (Zarit et al., 1985) was developed specifically to measure perceived strain associated with caring for community-dwelling persons with AD. This instrument includes 22 statements; the degree to which caregivers endorse each item is rated along a 5-point Likert-type scale. Response options range from *never* (0) to *nearly always* (4) with higher values reflecting greater burden. Two BI subscales (role strain and personal strain) can be calculated, but BI scores are most often reported as a combined total due to the high correlation between subscales (e.g., $r = .75$; Hadjistavropoulos et al., 1994).

Internal consistency of responses to the BI has been reported to range from $\alpha = .83$ (Majerovitz, 1995) to $\alpha = .94$ (O’Rourke & Wenaus, 1998). A recent reliability generalization meta-analysis (Bachner & O’Rourke, 2007) of the BI reported average internal consistency of $\alpha = .86$ across caregiver populations ($SD = .06$; median $\alpha = .88$). The same study reported a mean test-retest reliability correlation coefficient of $r = .59$ ($SD = .22$) over an average interval of 31.56 months ($SD = 27.72$). Zarit and Zarit (1990)
have reported the responses on the BI to be concurrently valid through correlations of total BI scores with a single-item global rating of burden ($r = .71$) and with responses to the Brief Symptom Inventory ($r = .41$; Derogatis & Melisaratos, 1983). The construct and discriminant validity of BI responses have been supported by number of hours of care provision and an inverse association with caregiver morale, respectively (Pratt, Schmall, & Wright, 1986).

*Satisfaction With Life Scale (SLS).* According to Pavot and Diener (1993), the SLS (Diener, Emmons, Larsen, & Griffin, 1985) measures perceived quality of life utilizing person-specific criteria. Respondents compare their current circumstances against subjective standards to produce a global appraisal of life satisfaction (Diener, 2000). This instrument is comprised of five items with seven response options ranging from *strongly disagree* (1) to *strongly agree* (7). Higher totals are indicative of greater life satisfaction.

Internal consistency of responses has been reported as $\alpha = .85$ in a sample ranging from 53 to 92 years of age (Pavot et al., 1991). Test-retest reliability over a one-month interval among the same participants was reported as $r(39) = .84$. The same authors reported the construct validity of SLS responses among older adults relative to the Fordyce Global Scale ($r[39] = .82$; Fordyce, 1977). Blais, Vallerand, Pelletier and Brière (1989) have also reported negative correlations between SLS scores and responses on measures of distress such as the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

*Demographics and Health Questionnaire.* A questionnaire designed to collect personal and relationship data was administered to participants. Current or past
occupation was grouped into categories as an index of socioeconomic status (Barona, Reynolds, & Chastain, 1984).

Several questions also gathered caregiver subjective and objective health information. Four subjective health questions were adapted from the Canadian Study on Health and Aging (CSHA Working Group, 1994). Responses were recorded along Likert-type scales with seven response alternatives for the first question and three options for the remaining three questions. A single, cumulative variable comprised of responses to all four questions was computed.

Twenty-two objective health questions were also adapted from the caregiver demographic questionnaire used in the CSHA-II (CSHA Working Group, 2002). Participants were asked to indicate whether or not they had experienced a series of health problems over the past year (i.e., allergies, kidney disease, cancer, diabetes, high blood pressure, stroke, insomnia). Higher scores indicate greater physical impairment.

All test materials were self-administered and printed in English in Times New Roman 12pt type-font. Completion of the scales required approximately 40 minutes. All study measures can be found in Appendix D.

*Functional Rating Scale (FRS).* The FRS (Tuokko, Crockett, Beattie, Horton, & Wong, 1985; Crockett, Tuokko, Koch, & Parks, 1989) was developed to quantify patient impairment across multiple cognitive and functional domains (i.e., memory, social/occupational, home and hobbies, personal care, language, problem solving/reasoning, affect, and orientation). This measure offers a cumulative rating of dementia severity while acknowledging disproportionate rates of decline across neurodegenerative disorders (e.g., global versus circumscribed deficits). FRS scores
range from 8 to 40, with higher totals suggestive of greater impairment. Reported inter-rater reliability coefficients range from $r = .63$ to $r = .93$ (Tuokko et al., 1985). Tuokko and Crockett (1991) report 94% correct patient classification comparing FRS scores with standard neuropsychological measures.

FRS scores were assigned during the interdisciplinary team meetings previously described. Within each of the eight domains, a consensus rating of symptom severity is identified along 5-point ordinal scales. Ratings of three or more on each domain are suggestive of clinically significant impairment. Duration of symptoms was also determined during these team meetings on the basis of collateral informant information and existing medical records.

Analytic Procedure

In order to test the aforementioned hypothesis, hierarchical regression analyses were performed (Cohen, Cohen, West, & Aiken, 2003). Linear regression attempts to model the relationship between variables by fitting a linear equation to the derived data. With hierarchical regression, the order of entry of the predictors is specified in separate sequential steps, in contrast to simultaneous entry into the equation.

This study used three separate 3-step hierarchical linear regression analyses to test psychological resilience as a predictor of caregiver burden, depressive symptomatology and life satisfaction, respectively among spousal caregivers of persons with AD over and above that provided by caregiver demographic and patient variables. A total of 130 participants were recruited for this study, a sample size sufficient to detect medium to large effect sizes at $\alpha = .05$ with ten independent variables (Cohen, 1992). As proposed,
regression analyses enabled determination of whether or not psychological resilience accounted for a significant degree of observed variance in each dependent measure.

Caregiver burden, depressive symptomatology and life satisfaction were the dependent variables for this thesis. Independent variables for each hierarchical model include socio-demographic variables, patient variables and psychological resilience. Patient variables were entered to control for contextual variability in care provision and include duration of patient symptoms and dementia severity. This was undertaken to identify the independent prediction of resilience factors, over-and-above variance shared with socio-demographic and patient illness factors.

Psychological resilience, conceptualized as scores on the challenge, commitment and control DRS subscales, were entered as a separate and final step. Step 1 included caregiver age, years of formal education, socioeconomic status, subjective health, and objective health. Step 2 included patient functional impairment and duration of memory problems. Lastly, Step 3 tested the predictive strength of the three psychological resilience subscales to caregiver burden, depressive symptomatology and life satisfaction.

It was hypothesized that each facet of psychological resilience would demonstrate a statistically significant association with caregiver burden, depressive symptomatology and life satisfaction after controlling for prior variables in the regression model. This would signify psychological resilience as a significant and distinct predictor of caregiver well-being. More precisely, the contribution of psychological resilience to the prediction of caregiver burden, depressive symptomatology and life satisfaction would attain statistical significance despite statistical control for socio-demographic and illness-related variables.
Entry of each psychological resilience construct enabled examination of the contribution of each relative to caregiver well-being (i.e., life satisfaction, absence of caregiver burden and depressive symptomatology; Funk, 1992). Based upon previous findings (e.g., L. Clark & Hartman, 1996; O’Rourke, 2004a), it is feasible that aspects of psychological resilience might vary across the three dependent variables and differ in relative strength.

Given that these three regression equations were computed with the same independent variables the Bonferroni correction, a more rigorous threshold for statistical significance (i.e., \( \alpha = .05/3 \)), was employed to reduce the risk of capitalization on chance.
CHAPTER 4: RESULTS

The order of questionnaire presentation was counterbalanced creating two alternate formats for this study. Initial comparative analyses indicated that response levels did not significantly differ between the two. It can therefore be concluded it is unlikely that order effects confounded participant responses.

The PRELIS program (Jöreskog & Sörbom, 1996) was used to estimate values for missing data (estimated at less than 1% of usable data). As opposed to substituting mean item scores, PRELIS imputes values on the basis of like-responses. This method is preferable to substitution with item mean values which can obscure between group differences (Little & Rubin, 1987). Visual inspection and summary statistics did not reveal a discernable pattern among missing data (i.e., not specific to a particular scale or set of questions).

Descriptive Features of Patient Sample

The average age of patients was 70.8 years ($SD = 8.19$, range 48 to 88). Patients had completed an average of 13.6 years of formal education ($SD = 3.25$, range 5 to 21). Patient memory problems had been apparent for an average of 4.84 years ($SD = 2.95$, range 1 to 19).

Descriptive Features of Caregiver Sample

Similar to most self-selected studies with caregivers of persons with Alzheimer disease (AD), the majority of participants were female ($n = 67$ of 130, 51.5 %) with an
overall average age of 69.2 years ($SD = 9.64$, range 45 to 89). On average, couples had been married for 41.6 years ($SD = 13.8$, range 1 to 66).

In terms of socioeconomic status, roughly equal proportions of spousal caregivers worked now (or prior to retirement) in professional ($n = 49$) or clerical/administrative positions ($n = 45$). The remainder of participants reported work as skilled or semi-skilled labourers. The majority of couples ($n = 90$) had a total family income of at least $40,000. The participants’ formal education on average was in the post-secondary range ($M = 14.4$ years, $SD = 3.50$, range 7 to 25).

Caregivers reported an average of 3.98 health conditions ($SD = 2.69$, range 0 to 11). When describing their health in general, the majority of respondents rated their health as very good ($n = 28$), good ($n = 39$), or satisfactory ($n = 34$). Compared to one year ago, the vast majority of participants indicated that their health is about the same ($n = 104$). Compared to most people their age, respondents reported having worse ($n = 47$) or equivalent health status ($n = 68$). Almost all participants indicated that their health problems interfere with desired activities either a little ($n = 59$) or a great deal ($n = 56$).

A notable proportion of participants ($n = 40$ or 30.8%) provided Center for Epidemiologic Studies Depression (CES-D) responses suggestive of clinically significant levels of depressive symptomatology ($M = 13.72$, $SD = 10.20$; range 0 to 49). Women reported significantly higher levels of depressive symptomatology ($M = 15.49$, $SD = 10.75$) than their male counterparts ($M = 11.84$, $SD = 9.29$; $t[128] = 2.06$, $p < .05$). Female participants also reported significantly greater burden ($M = 38.19$, $SD = 14.79$) than the men in this sample ($M = 31.95$, $SD = 12.78$; $t[128] = 2.57$, $p < .05$); however,
reported levels of life satisfaction did not significantly differ between male ($M = 22.00,\ SD = 6.22$) and female caregivers ($M = 19.73,\ SD = 7.25; \ t[128] = 1.91,\ ns$).

Table 1 presents descriptive statistics for participant responses to study instruments. The psychometric properties suggest normal distributions of responses as required for regression analyses (i.e., within optimal parameters (Tabachnick & Fidell; 2001); the internal consistency of responses on the commitment ($\alpha = .63$), control ($\alpha = .53$), and challenge subscales of the DRS ($\alpha = .59$) are less than ideal, however, despite adequate internal consistency for the full DRS ($\alpha = .77$).

Reported levels of Psychological Resilience. Reported levels of commitment did not significantly differ between male ($M = 35.48,\ SD = 3.77$) and female caregivers ($M = 34.22,\ SD = 4.46; \ t[128] = 1.72,\ ns$), nor did levels of control (men, $M = 32.65,\ SD = 3.84$; women, $M = 32.18,\ SD = 4.04; \ t[128] = .68,\ ns$) or challenge (men, $M = 25.33,\ SD = 4.69$; women, $M = 24.40,\ SD = 4.67; \ t[128] = 1.13,\ ns$).

Pearson product-moment correlation coefficients were computed to examine the relationships between caregiver socio-demographic variables, patient variables, and measures of depressive symptomatology (CES-D), burden (Burden Interview [BI]), life satisfaction (Satisfaction With Life Scale [SLS]) and psychological resilience (Dispositional Resilience Scale [DRS]; see Table 2). Moderate but statistically significant positive correlations were found between scores on all three DRS subscales (i.e., commitment, control, challenge), with the challenge subscale correlating least strongly.

Analysis of DRS subscales also revealed moderate, negative correlations with responses to the CES-D. Similar correlations emerged between the BI and scores on the
Table 1

*Psychometric Properties of Study Variables (N = 130)*

<table>
<thead>
<tr>
<th>Instrument</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>α</th>
<th>Kurtosis</th>
<th>Skewness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dispositional Resilience Scale:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commitment</td>
<td>34.83</td>
<td>4.17</td>
<td>24-43</td>
<td>.63</td>
<td>-.37</td>
<td>-.37</td>
</tr>
<tr>
<td>Control</td>
<td>32.41</td>
<td>3.94</td>
<td>20-40</td>
<td>.53</td>
<td>-.01</td>
<td>-.37</td>
</tr>
<tr>
<td>Challenge</td>
<td>24.85</td>
<td>4.69</td>
<td>11-38</td>
<td>.59</td>
<td>.34</td>
<td>.03</td>
</tr>
<tr>
<td>CES – Depression Scale</td>
<td>13.72</td>
<td>10.20</td>
<td>0-49</td>
<td>.90</td>
<td>1.04</td>
<td>1.16</td>
</tr>
<tr>
<td>Burden Interview</td>
<td>35.17</td>
<td>14.15</td>
<td>3-79</td>
<td>.92</td>
<td>.13</td>
<td>.32</td>
</tr>
<tr>
<td>Satisfaction With Life Scale</td>
<td>20.83</td>
<td>6.84</td>
<td>6-34</td>
<td>.88</td>
<td>-.85</td>
<td>-.13</td>
</tr>
<tr>
<td>Caregiver Years of Education</td>
<td>14.42</td>
<td>3.50</td>
<td>7-25</td>
<td>--</td>
<td>.22</td>
<td>.50</td>
</tr>
<tr>
<td>Caregiver Health Conditions</td>
<td>3.98</td>
<td>2.69</td>
<td>0-11</td>
<td>--</td>
<td>.24</td>
<td>.78</td>
</tr>
<tr>
<td>Caregiver Perceived Health</td>
<td>11.14</td>
<td>2.47</td>
<td>4-15</td>
<td>--</td>
<td>.15</td>
<td>-.64</td>
</tr>
<tr>
<td>Functional Rating Scale</td>
<td>23.86</td>
<td>5.12</td>
<td>15-38</td>
<td>.88</td>
<td>-.59</td>
<td>.28</td>
</tr>
<tr>
<td>Patient Years of Memory Problems</td>
<td>4.84</td>
<td>2.95</td>
<td>1-19</td>
<td>--</td>
<td>3.67</td>
<td>1.55</td>
</tr>
</tbody>
</table>

Commitment and challenge subscales of the DRS. Objective health and perceived health also correlated moderately and positively with the DRS subscale scores. Scores on the FRS only correlated negatively with commitment subscale scores and positively with BI scores. Caregiver years of formal education were found to correlate positively and significantly with commitment subscale and SLS responses.

As anticipated, responses to the BI and CES-D were strongly and positively correlated. Strong, negative correlations also emerged between SLS scores and both the CES-D and BI. Perceived and objective health correlated positively with SLS scores and
Table 2

Correlation Coefficients Between DRS Subscales, Combined Scale Scores, Caregiver Socio-Demographic Variables and Patient Variables (N = 130)

<table>
<thead>
<tr>
<th>MEASURE</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>DRS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCALES</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) COMM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) CONTR</td>
<td>.63**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) CHALL</td>
<td>.31**</td>
<td>.31**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) CES-D</td>
<td>-.39**</td>
<td>-.36**</td>
<td>-.34**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) BI</td>
<td>-.25**</td>
<td>-.28**</td>
<td>-.16</td>
<td>.68**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) SLS</td>
<td>.32**</td>
<td>.15</td>
<td>.07</td>
<td>-.58**</td>
<td>-.49**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) EDUCA</td>
<td>.29**</td>
<td>.02</td>
<td>.12</td>
<td>-.05</td>
<td>-.02</td>
<td>.21*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8) OHLTH</td>
<td>-.27**</td>
<td>-.22*</td>
<td>-.23**</td>
<td>.35**</td>
<td>.26**</td>
<td>-.34**</td>
<td>-.17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9) PHLTH</td>
<td>.45**</td>
<td>.33**</td>
<td>.37**</td>
<td>-.34**</td>
<td>-.26**</td>
<td>.44**</td>
<td>.29**</td>
<td>-.64**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10) FRS</td>
<td>-.24**</td>
<td>-.11</td>
<td>-.11</td>
<td>.11</td>
<td>.19*</td>
<td>-.16</td>
<td>.02</td>
<td>.09</td>
<td>-.08</td>
<td></td>
</tr>
<tr>
<td>11) MEM</td>
<td>-.05</td>
<td>.01</td>
<td>.05</td>
<td>.11</td>
<td>.12</td>
<td>-.12</td>
<td>-.08</td>
<td>.27**</td>
<td>-.19*</td>
<td>.21*</td>
</tr>
</tbody>
</table>

Note:  BI=Burden Interview; CES-D=Center for Epidemiologic Studies-Depression Scale; CHALL=Challenge subscale (DRS); COMM=Commitment subscale (DRS); CONTR=Control Subscale (DRS); DRS=Dispositional Resilience Scale; EDUCA=Caregiver years of formal education; FRS=Functional Rating Scale; MEM=Patient years of memory problems; OHLTH=Caregiver number of health conditions; PHLTH=Caregiver perceived health; SLS=Satisfaction with Life Scale

*p<.05, **p<.01
with one another \((r = .64, p < .01)\). In contrast, both objective and perceived health correlated moderately and negatively with both CES-D and BI responses.

Increasing age was not significantly correlated with DRS scores; however, moderate associations were found between age and CES-D, BI and SLS responses. As would be expected with this participant sample, the number of health conditions increased with advancing age.

**Regression Analyses**

Three separate hierarchical regression analyses were computed to ascertain whether the facets of psychological resilience predicted depressive symptomatology, burden and life satisfaction after controlling for socio-demographic factors and patient variables. It should be noted that colinearity was not identified among the independent variables as none exceeded \(r = .64\). A sample of 130 participants with 10 independent variables was sufficient to detect medium to large effect sizes at \(\alpha = .05\) (Cohen, 1992).

**Depressive Symptomatology.** With CES-D responses as the first dependent variable, socio-demographic variables were first entered to control for caregiver age, years of education, socioeconomic status, health conditions and perceived health status. The second block entered in the analysis included patient scores of the Functional Rating Scale (FRS; measure for dementia symptom severity) and duration of memory problems. This block served to equate for patient illness factors possibly contributing to depressive symptomatology. The three psychological resilience factors were added as a final step hypothesized to add to the prediction of depressive symptomatology over and above patient illness factors.
As shown in Table 3, the initial block of variables contribute significantly to prediction of CES-D scores ($R^2 = .24, p < .01$); these caregiver socio-demographic variables accounted for 24% of the variance in depressive symptomatology. The addition of patient dementia symptom severity and duration of memory problems accounted for a further 1% of the variance (not significant). Psychological resilience facets as a final step in the regression equation also contributed significantly to the prediction of depressive symptomatology as hypothesized, accounting for an additional 13% of the variance.

Examining caregiver socio-demographic variables as predictors for depressive symptomatology revealed a significant inverse relationship between age and depressive symptomatology ($\beta=-.35, F[5, 118]=19.28, p < .01$). A similar relationship was found between health conditions and depressive symptomatology ($\beta=.35, F[5, 118]=11.22, p < .01$) suggesting that an increase in the number of health conditions (e.g., arthritis, hypertension) results in an increase in depressive symptomatology. The addition of patient dementia symptom severity and duration of memory problems into the regression equation indicated that neither is a significant predictor of depressive symptomatology unto itself (nor as a block of variables).

The addition of psychological resilience facets emerged as a statistically significant predictor of depressive symptomatology, accounting for an additional 13% of the variance. Scores on the challenge subscale showed a significant negative relationship with depressive symptomatology ($\beta=-.23, F[10, 113]=7.61, p < .05$), supporting the hypothesis that higher levels of psychological resilience predict lower levels of
Table 3

*Regression Analysis of Caregiver Socio-Demographic, Patient, and Psychological Resilience Variables on Depressive Symptomatology (N=130)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>-.37</td>
<td>.08</td>
<td>-.35**</td>
</tr>
<tr>
<td>Caregiver Years of Education</td>
<td>.14</td>
<td>.27</td>
<td>.05</td>
</tr>
<tr>
<td>Caregiver Socioeconomic Status</td>
<td>.58</td>
<td>.75</td>
<td>.07</td>
</tr>
<tr>
<td>Caregiver Perceived Health</td>
<td>.29</td>
<td>.46</td>
<td>.07</td>
</tr>
<tr>
<td>Caregiver Health Conditions</td>
<td>1.31</td>
<td>.39</td>
<td>.35**</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FRSa</td>
<td>.09</td>
<td>.16</td>
<td>.04</td>
</tr>
<tr>
<td>Patient Years of Memory Problems</td>
<td>.17</td>
<td>.28</td>
<td>.05</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRSb Commitment</td>
<td>-.42</td>
<td>.27</td>
<td>-.17</td>
</tr>
<tr>
<td>DRS Control</td>
<td>-.39</td>
<td>.26</td>
<td>-.15</td>
</tr>
<tr>
<td>DRS Challenge</td>
<td>-.49</td>
<td>.18</td>
<td>-.23**</td>
</tr>
</tbody>
</table>

*Notes: R² = .24 (p < .01) for caregiver socio-demographic variables; ΔR² = .01 (ns) subsequent to entry of patient illness variables; ΔR² = .13 (p < .01) subsequent to entry of the three resilience scores.*

a FRS = Functional Rating Scale
b DRS = Dispositional Resilience Scale

* p < .05, ** p < .01
depressive symptomatology (Orr & Westman, 1990; Sharpley & Yardley, 1999; Sussman, 2003). However, the commitment and control subscales were not significant predictors of depressive symptomatology. This finding provides partial support of the hypothesis but is in line with previous research suggesting that one aspect of psychological resilience may hold greater predictive validity to others (L. Clark & Hartman, 1996; O’Rourke, 2004a).

**Burden.** The second hierarchical regression analysis examined responses to the BI. This equation included the same set of independent variables (entered in identical blocks of caregiver socio-demographic and patient illness factors) as previously described. The three psychological resilience factors were again added as a third and final step hypothesized to add to the prediction of burden.

As shown in Table 4, the initial block of variables contributed significantly to prediction of BI scores ($R^2 = .18, p < .01$) indicating that caregiver socio-demographic variables accounted for 18% of the variance in burden. The addition of patient illness variables accounted for a further 5% of the variance. As the final step in the regression equation, psychological resilience facets did not contribute significantly to the prediction of burden ($\Delta R^2 = .04, ns$).

As with depressive symptomatology, a significant inverse relationship emerged between age and burden ($\beta=-.36, F[1, 118]=17.06, p < .01$). A weaker positive association was found between health conditions and burden ($\beta=.26, F[5, 118]=5.32, p < .05$).
Table 4

Regression Analysis of Caregiver Socio-Demographic, Patient, and Psychological Resilience Variables on Burden (N=130)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>-.53</td>
<td>.13</td>
<td>- .36**</td>
</tr>
<tr>
<td>Caregiver Years of Education</td>
<td>.33</td>
<td>.40</td>
<td>.08</td>
</tr>
<tr>
<td>Caregiver Socioeconomic Status</td>
<td>-.99</td>
<td>1.13</td>
<td>-.08</td>
</tr>
<tr>
<td>Caregiver Perceived Health</td>
<td>.11</td>
<td>.70</td>
<td>.02</td>
</tr>
<tr>
<td>Caregiver Health Conditions</td>
<td>1.37</td>
<td>.59</td>
<td>.26*</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FRS\textsuperscript{a}</td>
<td>.53</td>
<td>.24</td>
<td>.19*</td>
</tr>
<tr>
<td>Patient Years of Memory Problems</td>
<td>.15</td>
<td>.42</td>
<td>.03</td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRS\textsuperscript{b} Commitment</td>
<td>-.03</td>
<td>.41</td>
<td>-.01</td>
</tr>
<tr>
<td>DRS Control</td>
<td>-.71</td>
<td>.39</td>
<td>-.19</td>
</tr>
<tr>
<td>DRS Challenge</td>
<td>-.17</td>
<td>.27</td>
<td>-.06</td>
</tr>
</tbody>
</table>

Notes: $R^2 = .18$ (p < .01) for caregiver socio-demographic variables; $\Delta R^2 = .05$ (p < .05) subsequent to entry of patient illness variables; $\Delta R^2 = .04$ (ns) subsequent to entry of the three resilience scores.

\textsuperscript{a} FRS = Functional Rating Scale
\textsuperscript{b} DRS = Dispositional Resilience Scale

* $p < .05$, **$p < .01$
In contrast to the depressive symptomatology, patient dementia severity showed a significant relationship with burden in this regression equation ($\beta=.19$, $F[7, 116]=4.74$, $p < .05$). The other patient illness variable, duration of memory problems, did not significantly predict burden. Contrary to the hypothesis, the addition of psychological resilience subscale scores also did not emerge as statistically significant predictors of burden.

*Life Satisfaction.* The third and final hierarchical regression equation examined caregivers’ reported life satisfaction. This included the same caregiver socio-demographic and patient illness factors as independent variables (entered as Steps 1 & 2, respectively) as the previous analyses. Responses to the three psychological resilience subscales were again added as the third and final step hypothesized to significantly contribute to the prediction of life satisfaction.

As shown in Table 5, the initial block of variables contributed significantly to prediction of SLS scores ($R^2 = .28$, $p < .01$) indicating that caregiver socio-demographic variables accounted for 28% of observed variance in life satisfaction. The addition of patient illness variables accounted for an additional 3% of variance (not significant). As the final step in the regression equation, psychological resilience did not account for significantly more variance in life satisfaction ($\Delta R^2 = .02$, *ns*).

Examining caregiver socio-demographic variables as predictors for life satisfaction revealed a significant relationship between age and life satisfaction ($\beta=.29$, $F[5, 118]=12.94$, $p < .01$). Additional associations were observed between health conditions and life satisfaction ($\beta=-.21$, $F[5, 118]=3.92$, $p < .05$), as well as between subjective health and life satisfaction ($\beta=.26$, $F[5, 118]=5.06$, $p < .05$). These findings
Table 5

*Regression Analysis of Caregiver Socio-demographic, Patient, and Psychological Resilience Variables on Life Satisfaction (N=130)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>.21</td>
<td>.06</td>
<td>.29**</td>
</tr>
<tr>
<td>Caregiver Years of Education</td>
<td>.09</td>
<td>.19</td>
<td>.05</td>
</tr>
<tr>
<td>Caregiver Socioeconomic Status</td>
<td>.12</td>
<td>.52</td>
<td>.02</td>
</tr>
<tr>
<td>Caregiver Perceived Health</td>
<td>.73</td>
<td>.32</td>
<td>.26*</td>
</tr>
<tr>
<td>Caregiver Health Conditions</td>
<td>-.54</td>
<td>.28</td>
<td>-.21*</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FRSª</td>
<td>-.21</td>
<td>.11</td>
<td>-.16</td>
</tr>
<tr>
<td>Patient Years of Memory Problems</td>
<td>.07</td>
<td>.19</td>
<td>.03</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRSᵇ Commitment</td>
<td>.24</td>
<td>.19</td>
<td>.15</td>
</tr>
<tr>
<td>DRS Control</td>
<td>-.08</td>
<td>.18</td>
<td>-.05</td>
</tr>
<tr>
<td>DRS Challenge</td>
<td>-.16</td>
<td>.13</td>
<td>-.11</td>
</tr>
</tbody>
</table>

*Notes: R² = .28 (p < .01) for caregiver socio-demographic variables; ΔR² = .03 (ns) subsequent to entry of patient illness variables; ΔR² = .02 (ns) subsequent to entry of the three resilience scores.*

ªFRS = Functional Rating Scale

ᵇDRS = Dispositional Resilience Scale

* p < .05, **p < .01
suggest having fewer health conditions and greater perceived subjective health both
significantly contribute to the prediction of life satisfaction. The addition of care-receiver
dementia symptom severity and duration of memory problems into the regression
equation indicated that neither contributed significantly to prediction of life satisfaction
(nor as a block).

Again contrary to the hypothesis, psychological resilience factors also did not
emerge as statistically significant predictors of life satisfaction. This finding is in
contrast to research identifying psychological resilience as predictive of life satisfaction
in related samples (e.g., Clark & Hartman, 1996; O’Rourke, 2004a; Rhodes, 1995; Rossi
et al., 2007).

Overall, these findings offer only partial support to the hypotheses that elevated
levels of each of the three components of psychological resilience would be predictive of
greater life satisfaction, and lower levels of both depressive symptomatology and
perceived caregiver burden. Psychological resilience (and the challenge subscale in
particular) emerged as a statistically significant predictor of depressive symptomatology;
however, psychological resilience did not predict caregiver burden nor life satisfaction.
CHAPTER 5: DISCUSSION

Hierarchical regression analyses were computed to examine the association between psychological resilience vis-à-vis depressive symptoms, caregiver burden and life satisfaction. It was hypothesized that psychological resilience would predict depressive symptomatology, burden and life satisfaction over and above that provided by both caregiver socio-demographic and patient illness variables.

Results of this thesis provide partial support for a significant association between psychological resilience and the well-being of spouses of persons with Alzheimer disease (AD). Psychological resilience as a whole emerged as a statistically significant predictor of depressive symptomatology, but neither burden nor life satisfaction. The contribution of the challenge subscale emerged as the sole predictor of depressive symptomatology. No other resilience facet predicted depressive symptomatology, burden and life satisfaction. These findings suggests that psychological resilience as defined by Kobasa and colleagues (1982) is significantly associated with depression symptoms in spousal caregivers of persons with AD over and above context-specific (e.g., caregiver age and health) and patient-specific features (e.g., severity of dementia symptoms).

Socio-demographic factors were significantly associated with all three outcome variables among participating caregivers, largely due to the contribution of age and physical health. These findings may reflect the fact that caring for a spouse with dementia at a younger age is a less anticipated role, and provide further support for the association between physical and mental health of older adults caring for persons with dementia (PWD; O’Rourke, Cappeliez, & Guindon, 2003).
The severity of patient dementia symptoms also emerged as a significant predictor of caregiver burden but neither life satisfaction nor depressive symptomatology. These results are in accord with inconsistent support that patient-specific variables have received as predictors of emotional health in caregivers of persons with AD (e.g., Wright, Clipp, & George, 1993); however, they are in line with work by Chappell and Reid (2002) suggesting that patient cognitive impairments are associated with increased caregiver burden but not other outcomes such as life satisfaction.

These findings suggest that the contribution of psychological resilience differs in strength and composition across various indices of caregiver well-being. The predictive strength of psychological resilience vis-à-vis depressive symptomatology identified with this sample is consistent with the findings of P. Clark (2002) and Sussman (2003); however, there is inconsistency between the results of this study and other research to date examining psychological resilience and caregiving outcomes other than depressive symptoms. For example, L. Clark and Hartman (1996) found that total resilience predicted both life satisfaction and depressive symptomatology, while resilience predicted caregiver burden, life satisfaction and symptoms of depression in the work by Nunley (2002). This incongruity of findings may be attributable to methodological and analytic differences between this research and that of these latter authors, including sample size, recruitment strategies, inclusion criteria, order of variable inclusion in the models, and measure of resilience (i.e., Personal Views Survey [PVS] vs. Dispositional Resilience Scale [DRS]).

Another finding of note pertains to the individual facets of psychological resilience. For example, why does challenge predict caregiver depressive
symptomatology and not the commitment and control facets? It is possible that challenge is integral to effective care provision for PWD as this resilience factor pertains specifically to coping under adversity. The ability to perceive opportunities for personal development in hardship may distinguish spouses who thrive from others who become overwhelmed by caregiving demands. For example, those caregivers who foresee the possibility of individual growth from caregiving may approach the role more positively. In contrast, the facet of control may be largely irrelevant when there is little one can do to alter the course of the disease.

Yet, the L. Clark and Hartman (1996) regression analyses with resilience components resulted in only commitment attaining significance as a predictor of psychological distress. These authors argue that commitment may be most germane to caregivers because it involves the propensity to persevere because of the belief in the significance and meaning of one’s actions.

While these disparate findings (and subsequent interpretations) could again be attributable to methodological differences, it is also possible that the issue lies with the measurement of psychological resilience. As previously noted, psychological resilience should be conceptualized as a multidimensional phenomenon and not as a singular construct (Funk, 1992). The full DRS was intended to measure resilience across a broad spectrum of physical and psychological functioning (Maddi & Kobasa, 1984), suggesting that DRS subscale scores are related but distinct components of psychological resilience (i.e., commitment; control, challenge).

L. Clark and Hartman (1996) utilized the PVS but suggested the use of a superior instrument in future research. Funk (1992) recommended the use of the 45-item DRS
over the PVS and other measures of resilience while acknowledging the reliability limitations of each. Although use of the full DRS in this study was an improvement over previous research in this area (e.g., P. Clark, 2002), internal consistency of responses to the commitment ($\alpha = .63$), control ($\alpha = .53$), and challenge subscales ($\alpha = .59$) were far less than ideal. Comparable reliability limitations of ‘third-generation’ resilience measures have been widely documented in various populations (see Funk, 1992 for a review). It is possible that the low reliability of the DRS obfuscated other findings that might have emerged with more effective measurement of the resilience facets.

From a theoretical perspective, these findings lend partial support to the theory of resilience as advanced by Maddi and Kobasa (1984). While greater psychological resilience significantly predicted reduced levels of depressive symptomatology, it did not predict less caregiver burden or greater life satisfaction as would be anticipated if resilience functions as a buffer to negative outcomes and fosters positive outcomes.

The rigour of the current analyses should be noted, however, as a possible factor accounting for the relative paucity of statistically significant findings. For depressive symptoms, burden and life satisfaction, initial steps in the regression equations accounted for 25%, 23% and 31% of observed variance prior to inclusion of resilience factors. In other words, the bar was set high such that shared variance between resilience and these covariates was claimed by the latter; only unique variance was captured by resilience factors as final steps in these hierarchical regression equations. This, combined with measurement limitations, may have led to under-statement of true association between resilience factors and psychological well-being of these PWD caregivers.
At present, psychological interventions for caregivers are administered only once psychopathology is apparent. Alternatively, screening for resilience (at least the absence of challenge) may enable identification of those at elevated risk of distress and lead to the development and implementation of interventions to foster resilience in spousal caregivers (see Maddi & Kobasa, 1984). This proactive strategy could help maintain caregiver well-being and avert the onset of major depressive disorder, for example. As crises within the caregiving experience are a precipitating factor for the early institutionalization of PWD (Dunkin & Anderson-Hanley, 1998), interventions designed to facilitate a caregivers’ ability to maintain care in the community may also prevent premature institutional placement of patients.

Limitations and Future Research

This study provides methodological advancements over previous research, including the use of hierarchical regression (cf. stepwise regression; Milne et al., 1994) and a sample of sufficient size to detect medium to large effect sizes (i.e., statistical power; Cohen, 1992). By limiting recruitment to a circumscribed sample (i.e., cohabiting spouses of persons with AD), findings are arguably more internally valid. Though there are limitations associated with use of a homogeneous participant sample such as decreased generalizability to other populations, these limitations instead advance research by enhancing understanding of the associations between psychological resilience and outcomes in this specific and substantial subset of dementia caregivers. This focus eliminates the known confounds of patient diagnosis and caregiver relationship with and proximity to the person with AD on caregiving outcomes; these findings should be replicated with other related samples, however, including adult child caregivers,
caregivers of institutionalized patients, and caregivers of persons with other dementing disorders (e.g., frontotemporal dementia).

Of note are other various methodological shortcomings that reduce the generalizability of findings. For instance, this was a self-selected sample from a single tertiary diagnostic clinic to which patients must be referred by a physician. While clinic staff referrals for study participation were not solicited in order to avoid some degree of selection bias (i.e., gatekeeper effect), this sample may not be representative of the population of spousal caregivers of persons with AD. It is possible that the most depressed or overwhelmed caregivers elected not to participate perhaps, in part, due to the time demands of caring for a cognitively impaired spouse. As stated previously, however, previous research suggests that participants recruited via this site are demographically indistinguishable from the Canadian population of informal PWD caregivers (O’Rourke et al., 1997).

This sample was also more educated than the current cohort of older adults. This limitation, while common to research with self-selected participants, decreases generalizability as responses may not correspond to those of spousal caregivers with less education. This observation highlights the need to conduct comparable research using randomized participant recruitment.

Also noteworthy is that all caregiver data were provided directly by participants without opportunity to corroborate responses. This limitation is particularly relevant with respect to objective physical health data. It is feasible, for instance, that psychological resilience may result in forgetting to report physical health problems while distressed caregivers are more likely to be cognizant of, and emphasize, health concerns. This
potential study limitation is consistent with research on mood congruent memory processes (i.e., the propensity for dysphoric individuals to recall negative information; Watkins, Vache, Verney, Muller, & Matthews, 1996).

An analytic shortcoming of this study is the absence of reported structure coefficients. As noted by Courville and Thompson (2001), both beta values and structure coefficients should be considered when interpreting the results of regression analyses. Whereas beta values represent the predictive strength of independent variables, structure coefficients convey the degree of association between independent and dependent variables.

An additional limitation of this research is the examination of multiple dependent variables in isolation. A supplementary analytic strategy that could have been undertaken to examine the association among study variables is canonical correlation. This statistical procedure might best be described as the multivariate equivalent of multiple regression (Tabachnick & Fidell, 2001). With regression analyses, several variables are used to predict scores of a single dependent (or outcome) variable. With canonical correlation, in contrast, there are several variables on both sides of the equation. Sets of variables are grouped to capture significant variance within both sets of responses and to maximize association between pairs of linear combinations (or canonical variate pairings).

The addition of canonical correlation could provide a more in-depth analysis of the data for a number of reasons. As psychological resilience is comprised of multiple constructs with little shared variance between factors and because depressive symptomatology, burden, life satisfaction and psychological resilience are multivariate in
nature, it may be ideal to utilize an analytic approach that allows for multiple independent and dependent variables.

As data were also derived at one point in time, causal conclusions cannot be made. For example, while there is some evidence that psychological resilience fosters well-being, the opposite may in fact be the case (i.e., the absence of depressive symptomatology leads to resilience). However, longitudinal research (such as that of which this study represents baseline analyses) is necessary to detect causal relationships between these constructs. It might also be most edifying to follow caregivers from the point of patient diagnosis in order to examine variation in psychological resilience across the course of the caregiving role. At the point of recruitment for this study, many of the participating patient-caregiver dyads had undergone several clinic assessments prior and subsequent to receiving AD diagnoses. Further research with this focus will help determine if psychological resilience is present prior to a spouse’s dementia diagnosis, or emerges as an effective response to the demands of caregiving.

Validation of responses to the DRS should also be undertaken with samples of caregivers of PWD, as no known published studies to date report this information. As noted previously, some researchers examining psychological resilience in older adults have elected to alter some DRS items to increase their relevance with this population (Wallace et al., 2001). For example, items related to employment (e.g., “It’s usually impossible for me to change things at work”) have been adapted to focus on hobbies or other leisure activities. Altering the wording of items can be problematic as it limits the generalizability of findings and can result in changes to the psychometric properties of responses to an instrument; however, the work of these authors raises the question of the
applicability of the DRS to older adults and spousal caregivers in particular. An additional item specific to caregiving and the relative age of the respondent (e.g., “I want to be sure someone will take care of me when I’m older”) may also be inappropriate to or poorly received by this population. Development and validation of other measures of psychological resilience or refinement of ‘third-generation’ measures such as the DRS would be worthwhile to improve the reliability of subscales and overcome other existing shortcomings.

Overall, the literature on psychological resilience in caregivers of persons with AD has been slow to emerge and is still in its infancy. This study examined the predictive strength of psychological resilience for depressive symptomatology, burden and life satisfaction among cohabitating, community-residing spousal caregivers of persons with AD. Despite the noted limitations, results of this study provide partial support for the assertion that psychological resilience is associated with caregiver well-being. Consistent with findings reported among both this and other related populations, endorsement of the beliefs that comprise resilience appear to buffer caregivers from depressive symptomatology despite the pronounced demands of caregiving. Ongoing research that redresses stated limitations may help to further advance the role that psychological resilience could play in reducing psychological distress.
REFERENCES


Bachner, Y.G., & O’Rourke, N. Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging and Mental Health, 11*, 678-685.


APPENDIX A: COVERING MEMO

Investigators: Norm O’Rourke, Ph.D., R.Psych. (SFU)
    B. Lynn Beattie, MD, FRCPC (UBC)
    Neena Chappell, Ph.D. (UVic)

Beliefs and Well-Being of Spouses of Those with Memory Loss

Dear Sir/Madam,

We are currently conducting a research study at the Clinic for Alzheimer Disease and Related Disorders at UBC Hospital which is concerned with the beliefs and well-being of spouses of persons with memory loss. The purpose of this study is to obtain greater understanding of factors related to the physical and psychological health of people such as yourself.

On the attached page is a description of the study and what your participation would involve. In roughly a week, you will be contacted to see if you might be willing to take part in this study. Rest assured that information acquired in this study will remain completely confidential and will in no way be associated with you as an individual. You will be paid $50 for your participation.

Thank you for taking the time to consider participating in this study. Please feel free to contact me should you require further information or clarification.

With regards,

Norm O’Rourke, Ph.D., R.Psych.    Anthony Kupferschmidt
Assistant Professor, Clinical Psychologist    Research Coordinator
Simon Fraser University

(778) 782-5062    (604) 822-2525 ext. 20385
ORourke@sfu.ca    akupfers@sfu.ca
APPENDIX B: INFORMATION LETTER

Investigators: Norm O’Rourke, Ph.D., R.Psych. (SFU)
B. Lynn Beattie, MD, FRCP (UBC)
Neena Chappell, Ph.D. (UVic)

Beliefs and Well-Being of Spouses of Those with Memory Loss

You are invited to take part in a study of beliefs and well-being of spouses of persons with memory loss. The purpose of this study is to obtain greater understanding of factors related to the physical and psychological health of people such as yourself. This research has been funded by the North Shore Health Research Foundation (Dr. Norm O’Rourke, Principle Investigator).

We would like you to complete a questionnaire in which you will be asked to respond to a series of questions. Should you agree, this will require about 40 minutes of your time. These questions ask how you have been feeling recently, how you cope with life’s ups-and-downs, and descriptive information (e.g., age, number of years married).

If you agree, a set of questionnaires will also be mailed to you a year from now. You will be asked to respond to these questions and send them back to us by mail in a postage-paid envelope. Completion of this follow-up set of questions will require about 30 minutes of your time. (Seventy minutes in total, today and a year from now.) You will not be asked to provide identifying information (e.g., name, address) at that time. A 6-digit code number will be assigned to you today known only by Dr. O’Rourke and his research assistants. In the unlikely event that these questionnaires get lost in the mail, no one would be able to identify you.

You will be paid $50 for your participation. If requested, you will also be sent a written summary of study findings at the conclusion of this study.

There are no anticipated risks to you as a result of participation in this study. We may, however, provide you with community resource information if appropriate.

Please be aware that responses from all participants will be grouped together. This will protect your privacy.

If you choose not to take part in this study, your involvement with the Clinic for Alzheimer Disease and Related Disorders will not be affected in any way. You will not be required to answer questions that make you uncomfortable and you are free to back out at any time. Participation now does not mean you are obligated to respond to further questions in the future if you choose not to.

The information obtained now and requested 1-year from now will be available only to the Drs. O’Rourke, Beattie and Chappell, and their research assistant(s). Printed pages will be kept
in a secure location and will be shredded five years after publication of findings. Responses will be kept in a password protected computer database accessible only by study staff. Completion of these questionnaires will be seen as agreement to take part in this study.

Thank you for taking the time to consider participating in this study. Please feel free to contact me should you require further information or clarification.

With regards,

Norm O’Rourke, Ph.D., R.Psych.
Assistant Professor, Clinical Psychologist
Simon Fraser University

(778) 782-5062

ORourke@sfu.ca
APPENDIX C: CONSENT FORM

Investigators: Norm O’Rourke, Ph.D., R.Psych. (SFU)
B. Lynn Beattie, MD, FRCPC (UBC)
Neena Chappell, Ph.D. (UVic)

Beliefs and Well-Being of Spouses of Those with Memory Loss

This study seeks to examine the beliefs and well-being of spouses of persons with memory loss with the hope of obtaining greater understanding of factors related to the physical and psychological health of people such as yourself. This research has been funded by the North Shore Health Research Foundation (Dr. Norm O’Rourke, Principle Investigator).

Having been asked by Drs. O’Rourke, Beattie or Chappell (or their Research Assistant from the Gerontology Research Centre at Simon Fraser University) to participate in this research project, you have read the procedures specified in this document and the Study Information Letter.

If you consent, you will be asked to respond to a series of questions requiring about 40 minutes of your time. These questions ask how you have been feeling recently, how you cope with life’s ups-and-downs, and descriptive information (e.g., age, number of years married).

If you agree, a set of questionnaires will also be mailed to you a year from now. You will be asked to respond to these questions and send them back to us by mail in a postage-paid envelope. Completion of this follow-up set of questions will require about 30 minutes of your time. (Seventy minutes in total, today and a year from now.) You will not be asked to provide identifying information at that time (e.g., name, address). A 6-digit code number will be assigned to you today known only by Dr. O’Rourke and his research assistants. In the unlikely event that these questionnaires get lost in the mail, no one would be able to identify you.

You will be paid $50 for your participation. If requested, you will also be sent a written summary of study findings upon completion of this study.

There are no anticipated risks to you as a result of participation in this study. We may, however, provide you with community resource information for community services if appropriate.

It is understood that you may withdraw from this study at any time and that you may register any complaint with Dr. O’Rourke or with Dr. Wister, Chair of the Department of Gerontology at Simon Fraser University (778-782-5044).

The information obtained now and requested 1-year from now will be available only to the Drs. O’Rourke, Beattie and Chappell, and their research assistant(s). Printed pages will be kept
in a secure location and will be shredded five years after publication of study findings. Responses will be kept in a password protected computer database accessible only by Dr. O’Rourke and his research assistant(s).

Please be advised that responses from all participants will be grouped together. This will protect your privacy.

If you choose not to take part in this study, your involvement with the Clinic for Alzheimer Disease and Related Disorders will not be affected in any way. You will not be required to answer questions that make you uncomfortable and you are free to back out at any time. Completing the first questionnaire does not mean you are obligated to respond to further questions in future if you choose not to.

If you require further information regarding these study procedures, feel free to contact Dr. Norm O’Rourke (ORourke@sfu.ca) at (778) 782-5062.

By signing this form, you agree to participate in the study as described in the Information Sheet provided to you. Your signature on this document and completion of these questionnaires indicates your willingness to take part in this study.

NAME (please type or print legibly): ________________________________________________

ADDRESS: ______________________________________________________________________
________________________________________________________________________________

SIGNATURE: ___________________ WITNESS: ______________________

DATE: __________________________ Once signed, a copy of this consent form is provided to the participant.
APPENDIX D: STUDY MEASURES

Dispositional Resilience Scale (DRS)

The following are statements about life that people often feel differently about. Select a response to indicate about how you feel about each. Using the following scale, indicate how much you think each is true. There are no right or wrong answers; just give your honest opinion.

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all true</th>
<th>2 A little true</th>
<th>3 Quite true</th>
<th>4 Completely true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Most of my life gets spent doing things that are worthwhile</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>Planning ahead can avoid most future problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Trying hard doesn’t pay, since things still don’t turn out right</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>No matter how hard I try, my efforts usually accomplish nothing</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>I don't like to make changes in my everyday schedule</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>The tried and true ways are always best</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>Working hard doesn’t matter since only the bosses profit by it</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>By working hard you can always achieve your goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Most working people are simply manipulated by their bosses</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>Most of what happens in life is just meant to be</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>It’s usually impossible for me to change things at work</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>New laws should never hurt a person’s paycheque</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>When I make plans, I’m certain I can make them work</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>It’s very hard for me to change a friend’s mind about something</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>It’s exciting to learn something about myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
16. People who never change their minds usually have good judgement
17. I really look forward to the tasks I perform
18. Politicians run our lives
19. If I’m working on a difficult task, I know when to ask for help
20. I won’t answer a question until I’m really sure I know the answer
21. I like a lot of variety in the tasks I perform
22. Most of the time, people listen carefully to what I say
23. Daydreams are more exciting than reality for me
24. Thinking of oneself as a free person just leads to frustration
25. Trying your best really pays off in the end
26. My mistakes are usually very difficult to correct
27. It bothers me when my daily routine gets interrupted
28. It’s best to handle most problems by just not thinking of them
29. Most good athletes and leaders are born, not made
30. I often wake up eager to take up my life wherever it left off
31. Most of the time, I don’t really know my own mind
32. I respect rules because they guide me
33. I like it when things are uncertain or unpredictable
34. I can’t do much to prevent it if someone wants to harm me
35. People who do their best should get full support from society
36. Changes in routine are interesting to me
37. People who believe in individuality are only kidding themselves
38. I have no use for theories that are not closely tied to facts
<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>39. Most days, life is really interesting and exciting to me</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. I want to be sure someone will take care of me when I’m older</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. It’s hard to imagine anyone getting excited about working</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. What happens to me tomorrow depends on what I do today</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. If someone gets angry at me, it’s usually no fault of mine</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. It’s hard to believe people who say their works helps society</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. Ordinary work is just too boring to be worth doing</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Satisfaction With Life Scale (SLS)**

Please indicate your degree of agreement to these five statements by selecting the appropriate response from the following response key.

1. Strongly Disagree  
2. Disagree  
3. Slightly Disagree  
4. Neutral  
5. Slightly Agree  
6. Agree  
7. Strongly Agree

1. In most ways my life is close to ideal  
2. The conditions of my life are excellent  
3. I am satisfied with my life  
4. So far, I have gotten the important things I wanted in life  
5. If I could live my life over, I would change almost nothing  

1 2 3 4 5 6 7


**Center for Epidemiologic Studies (CES-D)**

Now, I’d like to know how you have been feeling. For each of the following statements, please indicate how often you felt this way **during the past week** using this response key.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely or none (&lt; 1 day)</td>
<td>Some (1-2 days)</td>
<td>Occasionally (3-4 days)</td>
<td>Most (5-7 days)</td>
</tr>
</tbody>
</table>

1. I was bothered by things that don’t usually bother me 1 2 3 4
2. I did not feel like eating; my appetite was poor 1 2 3 4
3. I felt that I could not shake off the blues even with help from my family or friends 1 2 3 4
4. I felt that I was just as good as other people 1 2 3 4
5. I had trouble keeping my mind on what I was doing 1 2 3 4
6. I felt depressed 1 2 3 4
7. I felt that everything I did was an effort 1 2 3 4
8. I felt hopeful about the future 1 2 3 4
9. I thought my life had been a failure 1 2 3 4
10. I felt fearful 1 2 3 4
11. My sleep was restless 1 2 3 4
12. I was happy 1 2 3 4
13. I talked less than usual 1 2 3 4
14. I felt lonely 1 2 3 4
15. People were unfriendly 1 2 3 4
16. I enjoyed life 1 2 3 4
17. I had crying spells
18. I felt sad
19. I felt that people dislike me
20. I could not get going
Burden Interview (BI)

Here is a list of ways that people sometimes feel when caring for another person. Please indicate how often you have felt that way using the following response key. Remember, there are no right or wrong answers.

<table>
<thead>
<tr>
<th>1 Never</th>
<th>2 Rarely</th>
<th>3 Sometimes</th>
<th>4 Frequently</th>
<th>5 Nearly always</th>
</tr>
</thead>
</table>

How often...

1. do you feel that your spouse asks for more help than s/he needs? 1 2 3 4 5
2. do you feel that because of the time you spend with your spouse that you don't have enough time for yourself? 1 2 3 4 5
3. do you feel stressed between caring for your spouse and trying to meet other responsibilities for your family or work? 1 2 3 4 5
4. do you feel embarrassed over your spouse’s behaviour? 1 2 3 4 5
5. do you feel angry when you are around your spouse? 1 2 3 4 5
6. do you feel that your spouse currently affects your relationship with other family members or friends in a negative way? 1 2 3 4 5
7. are you afraid of what the future holds for your spouse? 1 2 3 4 5
8. do you feel that your spouse is dependent on you? 1 2 3 4 5
9. do you feel strained when you are around your spouse? 1 2 3 4 5
10. do you feel your health has suffered because of your involvement with your spouse? 1 2 3 4 5
11. do you feel that you don’t have as much privacy as you would like because of your spouse? 1 2 3 4 5
12. do you feel that your social life has suffered because you are caring for your spouse? 1 2 3 4 5
13. do you feel uncomfortable about having friends over 1 2 3 4 5
14. do you feel that your spouse seems to expect you to take care of him/her as if you were the only one s/he could depend on? 1 2 3 4 5

15. do you feel that you don’t have enough money to care for your spouse in addition to the rest of your expenses because of your spouse? 1 2 3 4 5

16. do you feel that you will be unable to take care of your spouse much longer? 1 2 3 4 5

17. do you feel that you have lost control of your life since your spouse’s condition? 1 2 3 4 5

18. do you wish you could just leave the care of your spouse to someone else? 1 2 3 4 5

19. do you feel uncertain about what to do about your spouse? 1 2 3 4 5

20. do you feel you should be doing more for your spouse? 1 2 3 4 5

21. do you feel you could do a better job in caring for your spouse? 1 2 3 4 5

22. Overall, how burdened do you feel in caring for your spouse? (Circle one)

1 – Not at all
2 – A little
3 – Moderately
4 – Quite a bit
5 - Extremely
Demographics and Health Questionnaire

Your gender (male/female) ______________________ Present age _____________

Number of years married _______________________

How many years of formal education did you complete?
   Self ________________________________
   Spouse ______________________________

What are/were your work or occupations (e.g., housewife, carpenter)?
   (Describe fully in the space below):
   Self __________________________________________
   Spouse ________________________________________

What is your current employment status? ________________________
If retired, what year did you leave the paid work force? _____________

How would you say your health is these days? (circle one response):
   • Very poor
   • Somewhat poor
   • Poor
   • Satisfactory
   • Good
   • Very Good
   • Excellent

Is your health better now, about the same, or worse than a year ago?
(circle one response):
   • Better
   • About the same
   • Worse

Would you say your health is better, about the same, or worse than most people your age?
(circle one response):
   • Better
   • About the same
   • Worse

How much do health troubles stand in the way of doing the things you want to do?
(circle one response):
   • Not at all
   • A little (some things)
   • A great deal
Regarding your health over the past year, do you have, or have you had any of the following conditions. Please respond either **Yes** or **No** as appropriate:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergies of any kind</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Broken hip</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Fractures or broken bones (not hip)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Hip replacement</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Breathing problems (e.g., asthma, TB, emphysema, pneumonia)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Heart or circulation problems (e.g., angina)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Pace maker inserted</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Paralysis of any kind</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Kidney condition or disease (including bladder troubles)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Surgery</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tumour or cancer</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Trouble with vision (e.g., cataracts, glaucoma)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Problems with hearing</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Arthritis or rheumatism</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Troubles with your stomach or digestive problems</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Stroke or the effects of a stroke</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Nervous or being tense</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Trouble getting to, or staying, asleep</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Other problem(s) not mentioned</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

If yes, specify: ________________________________________________________

Would you like to receive a summary of findings following completion of this study?

Y   N
# Functional Rating Scale (FRS)

<table>
<thead>
<tr>
<th></th>
<th>Healthy (1)</th>
<th>Questionable (2)</th>
<th>Mild (3)</th>
<th>Moderate (4)</th>
<th>Severe (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Memory</strong></td>
<td>No deficit or inconsistent forgetfulness evident only on clinical interview</td>
<td>Variable symptoms reported by patient or relative, seemingly unrelated to level of functioning</td>
<td>Memory lapses which interfere with daily living, more apparent for recent events</td>
<td>Moderate memory loss, only highly learned material retained, new material rapidly lost</td>
<td>Severe memory loss, unable to recall relevant aspects of current life, very sketchy recall of past life</td>
</tr>
<tr>
<td><strong>Social/ Community and Occupational</strong></td>
<td>Neither patient nor relative aware of any deficit</td>
<td>Variable levels of functioning reported by patient or relatives, no objective evidence of deficits in employment or social situations</td>
<td>Pt./relative aware of decreased performance in demanding work or social settings, appears normal to casual inspection</td>
<td>Pt./relative aware of ongoing deterioration, does not appear normal to objective observer, unable to perform job, little independent functioning outside home</td>
<td>Marked impairment of social functioning, no independent functioning outside home</td>
</tr>
<tr>
<td><strong>Home and Hobbies</strong></td>
<td>No changes noted by patient or relative</td>
<td>Slightly decreased involvement in household tasks and hobbies</td>
<td>Engages in social activities at home but definite impairment on some household tasks, some complicated hobbies and interests abandoned</td>
<td>Only simple chores/hobbies preserved, most complicated hobbies/interests abandoned</td>
<td>No independent involvement in home or hobbies</td>
</tr>
<tr>
<td><strong>Personal Care</strong></td>
<td>Fully capable of self-care</td>
<td>Occasional problems with self-care reported by patient/relatives or observed</td>
<td>Needs prompting to complete tasks adequately (i.e., dressing, feeding, hygiene)</td>
<td>Requires supervision in dressing, feeding, hygiene, and keeping track of personal effects</td>
<td>Needs constant supervision and assistance with feeding, dressing, or hygiene etc.</td>
</tr>
<tr>
<td></td>
<td>Healthy (1)</td>
<td>Questionable (2)</td>
<td>Mild (3)</td>
<td>Moderate (4)</td>
<td>Severe (5)</td>
</tr>
<tr>
<td>---------------------------</td>
<td>------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------------</td>
<td>-------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td><strong>Language Skills</strong></td>
<td>No disturbance of language reported by patient or relative</td>
<td>Subjective complaint of, or relative reports, language deficits, usually limited to word finding or naming</td>
<td>Pt./relative reports variable disturbances in such skills as articulation or naming, occasional language impairment evident during examination</td>
<td>Pt./relative reports consistent language disturbance, language disturbance evident on examination</td>
<td>Severe impairment of receptive and/or expressive language, production of unintelligible speech</td>
</tr>
<tr>
<td><strong>Problem Solving and Reasoning</strong></td>
<td>Solves everyday problems adequately</td>
<td>Variable impairment of problem solving, similarities, differences</td>
<td>Difficulty in handling complex problems</td>
<td>Marked impairment on complex problem solving tasks</td>
<td>Unable to solve problems at any level, trial and error behaviour often observed</td>
</tr>
<tr>
<td><strong>Affect</strong></td>
<td>No change in affect reported by patient or relative</td>
<td>Appropriate concern with respect to symptomatology</td>
<td>Infrequent changes in affect (e.g., irritability) reported by pt./relative, would appear normal to objective observer</td>
<td>Frequent changes in affect reported by patient or relative, noticeable to objective observer</td>
<td>Sustained alterations of affect, impaired contact with reality observed or reported</td>
</tr>
<tr>
<td><strong>Orientation</strong></td>
<td>Fully oriented</td>
<td>Occasional difficulties with time relationships</td>
<td>Marked difficulty with time relationships</td>
<td>Usually disoriented to time and often to place</td>
<td>Oriented only to person or not at all</td>
</tr>
</tbody>
</table>