Running Head: GENDER, KINSHIP AND CAREGIVING APPRAISAL

# Positive and Negative Caregiver Appraisal and Caregiver Health Outcomes

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## Abstract

The current study examined the role that positive appraisal (i.e., gain) and negative appraisal (i.e., burden) of caregiving can play in understanding caregivers' physical and mental health outcomes. Gender and kinship were examined to investigate any differences in caregiving appraisals or health outcomes. Secondary analyses of two databases, Resources for Enhancing Alzheimer Caregiver Health (REACH) and the Canadian Study of Health and Aging (CSHA) were conducted. Positive appraisal and negative appraisal were established as separate constructs that both change over time. These findings were contributed to the understanding of this newer variable. Adding positive appraisal at the last step of a hierarchical regression after demographics and negative appraisal improved the prediction of caregivers' anxiety, but not other health outcomes (i.e., self-rated health, number of illnesses diagnosed, and depression). Negative social interactions emerged as a significant predictor of health outcomes. Surprisingly, some robust findings from the literature were not replicated. In both databases, women did not report more burden than men. Women caring for men (as opposed to other combinations of caregivers and care recipients) did not report significantly more caregiver burden. Spouses were not more burdened than other caregivers. Gender and kinship differences on positive appraisal were equivocal and require replication. Specifically, the REACH data suggested that men report more gain than women, but there was no such gender difference in the CSHA data. With regard to spouses, one found that spouses reported more gain than other caregivers, while the suggested that spouses report less gain that others. Standardizing the measurement of positive appraisal in future research should help resolve these inconsistencies. Given the

lack of significant findings based on demographics, gender and kinship may not be the optimal variables with which to study caregiver appraisal and health. Personality factors and prior relationship quality may be viable new directions for future research.

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## Positive and Negative Caregiver Appraisal and Caregiver Health Outcomes

### *Caregiving for Dementia Patients*

Dementia will be a growing health concern in the coming decades, because the risk for dementia increases with age. While eight percent of Canadians overall were estimated to meet the criteria for dementia in 1991, the rate is 2.4% for those aged 65-74 years, but jumps to 34.5% in those aged 85 and over (CSHA, 1994b). As the North American population ages, it is therefore postulated that the prevalence of dementia will inevitably increase. Estimates show that in 1991, the proportion of the Canadian population over age 65 was 10.6%, but this is anticipated to increase to 15% in 2011, and 22% in 2036 (Perreault, 1990). In addition, the percentage of "old old" is increasing; if one were to split the elderly population into two groups, 65-74 years, and 75 years and older, one would see that the proportion of those 75 years and older will increase from 40% of the elderly population in 1989, to 52% in 2036. As people get older, the risk of dementia is greater (Ebly, Parhad, Hogan, & Fung, 1994), therefore, by 2036, the number of people in Canada with dementia is expected to be over 3/4 million people (CSHA, 1994b).

Many dementias have a gradual onset, and are, by definition, progressive (Cummings & Khachaturian, 1996). Hence, people suffering from dementia require progressively more assistance and care. While there are different types of dementia (e.g., Alzheimer's Disease (AD), vascular dementia, Pick's disease), there are some common symptomatic denominators (APA, 1994). Dementias are disorders with deterioration in memory and thinking, particularly with respect to the registration, storage and retrieval of new information, which is sufficient to impair personal activities of daily living (WHO, 1992). More specifically, dementias entail multiple cognitive deficits, including memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or executive functioning disturbance (APA, 1994).

The cognitive decline that defines the disorder is commonly concomitant with certain personality, mood and behaviour changes in the patient. For instance, agitation, aggression, incontinence, insomnia, wandering, and psychotic symptoms can arise along with the cognitive symptoms (Carrier & Brodaty, 1996). As dementia patients experience this complex set of cognitive, psychiatric and behavioural symptoms, they begin to require progressively more intensive care, including assistance with their instrumental activities of daily living (e.g., managing finances) and their activities of daily living (e.g., toileting, grooming, preparing meals) (Carrier & Brodaty, 1996). Research shows informal caregivers (i.e., unpaid caregivers, often family members) will provide much of this assistance (Goode, Haley, Roth, & Ford, 1998; Murray, Schneider, Banerjee, & Mann, 1999).

In the United States, it is estimated that 7 out of 10 of the 4 million people with A.D. live at home, 75% of them depending upon homecare provided by informal (i.e., unpaid) family caregivers (Winslow & Carter, 1999). Therefore, there is a substantial number of families who are caring for a loved one suffering from dementia, and a number of patients with numerous symptoms and multiple needs who will be under the care of an informal family caregiver (Winslow & Carter, 1999).

Because of the intensive and challenging nature of providing care to dementia patients, caregiving often embodies a major time commitment. Caregivers commonly report caregiver burden, reflecting a negative appraisal of the caregiving situation. However, many caregivers also appraise particular aspects of their caregiving experiences in positive ways, a construct often referred to as caregiver gain. (More detailed information on caregiver burden and gain will follow).

The ways in which caregivers appraise their situations (i.e., burden and gain) could influence the health outcomes they experience. Just as dementia will be a growing health concern, the health of informal dementia caregivers will also be of growing concern. The chronic stress of caregiving has been associated with increased risks of certain health conditions (e.g., hypertension, depression) (Beach, Schulz, Yee, & Jackson, 2000; Clyburn, Stones, Hadjistravropoulos, & Tuokko, 2000). However, the nature of the influence of caregiving appraisals (i.e., burden and gain) on health outcomes remains unclear. The following review of the existing literature aims to shed light on caregiving appraisals, caregiver physical and mental health, and the complex relationships between them.

### *Caregiver Burden.*

Providing care for a person with dementia is challenging and complex. While their intent and effort are admirable, family caregivers are generally unprepared (e.g., untrained to provide intensive nursing care, not knowledgeable about dementia) to complete the multitude of physical, mental and emotional tasks that are required when their loved one's decline in cognitive functioning starts to change his/her mood, personality and behaviours, and impede his/her ability to complete daily tasks such as housekeeping and self-care (Archbold, Stewart, Greenlick, & Harvath, 1990; Kramer, 1997a). In addition, many of these informal caregivers are juggling their caregiving duties with other roles, (e.g., employee, parent) (Kramer & Kipnis, 1993). Difficulties develop as time constraints mount, and physical, mental, and emotional resources are strapped in the process of completing the caregiving tasks along with one's other important roles. Many caregivers come to a point where they experience a feeling of burden; "a context-specific negative affective outcome occurring as a result of one's perceived inability to contend with role demands" (O'Rourke & Tuokko, 2003a). This feeling is referred to as subjective burden.

On the other hand, objective burden essentially encompasses the actual tasks and challenges a caregiver faces in his/her caregiving role. It is defined by the amount, duration or intensity of the actual caregiving experience (the tangible aspects of the caregiving tasks that could seemingly create burden; e.g., the number of activities of daily living with which the care recipient requires assistance).

There have been many conceptualizations of how to measure both objective and subjective caregiver burden in the literature. One approach to measuring caregiver burden has been to ask caregivers about the assistance the care recipient requires with Basic Activities of Daily Living (BADLs) and Instrumental Activities of Daily Living (IADLs), or what types of memory and behaviour problems the care recipient experiences, and then asking the caregiver to rate how much it bothers or upsets him/her to notice these problems or assist with such tasks (Coon et al., 2004; Haley et al., 2004; Roff et al., 2004). Such an approach is able to capture both the objective and subjective aspects of burden. Objective burden can be estimated by calculating the number of tasks with which the care recipient requires help, or the number of memory and behaviour problems the care recipient is demonstrating, while subjective burden is captured by the amount of bother and upset the caregiver experiences in relation to the objective burden. Such a measurement strategy demonstrates how it is possible to have objective and subjective burden be weakly correlated or uncorrelated; even if the objective burden is high (i.e., the care recipient requires assistance with many or all tasks, or exhibits most of all of the memory and behaviour problems) the subjective burden may be low (i.e., if the caregiver does not indicate that he/she is bothered or upset by dealing with these challenges).

While consideration of ADLs and memory and behaviour problems are important to consider when measuring burden, probably the most common approach to measuring subjective caregiver burden is with the Zarit Burden Interview (ZBI) (Hebert, Bravo, & Preville, 1994, , 2000; O'Rourke & Tuokko, 2003b; Zarit, Reever, & Bach-Peterson, 1980). The ZBI measures subjective burden in many facets of the caregiving experience. For instance, there are some items that inquire about whether the care recipient's behaviour is embarrassing to the caregiver, while others ask about role strain, (e.g., Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?) There is also an item that covers overall burden (i.e., "Overall, how burdened do you feel in caring for your relative?) The original ZBI had 29 items, but shortened versions have been derived from these items to increase clinical utility. Many clinicians felt that while the original version was psychometrically strong and appropriate for research purposes, its length may have deterred regular clinical use (Bédard et al., 2001). There have been a plethora of short forms of the ZBI investigated (from a 4 item screening version, to a 22 item long version). A shortened version with 12 items has been deemed psychometrically superior to the three main other versions, in terms of item composition, item reliability, factor structure, and concurrent validity of responses (O'Rourke & Tuokko, 2003b). This 12-item measure was found to have two factors; role strain (e.g., caregiver feeling as though relationships with others suffers due to caregiving duties) and personal strain (e.g., the caregiver wishing that he/she could leave the care of the care recipient to someone else). The ZBI is superior to some of the other methods for measuring subjective burden, but it leaves the task of measuring objective burden to other measures. This may be construed as an advantage in some cases (e.g., it enables one to utilize the best objective measures in addition to the ZBI, which some consider to be the best subjective measure), it is a disadvantage in other cases. For example, when length is a concern, it may be a more efficient use of time to combine the objective and subjective burden measurement.

Regardless of how subjective burden is measured, a number of variables contribute to its appraisal. The behavioural and psychological symptoms of dementia that care recipients display as a result of their illness, (such as disturbed perception, thought content, mood, and behaviours) are positively correlated with caregivers' appraisal of subjective burden (Black & Almeida, 2004). A review by Bédard and colleagues (2000) found that behaviour problems were the best predictor of subjective burden in over half of the studies providing a clear indication of the best burden predictor.

Aggression is a specific type of behaviour that many caregivers find particularly burdensome. Aggressive and frustrating behaviours accounted for 59% of the variability in the burden of female spousal caregivers (Bédard et al., 1999). Also, burden tends to peak in the middle phases of AD when the behavioural disturbances are most troublesome (Pruchno & Resch, 1989a).

However, along with the findings that the care recipients' various behaviours have a large influence on the appraisal of subjective burden, over one quarter of the studies Bédard and colleagues (2000) reviewed indicated that an attribute of the caregiver, (for example, personality variables), was the best burden predictor. There is a body of research that posits that much of the variability in caregiver burden could be attributed to the personality traits of the caregiver. Optimism and mastery are linked to positive physical and mental health outcomes for caregivers, while neuroticism is linked to increased perceived stress and burden and the accompanying negative health outcomes for caregivers (Connell, Janevic, & Gallant, 2001; Gallant & Connell, 2003; Patrick & Hayden, 1999).

Caregivers' ability to cope is another variable that lies within the caregiver and could contribute to the appraisal of subjective burden. Caregivers' coping resources are viewed as

> "a complex and dynamic set of cognitive, affective, and behavioural responses that are aimed to regulate their emotions, solve or improve the practical problems they face, and maintain the psychological resistance and fortitude needed to stay productively engaged in caregiving for a protracted period of time" (Gottlieb & Rooney, 2004).

Certain types of coping resources are related to appraisals of subjective burden. For example, those caregivers who utilize the avoidant-evasive coping (e.g., wishing a problem away) and regressive coping (e.g., overeating) styles are more likely to demonstrate higher levels of subjective burden (Kneebone & Martin, 2003). Also, a longitudinal study found that “counting one’s blessings” is the only coping strategy to influence initial and later caregiver burden; in fact, this coping strategy was negatively correlated with baseline and follow-up burden scores (Vitiliano, Russo, Young, Teri, & Maiuro, 1991). Therefore, the ways in which the caregiver elects to cope with the multiple stresses of caregiving could influence how they appraise how burdensome their situation is. However, it is difficult to determine directionality because the majority of studies on coping and burden are cross-sectional and correlational in nature. Therefore, it is possible that those experiencing greater subjective burden could find it more difficult to utilize the most optimal coping strategies, rather than the use of less optimal coping strategies leading to greater burden. Longitudinal studies about the coping resources that caregivers use would be beneficial to flesh out this dilemma.

Longitudinal studies would also be useful to better capture the dynamic nature of caregiver appraisal. Many factors contribute to the appraisal of burden and gain, and a number of these factors will change over time (e.g., ADL impairment, living arrangements), and when these factors change, it follows that appraisal of caregiving may also change. For example, Winslow and Carter (1999) found that wife caregivers experienced increased burden over time. In addition, they found that burden fluctuated when wives made the decision to institutionalize their demented husbands. At the time of placement, wives reported high levels of burden, which makes sense, because it is often high levels of burden that forces the wives to make the decision to institutionalize. Immediately after placement in an institution wives reported decreased burden (Winslow & Carter, 1999). These findings clarify that burden can change over time, depending upon the caregiving situation. Therefore, caregiver appraisal is at least partially determined by the caregiving situation. Although personality traits may influence how one appraises caregiving, appraisal cannot be inferred directly from personality traits within the caregiver.

However, it is interesting to note that the situational variables associated may have a lesser influence on caregiver burden than one would assume. Bédard and colleagues (2000) found that external variables (e.g., formal supports) were the best predictors of burden in only 8% of the studies they examined. Knowing that objective and subjective burden are not strongly correlated could partially explain the finding that external variables are not often the best predictors of burden, as these variables would likely ameliorate objective burdens (e.g., homemaking for the care recipient), but may have little influence on subjective burden appraisals.

Therefore, subjective burden is a complex construct that is not determined in a straightforward manner. Multiple factors within the caregiver and care recipient dyad, as well as the surrounding external situation all must be considered when attempting to understand this construct. Given the established relationship between subjective burden and health variables, it is imperative to understand the various determinants of this construct when examining the influence of caregiving on health, as the authors of this study purport to do.

While it may seem logical that objective burden would predict subjective burden, research consistently demonstrates that objective burden is not significantly related to subjective burden (the perception of the caregiver that they feel burdened by the demands placed on him/her) (Montgomery, Gonyea, & Hooyman, 1985). Objective burden is not necessarily related to the subjective sense of burden that people experience and report. For example, a caregiver who is providing care a few hours a week for an elderly parent who lives mostly independently may potentially feel more subjectively burdened than a second caregiver who is living with a severely demented patient who requires intensive self-care assistance for most hours of most days. Understanding the reasons behind such differences is important. Interventions are often focused on reducing objective burden (e.g., respite care or home care aid), but as objective burden is not necessarily related to subjective burden, these interventions may not actually reduce subjective burden (Mittelman et al., 1995).

The construct of subjective burden is often positively correlated with negative outcomes for both physical (e.g., cardiac problems, diabetes) and mental health (e.g., symptoms of depression or anxiety) (1994a; Williamson & Schulz, 1993). There is evidence that it is the subjective burden a caregiver experiences, and not necessarily the objective burden (e.g., cognitive impairment of care recipient) that has a negative impact on psychological well-being (Harwood, Ownby, Burnett, Barker, & Duara, 2000). Such findings point to the importance of the distinction of subjective burden and objective burden; it is subjective burden that appears to have greater health implications, rather than the tangible aspects of a caregiving situation. Therefore, returning to the two example cases above, the first caregiver would have more negative health outcomes than the second, despite the vast differences in objective burden, because it is the subjective burden that is implicated in the negative health outcomes.

*Gain in Caregiving.*

Burden is an important consideration for many reasons, but there is another side to the caregiving equation that has been often ignored. Generally, there has not been a balanced approach to examining the impact of caregiving; the majority of the focus has been on burden, for the most part overlooking the possibilities of rewards or gains received from caregiving. In 1989, Lawton and colleagues stated, "the positive aspects of caregiving have received far less attention than the negative" (p.62). Sadly, there has not been a great deal of progress in the past 18 years. Commonly, with the exception of the positive psychology movement, psychology tends to focus on the negative, studying psychopathology and risk factors more often than studying how people function well, or protective factors (Seligman & Czsikszentmihalyi, 2000; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). While one might argue that the reason for the emphasis on the negative is that there is little positive to be found in caregiving, studies have found that the majority of caregivers are able to find at least one positive aspect of the caregiving experience in addition to the multiple challenges they face in this role (Kinney & Stephens, 1989b; Murray et al., 1999; Roff et al., 2004; Tarlow et al., 2004). For example, Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken (1991) found that 90% of caregivers report positive aspects related to giving care. There have been a number of theories put forth on this subject in attempts to alleviate the imbalance in research and include both the positive and the negative in their conceptualization of caregiver impact. Recently, some researchers have begun to pay more attention to the positive aspects of caregiving, but the gains one can experience from caregiving remain poorly understood.

Viewing day-to-day caregiving as a series of hassles and uplifts is one way to address this imbalance (Kinney & Stephens, 1989b). Lazarus and Folkman (1984) define hassles as minor events that an individual sees as threatening to his or her well-being. Uplifts, on the other hand, are thought to buffer individuals from the consequences of these hassles (Kinney & Stephens, 1989b). Kinney and Stephens (1989) assessed the direct effects of hassles on caregivers, the interactive effects of hassles and uplifts, and the net effects of hassles and uplifts on caregivers' well-being. Looking at all three types of effects is important, because although it is helpful to merely consider the possible positive aspects of caregiving, considering them in isolation is no more enlightening than looking at the negative aspects of caregiving in isolation. Understanding the relationship between these two factors could be particularly informative. Another beneficial aspect of this conceptualization is that caregivers rated 110 events that typically occur while caregiving, and were asked to appraise each event as either a hassle, an uplift, both, or neither for the past week of caregiving (Kinney & Stephens, 1989b). They found that of the 110 items, 84.5% were appraised as both hassles and uplifts by different caregivers; only 14.5% were appraised as only hassles, and only 1 item was appraised solely as an uplift. The benefit of this approach is that any particular event could be construed as positive, negative or both, in various instances by various caregivers, and allows people to assess each individually, without assumptions of which events should be hassles or uplifts. Also interesting to note, the correlation between hassles and uplifts was 0.7, meaning that there is a relatively strong correlation between these two constructs. Therefore, caregivers may find the same events to be a hassle in some instances as are uplifts in other situations. These data could indicate that researchers attempting to understand caregiver burden and gain should not make assumptions about what would be considered a hassle or an uplift, as this determination not only varies between individuals, but also varies within individual caregivers depending on situational characteristics.

Finding meaning is another conceptualization of the positive aspects of caregiving (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Farran, Miller, Kaufman, Donner, & Fogg, 1999). The philosophical framework of existentialism was the basis for the concept of finding meaning in caregiving, and incorporates both the positive and negative aspects of caregiving (Farran et al., 1991). The existentialist ideals are based on four assumptions about making meaning. The first is that people create meaning by making choices (e.g., choosing to become a caregiver), the second is that choices are guided by values (e.g., a personal attitude that allows caregivers to persevere to provide care), the third is that each person has responsibility for right action and conduct (therefore caregiving involves accepting the responsibility for making the right decisions about whether to become a caregiver, and how to carry out these responsibilities), and the fourth is that provisional and ultimate meaning exist (Farran et al., 1991). Provisional meaning involves finding meaning in day to day tasks and experiences, while ultimate meaning involves embracing philosophical or spiritual beliefs (Farran et al., 1991). Research shows that higher levels of provisional meaning moderates levels of depression and role strain; therefore, the positive aspects may moderate some of the negative aspects of caregiving (Farran et al., 1991).

When the existentialist framework was applied to qualitative research about caregiving, main themes emerged, which encompassed both the negative (e.g., loss/powerlessness), and the positive (e.g., making personal decisions to choose to have a positive attitude) (Farran et al., 1991). Farran and colleagues (1991; 1997) found that 90% of the caregivers that participated in their studies valued the positive aspects of caregiving, such as the positive relationship with the care recipient, and seeing the care recipient appreciate and respond positively to the care provided. This framework of finding meaning has also led to the development of a scale entitled Finding Meaning Through Caregiving Scale (FMTCS) (Farran et al., 1999). This scale includes measures of loss/powerlessness, provisional meaning and ultimate meaning, in order to better understand how caregivers find and create meaning in their situations (Farran et al., 1999).

In addition to these broad conceptualizations of positive aspects of caregiving, there are also particular aspects of caregiving that are postulated to incur certain gains. For example, some people may experience a sense of mastery when acting as a caregiver (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Lawton and colleagues (1989) defined caregiving mastery as "a positive view of one's ability and ongoing behaviour during the caregiving process" (p. 62). Other measures attempt to show that caregivers can incur gains in terms of practical skills or a sense of purpose in life (Stetz, 1989). For example, Stetz (1989) used the Lewis Coherence 40 Scale to measure "the spouse's sense of meaning attributed to the caregiving experience" (p. 143).

The evolution of scales to measure caregiver gain has culminated in the Positive Aspects of Caregiving Scale (Tarlow et al., 2004). This scale has demonstrated strong psychometric properties in the context of a large, multi-site study (Tarlow et al., 2004). The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project (about which there will be more detailed information below) allowed Tarlow and colleagues to test the Positive Aspects of Caregiving Scale with over 1200 caregivers of Alzheimer patients of varying ages, cultures and situations, in multiple U.S. cities over the course of 4 years. Because the participants were tested up to 4 times with the same measure of positive aspects, concerns about cross-sectional samples are alleviated. The diverse nature of the samples allowed for intensive subgroup analysis, and efforts were made to avoid using only samples of convenience. Recruitment efforts were made to extend to groups usually poorly represented in such studies. For instance, Hispanic and African-American caregiver-care recipient dyads were actively sought for the REACH study at the various sites. However, as is the challenge for all psychological research, participants had to be volunteers, so samples always have an element of convenience, which means that they may not perfectly represent the population.

The Positive Aspects of Caregiving Scale includes 9 items, each measured on a 5-point Likert scale ranging from 'disagree a lot' to 'agree a lot'. Factor analysis revealed two factors: self-affirmation, which included 6 items, and outlook on life, with the remaining 3 items loading on this factor (Tarlow et al., 2004). (See Appendix A, Section 8 for items and loadings). Tarlow and colleagues (2004) found that at baseline, before any intervention, the majority of caregivers did perceive that caregiving provided them with a number of satisfying and positive experiences. This was an encouraging result that confirmed earlier findings by Kinney and Stephens (1989) and Farran and colleagues (1991).

Tarlow and colleagues (2004) examined the psychometrics of this scale and found that the internal consistency for the self-affirmation factor was .86, and the outlook on life factor had an internal consistency of .80. The correlation of .69 between the two components spoke in favour of creating a summary score from all nine items. The Chronbach's alpha for the whole scale equaled .89. Tarlow and colleagues (2004) concluded that the Positive Aspects of Caregiving Scale demonstrated face validity, as the items were derived from earlier conceptualizations of the positive aspects of caregiving, such as Lawton and colleagues (1989). They also examined convergent and discriminant validity, finding that the caregivers' scores on the PACS were positively associated with their level of well-being ($r = .24$), self-reported health ($r = .01$), and satisfaction with received social support ($r = .15$), but negatively associated with the amount of burden they experienced as caregivers ($r = -.23$) and their dissatisfaction with negative social interactions ($r = -.05$). They found that all of the relationships were in the anticipated directions, although smaller in magnitude than expected. Despite the smaller magnitude, Tarlow and colleagues felt that convergent and discriminant validity were confirmed through these analyses. However, one could argue that the use of likely insignificant correlations (i.e., self-reported health, negative social interactions), does not provide solid evidence of validity. The other correlations cited in their article do appear to be good evidence of the validity of their scale, but it would have been beneficial to include information regarding statistical significance of these correlations so the reader could make his own conclusions regarding this evidence.

While the basic psychometric analysis of the Positive Aspects of Caregiving Scale was thorough, Tarlow and colleagues commented on the cursory examination of the differences reflected in the PACS scores for the different subgroups involved in the study; they found that the average scores of Caucasian caregivers tended to be lower than the average scores of the other ethnic groups, and that men tended to score more highly on the PACS than women. They cautioned against over-interpretation of these findings, as they are univariate in nature, and do not take other factors (e.g., care recipient characteristics) into account. The authors also recommended that more thorough subgroup analyses take place, in order to better understand how the PACS measures positive aspects of caregiving for various types of caregivers. Although several authors have taken this advice, and compared gain and burden appraisals in different ethnic groups, this may not be the most efficient approach to understanding gain and burden in all caregivers (for the findings of these studies, see below). There are many factors that contribute to the appraisals of caregiving situations. Therefore, studying numerous subgroups (e.g., ethnic group A vs. ethnic group B, wives vs. husbands, employed caregivers vs. unemployed caregivers), could engender copious univariate data, each contributing a small percentage of the variance in gain and burden appraisals. These data would be difficult to assimilate into a model. It may be more beneficial to study a broad spectrum of caregivers, and attempt to develop a model of how the numerous factors relate and influence one another in the larger picture.

The few studies that have examined subgroup differences on the PACS have focused on racial or ethnic subgroups, replicating other studies that have found that African Americans tend to report more gain or benefits from caregiving than Caucasian caregivers (Roff et al., 2004). Roff and colleagues (2004) found that the following variables partially mediate the race-PACS relationship; education, SES, behavioural bother (a construct similar to burden), anxiety, and religiosity. Therefore, African Americans' lower SES, lower behavioural bother, lower anxiety and higher religiosity, compared to Caucasians, partially explain the relationship between PACS and race. Another study demonstrated that African American caregivers have more benign appraisals, both positive and negative (Haley et al., 2004). Haley and colleagues (2004) not only confirmed that African American caregivers appraised their situation more positively on the PACS (as reflected in their higher average scores), but also that African American caregivers appraise their caregiving situations less negatively, judging the memory and behaviour problems of their care recipients as less distressing than do Caucasian caregivers. The patterns of benign appraisal for Latina caregivers are similar to those for African Americans; they express less distress about memory and behavioural problems and have greater positive appraisals of the caregiving experiences than Caucasian caregivers (Coon et al., 2004). Therefore, race has been fairly well explored in the context of the REACH project with respect to PACS, but the comparisons of other subgroups (e.g., gender) on the basis of positive appraisals have been ignored to date.

These few studies of the PACS have left many unanswered questions about the influence that background and contextual variables could have on the positive appraisals, or the influence that positive appraisals of caregiving could have on health outcomes. Given that there is a great amount of variability in the health outcomes of caregivers, some hypothesize that incorporating the positive appraisals of caregiving will help to explain some of this heterogeneity (Lawton, Rajagopal, Brody, & Kleban, 1992).

### *A Conceptual Model of Caregiver Adaptation*

Models are useful tools to help conceptualize the burden and gain appraisals in the larger context of the caregiving situation. The literature to date has indicated that burden and gain are two different constructs, and do not represent opposites on a uni-dimensional continuum (Kinney & Stephens, 1989a; Kramer, 1997b). Therefore, it is important to use a conceptual model that reflects both positive and negative appraisals of caregiving. In addition, caregivers' appraisals do not occur in a vacuum. Understanding why certain caregivers appraise their situations in particular ways is a challenge due to the complex nature of the caregiving situation.

Models of caregiver adaptation are commonly multidimensional. By incorporating the key variables, appraisals and outcomes, and perhaps more importantly, the relationships between them, multidimensional models reflect the reality of complex caregiving situations. The use of a model also guides the development of a theoretical framework for research on these constructs. Incorporating both positive and negative factors into one model allows for the analysis of a plethora of hypotheses; for instance, the possibility that the presence of positive appraisals mitigate the effects of the negative appraisals on the health outcomes of the caregiver, whether positive and negative appraisals are two distinct constructs, or if they are two ends of a bipolar continuum, et cetera. In addition, by analyzing the relationship of both positive and negative appraisals, it could be possible to better understand the mediating variables that influence the appraisals of caregiving. This is one reason why Kramer's model of caregiver adaptation (1997b) is preferable in the present context. (See Figure 1).

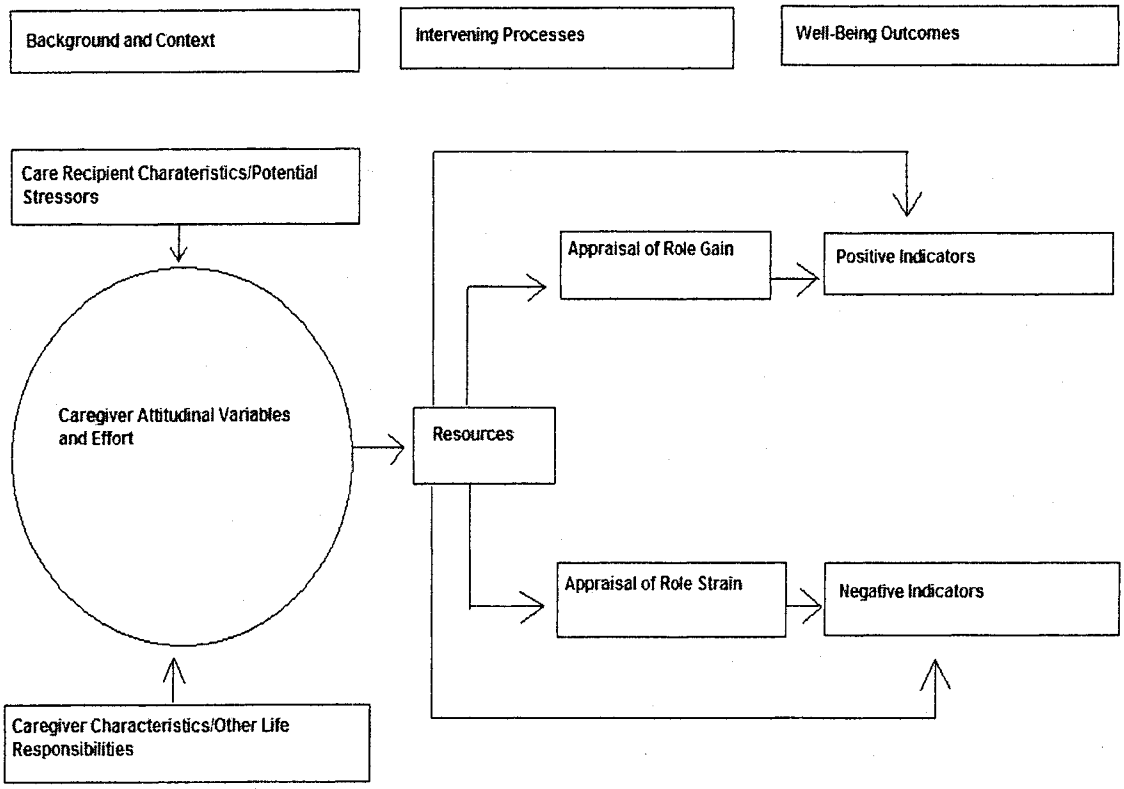
Another strength of Kramer's model is that caregiver adaptation is viewed as a dynamic process. The three domains of this process include the background and context variables, intervening processes, and well-being outcomes (Kramer, 1997b). (These domains will be defined and expanded upon below). Because the nature of caring for a person with dementia will change over time for a variety of reasons ranging from the progressive nature of dementia symptoms (1994a) to the shifting of caregiver resources and responsibilities outside of caregiving, it is helpful to also view adaptation to caregiving as a process. For example, the aspects that influence a caregivers' appraisal (be it positive or negative) at the start of his/her caregiving career may be different from the aspects that influence the appraisals after a long period of caregiving.

Another strength of this model is that appraisal is viewed as an intervening process, rather than an outcome. As the literature regarding objective and subjective burden and health outcomes suggests, it is the subjective burden, or appraisal of burden, and not the objective factors of the situation (e.g., level of care recipient impairment) that are related to the negative health outcomes (Harwood et al., 2000). Therefore, instead of seeing the appraisal as the outcome of a particular set of circumstances, the appraisal may instead be viewed as the intervening process between the context of the caregiving situation and the physical or mental health outcome. Using this model, one could determine whether the appraisals (whether they are positive or negative) could be mediating or moderating variables between the caregiving situation and the outcomes.

Another advantage is that this model incorporates a number of the theoretical frameworks that have been explored in this literature; stress theories, social exchange theory, role theory, existentialism, et cetera (Kramer, 1997b). Because none of these theories is adequate to explain caregiver adaptation in isolation, Kramer integrated and synthesized these broad theories into this conceptual model in order to capture much of the literature into a single model.

According to Kramer's model (1997b), the background and context of the caregiving situation is the first aspect that must be examined in order to better consider how the individual differences of the caregiver and care recipient in each caregiving situation influence the appraisal of caregiver burden and gain. It is not only these variables in isolation, but the interactions amongst the individuals and their environment that contribute to the understanding of the background and context of a particular caregiving situation (Kramer, 1997b). Examples of background and context variables include the caregiver and care recipient's gender, age, education, and ethnicity, the cognitive, functional, and behavioural impairments of the care recipient, the living arrangement of the caregiver and care recipient, and even the relationship between the caregiver and the care recipient (Kramer, 1997b). The consideration of what each participant in the caregiving situation brings to the situation in terms of immutable demographic factors and dynamic situational variables is an important basis on which to begin understanding the caregiving situation. In the present study, gender and kinship (explored in more detail below) will be considered as important variables to understanding the appraisal and outcomes of caregiving, and Kramer's model (1997b) incorporates these variables into the background and context domain of her model.

*Figure 1*



A conceptual model of caregiver adaptation (adapted from Kramer, 1997b)

The intervening processes include the resources that are available to the caregiver, in addition to the appraisal of gain and strain. Resources include both internal and external resources available to the caregiver. Examples of internal resources of the caregiver are religiosity (Picot, Debanne, Namazi, & Wykle, 1997), or coping strategies (Gottlieb & Wolfe, 2002; Hooker, Frazier, & Monahan, 1994; Kneebone & Martin, 2003). Social support (Miller et al., 2001b; Olstad, Sexton, & Sogaard, 2001b) or formal care or services (Bond, Clark, & Davies, 2003) are examples of external resources.

The positive and negative appraisals of the caregiving situation influence the outcomes of the caregiving experience. Unfortunately, this model does not consider how gain and strain interact to produce positive and negative outcomes. As seen in Figure 1, an arrow goes straight from the appraisal of role gain to positive indicators of well-being outcomes, while another arrow points straight from appraisal of role strain to negative indicators of well-being. Understanding how the negative appraisals of the different strains associated with caregiving (e.g., social, financial), and the positive appraisals of the gains that can be acquired through caregiving (e.g., sense of purpose or mastery), interact, could give a more complete picture of the caregiving experience, particularly when one considers that they are likely two distinct constructs (Kinney & Stephens, 1989b; Kramer, 1997b). If positive appraisal and negative appraisal were in fact two distinct constructs, it would be possible, in theory, that low negative appraisals could correlate with positive indicators of well-being, while low positive appraisals could correlate with negative indicators of well-being. The implications of this are that potentially, even if one's negative appraisals are low, (indicating low amounts of burden), health outcomes could still be negative in the absence of positive appraisals. This area could be further developed in a future permutation of this model if empirical results demonstrate that such a change is necessary.

The well-being outcomes outlined in Kramer's (1997b) model include both negative indicators, such as depression, anxiety, and physical morbidities, and positive indicators, such as quality of life and healthy behaviours. As for the inclusion of both positive and negative appraisals, the inclusion of positive and negative well-being indicators also permits for a more holistic and potentially more complete understanding of the health outcomes that caregivers experience. While many studies focus on the negative indicators, some more recent studies have examined both negative indicators (e.g., depression, physical morbidity) and positive indicators (e.g., subjective well-being, satisfaction with life) (Chappell & Reid, 2002; McConaghy & Caltabiano, 2005). A recent meta-analysis comparing caregivers to demographically similar non-caregivers found that caregivers fare worse on five indicators of physical and mental health: caregivers are more stressed, depressed, and have lower levels of subjective well-being and physical health, and self-efficacy (Pinquart & Sorensen, 2003). Findings about variables that are considered intervening processes in Kramer's (1997b) model indicate that certain resources (i.e., perceived social support), are strongly related to positive well-being outcomes (i.e., perceived well-being), but are unrelated to subjective burden, which has been shown to predict negative health outcomes (Chappell & Reid, 2002). This study clearly demonstrates why it is important to consider both positive and negative health outcomes; the same resource variable could have differential effects on these two types of physical or mental health outcomes. Kramer's (1997b) model encourages the consideration of how resources influence both positive and negative well-being outcomes. (Note the arrows that point directly from resources to both the positive and negative indicators).

While no conceptual model is perfect, Kramer's model offers many advantages, (as outlined above), for framing and understanding findings about caregivers that incorporate both the positive and negative appraisals and outcomes of caregiving, as the present study aims to do. Also, this model is flexible enough to incorporate the gender and kinship variables that are of particular interest in the present study.

## *Gender and Caregiving*

### *Gender Differences: Caregiving Experiences for Men and Women.*

For a variety of reasons, men and women give care and experience caregiving in very different ways. A classic study of gender and caregiving by Parks and Pilisuk (1991) found that "gender made an important contribution to differences in how the caregiver role was performed and experienced" (p. 507). To begin with, the most consistent finding in this literature is that women are much more likely to be caregivers than men (Bédard, Pedlar, Martin, Malott, & Stones, 2000; Finley, 1989; Miller & Cafasso, 1992; Parks & Pilisuk, 1991). The National Caregiver Study found that 71% of caregivers are either wives or daughters of the care recipient (Stone, Cafferata, & Sangl, 1987). Studies consistently find that men are the primary caregivers in approximately 30% of cases (Stone et al., 1987).

There is great debate as to why such a gender disparity exists within caregiving. One theory is based on what is known about demographics and dementia (Vinick, 1984). Vinick (1984) states that women are more often thrust into the caregiving role because women's life expectancy is longer than men's, and women generally marry men older than themselves. Therefore, because the likelihood of dementia increases with age, women are more likely to be married to men who become demented, than the opposite. However, this hypothesis only accounts for spousal caregivers, and there are many cases in which adult children act as the primary caregiver, and in this case, the gender disparity continues to exist, with daughters more likely to take on the caregiving role than sons (Dwyer & Seccombe, 1991).

Gilligan (1982) espouses the gender role socialization theory to help explain the inequality. This theory states that women are socialized to attach more importance nurturing the young, old and disabled, and hence they perform these tasks more often, while men are socialized to believe that these tasks are within women's roles (Gilligan, 1982). Evidence against this theory lies in research on filial responsibility (Blieszner & Hamon, 1992). Researchers have found that there are no sex differences in the sense of obligation, sense of duty or sense of willingness of adult children to assist with caring for aging parents' needs (Blieszner & Hamon, 1992). Therefore, women have not been socialized to feel more obligation or more willingness to provide care, and men have not been socialized to feel less obligated or willing to be a caregiver. Furthermore, Pinquart and Sorensen's (2006) meta-analysis argues against the gender socialization theory. The results they amalgamated from 229 studies led them to argue that it is more likely that the care recipient's functional impairments and the availability of informal caregivers dictate who will provide care, and what types of care will be provided, than the socialization or gender of the family members who would be potential caregivers. While Pinquart and Sorensen's (2006) proposition makes practical sense, and has empirical evidence, it does not contribute to the explanation of the reality that women more often provide care to impaired elderly relatives.

Gerstel and Gallagher's (2001) findings add an interesting wrinkle to the debate about how availability of informal caregivers influences how men and women provide care. While Pinquart and Sorensen's (2006) argument above would have one discount socialization completely, and believe that if care is a necessity, gender does not play a role in who provides the care, Gerstel and Gallagher's (2001) found that "men's caregiving is contingent on the women in their lives" (p. 213). Their study showed that even if men are available to provide needed care, the extent of the care they provided depended upon the care their female family members provided. Hence, if men had sisters, the more care the sisters provided, the less care the men provided, but as their wives provided more care, husbands also provided more care (i.e., to aging parents, regardless of who's parents they were). Furthermore, the care that the men provided was similar to that which the wives were already doing (Gerstel & Gallagher, 2001). Therefore, men's sisters acted as substitutes for the men's caregiving, while the care that husbands provided to parents/ parents-in-law was a supplement to their wives' caregiving.

Some will argue that this is because women are more available to provide care, as they are often in a homemaking role, while men are more likely to be otherwise occupied in paid employment and hence unable to provide the hands-on care required in the case of a dementia patient (Finley, 1989). While it may have been true for past cohorts that women were often homemakers, this argument no longer holds, as women's participation in the labour force continues to increase (Hawranik & Strain, 2000). Many women perform paid work outside the home, but paid work does not appear to decrease the likelihood that they will also take on the job of caregiving when necessary. While employment reduced time caregiving for males, this was not the case for females; women who worked outside the home provided similar hours of care as those who were not involved in paid employment (Neal, Ingersoll-Dayton, & Starrels, 1997; Stoller, 1983). Also, other studies have found that daughters provided the most care, regardless of whether they were working or not (Finley, 1989).

While working women do provide more care than working men, among caregivers who are working for pay, women appeared to experience more conflict in their roles of employee and caregiver than men in similar situations experience. For instance, women caregivers were more likely to miss time from work than men caregivers, and ¾ of those who considered quitting work in order to provide care were women (Kramer & Kipnis, 1993). Also, women are more likely than men to change their work schedules to accommodate caregiving, and daughters report more impact on other family responsibilities than men (Kramer & Kipnis, 1993). One may say that because women typically earn less than men, they are the first to compromise their paid work to take on caregiving duties.

Kramer and Kipnis (1993) hypothesized that men may be socialized to not express work role strain, and that socialization may prevent men from changing their work schedules for caregiving purposes. Neal, Ingersoll-Dayton, and Starrels (1997) found that employed women were more involved in caregiving than employed men, with women providing a mean of 6.2 hours a week of care while employed, compared to a mean of 4.1 hours of caregiving for employed men. Other research has demonstrated that even when men's employment situation is flexible, or they work fewer hours than their wives, they still do not provide as much care as their wives (Gerstel & Gallagher, 2001). Gerstel and Gallagher (2001) were surprised to discover that the characteristics of men's families (e.g., whether they had children, sisters, brothers etc.) influenced men's caregiving (in terms of both time spent and tasks completed) more than men's employment. On one level it appears that women make sacrifices in their other roles in order to provide care, while men do not make the same sacrifices. It is arguable that perhaps women feel more able to make these changes, where men do not, although research has not borne evidence for this contention.

Hawranik and Strain (2000) elucidated a different point of view about employment that has not been readily considered in the literature about employment and caregiving; the positive aspects that caregivers find in doing paid work along with providing care. Much of the literature explores the potential for added burden amongst those who are engaged in paid work while being a primary caregiver, but participants in Hawranik and Strain's (2000) focus groups (who were both male and female) expressed that the hours they spent working provided important socialization, intellectual stimulation, and a break from caregiving duties, all with positive implications for caregivers' mental health. This reframes caregiver employment as a variable that could be construed as a risk factor or a protective factor for subjective burden and the concomitant health implications, depending on the caregivers' perspective.

Regardless of the reasons why women and men combine paid work and caregiving in different ways, it is clear that men's employment cannot be the reason that they do not provide a more equitable share of the caregiving duties, because women provide a great deal of care in addition to performing their work duties. Hence, there is evidence against the socialization and employment arguments for why women take on more of the caregiving, while no other valid arguments exist. Therefore, the reasons for the gender disparity amongst caregivers remain poorly understood. In fact, Finley's (1989) study discounted these two theories: the socialization theory, the "time-available" theory (p. 80), in addition to two other family labour hypotheses: the external resources hypothesis, and the "specialization-of-tasks" (p. 81) theory. However, like others, Finley (1989) was at a loss to explain the disparity. That said, the focus of this research is not to answer why people of either gender become caregivers, but to understand how men and women experience and appraise their caregiving situations, and the physical and mental health outcomes they experience once they become caregivers.

With women representing the majority of caregivers, it is important to understand the differences in how women and men experience caregiving. To some extent, caring for a dementia patient is similar, regardless of caregiver gender. In fact, a number of studies have found that objective burden does not differ for men and women caregivers (Thompson et al., 2004). That said, numerous studies demonstrate that women report more subjective caregiver burden than men (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Fitting, Rabins, Lucas, & Eastham, 1986; Lutzky & Knight, 1994; Miller & Cafasso, 1992; Pinquart & Sorensen, 2006; Stoller, 1983; Thompson et al., 2004; Yee & Schulz, 2000). In fact, in Pinquart and Sorensen's (2006) meta-analysis of 229 studies, they found that burden was one of only a few gender differences that were of practical importance; they established that women caregivers reported significantly higher levels of subjective burden then men caregivers.

In addition to increased subjective burden, women suffer more stress than men in the caregiving role; women caregivers also reported feeling less internal control, more depression, more anxiety and more guilt than their male counterparts (Almberg, Jansson, Grafstrom, & Winblad, 1998; Gold et al., 1995; Kramer & Kipnis, 1995; Miller & Cafasso, 1992; Thompson et al., 2004; Yee & Schulz, 2000).

Researchers have investigated the caregivers' physiological responses to the stresses of caregiving (Atienza, Henderson, Wilcox, & King, 2001; Lutzky & Knight, 1994). The cardiovascular response of women caregivers is stronger than their male counterparts when confronted with an emotionally stressful situation within a laboratory (Atienza et al., 2001). This finding is interpreted to mean that women's heart rate and blood pressure may increase more in response to caregiving, potentially putting women caregivers at higher risk of health complications, such as cardiovascular disease. However, similar findings of gender differences have been inconsistent when cardiovascular responses were monitored outside a laboratory, weakening the ecological validity of the assumptions about women's increased health risks (Atienza et al., 2001).

The difference in the nature of the emotional task in the laboratory and actual caregiving may partially explain the differences in findings; in the laboratory, caregivers were asked to speak for six minutes about "what frustrates or disturbs you most or what angers or upsets you most about being a caregiver" (Atienza et al., 2001). As argued by Lutzky and Knight (1994), men are less likely than women to recognize and report emotional states. There is some evidence that men and women experience distress differently; men may be more reluctant to acknowledge distress or they may even be less aware of the distress, and therefore do not report it when asked (Lutzky & Knight, 1994). This could potentially mean that if men are less aware of their distress, asking them to talk about it may not lead them to react physiologically as strongly as women who may become more responsive when asked to talk about something upsetting. This same phenomenon may lead women to report more burden than men in similar caregiving situations (Lutzky & Knight, 1994). Further, unlike the natural caregiving situation, the laboratory situation asks people explicitly to talk about what bothers them about caregiving. While caregiving, people may just go about their tasks and not give a lot of thought to the things that frustrate and disturb them. Research about depression and anxiety demonstrates that when people ruminate about their distressing thoughts, they tend to feel worse (Lavender & Watkins, 2004; Leahy, 2003; Papageorgiou & Wells, 2003). This could be the case for caregivers also. Perhaps women's cardiovascular response is only stronger when talking about their distress, rather than when actually providing care, because women find that discussing their distress is more emotionally arousing than men do. With the established links between physical health and stress, the potential for various physiological measures to lend insight into caregivers' health outcomes is great. Unfortunately at this time, it is difficult to interpret the mixed results regarding cardiovascular responses of men and women caregivers.

Besides cardiovascular response, other studies of stress and immune function of caregivers incorporate emotional ratings with physiological measures. Immune function (i.e., the systems in the body that fight off infection) suffers when a person in under chronic stress (Selye, 1956). If caregivers have suppressed immune function attributed to the chronic stress under which they live, this could partially explain the myriad negative health outcomes from which they suffer at higher rates than non-caregivers. Thompson and colleagues (2004) took blood samples to determine if there were any sex differences between men and women caregivers with respect to immune function. They found that although there were no differences between the male caregivers and the male controls (i.e., non-caregivers), female caregivers had significantly lower immune function than the female controls (Thompson et al., 2004). The authors interpreted this to mean that women's immune function suffers to a greater extent than men's when women are placed under the stress of caregiving. Women caregivers were found to exhibit more physical manifestations of stress than men caregivers, as indicated by bioinstruments that measured skin temperature, skin conductance, and heart rate (Thompson et al., 2004). On one hand, these findings could lend credence to women's greater reports of stress or subjective burden; there is physical proof that women are actually under more stress. On the other hand, do women demonstrate more physical manifestations of stress because they are apparently more aware of and more willing to report their stress? It is unclear how physiological responses are related to self-report measures of stress and subjective burden. While these findings offer no insight into why women experience more stress, these physiological measures do increase the understanding of how caregivers' stress can directly influence their health.

Regardless of how one measures caregiving variables, physiologically or through self-report measures, men and women may experience and appraise caregiving differently because they provide different types of care. For example, women tend to be geographically closer to their care recipients, which leads to providing more day to day care, while men tend to live further away, and are more likely to provide "care management activities" (i.e., arranging for transportation or social services) than day to day personal care for the care recipient (Parks & Pilisuk, 1991).

There is a positive association between caregiver gender and care recipients' level of impairment; female caregivers care for more impaired and dependent care recipients than men (Miller & Cafasso, 1992; Neal et al., 1997). Women demonstrate greater task involvement in general, and women are more likely to perform housekeeping and personal care activities (e.g., toileting, bathing, dressing) than men caregivers (Miller & Cafasso, 1992). Women have also been found to provide help with a broader range of tasks (Stoller, 1990). In addition to being more likely than men to perform ADL and IADL tasks for care recipients, women are also more likely to provide more intensive care, and perform more complex tasks with little or no training (e.g., dressing changes, assistance with medical equipment use, administration of multiple prescription medications) (Navaie-Waliser, Spriggs, & Feldman, 2002). When considering the more intensive care that women are providing, it is also important to keep in mind that women caregivers are more likely than their male counterparts to be 65 years or older, meaning that older women are providing this intensive care in spite of their own advanced age, and likely their own physical health challenges (Navaie-Waliser et al., 2002).

With respect to resources, research shows that women's support networks tend to be broader than men's, and women are more likely to receive emotional support than men (Hibbard, Neufeld, & Harrison, 1996). However, Russell (2004) argues that men's social networks differ from women's, and therefore in studies comparing support networks, men's sources of support may be disregarded. While men often do not feel comfortable attending organized support groups, they will create situations which serve the same purpose (e.g., weekly shared meals) (Russell, 2004). Hence, men may receive similar social support to women, but men's support may be more difficult to capture if researchers use women as the norm. Russell (2004) admits that men may indeed have narrower social networks, due to men's difficulty in finding suitable settings in which to socialize after leaving the paid workforce, but he argues that the support that does occur may be missed by traditional definitions of "support".

While the differences between men and women with respect to emotional support are still questionable, research is clearer in demonstrating the gender differences in the amount of instrumental support (i.e., assistance with specific tasks involved in caregiving) received by caregivers. Research shows that men receive more informal and formal support than women (Kramer & Kipnis, 1993). For example, when wives are ill, adult children and other relatives will provide assistance in addition to the husband, but when husbands are not well, wives provide the lion's share of care, without as much assistance from other relatives (Stoller & Cutler, 1992). In addition, sons providing care tend to receive more support from their spouses than daughters providing care, which could be because men are perceived as needing more help (Kramer & Kipnis, 1993). Navaie-Waliser, Spriggs and Feldman (2002) found that women are less likely than men caregivers to solicit support from secondary informal caregivers or assistance from formal services, and when they do seek support, women tend to do so later in their caregiving career than men.

Interestingly, when a sample of college students read vignettes about caregivers and were then asked how much assistance of various types (e.g., emotional, instrumental) they would provide if this caregiver was a member of their family, the gender of the caregiver in the vignette was not related to how much assistance the students estimated they would provide (Mosher & Danoff-Burg, 2004). One possible interpretation of this finding is that family members may, in theory, be equally willing to provide assistance to men and women caregivers. If this is so, why does this not occur in practice, as evidence proves that men receive more instrumental support than women? Granted, there are often differences between what people say they would do in a given situation, and what they actually do, which could explain the discrepancy. Also, if women are less likely to seek help, perhaps family members are willing to provide it, but do not feel that their assistance is warranted, as women are less likely to express a need for help. The help-seeking behaviours of men and women caregivers could be an expression of the differences in the way men and women cope with stressful situations.

Research demonstrates that women and men do cope differently (Parks & Pilisuk, 1991). They found that women caregivers were more likely to use coping by fantasy than men caregivers, while men were more likely than women to use withdrawal in order to cope. Generally speaking, men tend to use more problem-focused coping strategies (e.g., planning solutions), while women use more emotion-focused strategies (e.g., avoiding confrontation, accepting personal blame and relying on social support) (Lutzky & Knight, 1994). Some researchers state that emotion focused strategies, the ones that women are more likely to use, are less efficient and lead to more distress than the problem-focused strategies that men use, and therefore this at least partially explains why women feel more stress and burden (Lutzky & Knight, 1994).

It has been also postulated that a broad repertoire of coping strategies may be necessary in order to cope with the myriad challenges of caregiving. In this respect, women appear to be doing better than men; women tend to demonstrate a greater number of different types of coping strategies. However, there is no correlation between the number of strategies utilized and decreased stress or relief of subjective symptoms (DeVries, Hamilton, Lovett, & Gallagher-Thompson, 1997). DeVries and colleagues (1997) have found that women used significantly more active cognitive and behavioural coping strategies than men, and that there were no significant differences between men and women with respect to avoidant strategies. In fact, they demonstrated that perhaps men and women are not as different in terms of coping strategies as some earlier research would have us believe; they pointed out that there was a great deal of overlap between the strategies used by men and women. This finding is important because some researchers would claim that the reason that women report more distress and burden than men is due to their use of so-called inefficient coping strategies. However, DeVries and colleagues (1997) demonstrate that men and women are not very different with respect to coping, and therefore the use of different types of coping strategies is not a sufficient explanation for the gender differences in reported burden. Furthermore, research has indicated that the relative contribution of coping strategies to the prediction of burden in caregivers is minimal compared to problem behaviours and the level of dependence of the care recipient, as indicated by activities of daily living (Bédard et al., 2000).

Complicating matters is the finding that women caregivers also report more aspects of caregiving enjoyable than men caregivers (Winslow & Carter, 1999). Gold and colleagues (1995) found that women actually reported both greater feelings of subjective burden, and reported a greater number of aspects of caregiving as enjoyable. Furthermore, women had higher scores on measures of psychological well-being in certain situations (Marks, Lambert, & Choi, 2002). For example, women reported more purpose in life than men when transitioning to caring for a parent out of their household, and women reported greater psychological well-being in the form of more autonomy, more personal growth, more purpose in life, and more self-acceptance than men when transitioning to providing care for someone to whom they were not related (Marks et al., 2002). This begs the question, if women are so poor at coping, why are they able to find more positives in the difficult caregiving experience? Because gain is so poorly understood in the literature to date, it is difficult to answer this question.

### *Interaction of Caregiver and Care Recipient Gender*

Caregiver gender is important to consider, as evidenced above, but it also useful to bear in mind the care recipient's gender. For example, the types of behavioural disturbances the care recipient displays vary by gender and this makes a significant contribution to the prediction of burden (Bédard et al., 2005). Therefore, the interaction between the caregiver's gender and that of the care recipient should be an essential consideration. By considering this interaction, Bédard and colleagues (2005) found that women caring for men were at risk for excessive caregiver burden. They determined that adding the gender interaction improved the prediction of burden by 3%, whereas the addition of caregiver resources and external support did not improve the prediction of burden (Bédard et al., 2000).

Bédard and colleagues' (1999) statement that "burden cannot be isolated from gender" (p. 28) is undeniable, and clearly demonstrated in the aforementioned literature. The characteristics of the caregiver are but one aspect of the caregiving situation to consider with respect to gender differences. Caregiver burden may be more related to behavioural disturbances of the care recipient than to cognitive or functional status of the care recipient (Coen, Swanwick, O'Boyle, & Coakley, 1997). Regardless of caregiver gender, the frequency and tolerability of behavioural disturbances were the strongest predictors of caregiver burden (Coen et al., 1997). There are indications that male care recipients are much more likely (as much as two times more likely) to be physically aggressive than female care recipients (Eastley & Wilcock, 1997; Nagamoto et al., 1999). In addition, 89% of female caregivers reported experiencing some form of physical aggression while performing caregiving duties (Cahill & Shapiro, 1993). This study also found that men are more sexually aggressive, therefore, women may be more threatened by aggression in general (Cahill & Shapiro, 1993).

In addition to aggressive behaviours, there are other behavioural disturbances that appear to differ in frequency for male and female care recipients, and male and female caregivers respond to these behavioural disturbances differently. Female caregivers of male patients reported higher frequency of the following behaviours; withdrawal, agitation, frustration, refusal to cooperate, and embarrassing behaviour in public (Bédard et al., 1999). Certain behaviours that were associated with higher burden differed for males and females. For female caregivers, the behaviours that were associated with higher burden were withdrawal, aggression, delusions that home is not home, and frustration (Bédard et al., 1999). For male caregivers, repetition, being demanding, hiding things, auditory hallucinations, and embarrassing behaviour in public were associated with higher burden, while wandering and getting lost were associated with lower burden for male caregivers (Bédard et al., 1999).

Regardless of caregiver gender, Nagamoto and colleagues (1999) have concluded that caregivers of men experience more burden and mental fatigue. Since spousal caregivers and daughters are the most common informal caregivers, women are more likely to be the caregivers of men. In addition, experiencing aggressive behaviours and providing personal care may be more challenging for women caring for men, due to the practical reality that men are generally physically larger than women (Bédard et al., 1999). Hence, it may not be fair to state that women's coping strategies are less efficient or effective than men's, because it appears that women are facing different and possibly more dangerous circumstances than men providing care for women (Bédard et al., 2005).

### *How Gender and Appraisal Interact and Subsequent Health Implications*

Generally speaking, women caregivers are at a higher risk for negative outcomes, in particular, within the domain of mental health. Although there seems to be little argument that women report more subjective burden (Dura et al., 1990; Fitting et al., 1986; Lutzky & Knight, 1994; Miller & Cafasso, 1992; Navaie-Waliser et al., 2002; Pinquart & Sorensen, 2006; Stoller, 1983; Thompson et al., 2004; Yee & Schulz, 2000), great debate exists in the literature about whether women and men differ in the rates of depression. Inconsistent findings abound and little clarity can be found. Meta-analyses by Pinquart and Sorensen (2006), and Miller and Carasso (1992), and a literature review by Yee and Schulz (2000) all demonstrate that women caregivers experience depression significantly more often than men caregivers. However, other large studies indicate that there are no gender differences with respect to depression symptoms (Gallichio, Siddiqi, Langenberg, & Baumgarten, 2002; Parks & Pilisuk, 1991).

One of the difficulties in generalizing about depression across genders is the fact that there are numerous factors that could potentially lead to a caregiver experiencing depression, and how these factors distribute across genders is not well understood. For example, Gallichio and colleagues (2002) found that the level of behaviour disturbance of the care recipient was significantly related to depression scores. They were unable to determine whether women's care recipients displayed greater behaviour disturbance than the care recipients of men.

Another source of confusion is that some studies discuss amount of depressive symptomatology, while others discuss the probability of caregivers being depressed. These are two very different discussions. It is difficult to tease apart, but it could be the case that women endorse a greater number of symptoms of depression than men, but that men and women are equally likely to experience some depressive symptoms. The confusion could be a matter of differing operational definitions of depression, or the use of different scales to measure depressive symptoms.

It is important to consider that studies of gender and caregiver burden may underestimate male caregivers' negative health outcomes, because the majority of studies examine depression as the primary mental health outcome. This may not capture men's experience of burden, because as the general epidemiological research indicates, women are much more likely than men to suffer depression, whereas men are more likely than women to suffer from substance use disorders, such as alcoholism (Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993; Lukassen & Beaudet, 2005). Studies show that men are more likely than women to cope with stressful situations, such as caregiving, by using drugs and alcohol (Kramer, 1997a). There could be reason to believe that male caregivers would experience different outcomes from feeling burden than female caregivers. For instance, there may be a higher rate of alcoholism in male caregivers than similar non-caregiving males, but unfortunately, data were not collected on alcoholism in previous studies, and this distinction is not well captured.

There appears to be a potential divide between the mental health of women caregivers compared to their male counterparts, but in terms of physical health, Hawranik and Strain (2000) found no gender differences in self-rated health. In fact, despite professionals' and researchers' concerns about caregiver physical health, over forty percent of caregivers rated their own health as very good, while fifty-one percent of caregivers rated their own health as pretty good, with less than one percent stating their health was poor or very poor. Therefore, although caregiver mental health appears to be related to gender, physical health of caregivers, at least if you are asking caregivers themselves, does not reflect any differences between men and women.

## *Kinship and Caregiving*

### *Kinship Differences: Do Spouses, Adult Children and Others Experience Caregiving Differently?*

Regardless of the relationship between the caregiver and care recipient, there are many commonalities in providing care to a dementia patient: the patient's symptoms of cognitive impairment will become progressively worse, behaviour disturbances may be prevalent, the patient will require increasing levels of assistance with ADLs and IADLs as his/her cognitive impairment worsens, et cetera (Archbold et al., 1990; Kramer, 1997a). However, there may be some unique elements of providing care to one's spouse, versus one's parent or other relative that lead spousal caregivers and adult children caregivers and other informal caregivers to experience and appraise the caregiving situation differently, and perhaps subsequently, experience different health outcomes.

There seems to be a consensus in the literature that spouses are most commonly the ones to take on the caregiving role (Connell et al., 2001). Furthermore, spouses provide a greater number of hours of support than adult children, spouses provide the most comprehensive care for dementia patients, and maintain the caregiving role for longer periods than other informal caregivers (Marks, 1998; Neal et al., 1997). The only aspect of caregiving in which spouses do not experience the most negative appraisals, is in the realm of personal burden: caregiving daughters experience greater personal burden than caregiving spouses (Bédard et al., 2005; Bédard et al., 2000). The items on the personal strain factor of the Zarit Burden Interview define personal burden in this study (O'Rourke & Tuokko, 2003a). Essentially, this factor captures "feelings of adequacy in the caregiving role"(Bédard et al., 2005).

Wives experience greater role burden than husbands (Bédard et al., 2005; Gallichio et al., 2002; Kramer & Kipnis, 1995; Miller & Cafasso, 1992; Miller et al., 2001a). Wives also provide more hours of support than husbands (Bédard et al., 2005; Bédard et al., 2000). Caregiving wives experience difficult behaviours as more problematic than caregiving husbands do (Bédard et al., 2005; Collins & Jones, 1997; Robinson, Adkisson, & Weinrich, 2001).

Furthermore, wives providing care receive less assistance than husbands who provide care (Arai & Ueda, 2003; Bédard et al., 2005; Miller & Guo, 2000). The reason for this is unclear, and as above, socialization or societal expectations are hypothesized to play a role; for instance, wives may feel that they should not seek out or accept informal or formal assistance, because they are supposed to fulfill a nurturing role, whereas men are not expected to know how to care for their demented spouse, so they are able to accept the help (Arai & Ueda, 2003; Bédard et al., 2005). On the other hand, people could be less apt to offer help to a woman than a man. For instance, a neighbour may consider cooking a meal for a man who is caring for his wife, because the neighbour may assume that the man cannot cook, whereas the same neighbour may not consider providing similar assistance to a wife caring for her husband, because the neighbour holds the assumption that the wife is able to prepare meals.

In addition, regardless of how altruistic friends, neighbors and family can be, it has been found that caregivers of care recipients who display greater dysfunctional behaviors receive less informal support (Bédard et al., 2005; Clyburn et al., 2000). Behavioural disturbances could also create barriers for caregivers seeking formal services as well. For example, participation in community programming may be contingent on a certain expectation of behaviour for the care recipient. Other studies demonstrate that men with dementia are more likely to display aggressive and disruptive behaviours than women with similar diagnoses (Cahill & Shapiro, 1993; Eastley & Wilcock, 1997; Ryden, 1988). Therefore, when spouses are providing care, if men are more likely to act disruptively, this could disproportionately influence the amount of assistance, both informal and formal, that the wives receive.

There are many reasons hypothesized for why spouses are considered more vulnerable than other caregivers, and why they appear to experience more burden than other informal caregivers. One cited reason is that spouses often live with the care recipient, meaning that they are more likely to provide 24-hour care than other caregivers who do not co-reside (Schneider, Murray, Banerjee, & Mann, 1999). It has been demonstrated that co-resident caregivers provide more informal support and use fewer formal services than caregivers who do not live with the care recipient (Connell et al., 2001).

Spouses are also a lot older than other family caregivers, and hence on average, spousal caregivers are more likely to be experiencing their own health problems while providing care (Schneider et al., 1999). Furthermore, due to societal conditioning that the spouse will be the primary caregiver for their ill partner, some caregiving could be relatively involuntary, meaning that the spouse is providing care out of a sense of obligation, rather than a desire to care for their spouse (Schneider et al., 1999).

In addition, due to societal changes, families tend to have more geographical distance between family members, which can mean that spouses have fewer informal secondary caregivers to call upon to provide assistance (e.g., adult children) (Schneider et al., 1999). These and other factors could contribute to the finding that spouses tend to retain the role of caregiver longer than other types of informal caregivers, they tolerate greater levels of care recipient disability, and are more likely to be care providers (i.e., providing daily, hands-on, personal care, rather than arranging services) than other caregivers (Nagamoto et al., 1999).

Also, some hypothesize that the spousal relationship is unique, and when one partner requires intensive home care, key aspects of the marital relationship (e.g., companionship, emotional support, shared responsibility, shared decision-making) are lost (Murray et al., 1999; Schneider et al., 1999). This is hypothesized to lead to greater burden and low morale. Murray and colleagues (1999) confirmed this hypothesis in a qualitative study. They found that, in addition to aggressive behaviours, the most troubling aspect of caring for a demented spouse was that of the caregivers' feeling of loss of their partner (e.g., their personality, memories etc.).

Gender and kinship interactions exist for transportation, housekeeping, meals, and arranging health and social services (Neal et al., 1997). When caregiving for spouses is considered, males spend about 1/3 as much time as females, while men and women provide equal amounts of care for relatives who are not parents or parents-in-law (Neal et al., 1997). Women spend about 1 hour less providing care for in-laws than their own parents (Neal et al., 1997).

Despite the greater burden and loss experienced by spousal caregivers, a minority of spousal caregivers (18%) reported that they experienced absolutely no gains from the experience of caregiving (Murray et al., 1999). Despite all the challenges that spousal caregivers of dementia patients face, many cite gains such as job satisfaction (meaning that caregivers experience satisfaction because they have made their spouse as comfortable as possible under the difficult circumstances), reciprocity and mutual affection (meaning that caregivers feel they are returning the care and affection given to them in the past), companionship (where the caregiver believed that the care recipient appreciated his/her efforts), and fulfilling a sense of duty (fulfilling the obligation of marriage by providing care in sickness and in health) (Murray et al., 1999). Murray and colleagues (1999) did not find any differences between husbands and wives on these factors. Perhaps gender is a less predictive variable for gain compared to burden. Due to the limited number of studies on gain and gender, it is difficult to state this conclusively.

In another study of kinship and gain in caregiving, it has been found that the majority of husbands report some gains as a result of caregiving (Kramer, 1997a). Pride, gratification, satisfaction, and feeling closer to his wife, are four gains that husbands often cited (Kramer, 1997a). Interestingly, for husbands, stressors are the strongest predictors of strain or burden, while stressors have no relationship to gain (Kramer, 1997a). Unfortunately, Kramer did not include wives in her sample, and therefore could not provide any direct comparison of wives and husbands in this study, so it is difficult to determine whether gain differs across gender. Only one study to date has compared spouses and adult children on caregiver gain, and this study found that adult children reported more rewards of caregiving than spousal caregivers (Raschick & Ingersoll-Dayton, 2004). Caregiver gain was based upon only two items in this study (i.e., 5 point Likert responses to two statements “Providing help to [care recipient] has made me feel good about myself” and “Providing help to [care recipient] has enabled me to appreciate life more” (Raschick & Ingersoll-Dayton, 2004)), so it may be the case that spouses find different rewards than adult children caregivers, and hence these were not captured by the two items selected by Raschick and Ingersoll-Dayton (2004).

While much of the research on family caregivers focuses on spouses, Li, Seltzer and Greenberg (1999) focused on adult daughter caregivers. They claimed that adult children face unique challenges when caregiving, due to the time in their life in which they are providing care (i.e., middle age when parenting and paid employment are common roles in addition to caregiving for parents). In addition, they point out that due to increases in the life span, and the concomitant increases in dementia in the population, it is now more likely than ever that adult children will be called upon to provide care for parents. Also, it is important to note that daughter caregivers outnumber sons by a ratio of 3 to 1 (Li, Seltzer, & Greenberg, 1999). This study found that 4/5 of daughter caregivers held roles other than caregiving (i.e., employed outside the home, parenting children at home, providing care to another person other than the parent) (Li et al., 1999). Not surprisingly, with numerous circumstances that would predict role strain and associated negative mental health outcomes for daughter caregivers, Li and colleagues (1999) determined that 25% of the daughter caregivers sampled met the clinical cutoff on the Centre for Epidemiology Scale for Depression (CES-D). They found that daughters who coped relatively well with the demands of caregiving tended to be those who were married or sharing the caregiving duties with a sibling. In addition, those who coped well tended to have higher levels of mastery, and used more problem-focused than emotional-focused coping strategies (Li et al., 1999).

### *How Kinship and Appraisal Interact and the Subsequent Health Implications*

There is limited research on whether health implications for wives, husbands, and adult children caregivers vary. It is noteworthy that caring for someone who is not a spouse, parent, or parent-in-law creates fewer negative health outcomes than caring for a parent (Neal et al., 1997). The only relationship more burdensome and detrimental to caregiver health than caring for a parent, is caring for a spouse (Neal et al., 1997).

Spouses are considered the most vulnerable group of caregivers, because they are the ones who are most likely to get ill themselves, they experience a higher rate of psychiatric symptoms, and have lower morale than other caregivers (Pruchno & Resch, 1989b). However, it may not be appropriate to lump all spousal caregivers together in one homogeneous group. There is great heterogeneity within this group on a number of factors. For example, caregiver husbands experience fewer stressors and depressive symptoms than their female counterparts (Bookwala & Schulz, 2000). Therefore, it would appear that caregiving has a differential influence on wives and husbands' health.

Prior relationship could be another important consideration for the health of spousal caregivers. Research demonstrates that lower prior relationship quality is associated with increased depression, decreased quality of life, and decreased caregiving satisfaction for spousal caregivers (Kramer, 1993). Those in this study who were only married once had higher levels of quality of life, and lower levels of depression than those married twice or more (Kramer, 1993). There is some evidence that a prior marital relationship of higher quality could be a buffer for the negative health effects from which spousal caregivers often suffer. For example, Beach, Schulz, Yee and Jackson (2000) found that when caregivers reported higher quality marital relationships, they tended to report fewer health risk behaviours (e.g., eating fewer than

3 meals a day, not getting enough rest, delaying a doctor visit if a health problem is suspected etc.) and fewer anxiety symptoms. However, despite the protective factor of a high quality marital relationship, higher caregiver strain consistently predicted negative changes in health outcomes (including perceived health, health risk behaviours, anxiety symptoms and depression symptoms) (Beach et al., 2000).

### *Purpose of Present Research*

The overarching purposes of the present research are as follows. First, this research aims to better understand the relationship between caregiver burden and caregiver gain, and how these appraisal variables influence the outcomes that caregivers experience, particularly over time. Secondly, this study aims to examine gender differences with respect to burden and gain, and increase the understanding of how the gender of the caregiver and the gender of the care recipient interact along with the other variables in the conceptual models, such as positive and negative appraisals and health outcomes. Thirdly, this study aims to gain a better understanding of how the caregiver's kinship relationship to the care recipient interacts with gender and other variables to impact upon appraisal and outcome. The fourth aim is to analyze whether appraisals of burden and gain change over time, and if they do, which factors influence such a change in appraisals. Ultimately, a model incorporating these variables could elucidate the relationships between these variables (i.e., mediating or moderating relationships) and how these variables contribute to the understanding of the caregiving experience for different types of caregivers (i.e., male and female, wives, husbands, daughters, sons) over the span of their caregiving careers. This increased understanding could later be applied to determine which types of interventions could be helpful to which types of caregivers.

## *Hypotheses*

### *Hypothesis A*

*Positive and negative appraisals will be found to be two distinct constructs, not one construct along a single bipolar continuum.*

This hypothesis stems from the literature that demonstrates that caregivers are able to appraise caregiving experiences as both very burdensome and very rewarding (Kinney & Stephens, 1989a). There are examples where there was no correlation between appraisals of strain or burden, and appraisals of gain (Kramer, 1997b). Therefore, it would appear that burden and gain are separate constructs. This study aims to confirm these findings.

### *Hypothesis B*

*Positive and negative appraisals will change over time.*

When examining the conceptual models, there are a number of dynamic aspects of caregiving situations that could influence the negative and positive appraisals of caregiving, such as changes in social support, changes in care recipient behaviour, changes in caregiver roles (Goode et al., 1998; Kramer, 1997b). These aspects have been proven to influence caregiver appraisal, and they have been proven to change over time, and therefore, it is logical to assume that appraisal will change over time in concert with these dynamic factors. Empirical confirmation of this logical assumption is required to improve the understanding of these constructs.

### *Hypothesis C*

*Including positive appraisal will increase the amount of variance in health outcomes accounted for over negative appraisals alone.*

Solely considering negative appraisals has not adequately explained the variability in caregiving health outcomes. It is postulated that the positive appraisals could represent a buffer to the negative outcomes expected in caregiving, and that positive appraisals will account for more of the variance in health outcomes once gender of caregiver and care recipient activities of daily living, memory and behaviour problems, and negative appraisal are considered.

*Hypothesis D*

*Women will appraise caregiving more negatively (i.e., higher burden scores) than men caregivers.*

Countless studies have found that women report caregiving to be more burdensome, and there is no reason to believe that the caregivers in this study will be different in this respect.

*Hypothesis E*

*Women will have more positive appraisals of caregiving.*

There is little existing research comparing men and women on positive appraisals. Because women outnumber men so significantly amongst caregivers, many researchers have limited their studies to women's positive appraisals (Coon et al., 2004; Haley et al., 2004). The research that does exist about gender and caregiving clearly demonstrates that women are more involved in caregiving and women caregivers report more burden than men caregivers. Given the items on the positive appraisal scale, the fact that women are more involved in caregiving would lead to the hypothesis that women have more opportunity to experience gain. Also, in many areas, women are more likely to self-report (i.e., depression, burden), so women may also be more likely to self-report gains. Gold and colleagues (1995) also found that although women reported greater feelings of subjective burden, they also reported more aspects of caregiving as enjoyable. There has been some research that did not specifically focus on measuring gain, but did find that women had higher scores on measures of psychological well-being in certain situations (Marks et al., 2002). This evidence lends credence to the hypothesis that women will incur more gain from caregiving than men.

### *Hypothesis F*

*Women caring for men will report more burden than other gender combinations of caregivers and care recipients.*

Due to the increased rates of physical and sexual aggression in male care recipients, the fact that women tend to be caregivers more often, and women's greater likelihood of reporting burden, it seems that women caring for men will report higher levels of burden than women caring for women, men caring for women, or men caring for men.

### *Hypothesis G*

*Spouses will appraise caregiving more negatively (i.e., higher burden scores) and more positively (i.e., higher scores on positive aspects scale) than daughters or other informal caregivers.*

This hypothesis is put forth in light of the unique aspects of the marital relationship. Co-residency is the norm, leading to greater hours of care for spouses, the fact that spouses will provide care for longer and under tougher conditions (e.g., worse care recipient symptoms and behaviours) than other caregivers, and the multiple losses associated with caring for a spouse with dementia (e.g., companionship), could contribute to a greater appraisal of burden. On the other hand, the long-term commitment and caring within a marriage, and the unique gains that stand to be experienced (e.g., feeling satisfied that one is making one's spouse as comfortable as possible) could produce higher scores on the positive aspects of caregiving scores than those of adult children caregivers or other informal caregivers. The one finding that adult children caregivers reported greater rewards than spouses (Raschick & Ingersoll-Dayton, 2004), could be attributed to the nature of the rewards measure; it was only two items, and did not capture the same constructs as the Positive Aspects of Caregiving Measure.

### *Hypothesis H*

*Kramer's model of caregiver adaptation will be confirmed as a structural model of the influence of background variables (e.g., caregiver and care recipient gender, kinship), on positive and negative caregiving appraisal, and in turn, appraisal influences the health outcomes that caregivers experience.*

This model has been put forth as a conceptual model of caregiver adaptation, but it has not been confirmed or disconfirmed with data to date. The literature offers a number of hypotheses about how the various aspects of this model relate to one another, but there has not been an attempt to model all the variables together, which would allow for greater understanding of the interrelationships therein. The present dataset is large enough to permit for such modeling, and Kramer's model is a reasonable starting point for confirming the postulated relationships.

# Method

## *The Use of Existing Databases: A Rationale*

As outlined in the literature review above, there remain many unanswered questions about caregiving, and in particular, the positive appraisals of caregiving. The nature of the questions posed in this study is amenable to analysis of existing large databases because two databases exist that can help researchers answer their questions through secondary data analysis. There are two databases that will be utilized for this secondary data analysis: Resources for Enhancing Alzheimer's Caregiver Health (REACH) and the Canadian Study of Health and Aging (CSHA), (both of which will be outlined in detail below). These databases each have their own unique advantages, but generally speaking, the use of secondary data for this type of research is advantageous for numerous reasons.

To begin with, the large scale of these studies allows for the analysis of data from many more participants than would have been feasibly included in a study collecting primary data, mainly due to reasons of geographic and financial limitations. In regards to geography, the large scale of these studies translates into the collection of data from numerous cities and research sites across either the United States or Canada. In a small city like Thunder Bay, Ontario, finding enough people caring for people with dementia who were willing to participate in a research study would have been challenging. Therefore, with over 1000 participants in each of the databases, the use of these databases allows the researchers to examine hypotheses with greater statistical power. Also, because of the broader sample of caregivers (i.e., from around the country, not just a small geographical area), there is potentially greater generalization of results.

For example, the REACH data had participants of different ethnic groups (e.g., Latin) that would not have been readily available in Thunder Bay, Ontario. Also, there are certain groups of caregivers that have lower base rates (e.g., there are fewer male caregivers than female caregivers). By having larger numbers of overall participants, there are large enough groups of these types of caregivers to facilitate comparisons on the basis of gender or other factors.

In addition to the statistical advantages offered, the use of existing data to answer multiple questions uses the data to a greater extent. Data collection is time consuming and expensive, so if the primary researchers have undertaken this process, it is an efficient use of time and resources to exploit the data collected to its greatest potential. In this vein, it is not only time consuming for the researchers, but also for the participants. Rather than asking a group of people (e.g., caregivers) to respond to multiple surveys or questionnaires, using existing data can allow researchers to answer many questions without exhausting the good will of participants.

Furthermore, within the time constraints of dissertation research, it is difficult to conduct longitudinal studies. While they have their value, cross-sectional studies limit the types of research questions that can be asked. Therefore, the use of existing databases that have followed up on participants over time facilitates the analysis of questions that could not be answered in cross-sectional research (e.g., how caregiving appraisals change over time).

Of course, the use of existing data has its disadvantages. For example, perhaps the primary researchers utilized a different scale than the secondary researchers would have selected. The secondary researchers are forced to cope with this selection as they conduct their secondary analyses. On a larger scale, the issue is that secondary data is only as good as the methods that were used to collect it. In this study, the two databases selected utilized scientifically strong methodologies (as will be outlined below), and so the advantages of this type of analysis far outweigh the disadvantages presented by using data collected by others.

## *The Resources for Enhancing Alzheimer's Caregiver Health (REACH) Project*

### *Overview of REACH*

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) Project, a joint project of the National Institute on Aging and the National Institute of Nursing Research, began in 1995 with the purpose of researching interventions designed to enhance family caregiving for patients with A.D. and related dementias (ADRD) (Schulz, Burgio et al., 2003). The REACH project is considered methodologically superior to many previous studies of caregivers for dementia patients. To begin with, the sample size was much larger than the typical studies in this area. Over 1800 people were screened for inclusion in the study, and 1229 caregivers were accepted into the project. This larger sample size will facilitate the detection of effects that were likely missed in studies with smaller samples (Schulz, Belle et al., 2003; Wisniewski et al., 2003). In addition, randomized control trials are not often conducted with this population, and when they are, often the interventions are not properly implemented. Because treatment implementation data is even more rarely collected, it is difficult to determine the fidelity of such trials (Schulz, Belle et al., 2003; Wisniewski et al., 2003). The REACH project utilized randomized control trials and collected implementation data to ensure intervention fidelity. Furthermore, minority populations are often disregarded in caregiving studies, and the REACH project made it a priority to both recruit and retain minority participants in the study (Schulz, Belle et al., 2003; Wisniewski et al., 2003). In addition to improving the methodology of caregiving studies, the main goals of the REACH project were three-fold; the first goal was to test diverse theory-driven caregiving interventions, the second goal was to develop a standardized outcome protocol to assess the impact of different strategies on caregivers and their care recipients. And thirdly, the goal was to create a common database to enable pooling of data across sites (Wisniewski et al., 2003). In the process of meeting the above goals, the researchers involved with the REACH project developed and tested new scales, such as the Positive Aspects of Caregiving Scale, which allowed for these authors to examine both the positive and negative appraisals of the caregiving experience, an area that is lacking in the literature.

The following six cities, Birmingham, AL; Boston, MA; Philadelphia, PA; Memphis, TN; Miami, FL; Palo Alto, CA, had sites that participated in the project. These sites tested nine theory driven interventions. These interventions aimed to improve the health and well-being of Alzheimer caregivers and were examined through the course of the 5-year project. Control conditions were also in place at each site. Control conditions in Boston, Memphis and Philadelphia were equivalent to the services caregivers might receive if they called a local A.D. and related disorders resource group for information and referral information (Wisniewski et al., 2003). At the other three sites, the control condition was a minimal support condition, which involved providing information and some emotional support to caregivers. The control conditions differed due to different financial resources, ethical obligations and recruitment/retention obligations at the various sites. The stress-health process applied to dementia caregiving was the theoretical model that guided the interventions and evaluations of the REACH study. Because the interventions are not the focus of the present study, the types of interventions will not be elaborated here. For a detailed introduction to the interventions tested, see Wisniewski and colleagues, (2003). Caregiver-care recipient dyads of different racial and ethnic minorities (e.g., African American and Hispanic) were actively sought for inclusion in the study (Schulz, Belle et al., 2003).

### *Participants.*

All participants in the present study were enrolled in the REACH project. Participants were family caregivers of individuals with dementia. They were recruited from memory disorder clinics, primary care clinics, social service agencies, and physician's offices (Wisniewski et al., 2003). In efforts to enrol diverse participants, there were outreach efforts in the community, including radio, television, targeted newsletters, public service announcements, and community presentations (Wisniewski et al., 2003). The researchers at each site tailored their recruitment strategies to their particular needs and circumstances, hence the precise recruitment strategy varied by site. For example, in order to capture Hispanic caregivers in Miami, researchers advertised specifically on Hispanic radio stations.

Caregivers were defined as family members of at least 21 years of age who lived with the care recipient, who had provided care for at least six months, and provided at least four hours of care each day. To qualify for the study, the care recipients had to have at least two impairments of the instrumental activities of daily living (IADLs) or one impairment of an activity of daily living (ADLs) and a medical diagnosis of probable A.D. or cognitive impairment as defined as a Mini-Mental Status Examination (MMSE) score of 23 or less. There were also logistical inclusion criteria. These included having a telephone, planning to remain in the geographical area for at least 6 months, and competency in the languages specified by each study site (i.e., either English or Spanish) (Wisniewski et al., 2003).

If the caregiver or care recipient was terminally ill, if the caregiver was involved in another clinical trial for caregivers, or were planning to institutionalize the care received within six months, the dyad was excluded from the study. All caregiver-care recipient dyads were screened over the telephone using a screening interview to ensure the dyad met the inclusion criteria outlined above. If the dyad met the inclusion criteria, they were invited to participate in the study. If consent was obtained, the REACH core measures (see Appendix A) were administered by interview to all caregivers at the baseline assessment. Data were collected on 1229 caregiver/care recipient dyads between September 1996 and March 2000, and the data from this sample of dyads will be utilized for the analyses in the present study. After baseline, three follow-up assessments took place 6 months, 12 months and 18 months following the baseline assessment. If dyads dropped out of the study, efforts were made to determine the reason. If a care recipient died during the course of the study, instruments were administered regarding bereavement and related issues.

### *Instruments*

After the screening interview, which was conducted over the telephone, all assessments were conducted in person. Standard measures, modified measures and new measures were utilized. Standard measures include Activities of Daily Living, Instrumental Activities of Daily Living, Revised Memory and Behaviour Checklist, and the Centre for Epidemiologic Studies-Depression. Modified measures include Caregiver Health and Health Behaviours, Anxiety Inventory, and Social Support. They were modified from their original form by means of changing the response scale and/or eliminating or adding items. The new measures specifically designed for the REACH project were the Positive Aspects of Caregiving Scale, Vigilance, Formal Care and Services, Religiosity, and Social Activities (Wisniewski et al., 2003). (See Appendix A). All intervention materials and assessment instruments were originally developed in English, and translated into Spanish for the Hispanic participants.

*Activities of daily living/Instrumental activities of daily living.*

The standard ADL measure (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and instrumental ADL measure (Lawton & Brody, 1969) have been combined into a single measure for REACH. Research demonstrates that it is appropriate to combine these two measures (Spector & Fleishman, 1998). Spector and Fleishman (1998) found that the resulting measure was unidimensional, and that a simple sum of item responses could be used to create a measure of functional disability. They argued that using both ADLs and IADLs in one measure was beneficial, because it allowed for a broader range of disability measurement.

Items a) to i) represent the IADL items, while j) to p) represent the ADL items. The IADL items included asking whether or not the caregiver had provided help in a certain area (e.g., shopping, handling finances) and if so, how much helping bothered or upset the caregiver (Response for the bother/upset items ranged from 0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely). Lawton and Brody (1969) found that interrater reliability for this measure was high; the lowest correlation was *r* = .85 while the highest correlation was *r* = .91, depending on the raters. The IADL measure also demonstrated convergent validity, as there were moderate correlations between the IADL measure and other related measures of competence (e.g., physical self-maintenance scale, mental status questionnaire). In the current database, the Chronbach's alpha was .70 (N = 1205).

For the ADL items, the caregiver was asked whether he/she helped in a certain area (e.g., toileting, bathing), and if yes, how often they helped with this task in the past week, how much time they spent doing that task in the past week, how bothered or upset they were by providing that help, and how confident they felt about helping the care recipient in that area. The responses for the confidence item were as follows: 1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident. The original intent that Katz and colleagues (1963) had when developing this scale was to be able to classify disabled people into one of 8 groups, which they referred to as a "grade". These grades ranged from A-G, depending on the assessed person's level of dependence or independence with the tasks on the ADL measure. In their study of 1001 participants, 96% of them could be classified by the ADL measure, and they deemed the classifications valid, in that they followed a logical ordered pattern of impairment (Katz et al., 1963). Katz and colleagues (1963) did not conduct any analyses of the reliability of this measure, which would have been helpful to assess the measure psychometrically. In the current database, the Chronbach's alpha was .86 (N = 1205).

*Revised memory and behaviour checklist.*

This measure is a revision of Zarit's original Memory and Behaviour Checklist with 26 items within three factors (depression, disruption, and memory related problems). Caregivers are asked whether each of the behaviours has occurred in the past week, and if so, how much it bothers or upsets the caregiver, on a 5 point scale (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely). Scores on this measure can range from 0 to 104. When this scale was developed, the internal consistency of each of the factors and the total were acceptable (i.e., depression alpha = .89, disruption alpha = .89, memory alpha = .88, total alpha = .90) (Teri et al., 1992). Discriminant and convergent validity of the depression and memory factors were confirmed, but it was not possible to assess this in the disruption scale, as the authors could not find any similar existing measures.

*Centre for epidemiological studies-Depression scale.*

"The CES-D is a short self-report scale designed to measure depressive symptomatology in the general population" (Radloff, 1977). The intent of this measure is not to diagnose depression, but instead to indicate the presence and frequency of depressive symptoms. There are 20 items on the scale, and each is scored on frequency (i.e., "How often this past week did you...") with responses ranging from zero to three (i.e., 0 = Rarely or none of the time [< 1 day], 1 = some or a little of the time [1-2 days], 2 = occasionally or moderate amount of time [3-4 days], 3 = Most or almost all of the time [5-7 days]). Therefore, the range of possible scores is 0-60, with higher scores indicating more depressive symptoms experienced more often in the past week. The standard cut-off score for the CES-D is 16+; if a person scores at this level, they can be considered at risk for depression. This measure underwent rigorous psychometric analyses to confirm the reliability and validity. There were numerous field tests of the CES-D with varied populations, including both general and psychiatric patient populations (Radloff, 1977). The internal consistency was high in the general population (*r* = .85), and even higher in the patient population (*r* = .90) (Radloff, 1977). In the current database, the Chronbach's alpha was .73 (N = 1205). Test-retest reliability varied by time interval; after two weeks, *r* =.51, but after four weeks, *r* =.67 for those who mailed back their follow-up questionnaires. For those participants who were re-interviewed, after three months, *r* = .48, and after 6 months, *r* = .54 (Radloff, 1977). Convergent validity was demonstrated with moderate (*r* = .44-.54 at admission to a psychiatric facility), and high (*r* = .69-.75 after four weeks of treatment) correlations with the Hamilton Depression Rating Scale (Radloff, 1977). Discriminant validity was evidenced by a negative correlation with the Bradburn Positive Affect Scale, and other measures of different variables (e.g., social functioning, aggression) (Radloff, 1977). Generally, with few exceptions, the results found for the total sample were confirmed for various subgroups (e.g., gender, race, age, education level), and therefore Radloff (1977) deemed that this measure would be acceptable for use with the general population.

### *Caregiver health and health behaviours*

This measure was revised from the Nutrition Screening Initiative checklist (Posner, Jette, Smith, & Miller, 1993). There are five main items, the first two tapping into perceived health, the third asks about diagnoses of various physical illnesses, the fourth about the recent occurrence of various symptoms, and the fifth about certain health behaviours. The health behaviours tapped in item 5 are a selection of the items from the nutrition checklist, as are some of the items regarding caregivers' perceived health. The remainder of the items were selected for the REACH study. Posner and colleagues (1993) did not conduct a psychometric analysis of their version of the checklist, and even if they had, this analysis would not apply to the present version, as it differs greatly from the original. To date, there have been no psychometric analyses of this version of the measure.

For the purposes of this study, these five items were broken into two scales. Self-rated health added each rating on the items: 1) In general, would you say your health is poor (1), fair (2), good (3), very good (4), excellent (5)" 2) How true or false are each of the following statements for you? (1 = definitely false, 2 = mostly false, 3 = neither false nor true, 4 = mostly true, 5 – definitely true) a) I seem to get sick a little easier than other people (reverse scored) b) I am as healthy as anybody I know c) I expect my health to get worse (reverse scored). Therefore, higher scores on this scale indicate better self-rated health. The Chronbach's alpha reliability coefficient was .72 (N=1205).

The number of illness diagnoses was determined by adding the number of yes responses to the question "Do you currently have, or has a doctor told you that you have, any of the following health problems? (Arthritis, high blood pressure, heart condition, chronic lung disease, diabetes, cancer, stroke). The Chronbach's alpha reliability coefficient was .43 (N =1205).

*Anxiety inventory.*

The Anxiety Inventory is modified from the State-Trait Anxiety Inventory. The original measure has 40 items; 20 items on the State Anxiety scale (which attempts to capture how anxious a person is within a particular immediate timeframe) and 20 items on the Trait Anxiety scale (which attempts to capture how anxious a person is generally)(Spielberger, 1983). The 10 items asked for the REACH project are half of the items from the State measure. The response scale was the same as the original measure. Participants indicated their level of agreement with each statement (e.g., I felt tense, I felt frightened) according to how they felt in the past week; 1 = not at all, 2 = somewhat, 3 = moderately, 4 = very much. Therefore, scores can range from 10-40.

Spielberger (1983) found that the internal consistency of the state anxiety scale was .90 when given to adults aged 50 to 69 years. In addition, the state anxiety scale was found to have adequate validity in a study conducted by Spielberger in which participants who were told to complete the measure as if they were about to write a final exam had higher scores on the state anxiety scale than those asked to complete the measure under normal conditions. However, these psychometric analyses should be viewed with caution in this context, as they apply to the full, 20-item scale, and not the modified, 10-item scale used for the REACH project. There are no psychometric analyses of this 10-item scale available. In the current database, the Chronbach's alpha was .89 (N = 1205).

*Social support.*

This measure attempts to capture three domains of social support: social networks of the caregiver (9 items, e.g., how many relatives do you see or hear from once a month?), received social support and satisfaction (14 items e.g., how often has someone provided transportation for you in the past month?) negative interactions (4 items e.g., how often in the past month has someone taken advantage of you?). Responses to the items vary according to the question, for example, many questions will ask the caregiver how often something occurred in the last month, and therefore, the responses vary from 0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often. Other types of items ask how satisfied caregivers were with certain aspects of social support, and in these items, the response choices were 0 = Not at all, 1 = a little, 2 = moderately, 3 = very. The authors of this scale conceptualized social support to include both tangible forms of assistance (e.g., provision of goods and services) and the intangible forms of assistance (e.g., guidance) (Barrera, Sandler, & Ramsay, 1981). The development of potential scale items was guided by three main principles: to emphasize behavioural specificity in items to reduce subjectivity, to write items that applied broadly, not just to a particular population, and explicit references to psychological adjustment were omitted from the scale. Barrera, Sandler and Ramsay (1981) tested the test-retest reliability by asking college students to complete the scale twice, with two days separating the two administrations. Test-retest correlations for individual items ranged from a low of .441 to a high of .912. Total scores had a test-retest correlation of .882. Barrera, Sandler and Ramsay found that the internal consistency of the scale was determined to be .926 and .940 respectively for the first and second administrations. Convergent validity was demonstrated with positive correlations with other social support network indices and perceived family support indices. In the current database, the Chronbach's alpha for the overall scale was .86 (N = 1087). For the social network total, the Chronbach's alpha was .75 (N = 1087). For the received support and satisfaction scale, the Chronbach's alpha was .86 (N = 1205). Finally, for the negative interaction scale, the Chronbach's alpha was .82 (N = 1205).

*Positive aspects of caregiving.*

This scale includes 9 items, each measured on a 5-point Likert scale ranging from 'disagree a lot' to 'agree a lot'. Factor analysis revealed two factors: self-affirmation (with 6 items loading on this factor) and outlook on life (with the remaining 3 items loading on this factor)(Tarlow et al., 2004). (See Appendix A for items and loadings).

Tarlow and colleagues (2004) examined the psychometrics of this scale and found that the internal consistency for the self-affirmation factor was .86, and the outlook on life factor had an internal consistency of .80. The correlation of .69 between the two components spoke in favour of creating a summary score from all nine items. The Chronbach's alpha for the whole scale equaled .89.Tarlow and colleagues (2004) concluded that the Positive Aspects of Caregiving Scale demonstrated face validity, as the items were derived from earlier conceptualizations of the positive aspects of caregiving, such as Lawton and colleagues (1989). They also examined convergent and discriminant validity, finding that the caregivers' scores on the PACS were positively associated with their level of well-being ($r$ = .24), and satisfaction with received social support ($r$ = .15), but negatively associated with the amount of burden they experienced as caregivers ($r$ = -.23). They found that all of the relationships were in the anticipated directions, although smaller in magnitude than expected. Despite the smaller magnitude, Tarlow and colleagues (2004) felt that convergent and discriminant validity was confirmed through these analyses.

*Vigilance.*

This measure includes 4 items that attempt to capture the extent to which caregivers experience a feeling of vigilance toward the care recipient. The items ask the caregiver whether and if so, how much, the care recipient can be left at home alone, how much the caregiver feels "on duty" even when not directly providing care to the care recipient. This measure was one of the new measures created for the REACH project. The concept of caregiver vigilance came out of a qualitative study of family caregivers who described a need to "be there", meaning that caregivers felt that their presence with the care recipient was important to ensure safety (Mahoney et al., 2003). Mahoney and colleagues (2003) confirmed that the vigilance items were unidimensional through factor analyses, and found that the Chronbach's alpha reliability coefficient was .66. They argue that this internal consistency is adequate because this measure is in its initial stages of development. To interpret the scale, Mahoney and colleagues (2003) developed a standardized summary scale, with T-scores with a mean of 50 and a standard deviation of 10. The authors attempted to determine the validity of the scale by correlating it with standard measures such as Mini-Mental Status Exam (MMSE) scores, and Revised Memory and Behavior Problems Checklist (RMBPC) (Mahoney et al., 2003). They found that vigilance and impairment were correlated ($r = -.34, p < .001$) meaning that the greater the cognitive impairment (i.e., the lower the MMSE score), the greater the scaled vigilance(Mahoney et al., 2003). Mahoney and colleagues (2003) stated that divergent validity was supported by the weak correlation ($r = .15, p < .001$) of vigilance with the RMBPC, because this indicated that vigilance measured a different construct that the memory and behaviour problem checklist does.

*Formal care and services.*

The purpose of this measure is to capture the formal service use of the caregiver or care recipient. There are 22 items, each asking about a different type of service (e.g., homemaking, meal delivery, hospital/physician visits, day programs, counselling) and how often that service has been utilized in the last month. To date there have been no studies indicating the psychometric properties of this scale. Based on the data from the current study, the Chronbach's alpha reliability coefficient for Time 1 was .57 (N =1205), for Time 2, alpha was .55 (N =874), for Time 3, alpha was .52 (N =680), and for Time 4, alpha was .54 (N =579).

*Religiosity.*

This is a five-item measure that attempts to determine the extent to which religion, faith or spirituality plays a role in the caregivers life. To date there have been no studies indicating the psychometric properties of this scale. Based on the data used in this study, the Chronbach's alpha reliability coefficient was 83 (N =1205). This measure was taken only at the first interview.

*Social activities.*

The purpose of this measure is to tap into the caregivers' satisfaction with the amount of time he/she has been able to spend in 7 different types of activities (e.g., hobbies, quiet time by self) in the past month. Satisfaction is rated on a 3-point scale (1 = not at all, 2 = a little, 3 = a lot). Therefore, the range of scores for this measure is 1 to 21. To date, there have been no studies indicating the psychometric properties of this scale.

If the caregiver's status changed (e.g., care-recipient's institutionalization or death), the battery of instruments was modified to reflect the changed status of the caregiver; items that are irrelevant in light of the changed status are removed (e.g., how many hours a day the caregiver spends caring for a care recipient who is deceased), while other scales appropriate to the situation were added (e.g., bereavement measures).

### *Data*

The datasets from the REACH project were made available for further analyses through the Interuniversity Consortium for Political and Social Research, at the University of Michigan, in Ann Arbor. Michigan (Schulz, 2001). These data are public domain and can be downloaded from the consortium's website, http://www.icpsr.umich.edu/ in either SPSS or SAS formats.

## *The Canadian Study of Health and Aging (CSHA)*

### *Overview*

The Canadian Study of Health and Aging (CSHA) began in 1989 with the following objectives:

1) To estimate the prevalence of dementia among elderly Canadians;
2) To identify risk factors for A.D. and for vascular dementia;
3) To describe patterns of caring for patients with dementia in Canada and to assess the burden that caring places on the caregivers;
4) To establish a database for subsequent follow-up studies (1994b).

Eighteen centres in five regions of Canada agreed to participate in developing and implementing the study (1994b). Through the discussions of various working groups, it was determined that it would be beneficial if the study included a range of health issues concerning the elderly population. Therefore, the screening interview included questions about general health problems, presence of specific disorder and limitations in performing activities of daily living (1994b).

### *Participants*

Randomly selected groups of people aged 65 years and older were recruited from the community for screening. Those who were identified by the screening interview as having cognitive impairment were included in the study. Also, a randomly selected group of those who were screened to be negative for cognitive impairment were asked to undergo a clinical assessment to determine whether dementia was present, and if so, to determine a diagnosis. Control groups were drawn from those who were found to be cognitively normal after clinical examination (1994b). In order to study caregiving, the caregivers of the participants with dementia were included in the study, as were a control group of caregivers of people without cognitive impairment.

Certain factors excluded potential participants from the CSHA. Those with a life-threatening illness (e.g., a condition necessitating life support or terminal cancer) were excluded from the study. Those unable to complete the screening due to conditions such as deafness, stroke, mental retardation or current illness were excluded in the clinical examination. Participants had to be fluent in either French or English. To be eligible for the community sample, participants had to be living at home during the recruitment phase of the study(1994b).

For the community sample, representative samples were drawn from 36 cities and their surrounding rural areas. These areas included about 60% of Canadians aged 65 and over. Computer procedures were utilized to randomly select people in the following age groups; 65-74, 75-84, and 85 and over. An optimal allocation procedure was utilized to oversample the older groups, so that there were twice as many people in the 75-84 group as the 65-74 group, and there were 2.5 times as many in the 85 and over group than the 65-74 group (1994b).

The institutional sample was drawn from nursing homes, chronic care facilities, and collective dwellings such as convents. Institutions were stratified into small (up to 25 beds for those 65 years and older), medium (26-100 beds), and large (100+ beds), and then a stratified sample of 17 institutions was randomly selected in each region. Once the institutions were selected, residents of these institutions were randomly selected (1994b). Target samples in each region included 1800 participants from the community and 250 participants from institutions.

### *Instruments*

Some of the measures used for the CSHA study were well established measures (e.g., Dementia Behaviour Disturbance Scale, Zarit Burden Interview, Centre for Epidemiologic Studies Depression scale, SF-12), while others were created specifically for CSHA (e.g., a service use measure to capture the use of nine different community support services (e.g., by whom was the service provided, who paid for the service, caregiver satisfaction with the service, or why the service was not used), positive aspects of caregiving, and a measure asking caregivers whether they had plans to admit the care recipient into an institution). The following is more detail on the measures used in the Canadian Study of Health and Aging caregiver questionnaire.

#### *Demographics.*

Twelve items regarding demographic information about the care recipient (e.g., gender, date of birth), and caregiver (e.g., relationship to care recipient, ethnicity, education level).

*Social situation.*

This measure had 9 items getting at the living arrangements of the caregiver and care recipient. For instance, whether they lived together, how many other people lived with them, how many friends and relatives lived within an hour drive et cetera.

*Caregiver employment.*

These items captured whether the caregiver was participating in paid work outside the home or not, and if they were, whether they had had to make certain accommodations to their work due to their caregiving duties (e.g., alter hours worked, miss work).

*Activities of daily living.*

This 14 item ADL measure was developed as the self care capacity domain for the Multidimensional Functional Assessment Questionnaire for the Older Americans Resources and Services project (Fillenbaum & Smyer, 1981). The first seven items represent activities of daily living, while the last seven items represent instrumental activities of daily living. Caregivers are asked whether the care recipient can manage these 14 tasks without help (= 1), or with some help (= 2), whether he/she cannot do it all (= 0), that is, someone has to do it for them. If the care recipient has someone help or do it for him/her, these items are followed up with questions about who helped the care recipient, the relationship of the helper to the care recipient, how often the helper helps, and how long helping takes. Fillenbaum and Smyer (1981) found that the Spearman's rank order correlation was acceptable ($r = .89, p >,001$), indicating that there was a high level of agreement between raters on the self-capacity measure.

*Care management.*

These two items captured whether the care recipient could be left unsupervised for any period of time, either with someone in the house (but not the same room), or when no one else was home. If the care recipient could not be left unsupervised in either type of situation, the caregiver was asked who had provided supervision to the care recipient in the past month, and how much time they spent supervising.

*Care recipient service use.*

This collection of items was intended to understand the external resources (i.e., services) that the care recipient utilized. Eleven types of services were inquired about, (e.g., respite care, day centres/hospitals, physiotherapy, homemakers, et cetera). If the caregiver indicated that the care recipient utilized each service, a number of follow-up questions were asked: how many times did they use that service in the past year, who provides the service (e.g., government, church), whether there was a wait list to receive service, and if so, how long the wait list was, whether the service was provided by the same individual each time (e.g., the same person doing homemaking duties rather than different employees of the same agency), whether the service was reliable, the extent to which the service met the family's needs, and satisfaction with the quantity and quality of help received. If the caregiver indicated that the service had not been used in the past year, they were asked if the service had ever been used. The caregiver was also asked whether he/she was aware that the service existed. This scale was created for the purposes of the CSHA study, and no psychometric analyses have been conducted to date.

*Caregiver service use.*

These items inquire about whether caregivers are using certain services (e.g., social work/psychology/clergy/self help groups), whether caregivers have incurred added expenses as a result of caregiving, whether caregivers feel that any of the services they are not currently using would be helpful, and a set of items regarding the living accommodation of the caregiver (e.g., number of rooms in home, whether repairs are needed, the overall adequacy of the accommodation). Like the care recipient service use items, this scale was created for the CSHA study and therefore, no psychometric analyses have been conducted to date.

*Dementia behaviour disturbance scale.*

This measure was designed to measure the "outward manifestation of some underlying cognitive, psychological, or physiological deficit-regardless of etiology-likely to cause stress to those caring for the patient" (Baumgarten, Becker, & Gauthier, 1990). The measure assesses 28 behaviours. The caregiver is asked whether the care recipient generally (i.e., in the past week) displays these behaviours, and if yes, the frequency with which he/she displays them (i.e., never, rarely, sometimes, frequently, all of the time). The internal consistency of this scale is adequate, at .83 (Baumgarten et al., 1990). In the current study, Chronbach's alpha was found to be .86 (N = 825).

Analyses of test-retest reliability demonstrate that with two weeks between baseline and second interview, the Pearson correlation between the scores was $r = .71$ (Baumgarten et al., 1990). Baumgarten, Becker and Gauthier (1990) also made efforts to evaluate the construct validity of this measure. First, they determined the correlation between the scores on the DBD scale with scores on Greene's Behavior and Mood Disturbance Scale, finding a positive correlation of .73. Secondly, they determined correlations between DBD scores and other variables expected to be associated with behaviour disturbance. The authors found that higher DBD scores were associated with longer duration of disease, and more cognitive and functional impairment, as expected (Baumgarten et al., 1990). Hence, the DBD has been found to have adequate reliability and construct validity.

*Zarit burden interview.*

CSHA uses the 22-item version of the ZBI (Zarit, Orr, & Zarit, 1985), shortened from the original 29 items version (Zarit et al., 1980). The 22 item version is the most consistently used version in dementia caregiving research (Bédard et al., 2000). Each item is rated on frequency of occurrence from never (0) to nearly always (4). Hence, scores can range from 0 to 88. The creators of the scale suggest the following interpretation of ZBI scores: between 61 and 88 equals severe burden, scores between 41 and 60 equals moderate to severe burden, scores between 21 and 40 equals mild burden, and scores below 21 would mean little or no burden (Zarit & Zarit, 1987). However, Hebert, Bravo and Preville (1994) argue that Zarit's suggestions are arbitrary, and that using quartile scores to suggest cut-offs is more valid, leading to the following categories: scores from 0 to 8 suggesting low burden, 9 to 17 suggesting moderate burden, 18 to 32 high burden, and 33 and up suggesting severe burden. The ZBI has been found to be reliable. The internal consistency of the ZBI is high, at 0.92, and the split-half correlation coefficient was 0.90 (Hebert et al., 1994). In the current study, Chronbach's alpha is .90 (N = 1054).

*Centre for epidemiological studies Depression scale.*

Please see the description of this scale in the REACH section. In the CSHA database, the Chronbach's alpha was .88 (N = 1426).

*Positive aspects of caregiving.*

This was a first attempt to capture any positive aspects of caregiving in a major study, with the intent to develop a measure from the responses to these items. The first item simply asked whether caregivers experienced any positive aspects of caregiving, and if so, if they could tell the interviewer what they were. The second item involved showing the caregivers a card with various simple faces (e.g., a happy face) to help them describe how they feel about caring for the care recipient. No psychometric information is available on this form of the positive aspects measure.

There were 11 items tapping into the positive appraisal of caregiving. The first 10 items asked about whether the caregiver experienced certain positive aspects (e.g., finding caregiving fulfilling/rewarding). These aspects were coded from the responses to the first item: Do you find any positive aspects of caregiving and if yes, could you briefly tell me what some of these are? If participants said yes to any of these 10 items, they received a score of 1, and if they said no, they were scored as 2. For the 11th item, participants were asked, overall, how do you feel about caring for (CR)? There was a 7-point Likert type scale for this item (1-7), with lower scores indicating a more positive appraisal of caregiving. (For any participants who refused to respond, skipped an item, etc., were coded as 0). Hence, scores on this measure could range from 0 to 27, with lower scores indicating a more positive appraisal of the caregiving situation. Scores actually ranged from 0 to 24 in this sample, with a mean of 4.3 and a standard deviation of 7.9. To ensure that it was appropriate to add these items in this fashion, the internal consistency of the positive appraisal scale was computed. The internal consistency of this measure had an alpha of .985, which is considered acceptable.

*Institutional admission.*

This measure had 4 items, each with a yes or no response. They attempt to capture whether the caregiver has thought about or made plans to admit the care recipient into a nursing home or institution.

*SF-12.*

The SF-12 (Short Form Health Survey) is a shorter version of the well-established SF-36. This measure offers a summary score for physical components of health (e.g., ability to do moderate and vigorous activities, the extent to which pain interferes with functioning), and a summary score for mental or emotional components of health (e.g., social functioning, feeling blue or sad) (Ware, Kosinski, & Keller, 1996). Items that best predicted the physical component and mental component were selected for the shorter form. The survey was shortened to facilitate use in large-scale health studies, like the CSHA. Ware, Kosinski and Keller (1996) found that the 12 selected items yielded a multiple $R^2$ of 0.911 in the prediction of the physical component summary of the SF-36, and a multiple $R^2$ of .918 in the prediction of the mental component summary of the SF-36. The two summary scores of the SF-12 has been found to be reliable; with a retest 2 weeks after baseline, $r = 0.890$ in the United States, and $r = 0.864$ in the United Kingdom. The construct validity of the measure was determined through a known-groups method, in which the summary scores were tested to see whether they could discriminate between four groups known to differ in physical or mental health. These analyses resulted in relative validity estimates of 0.43 to 0.93 (median = 0.67) for the physical component summary, and relative validity estimates for 0.60 to 1.07 (median = 0.97) for the mental component summary.

#### *Additional health measures.*

These items ask the caregiver about other aspects of health. The first set of items inquires about 22 possible health diagnoses or problems they may have experienced in the past year (e.g., stroke, broken bones, diabetes, vision problems). The next set of items attempts to capture the caregivers' self-perceived health. While the last few items ask about whether the caregiver has attended the physician, the emergency room, or been admitted to hospital in the past few months. As this measure was created for the CSHA project, there are no available psychometric analyses.

### *Data*

The datasets for the CSHA project are available for secondary analysis by request from the Canadian Study of Health and Aging website, http://csha.ca/default.asp.

## Results

### *Hypothesis A*

*Positive and negative appraisals will be found to be two distinct constructs, not one construct along a single bipolar continuum.*

For the REACH data, Pearson product moment correlations coefficients were computed between the Positive Aspects of Caregiving Scale and a negative appraisal scale comprised of the "bother" items on the ADL and memory and behaviour measures (e.g., How much does helping with X bother you? How bothered or upset were you by X behaviour?). Each of the 43 items is measured on a five-point scale ranging from 0 (meaning not at all) to 4 (extremely), hence scores on this scale can range from 0 to 172, with higher scores indicating a more negative appraisal of the caregiving situation, (i.e. the caregiver is more bothered or upset by the care recipient's behaviours or helping with activities of daily living).

The negative appraisal measure was taken at each of the 4 interviews conducted within the REACH study, so four separate totals were computed. The means, standard deviations, and minimum and maximum scores of this scale can be found in Table 1. To ensure that it was appropriate to add these items in this fashion, the internal consistency of this negative appraisal scale was computed. The internal consistency of the scale at each time point can also be found in Table 1. The internal consistencies ranged from 0.89 to 0.91, which is in the acceptable range.

The Positive Aspects of Caregiving Scale is a 9 item measure that has demonstrated strong psychometric properties in the context of a large, multi-site study (Tarlow et al., 2004). (See above for more detailed psychometric information). In this scale, possible scores can range from 9 to 45, with higher scores indicating a more positive appraisal of the caregiving situation. See Table 2 for the means, standard deviations, minimum and maximum values at each interview.

At each interview, the correlation between the Positive Aspects of Caregiving Scale, and the negative appraisal scale was found to be significantly negative; Time 1, $r$ (783) = -0.237, $p$ <.0.01, Time 2, $r$ (873) = -0.198, $p$ <.0.01, Time 3, $r$ (679) = -0.161, $p$ <.0.01, Time 4, $r$ (575) = -0.204, $p$ <.0.01. Because the correlations were negative, it would appear that these results do not support the hypothesis that positive and negative appraisals are two distinct constructs, since these results suggest that those who appraised the caregiving situation very positively, had lower negative appraisal scores, and those who appraised their caregiving situation very negatively, had lower positive appraisal scores, suggesting that in fact, these two types of appraisal are on a single bipolar continuum. However, if one examines the magnitude of the correlations, they are very small, suggesting a very weak correlation between the caregivers' positive and negative appraisals of their situations. The reason that these correlations are statistically significant, despite the fact that they are in fact, quite weak, can be attributed to the large sample size of the REACH study. Hence, these results can be interpreted as supporting the hypothesis that the positive and negative appraisals are two distinct constructs.

Further evidence for this hypothesis was sought using hierarchical regression analyses to determine which variables predict negative and positive appraisal, and whether these two constructs had any predictors in common. If different variables predict each type of appraisal, it is arguable that these two constructs are in fact distinct. In each of these analyses, various demographic and baseline information was entered in the first step; age of caregiver, gender of caregiver, age of care recipient, gender of care recipient, interaction of gender of caregiver and care recipient, care recipient variables were entered in the next step; level of cognitive impairment of the care recipient, ADL impairment of care recipient, memory/behaviour problems of care recipient (including 3 separate factor scores for depression, disruption and memory problems), and the amount

Table 1

*Means, Standard Deviations, Minimum and Maximum Values, and Internal Consistencies of Negative Appraisal Scale (REACH) at Each Interview*

| Time | *N* | Minimum | Maximum | *M* | *SD* | Alpha |
|---|---|---|---|---|---|---|
| 1 | 784 | 0 | 108 | 22.4 | 18.2 | .89 |
| 2 | 874 | 0 | 103 | 19.7 | 17.5 | .91 |
| 3 | 680 | 0 | 105 | 18.2 | 16.7 | .90 |
| 4 | 579 | 0 | 107 | 17.7 | 17.3 | .91 |

of social support and formal support caregivers received were entered at the third and final step.

The result of the analysis of the REACH data indicate that the demographic, care recipient impairment and support variables did account for a significant amount of the variability in negative appraisal, $R^2 = .551$, $F(6, 768) = 49.427$, $p < .001$., indicating that the older the caregiver, $t(1193) = .149$, $p = .003$, the younger the care recipient, $t(1193) = -.108$, $p = .037$, the greater the care recipients' cognitive impairment, $t(1205) = .261$, $p < .001$, the greater assistance required for instrumental activities of daily living, $t(1205) = 1.164$, $p < .001$, the greater the amount of depressive behaviours of the care recipient, $t(1205) = 2.647$, $p < .001$, the greater the amount of disruptive behaviours of the care recipient, $t(1205) = 4.302$, $p < .001$, the greater the amount of memory problems of the care recipient, $t(1205) = 1.20$, $p < .001$, the smaller the caregiver's social network, $t(1205) = -.209$, $p = .006$, the more negative social interactions the caregiver experiences, $t(1205) = .431$, $p = .014$, and the fewer formal services utilized by the caregiver, the more negative the caregivers' appraisal of his/her situation. See Table 3 for coefficients and significance values.

The result of the analysis of the REACH data indicate that the demographic, care recipient impairment and support variables did account for a significant amount of the variability in positive appraisal, $R^2 = .091$, $F(6, 1185) = 7.344$, $p < .001$, indicating that the less cognitive impairment of the care recipient, $t(1193) = -.096$, $p = .013$, the fewer disruptive behaviours of the care recipient, $t(1204) = -.503$, $p < .001$, the larger the caregiver's social network, $t(1205) = .090$, $p = .027$, and the greater satisfaction of the caregiver with the support he/she receives from his/her social network, $t(1205) =$

.170, $p < .001$, and the fewer formal supports the caregiver utilizes, the more positive the caregivers' appraisal of his/her situation. See Table 4 for coefficients and significance values. Finally, to confirm that these separate constructs exist, analyses were run to determine whether each of the four combinations of appraisal, (i.e., high burden and high gain, low burden and high gain, high burden and low gain, low burden and low gain), exist in these data. The median for each variable was determined; 35 for Positive Appraisal (the Positive Aspects of Appraisal Scale) and 19 for Negative Appraisal (as described above in Hypothesis A). Then any appraisal greater than or equal to the median was considered "high", while any appraisal below its respective median was considered "low". This analysis confirms that each type of combination does exist in the REACH data. Therefore, some caregivers do appraise their situation as highly positive and highly negative, while other caregivers appraise their situations not very positively and not very negatively, and still others appraise one type of appraisal highly and appraise the other as low. If these were not separate and distinct constructs, this pattern could not be found. Interestingly, although the distribution between the four combinations is relatively equal, the largest number of caregivers reported high gain and low burden (30.9%), while the smallest number of caregivers reported both low burden and low gain (18.4%). See Table 7.

For the CSHA data, Pearson product moment correlation coefficients were computed between the sum of the positive appraisal items that were asked in the second phase of the CSHA, and the corresponding Zarit Burden Interview total score. There were 11 items tapping into the positive appraisal of caregiving. The first 10 items asked about whether the caregiver experienced certain positive aspects (e.g., finding

Table 2

*Means, Standard Deviations, Minimum and Maximum Values of Positive Appraisal of Caregiving Scale (REACH) at Each Interview*

| Time | *N* | Minimum | Maximum | *M* | *SD* |
|---|---|---|---|---|---|
| 1 | 1205 | 9 | 45 | 33.9 | 8.99 |
| 2 | 874 | 9 | 45 | 34.7 | 8.90 |
| 3 | 680 | 9 | 45 | 34.7 | 8.90 |
| 4 | 577 | 9 | 45 | 35.0 | 8.56 |

caregiving fulfilling/rewarding). These aspects were coded from the responses to the first item: Do you find any positive aspects of caregiving and if yes, could you briefly tell me what some of these are? If participants said yes to any of these 10 items, they received a score of 1, and if they said no, they were scored as 2. For the 11th item, participants were asked, overall, how do you feel about caring for (CR)? There was a 7-point Likert type scale for this item (1-7), with lower scores indicating a more positive appraisal of caregiving. (For any participants who refused to respond, skipped an item, etc., were coded as 0). Hence, scores on this measure could range from 0 to 27, with lower scores indicating a more positive appraisal of the caregiving situation. Scores actually ranged from 0 to 24 in this sample, with a mean of 4.3 and a standard deviation of 7.9. To ensure that it was appropriate to add these items in this fashion, the internal consistency of the positive appraisal scale was computed. The internal consistency of this measure had an alpha of .985, which is considered acceptable. The CSHA uses the 22-item version of the ZBI (Zarit et al., 1985), shortened from the original 29 items version (Zarit et al., 1980). The 22 item version is the most consistently used version in dementia caregiving research (Bédard et al., 2000). Each item is rated on frequency of occurrence from never (0) to nearly always (4). Hence, scores can range from 0 to 88. The internal consistency of the ZBI is high, at 0.92, and the split-half correlation coefficient was 0.90 (Hebert et al., 1994). In this sample at CSHA-2, ZBI total scores ranged from 0 to 64, with a mean of 12.42 and a standard deviation of 12.16.

Table 3

*Hierarchical Regression Model for Negative Appraisal (REACH)*

| Group | Variable | Coefficient [1] | *p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing Variables | CG[2] Age | .149 | .003 | | |
| | CR[3] Age | -.108 | .037 | | |
| | CG Sex | ----- | .884 | | |
| | CR Sex | ----- | .341 | | |
| | CG-CR Sex | ----- | .611 | | |
| | Kinship | ----- | .371 | | |
| | | | | .003 | .201 |
| CR Impairment | Cognitive Imp [4.] | .261 | .001 | | |
| | IADL Imp. [4] | 1.640 | .005 | | |
| | ADL Imp. [4.] | ----- | .448 | | |
| | Mem./Bhvr[5] Dep.[6] | 2.647 | .001 | | |
| | Mem./Bhvr^ Dis[7] | 4.302 | .001 | | |
| | Mem./Bhvr^ Mem.[8] | 1.200 | .001 | | |
| | | | | .490 | .001 |
| External Variables | Social Network | -.209 | .006 | | |
| | Rec'd Support [9] | ----- | .114 | | |
| | Negative Interaction | .431 | .014 | | |
| | Formal Support | -.048 | .013 | | |
| | | | | .551 | .001 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

Table 4

*Hierarchical Regression Model for Positive Appraisal (REACH)*

| Group | Variable | Coefficient [1] | *p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing Variables | CG[2] Age | ----- | .394 | | |
| | CR[3] Age | ----- | .453 | | |
| | CG Sex | -3.129 | .001 | | |
| | CR Sex | ----- | .452 | | |
| | CG-CR Sex | ----- | .550 | | |
| | Kinship | ----- | .316 | | |
| | | | | .017 | .001 |
| CR Impairment | Cognitive Imp. [4] | -.096 | .013 | | |
| | IADL Imp. [4] | ----- | .621 | | |
| | ADL Imp. [4] | ----- | .052 | | |
| | Mem./Bhvr[5] Dep.[6] | ----- | .180 | | |
| | Mem./Bhvr[5] Dis[7] | -.503 | .001 | | |
| | Mem./Bhvr [5] Mem[8]. | ----- | .204 | | |
| | | | | .034 | .001 |
| External Variables | Social Network | .090 | .027 | | |
| | Rec'd [9] Support | .170 | .001 | | |
| | Negative Interaction | ----- | .774 | | |
| | Formal Support | -.038 | .001 | | |
| | | | | .091 | .001 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

Note: dashed lines represent non-significant coefficients

Table 5

*Frequency of Combinations of Positive and Negative Appraisal (REACH)*

| Appraisal Combination | Frequency | Percentage |
|---|---|---|
| Low Positive High Negative | 201 | 25.6 |
| Low Positive Low Negative | 144 | 18.4 |
| High Positive High Negative | 197 | 25.1 |
| High Positive Low Negative | 242 | 30.9 |

Table 6

*Hierarchical Regression Model for Negative Appraisal (CSHA)*

| Group | Variable | Coefficient $^1$ | $p$ | Adjusted $R^2$ | $p$ (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG$^2$ Age | ----- | .055 | | |
| Variables | CR$^3$ Age | ----- | .239 | | |
| | CG Sex | ----- | .692 | | |
| | CR Sex | ----- | .685 | | |
| | CG-CR Sex | ----- | .864 | | |
| | Kinship | -4.677 | .001 | | |
| | | | | .064 | .001 |
| CR | Cognitive Imp.$^4$ | -.244 | .001 | | |
| Impairment | ADL Imp.$^4$ | .786 | .001 | | |
| | IADL Imp. $^4$ | ----- | .163 | | |
| | DBD$^5$ | .399 | .001 | | |
| | | | | .391 | .001 |
| External | Formal Support | ----- | .513 | | |
| Variables | | | | .392 | .001 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Dementia Behaviour Disturbance Scale

Note: dashed lines represent non-significant coefficients Note: dashed lines represent non-significant coefficients

The correlation between the ZBI and the positive appraisal scale was not significant, $r$ (576) = -0.034 $p$ = .452, *ns*. This result supports the hypothesis that the positive and negative appraisals are two distinct constructs because there was no significant relationship between the positive appraisal and the negative appraisal of the caregiving situation by the same caregiver. Hence, a caregiver could express a high level of burden and a high level of positive appraisal or vice versa.

As above with the REACH data, hierarchical regression analyses were conducted to determine the significant predictors of negative appraisal and positive appraisal. The result of the analysis of the CSHA data indicate that the demographic, care recipient impairment and support variables did account for a significant amount of the variability in negative appraisal, $R^2 = .392$, $F$ (6, 256) = 14.713, $p < .001$., indicating that the less cognitive impairment of the care recipient, $t$ (805) = -.244 , $p<$ , .001, the greater assistance required for activities of daily living, $t$ (1114) = .786, $p < .001$, the greater the amount of difficult behaviours of the care recipient, $t$ (971) = 399, the more negative the caregivers' appraisal of his/her situation. See Table 6 for coefficients and significance values.

The result of the analysis of the CSHA data indicate that the demographic, care recipient impairment and support variables did account for a significant amount of the variability in positive appraisal, $R^2 = .463$, $F$ (6, 256) = 19.708, $p < .001$, indicating that the younger the caregiver, $t$ (1128) = -.070 , $p = .039$, the older the care recipient, $t$ (519) = .134 , $p = .047$, the greater assistance required with instrumental activities of

Table 7

*Hierarchical Regression Model for Positive Appraisal (CSHA)*

| Group | Variable | Coefficient [1] | $p$ | Adjusted $R^2$ | $p$ (F change) |
|---|---|---|---|---|---|
| Pre-existing Variables | CG[2] Age | -.070 | .039 | | |
| | CR[3] Age | .134 | .047 | | |
| | CG Sex | ----- | .516 | | |
| | CR Sex | ----- | .585 | | |
| | CG-CR Sex | ----- | .848 | | |
| | Kinship | -1.832 | .003 | | |
| | | | | .064 | .009 |
| CR Impairment | Cognitive Imp [4] | ----- | .645 | | |
| | ADL Imp. [4] | ----- | .880 | | |
| | IADL Imp. [4] | .868 | .001 | | |
| | DBD[5] | ----- | .865 | | |
| | | | | .404 | .001 |
| External Variables | Formal Support | .021 | .001 | | |
| | | | | .463 | .001 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Dementia Behaviour Disturbance Scale

Note: dashed lines represent non-significant coefficients

daily living, $t\ (1107) = .868, p < .001$ and the more formal supports the caregiver utilizes, $t\ (1125) = .868, p < .001$ the more positive the caregivers' appraisal of his/her situation. See Table 7 for coefficients and significance values.

These regression analyses further confirm that these constructs are distinct from one another. For the REACH data, negative appraisal was predicted by 10 of the variables entered, while only 6 predicted positive appraisal. The two constructs only had 4 predictors in common. Further, these predictors were not consistent in their direction or magnitude for each construct. In addition, much more of the variance in negative appraisal was accounted for by the significant predictors (i.e., adjusted $R^2 = .551$) versus the amount of variance in positive appraisal accounted for by its significant predictors (i.e., adjusted $R^2 = .091$). For the CSHA data, negative appraisal was predicted by 4 of the variables entered, while positive appraisal was predicted by 5 of the entered variables. More importantly, the two constructs had only one predictor in common, kinship, and both found that the closer the relationship (i.e., spouses vs. other types of caregivers), the more positive and the more negative the appraisal. Overall, the two constructs are generally predicted by different variables, lending further credence to the idea that they are two distinct constructs. If positive appraisal and negative appraisal were a single bipolar construct, the predictors should be similar for both constructs, (although the directions of the predictors would differ).

Finally, to confirm that these separate constructs exist, analyses were run to determine whether each of the four combinations of appraisal, (i.e., high burden and high gain, low burden and high gain, high burden and low gain, low burden and low gain), exist in these data. The median for each variable was determined; 19 for Positive

Appraisal and 12 for Negative Appraisal. Then any appraisal greater than or equal to the median was considered "high", while any appraisal below its respective median was considered "low". This analysis confirms that each type of combination does exist in the CSHA data. Therefore, some caregivers do appraise their situation as highly positive and highly negative, while other caregivers appraise their situations not very positively and not very negatively, and still others appraise one type of appraisal highly and appraise the other as low. If these were not separate and distinct constructs, this pattern could not be found. See Table 8.

### *Hypothesis B*

*Positive and negative appraisals will change over time.*

To establish whether mean positive appraisal for all participants changed over time, a one-way repeated measures ANOVA was conducted. The factor was time and the dependent variable was the PACS scores. The means for the ANOVA can be found in Table 9. The results for the ANOVA indicated that time was not a significant effect, Wilks' lambda = .998, $F(1, 523) = .356, p = .785$, *ns*. Hence, overall, across participants, the means PACS scores did not change over time.

However, examining only mean changes across the whole group of caregivers could be misleading, because the mean differences at each time point may mask any significant changes that individual caregivers expressed in their appraisals over time, and hence lead one to believe that appraisal does not actually change over time.

If individual changes are captured, rather than just group differences, it could lead to a better understanding of the patterns of caregivers' appraisal of positive aspects of caregiving, which is yet to be explored.

Table 8

*Frequency of Combinations of Positive and Negative Appraisal*

| Appraisal Combination | Frequency | Percentage |
|---|---|---|
| Low Positive High Negative | 119 | 40.8 |
| Low Positive Low Negative | 98 | 33.6 |
| High Positive High Negative | 21 | 7.2 |
| High Positive Low Negative | 54 | 18.5 |

Table 9

*Mean Positive Appraisal of Caregiving Scores at Each Interview*

| Time | M | N |
|---|---|---|
| 1 | 34.891 | 1205 |
| 2 | 35.179 | 874 |
| 3 | 35.130 | 680 |
| 4 | 35.048 | 577 |

In reference to negative appraisal, there are two competing hypotheses within the literature: the wear and tear hypothesis and the adaptation hypothesis. The wear and tear hypothesis states that as caregiving continues, (and ADL dependency, cognitive impairment, and behaviour problems accumulate), the caregiver gets worn down, and their appraisal of subjective burden increases, and concomitantly, their risk for negative health outcomes increases (Alspaugh, Zarit, & Greene, 1999; Gaugler, Davey, Pearlin, & Zarit, 2000; Walker, Acock, Bowman, & Li, 1996).

On the other hand, the adaptation hypothesis states that as caregiving continues, caregivers become acclimated to their duties, and perhaps even get better at completing them, hence making their appraisals of their situation remain stable or even become less negative over time (Stephens & Zarit, 1989; Townsend, Noelker, Deimling, & Bass, 1989). There have been studies in which burden scores remained stable over time which support this adaptation hypothesis (Suitor & Pillemer, 1994; Townsend et al., 1989).

To date these hypotheses have not been applied to positive appraisals, but theoretically, this is possible. For example, if the wear and tear hypothesis is the mechanism of change in positive appraisal for some caregivers, as caregiving continues, and the caregiver gets worn down and tired, he/she is less likely to appraise aspects of their situation as positive. However, if the adaptation hypothesis is the mechanism of change in positive appraisal for other caregivers, as time goes on and the caregiver gets more accustomed to his/her duties, he/she could begin to notice the positive aspects of their situation more readily, and appraise their situation more positively than before. It may be possible that the wear and tear hypothesis is true in some cases, while the adaptation hypothesis is true for other caregivers. The following analyses aim to empirically confirm or disconfirm that caregivers differ in their patterns of positive appraisal.

Therefore, in order to better understand the individual changes in appraisal over time, after conducting the analysis of variance, separate regression analyses were run for each participant, using Time and Time$^2$ to predict outcome (i.e., positive appraisal). After these regressions were complete, the regression coefficients were plotted on a scatterplot with Time on one axis and Time$^2$ on the other axis, to permit examination of patterns. The regression coefficient for Time would represent the linear pattern of change in positive appraisal over time. If an individual's regression coefficient for Time were positive, it would indicate an increasing linear trend; hence, that caregiver's appraisal of positive aspects is increasing over time. Such a pattern would support an adaptation hypothesis. If the individual's regression coefficient for Time were negative, the converse would be true; the caregiver's appraisal of positive aspects would be decreasing over time, which would support the wear and tear hypothesis. However, it is conceivable that individuals caregivers' pattern of appraisal over time may not be linear. To capture any curvilinear patterns, Time$^2$ was included.

Figure 2 represents some example of the variety of potential patterns that could arise when all the regression coefficients for Time and Time$^2$ are plotted. For instance, the cluster labeled A, would represent that a number of individuals cluster around zero for Time, but high for Time$^2$. This would represent a u-shaped distribution, with positive appraisal starting high at Time 1, decreasing over the intermediate interviews (Time 2 and Time 3), but then increasing again at Time 4, The cluster labeled D represent a group that clusters around zero for curvilinear trends, and but is also negative on Time, which means their positive appraisal scores are decreasing over time. A cluster of responses labeled E would indicate a group of exponentially increasing positive appraisal scores.See Figure 3 for the actual scatterplot of regression coefficients for positive appraisal scores.

The mean for b1 did not differ significantly from zero; $M = .0043$, $SD = .37886$, $t\,(561) = .268$, $p = .788$, *ns*. The mean for b2 also did not differ significantly from zero; $M = -.0016$, $SD = .06984$, $t\,(556) = -.539$, $p = .590$, *ns*. Upon visual inspection of the scatterplot, it appeared that the vast majority of cases clustered around 0 for both the b1 and b2 coefficients (See Figure 2). Therefore, for most participants, the slope (b1) is equal or close to zero, indicating that most participants' scores do not change a great deal from the intercept. As b2, representing $\text{Time}^{2,}$ was also zero (or close to zero) for most participants, curvilinear relationships between the PACS scores over time were not evident either. Overall, most individuals' PACS scores do not change appreciably over time.

However, statistical significance is only one way to assess whether individuals' appraisals change over time. In order to assess clinical significance, a threshold of 4 points difference in scores from Time 1 to Time 4 was set, as this represents approximately 10% of the potential range in the PACS (i.e., PACS scores can range from 9 to 45, and in the sample, the full range is represented, and therefore 3.6 points would be exactly 10% of the potential range. As only whole scores are recorded, the threshold for clinically significant change was set at 4 points.) Frequency tables demonstrate that 42.29% of participants' scores changed significantly from Time 1 to Time 4. Perhaps more germane to the question at hand is the finding that approximately equal numbers of participants had clinically significant decreases (20.80%) in their PACS scores as had clinically significant increases in PACS scores 21.49%). This clarifies the question of whether some people increase and others decrease, which was a potential explanation for the null ANOVA results. These results would support the hypothesis that for some people, the wear and tear hypothesis applies, while for others, the adaptation hypothesis explains the changes in their appraisal scores. Understanding who adapts and who experiences wear and tear is an important question for future research.

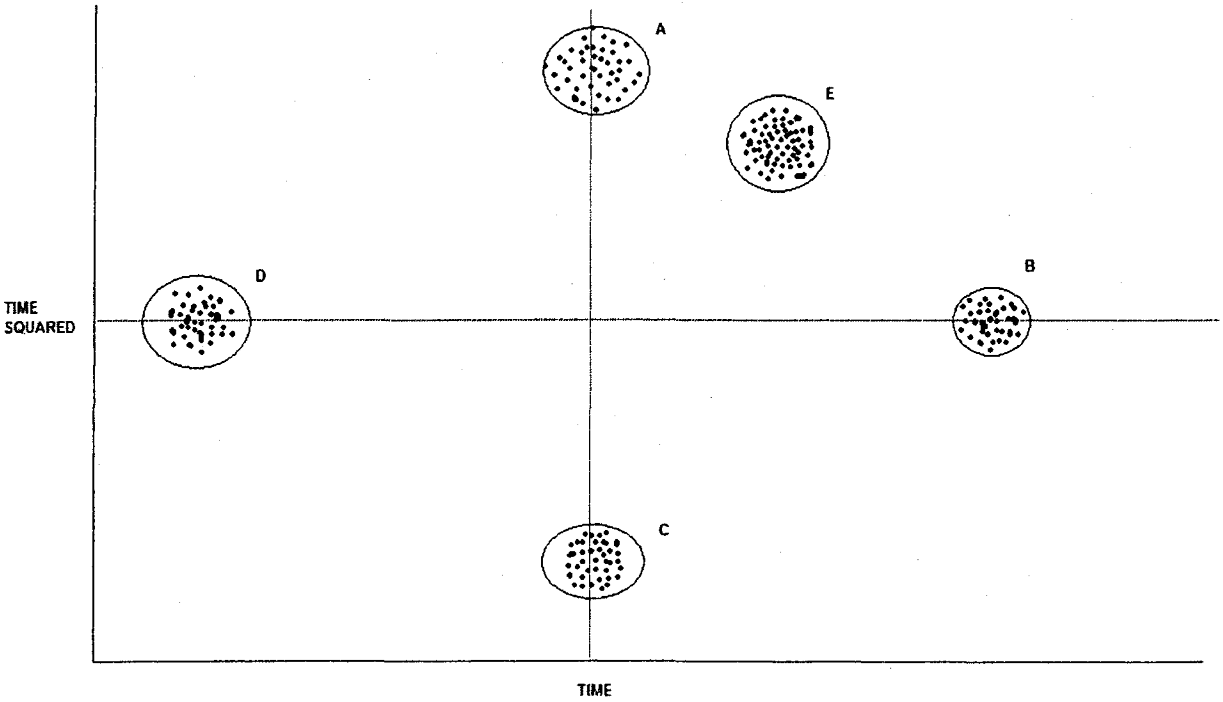
To establish whether mean negative appraisal for all participants changed over time, a one-way repeated measures ANOVA was conducted. The factor was time and the dependent variable was the total negative appraisal scores. The means for the negative appraisal scores for this ANOVA are presented in Table 10. The results for the ANOVA indicated that visit was a significant effect, Wilks' lambda = .92, $F$ (1, 527) = 15.286, $p < .001$. Hence, overall, across participants, the means negative appraisal scores did change over time. Examining the means, it appears that, on average, most people begin appraising their situation more negatively, and over time, start to appraise their situation less negatively.

Although the average negative appraisal scores indicated a decreasing trend on average, the same approach was undertaken as with the positive appraisal scores, (i.e., separate regression analyses with Time and Time$^2$ as predictors, and a scatterplot of the coefficients) to examine individual patterns.

The mean for b1 differed significantly from zero; $M$ = -1.4227, $SD$ = 4.912, $t$ (570) =-6.921, $p < .001$. However, the mean for b2 did not differ significantly from zero; *M* = -.4973, *SD* = 4.64103, *t* (564) = 2.547, *p* = .011. The scatterplots for positive and negative appraisal look remarkably similar. (See Figures 4 and 5). However, for negative appraisal, the slope (b1) is significantly different from zero, which represents a change from the intercept. As the mean of b1 is in the negative direction, it appears that on average, negative appraisal decreases over time. As b2, representing Time$^{2,}$ was also zero (or close to zero) for most participants, curvilinear relationships between the total negative appraisal scores over time were not evident either. See Figure 4 for the scatterplot of regression coefficients of negative appraisal scores.

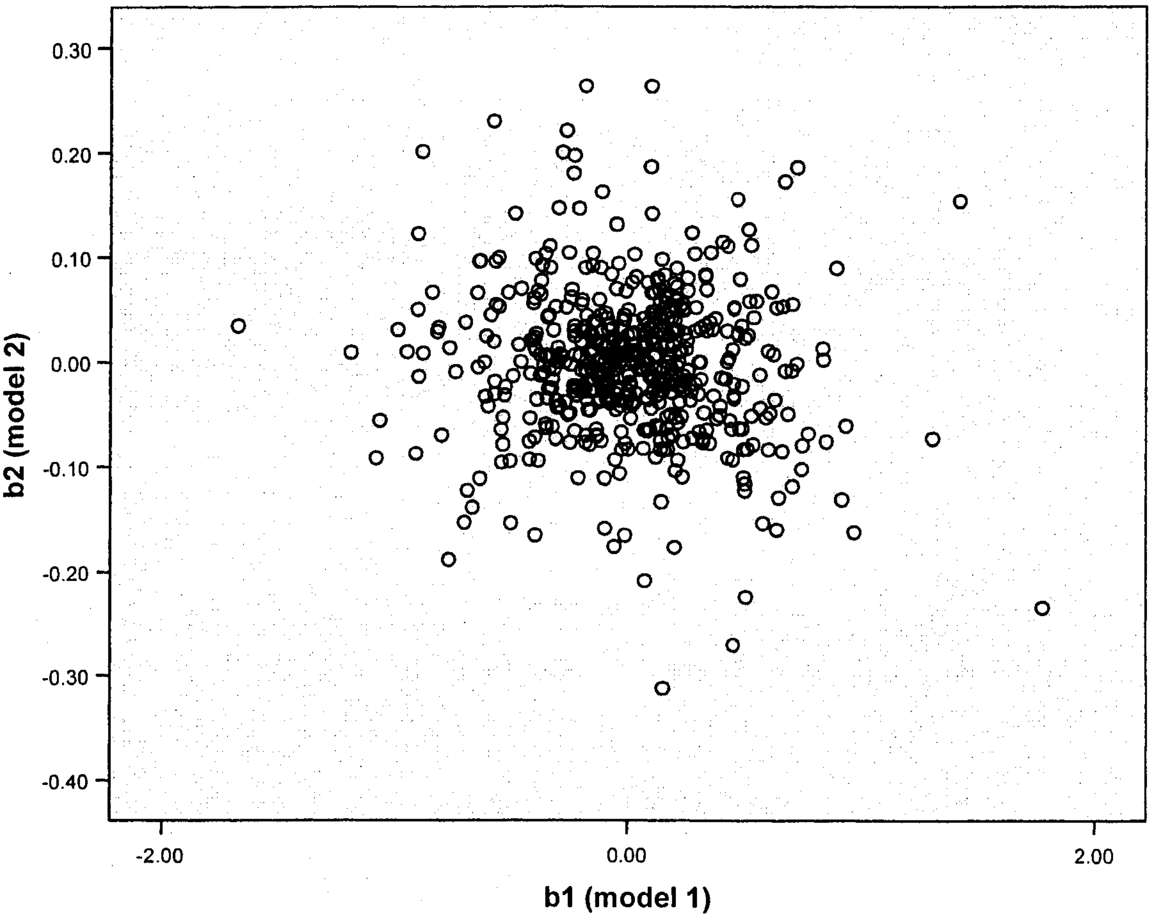
The question of clinical significance shed light on the changes in negative appraisal, as it did for positive appraisal. As with positive appraisal, difference scores between Time 1 and Time 4 were calculated. For the Negative Appraisal scores, a threshold for clinically significant change was set at 11 points, because although the potential range for Negative Appraisal scores is 172, in actuality, the sample scores ranged from 0 to 108. Therefore, 11 points was a 10% change in actual scores. In this case, 43.24% of participants had clinically significant differences in their Negative Appraisal scores. However, in this case, unlike with positive appraisal, many more participants experienced a clinically significant decrease in Negative Appraisal scores (32.80%) than a clinically significant increase (10.45%). This could be interpreted as support for the adaptation hypothesis, because despite the logical assumption that the care recipients' condition would worsen over time (as dementia is progressive), many caregivers did not appraise their situation much more negatively at Time 4 than Time 1. Hence, they were adapting to the demands of the caregiving role.

*Figure 2*



Example of potential scatterplot from regression coefficients

*Figure 3*



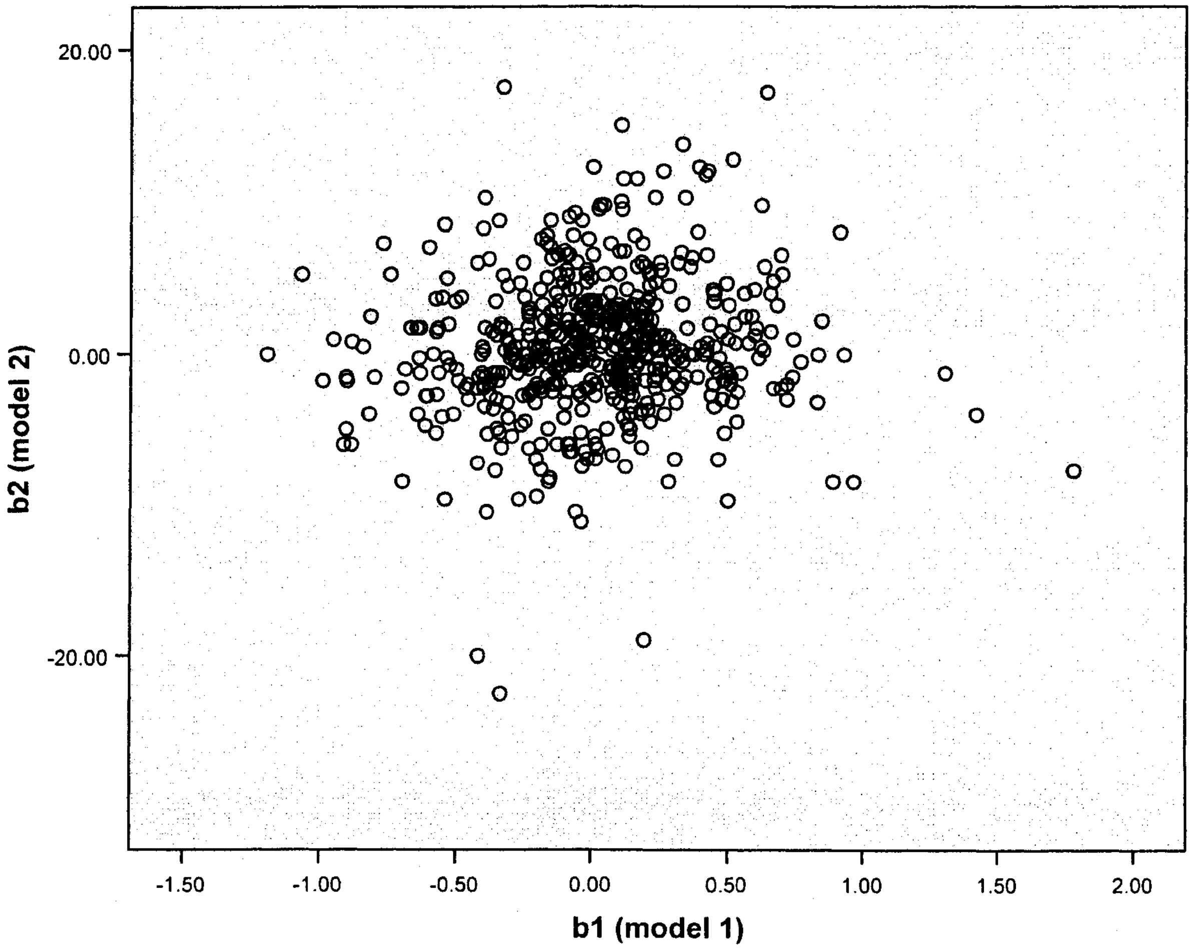
Scatterplot of regression coefficients for positive appraisal scores

Table 10

*Mean Negative Appraisal of Caregiving Scores at Each Interview*

| Time | M |
|---|---|
| 1 | 22.0814 |
| 2 | 19.5246 |
| 3 | 18.2992 |
| 4 | 17.9659 |

*Figure 4*



Scatterplot of regression coefficients for negative appraisal scores

*Hypothesis C*

*Including positive appraisal will increase the amount of variance in health outcomes accounted for over negative appraisals alone.*

Hierarchical multiple regression analyses were conducted to predict various physical and mental health outcomes for caregivers. In each of these analyses, various demographic and baseline information was entered in the first step; age of caregiver, gender of caregiver, age of care recipient, gender of care recipient, interaction of gender of caregiver and care recipient, level of cognitive impairment of the care recipient, ADL impairment of care recipient, memory/behaviour problems of care recipient (including 3 separate factor scores for depression, disruption and memory problems), amount of social support and formal support caregivers received. Negative appraisal was entered at the second step, while positive appraisal was entered at the third and final step. The means and standard deviations of all variables entered into the hierarchical regressions for each database are available in Table 11 (REACH) and Table 12 (CSHA).

The first such analyses predicted the self-rated health of caregiver. The result of the analysis of the REACH data indicate that the demographic, baseline and negative appraisal variables did account for a significant amount of the variability in self-rated health, adjusted $R^2 = .103$, $F\,(17, 757) = 6.226$, $p < .001$., indicating that the younger the caregiver, $t\,(1180) = -2.297$ , $p = .022$, the greater the caregivers' social network, $t\,(1189) = 3.206$, $p < .001$, the less negative interaction in the caregiver's social interactions $t\,(1189) = -3.842$, $p < .001$, the fewer services a caregiver used, $t\,(1189) = -2.196$, $p = .028$, and the lower the negative appraisal, $t\,(768) = -4.520$, $p < .001$, the poorer the caregiver's self-rated health. The model that added positive appraisal did not account for a significantly greater amount of the variability in self-rated health in this study, adjusted $R^2$ change = .001, $F$ change (1, 758) = 0.194, $p$ = .660, *ns*. See Table 13 for coefficients and significance values.

The result of the analysis of the CSHA data indicate that the demographic, baseline and appraisal variables did not account for a significant amount of the variability in self-rated health, adjusted $R^2$ = -.041, $F$ (13, 249) = 1.687, $p$ =.064, *ns*. See Table 14 for coefficients and significance values. Regardless, for both data sets, the addition of positive appraisal did not increase the amount of variance accounted for in self-rated health.

The second dependent variable dealing with physical health to be predicted by the set of demographic, baseline and appraisal variables is number of caregiver illness diagnoses. The result of the analysis of the REACH data indicate that the demographic, baseline and negative appraisal variables did account for a significant amount of the variability in number of illness diagnoses, adjusted $R^2$ = .146, $F$ (17, 757) = 8.761, $p$ < .001., indicating that the older the caregiver, $t$ (1180) = 8.648, $p$ < .001, the lower the score on the depression factor of the memory behaviour scale, $t$ (1180) = -2.703, $p$ = .007, the more negative interaction a caregiver experienced in their social interactions, $t$ (1189) = 2.662, $p$ = .008, and the more negatively a caregiver appraised his/her situation, $t$ (768) = 2.062, $p$ = .040, the greater the number of illnesses with which he/she was diagnosed. The model that added positive appraisal did not account for a significantly greater amount of the variability in number of illness diagnoses in this study, adjusted $R^2$ change = .001, $F$ change (1, 756) = 0.259, $p$ = .611, *ns*. See Table 15 for coefficients and significance values.

Table 11

*Means and Standard Deviations of Each Variable in Regression Analyses for REACH Data*

| Variable | *M* | *SD* | N |
|---|---|---|---|
| Self-Rated Health | 13.68 | 3.76 | 1205 |
| Total Number of Illnesses Diagnosed | 1.36 | 1.18 | 1205 |
| Anxiety Score | 21.50 | 7.02 | 1205 |
| Depression Score | 19.96 | 7.99 | 1229 |
| Caregiver Age | 61.80 | 13.62 | 1193 |
| Care Recipient Age | 78.93 | 10.10 | 1193 |
| Caregiver Sex | 1.82 | 0.39 | 1205 |
| Care Recipient Sex | 3.55 | 0.50 | 1205 |
| Sex Interaction | 0.564 | 0.50 | 1205 |
| Kin Relationship | 1.29 | 0.71 | 1205 |
| MMSE Score | 12.61 | 7.64 | 1195 |
| Total Number IADLs | 7.27 | 1.28 | 1205 |
| Total Number ADLs | 3.84 | 2.47 | 1205 |
| Total Number Memory/Behaviour Problems | 11.05 | 4.16 | 1205 |
| Social Network Total | 25.07 | 7.51 | 1229 |
| Received Support and Satisfaction | 17.63 | 7.95 | 1229 |
| Negative Interaction Total | 2.86 | 2.98 | 1229 |
| Formal Care and Services | 14.50 | 24.99 | 1205 |
| Total Negative Appraisal | 22.40 | 18.24 | 784 |
| Total Positive Appraisal | 33.87 | 9.02 | 1205 |

Table 12

*Means and Standard Deviations of Each Variable in Regression Analyses for CSHA Data*

| Variable | *M* | *SD* | N |
|---|---|---|---|
| Self-Rated Health | 5.13 | 1.45 | 1115 |
| Total Number of Illnesses Diagnosed | 3.15 | 2.31 | 1113 |
| Depression Score | 7.30 | 9.32 | 1106 |
| Caregiver Age | 63.87 | 12.72 | 1128 |
| Care Recipient Age | 85.57 | 6.40 | 519 |
| Caregiver Sex | 1.73 | 0.44 | 1103 |
| Care Recipient Sex | 3.67 | 0.47 | 1129 |
| Sex Interaction | 0.73 | 0.44 | 1129 |
| Kin Relationship | 2.25 | 0.79 | 1686 |
| 3MS Score | 75.92 | 18.89 | 805 |
| ADL Score | 7.92 | 5.44 | 1114 |
| IADL Score | 4.77 | 5.42 | 1107 |
| Dementia Behaviour Disturbance Score | 15.92 | 12.86 | 971 |
| Zarit Burden Interview Score | 15.51 | 13.76 | 1086 |
| Positive Appraisal Score | 4.31 | 7.96 | 1125 |

Table 13

*Hierarchical Regression Model for Self-Rated Health (REACH)*

| Group | Variable | Coefficient | [1]*p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG[2]Age | -.032 | .022 | | |
| Variables | CR[3] Age | ----- | .473 | | |
| | CG Sex | ----- | .425 | | |
| | CR Sex | ----- | .791 | | |
| | CG-CR Sex | ----- | .889 | | |
| | Kinship | ----- | .938 | | |
| | Cognitive Imp. [4] | ----- | .273 | | |
| | IADL Imp. [4] | ----- | .901 | | |
| | ADL Imp. [4] | ----- | .106 | | |
| | Mem./Bhvr [5] Dep.[6] | ----- | .350 | | |
| | Mem./Bhvr [5] Dis.[7] | ----- | .838 | | |
| | Mem./Bhvr [5] Mem.[8] | ----- | .887 | | |
| | Social Network | .067 | .001 | | |
| | Rec'd [9] Support | ----- | .602 | | |
| | Negative Interaction | -.187 | .001 | | |
| | Formal Support | -.012 | .028 | | |
| | | | | .099 | .001 |
| Negative | Negative App. | -.045 | .001 | | |
| Appraisal | | | | .123 | .001 |
| Positive | Positive App. | ----- | .600 | | |
| Appraisal | | | | .123 | .600 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

Table 14

*Hierarchical Regression Model for Self-Rated Health (CSHA)*

| Group | Variable | Coefficient [1] | $p$ | Adjusted $R^2$ | $p$ (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG[2] Age | .027 | .049 | | |
| Variables | CR[3] Age | ----- | .964 | | |
| | CG Sex | ----- | .760 | | |
| | CR Sex | ----- | .884 | | |
| | CG-CR Sex | ----- | .839 | | |
| | Kinship | ----- | .784 | | |
| | Cognitive Imp. [4] | ----- | .564 | | |
| | IADL Imp.[4] | ----- | .686 | | |
| | ADL Imp.[4] | ----- | .936 | | |
| | DBD[5] | ----- | .594 | | |
| | Formal Support | ----- | .663 | | |
| | | | | -.048 | .801 |
| Negative | Negative App. | ----- | .117 | | |
| Appraisal | | | | .-.028 | .119 |
| Positive | Positive App. | ----- | .786 | | |
| Appraisal | | | | -.041 | .786 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Dementia Behaviour Disturbance Scale

Note: dashed lines represent non-significant coefficients

Table 15

*Hierarchical Regression Model for Number of Illness Diagnoses (REACH)*

| Group | Variable | Coefficient [1] | *p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG[2] Age | .037 | .001 | | |
| Variables | CR[3] Age | ----- | .107 | | |
| | CG Sex | ----- | .254 | | |
| | CR Sex | ----- | .199 | | |
| | CG-CR Sex | ----- | .268 | | |
| | Kinship | ----- | .421 | | |
| | Cognitive Imp [4] | ----- | .257 | | |
| | IADL Imp [4] | ----- | .463 | | |
| | ADL Imp. [4] | ----- | .649 | | |
| | Mem./Bhvr [5] Dep.[6] | -.060 | .007 | | |
| | Mem./Bhvr [5] Dis.[7] | ----- | .247 | | |
| | Mem./Bhvr [5] Mem.[8] | ----- | .888 | | |
| | Social Network | ----- | .052 | | |
| | Rec'd [9] Support | ----- | .467 | | |
| | Negative Interaction | .039 | .008 | | |
| | Formal Support | ----- | .242 | | |
| | | | | .160 | .001 |
| Negative | Negative App. | .039 | .008 | | |
| Appraisal | | | | .164 | .040 |
| Positive | Positive App. | ----- | .611 | | |
| Appraisal | | | | .165 | .611 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

The results of the analysis of the CSHA data indicate similar results to that of the REACH data. The demographic, baseline and negative appraisal variables did account for a significant amount of the variability in the number of illnesses diagnosed, adjusted $R^2 = .059$, $F(12, 250) = 4.223$, $p < .001$, indicating that the older the caregiver, $t(1114) = 3.140$, $p = .002$, and the more burdened they felt, $t(1072) = 1.992$, $p = .050$, the more illnesses with which the caregiver was diagnosed. The model that added positive appraisal did not account for a significantly greater amount of the variability in number of illness diagnoses in this study, adjusted $R^2$ change = .012, $F$ change (1, 249) = .591, $p = .889$, *ns*. See Table 16 for coefficients and significance values. Therefore, for both data sets, the addition of positive appraisal did not increase the amount of variance accounted for in the number of illnesses with which caregivers are diagnosed.

Depression was the next variable to be predicted by this set of demographic, baseline and appraisal variables. The results of the analysis of the REACH data indicated that the demographic, baseline and negative appraisal variables did account for a significant amount of the variability in depression, adjusted $R^2 = .282$, $F(17, 757) = 18.866$, $p <.001$., indicating that the more ADLs with which the care recipient required assistance, $t(1189) = 2.587$, $p = .010$, the smaller the caregiver's social network, $t(1189) = -5.141$, $p < .001$, the more negative interactions a caregiver experienced in his/her social interactions, $t(1189) = 8.120$, $p < .001$, the more formal services the caregiver utilized, $t(1189) = 1.972$, $p = .049$, and the more burdened the caregiver felt, $t(768) = 6.949$, $p < .001$, the higher his/her depression score. The model that added positive appraisal did not account for a significantly greater amount of the variability in depression scores in this study, adjusted $R^2$ change = .016, *F* change (1, 758) = 0.045, $p = .833$, *ns*. See Table 17 for coefficients and significance values.

The results of the CSHA analysis indicated similar results to the REACH analysis, in that the demographic, baseline and negative appraisal variables did account for a significant amount of the variability in depression, $R^2 = .238$, *F* (12, 250) = 4.051, $p <.001$., indicating that the more burdened the caregiver experiences in his/her situation, *t* (1114) = 5.071, $p < .001$,the greater his/her depression score. The model that added positive appraisal did not account for a significantly greater amount of variability in depression scores in this study, adjusted $R^2$ change = -.003, *F* change (1, 249) = 0.000, $p = .986$, *ns*. See Table 18 for coefficients and significance values. Thus, for both data sets, the addition of positive appraisal did not increase the amount of variance accounted for in depression scores.

Finally, the REACH data included a measure of anxiety for which there was no equivalent in the CSHA study. The results the analysis of the REACH data indicated that the demographic, baseline, negative appraisal and positive appraisal variables did account for a significant amount of the variability in depression, adjusted $R^2 = .294$, *F* (17, 757) = 19.508, $p < .001$., indicating that being female , *t* (1189) = 2.490, $p = .013$, the more ADLS for which the care recipient required assistance, *t* (1189) = 2.331, $p = .020$, the greater the score on the depression factor of the memory behaviour scale, *t* (1189) = 2.524, $p = .012$, the smaller the caregiver's social network, *t* (1189) = -6.202, $p < .001$, the more formal services the caregiver utilizes, *t* (1189) = 4.034, $p < .001$, the

Table 16

*Hierarchical Regression Model for Number of Illness Diagnoses (CSHA)*

| Group | Variable | Coefficient $^1$ | *p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG$^2$Age | .064 | .002 | | |
| Variables | CR$^3$ Age | ----- | .712 | | |
| | CG Sex | ----- | .563 | | |
| | CR Sex | ----- | .855 | | |
| | CG-CR Sex | ----- | .760 | | |
| | Kinship | ----- | .851 | | |
| | Cognitive Imp. $^4$ | ----- | .885 | | |
| | IADL Imp.$^4$ | ----- | .885 | | |
| | ADL Imp.$^4$ | ----- | .866 | | |
| | DBD$^5$. ----- .893 | | | | |
| | Formal Support | ----- | .863 | | |
| | | | | .021 | .316 |
| Negative | Negative App. | .045 | .050 | | |
| Appraisal | | | | .059 | .045 |
| Positive | Positive App. | ----- | .899 | .047 | .899 |
| Appraisal | | | | -.041 | .786 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Dementia Behaviour Disturbance Scale

Note: dashed lines represent non-significant coefficients

Table 17

*Hierarchical Regression Model for Depression (REACH)*

| Group | Variable | Coefficient $^1$ | $p$ | Adjusted $R^2$ | $p$ (F change) |
|---|---|---|---|---|---|
| Pre-existing Variables | CG$^2$ Age | ----- | .372 | | |
| | CR$^3$ Age | ----- | .476 | | |
| | CG Sex | ----- | .096 | | |
| | CR Sex | ----- | .707 | | |
| | CG-CR Sex | ----- | .878 | | |
| | Kinship | ----- | .510 | | |
| | Cognitive Imp.$^4$ | ----- | .663 | | |
| | IADL Imp.$^4$ | ----- | .320 | | |
| | ADL Imp$^4$ | .327 | .010 | | |
| | Mem./Bhvr$^5$ Dep.$^6$ | ----- | .986 | | |
| | Mem./Bhvr$^5$ Dis.$^7$ | ----- | .638 | | |
| | Mem./Bhvr $^5$ Mem.$^8$ | ----- | .460 | | |
| | Social Network | -.205 | .001 | | |
| | Rec'd$^9$ Support | ----- | .261 | | |
| | Negative Interaction | .751 | .001 | | |
| | Formal Support | .020 | .049 | | |
| | | | | .253 | .001 |
| Negative Appraisal | Negative App. | .132 | .001 | | |
| | | | | .298 | .001 |
| Positive Appraisal | Positive App. | ----- | .833 | | |
| | | | | .298 | .833 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

Table 18

*Hierarchical Regression Model for Depression (CSHA)*

| Group | Variable | Coefficient[#] | $p$ | Adjusted $R^2$ | $p$ (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG[2] Age | ----- | .221 | | |
| Variables | CR[3] Age | ----- | .661 | | |
| | CG Sex | ----- | .427 | | |
| | CR Sex | ----- | .732 | | |
| | CG-CR Sex | ----- | .836 | | |
| | Kinship | ----- | .362 | | |
| | Cognitive Imp.[4] | ----- | .241 | | |
| | IADL Imp[4] | ----- | .076 | | |
| | ADL Imp[4] | ----- | .182 | | |
| | DBD[5]. | ----- | .157 | | |
| | Formal Support | ----- | .646 | | |
| | | | | .005 | .419 |
| Negative | Negative App. | .412 | .001 | | |
| Appraisal | | | | .238 | .001 |
| Positive | Positive App. | ----- | .399 | | |
| Appraisal | | | | .235 | .399 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Dementia Behaviour Disturbance Scale

Note: dashed lines represent non-significant coefficients

Table 19

*Hierarchical Regression Model for Anxiety (REACH)*

| Group | Variable | Coefficient [1] | *p* | Adjusted $R^2$ | *p* (F change) |
|---|---|---|---|---|---|
| Pre-existing | CG[2] Age | ----- | .582 | | |
| Variables | CR[3] Age | ----- | .438 | | |
| | CG Sex | 1.801 | .013 | | |
| | CR Sex | ----- | .054 | | |
| | CG-CR Sex | ----- | .168 | | |
| | Kinship | ----- | .111 | | |
| | Cognitive Imp.[4] | ----- | .785 | | |
| | IADL Imp.[4] | ----- | .275 | | |
| | ADL Imp.[4] | .258 | .020 | | |
| | Mem./Bhvr[5] Dep.[6] | .305 | .012 | | |
| | Mem./Bhvr[5] Dis.[7] | ----- | .202 | | |
| | Mem./Bhvr[5] Mem.[8] | ----- | .686 | | |
| | Social Network | -.216 | .001 | | |
| | Rec'd[9] Support | ----- | .471 | | |
| | Negative Interaction | .467 | .001 | | |
| | Formal Support | .036 | .001 | | |
| | | | | .256 | .001 |
| Negative | Negative App. | .121 | .001 | | |
| Appraisal | | | | .289 | .001 |
| Positive | Positive App. | -.067 | .009 | | |
| Appraisal | | | | .294 | .009 |

1= unstandardized 2=caregiver 3 =care recipient 4 = Impairment 5 = Revised Memory and Behaviour Checklist 6 = Depression Subscale 7 = Disruption Subscale 8 = Memory Subscale 9 = Received

Note: dashed lines represent non-significant coefficients

more negative interaction the caregiver experienced in his/her social interactions, $t$ (1189) = 7.275, $p < .001$, the more social support the caregiver received, $t$ (1189) = 3.980, $p < .001$, the more burden they reported, $t$ (768) = 6.408, $p < .001$,and the less positive appraisal they reported, $t$ (1189) = -2.413, $p = .016$, the higher the caregivers' anxiety score. Unlike the other health outcomes, (self-rated health, number of illness diagnoses, and depression scores), the amount of variance accounted for in anxiety was increased with the addition of positive appraisal, adjusted $R^2$ change = .006, $F$ change (1, 756) = 6.805, $p = .009$. See Table 19 for coefficients and significance values.

*Hypothesis D*

*Women will appraise caregiving more negatively (i.e., higher burden scores) than men caregivers.*

An independent samples *t*-test was conducted to evaluate the hypothesis that women appraise caregiving more negatively than men. The test was not significant for either the REACH data, $t$ (782) = -1.436, $p = .151$, *ns*, or the CSHA data, $t$ (291) = -1.205, $p = .229$, *ns*. The eta square index indicated that very small amounts of the variance in negative appraisal were accounted for by caregiver gender. (For the REACH data, $\eta^2 = .00263$, for the CSHA data, $\eta^2 = .00497$). Therefore, there are no significant differences in how men and women appraise caregiver burden in these two studies.

*Hypothesis E*

*Women will have more positive appraisals of caregiving.*

An independent samples *t*-test was conducted to evaluate the hypothesis that women appraise caregiving more positively than men. The test was significant for the REACH data, $t$ (1203) = 3.955, $p < .0001$, however, the results were counter to the hypothesis, in that men ($M = 36.05$, $SD = 7.67$) actually appraised their caregiving situations more positively than women ($M = 33.42$, $SD = 9.19$). On the other hand, the CSHA data showed a non-significant result for this hypothesis, $t\ (291) = -1.205$, $p = .229$, *ns*. The eta square index indicated a small effect size for the REACH data, $\eta^2 = .0128$, meaning that caregiver gender accounted for about 1% of the variance in positive appraisal, while in the CSHA data, $\eta^2 = .002056$, indicating that only a very small amount of the variance in positive appraisal was accounted for by caregiver gender.

### *Hypothesis F*

*Women caring for men will report more burden than other gender combinations of caregivers and care recipients.*

An independent samples *t*-test was conducted to evaluate the hypothesis that women caring for men appraise caregiving more negatively than other gender combinations of caregivers and care recipients. The test was not significant for either the REACH data, $t\ (782) = -.371$, $p = .711$, *ns*, or the CSHA data, $t\ (291) = .269$, $p = .788$, *ns*. The eta square index indicated that very small amounts of the variance in negative appraisal were accounted for by caregiver-care recipient gender combination. (For the REACH data, $\eta^2 = .0001744$, for the CSHA data, $\eta^2 = .0002486$). Hence, there are no significant differences in how women caring for men appraise caregiver burden in relation to other gender combinations of caregivers and care recipients in these two studies.

Some follow-up analyses were conducted to determine the similarities or differences between the REACH and CSHA datasets and the findings of previous studies, in order to more effectively interpret the current findings.

An independent samples T-test was conducted to evaluate whether the care recipients for whom female and male caregivers provide care differ in the amount of assistance they require (i.e., number of ADL or IADL tasks with which their care recipient requires their help). The test was significant for the REACH data, *t* (1203) = -2.715, *p* = .007, with the care recipients for whom female caregivers were providing care requiring help with significantly more ADLs and IADLs than the care recipients for whom male caregivers were providing care. However, in contrast, the test was not significant in the CSHA data, *t* (1003) = 1.746, *p* = .081. Therefore, in the CSHA data, the care recipients who were cared for by female caregivers did not require assistance with significantly more ADLs or IADLs than those cared for by male caregivers.

Another independent samples *t*-test was conducted to determine whether male and female caregivers differed in terms of the number of ADLs or IADLs they actually provided assistance with to the care recipients themselves (i.e., the caregiver helped with the task rather than another family member, friend, or paid worker). The test of the REACH data was not significant, *t* (1203) = -1.441, *p* = .150, *ns*. Therefore, male and female caregivers do not differ in the number of ADL or IADL tasks with which they personally provide help, despite the fact that the care recipients of female caregivers required more help with these tasks than the care recipients of male caregivers.

An additional independent samples *t*-test was conducted to evaluate whether male and female caregivers had the same amount of formal support. The test of the REACH data was non-significant, *t* (1203) = .167, *p* = .867, *ns*, meaning that men and women caregivers do not differ in the amount of formal support they receive in their caregiving duties. However, the test of the CSHA data showed that men caregivers receive significantly more support in their caregiving duties than women caregivers, *t* (1127) = 2.039, *p* = .042.

Another independent samples *t*-test was conducted to determine whether the care recipients for whom women caregivers provide care engage in more behavioural disturbances than the care recipients for whom men caregivers provide care. For the REACH data, the Memory and Behavior Checklist was the measure of behavior disturbance. The test was significant, *t* (1202) = -3.362, *p* <.001. The Dementia Behaviour Disturbance scale was the measure in the CSHA data. This test was also significant, *t* (969) = -2.567, *p* = .010. This means that in both databases, women's care recipients are engaging in more behavioural disturbances than men's care recipients.

Finally, an independent samples *t*-test was conducted to determine whether there was any difference between wives and husbands on subjective burden measures. The results for both datasets were non-significant. Specifically for the REACH data, *t* (361) = -.796, *p* = .426, *ns,* and for the CSHA data, *t* (168) = .806, *p* = .421, *ns*. Therefore, husbands and wives are not significantly different in terms of their perceived subjective burden.

### *Hypothesis G*

*Spouses will appraise caregiving more negatively and more positively than other caregivers.*

An independent samples *t*-test was conducted to evaluate the hypothesis that spouses will appraise caregiving more negatively than caregivers with other relationships to the care recipient. The test was not significant for either the REACH data, *t* (782) = .295, *p* = .768, *ns*, or the CSHA data, *t* (291) = .230, *p* = .818, *ns*. The eta square index indicated that very small amounts of the variance in negative appraisal were accounted for by caregiver-care recipient gender combination. (For the REACH data, $\eta^2 = .0001112$, for the CSHA data, $\eta^2 = .000018$). Hence, there are no significant differences in how spouses appraise caregiver burden in relation to other caregivers.

Another independent samples *t*-test was conducted to evaluate the other part of this hypothesis, that spouses will appraise caregiving more positively than other caregivers. The test was significant for both datasets, REACH, $t\,(1203) = -2.216, p = .027$, and CSHA data, $t\,(1123) = .6.676, p < .0001$. However, the tests revealed results in opposite directions; REACH showed that the spouses ($M = 33.31$, $SD = 9.479$) appraised caregiving less positively than other caregivers ($M = 34.46$, $SD = 8.47$), while CSHA showed that spouses ($M = 7.247$, $SD = 9.169$) appraised caregiving more positively than other caregivers ($M = 3.490$, $SD = 7.39$). Therefore there is conflicting evidence about whether spouses appraise caregiving more or less positively than other caregivers.

However, the eta square index revealed some interesting results. For the REACH data, the effect size was medium to large, $\eta^2 = .1328$, meaning that being a spousal caregiver (vs. other caregivers) accounted for about 13% of the variance in positive appraisal, while in the CSHA data, $\eta^2 = .004065$, indicating that only a very small amount of the variance in positive appraisal was accounted for by caregiver-care recipient kin relationship.

### *Hypothesis H*

*Kramer's model of caregiver adaptation will be confirmed as a structural model of the influence of background variables (e.g., caregiver and care recipient gender,* *kinship), on positive and negative caregiving appraisal, and in turn, how appraisal influences the health outcomes that caregivers experience.*

The statistical program AMOS (Arbuckle, 2005) was used to estimate parameters for the latent constructs and structural equations implied in the models. Models are assessed by inspecting the statistical significance of estimated path coefficients and goodness-of-fit statistics for the model as a whole. These calculations are based upon covariance matrices. Generally speaking, goodness-of-fit statistics with higher values (i.e., normed fit index [NFI], comparative fit index [CFI], and incremental fit index [IFI]) indicate better fitting models. For such indexes, it is desirable for the values to exceed .9 (Bentler, 1990). The exception is root mean square error of approximation (RMSEA). For this index, lower values indicate better fit, and ideally, the RMSEA will be below .06 (Hu & Bentler, 1999).

The initial hypothesis proposed a higher-order model, in which lower order latent variables were proposed to predict higher order latent variables. (See Figure 5). For example, care recipient impairment, is itself a lower order latent variable (with observed variables contributing to its estimation), while it is also contributing to the estimation of higher order latent variables, such as positive and negative appraisal. With such a model, it is recommended for appropriate model fit, that the lower level variables are adequately correlated before attempting to add higher order latent variables to the model. Correlations of .3 are the recommended minimum (Baer, 2006).

The lower level latent variables included demographics, care recipient impairment and caregiver effort. The demographic variables included caregiver sex, care recipient sex, interaction of caregiver and care recipient sex, caregiver age and care recipient age. The measurement model for the latent variable Caregiver Impairment is manifest by the five additive scale scores for ADL, IADL and three factors of the Memory Behaviour Checklist; Disruption, Depression and Memory. The measurement model for Caregiver Effort was manifest by three variables; duration of caregiving in years, hours a day caregiving, and hours a week in paid employment. In this case, the minimum correlations were not found between these lower level latent variables (See Table 20). Therefore, it would have been inappropriate to attempt to fit the proposed model with the higher order latent variables. Hence, Kramer's model of caregiver adaptation was not confirmed as a structural model of how the variables associated with caregiving influence the caregiver's health outcomes. The REACH data did not adequately fit this model.

A simpler model based only on positive and negative appraisal and caregiver health was modeled. (See Figure 6). In this figure, circles represent latent variables, and rectangles represent measured variables (i.e., indicators). Absence of a line connecting variables implies no hypothesized direct effect. A solid line indicates a direct effect. A dashed line indicates an effect that was hypothesized but found to be non-significant. (See Appendix C for tables of means, standard deviations, minimum and maximum values, correlations, and covariances in the simpler model). (See Table 21 for regression weights.)

The measurement model for the latent variable Negative Appraisal is manifest by the five additive scale scores for the bother items for the ADL, IADL and three factors of the Memory Behaviour Checklist; Disruption, Depression and Memory. This measurement model has reasonable fit, (chi square [5, $N = 1205$] = 58.9, $p < .001$; CFI

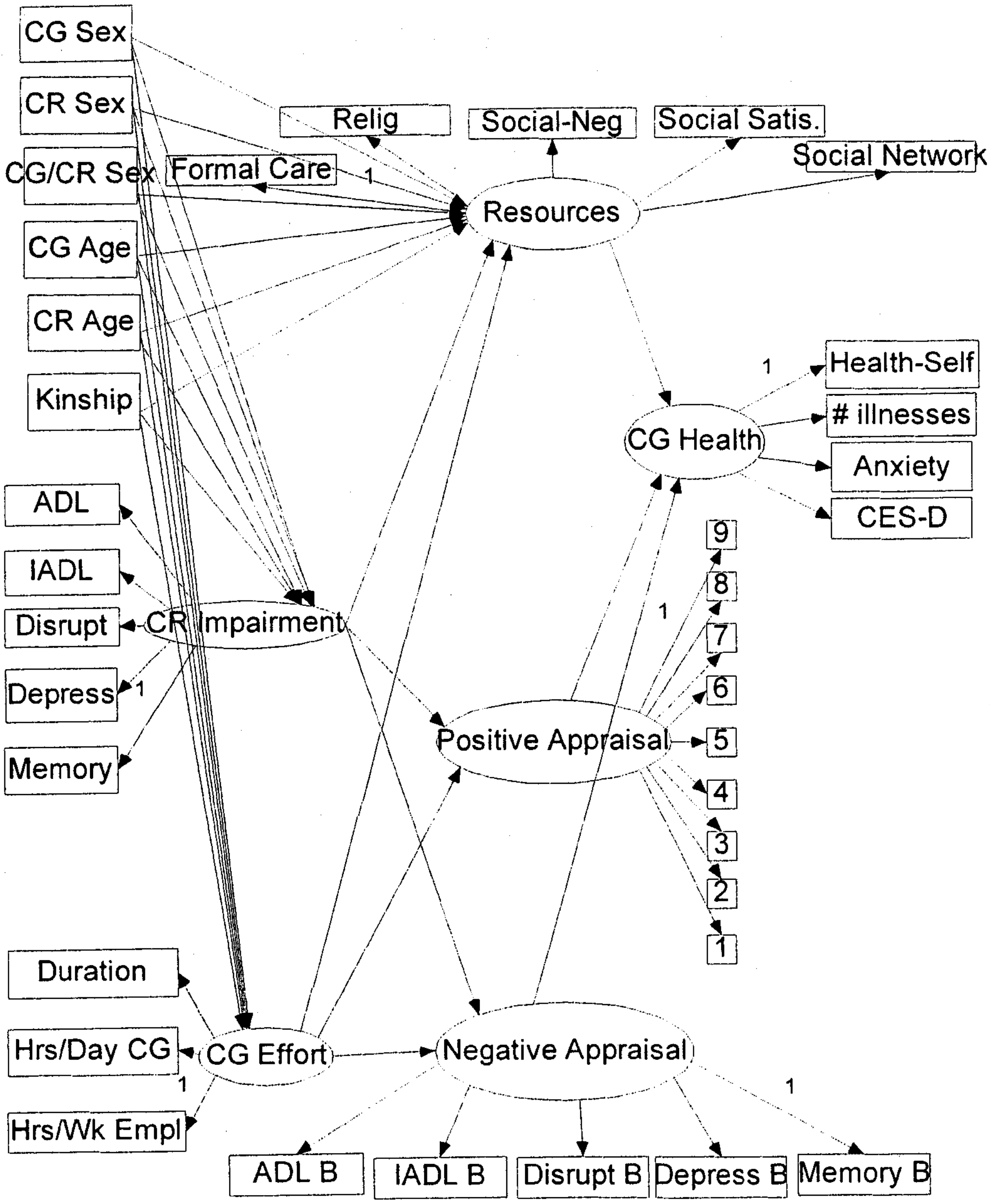
= .961, NFI = .958, IFI = .962, RMSEA = .095). The regression weights indicate that all paths in this model were statistically significant ($p < .001$). (See Table 21 for regression weights).

The measurement model for the latent variable Positive Appraisal is manifest by each of the 9 items on the scale. This measurement model has reasonable fit, (chi square [11, *N* =1205] = 19.018, $p < .001$; CFI = .998, NFI = .996, IFI = .998, RMSEA = .025). The regression weights indicate that all paths in this model were statistically significant ($p <$ .001).

Finally, the latent variable Caregiver Health is manifest by four additive scale scores; self-rated health, number of illnesses, anxiety scale, and CES-D. This measurement model has reasonable fit, (chi square [1, *N* = 1205] = 1.9, $p < .001$; CFI = 999, NFI = .998, IFI = .999, RMSEA = .028). The regression weights indicate that all paths in this model were statistically significant (p < .001). As each of the measurement models of the latent variables are adequate, it is suitable to attempt to fit the structural model (i.e., modelling relationships between these latent variables).

This structural model has reasonable fit (chi square [114, *N* = 1205] = 421.95, $p$ < .000; CFI = .961, NFI = .948, IFI = .961, RMSEA = .047). The regression weights indicate that all paths in this model were statistically significant (as indicated by solid lines in the diagram), with the exception of the path from Positive Appraisal to Caregiver Health (as indicated by the dashed line in the diagram). The regression weights represent the direct partial effect of an exogenous (or observed) variable on an endogenous (or latent) variable. A regression weight for a particular variable is considered statistically significant in the prediction of a latent variable when it is

*Figure 5*



Proposed higher order structural model of Kramer's conceptual model

Table 20

*Correlations Between Lower Level Latent Variables for Full Structural Equation Model*

| Variables | | | *r* |
|---|---|---|---|
| CG Effort | <--> | CR Impairment | -.493 |
| CG Sex | <--> | CR Impairment | .080 |
| CR Sex | <--> | CR Impairment | -.329 |
| Kin Relationship | <--> | CR Impairment | -.059 |
| CG Age | <--> | CR Impairment | -.256 |
| CR Age | <--> | CR Impairment | .058 |
| Gender Interaction | <--> | CR Impairment | .385 |
| CG Sex | <--> | CG Effort | .030 |
| CR Sex | <--> | CG Effort | .710 |
| Kin Relationship | <--> | CG Effort | .192 |
| CG Age | <--> | CG Effort | -.073 |
| CR Age | <--> | CG Effort | .032 |
| Gender Interaction | <--> | CG Effort | -.656 |

* CG = caregiver ** CR = care recipient

Table 21

*Regression Weights for Simplified Structural Equation Model*

| Variables | | | Estimate | S.E. | C.R.** | *p* |
|---|---|---|---|---|---|---|
| CG[1] Health | <--- | d1 | 1.433 | .096 | 14.913 | *** |
| CG[1] Health | <--- | Negative Appr. | .963 | .119 | 8.074 | *** |
| CG[1] Health | <--- | Positive Appr. | -.099 | .054 | -1.846 | .065 |
| IADLBother[2]* | <--- | Negative Appr. | 1.000 | | | |
| ADLBother[3] | <--- | Negative Appr. | .913 | .093 | 9.803 | *** |
| MemBhrDepBother[4] | <--- | Negative Appr. | 3.961 | .189 | 20.926 | *** |
| MemBhrDisBother[5] | <--- | Negative Appr. | 3.793 | .157 | 24.164 | *** |
| MemBhrMemBother[6] | <--- | Negative Appr. | 3.676 | .163 | 22.546 | *** |
| Self-Rated Health* | <--- | CG Health | 1.000 | | | |
| Number of Illnesses | <--- | CG Health | .100 | .019 | 5.389 | *** |
| Anxiety | <--- | CG Health | 3.613 | .406 | 8.907 | *** |
| CES-D Total | <--- | CG Health | 3.649 | .421 | 8.660 | *** |
| feel more useful | <--- | Positive Appr. | 1.000 | | | |
| feel good about self | <--- | Positive Appr. | 1.009 | .038 | 26.427 | *** |
| feel needed | <--- | Positive Appr. | .675 | .040 | 16.967 | *** |
| feel appreciated | <--- | Positive Appr. | 1.066 | .049 | 21.546 | *** |
| feel important | <--- | Positive Appr. | 1.040 | .043 | 24.341 | *** |
| feel strong and confident | <--- | Positive Appr. | 1.159 | .041 | 28.279 | *** |
| appreciate life more | <--- | Positive Appr. | .740 | .040 | 18.491 | *** |
| more positive attitude toward life | <--- | Positive Appr. | .924 | .042 | 21.823 | *** |

| Variables | | | Estimate | S.E. | C.R.** | *p* |
|---|---|---|---|---|---|---|
| strengthened relationship | <--- | Positive Appr. | .789 | .042 | 18.958 | *** |

* reference indicator
** C.R. = critical ratio
***$p < .001$
1 = caregiver 2 = Bother due to helping with Instrumental Activities of Daily Living 3 = Bother due to helping with Activities of Daily Living 4 = Bother due to Memory and Behaviour Problems Depression Subscale 5 = Bother due to Memory and Behaviour Problems Disruption Subscale 6 = Bother due to Memory and Behaviour Problems Memory Subscale

significantly different from zero, i.e., the probability of getting a critical ratio as large as the regression weight is less than .001.

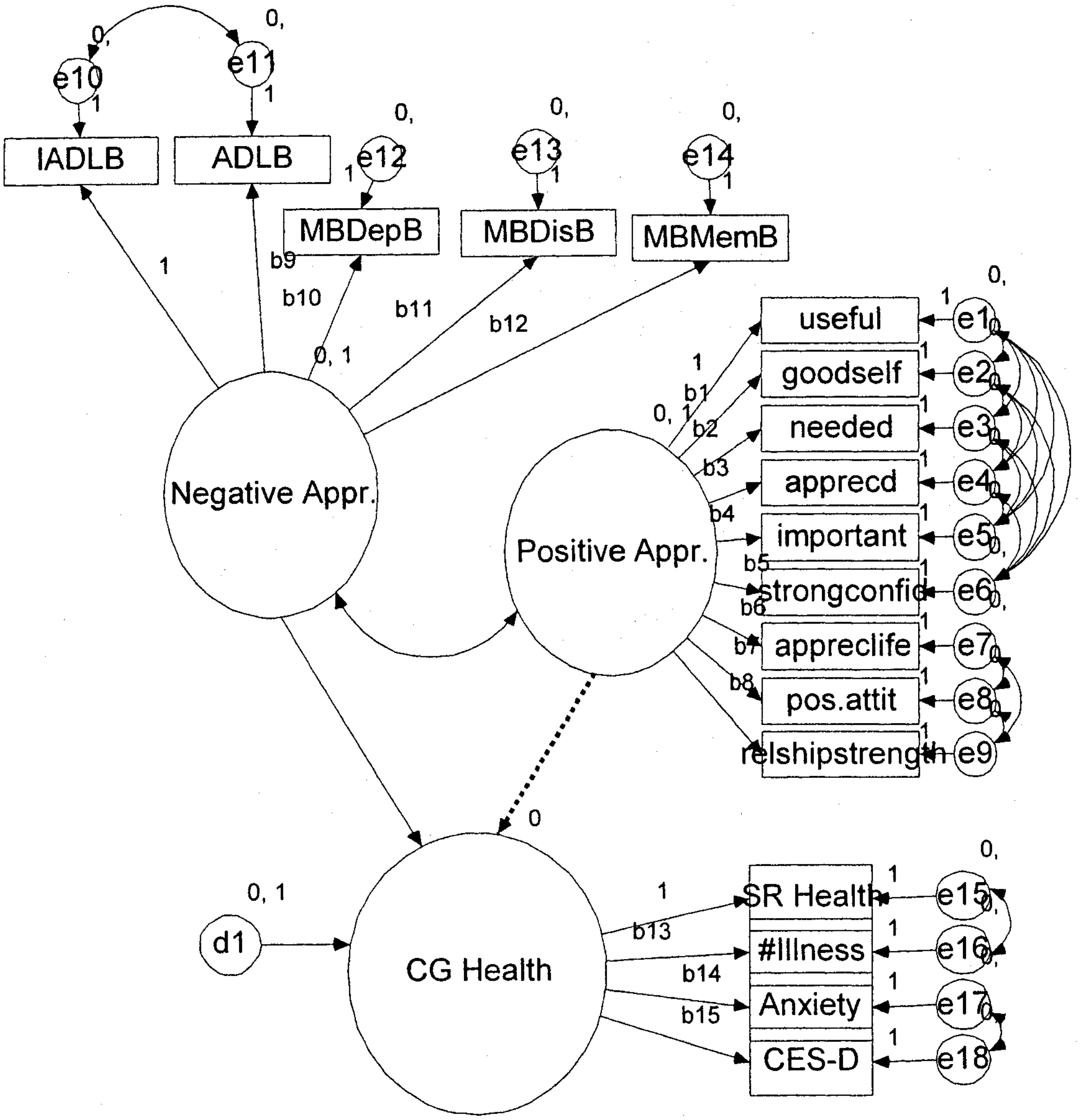
More specifically, the model shows that negative appraisal has a significant direct influence on caregiver health; the regression weight is .96, $p$ <.001. This means that the more negative a caregivers' appraisal is, the worse their health (as higher scores on caregiver health mean worse health). Hence, when the negative appraisal score increases by 1, caregiver health score increases by .96. Therefore, this structural model shows that caregiver burden (i.e., negative appraisal) and the physical and mental health of the caregiver are related. Because the data are not experimental, it is impossible to state that burden causes poorer health, or whether poorer health causes burden, or if there is another variable that is not modelled that could explain the relationship.

The regression weight for the relationship between positive appraisal and caregiver health was not significant, regression weight = -.099, $p$ = .065. Thus, when positive appraisal scores increased by 1, caregiver health scores decreased by -.099. The covariance between positive appraisal and negative appraisal was significant = -.260, $p$ < .001. Therefore, as negative appraisal increases positive appraisal decreases, and vice versa.

## Discussion

Understanding the complex relationships between demographics, appraisal and the health of Alzheimer caregivers was the overarching theme of this research. There were three more specific goals of this study.

*Figure 6*



Specifications of simplified structural model

The first goal was to better understand the construct of positive appraisal of caregiving. The creation of the Positive Aspects of Caregiving Scale was a vital contribution to this understanding. This measure has proven psychometrics, which permitted a more fine-grained analysis of how positive appraisal "behaves" both in isolation and in the context of many related caregiving variables.

The second goal was to gain insight into the influence of gender and kinship on caregiver appraisal, both positive and negative. Adding to the existing literature with respect to gender and kinship differences regarding negative appraisal (i.e., caregiver burden) was part of this goal, but it was also important to contribute to the sparse knowledge of how various caregiver groups appraise the positive aspects of caregiving.

Finally, the third goal was to utilize the findings about positive and negative appraisal, gender and kinship, in order to increase the understanding of caregivers' health outcomes. Incorporating both caregivers' physical health and mental health within this context was a priority. The extent to which these goals were met can be gauged as the results are discussed in the context of the existing caregiving literature. Limitations of the current research and suggestions for future research are also outlined.

### *Hypothesis A*

*Positive and negative appraisals will be found to be two distinct constructs, not one construct along a single bipolar continuum.*

Kramer (1997b) posited the hypothesis "that strain and gain are not simply opposites on a unidimensional continuum" (p. 226). (In this case, strain is another term for burden). However, Kramer (1997b) was referring to parallels with related literature on the differential correlates of positive and negative affect (Bradburn, 1969; Costa &

McCrae, 1980; Diener & Emmons, 1984). She did not test this hypothesis explicitly, as was done in the present study. Through various analyses, it is clear that subjective caregiver burden and caregiver gain are two separate and distinct constructs. Very weak negative correlations between positive and negative appraisal (i.e., $r$ = 0.1-0.2) in the REACH data, and the non-significant correlation in the CSHA data showed that positive and negative appraisal are distinct from one another. Hierarchical regression analyses indicated that positive appraisal had different predictors than negative appraisal. For example, in the REACH study, these two constructs had only 4 of 16 predictors in common (i.e., amount of cognitive impairment, number of care recipient disruptive behaviours, size of caregivers' social network, and the number of formal services utilized by caregivers) and the directions of these findings differed by construct. The CSHA data showed only one predictor in common for positive and negative appraisal (i.e., kinship). Also, examining the distribution of four patterns of appraisal (i.e., high burden and high gain, low burden and high gain, high burden and low gain, low burden and low gain) demonstrated that in fact, caregivers can, and do, appraise their situations in any of these four combinations.

Because the focus on positive aspects of caregiving is a newer development in the literature, this construct, also known as caregiver gain, is less well understood. The finding that caregiver burden and caregiver gain are not simply two ends of a bipolar continuum of caregiving appraisal is important to further explicate the construct of positive appraisal. The fact that there are two distinct constructs means that there is a group of caregivers who report very high levels of burden, but still find numerous positives in their caregiving situation. In fact, one quarter of caregivers in the REACH database reported this pattern, while 7.2% of caregivers in the CSHA database reported this pattern. In particular, one REACH participant reported that she experienced some strong positive aspects of caregiving, including feeling needed and appreciating life more, while also feeling extremely burdened by having to help her care recipient with certain tasks, such as laundry and finances. Therefore, although this woman was feeling quite overwhelmed and burdened by her caregiving, she simultaneously reported gaining a great deal from undertaking this task. A parallel, in a different context, would be parents caring for their children; while many parents report worry and experience distress in their role as parents, most parents also report that caring for children is also very meaningful and a frequent source of pleasure for them (Umberson & Gove, 1989).

Of course the opposite is also true; a particular caregiver could have very low levels of burden and find very few positive aspects of caregiving. Approximately one fifth of caregivers in the REACH database reported this pattern, while approximately one third of CSHA participants did. Such a situation would be less demanding or difficult, but also less rewarding that the previously described caregiving situation. Other caregivers report high burden and low gain. Approximately one quarter of REACH participants reported this pattern, while 41% of CSHA participants did. These caregivers were experiencing a very overwhelming caregiving situation and did not report experiencing many positive aspects from these situations. Finally, the largest group of REACH participants (30.9%) and approximately 1/5 (18.5%) of CSHA participants experienced a lot of positives from caregiving and low amounts of negative appraisal. These caregivers did not feel particularly burdened by their situations, but did find that they gained a lot from caregiving.

A similar analogy can be made with constructs of objective and subjective caregiver burden. Caregiver burden is a fairly robust construct within caregiving research. It has been well researched and well validated in the literature over a number of years (Coon et al., 2004; Haley et al., 2004; Hebert et al., 1994; O'Rourke & Tuokko, 2003a; Roff et al., 2004; Zarit et al., 1980). However, there is a clear delineation between objective burden and subjective burden. Objective burden entails the actual tasks with which the caregiver must provide assistance. Subjective burden is defined as the negative appraisal of the caregiving situation, for example, feeling overwhelmed, feeling incompetent. There are good psychometric tools to measure these constructs, which has facilitated the finding that objective burden and subjective burden are not strongly correlated (Mittelman et al., 1995; Montgomery et al., 1985).

This finding had serious implications for the understanding of the caregivers' experiences. For example, subjective burden is more strongly related to negative health outcomes (i.e., cardiac problems, diabetes, symptoms of depression or anxiety) (Harwood et al., 2000; Williamson & Schulz, 1993). Hence, interventions focusing solely on objective burden may not be the most effective at reducing subjective burden, and in turn, improving associated health outcomes. Furthermore, without understanding that objective burden and subjective burden are distinct constructs, it would have been difficult to understand why subjective burden did not necessarily decrease with interventions such as respite care despite decreased objective burden (Acton & Kang, 2001; George & Gwyther, 1986; Montgomery et al., 1985). Similarly, understanding the differences between subjective burden (or negative appraisal) and caregiver gain (or positive appraisal) will lead a to better understanding of their respective contributions towards health outcomes.

While the data confirm that positive appraisal and negative appraisal can co-exist, it is important to have theory to explain how these constructs can co-exist. For instance, how can a caregiver report immense burden and still find positives in their situation? Yet, the broader psychological literature offers a possible explanation. As Kramer (1997) alluded, the literature on positive affect and negative affect demonstrates that caregivers are not unique in their ability to report positive and negative aspects concurrently. When Bradburn (1969) measured positive and negative affect, he also found that they were not mere opposites. They were two independent constructs that had separate predictors and related to other external variables differently. Costa and McCrae (1980) posited that broad personality traits are the reason why these two affective states can exist independent of one another. For instance, those low in neuroticism are seldom depressed, but also seldom elated. Perhaps it is these people that report low subjective negative appraisal and low positive appraisal. Conversely, Costa and McCrae (1980) hypothesized that those high in extraversion tend to experience extreme affect, so these people are often elated but also often depressed. Hence, it is possible that caregivers who report high negative appraisal and high positive appraisal are highly extraverted people.

Therefore, to better understand how and why positive and negative appraisal can be distinct, studying caregivers' personalities may be necessary. This may be helpful to understand how to help certain caregivers. According to Diener and Emmons (1984), once clinicians applied the Bradburn's findings, they soon realized that some clinical problems were related to a lack of positive affect, rather than simply an abundance of negative affect. Perhaps this is the case for caregivers: those who experience little gain (or positive appraisal) in their caregiving situation could suffer more than those with similar levels of negative appraisal but greater levels of positive appraisal. Should this prove to be true, interventions could focus not only on reducing burden, but also increasing gain. To date, these are merely speculations as it was beyond the scope of this research to establish how or why these two constructs co-exist. It was a vital first step to simply establish that they can co-exist. These further questions hold potential to provide rich qualitative data in future research.

### *Hypothesis B*

*Positive and negative appraisals will change over time.*

Understanding whether appraisal changed over time was important on both a theoretical level and on an applied level. Whether or not Kramer's (1997b) conceptual model of caregiver adaptation is confirmed or disconfirmed depends partially upon whether appraisal is dynamic or static. This model incorporates various theoretical frameworks and includes background variables, such as age and gender of caregivers and care recipients, intervening processes (including resources and caregiver appraisals), and well-being outcomes (such as mental health and physical health variables) (See Figure 1). The word *process* implies that appraisal is dynamic, that is, has the potential to change. If appraisal does change over time, the model holds, because according to the model, if background characteristics change, or resources change, then the intervening process of appraisal should change, and in turn, the well-being outcomes should change. The mechanisms of change for health outcomes are important to understand in terms of devising effective caregiver interventions. For example, interventions could be tailored to specifically decrease negative appraisal or increase positive appraisal if these changes are shown to effect positive influence on the manifestations of chronic physical or mental illness. On the other hand, if appraisal is simply the product of the background and context variables and the resources available, and hence is not malleable to intervention, then interventions should focus on providing tangible resources (i.e., respite care) to caregivers in order to positively influence their well-being outcomes.

Two approaches were taken to answer this question; examining group mean differences over time (i.e., statistical significance), and examining individual change over time (i.e., clinical significance). For negative appraisal the results were fairly consistent; on average, caregivers appraised their situations less negatively as time went on. Specifically, the analysis of variance showed that as a group, participants had significantly lower negative appraisal scores over time. Individual regression analyses showed that the slope was negative, also suggesting that negative appraisal decreases over time. Finally, of the 43.24% of participants who demonstrated a clinically significant change in their scores from Time 1 to Time 4, 32.8% of them decreased their negative appraisal scores. Clearly, for a large portion of REACH participants, negative appraisal begins at a high level and tempers as time passes, but for others, burden increases significantly. It is important to keep in mind that some of the participants were randomized into active interventions, which could have influenced their appraisals at Time 4. The focus of the current study was not to examine the effectiveness of the interventions, which is why the participants were not separated on this basis. The important take-home message of the results of this hypothesis is that appraisal can be dynamic. Therefore, this aspect of Kramer's conceptual model of caregiver adaptation is confirmed.

A study by Winslow and Carter (1999) further confirms that appraisal has the potential to change over time, and therefore is not generally a static variable. However, they found that a subset of caregivers experienced more burden over time. In their study, Winslow and Carter (1999) were attempting to compare the caregiver burden over time between female spouse caregivers who continued to care for their demented husbands, and those who placed their husbands in long term care. For each of the placement cohorts (the spouses who placed their husbands in care at some point during the 36 month study), the wives reported increased burden until such time that they placed their spouses in long term care, after which there was a precipitous decline in burden at the next interview. The group that continued to care for their spouses at home throughout the 36 months of the study did not appear to report clinically significant increases or decreases in their burden levels throughout the study. It makes sense to assume that as subjective burden increased to intolerable levels, wives would place their husbands in care, after which their subjective burden would decrease. Therefore, the placement group experienced important substantive differences compared to the continuing care group. The placement group demonstrated further evidence that for at least a proportion of caregivers, appraisal is dynamic. However, the continuing care group seems to align with the portion of REACH participants who did not evidence clinically significant change in their appraisals over the course of the study.

Gaugler, Kane, Kane and Newcomer's (2005) study offers some explanation of who's appraisal is dynamic, and who's is static. In this study, when the care recipient was institutionalized, participation in the study ended (Gaugler, Kane, Kane, & Newcomer, 2005). Gaugler and colleagues (2005) found that the participants who remained in the study for longer periods (i.e., delayed institutionalization of the care recipient longer) were caring for care recipients who suffered less severe functional and behavioural impairment compared to participants who remained in the study for shorter periods. These caregivers who remained in the sample indicated less intense feelings of burden over time (Gaugler et al., 2005). Gaugler and colleagues (2005) found that in the short term, appraisals of burden were very dynamic. For caregivers who institutionalized within the first year of the study, behaviour problems were closely associated with caregiver burden. Conversely, the longer a caregiver remained in the study, the more static their burden appraisals became in light of key covariates (i.e., what Kramer would classify as background and context variables). Hence, these results show how in some situations, appraisal can be quite dynamic, but once other contextual variables are considered, burden becomes more static. This could explain why some caregivers in the REACH study do not appear to evidence clinically significant change in their appraisal scores over the course of the study, while others demonstrated dramatic changes in their appraisals over the same time frame. Regardless, it seems clear that appraisal can change over time, which supports Kramer's model. The question of how it changes and for what reasons remains to be clarified.

The current data show that decreases in burden is the predominant pattern of change in appraisal (i.e., less burden over time). The REACH data showed that one third of caregivers' negative appraisals increased significantly over time, while two thirds of caregivers' negative appraisals decreased significantly. Townsend and colleagues (1989) found that more caregivers decrease in burden over time than those that increase in burden over time. Others conclude from their data that over time, caregivers improve in their ability to tolerate difficult situations in caregiving, even as the problematic situations increase, hence, they express less burden over time (Zarit, Todd, & Zarit, 1986). There is little evidence to corroborate Winslow and Carter's (1999) contention that burden increases over time. However, their results showed a peak in burden just before a transition (i.e., institutionalization) followed by a decrease in burden. Therefore, looking at the overall trend, even these caregivers' burden decreased over time. However, it is important to consider survivor bias in this case. If caregivers are thoroughly overwhelmed and expressing a lot of negative appraisal, they may be less likely to continue caregiving, whereas those who learn to cope with their situations effectively may be more likely to continue providing care. Therefore, for those who have long caregiving careers, they could be more likely to experience a decrease in negative appraisal over time. Therefore, there could be a significant portion of caregivers for whom burden does not decrease over time. This raises the important issue that changes in appraisal may not move in only one direction, particularly in light of Winslow and Carter's (1999) findings that burden peaks at transition times. Burden could spike or drop at various stages of caregiving. This does not diminish the importance of these findings in light of Kramer's model. The model does not specify a direction, it simply posits that appraisal is dynamic and intervenes between the background and contextual variables and the well-being outcomes.

Accepting the idea that burden can increase and decrease at various points during the caregiving career complicates the matter of determining a theory that can explain the dynamic nature of caregiver appraisal. Much of the current data supports the prevailing wisdom that the adaptation hypothesis is a more appropriate theory than the wear and tear theory, with which to understand change in the appraisal of burden over time, as the amount of burden decreases over time (Stephens & Zarit, 1989; Townsend et al., 1989). Hence, as caregiving continues, caregivers become acclimated to their duties, and perhaps even become better at completing them, hence making their appraisals of their situation remain stable or even become less negative over time. The studies by Suitor and Pillemer (1994) and Townsend, Noelker, Deimling and Bass (1989) are examples of earlier studies that support the adaptation hypothesis. Although they found that burden scores remained stable over time, whereas the current study noted that the majority of caregivers experience a decrease over time, these can both be interpreted as support for the adaptation hypothesis (Suitor & Pillemer, 1994; Townsend et al., 1989).

Nevertheless, approximately 10% of participants had a significant increase in their negative appraisal over time, so the adaptation theory obviously does not apply to all caregivers. The factors that determine whether one adapts to the situation or experiences wear and tear are poorly understood. Walker, Acock, Bowman and Li (1996) propose that it depends upon the amount of care given, but this does not explain the entire picture. Therefore, it may not be appropriate to determine which theory is "right", but rather understand that they are probably both helpful in understanding certain aspects of caregiving situations. Future research could illuminate the appropriate applications of these theories. For example, longitudinal studies like Gaugler and colleagues' (2005) which examined the changes over time and which covariates best explained those changes, would be particularly beneficial to flesh out the answer to this theoretical question. Such growth-curve analyses could determine the background and contextual variables that predict a period of adaptation (e.g., length of caregiving) versus the circumstances that would precipitate a period of wear and tear for caregivers (e.g., care recipient's functional decline).

Unfortunately, the data are somewhat murkier regarding whether positive appraisal changes over time. The group data showed no significant difference in positive appraisal over time. The analysis of variance was not statistically significant, and the slope on the scatterplot of regression coefficients was not significantly different from zero, suggesting that on average, there was no significant change in positive appraisal over time. However, this can be explained by the information gleaned from the analysis of clinical significance. It would appear that a large number (42%) of the participants experienced changes in their positive appraisal scores by more than 10% from baseline to the final interview, an approximately equal number of people increased as decreased their PACS scores by 10%. Therefore, when the group means are examined, the effects of these clinically significant differences are washed out. So, it would appear that positive appraisal of caregiving does in fact change significantly over time for many individuals. However, understanding the reason for this variability is difficult. Neither the wear and tear hypothesis nor the adaptation hypothesis can adequately explain why changes occur in one direction for some caregivers, and the opposite direction for other caregivers. Walker and colleagues (1996) suggest that perhaps both of these theories are at work for certain caregivers in certain situations. Similar longitudinal research as described above (i.e., using growth curve analysis to find covariates) could illuminate the factors regarding changes in positive appraisal also.

Very few studies exist that examine caregiver gain or positive appraisal over time, as the construct is still relatively new. However, Walker and colleagues (1996) studied caregiver satisfaction over time. Caregiver satisfaction was measured with a 10 item semantic differential measure. Caregivers, all of whom were daughters, were asked "Here are some words and phrases that we would like you to use to describe how you feel about assisting your mother". Examples of the semantic pairs would be enjoyable & miserable, hopeful & discouraging, rewarding & disappointing. Although this is a somewhat different construct than how the current study has conceptualized positive appraisal, it is the only example in the literature of how a positive construct changed over time. Similar to the results of the current study, Walker and colleagues (1996) found that there was great individual variability in caregiving satisfaction over time. Unlike the current study, Walker and colleagues (1996) found that there was a mean decline in caregiver satisfaction over time (i.e., the duration of the study), but the decline was not associated with duration of caregiving. However, they found a relationship between the amount of care given and decline in caregiver satisfaction. They explain these relationships in the context of an elaborated wear and tear hypothesis. Rather than the simplistic wear and tear hypothesis, that posits that the longer care is provided, the more negative the outcomes, the elaborated hypothesis incorporates that as the amount of care (e.g., number of ADL/IADL tasks the caregiver is performing for the care recipient) provided increases, so does the rate of negative outcomes. In Walker and colleagues' (1996) study, for each one standard deviation increase in the amount of care provided, there was a corresponding ½ standard deviation decrease in caregiver satisfaction. Future research could specifically examine this elaborated hypothesis specifically in respect to the construct of positive appraisal.

### *Hypothesis C*

*Including positive appraisal will increase the amount of variance in health outcomes accounted for over negative appraisals alone.*

It was an important goal of this research to understand how caregivers' appraisals influenced their health outcomes. Hierarchical multiple regression analyses were conducted to achieve this goal. Demographic and baseline data were entered in the first step of each regression, negative appraisal was entered at the second step and positive appraisal was entered in the last step. This process was used to predict four types of outcomes: self-rated health, number of illness diagnoses, depression, and anxiety.

Self-rated health was significantly predicted in the REACH data by caregiver age, social network, negative social interactions, formal service utilization and negative appraisal. The parallel analysis with the CSHA data also did not increase the amount of variance accounted for in self-rated health.

Both REACH and CSHA data significantly predicted the number of illnesses with which a caregiver had been diagnosed. Age and negative appraisal were significant predictors in both datasets, while in the REACH data, care recipient depressive behaviours and negative social interactions also significantly predicted illness diagnoses. Positive appraisal did not increase the amount of variance accounted for in the number of illnesses diagnosed in caregivers.

Depression was predicted significantly in both the datasets. In the REACH dataset depression was significantly predicted by number of ADLs with which the care recipient required assistance, size of social network, negative social interactions, formal services used, and negative appraisal. Interestingly, in the CSHA data, only negative appraisal was a significant predictor of depression. Once again, positive appraisal did not account for more of the variance over the demographic/baseline variables and negative appraisal.

Anxiety was only included in the REACH data. Gender, number of ADLs with which the care recipient required assistance, depressive behaviours of the care recipient, size of social network, negative social interactions, formal service utilization, social support, and negative appraisal were all found to predict anxiety scores. Positive appraisal was a significant predictor in the case of anxiety, hence, it did increase the amount of variance accounted for beyond the demographic/baseline variables and negative appraisal. With positive appraisal included, 29.4% of the variance was accounted for.

The analysis revealed that less positive appraisal predicted more anxiety in caregivers. This could mean that when one is more anxious, it is more difficult to see positives in ones' situation. Conversely, if one cannot see positives in ones' situation, one becomes more anxious than those who can find a bright side to caregiving. In theory, the same sentences could be true with the word depression replacing anxiety. In fact, in the REACH dataset, depression and anxiety scores were strongly correlated (i.e., $r = .646, p < .001$). Therefore, why does positive appraisal add significantly to the prediction of anxiety, but not depression, given that these constructs are so seemingly similar? One possible rationale could be related to the way in which anxiety and depression were measured in the REACH study. Depression was measured with the CES-D scale, which examines a number of symptoms of a major depressive episode in the previous week, in order to determine whether the subject is at risk of suffering from major depression. On the other hand, anxiety was measured with part of the State scale from the State-Trait Anxiety Inventory. Therefore, rather than establishing whether a person is by nature, anxious (i.e., trait anxiety), the REACH study only captures symptoms that a person has been anxious in the week prior to completing the questionnaire, with items such as "I felt tense", "I felt nervous" and "I felt jittery". Therefore, using this measure only captures how anxious a caregiver was in the week prior to the data collection, not whether they tend to be this way on a regular basis. For example, if the caregiver had a particularly stressful week, he or she could have reported experiencing many anxiety symptoms, but this does not necessarily mean that this person would be diagnosed with an anxiety disorder. Hence, unlike the CES-D that gives an approximation of risk of a major depressive episode given particular sequelae of symptoms during the previous week, the state anxiety measure does not include the symptoms of a particular diagnosable anxiety disorder. Instead this measure describes a state of heightened stress and worry. Therefore, the constructs examined in these scales are actually quite different, despite the seeming similarity in the constructs they purport to measure. This may partially explain the differences in the predictive nature of positive appraisal scores. Specifically, if a caregiver is at risk of suffering a major depressive episode, whether or not they appraise any positives to their caregiving situation may be inconsequential to predicting such a diagnosis. Therefore, positive appraisal may not add anything to the prediction of a possible depressive episode. However, if one is currently experiencing a higher amount of stress and worry, the extent to which one is able to note positive aspects of their situation could be important to the prediction of their current anxiety level. The amount of positive appraisal may not be predictive of an anxiety disorder, like it was not predictive of a depressive disorder, but trait anxiety and state anxiety are quite different. In the current study, the comparison of an anxious state and a possible episode of depression is akin to comparing apples to oranges. Investigations that utilize standardized structured interviews for anxiety and depressive symptoms or disorders could be beneficial to understanding the role of positive appraisal in psychopathology and caregivers' mental well-being.

Although caregivers' amount of positive appraisal was not found to be predictive of all the health variables, one aspect of social support (i.e., negative interaction) was related to all four of the health outcomes. This subscale tapped into the number of times in the previous month that the caregiver perceived that he or she had been taken advantage of, had too many demands placed on him or her by others, had others prying into his or her affairs or when others had been critical of him or her. The higher the caregiver's score on this subscale, the poorer his/her self-rated health, the more chronic illnesses he/she endorsed as having been diagnosed with, and the higher his/her scores on the anxiety and depression measures. This was not the case for the other two aspects of social support (i.e., caregivers' social network, and received social support and satisfaction).

It appears that there is something specific about negative interactions that wield a strong influence on health or vice versa. As always, direction of the effect is difficult to establish. Are people who have a lot of negative social interactions less healthy, or are more depressed, anxious and physically unwell people more prone to such interactions with others? Current literature does not elucidate the answer to this question well, despite great amounts of discussion about social support in the caregiver literature. Chang, Brecht and Carter (2001) point out that the caregivers who were handling a larger number of roles (i.e., caring for more than one care recipient, employment outside of the home etc.) tended to have the most difficulty with their social networks. Such role overload is also related to burden and depression. Hence, when one is "overloaded", one may have more people with whom they could have a negative interaction, and these two factors could both be related to poorer health outcomes. Therefore, negative interactions may not have a simple linear relationship with health outcomes.

Specific hypotheses exist to explain how social networks influence the health of caregivers. The buffer hypothesis posits that the effect of social network and social support is to buffer or moderate the effect of stress on mental health (Olstad, Sexton, & Sogaard, 2001a). Olstad, Sexton and Sogaard (2001) found that the total network/support level (i.e., number of families with which the individual had regular contact) buffers the adverse effects of all types of stress. Hence, mental health was better in spite of great stress, if the caregiver reported larger social networks.

But what if the social network causes more stress than it relieves? In light of the popular buffer hypothesis, much of the research on caregivers' social support frames it in a solely positive light and completely ignores any possibility of social networks having any negative implications (i.e., increasing numbers of people with whom the caregiver has contact regularly acts as a buffer for the stresses of caregiving). For instance, some studies even explicitly state that caregivers are to list the people they perceive as important in their lives, whether they like them or not (Wallsten, 2000). This type of question assumes that everyone important in a caregiver's life could positively buffer the caregivers' mental health. However, what if these important people are not particularly supportive of the caregiver in question, or worse, what if these people are a negative influence on a caregivers' mental health because they are creating more stress for the caregiver? Some measures of social support completely ignore the possibility that social support could have a negative result (Olstad et al., 2001a). Despite this, there is some evidence that social networks can be an additional source of stress for caregivers. Women reported that there was more conflict in their social networks than men (Hibbard et al., 1996). Such conflict (another term for negative interactions) has been shown to be a predictor of both burden and caregiver depression (Chang, Brecht, & Carter, 2001; Rankin, Haut, & Keefover, 1992). Chang, Brecht and Carter (2001) also found that conflict was positively correlated with caregiver burden and negatively correlated with satisfaction. Rankin, Haut and Keefover (1992) concluded that such conflict could potentially be more harmful to the caregivers' health than the absence of a social network.

Therefore, discovering that the negative interactions in a caregiver's social life have a negative influence on caregiver health outcomes was an important unforeseen result of this study. This finding reiterates the importance of considering both positive and negative implications when researching social aspects of a caregiver's life. It is also important for clinicians and agencies providing intervention or assistance to caregivers to not assume that having certain social networks always make a positive contribution to the caregivers' health and well-being. These data clearly show that there is a relationship between negative social interactions and poorer health outcomes.

### *Hypothesis D*

*Women will appraise caregiving more negatively (i.e., higher burden scores) than men caregivers.*

Although caregivers in the REACH and CSHA studies are overwhelmingly women, and often spouses, it is important not to ignore caregivers who are men or have different kinship relationships to their care recipients. The current study found numerous interesting findings about the similarities and differences between men's and women's caregiving appraisals, and those between spouses and other caregivers.

To date, it appears to be a well-substantiated finding that female caregivers experience more caregiver burden than male caregivers. (Dura et al., 1990; Fitting et al., 1986; Lutzky & Knight, 1994; Miller & Cafasso, 1992; Pinquart & Sorensen, 2006; Stoller, 1983; Thompson et al., 2004; Yee & Schulz, 2000). However, in the case of caregivers in the current study, no significant differences were found between men and women on negative appraisal or burden.

These non-significant findings could be partially explained by cohort effects. Gender differences in caregiving are diminishing over time according to some researchers. Therefore, the trend is that, "caregiving experiences of men and women have become more similar in recent cohorts" (Pinquart & Sorensen, 2006). There are examples of recent studies in which male and female caregivers do not show significant differences on measures of caregiver burden (McConaghy & Caltabiano, 2005; Takano & Arai, 2005). The current results replicate these findings. McConaghy and Caltabiano (2005) and Takano and Arai (2005) both use the Zarit Burden Interview like many of the older studies, so it is not a matter of different measures leading to different results in burden scores. However, cohort effects may not account for the entire effect (or more appropriately, lack thereof) because the REACH study began collecting data in 1995, and the CSHA study began collecting data in 1991, not long after some of the older studies were published. Also, it is unclear how gender differences in burden, which were robust findings for many years, essentially disappeared in a number of recent studies. Surely gender roles and socialization have not changed so dramatically so quickly as to explain these changes? Future research will have to continue to monitor whether gender differences in negative appraisal continues or whether McConaghy and Caltabiano (2005), Takano and Arai (2005) and the current results are anomalies or the continuance of the trend noted by Pinquart and Sorensen (2006).

### *Hypothesis E*

*Women will have more positive appraisals of caregiving.*

To date, the research has been sparse comparing positive appraisal in men and women. The literature has been consistent in the finding that women report more burden and psychological distress in the caregiving role than men (Marks et al., 2002; Miller & Cafasso, 1992; Stoller & Cutler, 1992; Yee & Schulz, 2000). The few studies that have directly compared men and women on gain, positive appraisal or psychological well-being, have found that women caregivers tend to experience more of these positive constructs than men caregivers (Gold et al., 1995; Kinney & Stephens, 1989b; Marks et al., 2002). The current study aimed to replicate these results. When researchers examine gender differences in burden, they increase their understanding of how women and men experience caregiving. This provides insight into how to intervene and help caregivers more effectively. A better understanding of the gender differences in gain or positive appraisal could provide similar insight in terms of developing helpful interventions in the future.

The findings of the current study do not support the hypothesis that women appraise caregiving more positively than men. The CSHA data revealed no significant gender difference on positive appraisal. The results of the REACH study were opposite to the expected relationship; male caregivers were found to have higher positive appraisal scores than female caregivers.

These results run counter to the two existing studies which have addressed this gender difference. Gold and colleagues (1995) found that women caregivers reported more burden, but also more enjoyable aspects of caregiving. The way in which positive or enjoyable aspects of caregiving were measured was quite different in Gold's study than the REACH data. The REACH study included a psychometrically strong instrument to measure the positive aspects of caregiving. This measure allowed caregivers to read a number of possible positive aspects of caregiving and rate them on each of these dimensions. Gold and colleagues (1995) asked caregivers an open-ended question in which they were to identify "any aspects of caregiving which they enjoyed or which gave them satisfaction" (p.190). This task is quite different, in that caregivers have to spontaneously generate examples of what they enjoyed about caregiving, rather than look at possibilities and rate themselves. Perhaps men were not as able as women to identify the things they found enjoyable about caregiving. However, once they saw the options of what other people had identified as enjoyable, they saw that they did in fact find some aspects of caregiving enjoyable, even if they had not previously articulated this notion.

The measurement issue would at least partially explain the different results for the REACH study, but it fails to explain the CSHA results. The CSHA study had a component of their questionnaire in which they asked people a similar open-ended question: "Do you find any positive aspects of caregiving? If Yes: Could you briefly tell me what some of these are?" (CSHA, 2002). In responding to this question, men and women did not differ. Therefore, something else must explain the difference in results.

Also, the Kinney and Stephens (1989) study does not bear out the idea that men will report more positive appraisal if given the option to choose from a pre-established list. In this study, Kinney and Stephens examined the hassles and uplifts of caregiving. They had previously developed the Caregiving Hassles and Uplifts Scale. This scale was composed of a list of things that typically happen while caregiving and asked caregivers to identify whether each event was a hassle, an uplift, neither or both. They found that while women appraised more events as hassles than men, they also report more uplifts than men.

Perhaps these inconsistent results are merely an artifact of the inconsistency in measuring positive appraisal to date. Until the REACH study, an instrument measuring positive appraisal with strong psychometric properties did not exist, and therefore each study used different methods to tap into this domain. These different methods could warrant different results, as they demand different behaviours in order to respond (i.e., rating certain items, generating possible positive outcomes of caregiving). Now that the Positive Aspects of Caregiving Scale is available, future research should aim to examine this hypothesis again in other populations in order to determine whether there are consistent gender differences on positive appraisal.

Although there is a dearth of literature on positive appraisal with which to posit a hypothesis, it was surprising to find that males appraised their situations more positively than females. However, one could question the clinical significance of the differences in positive appraisal between men and women caregivers. Because the REACH study has a large sample size, statistically significant results can be found even when effect sizes are small. It may be unwise to overinterpret this gender difference. This finding has a very small effect size and the difference between the mean for females ($M = 33.42$) and the mean for males ($M = 36.05$) is not clinically significant, according to the criteria utilized above (i.e., 4 points, or 10% difference in score).

However, if these differences are real, research on gender differences in other factors could explain why men appraise their situations more positively than women. For example, women caregivers experience less internal control, more depression, more anxiety, and more guilt than male caregivers (Almberg et al., 1998; Gold et al., 1995; Miller & Cafasso, 1992; Thompson et al., 2004; Yee & Schulz, 2000). In addition, women care for more impaired care recipients, (Miller & Cafasso, 1992; Neal et al., 1997). Women also do a broader range of tasks (for instance, more ADLs and IADLs) (Stoller, 1990). In light of these difficult negative emotions and psychiatric morbidities, and apparently more challenging caregiving situations, it may be more difficult for women to perceive the positive aspects of their situation as readily as men do. However, this is purely speculative. Future research needs to first determine whether this finding is replicable, and if so, research needs to address the question of why male caregivers appraise more positively than female caregivers directly.

One theory of gender differences may shed light on this particular question. Later-life role changes (i.e., retiring, children leaving home) may result in changing psychological needs for men and women (Guttman, 1994). Guttman posited that due to these changes, men want to be more nurturing toward others, while women want to shift away from a nurturing focus toward a focus on productivity and assertiveness. These changing needs could influence how men and women interpret their caregiving roles. In keeping with the current result, men may find more positive aspects in caring for the care recipients than women because they have a current desire or goal to be more nurturing at this particular stage of their lives. On the other hand, women, who have in most cases, been nurturing for much of their adult lives, may currently want a change in role, aiming toward freedom from caregiving. Consequently, women may find fewer positive aspects of caregiving than men, because this role no longer fits with their goals and desires for their current stage in life.

Some researchers have found gender differences on measures of psychological well-being, both positive and negative, that lend some credence to the current findings. For example, while transitioning into a spousal caregiving role, women experience a greater decline in well-being dimensions, such as significantly greater hostility, greater decline in personal mastery, lower levels of environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance than male caregivers in parallel situations (Marks et al., 2002). However, women caregivers of parents experience less happiness, less autonomy and more hostility than men caregivers of parents, while men experience increases in distress, less personal mastery, decreased positive relations with others, and less self-acceptance than women caregivers (Marks et al., 2002). Therefore, Marks, Lambert and Choi (2002) conclude that generally women caregivers experience greater declines in psychological well-being, but this finding is inconsistent across caregiver-care recipient relationships. Hence, they conclude that while gender differences exist, it is not the case that neither women caregivers nor men caregivers as a whole experience more suffering as caregivers. While psychological well-being is a different construct than appraisal, the lessons of this study could hold in appraisal research also. Because the mean difference between men and women on positive appraisal in the REACH study was so small, it may be erroneous to assume that there are consistent or global gender differences on this construct. Perhaps clearer findings would result from examining smaller subgroups in future research.

Furthermore, as noted in the discussion of the previous hypothesis, there may be a trend in which gender differences in caregiving are diminishing over time, and that in more recent caregiver cohorts, caregiving experiences of men and women are more similar than in the past (Pinquart & Sorensen, 2006). If Pinquart and Sorensen (2006) are correct, and differences in caregiving appraisals are diminishing, perhaps this applies to both positive and negative appraisal. Because there has not been as long a history in measuring positive appraisal as there has been in terms of burden, it may be difficult to capture these cohort changes. However, it may be important to keep this finding in mind in future studies of gender and positive appraisal.

*Hypothesis F*

*Women caring for men will report more burden than other gender combinations of caregivers and care recipients.*

While much has been said about simple gender differences in caregiving, it is also important to consider the interaction between the gender of the caregiver and the gender of the care recipient. For a variety of reasons, women caring for men are believed to be at the greatest risk for excessive burden (Bédard et al., 2005). Male care recipients are much more likely to be physically and sexually aggressive (Eastley & Wilcock, 1997; Nagamoto et al., 1999). The vast majority of female caregivers report experiencing physical aggression while caring for their loved ones (Cahill & Shapiro, 1993). This can be particularly challenging, as men are generally physically larger than the women caring for them, making such physical or sexual aggression potentially even more difficult for women to cope with.

Also, there is evidence that women care for more impaired and dependent care recipients than men (Miller & Cafasso, 1992; Neal et al., 1997). In addition, women perform more complex tasks than their male counterparts (Navaie-Waliser et al., 2002).

However, despite the various aspects noted in the literature that would suggest that this study should find similar results, the findings of the current study do not support the hypothesis that women caring for men experience more subjective burden than other gender combinations of caregivers and care recipients. There were no significant differences in subjective burden found between women caregivers caring for men, and the subjective burden of the caregivers in the other three types of gender combinations in either the REACH or CSHA data.

In order to determine why this hypothesis resulted in a non-significant finding, additional analyses were conducted to determine if the databases in the current study had similar characteristics to those in previous literature. The REACH data confirms that the care recipients for whom women are caring require assistance completing more IADLs and ADLs than the care recipients for whom men are caring. Also, women caregivers in the REACH study have care recipients who demonstrate significantly more behaviour problems than the care recipients for whom men are caring. Therefore, in the REACH data, it appears that women's care recipients are more impaired than men's. However, there was no significant difference between the number of ADL or IADL tasks that women caregivers completed personally (i.e., they completed the tasks themselves rather than another informal or formal caregiver) versus men caregivers. Therefore, despite the fact that women are caring for more dependent care recipients, they do not appear to have significantly more objective burden than men caregivers. In contrast, the CSHA data shows no differences between the number of IADL or ADL tasks requiring assistance for the care recipients for men or women, meaning that the care recipients for whom men and women are caring do not differ in this type of impairment. However, in both databases, the care recipients for whom women are providing care demonstrated significantly more behaviour problems than the care recipients for whom men are providing care. Coen and colleagues (1999) found that such behavioural disturbances were more closely related to subjective burden than the cognitive or functional status of the care recipient. Therefore, although in the CSHA database the care recipients for men and women may be similar in terms of ADL/IADL assistance required, female caregivers could suffer more subjective burden due to greater behavioural problems. However, these findings are generally similar to those in the literature that led to the current hypothesis, so they do not clearly elucidate why the current data did not find that women caring for men were not more subjectively burdened in the REACH or CSHA studies.

Furthermore, there is evidence from the literature that men receive more support in doing caregiving tasks than women (Kramer & Kipnis, 1995; Navaie-Waliser et al., 2002). While the CSHA data bore out this relationship, with men caregivers receiving significantly more support than women caregivers, there was no significant difference in formal support between men and women caregivers in the REACH study.

Finally, in order to determine whether these findings were confounded by kinship, a comparison of husbands and wives' burden was undertaken. In both datasets, there were no significant differences between the perceived subjective burden in husbands and wives. This non-significant finding lends credence to the main finding regarding this hypothesis; that women caring for men are not significantly more subjectively burdened than other gender combinations of caregiver/care recipient. Because the literature suggests differences in subjective burden according to kinship, particularly between adult children caregivers (i.e., sons and daughters of care recipients) and spouses of care recipients (Coen et al., 1997), it was important to determine that such differences between these groups of caregivers was not influencing the non-significant finding for this hypothesis.

Some of the findings mentioned above could partially explain the inconsistency between the hypothesized relationship between gender combination and subjective burden, and the actual non-significant findings. For instance, in the REACH study, there was no significant difference in amount of instrumental support that female caregivers received over male caregivers. Therefore, perhaps if there is sufficient support in place for male and female caregivers, differences in subjective burden are not found when women care for men.

Otherwise, it is difficult to determine why the current study found non-significant results. Perhaps other factors (e.g., care recipient impairment, caregiver social support etc.) were more important to understanding caregivers' appraisals of their situations than the combination of caregiver-care recipient gender. Unfortunately, the literature does not offer many clues as to why such a relationship would be non-significant. Despite a plethora of studies on gender differences in caregiving, there were no other studies that found differences in burden attributed to the gender combination of the caregiver and care recipient. Perhaps the classic "file-drawer problem" could explain this lack of data. Perhaps if the finding of the current hypothesis is, in fact, objectively true, any researchers studying this phenomenon would also find that there are no differences between women caring for men and other gender combinations. These studies would be less likely to be published than studies that do have statistically significant findings, and soon, researchers would cease their focus on this variable, as it had not warranted further study.

One study of simple gender differences noted a number of interesting similarities in male and female caregivers (Hepburn et al., 2002). Hepburn and colleagues (2002) replicated the finding that female caregivers are more likely to report greater burden/distress regarding caregiving that male caregivers. However, they also found that there were more areas in which there was no significant difference between male and female caregivers, than there were significant differences between genders. Although this study does not capture the precise comparison the current hypothesis is attempting to elucidate, it does make an interesting point; that perhaps learning in what ways caregivers are similar is also a worthy pursuit. For instance, if we know that the gender combination of caregiver and care recipient is not a significant factor in caregiver burden, we can focus on other areas to find the answers we seek. Regardless of the reason behind the non-significant finding, it would be useful to replicate these results in future research to determine whether these data are an anomaly, or whether they clarify a similarity amongst caregivers.

### *Hypothesis G*

*Spouses will appraise caregiving more negatively and more positively than other caregivers.*

The results regarding spouses and positive appraisal raised somewhat of a conundrum. The REACH data showed that spouses appraised their caregiving situations more positively than other caregivers, but the CSHA data showed the opposite, that spouses appraised their situation as less positive than other caregivers. One possible reason for such a difference was the ways in which each study measured the positive appraisal of caregiving. As outlined above, the REACH study used the Positive Aspects of Caregiving Scale (PACS), which has been found to have strong psychometric properties. The measure of positive appraisal that was used in the CSHA study was part of the groundwork for the PACS, but does not have established psychometric properties. In fact, the CSHA measure asked whether caregivers found any positive aspects of caregiving (to which the caregivers responded yes or no), and then if the participant said yes, there was a follow-up question asking them to list some of the positive aspects they experienced. These qualitative responses were coded and then each participant was scored as to whether they endorsed that particular aspect. Finally, the CSHA measure asked caregivers their general feeling about caregiving using pictures of faces with various emotions represented. The more positive the emotion indicated, the higher the score on positive appraisal. This is contrasted by the format of the PACS, on which participants were asked to use a Likert rating to respond to 9 specific possible positive aspects of caregiving. Hence, the types of responses demanded of participants were very different between the REACH study and the CSHA study. Asking CSHA participants to generate responses about positive appraisal is a more demanding task than asking the REACH participants to rate how much they have experienced certain specific positive aspects. This could have led to different response styles and consequently, different outcomes. Unfortunately, this reasoning does not lead us any closer to an answer about which is the true status of positive appraisal and spouses. If one was pressed to choose one result over the other, one could argue that the REACH measure is stronger psychometrically, and the sample size is larger so perhaps this result, that spouses appraise caregiving more positively than other types of caregivers, is more likely to be true. However, replication is necessary before conclusions can be drawn about positive appraisal and kinship relationships. There are no other studies available currently that assess positive appraisal specifically in spouses.

On the other hand, the results for negative appraisal were consistent. Both the REACH and CSHA databases found that there was no significant difference in negative appraisal for spouses versus caregivers with other relationships to the care recipient.

This finding is in contrast to many studies that posit that spousal caregivers should be more vulnerable than other caregivers to both burden and various negative health outcomes (Beach et al., 2000; Connell et al., 2001; Kramer, 1993; Murray et al., 1999; Nagamoto et al., 1999; Neal et al., 1997; Pruchno & Resch, 1989b; Schneider et al., 1999). Perhaps prior marital relationship is a stronger predictor of burden than simply the kin relationship to the care recipient. Both Kramer (1993) and Beach and colleagues (2000) stated that relationship quality before caregiving began predicted health outcomes. Perhaps these relationship factors influence the negative appraisal scores more than the kin relationship alone. Of course, this is merely speculation, and future research would be necessary to confirm or deny such a hypothesis. Furthermore, both Kramer and Beach and colleagues were referring only to spouses when they made these statements, but similar measures could be applied to caregivers with other kin relationships. For instance, if a child was neglected or had a very conflicted relationship with a parent, their perceptions of burden when caring for said parent could differ dramatically from those of a child who felt quite loved and supported by their parent throughout their lives.

### *Hypothesis H*

*Kramer's model of caregiver adaptation will be confirmed as a structural model of the influence of background variables (e.g., caregiver and care recipient gender, kinship), on positive and negative caregiving appraisal, and in turn, how appraisal influences the health outcomes that caregivers experience.*

In the caregiving literature there are many studies of the various aspects of caregiving, including the contribution that background variables, like gender and kinship, make to the appraisals caregivers provide, and in turn, how such background variables and positive and negative appraisals, influence the health outcomes that caregivers experience. However, these studies tend to examine only a few of the pertinent variables together, making it a challenge to establish how all the known factors influence one another when they are considered together in one model. Synthesizing the background variables, appraisals and health outcomes into a comprehensive model would make an important contribution to the caregiving literature, and that is what was proposed in the current study.

Kramer (1997b) posited a model that provided the basis for many possible hypotheses about caregivers, their appraisal and the outcomes caregivers experience. The intent of this hypothesis was to confirm this promising model as a structural model for caregiver adaptation, by using the large databases to facilitate this goal. Essentially, Kramer put forth that the background and context variables (i.e., care recipient characteristics/potential stressors, caregiver characteristics/life stressors such as gender, age, kinship, impairment etc.), were related to both role gain (i.e., positive appraisal) and role strain (i.e., negative appraisal), either directly, or through the acquisition of certain resources. Kramer viewed these intermediary factors as intervening processes between the background and context variables and the well-being outcomes in her model. Some of the well-being variables were positive indicators, while others were negative indicators of well-being (see Figure 1). Because Kramer's model was a higher-order model, meaning that lower order latent variables were proposed to predict higher order latent variables, it was necessary to determine that the lower-level variables were sufficiently correlated before they could predict the higher-level variables. Therefore, it was necessary to determine that the lower level variables, which included each of the demographic variables, the latent variable of care recipient impairment and the latent variable of caregiver effort, were correlated at the minimum level of positive or negative 0.3. Unfortunately, the data did not fit these lower level variables adequately, as many of the correlations were weaker than the 0.3 level. Therefore, it was not recommended to attempt to fit the remainder of the higher order model. Hence, Kramer's model of caregiver adaptation was not confirmed as a structural model of the influence of background variables (e.g., caregiver and care recipient gender, kinship), on positive and negative caregiving appraisal, and in turn, how appraisal influences the health outcomes that caregivers experience.

Given the numerous variables that contributed to such a model, it is difficult to pinpoint the reasons why the model did not fit as hypothesized. One possible explanation is that the variables used from the REACH dataset did not map onto the proposed model as Kramer originally intended. Kramer's model was fairly general, and particular variables in each category were not specifically articulated, so there are many possible interpretations of the variables that she included in her model of caregiver adaptation. For example, Kramer outlines caregiver characteristics/other life responsibilities as a part of the background and context section of her model. The current hypothesis posited that the structural model should include caregiver sex, caregiver age, and various aspects of caregiver effort, as caregiver characteristics. Kramer could have defined this category very differently. For instance, such characteristics could have been things not necessarily measured in the databases used in this study, such as caregiver personality factors. Because the REACH study was not specifically designed to test Kramer's model of caregiver adaptation, some of the measures may not have been the ones Kramer would have selected for such an analysis, (which is one downside of secondary data analysis). Therefore, in the case of both the dependent and independent variables, Kramer could have measured the aspects of her model very differently, which could at least partially explain why the structural model did not hold as specified.

However, despite the theoretical challenges in using this database, the very large sample size found in the REACH dataset was an incredibly important consideration for this type of analysis. Given the large number of variables, and the complicated relationships hypothesized between them, such a structural equation model could not have been attempted with a smaller sample size. Even so, the complex relationships posited by Kramer may require an even larger sample size to adequately test her model of caregiver adaptation as it currently stands. Surprisingly, despite Kramer's paper being oft cited, no other researchers have endeavoured to test this model. Perhaps in the future, this complex model can be adequately tested with a very large sample size and the state of the art psychometric measurements of all variables involved. Until then, Kramer's model remains a good hypothetical conceptualization of the relationships between the various aspects of the caregiving situation, particularly because it incorporates the positive appraisal where most models do not. However, it remains an unproven model of caregiver adaptation.

Because the larger higher-order model could not be confirmed, as described above, the author of the current study proceeded to attempt to fit a simpler model, that would still have important implications for understanding caregiver appraisals and health outcomes. Even without understanding the complicated relationships between the background variables, appraisal and health outcomes, having a better understanding of how appraisal directly influences health outcomes would make an important contribution to the caregiving literature.

In the simpler model, the latent variable of negative appraisal was manifested by certain items from the five different scales, ADLs, IADLs, and the three Memory Behaviour Checklist factors; Disruption, Depression, and Memory. In each case, the items denoting the extent to which assisting or coping with each behaviour or task bothered the caregiver (i.e., the "bother" items) were utilized to represent the latent variable of negative appraisal. The latent variable of positive appraisal was manifest by the nine items on the Positive Aspects of Caregiving Scale, and the Caregiver Health latent variable was manifest by the additive scales of the four health related variables, self-rated health, number of illnesses diagnosed, anxiety and depression. The proposed structural model had an overall acceptable fit. Of note, however, are the relationships between each of the latent variables. These relationships are in line with findings from other analyses.

Negative appraisal and positive appraisal had a direct significant negative relationship. Although the relationship is significant, it is relatively weak in magnitude, which concurs with the weak negative correlations found in Hypothesis A. Therefore, as negative appraisal increased, positive appraisal decreased, and vice versa. However as the relationship was so weak, this finding confirms that positive appraisal and negative appraisal are two distinct constructs.

There was also a significant direct relationship between negative appraisal and the latent variable of caregiver health, while there was no statistically significant relationship between positive appraisal and caregiver health. These findings are similar to the findings of the hierarchical regressions, which found that negative appraisal explained significantly more of the variance beyond the background variables, while positive appraisal did not explain significantly more variance of the health outcomes, (except in the case of anxiety). It is useful to find that even without considering the background variables these relationships between health and appraisal held. Such convergent findings lend credence to the conclusion that negative appraisal has a negative influence on health outcomes for caregivers. It also repeats the point that the relationship between positive appraisal and caregiver health outcomes is less well understood, and that such a relationship may not exist. In fact, except in the case of anxiety, which has been discussed at length above, positive appraisal does not appear to have a significant influence on the health outcomes of Alzheimer's caregivers.

With the confines of the database (i.e., the health variables measured in the REACH study), modelling caregiver health as one latent variable was the most logical approach, because the standard is to have at least three predictors for each latent variable in a structural equation model. (The REACH data had only 4 health variables in total, including two for physical health and two for mental health). However, in the future, to allow for more detailed analysis, it would be interesting to determine whether there is a different underlying construct (i.e., latent variable) for physical health versus mental health. Therefore, it would be interesting to have a separate latent variable for mental health and another latent variable for physical health. Then one could model possible direct relationships between negative appraisal and positive appraisal and each aspect of health more explicitly. The literature is silent on whether these two facets of health actually have differences in their underlying constructs or whether the same underlying constructs underlie good health overall. However, it may simply clarify the relationships between these two aspects of health and the other variables in this model.

### *Conclusions*

In general, this study contributed to the caregiving literature in three areas: the understanding of positive appraisal, the influence of gender on caregiver appraisal and health, and the influence of kinship on caregiver appraisal and health. Overall, the findings in these areas hold implications for the understanding of caregiver appraisal and health outcomes and the future research to be conducted in these areas.

To date, the literature on positive appraisal, particularly in reference to health outcomes, has been limited. This study made strides in understanding some of the specifics of this variable. For instance, the current research established that positive appraisal and negative appraisal are separate constructs, and that positive appraisal can change over time. In addition, this research established that while positive appraisal does not significantly add to the prediction of self-rated health, number of illness diagnoses, or depression, it does add to the prediction of anxiety. While these were important aspects to establish, there is much more that remains to be understood about positive appraisal of caregiving. For example, the reasons why certain people appraise their situations more positively than others remain poorly understood. Even looking at group differences, the current findings were not clear. In one database there were no significant gender differences in positive appraisal, while in the other, men appraised their situations more positively than women. Similarly, one database showed significant differences between spouses and other caregivers, while the other showed no significant differences based on kinship. Although these findings require replication, an alternative theory could be that there are differences in positive appraisal that cannot be captured within these broad categories of gender or kinship. A number of years ago some researchers posited that appraisal of caregiving could be related to certain personality factors, such as neuroticism (Hooker et al., 1994; Reis, Gold, Gauthier, Andres, & Markiewicz, 1994). It could make a great contribution to determine whether these findings, which focused on negative appraisal, also translate to a better understanding of positive appraisal. Perhaps positive appraisal is merely a manifestation of a particular personality profile, for example, low neuroticism and high extraversion. However, it would be prudent to examine an interaction between circumstances and personality, given that many caregivers' positive appraisal scores did change significantly over time. Perhaps there is a range in which a person will fall on a measure of positive appraisal given their personality, but where exactly they fall in that range is related to their caregiving situation. Such questions provide rich possibilities for future research.

Personality may play a more important role than demographic categories in other circumstances also. While many of the questions asked in this research were based on gender or kinship groups, a number of the findings were non-significant. Although there has been previous research stating that such groupings are beneficial in understanding caregiving variables, this was not evidenced in the current analyses. One could argue that these non-significant findings could be attributed to Type II error. This is conceivable in theory, but in numerous cases these non-significant findings were consistent with both the REACH and CSHA databases. Given that these were two major multi-site studies with large sample sizes, it seems unlikely that they would have so many Type II errors in common.

Assuming for a moment that these non-significant findings are true and not Type II errors, they could speak to the idea that grouping caregivers in this fashion (i.e., according to gender or kinship) is not the most illuminating way to learn about why caregivers appraise their situations the way they do, and why their health outcomes vary as they do. Just as the personality factors may be another route to determine what makes a caregiver behave the way they do, there is some evidence that the quality of pre-caregiving relationships could also account for some of the individual differences between caregivers. Kramer (1993) posited that relationship quality could be more important than simply having a spousal relationship in and of itself. For example, a wife who had suffered physical and emotional abuse at the hands of her husband for many years could appraise her caregiving situation very differently than a wife who had a caring and loving relationship with her husband throughout their lives. This difference in relationship quality could be much more powerful than the difference between the average spouse and the average daughter caregiver. In addition, Beach, Schulz, Yee and Jackson (2000) also found that there was a relationship between marital relationship quality and health outcomes. Hence, it may be worthwhile to consider both personality factors and prior relationship quality when examining caregiving appraisal. Given that human relationships are complex, these types of factors could provide a subtler understanding of caregiving appraisal and health outcomes than groups based on demographics. Such analyses could lead to better assignment of interventions for caregivers and their care recipients, because we could garner a better understanding of what makes caregiving challenging for each caregiver more specifically, and hence cater to that aspect. For instance, if the caregiver's personality dictates that they prefer to spend time alone, then a support group may not be particularly beneficial, but respite care could be just the intervention necessary to help the caregiver continue caring for their loved one. Therefore, the main implication of the non-significant findings related to gender and kinship could be to take caregiving research in a different direction, away from demographic groupings, and into a new focus on individual differences in areas such as personality and relationship factors. In addition, this new direction could still fit with Kramer's (1997) conceptual model of caregiver adaptation. Instead of demographic variables acting as the lower level variables, for example, it is conceivable that personality factors could be the caregiver characteristics.

When contemplating the possible implications of this study, it is important to consider the overall strengths and weaknesses of this research. While the general advantages and disadvantages of conducting secondary analyses of large databases has been outlined above, there are other issues more specific to the current study that warrant addressing. The use of two different databases in this study had both advantages and disadvantages. Because REACH and CSHA were both examining caregiving as their main focus, they both measured a large number of variables. However, due to the plethora of measures available for many of these variables, the researchers in these two studies did not always elect to utilize the same measure for a certain variable. On one hand, this holds a potential advantage; if a finding is consistent despite the use of different measures, it could be argued that the finding is more robust, because not only is it found in different samples, but also with different measures. However, on the other hand, when a finding is inconsistent between the two studies, it is challenging to explain such an inconsistency in light of the different measures. Specifically, if a question results in the two studies drawing different conclusions, are the different measures to blame? It is certainly logical to conclude that a possible reason for the different results is the different method of measurement, but this does not lead one to a particularly satisfying explanation. If the different measurement is at fault for finding two different conclusions, how does the researcher then attempt to determine which measurement is the better one from which to draw the conclusion? Simply stated, if the findings are inconsistent, and the measures are different, it is impossible to answer the question at hand unequivocally. Therefore, such investigations only serve to ask more questions than they answer. While in and of itself, creating more questions is not necessarily negative, it is frustrating to realize that one cannot answer the questions one has put forth, due to inconsistent measurement. The latter situation is certainly an issue in the current research. While there have been a number of analyses in which the REACH and CSHA data were in agreement, there have also been a number of questions asked in this study that cannot be answered mainly due to this reason.

Despite the varying measurements, the use of the REACH and CSHA databases allowed more complex questions to be asked, given the large sample size in each of these studies. The downside of such a large sample size is the difficulty in collecting any qualitative data. When attempting to synthesize quantitative findings, often some qualitative data can fill in the picture. This weakness could be ameliorated in future research. In light of the types of future research suggested above (i.e., personality and relationship factors), qualitative data could be especially enlightening.

With the aging population, more family members will inevitably take on the role of providing care to dementia patients in the coming years. Gaining a better understanding of how this role influences caregivers' physical and mental health is an important public health issue. This is the case for both the caregivers, who may utilize health resources more readily if they are burdened by their caregiving duties, but also in the case of the care recipients. If caregivers are too unhealthy or too overwhelmed by caregiving, they will not be either willing or able to continue to provide care from home. If this is the case, more dementia patients will require professional care in settings like nursing homes. While caregiver burden has been researched for many years, many questions remain to be answered about caregivers and caregiving. The current research provides some answers, particularly about positive appraisal, but also provides another direction in which to ask more questions about caregivers, their appraisal, and its influence on health.

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# Appendix A

REACH Core Measures

1) Activities of Daily Living/Instrumental Activities of Daily Living
2) Anxiety Inventory
3) Caregiver Health and Health Behaviours
4) Formal Care and Services
5) Caregiver Medications
6) Caregiver Sociodemographic Information
7) Revised Memory and Behaviour Checklist
8) Positive Aspects of Caregiving
9) Religiosity
10) Care Recipient Medications
11) Care Recipient Sociodemographic Information
12) Care Recipient Tracking
13) Social Activities
14) Depression Inventory (Center for Epidemiological Studies Depression Scale)
15) Social Support
16) Vigilance

1) Activities of Daily Living/Instrumental Activities of Daily Living

Now I am going to ask you some questions about the specific kinds of problems (CR) might have been having this past week. For each area, I will ask you whether he/she has needed any kind of help. "Help" means supervision, direction, or personal assistance.

- **a)** During the past week, has (CR) needed any kind of help using the telephone? (yes/no)
    - **i.** (If yes) Did you help with this? (yes/no)
        1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely)
- b) During the past week, has (CR) needed any kind of help with shopping *(going to a store for light groceries)*? (yes/no)
    - i. (If yes) Did you help with this (yes/no)
        1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 = a little, 2= moderately, 3= very much, 4= extremely)
- c) During the past week, has (CR) needed any kind of help with food preparation (*making lunch or a light meal*)?
    - i. (If yes) Did you help with this (yes/no)
        1. (If yes) How much does helping with this bother or upset you? (0= not at all, 1= a little, 2= moderately, 3 = very much, 4 = extremely)

d) During the past week, has (CR) needed any kind of help with housekeeping *(making bed, vacuuming, dusting)*?

   i. (If yes) Did you help with this (yes/no)

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely)

e) During the past week, has (CR) needed any kind of help with doing laundry?

   i. (If yes) Did you help with this (yes/no)

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

f) During the past week, has (CR) needed any kind of help traveling by car, bus, etc.? (If yes)

   i. Did you help with this (yes/no)

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

g) During the past week, has (CR) needed any kind of help taking his/her medications in the correct dosages or at the correct time?

   i. (If yes) Did you help with this (yes/no)

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

h) During the past week, has (CR) needed any kind of help handling his/her finances?

   i. (If yes) Did you help with this (yes/no)

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

i) On average, how much time do you spend per day helping with all of the above activities? _________ (minutes/day)

j) During the past week, has (CR) needed any kind of help getting into or out of a bed, chair or wheelchair?

   i. (If yes) Did you help with this (yes/no)

   ii. In the past week, how often did you help (CR) getting into or out of a bed, chair or wheelchair?

   iii. On average, how much time does it take each time you help (CR) with getting into or out of a bed, chair or wheelchair?

      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

      2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

k) During the past week, has (CR) needed any kind of help eating meals?

   i. (If yes) Did you help with this (yes/no)

   ii. In the past week, how often did you help (CR) with eating?
   iii. On average, how much time does it take each time you help (CR) with eating?
      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)
      2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

l) During the past week, has (CR) needed any kind of help bathing, either in the tub, shower, or a sponge bath such as rinsing or drying the body, excluding the back?
   i. (If yes) Did you help with this (yes/no)
   ii. In the past week, how often did you help (CR) with bathing?
   iii. On average, how much time does it take each time you help (CR) with bathing?
      1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)
      2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

m) During the past week, has (CR) needed any kind of help dressing above the waist?

  i. (If yes) Did you help with this (yes/no).

  ii. In the past week, how often did you help (CR) with dressing above the waist?

  iii. On average, how much time does it take each time you help (CR) with dressing above the waist?

    1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)
    2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

n) During the past week, has (CR) needed any kind of help dressing from the waist down?

  i. If yes) Did you help with this (yes/no)

  ii. In the past week, how often did you help (CR) with dressing from the waist down?

  iii. On average, how much time does it take each time you help (CR) with dressing from the waist down?

    1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)

            2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

o) During the past week, has (CR) needed any kind of help toileting such as adjusting clothing before and after toilet use or cleansing?
    i. If yes) Did you help with this (yes/no)
    ii. In the past week, how often did you help (CR) with toileting?
    iii. On average, how much time does it take each time you help (CR) with toileting?
        1. If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)
        2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

p) During the past week, has (CR) needed any kind of help grooming, such as brushing teeth, combing or brushing hair, washing hands, washing face and either shaving or applying makeup?
    i. If yes) Did you help with this (yes/no)
    ii. In the past week, how often did you help (CR) with grooming?
    iii. On average, how much time does it take each time you help (CR) with grooming?

1. (If yes) How much does helping with this bother or upset you? (0 = not at all, 1 =a little, 2 = moderately, 3 = very much, 4 = extremely)
2. How confident do you feel about helping your (CR) in this area? (1 = not at all confident, 2 = a little confident, 3 = neutral, 4 = fairly confident, 5 = very confident)

q) How many days in the past week have other family members or friends (who are not being paid) provided help? ("Help" means supervision, direction or personal assistance). (0= no others have provided help, 1-7= # of days in past week someone provided help)

i. How useful is this help to you? (1 = not at all useful, 2 =somewhat useful, 3 = moderately useful, 4 = very useful)

2) Anxiety Inventory

I will list a number of statements that people use to describe themselves. Please indicate how much you agree with each statement according to how you felt in the past week. Here again, there are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your feelings during the past week. Please refer to the responses listed on the card. (1= not at all, 2= somewhat, 3= moderately, 4= very much).

1. I felt calm.
2. I was tense.
3. I felt at ease.
4. I was worrying over possible misfortunes.
5. I felt nervous.
6. I was jittery.
7. I was relaxed
8. I was worried.
9. I felt steady.
10. I felt frightened.

3) Caregiver Health and Health Behaviours

Now I would like to ask a few questions about <u>your</u> health.

1. In general, would you say your health is: poor (1), fair (2), good (3), very good (4), excellent (5)
2. How true or false are each of the following statements for you? (1 = definitely false, 2 =mostly false, 3 =neither false nor true, 4 = mostly true, 5 = definitely true)
    a. I seem to get sick a little easier than other people..
    b. I am as healthy as anybody I know.
    c. I expect my health to get worse.
3. Do you currently have, or has a doctor told you that you have, any of the following health problems? (yes/no/unknown/refused)
    a. Arthritis
    b. High Blood Pressure
    c. Heart Condition (specifically heart disease, heart attack, chest pain due to your heart, congestive heart failure, angina, MI)
    d. Chronic Lung Disease such as chronic bronchitis or emphysema (not asthma)
    e. Diabetes
    f. Cancer
    g. Have you ever had or been told by a doctor that you had a stroke?

4. During the past two weeks, to what extent have you experienced the following symptoms? (0 = not at all, 1 = a little, 2 = a lot)
    a. Dizziness
    b. Headaches
    c. Stomach or bowel problems
5. The following questions ask about your daily routine. (yes/no/unknown/refused)
    a. Do you typically eat fewer than 2 meals per day?
    b. Do you have three or more drinks of beer, liquor, or wine almost every day?
    c. Without wanting to, have you gained or lost 10 lbs or more in the last 6 months?
    d. Do you do vigorous exercise for 15-30 minutes or more at least 3 times a week? (Examples include running, sports, swimming, brisk walking, job that involves physical labour)
    e. Do you smoke cigarettes now?
        i. About how many cigarettes do you usually smoke in a day now? (# of cigarettes per day)

4) Formal Care and Services

Now I have some questions about services that you or (CR) may have received in the past month from an agency or from someone paid privately to provide this help.

1. Do you or (CR) have a homemaker who helps with shopping, cleaning, laundry, preparing meals etc.?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
2. Do you or (CR) have a home health aid come to the home to help with person care (i.e., bathing, feeding, health care tasks)
    a. In the past month, how often did you make use of/receive this service? (# times per month)
3. Do you or (CR) have cooked meals delivered to home or go to a center for low cost meals?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
4. Do you or (CR) have a formal service that provides transportation to places outside the home (i.e., doctors, clinics, shopping)?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
5. Do you or (CR) have a visiting nurse come to check medications, blood pressure or other medical needs?

   a. In the past month, how often did you make use of/receive this service? (# times per month)

6. Do you or (CR) attend a senior day care or senior day health program?
   a. In the past month, how often did you make use of/receive this service? (# times per month)
7. Are you (CG only) attending any support groups on a regular basis?
   a. In the past month, how often did you make use of/receive this service? (# times per month)
8. Have you (CG only) had any visits to the physician?
   a. In the past month, how often did you make use of/receive this service? (# times per month)
9. Has (CR) had any visits to the physician?
   a. In the past month, how often did you make use of/receive this service? (# times per month)
10. Have you (CG only) had any visits to a nurse, physician's assistant, or non-physician practitioner?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
11. Has (CR) had any visits to a nurse, physician's assistant, or non-physician practitioner?
    a. In the past month, how often did you make use of/receive this service? (# times per month)

12. Do you or (CR) see a counselor, psychiatrist, psychologist, or clergy for help with personal or family problems?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
13. Have you (CG only) had any visits to an emergency room?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
14. Has (CR) had any visits to an emergency room?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
15. Have you (CG only) had any x-rays, blood tests, urine tests, MRIs, or CAT scans?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
16. Has (CR) had any x-rays, blood tests, urine tests, MRIs, or CAT scans?
    a. In the past month, how often did you make use of/receive this service? (# times per month)
17. Have you (CG only) been a patient in a hospital overnight or admitted as a patient to hospital and discharged on the same day?
    a. How often? (times/month)
    b. How long? (total days)
18. Has (CR) been a patient in a hospital overnight or admitted to a hospital and discharged on the same day?

  a. How often? (times/month)
  b. How long? (total days)

19. Have you (CG only) been a patient in a nursing home?
    a. How often? (times/month)
    b. How long? (total days)
20. Has (CR) been a patient in a nursing home?
    a. How often? (times/month)
    b. How long? (total days)
21. Do you or (CR) receive any other service from an agency or organization, and if so, how often, per month, do you receive this service?
    a. Specify service and how often (times/month)
22. Is (CR) in any other study for Alzheimer's disease or dementia?

5) Caregiver Medications

For each medication the caregiver is taking, write the name on a separate line, followed by the appropriate code.

Record the two digit code(s) associated with the medications listed in 4.1. This should be done by a) locating the drug in the IDI, b) identifying the drug category(s) to which the drug belongs (right column in the IDI) and, c) locating the numeric code for each drug category in the Medication Code Table.

If a drug is listed as a psychotherapeutic agent (PSY) in the IDI, consult the Psychotherapeutic Subcategory Table and assign the appropriate code from that list (there is no general code for PSY, only subcategory codes).

If a drug is listed as a central nervous system (CNS), cardiovascular (CV), gastrointestinal (GI), genitourinary (GU), hypnotic (HYP), ophthalmologic (OPH), sedative (SED) or Tranquilizer (TRAN) in the IDI, assign the appropriate code for the category and consult the Psychotherapeutic Subcategory Table to see if the drug appears there. If the medication is listed in the Psychotherapeutic Subcategory Table, assign this code as well.

If a medication is encountered that is not currently on the list check the IDI addendum. If the drug is not listed there contact the Coordinating Center after the interview, and the drug will be assigned to the appropriate category.

6) Caregiver Sociodemographic Information

Now I would like to obtain some general information about you.

1. What is your marital status? (1 = married or living as married, 2 = widowed, not currently married, 3 = divorced, not currently married, 4 =separated)
    a. What is the primary occupation that your spouse has had most of his/her working life? Since many people have more than one job at a give time, we would like to know about the job that is/was your spouses' primary source of income.
2. How many years of formal education did you complete? (0 = no formal education, 1 = Grade 1, 2 = Grade 2, 3 =Grade 3, and so on until 12 = Grade 12/high school diploma, GED [General Education Diploma], 13 =Vocational/Training school after high school, 14 = some college/associate degree, 15 = college graduate [4-5 year program], 16 = Master's degree [or other post-graduate training], 17 = Doctoral degree [PhD., MD., EdD., DVM, DDS, JD, etc.])
3. What country did you reside in during the last year of formal education? (1 = United States, 2 = Canada, 3 =Cuba, 4 = Mexico, 5 = Other-specify)
4. How would you describe your primary racial or ethnic group? (1 = White/Caucasian, 2 = Black/African-American, 3 = Native American/Eskimo/Aleut, 4 = Asian or Pacific Islander, 5 =Hispanic/Latino)

   a. (If Hispanic/Latino) Would you describe yourself as Mexican, Mexican American, Chicano, Cuban or Cuban American (= 1), Puerto Rican (= 2) or Dominican (= 3)?
   b. (If no primary group) Specify:

5. In which country were you born? (1 = United States, 2 = Canada, 3 = Cuba, 4 = Mexico, 5 = Other: specify)
6. How many years have you lived in the United States? (# years)
7. What is the primary occupation you have had most of your working life? Since many people have more than one job at a given time, we would like to know about the job that is/was your primary source of income.
8. What is your current employment status? (1 = Employed at a job for pay full time, 2 = Employed at a job for pay part time, 3 = homemaker, not currently working for pay, 4 = not currently employed, retired, 5 = not currently employed, not retired)
   a. Are you employed outside of the home (yes/no)
   b. How many hours per week do you work at your paid job? (hours/minutes)
   c. Have you had to reduce the number of hours you work in an average week in order to provide care to CR?
      i. (If yes) How many hours have you had to reduce per week? (hours/minutes)
   d. Did you stop working because of (CR)'s need for care?

i. Why? (1 = you anticipated having to care for (CR), 2 = To provide additional care for (CR))?

Next I would like to ask you about your household income. Some people may not be comfortable answering this question, but I want to assure you that your responses will be kept strictly confidential. This information is very important to the project because it helps us understand how caregiving affects people with different incomes.

9. Which category best describes your yearly household income before taxes? Do not give the dollar amount just give me the category. Include all income received from employment, social security, support from children or other family, welfare, Aid to Families with Dependent Children, bank interest, retirement accounts, rental property, investments etc. (0 = less than $5000, 1 = $5000-$9,999, 2 = $10, 000-14,999, 3 = 15,000-19,999, 4 = 20,000-29,999, 5 = 30,000-39,999, 6 = $40,000-49,999, 7 = $50,000-59,999, 8 = 60,000-69,999, 9 = $70,000 or more)
10. How hard is it for you to pay for the very basics, like food, housing, medical care, and heating? Would you say it is? 1 = not difficult at all, 2 = not very difficult, 3 = somewhat difficult, 4 = very difficult
11. How many people are living in your home excluding yourself? (# people)
12. How long have you lived with (CR)? (# years)
13. Did you and (CR) start living together so that you could take care of him/her? (yes/no)

7) Revised Memory and Behaviour Checklist

Now I'd like to ask you about some of the problems you may have encountered while caring for (CR).

1. Within the past week, has (CR) experienced any memory or behaviors problems?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

I will read a list of specific problems participants sometimes have. Please indicate if any of these problems have occurred during the past week. IF so, how much ahs this bothered or upset you when it happened.

2. Within the past week, has (CR) been asking the same questions over and over?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
3. Within the past week, has (CR) had trouble remembering recent events (e.g., items in the newspaper or on tv)?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
4. Within the past week, has (CR) had trouble remembering significant past events?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
5. Within the past week, has (CR) been losing or misplacing things?

   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

6. Within the past week, has (CR) been forgetting what day it is?
   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
7. Within the past week, has (CR) been starting but not finishing things?
   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
8. Within the past week, has (CR) had difficulty concentrating on a task?
   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
9. Within the past week, has (CR) been destroying property?
   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
10. Within the past week, has (CR) been doing things that embarrass you?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
11. Within the past week, has (CR) been waking you or other family members up at night?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
12. Within the past week, has (CR) been talking loudly and rapidly?

   a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

13. Within the past week, has (CR) appeared anxious or worried?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
14. Within the past week, has (CR) been engaging in behavior that is potentially dangerous to him/herself or others?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
15. Within the past week, has (CR) threatened to hurt him/herself?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
16. Within the past week, has (CR) threatened to hurt others?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
17. Within the past week, has (CR) been aggressive to others verbally?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
18. Within the past week, has (CR) appeared sad or depressed?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

19. Within the past week, has (CR) been expressing feelings of hopelessness or sadness about the future? (such as “nothing worthwhile ever happens”, or “I never do anything right”)
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
20. Within the past week, has (CR) been crying and tearful?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
21. Within the past week, has (CR) been commenting about the death of him/herself or other (such as “life isn’t worth living” or “I’d be better off dead”)?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
22. Within the past week, has (CR) been talking about feeling lonely?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
23. Within the past week, has (CR) made comments about feeling worthless or being a burden to others?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
24. Within the past week, has (CR) made comments about feeling like a failure or about not having any worthwhile accomplishments in life?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

25. Within the past week, has (CR) been arguing, irritable, and/or complaining?
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)
26. Within the past week, has (CR) had any other memory or behavior problems that I haven't already mentioned? (If so specify and rate how bothered or upset were you by each problem listed)
    a. How bothered or upset were you by this? (0 = not at all, 1 = a little, 2 = moderately, 3 =very much, 4 = extremely)

8) Positive Aspects of Caregiving

Some caregivers say that, in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements. Please refer to the responses listed on this card.

Possible Responses

| | | |
|---|---|---|
| Disagree a lot | Disagree a little | Neither agree nor disagree |
| Agree a little | Agree a lot | |

Providing care to (CR) has…

Made me feel more useful[1]

Made me feel good about myself[1]

Made me feel needed[1]

Made me feel appreciated[1]

Made me feel important[1]

Made me feel strong and confident[1]

Enabled me to appreciate life more[2]

Enabled me to develop a more positive attitude toward life[2]

Strengthened my relationship with others[2]

[1] this item loads on the first factor, self-affirmation

[2] this item loads on the second factor, outlook on life

9) Religiosity

Now I would like to ask you a few questions about your religious preference and spiritual beliefs.

1. What is your current religious preference? (1 = Lutheran, 2 = Methodist, 3 = Baptist, 4 = Episcopal, 5 = Presbyterian, 6 = Other Protestant [specify], 7 =Roman Catholic, 8 = Orthodox Christian [e.g., Greek, Russian, Eastern], 9 = Jewish [Would you consider yourself? 1 = Orthodox, 2 = Conservative, 3 = Reform, 4 = Other], 10 = Islam, 11 = Buddhist, 12 = Confucian, 13 = Shintoist, 14 = Hindu, 15 = Jehovah's Witness, 16 = Spiritual, not religious, 17 = Other, 18 = None)
2. How often do you usually attend religious services, meetings, and/or activities? (1 = Never, 2 = Once a year, 3 = A few times a year, 4 = At least once a month, 5 = At least once a week, 6 = Nearly every day)
    a. To what extent has participation in religious services, meetings and/or activities been a source of help and comfort to you in providing care to (CR)? (1 = Not at all, 2 = Some, 3 = Quite a bit, 4 = A great deal)
3. How important is your spirituality or religious faith to you? (1 = Not important, 2 = Somewhat important, 3 = Important, 4 = Very important)
4. How often do you pray or meditate? (1 = Never, 2 = Once a year, 3 = A few times a year, 4 = At least once a month, 5 = At least once a week, 6 = Nearly every day)

a. To what extent has prayer or meditation been a source of help and comfort to you in providing care to (CR)? (1 = Not at all, 2 = Some, 3 = Quite a bit, 4 = A great deal)

10) Care Recipient Medications

For each medication the care recipient is taking, write the name on a separate line, followed by the appropriate code.

Record the two digit code(s) associated with the medications listed in 4.1. This should be done by a) locating the drug in the IDI, b) identifying the drug category(s) to which the drug belongs (right column in the IDI) and, c) locating the numeric code for each drug category in the Medication Code Table.

If a drug is listed as a psychotherapeutic agent (PSY) in the IDI, consult the Psychotherapeutic Subcategory Table and assign the appropriate code from that list (there is no general code for PSY, only subcategory codes).

If a drug is listed as a central nervous system (CNS), cardiovascular (CV), gastrointestinal (GI), genitourinary (GU), hypnotic (HYP), ophthalmologic (OPH), sedative (SED) or Tranquilizer (TRAN) in the IDI, assign the appropriate code for the category and consult the Psychotherapeutic Subcategory Table to see if the drug appears there. If the medication is listed in the Psychotherapeutic Subcategory Table, assign this code as well.

If a medication is encountered that is not currently on the list check the IDI addendum. If the drug is not listed there contact the Coordinating Center after the interview, and the drug will be assigned to the appropriate category.

11) Care Recipient Sociodemographic Information

Now I would like to obtain some general information about you.

1. What is your marital status? (1 = married or living as married, 2 = widowed, not currently married, 3 = divorced, not currently married, 4 = separated)
2. What is the primary occupation that your spouse has had most of his/her working life? Since many people have more than one job at a give time, we would like to know about the job that is/was your spouses' primary source of income.
3. How many years of formal education did you complete? (0 = no formal education, 1 = Grade 1, 2 = Grade 2, 3 = Grade 3, and so on until 12= Grade 12/high school diploma, GED [General Education Diploma], 13 =Vocational/Training school after high school, 14 = some college/associate degree, 15 = college graduate [4-5 year program], 16 = Master's degree [or other post-graduate training], 17 = Doctoral degree [PhD., MD., EdD., DVM, DDS, JD, etc.])
4. What country did you reside in during the last year of formal education? (1 = United States, 2 = Canada, 3 =Cuba, 4 = Mexico, 5 = Other-specify)
5. How would you describe your primary racial or ethnic group? (1 = White/Caucasian, 2 = Black/African-American, 3 = Native American/Eskimo/Aleut, 4 = Asian or Pacific Islander, 5 = Hispanic/Latino)

6. (If Hispanic/Latino) Would you describe yourself as Mexican, Mexican American, Chicano, Cuban or Cuban American (= 1), Puerto Rican (= 2) or Dominican (= 3)?
7. (If no primary group) Specify:
8. In which country were you born? (1 = United States, 2 = Canada, 3 = Cuba, 4 = Mexico, 5 = Other: specify)
9. How many years have you lived in the United States? (# years)
10. Other than problems with memory or confusion, how would you rate the physical health of (CR)? (1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent)

12) Care Recipient Tracking

Indicate the care recipient's significant event.

1. Death of care recipient
    a. Cause of death
    b. Date of death (month/day/year)
2. Change of caregiver
    a. Relationship of new caregiver to care recipient (Husband, Wife, Son, Daughter, Son-In-Law, Daughter-In-Law, Brother, Sister, Nephew, Niece, Grandson, Granddaughter, Stepson, Stepdaughter, Other [specify])
    b. Why was there a change in caregiver?
    c. Date of change (month/day/year)
3. Institutionalization of care recipient
    a. Date of Institutionalization (month/day/year)
    b. Where is the care recipient living? (1 = Personal care home, 2 = Rehabilitation facility, 3 = Long-term care facility [skilled], 4 = Long-term care facility [intermediate], 5 = Assisted living facility, 6 = Other [specify])
4. Other
    a. Specify
    b. Date (month/day/year)
5. Change of Institutionalization

a. Date of change (month/day/year)

b. Where is the care recipient living? ? (1 = Personal care home, 2 = Rehabilitation facility, 3 = Long-term care facility [skilled], 4 = Long-term care facility [intermediate], 5 = Assisted living facility, 6 = Home, 7 = Other [specify])

13) Social Activities

We are interested in how satisfied you are with the amount of time you have been able to spend in various activities that you might enjoy.

Over the past month, how satisfied are you with the amount of time you have been able to spend: (1 = Not at all, 2 = A little, 3 = A lot)

In activities you enjoy?

In quiet time by yourself?

Attending church services or going to other meetings of groups or organization?

Taking part in hobbies or other interest?

Going out for meals or other social activities?

Doing fun things with other people?

Visiting with family and friends?

14) Depression Inventory (Center for Epidemiological Studies Depression Scale)

This section deals with statements people might make about how they feel. Let me give you a card with possible responses. For each of the statements, please indicate how often you felt that way during the past week. (0 = Rarely or none of the time [< 1 day], 1 = some or a little of the time [1-2 days], 2 = occasionally or moderate amount of time [3-4 days], 3 = Most or almost all of the time [5-7 days])

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating, my appetite was poor.
3. I felt that I could not shake off the blues, even with help from my family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.

16. I enjoyed life.

17. I had crying spells.

18. I felt sad.

19. I felt that people disliked me.

20. I could not get going.

15) Social Support

Now I would like to ask you some questions about your friends and family.

1. Social Networks
    a. Overall, how satisfied have you been in the last month with the help you have received from friends, neighbors, or family members? (0 = Not at all, 1 = a little, 2 = moderately, 3 = very)
    b. How many relatives other than (CR) do you see or hear from at least once a month? (0 = None, 1 = One, 2 = Two, 3 = Three or four, 4 = Five to eight, 5 = Nine or more)
    c. Think about the relative other than (CR) with whom you have the most contact. How often do you see or hear from that person? (0 = Less than monthly, 1 = Monthly, 2 = A few times a month, 3 = Weekly, 4 = A few times a week, 5 = Daily)
    d. How many relatives other than (CR) do you feel close to? That is, how many do you feel at east with, can talk to about private matters, or can call on for help? (0 = None, 1 = One, 2 = Two, 3 = Three or Four, 4 = Five to eight, 5 = Nine or more)
    e. How many friends to you feel close to? That is, how many friends (not including relatives) do you feel at ease with, can talk to about private matters, or can call on for help? ? (0 = None, 1 = One, 2 = Two, 3 = Three or Four, 4 = Five to eight, 5 = Nine or more)

f. How many of these friends do you see or hear from at least once a month (not including relatives)? ? (0 = None, 1 = One, 2 = Two, 3 = Three or Four, 4 = Five to eight, 5 = Nine or more)

g. Think about the friend (not including relatives) with whom you have the most contact. How often do you see or hear from that person? (0 = Less than monthly, 1 = Monthly, 2 = A few times a month, 3 = Weekly, 4 = A few times a week, 5 = Daily)

h. When you have an important decision to make, do you have someone other than (CR) you can talk to about it? (0 = Never, 1 = Seldom, 2 = Sometimes, 3 = Often, 4 = Very often, 5 = Always)

i. When other people you know have an important decision to make, do they talk to you about it? (0 = Never, 1 = Seldom, 2 = Sometimes, 3 = Often, 4 = Very often, 5 = Always)

2. Received Support and Satisfaction

a. In the past month, how often has someone, such as a friend, neighbor, or family member other than (CR), provided transportation for you? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

b. In the past month, how often has someone, such as a friend, neighbor, or family member other than (CR), pitched in do help you with something that needed to get done, like household chores or yardwork? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

c. In the past month, how often has someone helped you with shopping? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

d. Overall, how satisfied have you been in the last month with the help you have received with transportation, housework and yard work, and shopping? (0 = Not at all, 1 = A little, 2 = Moderately, 3 = Very)
e. In the past month, how often as someone right there with you (physically) in a stressful situation? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
f. In the past month, how often has someone provided comfort to you? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
g. In the past month, how often has someone listened to you talk about your private feelings? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
h. In the past month how often has someone expressed interest and concern in your well-being? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
i. In the past month, how satisfied have you been with the support received during difficult times, comforting from others, how others have listened, and interest and concern from others? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
j. In the past moth, how often has someone suggested some action you should take in dealing with a problem you were having? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

k. In the past month, how often has someone made a difficult situation clearer and easier to understand? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

l. In the past month, how often has someone helped you understand why you did and did not do something well? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

m. In the past month, how often has someone told you what they did in a situation that was similar to one you were experiencing? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

n. Overall, how satisfied in the last month have you been with the suggestions, clarifications, and sharing of similar experiences you have received from others? (0 = Not at all, 1 = A little, 2 = Moderately, 3 = Very)

3. Negative Interaction: I'd like to ask you a few more questions about your relationship with others. Remember, when the term "others" is used, it includes friends, neighbors, or family members other than your (CR).
    a. In the past month, how often have others made too many demands on you? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
    b. In the past month, how often have others been critical of you? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)
    c. In the past month, how often have others pried into your affairs? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

d. In the past month, how often have others taken advantage of you? (0 = Never, 1 = Once in a while, 2 = Fairly often, 3 = Very often)

16) Vigilance

The last set of questions were about the kinds of assistance (CR) requires with daily activities. What I want to ask you now concerns the time you spend supervising, or just "being around" for (CR).

1. In the case of a family emergency, are you able to leave (CR) home alone, that is with no one else there? (Yes/no)
    a. How long can you leave (CR) home alone? (hours/minutes)
2. Can (CR) be left alone in a room as long as someone is in the house? (Yes/no)
    a. How long can you leave (CR) alone in a room? (hours/minutes)
3. Some people have told us that they feel their caregiving is a time-consuming job. They say that even when they aren't actually doing something special for or with their relative, they feel "on duty" or the need to "be there" for him/her. About how many hours a day do you feel the need to "be there" or "on duty" to care for (CR)? (# hours)
4. About how many hours a day do you estimate that you are actually doing things for (CR)? (# hours)

# Appendix B

## CSHA Caregiver Questionnaire

1) Demographics
2) Social Situation
3) Caregiver Employment
4) Activities of Daily Living
5) Care Management
6) Care Recipient Service Use
7) Caregiver Service Use
8) Dementia Behaviour Disturbance Scale
9) Zarit Burden Interview
10) Centre for Epidemiologic Studies Depression Scale
11) Positive Aspects of Caregiving
12) Institutional Admission
13) SF-12
14) Additional Health Measures

1) Demographics

   1. Caregiver Sex
   2. Care Recipient Sex
   3. Care Recipient Date of Birth
   4. Are you involved in caring for (CR)? (If no: Why are you no longer caring for (CR)? 1 = CR is ill/hospitalized, 2 = CR is institutionalized, 3 = CR moved out of town, 4 = CG could no longer cope with caring, 5= Other)
   5. Are you (CR)'s primary caregiver (If no: Who is (CR)'s primary caregiver? What is his/her relationship to CR)
   6. What is your relationship to (CR)? (1 = wife, 2 = husband, 3 = daughter, 4 = son, 5 = sister, 6 = brother, 7 = friend, 8 = daughter-in-law, 9 = son-in-law, 10 = sister-in-law, 11 = brother-in-law, 12 = paid caregiver, 13 = volunteer, 14 = formal service, 15 = other, 16 = nephew, 17 = niece, 18 = grandson, 19 = granddaughter, 20 = nephew's wife, 21 = niece's husband, 22 = cousin, 23 = great granddaughter, 24 = great grandson, 25 = niece's daughter, 26 = niece's son, 27 = father, 28 = mother, 29 = institutional staff, 30 = family (unspecified), 31 = no one exclusive)
   7. Where were you born? (city & country)
      i. If not in Canada: When did you come to Canada? (year of arrival)
   8. When were you born? (day/month/year)

9. Are you single, married, widowed, divorced, or separated? (0 = never married, 1 = married, 2 = common-law marriage, 3 = divorced, 4 = separated, 5 = widowed, 6 = other)
10. What languages do you speak?
11. What is your ethnic or cultural background?
12. How many years of education did you complete?
    a) So that means that you completed… (select a suitable category)
13. In order to complete the health service utilization component of our study, we would very much appreciate your consent to access your health records. Please remember, all information will be confidential as described on the consent form.

2) Social Situation

I would like to ask you a few questions about (CR)'s household.

1. Do you live in the same house as (CR)?

*If Yes:*

2. How long have you lived together (# years)
3. Aside from (CR), do any other people live with you?
    a. If yes: How many? (# of (CR)'s children, # of caregiver's children, # of children of both, # of others)
4. Do you or (CR) have any other close relatives who live within a one-hour drive? (Close relatives= siblings, nieces, nephews, adult grandchildren)
    a. How many? (# of relatives of CR, # of relatives of caregiver, # of relatives of both)

(Continue at Question 8)

*If No:*

2. Do any people live with you?
    a. If yes: How many?
3. Do you have any children who do not live with you?
    a. If yes: How many?
4. Do you have any other close relatives who live within a one-hour drive? (Close relatives= siblings, nieces, nephews, adult grandchildren)
    b. If Yes: How many? (# of relatives of caregiver)

Now tell me about (CR)'s household. How many people live with him/her? I'm just interested in adult, aged 18 and over.

5. Do any people live with (CR)?
    a. If Yes: How many? (# of people)

Now thinking of relatives and friends who do not live with (CR).

6. Does (CR) have any children that do not live with him/her?
    a. If Yes: How many (# children)
7. Does he/she have any other close relatives that live within a one-hour drive? (Close relatives = siblings, nieces, nephews, adult grandchildren)
    a. If Yes: How many? (# of relatives of caregiver)
8. How many close friends does (CR) have that live within a one-hour drive? (Close friends are those who he/she is in regular contact, and on whom he/she can rely on in times of need). (# friends)
9. Who would take over your role of caring for (CR) if you were not available? (Code the relationship to CR: W = wife, H = husband, D = daughter, So = son, Si = sister, DIL = daughter-in-law, SOL = son-in-law, BIL = brother-in-law, PC = paid caregiver, V = volunteer, FS = formal service, O = other)

3) Caregiver Employment

   1. Do you currently work for pay?

*If Yes:*

   2. About how many hours a week do you work? (# hours/week)
   3. Because of caring, did you ever: (yes/no)
      a. Change jobs or employers
      b. Decrease the hours you worked
      c. Increase the hours you worked
      d. Change the shift you worked
      e. Feel that your performance at work was affected
      f. Come late to work
      g. Miss work
      h. Need to leave work for a doctor's appointment pertaining to (CR)
      i. Need to leave work suddenly
      j. Decline a job advancement (transfer or promotion)
      k. Quit your job
      l. Consider quitting your job
      m. Get interrupted repeatedly with phone calls pertaining to (CR)
      n. None of the above

*If No:*

   2. When did you last work?

3. Why did you stop working? (Circle any responses they list: 1 = to care for CR, 2 = Reached retirement age, 3= Own health problems, 4= Other family commitments, 5 = Laid off/fired, 6 = Early retirement, 7 = Company closed, 8 = Other [specify])

4) Activities of Daily Living

Now I want to ask you about how (CR) manages (his/her) life. I will mention a number of common, daily activities and for each I want you to say if (CR) can manage this without help (=1), or with some help (=2), whether he/she cannot do it all (=0), that is, someone has to do it for them.

(For all responses, even if the person can do something, ask: Has anyone helped him/her with (the task) during the last month? Include yourself and any family members, friends and neighbours, paid workers, visiting nurses etc. What is the relationship of this person to (CR)? How often do you/they help? How long does this take?)

| **Task (in the last month)** | **Who Helped?** | **Rel'ship to CR** | **Frequency** | **Min./Task** |
|---|---|---|---|---|
| Can CR eat? | | | # D/W/M | |
| Can CR dress/undress? | | | # D/W/M | |
| Can CR take care of his/her appearance? For example, combing his/her hair or shaving? | | | # D/W/M | |
| Can CR walk? | | | # D/W/M | |
| Can CR get in and out of bed? | | | # D/W/M | |
| Can CR take a bath or shower? | | | # D/W/M | |
| Can CR use bathroom or toilet? | | | # D/W/M | |
| Can CR use the telephone? | | | | |
| Can CR get to places out of walking | | | # D/W/M | |

| | | | | |
|---|---|---|---|---|
| distance? | | | | |
| Can CR go shopping for groceries or clothes? | | | # D/W/M | |
| Can CR prepare his/her own meals? | | | # D/W/M | |
| Can CR do his/her housework? | | | # D/W/M | |
| Can CR take his/her own medicine? | | | # D/W/M | |
| Can CR manage his/her own money? | | | # D/W/M | |

5) Care Management

   1. Can (CR) be left alone at all? That is, can he/she remain at home… (yes/no)
      a. Unsupervised for 30 min to 2 hrs when no one else is at home?
      b. Unsupervised for 30 min to 2 hrs while someone is in the house?

         *If No* (to either 1a) or 1b))

   2. Please tell who has stayed with (CR) in the last month, and how much time each person devoted to being with them. (Do not count time already mentioned in ADL section actually assisting the person. We want only the time spent supervising.) (Record person, their relationship to CR, frequency and time spent in minutes/hours)

6) Care Recipient Service Use

Now I would like to ask you about (CR)'s contact with health professionals and services.

1. During the last 2 weeks, did (CR) see or talk to a doctor…
    a. In an office or clinic? (If Yes: # of times)
    b. Over the telephone? (If Yes: # of times)
    c. At home? (If Yes: # of times)
2. During the last 3 months, did (CR) go to a hospital emergency room for help with a health problem?
    a. If Yes: # of times
3. During the last 6 months, was (CR) admitted to hospital?
    a. If Yes: # of times

Many services are available to elderly people and those who care for them. Services may be provided by the government, hospitals, private or volunteer agencies. You have probably heard of some of these: for example, Homemaker Services, In-Home Nursing, Self-Help Groups. Now I want to ask you about services (CR) or his/her family have been using in the past year.

4. Has a homemaker service or cleaning lady been used in (CR)'s household in the past year (e.g., to help with cleaning, laundry, meal preparation)?

*If Yes*, please respond to parts a) through j).

*If No*, please skip a) through j) and respond to k) through l).

  a. How many times has this service been used in the past year?

b. Which type of service was this? (1 = cleaning, 2 = laundry, 3 = meal preparation, 4 = other [specify])

c. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])

d. When the family applied to receive this service, was there a waiting list?

    i. If Yes: How long? (days/weeks/months)

e. Does the family have to pay for all or part of this service?

    i. If Yes: About how much does the family pay per month?

f. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

g. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)

h. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)

i. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

j. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

k. Have homemaker services ever been used?
    i. If Yes: How long was this service used? (days/weeks/months/years)
    ii. Why was this service stopped?

l. Are you aware that homemaking services were available?
    i. If Yes: What were your reasons for not using this service?

5. Has (CR) received home-delivered meals (e.g., Meals-On-Wheels) in the past year?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?

b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])

c. When the family applied to receive this service, was there a waiting list?
    i. If Yes: How long? (days/weeks/months)

d. Does the family have to pay for all or part of this service?
    i. If Yes: About how much does the family pay per month?

e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)

g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met , 4 = none of their needs met)

h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Have home delivered meal services ever been used?

  i. If Yes: How long was this service used? (days/weeks/months/years)

  ii. Why was this service stopped?

k. Are you aware that home delivered meal services were available?

  i. If Yes: What were your reasons for not using this service?

6. Has (CR) received home help for personal tasks (e.g., bathing, dressing, grooming, toileting, etc.) in the past year?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?
b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])
c. When the family applied to receive this service, was there a waiting list?
    i. If Yes: How long? (days/weeks/months)
d. Does the family have to pay for all or part of this service?
    i. If Yes: About how much does the family pay per month?
e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)
f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)
g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)
h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

- i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

- j. Has home help for personal tasks ever been used?
    - i. If Yes: How long was this service used? (days/weeks/months/years)
    - ii. Why was this service stopped?
- k. Are you aware that home help for personal tasks was available?
    - i. If Yes: What were your reasons for not using this service?

7. Has (CR) received in-home nursing care (e.g., for changing dressings, checking blood pressure, medications etc.) in the past year?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

- a. How many times has this service been used in the past year?
- b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])
- c. When the family applied to receive this service, was there a waiting list?
    - i. If Yes: How long? (days/weeks/months)
- d. Does the family have to pay for all or part of this service?
    - i. If Yes: About how much does the family pay per month?

e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)

g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met , 4 = none of their needs met)

h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Have in-home nursing care services ever been used?
    i. If Yes: How long was this service used? (days/weeks/months/years)
    ii. Why was this service stopped?

k. Are you aware that in-home nursing care services were available?
    i. If Yes: What were your reasons for not using this service?

8. Has (CR) had physiotherapy, occupational therapy, podiatry or chiropractic treatments in the past year?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?
b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4= other [specify])
c. When the family applied to receive this service, was there a waiting list?
    i. If Yes: How long? (days/weeks/months)
d. Does the family have to pay for all or part of this service?
    i. If Yes: About how much does the family pay per month?
e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)
f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)
g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)
h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Have physiotherapy, occupational therapy, podiatry or chiropractic services ever been used?

    i. If Yes: How many times was this service used?
    ii. Why was this service stopped?

k. Are you aware that physiotherapy, occupational therapy, podiatry or chiropractic services were available?

    i. If Yes: What were your reasons for not using this service?

9. Has (CR) attended a day centre or day hospital in the past year?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?

b. Who provides this service? (1= public agency [e.g., part of health care system or government agency, etc.], 2= non-government, not for profit agency [e.g., volunteer or church group], 3= private [for profit] company, agency or individual, 4= other [specify])

c. When the family applied to receive this service, was there a waiting list?

    i. If Yes: How long? (days/weeks/months)

d. Does the family have to pay for all or part of this service?

    i. If Yes: About how much does the family pay per month?

e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)

g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)

h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Has (CR) ever attended a day centre or day hospital?
    i. If Yes: How many times did (CR) attend?
    ii. Why did (CR) stop going to the day centre or day hospital?

k. Are you aware that day hospitals or day centers were available?
    i. If Yes: What were your reasons for not using this service?

10. Has (CR) used a hospital or nursing home for respite care in the past year? (i.e., he/she was admitted temporarily to hospital or nursing home to give relief to the

family or caregiver. Do not include admissions for assessments or treatments, etc.)

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?
b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])
c. When the family applied to receive this service, was there a waiting list?
    i. If Yes: How long? (days/weeks/months)
d. Does the family have to pay for all or part of this service?
    i. If Yes: About how much does the family pay per month?
e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)
f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)
g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)

h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Has respite care (hospital or nursing home) ever been used?
   - i. If Yes: How many times was this service used?
   - ii. Why was this service stopped?

k. Are you aware that respite care (hospital or nursing home) were available?
   - i. If Yes: What were your reasons for not using this service?

11. Has (CR) used in-home respite care services in the past year? That is, was someone paid to come and sit with (CR) while you went out?

*If Yes*, please respond to parts a) through i).

*If No*, please skip a) through i) and respond to j) through k).

a. How many times has this service been used in the past year?

b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])

c. When the family applied to receive this service, was there a waiting list?
   - i. If Yes: How long? (days/weeks/months)

d. Does the family have to pay for all or part of this service?
   - i. If Yes: About how much does the family pay per month?

e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)

g. To what extent has the service met the family's needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met, 4 = none of their needs met)

h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

j. Has in-home respite care ever been used?
    i. If Yes: How many times was this service used?
    ii. Why was this service stopped?

k. Are you aware that in home respite care services were available?
    i. If Yes: What were your reasons for not using this service?

7) Caregiver Service Use

The next few questions will ask about services you, the caregiver, may have used to help you care for (CR).

1. Have you received counseling or support from a social worker, psychologist, clergyman, self-help or support group, including telephone lines [e.g., The Alzheimer's Society] etc., during the past year to support you in caring for (CR)?
   a. Which services were used? How many times did you use each service?
   b. Who provides this service? (1 = public agency [e.g., part of health care system or government agency, etc.], 2 = non-government, not for profit agency [e.g., volunteer or church group], 3 = private [for profit] company, agency or individual, 4 = other [specify])
   c. When you applied to receive this service, was there a waiting list?
      i. If Yes: How long? (days/weeks/months)
   d. Do you have to pay for all or part of this service?
      i. If Yes: About how much do you pay per month?
   e. Over the past few months, has the service always been provided by the same individual? For example, is the homemaker always the same person? (1 = always the same person, 2 = usually the same person, 3 = rarely or never the same person)

- f. Would you say the service is reliable? For example, if someone promises to visit, do they come at the appointed time? (1 = very reliable, 2 = usually reliable, 3 = not very reliable)
- g. To what extent has the service met your needs? (1 = almost all needs met, 2 = most of needs met, 3 = only a few needs met , 4 = none of their needs met)
- h. How satisfied were you with the quantity of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)
- i. How satisfied were you with the quality of the help received? (1 = very satisfied, 2 = mostly satisfied, 3 = not satisfied, 4 = quite dissatisfied)

*If No:*

- j. Have you ever received counseling or support services to support you in caring for (CR)?

  If Yes:

  - i. How many times was this service used?
  - ii. Why did you stop using this service?
- k. Are you aware that counseling and support services were available?
  - ii. If Yes: What were your reasons for not using a service of this type?

2. Did you incur any added expenses while caring for (CR)? For example, did you need to buy special foods, linens, diapers etc.?
   - a. If Yes: How much extra do you pay per month?

3. Now I would like you to think about services you or (CR) are not currently receiving. Which services would help you in caring for (CR)? (Circle all that apply: 1 = homemaker service, 2 = home delivered meals, 3 = help for personal tasks, 4 = in-home nursing care, 5 = physiotherapy, occupational therapy, podiatry, chiropractic services, 6 = day centre or day hospital, 7 = hospital or nursing home for respite care, 8 = in-home respite care, 9 = counseling from social worker or psychologist, 10 = self-help or support groups, 11 = clergyman, 12 =none, 13 = other)

The next few questions concern (CR)'s living accommodation in the community in the past year.

4. How many rooms are there in (CR)'s house/apartment/unit? (Include kitchen, bedrooms, living room, and finished rooms in basement or attic. Do not include bathrooms, halls, vestibules, and rooms used solely for business.)
5. Is (CR)'s house/apartment/unit owned or being rented by another member of his household? (1 = rented, 2 = owned, 3 = other)
6. Is the rent for (CR)'s dwelling subsidized by the government for any reason? Examples of government subsidization are low-income housing projects, cooperative housing projects, public housing. (yes/no)
7. Is (CR)'s dwelling in need of any repairs? (Do not include desired remodeling, additions or regular maintenance). (yes/no)

   If Yes:

   a. Are repairs major, such as sagging floors, bulging walls or damaged electrical wiring? Or are they minor, such as broken windows, leaking sink, or small cracks in interior walls? (1 = major repairs, 2 = minor repairs, 3 = major and minor repairs)

b. How adequate is (CR)'s accommodation? (1 = very adequate, 2 = adequate, 3 = not adequate, 4 = very inadequate)
c. Has (CR) changed living accommodation in the past five years?
    i. If No: Would you like (CR) to change accommodation in order to help you care for him/her?

8) Dementia Behaviour Disturbance Scale

I am going to read you a list of common problems. Please tell if (CR) has had any of these problems generally these days (e.g., in the past week). If so, how often they have occurred: Never, rarely, sometimes, frequently, all of the time. Remember, there are no right and wrong answers. CR:

1. Shows lack of interest in daily activities
2. Makes unwarranted accusations
3. Is verbally abusive, curses
4. Empties drawers or closets
5. Dresses inappropriately
6. Exposes him/herself indecently
7. Screams for no reason
8. Makes physical attacks (hits, bites, scratches, kicks, spits)
9. Makes inappropriate sexual advances
10. Paces up and down
11. Moves arms and legs in an agitated way
12. Gets lost outside
13. Is incontinent of urine (wets him/herself)
14. Is incontinent of stool (soils him/herself)
15. Wakes up at night for no obvious reason
16. Wanders in the house at night
17. Sleeps excessively during the day

18. Overeats

19. Refuses to eat

20. Cries or laughs inappropriately

21. Refuses to be helped with personal care tasks such as bathing, brushing teeth

22. Throws food

23. Wanders aimlessly outside or in the house during the day

24. Hoards things for no obvious reason

25. Destroys property or clothing, breaks things

26. Loses, misplaces or hides things

27. Asks the same question over and over again

28. Repeats the same action (e.g., wipes table) over and over again

9) Zarit Burden Interview

Here are a list of ways that people sometimes feel when caring for another person. After I read each question, please indicate how often you have felt that way: never, rarely, sometimes, frequently, or nearly always. Remember, there are no right or wrong answers.

How often…

1. Do you feel that (CR) asks for more help than he/she needs?
2. Do you feel that because of the time you spend with (CR) that you don't have enough time for yourself?
3. Do you feel stressed between caring for (CR) and trying to meet other responsibilities for your family or work?
4. Do you feel embarrassed over (CR)'s behaviour?
5. Do you feel angry when around (CR)?
6. Do you feel that (CR) currently affects your relationship with other family members or friends in a negative way?
7. Are you afraid of what the future holds for (CR)?
8. Do you feel (CR) is dependent upon you?
9. Do you feel strained when you are around (CR)?
10. Do you feel your health has suffered because of your involvement with (CR)?
11. Do you feel that you don't have as much privacy as you would like, because of (CR)?
12. Do you feel that your social life has suffered because you are caring for (CR)?

13. (Only when respondent lives with (CR)) Do you feel uncomfortable about having friends over because of (CR)?
14. Do you feel that (CR) seems to expect you to take care of him/her as if you were the only one he/she could depend on?
15. Do you feel that you don't have enough money to care for (CR), in addition to the rest of your expenses?
16. Do you feel that you will be unable to care for (CR) much longer?
17. Do you feel that you have lost control of your life since (CR)'s condition?
18. Do you just wish you could leave the care of (CR) to someone else?
19. Do you feel uncertain about what to do about (CR)?
20. Do you feel that you should be doing more for (CR)?
21. Do you feel you could be doing a better job in caring for (CR)?
22. Overall, how burdened do you feel in caring for (CR)?

10) Centre for Epidemiologic Studies Depression Scale

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

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

17. I had crying spells.

18. I felt sad.

19. I felt that people disliked me.

20. I could not get going.

11) Positive Aspects of Caregiving

Many people report that they experience positive or rewarding aspects of caregiving. I would like you to think about any enjoyable or positive features you find in being a caregiver.

1. Do you find any positive aspects of caregiving?
    a. If Yes: Could you briefly tell me what some of these are?
2. Here are some faces showing various feelings. Overall, how do you feel about caring for (CR)?

12) Institutional Admission

Next I would like to ask you some questions about placement in institutions for long-term care. Naturally these questions will not apply to everyone.

1. In the last year, have you or (CR) thought about moving him/her to a nursing home or other institution?
2. In the last year, have either of you discussed this with anyone?
3. During the last year, have either of you visited a nursing home or institution with the intention of living there?
4. During the last year was an application made for (CR) to enter a nursing home or institution?

13) SF-12

Now I would like to ask you about your health and how you have been feeling.

1. In general, would you say your health is: Excellent, Very Good, Good, Fair, Poor
2. The following are items about activities you might do during a typical day. Does <u>your health</u> now limit you in these activities? If so, how much?
    i. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf? (1 =yes, limited a lot, 2 = yes limited a little, 3= no, not at all)
    ii. Climbing several flights of stairs (1 =yes, limited a lot, 2 = yes limited a little, 3 = no, not at all)
3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of <u>your physical health</u>?
    i. Accomplished less than you would like (yes/no)
    ii. Were limited in the kind of work or other activities you could do (yes/no)
4. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?
    i. Accomplished less than you would like (yes/no)

   ii. Didn't do work or other activities as carefully as usual (yes/no)

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (1 = not at all, 2 = a little bit, 3 = moderately, 4 = quite a bit, 5 = extremely)
6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks-(1 = all of the time, 2 = most of the time, 3 = a good bit of the time, 4 = some of the time, 5 = a little of the time, 6 = none of the time)
   i. Have you felt calm and peaceful?
   ii. Did you have a lot of energy?
   iii. Have you felt downhearted and blue?
7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.) (1 = all of the time, 2 =most of the time, 3 = some of the time, 4 = a little of the time, 5 = none of the time)

14) Additional Health Measures

Now I would like to ask you some questions about you and your health in the past year. Tell me whether you have, or have had, any of the following conditions. (yes/no)

1. In the past year, have you had…
    a. Stroke or effects of a stroke
    b. Paralysis of any kind
    c. Broken hip
    d. Other broken bones
    e. Hip replacement
    f. Parkinson's disease
    g. Thyroid disease
    h. Surgery (Circle either heart, vascular, other)
    i. Tumour or cancer?
    j. Heart or circulation problems? (Circle heart trouble, angina, hardening of arteries)
    k. Pacemaker inserted?
    l. Diabetes?
    m. High blood pressure?
    n. Problems with vision? (Circle cataracts, glaucoma, blindness)
    o. Breathing problems? (Asthma, COPD, emphysema)
    p. Problems with hearing?
    q. Arthritis or rheumatism?

  r. Troubles with your stomach or digestive system?
  s. Nervousness or been tense?
  t. Trouble getting to or staying asleep?
  u. Allergies of any kind?
  v. Kidney condition or disease?

2. How would you say your health is these days? Would you say your health is very good, pretty good, not too good, poor or very poor?
3. Is your health now better, about the same, or worse than it was one year ago?
4. How much do your health troubles stand in your way of your doing the things you want to do? (1 = not at all, 2 = a little sometimes, 3 = a great deal)

The next few questions are about your contact with health professionals.

5. During the last 2 weeks, did you or talk to a doctor…
   a. In an office or clinic? (If Yes: # of times)
   b. Over the telephone? (If Yes: # of times)
   c. At home? (If Yes: # of times)
6. During the last 3 months, did you go to a hospital emergency room for help with a health problem?
   a. If Yes: # of times
7. During the last 6 months, were you admitted to hospital?
   a. If Yes: # of times

# Appendix C

## *Tables of Information for Simplified Structural Equation Model*

Table 22

*Means, Standard Deviations, Minimum and Maximum Values of All Variables in Simplified Structural Equation Model*

| Variable | *M* | *SD* | Min | Max |
|---|---|---|---|---|
| Memory Behaviour Depression Bother | 5.5930 | 6.29218 | 0 | 32 |
| Memory Behaviour Disruption Bother | 4.8829 | 5.28918 | 0 | 28 |
| Memory Behaviour Memory-Related Problems Bother | 6.2284 | 5.46296 | 0 | 28 |
| IADL Bother | 2.0598 | 4.00785 | 0 | 32 |
| ADL Bother CR | 1.6116 | 3.54002 | 0 | 28 |
| Self-Rated Health Total | 10.2697 | 3.71731 | 3 | 20 |
| Total Number of Illness Diagnoses | 1.3552 | 1.17490 | 0 | 5 |
| Anxiety Total | 21.5012 | 7.02388 | 10 | 40 |
| CES-D Total Score | 19.9568 | 7.98450 | 3 | 53 |
| PACS-feel more useful | 3.8730 | 1.34670 | 0 | 5 |
| PACS- feel good about self | 3.9992 | 1.27035 | 1 | 5 |
| PACS- feel needed | 4.2423 | 1.17393 | 0 | 5 |
| PACS- feel appreciated | 3.6008 | 1.48609 | 0 | 5 |
| PACS- feel important | 3.1668 | 1.49736 | 0 | 5 |
| PACS- feel strong and confident | 3.5900 | 1.41992 | 0 | 5 |
| PACS- appreciate life more | 4.0481 | 1.35764 | 0 | 5 |
| PACS- more positive attitude toward life | 3.6996 | 1.44766 | 1 | 5 |
| PACS- strengthened relationship | 3.6822 | 1.41341 | 1 | 5 |

Table 23

*Bivariate Correlations Between All Variables In Simplified Structural Equation Model*

| | MB Dep B | MB Dis B | MB Mem B | IADLB | ADL | SR Health | # Ill | Anx. | CES-D | useful | good | needed | apprec'd | import | strong | posatt | rel'ship |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| MB DepB | 1 | .461** | .432** | .122** | .125** | .136** | -.021 | .379** | .314** | -.012 | -.006 | -.025 | -.067* | -.065* | -.086** | .117** | -.040 |
| MB Dis B | | 1 | .478** | .236** | .267** | .197** | .052 | .346** | .333** | -.146** | -.145** | -.128** | -.274** | -.137** | -.143** | -.149* | -.102** |
| MB Mem B | | | 1 | .309** | .214** | .188** | .109** | .344** | .263** | -.160** | -.184** | -.110** | -.169** | -.138** | -.127** | -.201** | -113** |
| IADLB | | | | 1 | .605** | .192** | .088** | .119** | .144** | -.125** | -.120** | -.064* | -.090** | -.062* | -.026 | -.016 | -.050 |
| ADLB | | | | | 1 | .157** | .043 | .115** | .153** | -.088** | -.088** | -.033 | -.090** | -.054 | -.041 | -.010 | -.053 |
| SR Health | | | | | | 1 | .438** | .414** | .392** | -.003 | -.044 | -.027 | -.059 | -.051 | -.088** | -.086** | -.078** |
| # Ill | | | | | | | 1 | .120* | .144** | -.028 | -.060** | .039 | -.043 | -.039 | -.022 | -.013 | -.051 |
| Anx | | | | | | | | 1 | .646** | -.081* | -.123** | -.035 | -.185** | -.093** | -.185** | -.251** | -.169** |
| CES-D | | | | | | | | | 1 | -.048 | -.035 | -.003 | -.137** | -.041 | -.111 | -.141** | -.103** |
| Useful | | | | | | | | | | 1 | .643** | .530** | .491** | .496** | .443** | .437** | .403** |
| Good | | | | | | | | | | | 1 | .499** | .516** | .511** | .518** | .504** | .410** |
| Needed | | | | | | | | | | | | 1 | .489** | .470** | .428** | .354** | .335** |
| Apprec'd | | | | | | | | | | | | | 1 | .583** | .484** | .433** | .381** |
| Import | | | | | | | | | | | | | | 1 | .557** | .416** | .411** |
| Strong | | | | | | | | | | | | | | | 1 | .514** | .453** |
| Posatt | | | | | | | | | | | | | | | | 1 | .591** |
| Rel'ship | | | | | | | | | | | | | | | | | |