Running head: CAREGIVING STRESS PROCESS

The caregiving stress process: Examining the influence of the nature of the care-recipient illness, stress-buffering variables, mediating factors, and caregiving transitions on caregiver health.

Mun H. V. Tran
Department of Psychology
Lakehead University, Thunder Bay, ON

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Abstract

Providing care for an impaired older adult has been described as a stressful endeavour involving a pleathora of responsibilities that can place the caregiver at risk for negative psychological and physical health outcomes. The goal of this study was to investigate several issues relating to the caregiving stress process: 1) whether caregivers were at greater risk for adverse health outcomes compared to non-caregivers 2) whether the nature of the care-recipient's illness had a negative influence on caregiver health, 3) whether health behaviours mediated the association between caregiving stressors and physical health, 4) whether social support and the quality of the pre-illness relationship had stress-buffering influences on physical health, and 5) whether relinquishing the caregiving role had an effect on caregiver health. The data analyzed in this dissertation were derived from three separate studies of older adults and their caregivers. Caregivers were re-contacted to participate in a follow-up even if the care-recipient had died or was institutionalized. A control group of married older adults who were not actively serving as caregivers to their spouses was included in one of the studies. Spouse caregivers of individuals with cognitive impairments (i.e., dementia), those providing care to cognitively-intact individuals (i.e., non-dementia), as well as a control group of non-caregivers were selected for analyses. Results concerning differences between caregivers and non-caregivers suggested that the consequences of caregiving were manifested by psychological distress but not by physical morbidity. In addition, being a dementia caregiver is an additional risk factor for poorer psychological, but not physical health outcomes. Results also revealed that associations between caregiving stressors, in the form of care-recipient impairments, and physical health were unlikely to be mediated through changes in health promoting practices. With regard to stress-buffering effects, data suggested that positive pre-illness relationship appraisals did not confer health benefits, either in the presence or absence of stress. The stress-buffering effect of social support depended on the composition of the caregiver sample as well as the type of social support that was considered. Finally, results demonstrated that transitioning into widowhood was accompanied by improvements in physical health, while institutional placement of the care-recipient was associated with declines in mental health. Clinical and theoretical implications of the present findings were discussed.

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Background

Over the next few decades, the aging of the Canadian population will increase dramatically. The number of persons over the age of 65 will rise from 4.3 million in 2006 to over 9 million in 2031, owing primarily to the arrival of the baby boomers in this age group (Statistics Canada, 2005). Most individuals who live to early old age are likely to develop a common disabling illness, such as heart disease, arthritis or emphysema (Ahmed, Ness, Howard, & Aronow, 2005; Goebeler, Jylha, & Hervonen, 2003). Aging is also associated with a high prevalence of cognitive impairment. It is estimated that 1 in every 13 Canadians over the age of 65 have Alzheimer disease (AD) or a related dementia (Canadian Study of Health and Aging [CSHA] Working Group, 1994a). Chronic illnesses, such as dementia, may render it difficult or even impossible for individuals to carry out everyday activities without the assistance of a caregiver. Therefore, as the number of older adults continues to increase, so will the number of individuals who need assistance from others.

Age-associated chronic illnesses, such as AD, not only threaten the quality of life of older people, but will also create challenging pressures on health and social services. In Canada, an estimated $5.5 billion is spent annually on persons with AD and related dementias (Ostbye & Crosse, 1994). Costs of care increased significantly with the severity of AD, from $9,451 per individual with mild AD to $36,794 for a senior with severe AD (Hux, O'Brien, Iskedjian, Goeree, Gagnon, & Gauthier, 1998). The increased costs of health care coupled with the growth in the numbers of seniors have generated interest on alternatives to institutional care. The CSHA Working Group (1994b), for example, found that almost half of all Canadians with dementia were living in the community, and of these, 94% were cared for by informal caregivers (i.e., individuals who are not financially compensated for their services), usually the spouse or an adult child. Similarly, in the United States, care services to the physically frail elderly are provided primarily by spouses or adult children (Stone, Cafferata, & Sangl, 1987).

Previous studies have consistently found a lower risk of institutional placement for elders who have a spouse or child available to care for them (see Hanley, Alecxih, Wiener, & Kennell, 1990 for a review). In addition to financial costs, institutionalization may carry a "human" cost. Specifically, a long tradition of research has shown that older adults prefer to reside in their own home (e.g., Butler & Lewis, 1982; Vladeck, 1980).

While informal care providers perform a critical service for society and their care-recipients, they may do so at considerable expense to their health and well-being (Schulz & Beach, 1999). Comparable to findings of a U.S. population survey (Stone et al., 1987), the CSHA Working Group (1994b) found that half of informal caregivers were aged over 60, and they often had health problems of their own. Caregivers who are themselves in poor physical health are more likely to make the decision to institutionalize care-recipients than those in better health (Pratt, Wright, & Schmall, 1987). Since the presence of an informal caregiver is often the crucial factor in keeping care-recipients in the community, preventing and treating health problems among caregivers may reduce health care costs (Baumgarten, 1989; Jutras & Lavoie, 1995). Therefore, it is critical to determine the impact of caregiving on health to avoid adverse effects that lead to the cessation of public assistance. Furthermore, this evaluation is necessary so that health problems are not simply transferred from one group of the population to another; that is, from the impaired care-recipient to their caregivers (Jutras & Lavoie, 1995).

In order to gain a better understanding of the influence of caregiving on health, it is necessary to identify which caregivers are especially vulnerable to negative health consequences, as well as to determine possible reasons why caregivers are at greater risk. Furthermore, identification of factors that may lessen the negative health impact of caregiving stress may suggest new strategies for interventions. Finally, it is important to investigate the impact of long-term care placement or death of the care-recipient on caregiver health, as interventions may be required to aid caregivers through these transitions. Therefore, a detailed examination of the caregiving experience is needed to ultimately facilitate the development and effective targeting of interventions. The current study endeavours to undertake such a thorough evaluation.

Caregiving as a chronic stressor

The idea that caregivers may be at risk for adverse health outcomes is supported by a large body of research demonstrating that stressful experiences can result in poor physical and mental health (e.g., Cohen, Frank, Doyle, Skoner, Rabin, & Gwaltney, 1998; Cohen, Kamarck, & Mermelstein, 1983; Storseth, 2006). The predicament of the informal caregiver is now widely recognized to be highly stressful across a variety of caregiving contexts (i.e., care for individuals with dementia or chronic physical impairments). The stressfulness of care provision often stems from its novelty and lack of formal training (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992). Furthermore, caregivers generally endure many years of continuous exposure to the daily demands of providing care, as well as restrictions on their personal and social life (Kosberg & Cairl, 1986). This chronic and primarily uncontrollable experience would be expected to exact a toll on caregivers. It is therefore fitting that long-term care provision has been conceptualized as a prototypical chronic stressor. In fact, the study of caregiving provides a unique opportunity for testing the complex relationships between stress and health outcomes (Vitaliano, Young, & Zhang, 2004).

Psychological health

Research on the consequences of care provision has predominately examined psychological health outcomes. In the caregiving literature, psychological health is generally assessed using self-reported standardized depression scales or psychiatric symptoms checklists. The use of such scales allows for comparisons with age and gender based population norms. Only rarely have structured clinical interviews been used to assess psychiatric symptoms (Wright, Clipp, & George, 1993). On the whole, studies have consistently found that psychological distress is particularly common among caregivers as they generally report more symptoms of depression compared to population norms or control groups of non-caregivers (Baumgarten et al., 1992; Haley, Levine, Brown, Berry, & Hughes, 1987; Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987; Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson, 1997a; Shields, 1992). As an example, Schulz and his colleagues (1997a) discovered that strained caregivers reported more depressive symptoms, as measured by the Center for Epidemiological Studies-Depression scale (CES-D; Radloff, 1977) than non-caregivers, and a comparable study found that scores on the CES-D were almost twice as high among caregivers compared to their non-caregiving counterparts (Baumgarten et al., 1992).

Moreover, a few studies using diagnostic interviews have reported a higher prevalence of clinical depression and anxiety among caregivers compared to non-caregivers (Dura, Stukenberg, & Kiecolt-Glaser, 1991; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Russo, Vitaliano, Brewer, Katon, & Becker, 1995). In one study, for instance, 26% of caregivers experienced a depressive disorder and 10% met criteria for an anxiety disorder during the years spent caregiving, even though they had never been diagnosed with depression or anxiety prior to becoming caregivers. Only 4% of the comparison sample of non-caregivers met criteria for depressive disorders and 1% experienced anxiety disorders during this time (Dura et al., 1991). Similarly, results of another investigation indicated that 25% of dementia caregivers met diagnostic criteria for a depressive disorder compared to 0% of control participants. Approximately 1 year later, 32% of the caregivers and 6% of the comparison sample had suffered a depressive disorder in the intervening time period (Kiecolt-Glaser et al., 1991).

Self-reported physical health

Traditionally, physical health effects of caregiving have been given less research attention compared to psychological health. However, over the past few years, studies examining the impact of caregiving on physical health have become more common (Martire & Schulz, 2001). While the evidence linking psychiatric morbidity and caregiving is relatively robust, the available studies examining the influence of caregiving on physical health, such as illnesses or self-rated physical health status, are generally equivocal (Fuller-Jonap & Haley, 1995; George & Gwyther, 1986; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

The caregiving literature is characterized by diverse measures of physical health status ranging from composite health measures, either based on self-reported symptom counts or presence of chronic illnesses, to measures of immune functioning (Schulz et al., 1995). One of the most common measures of physical health status in caregiving studies is a single question, asking caregivers to rate their overall health on a four-point scale, with anchors ranging from excellent to poor (Schulz et al., 1995). The use of self-rated health measures has been defended by researchers on the grounds that it is highly correlated with ratings made by physicians, and it is predictive of mortality above and beyond the variance attributed to objective health measures alone (Idler & Kasl, 1991; LaRue, Bank, Jarvik, & Hetland, 1979; Mossey & Shapiro, 1982).

Some caregiving studies have found that caregivers' self-ratings of overall health were consistently lower than non-caregivers as well as population norms (Grafstrom et al., 1992; Haley et al., 1987; Schulz et al., 1995). For instance, using a population-based sample of spousal caregivers, researchers have found that non-caregivers reported higher levels of physical health status than caregivers (Schulz et al., 1997a), and in another investigation, caregivers judged their own health to be worse than did non-caregivers (Grafstrom et al., 1992).

Other studies, in contrast, have found no reliable differences between caregivers and controls with respect to self-rated health (Fuller-Jonap & Haley, 1995; George & Gwyther, 1986). In George and Gwyther's (1986) study, for instance, there was no evidence that caregivers of memory-impaired older adults experienced decreases in physical health relative to random community samples. Fuller-Jonap & Haley (1995) also failed to find a significant difference in physical health between care providers and demographically-equivalent controls.

Studies examining chronic disease conditions and illness episodes among caregivers have also yielded mixed findings. A few cross-sectional studies revealed that caregivers report a greater number of physical symptoms than non-caregivers (Deimling, Bass, Townsend, & Noelker, 1989; Haley et al., 1987; Stone et al., 1987) as well as more chronic illnesses (Baumgarten et al., 1992; Haley et al., 1987; Pruchno & Potashnik, 1989). Pruchno and Potashnik (1989), for example, found that after controlling for age and gender, caregivers of individuals with AD reported higher rates of health problems, such as diabetes, arthritis, ulcers, and anemia than people in the general population. Other studies, on the other hand, have not replicated these findings (Gallant & Connell, 1997; Kiecolt-Glaser et al., 1991). Caregivers in Gallant and Connell's (1997) investigation, for example, exhibited similar levels of high blood pressure and heart problems, and higher levels of arthritis compared to national samples of older adults. In a similar vein, results from another study indicated that caregivers and non-caregivers did not differ in the number of illness episodes they experienced in a one-year time period, despite decreasing immunity in caregivers. However, the illness episodes of caregivers were of a longer duration and resulted in a greater number of visits to the physician than those of the comparison group (Kiecolt-Glaser et al., 1991).

Although self-rated health measures are correlated with objective health indices, self-assessed physical health is confounded by psychological variables. Emotional distress and life satisfaction are likely to influence global appraisals of physical health (Hooker & Siegler, 1992). Furthermore, caregivers high in the trait of neuroticism generally rate themselves as less physically healthy and report having more chronic physical symptoms (Hooker et al., 1992; Reis, Andres, Pushkar-Gold, Markiewicz, & Gauthier, 1994).

Objective indicators of physical health

Taking these shortcomings into account, some researchers have used more objective measures to assess physical health status, such as immune functioning and mortality risk (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Kiecolt-Glaser et al., 1991; Kiecolt-Glaser et al., 1987; Schulz & Beach, 1999; Shaw et al., 1997; Vitaliano, Scanlan, Zhang, Savage, Hirsch, & Siegler, 2002). As an example, one investigation found that caregivers had significantly lower percentages of both total T lymphocytes and helper T lymphocytes than a comparison group of non-caregivers (Kiecolt-Glaser et al., 1987). These results may have important ramifications for older adults as helper T cells stimulate vital immunological activities, including the production of specific antibodies that help defend against bacterial infections. Furthermore, caregivers exhibited significantly higher antibody titers to Epstein-Barr virus than did comparison participants, reflecting poorer cellular immune system control of the latent virus in caregivers. These differences in immune functioning between caregivers and non-caregivers were not a function of nutrition, alcohol use, or caffeine intake. The researchers concluded that the observed immunological differences were consistent with the type of changes typically found among immune-suppressed patients (Kiecolt-Glaser et al., 1987). In a longitudinal investigation of immune functioning, Kiecolt-Glaser and her colleagues (1991) found that spouse caregivers exhibited significant decreases in cellular immunity compared to controls over a period of 13 months. However, these findings were not replicated in a study using a heterogeneous sample of both spousal and adult children caregivers (Reese, Gross, Smalley, & Messer, 1994).

Findings from studies examining mortality and illness risks provide further support for the heightened vulnerability of caregivers to negative health outcomes. Vitaliano and his colleagues (2002), for instance, found that over a period of 27 to 30 months, dementia caregivers had a higher rate of new cases of coronary heart disease than non-caregivers. In a population-based study, researchers discovered that spousal caregivers who reported strain related to caregiving were 63% more at risk of dying within 4 years of entering the study than non-caregivers (Schulz & Beach, 1999). Premature death is considered the ultimate negative consequence of caregiving (Wright et al., 1993).

Meta-analyses

A recent investigation used quantitative procedures to summarize the 23 studies that compared self-reported health and physiological functioning of dementia caregivers to that of non-caregivers (Vitaliano, Zhang, & Scanlan, 2003). Results indicated that caregivers of individuals with dementia reported more physical health problems than did non-caregivers, including poorer global health, more chronic illnesses and physical symptoms, as well as greater usage of somatic medications and health services. In addition, researchers found that caregivers had higher levels of stress hormones and poorer antibody production than non-caregivers. However, this investigation did not evaluate studies that consisted of caregivers of individuals without dementia. As a consequence, it is not possible to determine whether these findings are unique to dementia caregivers or whether they also pertain to other types of care providers.

A meta-analysis conducted by Pinquart and Sorensen (2003), however, included both dementia and non-dementia caregivers in their analyses. These researchers quantified the degree of added risks in this heterogeneous sample of caregivers relative to non-caregivers with respect to physical as well as psychological outcomes. Results indicated that caregivers had higher levels of stress and depression, as well as lower ratings of subjective well-being, self-efficacy, and physical health compared to non-caregivers. However, differences between caregivers and non-caregivers were significantly smaller for physical health than for psychological outcome variables.

Findings from this study also revealed that moderator variables influenced the observed differences between caregivers and non-caregivers. That is, the association between caregiver status (caregiver versus non-caregiver) and health outcomes was attenuated or enhanced based on certain factors such as gender, kinship, and type of care-recipient illness (Pinquart & Sorensen, 2003). In particular, differences between caregivers and non-caregivers with respect to perceived stress, self-efficacy, and physical health were more pronounced for spouses than for adult children caregivers. Additionally, there was a moderating effect of gender on the relationship between caregiver status and health outcomes. More specifically, in samples with a higher percentage of female respondents, caregivers were more impaired than non-caregivers with regard to self-efficacy, general well-being, depression, and physical health. Finally, greater differences between caregivers and non-caregivers were found in studies with only dementia caregivers compared to studies that combined dementia and non-dementia caregivers, suggesting that dementia caregivers may experience greater stress, depression, lower subjective well-being and self-efficacy, as well as poorer physical health than their non-dementia counterparts (Pinquart & Sorensen, 2003).

These findings indicate that negative effects of caregiving are not uniformly distributed across caregivers but vary according to gender, type of care-recipient illness, and specific kin relationship; that is, certain subgroups of caregivers may be at greater risk for poorer health and psychological outcomes than others. Studies examining these subgroup differences in health outcomes are briefly presented below.

Kinship tie and living arrangement

Given the changes taking place in the structure of the nuclear family, reliance on family members to carry out the caregiving role may rest more completely with the spouse (Shanks-McElroy & Strobino, 2001). In fact, a national survey of caregivers found that about one half of primary caregivers were spouses, and of these, 80% were older than 65 years of age (Stone et al., 1987). Given their own advanced old age and concomitant chronic health difficulties, care provision may be more difficult for spousal caregivers (Sorensen & Pinquart, 2005). Additionally, they often provide more assistance to care-recipients than other family caregivers (Stone et al., 1987). It is therefore not surprising that studies have found that spousal care providers are more adversely affected than adult children caring for demented and physically frail elders (Baumgarten et al., 1992; Cantor, 1983; Cohen et al., 1990), with 84% of spousal caregivers reporting their health as fair or poor, in contrast to only 35% of adult child care providers (Cantor, 1983). Likewise, when compared to other family caregivers, spouse caregivers reported significantly more visits to physicians, poorer ratings of physical health status (Deimling et al., 1989; George & Gwyther, 1986; Grafstrom et al., 1992), and higher levels of depression, even after controlling for age differences (George & Gwyther, 1986).

The type of living arrangement (i.e., shared versus separate residences) of the caregiver and care-recipient is often related to kinship tie as spouses are more likely to reside with the care-recipient than are any other family members. It is frequently the case that caregivers living in the same residence as the care-recipient provide care 24 hours a day (Acton, 2002), and as a result, suffer greater negative health outcomes than caregivers who do not live with care-recipients (Bédard, Raney, et al., 2001). One study found that spouses and children living in shared households with the care-recipient experienced similar levels of health decline (Deimling et al., 1989). Since spouse caregivers often co-habitate with the care-recipient, it is not surprising that they are more likely than other family caregivers to experience poorer health outcomes.

Gender

Findings that female caregivers are more adversely affected by their caregiving role have been replicated among care providers of physically and cognitively impaired elderly patients (e.g., Gallant & Connell, 1997; Tennstedt, Cafferata, & Sullivan, 1992). Female caregivers are an especially vulnerable subgroup as they provide more caregiving assistance and often contend with greater care-recipient behavioural problems compared to their male counterparts (Bédard, Chambers, Molloy, Lever, Stones, & Martin, 1999; Pinquart & Sorensen, 2006). Studies have found that female caregivers generally demonstrate significantly higher levels of depressive symptoms than their male counterparts (Gallant & Connell, 1997; Grafstrom et al., 1992; Pruchno & Resch, 1989; Schulz & Williamson, 1991), and they generally report more health problems (Rahman, Strauss, Gertler, Ashley, & Fox, 1994; Ross & Bird, 1994). Furthermore, a meta-analysis of dementia and non-dementia caregivers found that female caregivers experienced lower levels of subjective physical health compared to their male counterparts (Pinquart & Sorensen, 2006). The finding that female caregivers are at greater risk for adverse health outcomes is made even more remarkable by the fact that that 72% of informal caregivers in Canada are women (CSHA Working Group, 1994b).

Nature of the care-recipient's illness

As noted above, kinship, living arrangements, and gender have been found to be important predictors of health outcomes. The nature of the care-recipient's illness may be another risk factor for poorer health among caregivers. The caregiving role has been described as an intensive endeavour involving a pleathora of responsibilities, such as home health care and psychological support. These responsibilities apply to caregiving in the general sense; however, caring for individuals with AD and related dementias involve additional tasks that are specific to the clinical course of the disease. Alzheimer disease resembles other chronic degenerative conditions in which the individual lingers for years in poor health (Harwood, Barker, Ownby, & Duara, 2000). However, it also presents with a complex series of physical limitations as well as with symptoms of serious psychiatric illness, such as hallucinations and delusions, and disruptive behaviours (Koin, 1989). In particular, individuals with dementia progressively lose their ability to perform domestic tasks and to maintain their own personal hygiene. They may also exhibit inappropriate sexual and social behaviours, and may become verbally or physically aggressive (Baumgarten, 1989). Indeed, previous research (e.g., Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999;

Williamson et al., 2005) has demonstrated that dementia caregivers contend with more care recipient disruptive behaviours and provide more assistance with activities of daily living (ADL) than do caregivers of those with primarily physical disabilities.

Given these unique responsibilities, informal caregivers of persons with dementia provide care for more hours each week compared to care providers of individuals with non-dementia (Ory et al., 1999). Other investigators have found that dementia caregivers spend an average of 69 hours per week engaging in caregiving activities, and they typically provide care for a period of 4 years (National Alzheimer's and Related Disorders Association, 1998). The care-recipient's progressive need for care and the associated lack of leisure time for caregivers, as well as the possible social isolation due to care-recipient disruptive behaviours may collectively contribute to feelings of distress among dementia caregivers (Grafstrom et al., 1992). Thus, taking the nature of the care-recipient illness into consideration is important because it is a major determinant of the extent and type of care required and, as a consequence, the caregiver's level of stress (Deimling et al., 1989). This stress could potentially lead to negative physical health outcomes.

Unfortunately, however, research comparing physical and mental health outcomes of dementia caregivers with care providers of individuals with other chronic conditions is rather limited and inconclusive. The existing studies generally compare health outcomes of different illness groups characterized by predominance of cognitive impairments versus those characterized primarily by functional limitations (i.e., cognitively intact, but physically frail older adults). One investigation, for example, examined the differential health impact of caring for a spouse with AD versus a spouse diagnosed with Parkinson's disease (Hooker et al., 1998). Because individuals with Parkinson's disease may develop dementia, care-recipients who had co-existing dementia as well as those who scored below a cutoff on a cognitive test were excluded from the Parkinson's group. Findings indicated that spousal caregivers of AD individuals were more depressed, more anxious, and had lower psychological well-being than caregivers of individuals with Parkinson's disease; however the former group actually reported better physical health than the latter (Hooker et al., 1998).

In another study using a nationally representative sample of caregivers in the United States, care providers of individuals with dementia reported greater levels of emotional and physical strain than those caring for persons without dementia. The classification of dementia and non-dementia caregivers was based on care-providers' reports of patient symptoms. Those who indicated that they provided care to someone with AD, confusion, dementia, or forgetfulness were classified as "dementia" caregivers (Ory et al., 1999). Similar results were obtained in a descriptive study of care providers in Canada (CSHA Working Group, 1994b). However, in this study, a more rigorous procedure was followed in the diagnosis and classification of dementia care-recipients. Results indicated that individuals caring for persons with dementia were more likely to report chronic health problems and depression symptoms than those caring for care-recipients without dementia (CSHA Working Group, 1994b). Finally, Gonzalez-Salvador, Arango, Lyketsos, and Barba, (1999) found that AD caregivers exhibited greater psychological morbidity than caregivers of those who had progressive physical impairments (non-AD).

Other studies, however, have not found any differences in health between dementia caregivers and care providers of individuals with illnesses characterized by physical impairments (Cattanach & Tebes, 1991; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Reese et al., 1994). One cross-sectional study, for instance, compared caregivers of cognitively-intact stroke patients with dementia caregivers on various health outcomes. Researchers found that caregivers in both groups experienced high levels of psychological distress, including symptoms of anxiety, stress, and depression; however, no group differences were observed on these measures. Similar null findings were found on ratings of physical health (Draper et al., 1992). While no meaningful differences were found between the two groups with respect to health outcomes, behavioural and mood disturbances among care-recipients in both groups were predictive of greater psychiatric morbidity (Draper et al., 1992).

Finally, Cattanach and Tebes (1991) compared the health consequences for daughter caregivers across three types of elderly parents: cognitively impaired (e.g., AD, stroke, multi-infarct dementia), functionally impaired (e.g., lung cancer, congestive heart failure), and non-impaired (e.g., minor arthritis, hearing loss, controlled diabetes). Although the nature of the care-recipient's illness was expected to differentiate caregivers on various health factors, no significant group differences were found on measures of depressive symptomatology, psychological distress and physical symptoms. Given these inconsistent findings, as well as the relatively few studies comparing dementia and non-dementia caregivers, additional research is warranted.

While the nature of the care-recipient illness may be an important stressor that may adversely impact caregiver health, research has suggested that individual difference factors may moderate or mediate its impact (Schulz & Martire, 2004). In other words, health outcomes are not based solely on inherent qualities of the stressor, but are also dependent on personal factors, such as appraisals of the stressor. A common approach in studies of caregivers' health has been to conceptualize their experiences in terms of a stress, appraisal, and coping framework (Martire & Schulz, 2001).

Stress process models

Various stress process models of caregiving have been derived from Lazarus and Folkman (1984)'s stress and coping theory. These models have been adapted to a number of caregiving contexts, including caregivers of stroke, cancer, and dementia patients, as well as caregivers of the physically frail elderly (Haley et al., 1987; Martire & Schulz, 2001; Nijboer et al., 1998; Pearlin, Mullan, Semple, & Skaff, 1990; Schulz, Tompkins, & Rau, 1988).

In general, stress process models delineate the manner in which the various components of stress are interconnected to form a process, as well as the possible factors that may mitigate the negative effects of stress. Recently, Martire and Schulz (2001) developed a model of the health effects of caregiving based on Cohen, Kessler, and Gordon's (1995) unified model of the stress process. The latter approach amalgamated the environmental, biological, and psychological conceptualizations of the role of stress in disease risk from the broader stress literature (Cohen, Kessler, & Gordon, 1995). According to the model advanced by Martire and Schulz (2001; see Figure 1), the environmental demands specific to the caregiving experience may include providing assistance with ADL, managing disruptive behaviours, and contending with care-recipient cognitive impairments. If caregivers appraise these stressors as threatening and

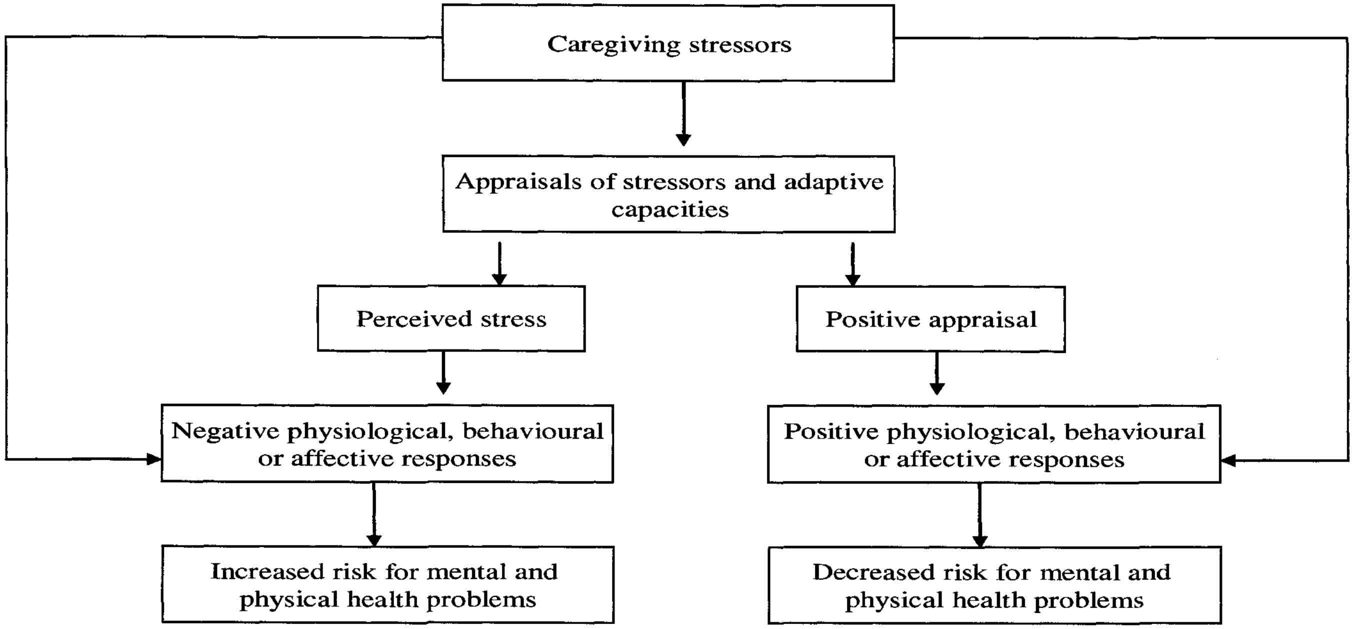

Figure 1. A stress process model of caregiver health (Martire & Schulz, 2001): The left pathway represents negative outcomes associated with caregiving, while the right pathway denotes positive outcomes.

if they perceive that these demands exceed their available resources to cope, they perceive themselves to be under stress. In the caregiving literature, subjective burden has been conceptualized as the appraisal of stress generated by the demands caused by care provision (Chwalisz, 1996; Pushkar-Gold, Reis, Markiewicz, & Andres, 1995; Schulz et al., 1988). This appraisal of stress is thought to initiate the stress response; that is, physiological, behavioural, or affective responses that place the caregiver at increased risk for physical and psychiatric disease. These responses may be thought of as mediators in the stress process because they help explain how caregiving experiences are expressed in altered mental or physical health. It should be noted that the stress process model allows for the possibility that caregivers derive satisfaction from caregiving (as represented in the second pathway in Figure 1). However, positive outcomes associated with care provision have been generally disregarded in studies and are less understood than the negative outcomes (Beach, Schulz, Yee, & Jackson, 2000). Not shown in Figure 1 are the many moderator variables and feedback loops that have been postulated to affect relations between elements of the model (see Martire & Schulz (2001) for a detailed description).

Health behaviours as a possible mediator of stress and physical health

According to Martire and Schulz (2001), physiological or behavioural factors, such as hormonal changes and changes in preventative health practices, are likely to serve as mediators of physical health outcomes. In other words, physiological and behavioural factors are possible mechanisms through which stressors exert their influence on physical health. Unfortunately, however, relatively little attention has been given to empirically examining such relations in the caregiving context (Gallant & Connell, 1998; Martire and Schulz, 2001).

With respect to changes in health behaviours, it is possible that the emotional and physical demands of providing care precludes or alters normal patterns of diet, exercise, and other health promoting activities, which in turn, may lead to adverse physical health outcomes. Alternatively, health risk behaviours, such as smoking, may be used as a method of coping with caregiving stress (Gallant & Connell, 1997). Thus, change in health-related behaviours is one possible mechanism through which caregiving stressors exert their influence on physical health.

The potential mediating role of health behaviours is bolstered by two bodies of research, one that links stress with decrease in health promoting behaviours and a second that links health-related behaviours to physical health outcomes (Gallant & Connell, 1997). Indeed, a mediator variable has to be shown to be related to both the predictor variable, in this case caregiver stressors, as well as the outcome variable, physical health status (Baron & Kenny, 1986).

Caregiving stressors and health behaviours

Researchers have generally found that the stressors accompanying care provision have a negative impact on health care practices (Gallant and Connell, 1998; McKibbin, Walsh, Rinki, Koin, & Gallagher-Thompson, 1999; Shaw et al., 1997). As illustrated by the arrows directly linking caregiving stressors to negative and positive outcomes in Figure 1 (on page 30), caregiver's perception of stress is not always necessary in order for stressors to place the caregiver at risk for negative health outcomes. Caregivers, for instance, may not feel burdened or stressed by caregiving but respond negatively by neglecting their self care, such as exercising or eating regularly (Martire & Schulz, 2001). Indeed, Gallant and Connell (1998) found that caregiving stressors, such as greater intensity of care provided in response to care-recipient physical impairment, were associated with more negative health behaviour changes, in the form of sleep, exercise, alcohol consumption, smoking and weight maintenance. Similarly, McKibbin and others (1999) found that increased dependence in instrumental ADL among dementia care-recipients was associated with less incidence and frequency of exercise among caregivers. Moreover, other researchers found that family caregivers of individuals with greater physical limitations reported less participation in health promoting activities than those who were caring for less physically impaired care-recipients (O'Brien, 1993; Tang & Chen, 2002).

Another investigation found that when care recipients were exhibiting more problem behaviours, caregivers were less likely to schedule overnight appointments for their own health care (Shaw et al., 1997). Finally, Gallant and Connell (1997) found that spousal dementia caregivers who performed more ADL tasks and who spent more hours a day providing care were at greater risk for negative health behaviour change. According to some care providers in another study, their caregiving duties have decreased the opportunity or incentive to engage in preventative health behaviours, such as eating nutritiously or exercising (Connell, 1994). Similarly, caregivers in one investigation reported having more barriers to health promotion practices in comparison to non-care givers, suggesting that caregiving responsibilities may leave little time for them to engage in preventative health care activities (Acton, 2002). Certainly, the evidence indicates that the more demanding the care is, the less likely it is that caregivers will have time to take care of their own health. For example, Burton, Newsom, Schulz, Hirsch, and German (1997) found that, compared to non-caregivers, caregivers who provided more intense care were more than twice as likely to not get enough rest, not have enough time to exercise, and not have enough time to recuperate from illness. In addition, the odds of forgetting to take prescription medications were greater among high-level caregivers compared to non-caregivers. These differences remained significant even when controlling for demographic variables, perceived social support, and sense of control. Finally, results from a longitudinal study indicated that increases in spouse ADL difficulties predicted increases in caregiver health-risk behaviours, such as not having enough time to exercise (Beach et al., 2000).

Health risk behaviours, such as smoking, may be used as a method of coping with the stress associated with caregiving. In fact, empirical evidence suggests that stress influences health risk behaviours and can lead to increased cigarette smoking, alcohol consumption, as well as calorie and fat intake among individuals in the general population (Cohen, Schwartz, Bromet, & Parkinson, 1991; McCann, Warnick, & Knopp, 1990). In the caregiving literature, however, these findings are conflicting. For instance, a pilot study of health behaviour patterns among 44 spouse caregivers examined the extent to which they engaged in specific health behaviours as a means of coping with the stress of caregiving. Results indicated that close to one-half of the caregivers who smoked reported increasing the number of cigarettes smoked per day since they began providing care to their spouse (Connell, 1994). Similarly, Schulz and his colleagues (1997a) found that strained caregivers had a tendency to smoke more than usual compared to non-strained caregivers and non-caregivers. Other studies, however, failed to find a significant relationship between caregiving stress and increased smoking frequency (Gallant & Connell, 1997; McKibben et al., 1999). McKibben and others (1999), for instance, did not find a significant association between indices of caregiving stress, such as care-recipient functional impairments, and smoking frequency among female dementia caregivers. However, they did find that greater caregiving demands were significantly related to *lower* alcohol consumption. Similarly, Gallant and Connell (1997) found that very few caregivers reported an increase in drinking and smoking since they started providing care. While a small portion of caregivers may engage in health risk practices as a behavioural coping strategy, the actual prevalence of tobacco and alcohol consumption generally do not differ between caregivers and non-caregivers (Gallant & Connell, 1997; McKibben et al., 1999; Reese et al., 1994; Schulz et al., 1997a; Vitaliano, Russo, Scanlan, & Greeno, 1996).

Taken together, these findings suggest that caregiving does not necessarily have a deleterious impact on all health behaviours. In particular, caregivers do not appear to be at risk for increased alcohol or tobacco consumption compared to non-caregivers, nor is there consistent support for the contention that caregivers consume more tobacco or alcohol as a coping strategy to deal with caregiving stress. On the other hand, existing studies generally indicate that the stress associated with providing "around the clock care" may preclude caregivers from participating in daily or routine self care activities, such as exercising, visiting their family physician, and getting adequate rest. Neglecting to engage in health promoting practices may increase the likelihood of physical morbidity among caregivers.

Health behaviours and physical health

The next line of research that supports the possible mediating role of health behaviours involves examining the relationship between health behaviours and physical health outcomes. There is a consistent body of evidence indicating that good health practices are associated with better physical health status and reduced mortality, independent of age, sex, and economic status among the general population (Belloc & Breslow, 1972; Breslow & Enstrom, 1980; Buchner, Beresford, Larson, Lacroix, & Wagner, 1992; Wiley & Camacho, 1980; Wingard, Berkman, & Brand, 1982). Belloc and Breslow (1972), for instance, found that eating at regular times, weight control, obtaining adequate sleep, engaging in physical activities, and avoidance of smoking and excessive alcohol consumption were all positively related to physical health status. A longitudinal extension of this study found that good health practices were associated with longevity and curtailment of physical disability over a 10-year period (Breslow & Breslow, 1993). Finally, the number of health promoting practices has been found to have an additive effect on health. In other words, each additional health promoting practice is cumulatively associated with better physical health (Belloc & Breslow, 1972; Reed, 1983).

While the link between health behaviours and physical health status has been primarily based on findings from the general population, there have only been a few studies that examined the relationship between health behaviours with physical health status among caregivers (Acton, 2002; Tang & Chen, 2002; Vitaliano et al., 2002). One study, for example, found that among male caregivers, poor health habits, such as engaging in minimal physical activity and increased fat and caloric intake, predicted metabolic syndrome (e.g., blood pressure, insulin, glucose, obesity, and lipids) 15 to 18 months later, and metabolic syndrome predicted new cases of coronary heart disease over 27 to 30 months (Vitaliano et al., 2002). Other investigators found that greater frequency of engaging in health promoting activities was associated with increased well-being and better perceived health status among caregivers (Acton, 2002; Tang & Chen, 2002). Although the evidence is robust with respect to the link between health practices and physical health among the general population, further research is needed to replicate these findings in caregiver samples.

Test of mediation

The above studies provide indirect support for health behaviours as a possible mechanism linking caregiving stress to physical health outcomes. To date, however, only a few studies have directly tested the mediational role of health behaviours (Acton, 2002; Vitaliano et al., 2002). Results from one study, for instance, indicated that among dementia caregivers, health promoting practices served as a mediator between caregiving stress and well-being (Acton, 2002). Because well-being may tap into both emotional and physical health, the mediational effect of health behaviours on physical health can not be clearly demonstrated in this study. However, another investigation used a more specific indicator of physical health rather than a general well-being measure. Researchers found that caregiver status (caregiver versus non-caregiver) as well as care-recipient cognitive and functional impairments explained variance in distress among dementia caregivers. This, in turn, explained variance in poor health habits, which predicted elevated cardiovascular and metabolic risk 15 to 18 months later (Vitaliano et al., 2002).

Given the results from the aforementioned investigations, there is preliminary evidence to suggest that changes in self care practices may partially explain the relation between caregiving stress and adverse physical health outcomes. More specifically, the stressors associated with caregiving may lead to decreases in health promoting behaviours, which in turn, contribute to poorer physical health. However, additional empirical studies are needed to reproduce these introductory findings. If reductions in health promoting behaviours help explain the negative impact of caregiving stressors on physical health, then interventions aimed at increasing health promoting practices may lessen the adverse effect of stressors on health. Understanding health practices of caregivers may help prevent or forestall the onset of new health problems and facilitate the management of existing illnesses, as well as extend the caregivers' ability to provide care (Connell & Gallant, 1999).

Social support as a potential moderator

As previously mentioned, moderator variables may affect relations between components in the stress process model, such that the negative effects of stress are attenuated or enhanced under certain conditions. Proposed moderators include, but are not limited to, coping style, perceived control, personality characteristics, as well as the relationship quality between the caregiver and care-recipient (Martire & Schulz, 2001). Social support may be another important moderating factor that buffers (i.e., lessens) the detrimental effects of stress (Martire & Schulz, 2001).

In the broader stress literature, the moderating stress-buffering model has been widely tested as one way that social support can offset the negative effects of stress (e.g., Cohen & Wills, 1985; Wheaton, 1985). This model posits that the beneficial effect of social support derives primarily from its protective properties in the presence of high stress, while the effect of high and low amounts of support on health is similar at low levels of stress. The moderating effect occurs when there is a statistical interaction between caregiving stress and social support (Wheaton, 1985).

Some researchers have suggested that perceived quality and availability of social support (i.e., the perception of the supportive value of supportive ties) may be more important than the structural aspects of social support (i.e., size and composition of the support network in predicting health outcomes; Heller, Swindle, & Dusenbury, 1986; Monahan & Hooker, 1995; Schaefer, Coyne, Lazarus, 1981). In the general stress literature, most of the stress-moderating effects have been demonstrated in studies utilizing measures of perceived support (e.g., Kessler & McLeod, 1985), while structural measures of social support are less likely to show buffering effects (Cohen & Wills, 1985; Thoits, 1995).

Generally, perceived social support measures differ from structural measures of support in that they do not quantify the number of supporters or the frequency of social contact a person has. Instead these measures attempt to capture individuals' confidence that adequate support would be available if it was needed or to characterize an environment as helpful or cohesive (Barrera, 1986). While structural aspects of social support assess the existence or number of important relationships, some researchers argue that it is erroneous to assume that all such linkages involve the provision of social support (Wellman, 1981). Furthermore, previous research has demonstrated that perceived satisfaction with support does not correlate highly with objective measures of support, such as network size (Given, Collins, & Given, 1988), suggesting that larger social networks do not necessarily translate into greater satisfaction with the support provided by the network.

Caregiver outcomes have been found to correlate more strongly with perceived satisfaction with support than with the size of the caregiver's network (Fiore, Coppel, Becker, & Cox, 1986; O'Rourke & Tuokko, 2000). O'Rourke & Tuokko (2000), for instance, discovered that the relative size of caregivers' support networks was unrelated to physical health, while Clipp and George (1990) found that better health outcomes were reported by caregivers who perceived high stable social support over the course of a year. Similarly, other researchers have found that higher levels of perceived support predicted better reported health (Monahan & Hooker, 1995), as well as lower metabolic and cardiovascular risk (Vitaliano et al., 2002). Dementia caregivers who perceived higher initial levels of satisfaction with social support resources actually exhibited improved health over time, while those who reported the greatest increases in negative health symptoms also reported receiving low support at the beginning of the study (Goode, Haley, Roth, & Ford, 1998). Another investigation found that AD caregivers with low perceived support at baseline experienced greater negative changes in immune function compared to non-caregivers, even after controlling for differences in depression (Kiecolt-Glaser et al., 1991).

While these studies have established a link between greater social support and positive health outcomes among caregivers, there was no information provided regarding the possible interactive effects of caregiving stress and social support to test the buffering hypothesis. In other words, while these studies have demonstrated that social support is beneficial for caregivers, the specific conditions under which support exerts its positive effect were not assessed.

Only a handful of studies in the caregiving literature have examined the moderating effect of social support on physical health (Bass, Noelker, & Rechlin, 1996; Franks & Stephens, 1996; Uchino, Kiecolt-Glaser, & Cacioppo, 1992). One study, for instance, found that caregiver status (i.e., dementia caregiver versus non-caregiver) interacted with perceived social support, such that caregivers with low levels of perceived emotional and instrumental (i.e., tangible) support from significant others were characterized by atypical age-related increases in heart reactivity in response to stressor tasks, while those with high social support exhibited typical heart rate response. Non-caregivers, with both high and low levels of social support, also displayed typical cardiovascular responses to the stressor tasks (Uchino et al., 1992). Researchers in another study used care-recipient impairments (i.e., care-recipient physical disabilities and disruptive behaviours) as indicators of stress, rather than caregiver status. They found that instrumental support lessened the effects of caregiving stress on health deterioration among caregivers of elderly individuals with a range of physical and cognitive impairments (Bass et al., 1996). Finally, Franks and Stephens (1996) found a buffering effect of perceived emotional and instrumental support on physical health among daughter caregivers of physically and/or cognitively impaired elderly parents. In particular, caregivers who perceived less support experienced poorer physical health at higher levels of stress due to caregiving responsibilities. They also found the perspectives of the support perceived by caregivers were comparable to the actual supportive behaviours provided.

Quality of pre-illness relationship as potential moderator

The quality of the premorbid relationship between the caregiver and care-recipient has been proposed as another possible moderator in the stress process (Martire & Schulz, 2001); however, no studies have empirically tested its interactive effect on health outcomes. Similar to perceived social support, a positive appraisal of the pre-illness relationship may serve as a stress-buffering personal resource that can facilitate caregiver adaptation to stress. It is within the interactions of this earlier relationship that longstanding patterns of cohesion and reciprocity have been established. These patterns of interaction provide a foundation for coping that the caregiver carries into the caregiving role (Kramer, 1993; Williamson & Schulz, 1990). Caring for a spouse with whom the pre-morbid relationship was warm and positive may be less stressful than if the pre-illness relationship was strained (Schulz & Williamson, 1991). One study, for instance, found that caregivers who had a close relationship with the care-recipient prior to the onset of AD felt less burdened than those whose relationship was not close (Williamson & Schulz, 1990). Another investigation demonstrated that psychological distress was associated with a poor pre-morbid relationship with the care-recipient among caregivers of those with depression and care providers of individuals with dementia (Wijeratne & Lovestone, 1996). Furthermore, other studies have found that caregivers of individuals with dementia were less likely to be depressed if they reported a better relationship with the care-recipient prior to the development of the disease (Morris, Morris, & Britton, 1988; Schulz & Williamson, 1991). Finally, care providers who experienced better physical health also reported a better quality relationship with the care-recipient before the onset of illness (Cairl & Kosberg, 1993). Taken together, these findings suggest that the negative effects of caregiving stress may be attenuated among caregivers with positive pre-illness relationships with their care recipients.

Caregiving transitions

Aside from the variety of factors that may render the nature of the caregiving experience to differ between caregivers, it is evident that providing in-home care can be a demanding and often stressful process. The evolution of the caregiving situation generally involves different transition phases; for many caregivers the transition out of the caregiving role most commonly occurs with either the admission to permanent institutional care or death of the care-recipient. The effect of these transitions on caregiver health is not fully understood. More specifically, there is uncertainty as to whether relief from the demands of care provision translate into better health for the caregiver, or whether transitions away from in-home care produce additional stressors that may be detrimental to caregiver health (Grant, Adler, Patterson, Dimsdale, Ziegler, & Irwin, 2002). For instance, while caregivers who institutionalize their care-recipients are relieved of some of their central caregiving activities, such as providing assistance with bathing and toileting, they still often retain their involvement with the care-recipient. Caregivers often discuss care with long-term care staff, and some even provide active ADL assistance (CSHA Working Group, 2002). In fact, the informal support provided by these former caregivers has been described as “invisible caregiving” (Stevens, Walsh, & Baldwin, 1993). Compared to the institutional stage of the transition, bereavement involves the ultimate termination of the caregiving role.

Cross-sectional studies have compared caregivers of community-dwelling care-recipient to caregivers of those in long-term care to isolate the effects of caregiving and the effects of institutionalization (Pratt et al., 1987; Stephens, Kinney, & Ogrocki, 1991). This design has also been used to study the effects of bereavement (see Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997b for a review). However, the course of caregiver health before and after the death or placement of the care-recipient can not be examined with cross-sectional designs (Collins, Stommel, Wang, & Given, 1994; Schulz et al., 1997b). Fortunately, there have been several longitudinal studies that followed caregivers over time to determine if there was a different pattern of change manifested by those who experienced a transition in caregiving status compared to those who did not. These studies are described below.

Transition to long-term care

Studies on the effects of long-term care placement on health outcomes reveal a variety of results. Some investigators have found that having ceased to provide home care, the health of caregivers who institutionalized their care-recipients improved over time in comparison to those continuing to provide in-home care (Bond, Clark, & Davies, 2003; Grant et al., 2002; Kramer, 2002; Pot, Deeg, & Van Dyck, 1997; Seltzer & Li, 2000). In Kramer's (2000) study of dementia caregivers, self-rated physical health improved for those who placed their spouses, while continuing caregivers exhibited stability in health over time. Other studies have found that those who institutionalized their spouses reported less physical health declines over time compared to in-home dementia caregivers (Bond et al., 2003), and reported fewer serious symptoms in the immediate period after placement, as well as at the final follow-up period. The presence of serious symptoms was based on physician judgments as to the likelihood that a particular symptom connoted a medical condition that either should be treated or further evaluated (Grant et al., 2002). Furthermore, Bond and his colleagues (2003) found that mental health significantly improved for the institutional group in comparison to those who continued to provide in-home care. In a similar vein, findings from another study revealed that caregivers who institutionalized their spouses experienced a decline in depressive symptoms in the 6-month period during which placement occurred, and these symptoms lessened even further within 12 months of placement. This trajectory was in contrast to the relatively stable patterns of depression among continuing caregivers (Grant et al., 2002). Findings from another investigation indicated a trend for psychological morbidity to decrease among caregivers who institutionalized their care-recipient, while continuing caregivers exhibited significantly greater psychological morbidity over time (Pot et al., 1997). Similar patterns were observed in a study of caregivers of those with physical and mental impairments. Continuing caregivers in this investigation, however, experienced relative stability in psychological health during the study period (Resource Implications Study Group of the MRC Study of Cognitive Function and Ageing [RIS MRC CFAS], 2000).

A few studies, on the other hand, found that the pattern of change for those who institutionalized their care-recipients were comparable to that of caregivers who maintained their caregiving role in the community (Collins et al., 1994; RIS MRC CFAS, 2000). More specifically, researchers failed to find significant changes in emotional well-being over the study period for both institutionalized and continuing caregivers (Collins et al., 1994; RIS MRC CFAS, 2000).

Transition to widowhood

Studies contrasting changes in health between bereaved caregivers and those who continued to provide in-home care have found greater improvements in health outcomes following the death of the care-recipient (Bond et al., 2003; Grant et al., 2002; Pushkar-Gold et al., 1995), while others have found no comparative changes in functioning (Bodnar & Kiecolt-Glaser, 1994; Collins et al., 1994; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001).

One study, for example, found that among dementia caregivers whose spouses died, there were no significant changes in depressive symptoms at 6 months; however, by 12 months, there were substantial improvements. The average serious medical symptom score for this group was unchanged immediately after death of spouse, but dropped about 30% by the final follow-up period (approximately 12 months after death). Continuing caregivers in this study, however, demonstrated relative stability in health outcomes (Grant et al., 2002). Similarly, Bond and his colleagues (2003) found greater improvements in physical and mental health among widows compared to continuing caregivers.

Other investigators, however, found that bereaved and continuing caregivers did not differ in depressive symptoms over time, suggesting that the former group had not becomes less depressed after the cessation of caregiving (Bodnar & Kiecolt-Glaser, 1994; Collins et al., 1994).

Schulz and his colleagues (1997b) reviewed the available literature on the effects of bereavement. They reported that although some studies have found short-lived (i.e., less than 1 year) increases in negative affect among caregivers following the death of their family member, these negative outcomes generally do not persist. In fact, they found strong evidence to suggest that caregivers experienced positive outcomes, such as feelings of relief from caregiver burden and increased quality of life.

Taken together, these findings add credence to the notion that alleviation from the stresses of caregiving, either through placement or death of the care-recipient, is generally accompanied, in the longer term, by health benefits to the caregiver. These studies, however, have not examined whether health trajectories of transition groups differed by caregiver type (dementia versus non-dementia). Instead, researchers have either combined caregivers of individuals with different impairments or they simply focused on one illness group. Transitions involving dementia care may be qualitatively distinct from transitions involving care of non-dementia care-recipients (Collins et al., 1994), and examining these potential differences is an area worthy of further research exploration.

Bridging gap in literature

The current investigation attempts to bridge the gap in the caregiving literature by addressing some of the limitations of its predecessors. First, to minimize variance attributed to different living arrangements and relationship to care-recipients, a homogenous sample of spouse caregivers who were currently residing with the care-recipient was contrasted with a group of married non-caregivers who resided with their spouses. Moreover, we separated dementia from non-dementia caregivers as these groups are not always differentiated in studies of caregiving (Pinquart & Sorensen, 2003). In a similar vein, the two caregiver groups were compared on health outcomes as relatively few studies have examined potential differences between these subgroups (Wright et al., 1993).

In general, cross-sectional studies have dominated the literature; however, such designs only provide a snapshot of the caregiving experience, thus limiting the understanding of the evolution of the caregiving experience. Consequently, a longitudinal design was used to compare changes in caregiver health outcomes as well as changes in care-recipient functioning between dementia and non-dementia caregivers.

The present investigation also examined possible mediators and moderators of caregiver physical health as this outcome has been given relatively little empirical attention in favor of mental health outcomes (Martire & Schulz, 2001). Finally, the majority of studies in the caregiving literature have used volunteer samples of convenience that are generally recruited through support groups or public service organizations (Schulz, Visintainer, & Williamson, 1990). Some researchers have criticized the use of such samples as they may provide an inflated view of the problems encountered by caregivers as those who are coping well may not need support services. Alternatively, caregivers who are extremely distressed may be under-represented in these studies as they may be unable to take part in support groups or use services (Dura & Kiecolt-Glaser, 1990; Schulz et al., 1990). Regardless of the direction of bias, it is clear that the use of convenience samples may compromise generalizability of findings. The current investigation used data from two nationally representative studies of older adults and their caregivers to supplement data derived from a convenience sample of caregivers. Because participants in the former datasets were identified in a random population-based study, the results are more generalizable than those obtained from convenience samples.

Furthermore, using multiple datasets with a uniform analytic strategy is an additional strength of the current study as conceptual replication of findings across datasets validates the robustness of the phenomenon under investigation. It is anticipated that results of the current study will contribute to the growth and advancement of the caregiving literature by improving the understanding of the complex relationship between chronic stressors and health outcomes.

Purpose

The first purpose of the current study was to examine whether the nature of the care-recipient illness influences health and psychological outcomes among caregivers. To achieve this objective, dementia caregivers and non-dementia caregivers were compared with respect to physical health and psychological outcomes. A control group of non-caregivers was also used for the purposes of comparison. Based on the available studies documenting differences between caregivers and non-caregivers on physical and psychological health, we expected that both caregiver groups would experience poorer psychological and physical health outcomes compared to their non-caregiving counterparts. Furthermore, given the findings that dementia caregivers contend with greater care-recipient impairments than other caregivers, we anticipated that dementia caregivers would exhibit poorer health outcomes compared to their non-dementia counterparts. Although physical and psychological health were the main outcome variables in the present study, we were also interested in contrasting groups with respect to other stress process variables, such as perceived support, relationship appraisals, service use, health behaviours, and subjective burden. Group differences on these factors may help explain potential differences observed for physical and mental health.

The next two objectives of the present study involve examining the roles of mediator and moderator variables on physical health. In other words, we sought to explore the pathway through which stressors exert their negative influence on physical health, as well as to identify protective resources that may mitigate the adverse impact of appraised stress on health. The caregiving stress process model advanced by Martire and Schulz (2001) was used as a broad conceptual framework to guide the examination of these objectives. However, only select relations among components of their model were investigated. Within this framework, caregiving stressors were operationalized as the care-recipient's functional impairment, disruptive behaviours, and cognitive impairment, health behaviours served as the mediator variable, and caregiver physical health was used as the outcome variable. The mediator hypothesis proposes that increases in caregiving stressors will lead to decreases in health promoting behaviours, which in turn, will predict poorer physical health.

Resources, such as perceived social support and appraisals of the quality of the pre-illness relationship, served as moderating factors in the stress process. While moderator variables can exert their influence on physical health at any stage in the stress process (Cohen & Wills, 1985; Cohen et al., 1995; Martire & Schulz, 2001), we chose to examine the moderating effect of perceived support and relationship quality on the pathway between perceived stress and physical health. Consistent with the stress-buffering hypothesis of social support, we predicted that greater perceived support would buffer the negative effects of burden (i.e., perceived stress) on physical health, such that under conditions of high burden, caregivers who perceived greater support would experience better health than those who perceived less support. However, under conditions of low burden, caregivers who perceived greater support would not differ from those who perceived less support in terms of physical health. It is further expected that appraisals of the premorbid relationship and burden would interact to predict physical health in a similar manner. Tests of mediators and moderators were applied to dementia caregivers and non-dementia caregivers separately (when sample sizes permitted) to assess whether or not relationships between variables in the stress process model operate in a comparable fashion. Given that there have only been a few studies that examined health behaviours as a mediator, and perceived social support and quality of the pre-illness relationship as moderators of physical health, these hypotheses should be viewed as exploratory in nature.

In addition to our main objectives, a secondary goal of this study was to assess the differential changes in physical and mental health between continuing caregivers, those who had yielded to institutional care, and those who had been widowed. Given that the adverse health consequences of caregiving have been well documented in the literature, and given the findings that caregivers who ceased providing in-home care generally report improvements in health, it was hypothesized that caregivers who placed their spouses in long-term care and caregivers whose spouses were deceased by the follow-up assessment would demonstrate greater improvements in physical and mental health compared to those who continue to provide in-home care. We also examined whether health trajectories of transition groups varied by caregiver type (dementia versus non-dementia). Finally, we were interested in contrasting groups with respect to other stress process variables as differences on these variables may help explain potential group differences observed for physical and mental health.

Method

Participants and Procedure

Dataset 1

Dementia caregivers

Dementia caregivers were recruited through local and regional service delivery agencies, a geriatrician, advertising, and media releases in Thunder Bay and Hamilton, Ontario to take part in a study comparing rural and urban caregivers between 2002 and 2004. Only spouse caregivers who lived in the same household as the care-recipient were eligible for participation to ensure a relatively homogeneous sample. Service providers identified and approached potential participants, explained the study briefly and asked whether they would be willing to have a research assistant contact them. Caregivers who agreed to have their names released were then contacted by phone. The study was described in more detail and informed consent was obtained verbally (see Appendix A). Upon informed consent, a phone interview was scheduled. A copy of the questionnaire was mailed to the caregiver in advance of the phone interview. A total of 66 spouse caregivers of individuals with possible or probable Alzheimer Disease or other forms of dementia were interviewed for the study.

In 2006, the current investigator re-contacted these participants to determine whether or not they would be interested in taking part in a follow-up investigation. Caregivers who were no longer providing care due to the death or institutionalization of the care-recipient were also invited to participate in this study. Similar procedures were used to collect follow-up information. In addition, written informed consent was obtained in the follow-up study. A consent form, copy of the questionnaire, and cover letter were mailed prior to the telephone interview (see Appendices B and C). Participants were asked to sign the consent form and return this document to the investigator. A self-addressed, stamped envelope was included with the questionnaire package to facilitate returns. Thirty-nine of the 66 dementia caregivers agreed to complete the follow-up interview.

Non-dementia caregivers and non-caregivers

The present investigator also recruited spouse caregivers of individuals with primarily physical impairments (non-dementia caregivers) as well as a sample of married older adults who were not actively serving as caregivers to their spouses (non-caregivers). Only spouses who were currently residing with their partners were eligible for participation. Non-dementia caregivers were recruited from a variety of sources in Thunder Bay, including senior citizen’s agencies, support groups, and different service delivery organizations, such as day programs for individuals with chronic illnesses as well as other homecare and support services. Recruitment letters (see Appendices D and E) were distributed at support groups and senior citizen’s agencies. Non-caregivers were recruited from senior citizen’s agencies. Interested participants were provided further details of the study. For those who agreed to participate, a phone interview was scheduled and participants were given a copy of the questionnaire and cover letter prior to the interview (see Appendix F). Non-dementia caregivers recruited from community service organizations were initially approached by their respective service providers, who briefly explained the purpose of the study, provided potential participants with a cover letter delineating the nature of the investigation (see Appendix G), and ascertained whether or not they would agree to have their names and contact information released to the current investigator. A verbal agreement of interest prompted the initial phone contact by the investigator, whereby details of the study were outlined in greater detail.

The procedures used to collect information from non-dementia caregivers and non-caregivers were similar to those used with dementia caregivers. However, follow-up data were not obtained with the former groups. Thirty-one non-dementia caregivers and 34 non-caregivers were interviewed.

Criteria for eligibility in the current analyses

For the purposes of the present study, care-recipients in the non-dementia group had to be cognitively intact, as defined by a score of 4 or less on the Informant Questionnaire on Cognitive Decline in the Elderly – short form (IQCODE; Jorm, 1994). Given that a variety of cut-off scores have been used for dementia screening, Jorm (2004) recommended that the best approach to selecting a cut-off score is to choose one that has been used in a sample that is similar in composition to the population the user wants to screen. Of the studies to use cut-off scores for dementia screening, the sample used in Jorm and Jacomb's (1989) investigation was judged to be comparable to the one used in the current study. They found that using a cut-off point of 4.0 to define likely dementia classified 93% of the dementia sample as demented and 88% of the general population sample as normal. In other words, a sensitivity of 93% indicates that using this cut-off misses 7% of cases of dementia. In the present study, 10 of the 31 non-dementia caregivers who were interviewed were not included in the data analyses because their spouses had an IQCODE score greater than 4.0. None of the remaining 21 care-recipients had a co-existing diagnosis of dementia.

Dataset 2

Overview

The Canadian Study of Health Aging (CSHA) is a longitudinal study that began in 1991 (CSHA-1) with follow-ups in 1996 (CSHA-2) and in 2001 (CSHA-3). It was funded by the Seniors Independence Research Program, administered by the National Health Research and Development Program of Health and Welfare Canada (Project No. 6606-3954-NC[S]). The study was coordinated through the University of Ottawa and the Canadian government's Laboratory Centre for Disease Control.

The methodology used by the CSHA is described in greater detail elsewhere (CSHA Working Group, 1994a; Lindsay, Sykes, McDowell, Verreault, & Laurin, 2004; McDowell, Aylesworth, et al., 2001; McDowell, Hill, et al., 2001). Each phase of the study is briefly presented below.

CSHA-1

In the first phase of the study, data were collected in 1991 to 1992 from a representative cohort of Canadians 65 years of age and over, which included both community and institutional samples. Figure 2 depicts the flow of participants through components (i.e., screening, clinical, and caregiver interviews) of the CSHA-1. Community-dwelling persons aged 65 years and older ($N = 9{,}008$) were randomly identified from 36 urban centres and surrounding rural communities across Canada. Community samples were randomly drawn from computerized records of the provincial health insurance plans, except in Ontario, where the Enumeration Composite Record was used. The institutional sampling frame included nursing homes, chronic care facilities, and collective dwellings, such as convents. Institutions were stratified by size, and a

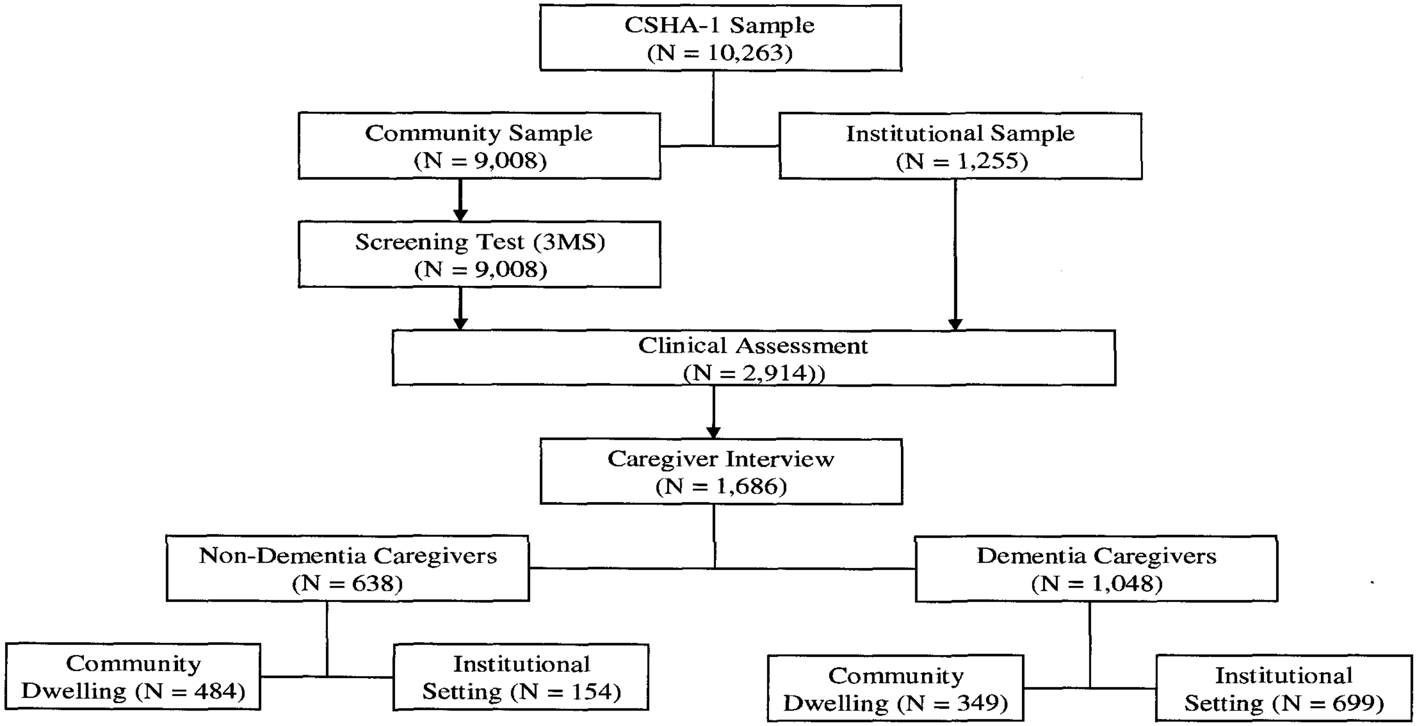

Figure 2. Flow of CSHA-1 participants through the screening test, clinical assessment, and caregiver interview.

stratified random sample of institutions was drawn in each region, followed by a random sample of people in those institutions (*N* = 1,255).

Care-recipients

Screening test

As can be seen in Figure 2, 9,008 community-dwelling participants were screened for cognitive impairment using the Modified Mini-Mental State Examination (3MS, Teng & Chui, 1987). A 3MS score below 78 out of a possible 100 was taken as indicative of cognitive impairment. Those who screened positive (3MS score < 78) and those who could not complete the 3MS were asked to take part in the clinical component of the study. A random sample that screened negative (i.e., 3MS score > 78) was also invited to undergo a clinical assessment, while all participants from institutions were asked to attend the clinical evaluation.

Clinical assessment

A total of 2,914 participants received a clinical exam (see Figure 2); 1,255 from institutions, 1,165 who screened positive in the community, and 494 who screened negative. Subsequent to clinical examination, a consensus diagnosis was reached according to American Psychiatric Association (1987) criteria for dementia by interdisciplinary teams, comprising a physician, neuropsychologist, nurse, and/or psychometrician. Those diagnosed with dementia were subclassified using the National Institute of Neurological and Communicative Disorders and stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria for Alzheimer Disease (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984) and other specific criteria for cognitive impairment and vascular dementia.

Caregivers

Caregiver interview

Primary caregivers of those diagnosed with dementia (care-recipients) were invited to take part in a separate interview (i.e., caregiver interview). The primary caregiver was defined as the person perceived by the care-recipient and/or family members as ordinarily being the most responsible for the day-to-day decision making and provision of care to the care-recipient. Caregivers of a random sample of individuals without cognitive impairment (i.e., those who scored above 77 on the 3MS) were also asked to participate in the caregiver interview. Participants in this group included those with physical disabilities as well as some who were healthy (i.e., no cognitive or physical impairments) and not actively receiving care. In these cases, the person who *would be responsible for providing care* should the need arise was given the caregiver interview. Thus, those *responsible for* and those *actively caring for* individuals who were shown to have no cognitive impairments were included in the non-dementia group. In total, 1,048 dementia and 638 non-dementia caregivers completed the caregiver interviews (see Figure 2 on page 56). Of these, 1,472 were unpaid, informal caregivers (e.g., spouses, family members, and other relatives) and 214 were paid (e.g., nurses; CSHA Working Group, 1994b). The participation rate for the caregiver interview was 90% (Lindsay et al., 2004).

CSHA-2

The second phase of the CSHA (CSHA-2) began in late 1995 and followed the same protocol as CSHA-1. A screening survey was administered to all surviving participants who resided in the community and who were not diagnosed with dementia.

Those who screened positive on the 3MS and all those who had a clinical exam in CSHA-1 (including all those who resided in an institution) were sent for a clinical exam. Furthermore, 500 of those who screened negative were asked to undergo a clinical evaluation.

CSHA-2 re-contacted informal, but not formal (i.e., paid), caregivers, even if the care-recipient had died or was institutionalized. Caregivers of care-recipients who had died were given an abbreviated questionnaire. If the CSHA-1 caregiver could not be located, new caregivers of community-dwelling care-recipients were interviewed (*N* = 33). In total, 1,129 interviews were conducted with caregivers, and 1,092 of these were follow-up with caregivers who took part in the CSHA-1 survey. The participation rate for the CSHA-2 caregiver interview was 75% (McDowell, Aylesworth, et al., 2001).

CSHA-3

A second follow-up (CSHA-3) was conducted between 2001 and 2002. The CSHA-3 study methods were generally the same as its predecessors, except that the 3MS cut point was set at 89/90 to screen for cognitive impairment not dementia (CIND) rather than dementia, and the neuropsychological evaluation determined which participants received a clinical exam. Previous caregivers (i.e., from CSHA-1 and 2) were not assessed in CSHA-3. In other words, the caregiver component was cross-sectional as new caregivers were interviewed in CSHA-3 (Lindsay et al., 2004).

Criteria for eligibility in the current analyses

A total of 833 informal and formal caregivers (dementia: *N* = 349; non-dementia: *N* = 484) of *community-dwelling* care-recipients were interviewed as part of the CSHA-1 (see Figure 2 on page 56). However, to ensure that the samples were similar to those in the other datasets used in the current study, the CSHA sample was restricted to informal spousal caregivers. Given that some healthy (not physically or cognitively impaired) participants were included in the non-dementia group, they may or may not be actively receiving care. Therefore, for the purposes of the current study, only those who had ratings of mild to complete ADL impairments, according to the Fillenbaum Functional Ability Rating system (Fillenbaum, 1988), were included in the non-dementia group. Including those with mild to complete functional impairments increases the probability that care-recipients in the non-dementia group were actively receiving care. Stated differently, those with excellent to good functional capacities (*N* = 114) were excluded as they are unlikely to require the assistance of a caregiver Application of these eligibility criteria resulted in a sample informal spousal caregivers of 105 dementia and 72 non-dementia care-recipients living in the community. Given that caregivers from CSHA-1 were not followed in the CSHA-3 study, the latter dataset was excluded from analyses.

Dataset 3

Overview

The National Long Term Care Survey (NTLCS) is a nationally representative survey of persons aged 65 or older. The study was sponsored by the National Institute of Aging and conducted by the Duke University Center for Demographic Studies under Grant No. U01-AG007198. The methodology and sampling used have been described in greater detail elsewhere (Ingersoll-Dayton & Raschick, 2004; Manton & Gu, 2001; Manton, Stallard, & Corder, 1995; Spector & Fleishman, 1998). In brief, the NLTCS was first conducted in 1982 and has been repeated every 5 years since 1984. It was originally designed to describe the population of chronically disabled elderly persons in the United

States. It is longitudinal in that sample persons remain in the study until they die or are lost to follow-up. Furthermore, the survey is refreshed each wave with a new sample of persons who have turned 65 since the previous survey to ensure a nationally-representative sample at each time point. The initial survey, conducted in 1982, was given to a random sample of Medicare beneficiaries 65 years of age and older who resided in the community. The subsequent surveys also included older adults residing in institutions. The Informal Caregiver Surveys (ICS) were administered to the primary informal caregiver of community-dwelling NLTCS participants in 1982, 1989, 1999, and 2004, with an extensive revision and expansion from 1999.

1999 and 2004 Waves of the NTLCS

The sample used for the present analyses was derived from the 1999 and 2004 NLTCS, the fifth and sixth waves of the study, as well as their accompanying caregiver surveys (i.e., the ICS). Data from the NTLCS were used to select eligible care-recipients (i.e., those with and without cognitive impairments), while information pertaining to their respective caregivers were obtained from the ICS. Although all four waves of the ICS (1982, 1989, 1999, and 2004) were in the public domain, several modifications to their design impede longitudinal analyses between the 1982 and 1989 survey and later waves. Most notably, the 1982 caregiver survey was restricted to ADL caregivers (i.e., caregivers who provided assistance with IADL tasks were excluded). Thus, the 1999 and 2004 versions of the NTLCS and ICS were selected for analyses because they had similar items of interest (e.g., perceived emotional support), and the method of selecting caregivers were similar across surveys.

Care-recipients

Figure 3 illustrates the flow of participants through the 1999 wave of the NTLCS. The sample for the 1999 NLTC survey consisted of 19,875 Medicare enrollees. The NLTCS interviewing included a screener questionnaire, a community survey, an institutional survey, and an informal caregiver questionnaire (see Figure 3). In 1999, 17,633 sample persons completed the screening survey. The screener determined if the sample person was eligible to receive a detailed interview (community or institutional) based on the following criteria. The sample person identified could not be deceased, in a correctional facility, or living outside the survey area. Furthermore, the screening questions were designed to identify persons who, at the time of the 1999 NLTC survey, had certain physical disabilities or health problems lasting three months or longer (i.e., were considered chronically physically disabled). Those identified as "physically disabled" received detailed interviews. Furthermore, the 1999 survey administered detailed interviews to a sub-sample of "healthy" persons (*N* = 1,577) to provide data on non-physically disabled, non-institutionalized persons age 65 and over (normally, persons determined by the screener survey to be physically unimpaired and not residing in institutional settings would not have been interviewed further). As can be seen in Figure 3, application of the screener yielded a sample of 6,631 persons who screened-into the study (i.e., those eligible for detailed interviews) and 11,002 individuals who were screened-out. Of the 6,631 persons designated for detailed interviews, 3,901 completed the community interview (i.e., those living at home), and 1,849 persons completed the institutional survey (i.e., those residing in institutional settings).

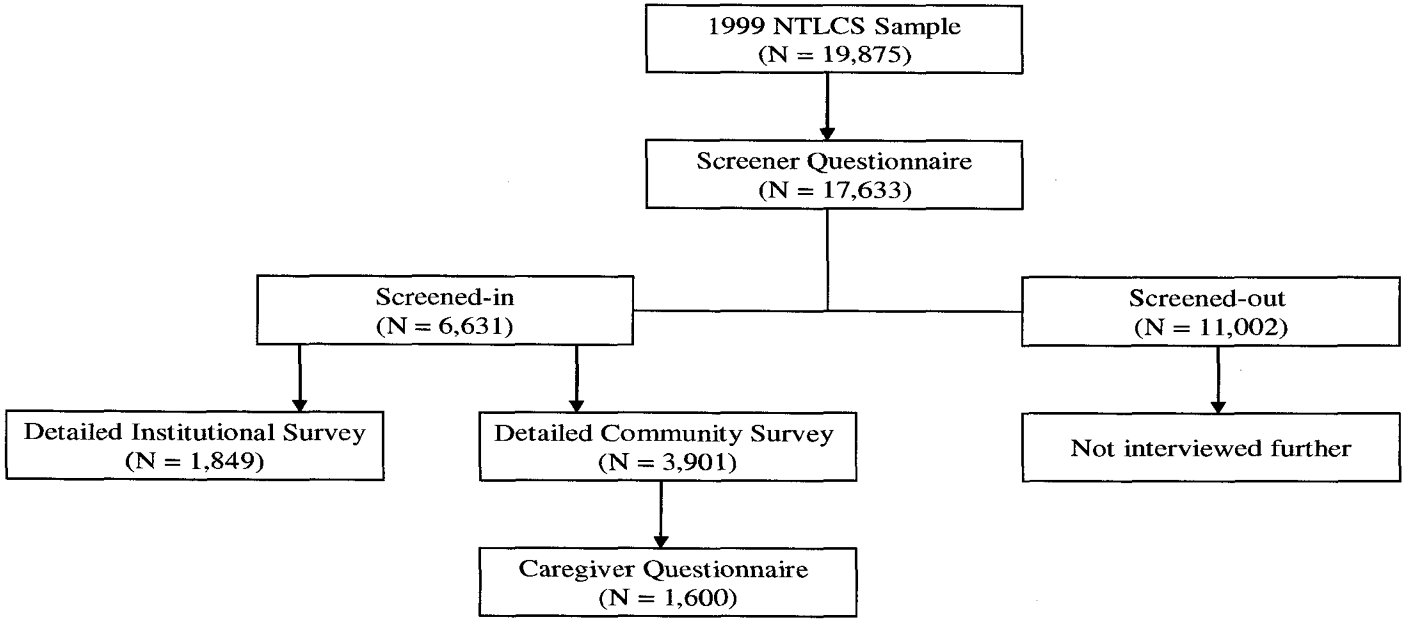

Figure 3. Flow of participants through the 1999 Wave of the NTLCS.

Caregivers

Of the 3,901 individuals who completed the community survey, 1,600 reported receiving assistance from primary informal caregivers (see Figure 3). Caregivers included relatives or unpaid non-relatives who had provided one or more hours of help to NLTCS participants (care-recipients) with ADL or IADL activities in the week prior to the community interview. When more than one caregiver met eligibility criteria, the primary caregiver was designated as the helper who provided the greatest number of ADL assistance to the care-recipient in the previous week, or if no ADL help was provided, the caregiver who provided the greatest hours of help with IADL tasks. Of the 1,600 who were eligible to take part in the ICS (i.e., individuals who were chosen as the primary caregiver of care-recipient), 80% (*N* = 1,283) completed the caregiver interview.

Criteria for eligibility in the current analyses

Figure 4 depicts the process of selecting caregivers for the present analyses and caregiver grouping based on care-recipient cognitive status. A total of 1,283 caregivers were interviewed as part of the 1999 ICS. For the purposes of the current study, only spousal caregivers were selected from the full caregiver sample, yielding a subsample of 514 caregivers. Furthermore, physically disabled care-recipients screened-in to the 1999 NTLC survey because they were institutionalized (*N* = 40), and "healthy" (i.e., not physically disabled) individuals who were given detailed interviews in previous NTLC surveys (*N* = 58) were excluded. These exclusions were made to ensure that the final sample included only spouse caregivers of physically disabled older adults living in the community.

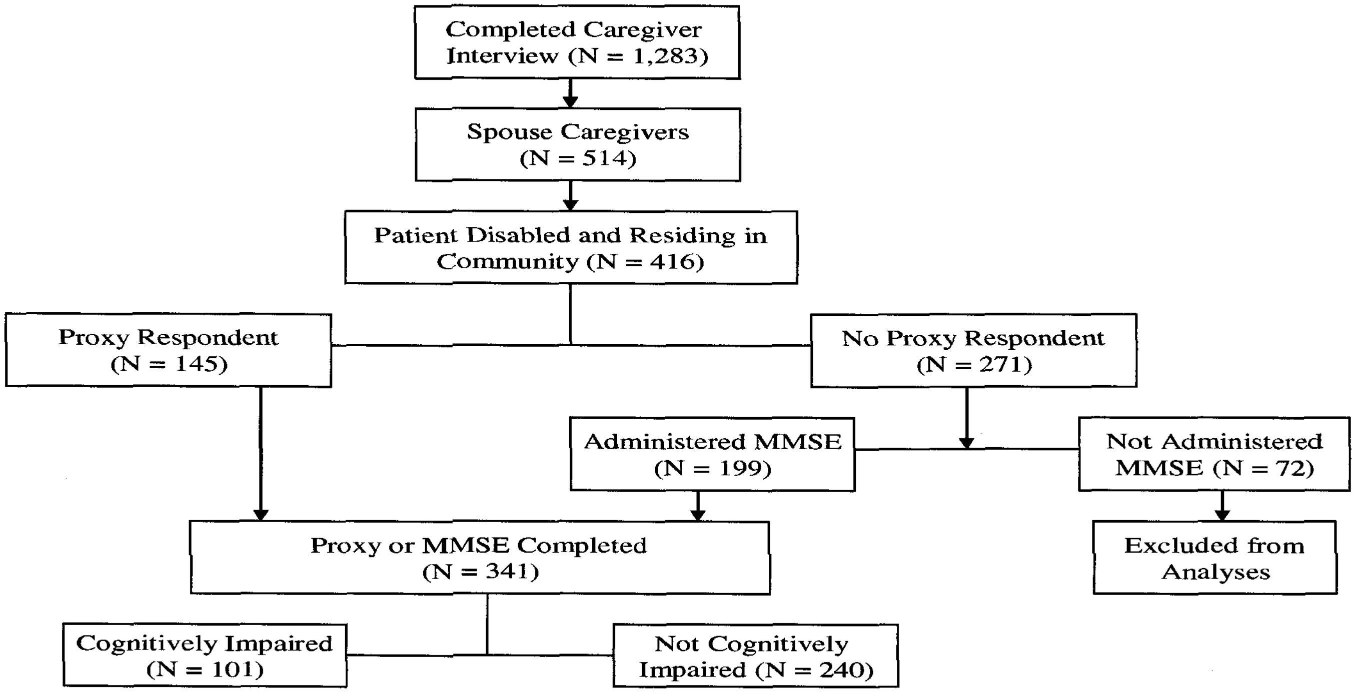

Figure 4. Criteria of eligibility for inclusion in present analyses (i.e., spousal caregivers of physically and cognitively impaired community-dwelling patients), and grouping of caregivers based on care-recipient cognitive functioning (i.e., MMSE score or proxy rating).

Grouping care-recipients based on cognitive functioning

The remaining 416 care-recipients were further grouped on the basis of their cognitive functioning (cognitively impaired versus not cognitively impaired), rather than on dementia diagnosis as this information was not available on either the NTLCS or ICS. The determination of a care-recipient's cognitive functioning was based on two sources of information: Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) scores or proxy ratings. This approach is similar to that used in previous studies (e.g., McFall & Miller, 1992). Because some care-recipients could not complete the community interview (e.g., because they had a speech problem or were too cognitively impaired), proxy respondents completed the survey on their behalf ($N = 145$; see Figure 4). Therefore, those who had proxy respondents were not administered the MMSE (i.e., did not have MMSE scores). Because the cognitive status of care-recipients with proxy respondents could not be directly assessed (i.e., using MMSE scores), indirect indicators were used. More specifically, proxies were asked to indicate whether or not the care-recipient has senility or Alzheimer Disease.

Of the 271 care-recipients who completed the community survey (i.e., did not have proxies complete survey on their behalf), 199 were administered the MMSE. Prorated scores were computed for those who completed enough items such that they could have scored a maximum of 22 out of 30 (i.e., 75% completed) on the MMSE. Only care-recipients for whom cognitive functioning (i.e., those who had an MMSE score or a proxy rating) could be computed were retained, leaving a subsample of 341 individuals (see Figure 4).

Proxy ratings for persons who lacked data on the MMSE were combined with those who completed the MMSE to determined group membership. Care-recipients who had either had a MMSE score less than or equal to 23 (for those who were given the MMSE), or a proxy rating of the presence of senility or of AD (for those who could not complete the MMSE) were placed in the cognitively impaired (CI) group (*N* = 101). All other participants were placed in the non-cognitively impaired (NCI) group (*N* = 240).

According to Folstein, Folstein, McHugh, and Fanjiang (2001), the most widely used and accepted cut-off for the MMSE to indicate cognitive impairment is a score less than or equal to 23. Data from one study found that 30% of participants with MMSE scores less than or equal to 23 did not have dementia and 3% of individuals with scores greater than 24 had a diagnosis of dementia (Fratiglioni et al., 1991). Another investigation found a sensitivity of 86% and a specificity of 91% of the MMSE in distinguishing dementia from non-organic psychiatric disorders and those with no psychiatric disorders among community-dwelling older adults using 23 as the cut-off (Cullen et al, 2005).

The 2004 NTLC survey included longitudinal follow-up of respondents (care-recipients) still living in the community. Of the 341 care-recipients whose spousal caregivers completed the caregiver interview in 1999, 193 died before April 1, 2004 (the reference date for the NTLCS) and 17 died during the 2004 survey (i.e., after April 1, 2004), 7 refused to complete the screening survey, 2 were ineligible or could not be located. Only 122 (36%) of the 341 care-recipients completed the screening survey in 2004. Of these, 73 had a primary caregiver selected for a caregiver interview in 2004. Sixty-three (86%) of the 73 eligible caregivers completed the caregiver interview, 3 (4%)

refused, and 7 (10%) could not be located. While the ICS does not follow the same caregiver over time, we expected that spouse caregivers selected to complete the 1999 ICS would still fulfill this role in 2004 as studies have shown that spouses tend to sustain the caregiving role longer than other relatives (Colerick & George, 1986). However, none of the caregivers who were selected for a caregiver interview in 2004 were spouses of the care-recipient; therefore, longitudinal analyses could not be conducted using this dataset.

Measures

While each of the datasets contained a wealth of information, only measures pertinent to the main objectives of the current investigation were selected for analyses. They are described below.

Dataset 1

As previously mentioned, non-dementia caregivers and non-caregivers were assessed at Time 1, while dementia caregivers were assessed during both time periods. At Time 2, data were collected from dementia caregivers who continued to provide in-home care as well as from those who had relinquished care. However, questions were slightly modified for dementia caregivers who were no longer providing care to their spouses at follow-up, either due to the death of the care-recipient or because they were placed in long-term care. Information pertaining to help received for caregiving and caregiver burden were gathered in the context of the year they were still providing in-home care. In addition, for deceased and institutionalized care-recipients, caregivers were asked how the care-recipient functioned the year before they ceased caregiving.

Caregiver and non-caregiver information

Demographics and service use. Demographic information was obtained from caregivers and non-caregivers, including their date of birth and gender as well as the date of birth of their spouses. Only caregivers were asked to indicate the number of years they served as care providers, how often they used respite or home care services, and the number of hours of help received from either formal or informal sources in caring for their spouses (see Appendix H – Part A)

Physical and mental health status. The Physical Component Summary (PCS) and Mental Component Summary (MCS) scale scores of the Short Form-12 Health Survey (SF-12; see Appendix H – Part B; Ware, Kosinski, & Keller, 1998) were used as indicators of caregiver mental and physical health, respectively. Although the SF-12 is the short version of the 36-item Short-Form Health Survey (SF-36; Ware, 1988), it still retains the validity, reliability, and responsiveness of the longer version (Dempster & Donnelly, 2001; Ware et al., 1998). In the numerous tests of validity performed to date, the SF-12 has demonstrated favourable construct and predictive validity (Ware, Kosinski, & Keller, 1996). One study, for instance, found that the SF-12 was a reliable and valid measure of health status in independent living older adults (Resnick & Nahm, 2001). The PCS and the MCS summary scale scores are calculated using norm-based methods. There are several steps involved in scoring both summary scales: (1) items 1, 8, 9, and 10 are reversed scored so that a higher score denotes better health; (2) indicator variables are created for the item response choice categories; (3) indicator variables are weighted using regression coefficients from the general U.S. population, then they are aggregated; (4) finally, a constant or regression intercept is added, and the aggregate PCS and MCS scores are standardized to have the same mean as the SF-36 versions in the general U.S. population. Both scales are transformed to have a mean of 50 and a standard deviation of 10 in the U.S. general population (Ware et al., 1998). Higher scores on the PCS and MCS indicate better physical and mental health, respectively. Cronbach's alphas for the SF-12 were .86 and .89 and .90 for dementia caregivers, non-dementia caregivers, and non-caregivers, respectively.

Depression. The Centre for Epidemiologic Studies – Depression Scale (CES-D; see Appendix H – Part C; Radloff, 1977) was used to evaluate caregiver depression. This screening instrument is a 20 item self-report scale designed to assess the overall level of depression experienced in the past week. Respondents were asked to rate the frequency with which they experienced various depressive symptoms during the previous week. Four of the 20 items encompass positive affect, and are reversed scored. Possible total scores range from 0 to 60 with higher scores reflecting more depressive symptoms. Although developed and initially validated with general adult populations, the CES-D appears appropriate for use with older adults (Lewinsohn, Seeley, Roberts, & Allen, 1997; Radloff & Teri, 1986). The CES-D has shown strong psychometric characteristics in studies specifically using samples of spouse caregivers (e.g., Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Pruchno & Potashnik, 1989). Among informal caregiver samples, the CES-D scale is one of the most frequently used measures of caregiver depression (Schulz et al., 1995), and it has been found to have good reliability and validity. In the current study, internal consistency reliabilities were .91, .79, and .79 for dementia caregivers, non-dementia caregivers, and non-caregivers, respectively.

Subjective burden. Caregiver appraised burden was assessed using the Short version of the Zarit Burden Interview (S-ZBI; see Appendix H – Part D; Bédard, Molloy, et al., 2001). The full version, the ZBI (Zarit, Orr, & Zarit, 1985), consists of 22 items and is the most consistently used instrument in caregiving research (Bédard, Pedlar, Martin, Malott, & Stones, 2000). Although the ZBI was specifically designed for caregivers of individuals with dementia, it has been used with caregivers of those with other illnesses (see Grunfeld et al., 2004). The S-ZBI is a 12-item questionnaire, with possible scores ranging from 0 to 48; higher values denote greater caregiver burden. Several studies have found that the S-ZBI has excellent internal consistency, with alpha ranging from .77 to .89, and that it is highly correlated with the longer version (r = .92 to .97) in different situations (Bédard, Raney, et al., 2001; Hébert, Bravo, & Preville, 2000; O'Rourke & Tuokko, 2003; Whitlatch, Zarit, & von Eye, 1991). In the present study, internal consistency was sufficient for the dementia sample (α = .88); however, less than adequate levels were found for non-dementia caregivers (α = .63).

Perceived social support. The Perceived Social Support – Family (PssFa) and Friends (PssFr) scales (see Appendix H – Part E; Procidano & Heller, 1983) were used to assess social support. The Pss scales consist of 20 items each, and were designed to determine whether the individual perceives his or her needs for support, information, and feedback are being met by family and friends (Kane & Kane, 2000). Validation studies have confirmed that the two scales reflect related yet distinct constructs, which supports the difference between family support, and support from friends (Procidano, 1992). In other words, individuals may rely on or benefit from family or friend support to different extents at different times and in different situations (Procidano & Heller, 1983). Possible scores on each of the scales range from 0 to 20, with higher scores denoting greater levels of perceived social support. A meta-analysis of studies using the Pss scales found adequate internal consistency of both the PssFa and PssFr scales, with Cronbach's alpha values ranging from .88 to .91, and .84 to .90, respectively (Procidano, 1992). In the present study, Cronbach's alphas for PssFa were .90 for dementia caregivers, .86 for non-dementia caregivers, and .84 for non-caregivers. Alphas for PssFr were .93, .81, and 84 for dementia, non-dementia, and non-caregiver samples, respectively.

Health behaviours. Caregiver health promoting behaviours were measured using 42 items from the Health-Promoting Lifestyle Profile (HPLP; see Appendix H – Part F Walker, Sechrist, & Pender, 1987). This instrument was based on the Health Promotion Model proposed by Pender (1982), and includes items that reflect health-promoting self care actions, such as getting enough rest, eating nutritiously, and getting enough exercise. While the original HPLP consists of 48 items, the current study only used 42 of the 48 original items. Six items were not included because they are not relevant to a population of older adults. The HPLP employs a 4-point response format (1 = never, 2 = sometimes, 3 = often, 4 = routinely) to measure the frequency of engagement in various health-promoting behaviours. A total HPLP score was obtained by calculating the sum of the individual's responses to the 42 items, with possible total scores ranging from 42 to 168. Higher scores indicate greater frequency of engagement in health-promoting behaviours.

Content validity has been established in the HPLP, and it also has excellent internal consistency (Cronbach's alpha = .92) in large samples of community-dwelling adults (Walker et al., 1987; Walker, Volkan, Sechrist, & Pender, 1988). A study using a sample of caregivers found that the alpha coefficient for the overall HPLP was .93 (Sisk, 2000). In the present study, Cronbach's alphas were .89, .94, and .85 for dementia caregivers, non-dementia caregivers, and non-caregivers, respectively.

Quality of the pre-morbid relationship. The quality of the marital relationship between the care provider and care-recipient prior to the onset of illness was assessed using the Social Interaction Scale (SIS; see Appendix H – Part G; Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984). This scale requires the respondent to rate the quality of the relationship between him or herself and the care-recipient prior to the onset of the care-recipient's illness. For the purposes of the present study, the term "elderly relative" was replaced with "spouse." The SIS consists of six items pertaining to the frequency of previous social interactions. Five of the six items refer to negative social interactions, such as "did you feel cross or angry with your spouse," and "did you have upsetting disagreements or arguments, or find yourselves not speaking?" One item captures a positive social interaction; "did you laugh and joke together", and this item was reversed scored. Scores on this scale could range from 0 to 12, with higher scores denoting more negative perceptions of the quality of the pre-illness relationship. Cronbach alphas in the present study were .71 and .78 among dementia caregivers and non-dementia caregivers, respectively.

Care-recipient information

Given the potential lack of insight among some care-recipients, all relevant information pertaining to them were obtained from their respective caregivers. Non-caregivers were not asked to complete the following instruments as they pertain to care-recipient functioning.

Dependence in ADL. Care-recipient functional status was measured using an instrument developed by Lawton and Brody (see Appendix H – Part H; Lawton & Brody, 1969). This scale measures two important domains of functioning of older people. It includes the basic ADL scale, a six-item scale measuring the care-recipient's ability to perform basic self-maintenance chores, such as feeding and toileting, as well as the Instrumental ADL scale, which consists of eight items that assess the ability to function independently, such as handling finances. The minimum and maximum scores are 6 and 30 for the basic ADL subscale, and 8 and 30 for instrumental ADL subscale, respectively. The total ADL scale has possible scores ranging from 14 to 60, with higher scores indicating greater independence in daily functioning. This instrument has documented psychometric properties (e.g., Tong & Man, 2002). Cronbach's alphas in the present study were .89 and .90 for dementia and non-dementia caregivers, respectively.

Disruptive behaviours. To measure the occurrence of dysfunctional problem behaviours among care-recipients, the Cohen-Mansfield Agitation Inventory for Relatives (CMAI-R; see Appendix H – Part I; Cohen-Mansfield, Werner, Watson, & Pasis, 1995) was used. This instrument is designed to assess the frequency of manifestations of agitated behaviours in older adults. The CMAI-R is an expanded version of the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, Marx, & Rosenthal, 1989). The CMAI-R includes 34 agitated behaviours, selected on the basis of previous relevant literature, nurses' perceptions, and input from day-care staff. Caregivers rate the frequency at which each behaviour has occurred in the preceding two weeks; possible scores range from 0 to 204. Inter-rater agreement values for the CMAI range from .71 and .81 (Cohen-Mansfield et al., 1995). Furthermore, the CMAI has demonstrated good test-retest reliability over a month period ($r = .74$ to .92) in a sample of individuals with AD residing in the community (Koss et al., 1997). High internal consistency was found for dementia caregivers ($\alpha = .90$) in the present study; however less than acceptable levels were found for non-dementia caregivers ($\alpha = .42$). Therefore, caution must be exercised when interpreting findings with respect to non-dementia caregivers using this scale.

Cognitive functioning. A short form of the IQCODE (see Appendix H - Part J; Jorm, 1994) was used to evaluate the presence or absence of cognitive decline among the care-recipient. This questionnaire does not require the participation of the care-recipient, and can therefore be completed by the caregiver. Informants were asked questions pertaining to declines in cognitive performance over the last 10 years in a variety of functional domains, such as the capacity to follow a story on television or in a book, or the ability to remember family addresses and birthdays. For each area of inquiry, the caregiver was asked to rate the care-recipient's change in cognitive functioning in relation to performance 10 years ago. The degree of change was rated on a 5-point scale, with 1 = much improved, 2 = somewhat improved, 3 = not much change, 4 = a bit worse, and 5 = much worse. Ratings are averaged over the 16 items to yield a total score, which can range from 1 to 5. Higher scores are indicative of a greater decline in cognitive function over the past ten years.

The original IQCODE has 26 items, and has been shown to have high internal consistency in the general population ($\alpha = .95$) and a reasonably high test-retest consistency over a one year period in a sample of individuals with dementia ($r = .75$; Jorm & Jacomb, 1989). The shortened 16-item version that was used in the present study has been found to be as effective as its longer counterpart, with a correlation of .98 between the two tests (Jorm, 1994; Jorm, Christensen, Korten, Jacomb, & Henderson, 2000). Furthermore, the IQCODE has demonstrated comparable sensitivity and specificity to the MMSE (Jorm, 1994; Jorm, Scott, Cullen, & MacKinnon, 1991). One study found that individuals who score in the range of moderate or severe cognitive decline in daily cognitive abilities exhibit deteriorating performance on cognitive tests that were directly administered to the patient after a period of 7 to 8 years, suggesting that knowledgeable informants are able to identify subtle changes in every day abilities that precede future decline (Jorm et al., 2000). In the current study, internal consistency for this scale was deemed adequate among dementia ($\alpha = .92$) and non-dementia samples ($\alpha = .76$).

Dataset 2

The interviews with caregivers were roughly comparable at CSHA-1 and CSHA-2. The same instruments were used as in CSHA-1, with the exception of an expansion of the section on community service use. Furthermore, caregivers of individuals who died prior to the follow-up interview were asked to rate their functional status as of 3 months before death. Unlike dataset 1, measures of mental health, perceived social support, appraisals of the pre-illness relationship, and health behaviours were not collected. However, the following comparable constructs were included in dataset 2: physical health, depression, subjective burden, care-recipient dependence in ADL, disruptive behaviours, and cognitive functioning. These measures are described below.

Caregiver information

Demographics and service use. Demographic information was obtained from caregivers, such as their date of birth, gender. In dataset 1, frequency of service use was measured, while this dataset assessed the number of services used. Caregivers were asked whether a service, from a list of community services, was used by the care-recipient in the year preceding the interview (see Appendix I – Part A). Some of these services included housekeeping support, in-home nursing care, day-centre care, and respite care. The service use items in CSHA-2 were slightly expanded from the CSHA-1; however, only services that were directly comparable were included in the present analyses to allow for assessment of change. Thus, 8 items were used for which responses of yes (1) or no (0) were summed. These services provided only apply to community-dwelling participants.

Physical health status. Caregivers were asked the following questions regarding their physical health status: 1) to rate their health compared to one year ago; 2) to rate the degree to which health problems interfered with their ability to engage in activities; 3) to rate their overall health. Responses to the first two questions were rated on 3-point Likert-type scales, while five response choices were given for the third item. A composite score was created through the summing of these items (see Appendix I – Part B; O'Rourke & Tuokko, 2000), with possible values ranging from 3 to 11. This composite variable reflects subjective physical health status, with higher scores suggestive of poorer subjective ratings of physical health. In the present study, Cronbach alphas were .66 for dementia and .64 for non-dementia caregivers. These low reliability coefficients may reflect the small number of items that comprise this composite scale.

Depression. The CES-D was used to assess caregiver depression (see dataset 1 for a more detailed description). Internal consistency for this scale was reasonably high (dementia: $\alpha = .85$; non-dementia: $\alpha = .84$).

Subjective burden. Caregiver subjective burden was measured with the 22-item ZBI (Zarit et al., 1985). It was not required that caregivers of non-dementia care-recipients complete the ZBI at CSHA-1, while both dementia and non-dementia were asked to complete the ZBI for CSHA-2. To be consistent with dataset 1, we calculated the corresponding S-ZBI score from the full version, and this was used a measure of burden in subsequent analyses. Cronbach's alphas for the S-ZBI and the ZBI were .89 and .92, respectively, among dementia caregivers in the present study.

Care-recipient variables

Dependence in ADL. Questions regarding care-recipient dependence in ADL were taken from the Older Americans Resources and Services questionnaire (see Appendix I – Part C; Fillenbaum, 1988). Caregivers were asked to assess the care-recipient's ability to perform basic (e.g., walking, eating, dressing) and instrumental ADLs (e.g., meal preparation, housework, handling finances). Each item was rated along a 3 point Likert-type scale, with higher scores indicating greater independence in ADL. The basic ADL and instrumental ADL scales each included 7 items, with scores ranging from 0 to 14 for each scale. Total ADL was computed by combining basic ADL items and instrumental ADL items to yield an overall score ranging from 0 (totally dependent) to 28 (totally independent). In the current study, internal consistency was deemed adequate, $\alpha = .92$ and $\alpha = .75$ for dementia and non-dementia samples, respectively.

Disruptive behaviours. Care-recipient disruptive behaviours were assessed using the Dementia Behaviour Disturbance Scale (DBD; see Appendix I – Part D; Baumgarten, Becker, & Gauthier, 1990). This scale consists of 28 behavioural disturbances, such as hoarding things for no obvious reason, nocturnal wakefulness, unwarranted accusations, and pacing. Caregivers were asked how frequently each of these behaviours occurred in the past week; responses are reported along a 5-point Likert-type scale ranging from 0 (never) to 4 (all of the time). Total scores could fall between 0 and 112, with higher scores indicating greater frequency of disruptive behaviours.

The DBD has been found to possess high internal consistency (α = .83) and moderate test-retest reliability (α = .71; Baumgarten et al., 1990). Construct validity has been established relative to the Behavior and Mood Disturbance Scale (Greene, Smith, Gardiner, & Timbury, 1982), as the two measures are strongly correlated (r = .73; Baumgarten et al., 1990). In this dataset, all dementia caregivers were administered the DBD, however, it was not required for caregivers of non-dementia care-recipients to complete these questions. Cronbach's alpha in the current study was .87 for the dementia sample.

Cognitive functioning. The MMSE (Folstein et al., 1975) was used to assess care-recipient cognitive functioning. The CSHA administration of the 3MS (Teng & Chui, 1987) included extra questions that permitted the corresponding MMSE score to be computed. Therefore, the current study used the MMSE as a measure of cognitive functioning to be consistent with dataset 3. This scale has been extensively used to screen for cognitive status in medical and neuropsychological research (see Tombaugh & McIntyre (1992) for a review). It has been shown to demonstrate satisfactory reliability and construct validity (Fischer, Visintainer, & Schulz, 1989; Folstein et al., 1975; Tombaugh & McIntyre, 1992). Scores on the MMSE range from 0 to 30, with higher scores indicative of better cognitive functioning.

Dataset 3

Unlike dataset 1, measures of caregiver mental health, depression, quality of the pre-illness relationship, and health behaviours were not assessed. However, the following comparable constructs were included in dataset 3: physical health status, caregiver burden, and perceived social support. Similarly, care-recipient dependence in ADL and disruptive behaviours were assessed. While the MMSE was administered to care-recipients in dataset 3, this measure could not be used as measure of cognition in the present study as MMSE scores were used in conjunction with proxy ratings to determine group allocation (CI versus NCI). Fifty (of the 101) CI care-recipients and 95 (of the 240) NCI care-recipients were missing scores on the MMSE as they had proxy respondents complete the survey on their behalf.

Caregiver information

Demographics and service use. Information regarding caregiver age, gender, and duration of caregiving were obtained from the ICS. Furthermore, caregivers were asked whether or not they have ever used formal services, such as support groups, respite services, day-centre care, and housekeeping support (see Appendix J – Part A). Ten items were used for which responses of yes (1) or no (0) were summed. In dataset 1, frequency of service use was measured, while datasets 2 and 3 assessed the number of services used.

Physical health status. Caregiver physical health status was assessed using one item; “compared to other people your age, would you say your health is.” Response choices ranged from excellent (1) to poor (4), with higher scores indicating poorer physical health.

Subjective burden. The 6-item Personal Burden Scale (Appendix J – Part B; Miller, McFall, Montgomery, 1991) was used to measure subjective burden. It assesses the caregiver's appraisal of the limitations in personal activities as a result of providing care. Items included: caring for care-recipient has worsened the caregiver's health, caregiving costs more than the caregiver can afford, caring is emotionally hard on the caregiver, caregiving has limited the caregiver's social life, caring is necessary even when the caregiver is not feeling well, and the caregiver needs to give the care-recipient constant attention. Other studies have also used the Personal Burden Scale to measure caregiver burden (Fredman, Daly, Lazur, 1995; McFall & Miller, 1992). Responses of true (1) or false (0) were summed, with higher scores reflecting greater appraised burden. Cronbach's alphas were .82 and .80 for CI and NCI caregivers, respectively.

Perceived social support. A summary variable was created from 8 items on the ICS that reflected perceived support from family and friends (see Appendix J – Part C). Caregivers were asked the extent to which they agreed or disagreed with statements such as, "there are people in your life who make you feel good about yourself", "you have people around you who help you to keep your spirits up", "the people close to you let you know that they care about you." Values for this summary variable could range from 8 to 32, with higher values indicating greater perception support from family and friends. High internal consistency was found for both CI and NCI samples, $\alpha = .88$ and $\alpha = .91$, respectively.

Care-recipient variables

Dependence in ADL. Care-recipient dependence in ADL was evaluated using 17 items on the ICS (see Appendix J – Part D). Care-recipients were defined as disabled on an ADL task if they reportedly received assistance with that task in the past week. To be consistent with the ADL measure (Lawton & Brody, 1969) used in dataset 1, the following items were considered basic ADL tasks: getting around inside and outside, getting in or out of bed, dressing, eating, bathing, and toileting. If the care-recipient did not get around inside, out of bed, dressed, or did not bathe, he or she was deemed disabled on that particular task. Instrumental ADL tasks consisted of taking medication, getting shots or injections, meal preparation, managing money, making phone calls, doing laundry, light housework, shopping, running errands, and transportation. In cases where the care-recipient did not get injections or take medications, the item was coded as "not applicable". Items were recoded so that higher scores indicated greater limitations in performing a particular ADL activity. Total scores for basic ADL items and for instrumental ADL items could range from 0 to 7 and from 0 to 10, respectively. In the current study, Cronbach's alpha for basic ADL were .82 and .83 among the CI and NCI samples, respectively. The instrumental ADL scale had reliability coefficients of .77 and .76 for CI and NCI caregivers, respectively.

Disruptive behaviours. On the ICS, caregivers were asked how many days they had to "deal" with a series of 15 behaviours exhibited by the care-recipient in the past week. A summary score (CI: α = 81; NCI: α = .75) was created by summing the ratings across 11 of the 15 items (see Appendix J – Part E). Two of the 15 items were deemed to reflect dependence in basic ADLs, such as having a bowel or bladder accident, rather than disruptive behaviours and two other items were thought to measure care-recipient depression, such as act depressed or downhearted. Therefore, items used in the disruptive behaviour index included keeping the caregiver up at night, repeating questions, hiding belongings, clinging to the caregiver, becoming restless, becoming irritable, swearing, becoming suspicious, threatening others, exhibiting inappropriate sexual behaviour, and destroying property. Summary scores could range from 11 to 44, with higher scores reflecting greater frequency of disruptive behaviours.

Data screening

Missing values

Prior to analyses, all datasets were evaluated for missing values, univariate outliers, and multivariate outliers. For scales with missing items, a prorated total score was computed. More specifically, if more than 25% of the items on a scale were missing, the total score was not calculated (i.e., the total score was considered to be missing). Listwise deletion was used in datasets that had a small proportion of missing values (i.e., less than 10%) relative to entire dataset. In datasets where the proportion of missing values exceeded 10% of the sample, expectation maximization (EM) algorithm for maximum likelihood estimation was used to impute missing values. In the EM procedure, multiple regression is initially used to impute a value for a missing score, adds random error, estimates a covariance matrix, and this process is repeated each time a missing value is imputed (Rubin, 1987). Current evidence supports the use maximum likelihood estimation as a method of data imputation, and generally discourages the use of older methods (e.g., mean substitution; see Schafer & Graham, 2002).

Outliers

Influential cases were defined as z scores greater than 3.29 ($p < .001$, two-tailed test). These scores were changed to a less extreme value. That is, an outlying case was assigned a raw score that is one unit larger (or smaller) than the next most extreme score in the distribution (Tabachnick & Fidell, 2001). Multivariate outliers were identified using Mahalanobis distance with a chi-square criterion $p < .001$. Mahalanobis distance is the distance of a case from the centroid of the remaining cases, where the centroid is the point created by the mean of all the variables (Tabachnick & Fidell, 2001). Multivariate outliers were subsequently excluded from their respective analysis.

Dataset 1

Cross-sectional analyses

Missing items. None of the variables had missing values exceeding 5% of the sample. Therefore, listwise deletion of missing cases was employed for subsequent analyses.

Outliers. Two univariate outliers were identified for the CMAI. These participants had raw scores of 96 and 100, and standardized scores of 3.70 and 3.89. One case had an extremely high score on the SIS (raw score = 10, $z = 3.43$).

Longitudinal analyses

Missing items. None of the follow-up variables had missing values exceeding 5%.

Outliers. One univarite outlier was found for the instrumental ADL subscale (raw score = 27, $z = 3.86$) and for IQCODE (raw score = 3.13, $z = -3.61$).

Dataset 2

Cross-sectional analyses

Missing items. Less than 8% of participants did not have total scores computed for the variable of interest as they did not have at least 75% of the items answered on the scale. Given that the missing values are a relatively small proportion of the entire dataset (e.g., only two variables had missing values for more than 5% of the cases), listwise deletion was used.

Outliers. One extreme case was identified for DBD. This participant had a raw score of 57 (z = 3.44). One caregiver had an extremely high score on the S-ZBI, with a raw score of 79 and a z score of 3.37. A single outlier was found for number of formal services used in the past year. This case had a raw score of 5 and was 3.49 standard deviations above the mean.

Longitudinal analyses

Missing items. Close to 30% of the participants were missing follow-up MMSE scores. The majority of missing cases were for dementia care-recipients who were institutionalized. The nature of the missing data is biased as those who are severely cognitively impaired (e.g., institutionalized care-recipients with dementia) could not complete this test; therefore, rather than imputing MMSE scores for these individuals, the entire variable was excluded from Time 2 analyses. Less than 5% of the participants were missing scores on the remaining variables of interest; therefore, listwise deletion was used.

Outliers. One outlying case was found for CES-D (raw score = 52, z = 3.79).

Dataset 3

Cross-sectional analyses

Missing items. Most of the variables in this dataset had more than 10% missing values. Using listwise deletion would have resulted in a substantial reduction in sample size, and consequently diminished the statistical power of the analyses. Therefore, the

EM algorithm for maximum likelihood estimation was used a method of missing value estimation and imputation.

Outliers. There were several univariate outliers found in the dataset. Seven outliers were identified for disruptive behaviours (raw scores ranged from 28 to 36 and *z* scores ranged from 3.42 to 5.37). Three outlying cases were found for the formal service use scale. These participants had raw scores of 6 and 7, and standardized scores of 3.33, and 4.06. One extreme value was found for health behaviours (raw score = 28, $z = 3.39$).

Longitudinal analyses

Longitudinal data was not available for this dataset.

Assessing Assumptions

Analyses were conducted to assess assumptions relevant to the statistical tests used. Assumptions of normality, linearity, and homoscedasticity (for ungrouped data) were tested through examination of scatterplots of residuals. If variables are normally distributed and linearly related, the scatterplot is oval shaped (Tabachnick & Fidell, 2001). For grouped data, Levene's test for the homogeneity of variance among groups was computed to determine the likelihood that samples were drawn from different populations. In cases where the Levene's test was found to be significant (i.e., presence of heterogeneity of variances for the dependent variable), the ratio of variances (largest to smallest) was examined to determine if it was greater than 4.0. If the ratio of variances did not exceed 4.0 and the sample size was large, no transformations were made to the data (see Tabachnick & Fidell, 2001). Homogeneity of regression was assessed using hierarchical regression procedures. The significance test for homogeneity of regression is the interaction between the covariate and the independent variable (Tabachnick & Fidell, 2001).

Multicollinearity was assessed using SPSS collinearity diagnostics. Collinearity occurs when there are moderate to high correlations among a set of predictor variables. Criteria for multicollinearity included a conditioning index greater than 30 and variance inflation factor greater than 10 (Tabachnick & Fidell, 2001).

Analysis Plan

The analysis plan represents a simplified outline of the analyses. Specific analytic steps are described in greater detail in their respective sections.

Follow-up data were not available in dataset 3 therefore only cross-sectional analyses were performed using this dataset. For analyses using independent t-tests, Levene's test for equality of variances was performed; in cases where Levene's test was significant at the .05 level, t-values and associated significance values were reported according to calculations using unequal variances. Fisher's Least Significant Difference (LSD) was used as a post hoc test in analysis of variance (ANOVA). Due to the number of t-tests and ANOVAs carried out, Type I error was minimized by adopting a conservative significance level of $p < .01$ for these analyses. Finally, for Chi-square tests, the reported values are Pearson Chi-square values.

Descriptive analyses

Demographic characteristics

Cross-sectional analyses

Dataset 1

Analyses of variance. Analyses of variance were used to examine demographic differences between the dementia caregivers, non-dementia caregivers, and non-caregivers.

Chi-square tests. Comparisons of dementia caregivers, non-dementia caregivers, and non-caregivers on categorical variables were conducted using Chi-square tests.

T-tests. Independent samples t-test were used to compare dementia caregivers and non-dementia caregivers on care-recipient characteristics.

Datasets 2 and 3

Used similar statistical procedures as dataset 1; however non-caregivers were not included in these datasets.

Longitudinal analyses

Datasets 1 and 2

T-tests. Independent samples t-test were used to compare caregivers who completed both Time 1 (initial) and Time 2 (follow-up) assessments with those who completed only Time 1 interviews on baseline characteristics.

Analyses of variance. Analyses of variance were used to examine demographic differences between caregivers who were still providing in-home care at Time 2 (continuous care group), individuals who ceased to provide care due to the death of their spouses (deceased group), and caregivers who placed their spouses in long-term care (institutionalized group).

Chi-square tests. Comparisons of the three groups on categorical variables were conducted using Chi-square tests.

The following analyses were used to test the following objectives, using both cross-sectional (Time 1) and longitudinal (Time 1 and Time 2) data.

Objective 1. To compare dementia caregivers, non-dementia caregivers, and non-caregivers on physical and psychological health, as well other stress process variables.

Cross-sectional analyses

Dataset 1

Analyses of variance were used to examine differences between the three groups on health and stress process variables, followed by post hoc comparisons using Fisher's LSD. Independent samples t-test were used to compare dementia caregivers and non-dementia caregivers on caregiver-specific variables (e.g., such as burden and quality of the pre-illness relationships).

Datasets 2 and 3

Used similar statistical procedures as dataset 1; however, non-caregivers were not assessed in these databases.

Longitudinal analyses

Dataset 1

Follow-up data were not available for non-dementia caregivers and non-caregivers; therefore this objective could not be addressed longitudinally.

Dataset 2

The longitudinal portion of this objective was evaluated under Objective 4 analyses (see below). Of interest is the time-by-transition status-by-caregiver type interaction.

Objective 2. To examine the role of health behaviours as a potential mechanism linking caregiving stressors to poor physical health. This objective could not be addressed using longitudinal data due to insufficient sample size.

Cross-sectional analyses

Dataset 1

Baron and Kenny's (1986) guidelines for establishing mediation were tested using ordinary least squares (OLS) regression analyses. Separate analyses were performed with each of the indicators of caregiving stressors (i.e., care-recipient dependence in ADL, disruptive behaviours, and cognitive impairment). Caregiver gender and age were included as covariates.

Datasets 2 and 3

This hypothesis could not be addressed as these datasets did not measure health behaviours.

Objective 3. To examine the roles of perceived social support and quality of the pre-illness relationship in moderating the relationship between burden and health outcomes. These predictions could not be evaluated using longitudinal data due to insufficient sample size.

Cross-sectional analyses

Dataset 1

A series of hierarchical multiple regression analyses were conducted with each moderator variable separately. Predictor and moderator variables were centered and product terms were created for each centered predictor/moderator combination. Covariates, such as caregiver gender and age, were entered into the equation first followed by main effects, and then the product term. To maximize power, both caregiver groups were combined for these analyses.

Dataset 2

This objective could not be evaluated as measures of perceived social support and quality of the pre-illness relationship were not available.

Dataset 3

Used similar statistical procedures as dataset 1; however, large sample sizes in this dataset permitted separate analyses for each caregiver group.

<u>Objective 4.</u> To examine whether the trajectory of change in caregiver health and psychosocial outcomes and care-recipient characteristics differed depending on transition status (continuous care versus institutionalized versus deceased) and caregiver type (dementia versus non-dementia).

Dataset 1

Several 2X3 mixed design analyses of variance were performed on caregiver and care-recipient variables with time of assessment (Time 1 versus Time 2) as the within subjects factor and transition status (continuous care versus institutionalized versus deceased) as the between subjects factor. Post hoc analyses were conducted using Fisher's LSD. In cases where the time by group interaction was significant, multiple comparisons were performed on change scores (Time 2 minus Time 1).We could not examine caregiver type (dementia versus non-dementia) as a between-subjects factor as non-dementia caregivers were not assessed at Time 2.

Dataset 2

Used similar tests as dataset 1; however, caregiver type was used as an additional between-subjects factor.

Results

Cross-sectional analyses (Time 1)

Dataset 1

Participants

A total of 121 participants (*N* = 66 dementia caregivers; *N* = 21 non-dementia caregivers; *N* = 34 non-caregivers) were included in Time 1 analyses. Telephone interviews lasted on average 52 minutes (*SD* = 24.0). Seven of the participants (2 non-caregivers, 1 non-dementia caregiver, and 4 dementia caregivers) requested returning the completed questionnaire by mail rather than conducting the interview over the phone.

Among the 21 care-recipients in the non-dementia group, the type of illnesses that necessitated care included cardiovascular disease (*N* = 8), Parkinson's disease (*N* = 3), cancer (*N* = 1), diabetes (*N* = 2), emphysema (*N* = 1), liver encephalopathy (*N* = 1), and multiple sclerosis (*N* = 5). Care-recipients in the dementia group were diagnosed with possible or probable Alzheimer Disease or other forms of dementia.

Caregiver and non-caregiver demographics

Dementia caregivers were on average 75 years old (range = 49 to 93, *SD* = 9.13), and the majority were female (68%). Fifty-seven percent of non-dementia caregivers were female, and the mean age of non-dementia caregivers was 69 years (*SD* = 7.85), with ages ranging from 59 to 86. Non-caregivers ranged in age from 60 to 83 years (*M* = 69, *SD* =6.81), and 65% were female. The proportion of males to females were similar across groups, $\chi^2(2, N = 121) = 0.86, p = .65$, and groups did not differ with respect to age, $F(2, 120) = 2.71, p = .07$.

Dementia caregivers spent an average of 5.03 ($SD = 3.70$) years providing care, while non-dementia caregivers had been providing care for an average of 7.24 years ($SD = 6.52$); however, no significant differences were observed between groups, $t(24) = -1.48, p = .15$. Furthermore, dementia caregivers reported receiving on average 13.30 ($SD = 12.41$) hours of help per week with caregiving from both formal and informal sources, while the latter received 7.68 hours of help ($SD = 9.62$). This difference, however, did not reach statistical significance, $t(85) = 1.91, p = .06$.

Care-recipient demographics and functioning

Dementia care-recipients ranged in age from 54 to 88 years ($M = 75, SD = 9.14$). The mean age of non-dementia care-recipients was 69 (range = 50 to 93, $SD = 10.3$). “Care-recipients” of non-caregivers were on average 69 years old ($SD = 6.58$), with ages ranging from 59 to 84. Significant group differences were found for care-recipient age, $F(2, 120) = 8.01, p < .01$. Fisher’s LSD revealed that dementia care-recipients were older than non-dementia care-recipients and “care-recipients” of non-caregivers, while the latter two groups did not differ.

Care-recipients with dementia exhibited greater frequency of disruptive behaviours ($M = 24.74, SD = 19.10$) than their non-dementia counterparts ($M = 3.00, SD = 3.33$), $t(75)=8.79, p < .001$. Furthermore, individuals in the dementia group were more cognitively impaired ($M = 4.63, SD = 0.42$) than non-dementia care-recipients ($M = 3.24, SD = 0.23$), $t(85)=14.56, p < .001$. Finally, scores on the instrumental ADL subscale showed significant differences between the two groups, $t(85) = -5.60, p < .001$, with dementia care-recipients exhibiting greater dependence in instrumental ADL ($M = 12.41$, $SD = 4.58$) compared to those with non-dementia ($M = 19.22$, $SD = 5.62$). However, dementia ($M = 20.55$, $SD = 5.10$) and non-dementia care-recipients ($M = 22.00$, $SD = 4.17$) were similar with respect to dependence in basic ADL, $t(85) = -1.19$, $p = .24$.

Objective 1: Analyses of group differences

Physical and psychological health

Table 1 presents means and standard deviations of caregiver physical and psychological health, as well as other stress process variables for dementia caregivers, non-dementia caregivers, and non-caregivers. Analyses revealed that groups did not differ systematically with respect to self-reported physical health, $F(2, 119) = 1.65$, $p = .20$. However, results indicated significant group differences in depressive symptoms, $F(2, 119) = 17.2$, $p < .001$, and mental health scores, $F(2, 119) = 20.54$, $p < .001$. Post hoc tests indicated that dementia caregivers exhibited greater depressive symptoms than non-caregivers and non-dementia caregivers, while no differences were observed between the latter two groups. Furthermore, results of Fisher's LSD indicated that dementia caregivers reported poorer mental health compared to both non-dementia caregivers and non-caregivers. Non-dementia caregiver, in turn, reported poorer mental health in comparison to non-caregivers.

Other stress process variables

There were no significant group differences found for perceived support from family members, $F(2, 119) = 1.27$, $p = .28$. However, there was a trend for both dementia and non-dementia caregiver groups to perceive less social support from friends compared

Table 1

Means and (Standard Deviations) of Caregiver Health and Stress Process Variables for Dementia Caregivers, Non-Dementia Caregivers, and Non-Caregivers

	Dementia *n* = 66	Non-Dementia *n* = 21	Non-Caregivers[a] *n* = 34
Physical health	43.29 (13.63)	40.19 (11.46)	46.42 (10.29)
Mental Health	41.78 (12.05)	49.16 (10.60)	56.09 (7.43)
Depression	16.66 (10.84)	9.14 (6.96)	6.03 (5.47)
Family Support	14.52 (5.26)	15.40 (4.30)	16.09 (3.89)
Friend Support	12.12 (6.38)	11.90 (4.65)	15.15 (4.11)
Health behaviours	104.59 (18.50)	107.00 (21.84)	123.85 (14.88)
Burden	17.97 (10.03)	10.57 (6.46)	--
Quality of pre-illness Relationship	3.45 (2.01)	2.76 (1.79)	--
Service use (% using services at least once per week)	86.00	62.00	--

[a] Burden, quality of the pre-illness relationship, and burden were not assessed among non-caregivers.

to non-caregivers, while no differences were observed between the two caregiver groups, $F(2, 119) = 3.77, p = .03$.

Analyses of variance also revealed significant group differences in health behaviours, $F(2, 120) = 13.01, p < .001$. Follow-up inspection using Fisher's LSD indicated that non-caregivers reported engaging in more health-promoting behaviours compared to dementia caregivers, and compared to non-dementia caregivers. No significant differences were found between the two caregiver groups on health-promoting practices.

Dementia and non-dementia caregivers did not differ with respect to their appraisals of the pre-illness relationship, $t(85) = 1.41, p = .16$. However, a significant difference across caregiver groups was found for overall burden scores, $t(53) = 3.95, p < .001$, with dementia caregivers reporting greater levels of subjective burden than non-dementia caregivers. The frequency of respite or home care service use also differentiated the groups, $\chi^2(1, N = 85) = 5.89, p < .05$. A greater proportion of dementia caregivers reported using services at least once per week compared to non-dementia caregivers (86% versus 62%).

Objective 2: Test of mediator hypothesis

Baron and Kenny's (1986) guidelines for analyses of mediation processes were used to establish whether health behaviours have mediating influences on the relation between caregiving stressors (disruptive behaviours, cognitive impairments, and dependence in ADL) and physical health. A series of OLS regressions were estimated to test the following steps, with each of the caregiving stressors examined separately. In each of these analyses, caregiver gender and age were included as covariates. Both dementia and non-dementia caregivers were combined in the following analyses to maximize power.

The first step involves establishing a link between the predictor and outcome by testing Path C (see *Part 1* of Figure 5). Therefore, physical health is regressed on caregiving stressors. The next step involves demonstrating an association between the predictor and mediator by estimating Path A (see *Part 2* of Figure 5). This can be accomplished by regressing health behaviours on caregiving stressors. Step 3 requires showing that the mediator is related to physical health after controlling for the effect of the predictor. In this step, physical health is regressed on both health behaviours and caregiving stressors (Path B in Figure 5). If all these conditions are met, then it is necessary to examine whether the predictor and outcome association is reduced after controlling for the mediator (Step 4). This step involves testing the effect of caregiving stressors on physical health, controlling for health behaviours (Path c in Figure 5). This can be accomplished by estimating the coefficient for caregiving stressors in the regression performed in Step 3. For complete mediation, caregiving stressors should have no effect on physical health when the mediator is controlled. In other words, Path C (*Part 1* of Figure 5) should be significantly different from zero and Path c (*Part 2* of Figure 5) should be non-significant. To demonstrate partial mediation, the regression weight associated with the stressor variable in Step 3 should be smaller in magnitude than the coefficient in Step 1. In other words, the mediator should account for variation in physical health (Step 3) while also attenuating the effect of stressors on physical health (Step 4).

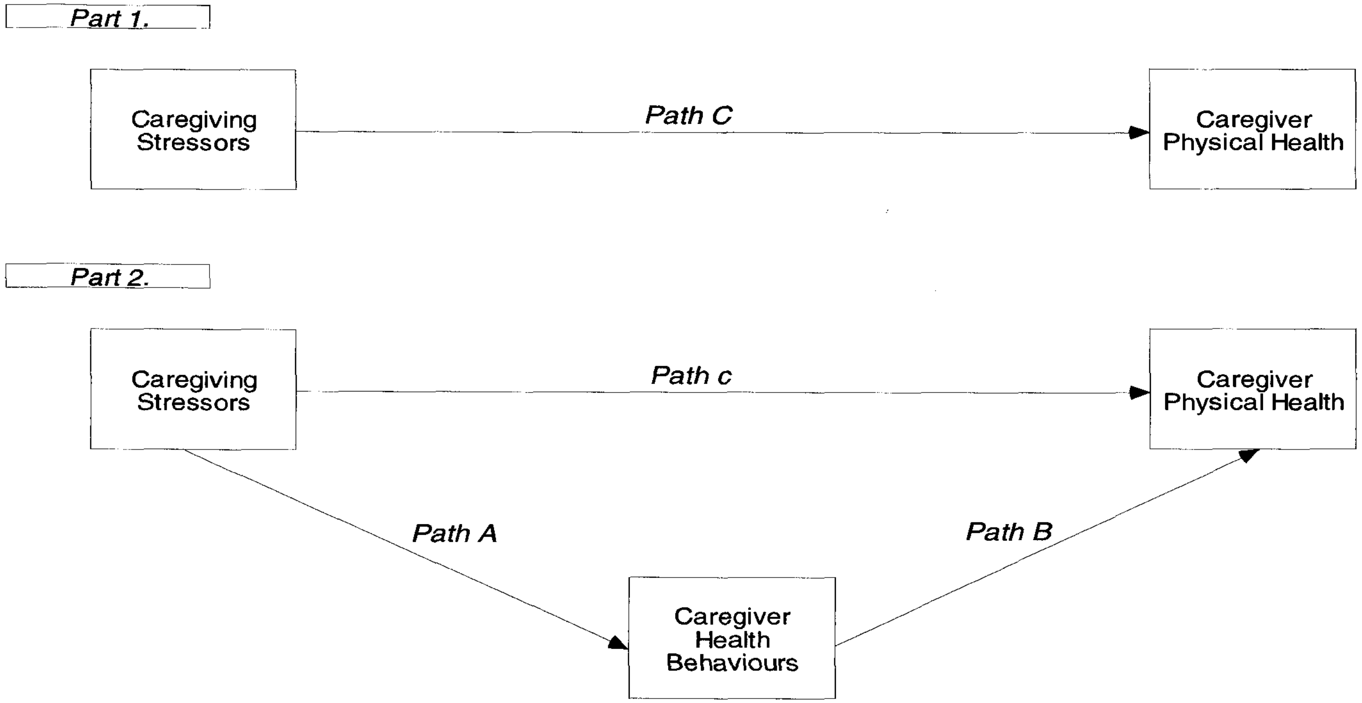

Figure 5. Path models displaying total effect (*Part 1*) and mediated effect (*Part 2*) of caregiving stressors on caregiver physical health. When mediation occurs, the Path c in *Part 2* is smaller than Path C in *Part 1*.

Finally, the statistical significance of this reduction (i.e., the mediated effect of health behaviours) should be formally tested using bootstrap methods to obtain the 95% confidence intervals. While the most commonly used procedure to test the significance of the mediated effect is the multivariate delta method (Sobel, 1986), this test assumes a normal distribution of the mediated effect. However, it has been demonstrated that the sampling distribution of the mediated effect estimates is asymmetrical (Bollen & Stine, 1990; MacKinnon, Lockwood, & Williams, 2004; Shrout & Bolger, 2002). In this situation, the bootstrap procedure is superior to the delta method as the confidence limits in the former procedure are established directly from the bootstrap distribution, thereby reflecting the asymmetry found in the distribution of the mediated effect (Shrout & Bolger, 2002).

No multivariate outliers were identified based on the Mahalanobis distance with a chi-square criterion $p < .001$. Inspection of residuals plotted against fitted values indicated that the assumptions of normality, linearity and homoscedasticity were within acceptable limits. Multicollinearity between predictors was assessed using variance inflation factor values greater than 10 and a condition index value greater than 15. None of the predictors evidenced collinearity based on these criteria.

Table 2 presents the results of the multiple regressions testing health behaviours as the mediator between disruptive behaviours and physical health, controlling for caregiver gender and age. As can be seen from Table 2, disruptive behaviours failed to demonstrate a significant relationship with physical health (Path C). Furthermore, disruptive behaviours were not significantly related to health behaviours (Path A). Furthermore, the partial effect of health behaviours on physical health, holding disruptive

Table 2

Results of Multiple Regressions Testing Health Behaviours as a Mediator between Disruptive Behaviours and Physical Health for Dementia and Non-Dementia Caregivers

		B	Std. Error	*β*	*t*-value	*p*-value[a]	R^2
Dependent Variable: PCS							
Covariates	Gender	-6.37	3.02	-0.23	-2.11	0.04	--
	Age	-0.13	0.15	-0.09	-0.89	0.37	--
Path C:	CMAI	-0.11	0.08	-0.16	-1.41	0.16	0.10
Dependent Variable: HPLP							
Covariates	Gender	-6.83	4.58	-0.17	-1.49	0.14	--
	Age	0.04	0.22	0.02	0.18	0.86	--
Path A:	CMAI	0.002	0.12	0.002	0.02	0.98	0.03
Dependent Variable: PCS							
Covariates	Gender	-5.60	3.05	-0.20	-1.83	0.07	--
	Age	-0.14	0.15	-0.10	-0.97	0.34	--
Path B:	HPLP	0.10	0.07	0.15	1.39	0.17	--
Path c:	CMAI	-0.11	0.07	-0.16	-1.45	0.15	-0.12

Note. PCS=Physical Component Summary; CMAI=Cohen-Mansfield Agitation Inventory; HPLP: Health-Promoting Lifestyle Profile

[a] Probability values (two-tailed) associated with the statistical tests.

behaviours and covariates constant, fell short of statistical significance (Path B). Because the conditions necessary to establish mediation were not met, the remaining steps were not examined.

None of the conditions specified for mediation was met when cognition and dependence in ADL were used as measures of caregiving stressors (see Tables 3 and 4). Specifically, cognition and dependence in ADL were not significantly related to physical health (Path C). In addition, they were not significant predictors of health behaviours (Path A). Health behaviours were not associated with physical health, controlling for either ADL or cognition (Path B). Collectively, these results suggest that health behaviours do not serve as a mediator between caregiving stressors and physical health among dementia and non-dementia caregivers. However, findings indicated that gender was a consistent predictor of physical health, with females reporting poorer health than their male counterparts (see Tables 2 to 4).

Objective 3: Test of moderator hypotheses

The interaction tests followed the method in which predictor and moderator variables were centered. In other words, variables were re-scaled by subtracting the sample mean from individual scores (Aiken & West, 1991). The new centered scores, each with a mean equal to 0, are sufficiently independent of one another. According to Aiken and West (1991), the rescaling has no effect on the significance of the linear regression. This transformation does, however, help reduce multicollinearity between the predictor variables and the interaction variable. Once centering had been accomplished, multiplicative interaction terms were created for each predictor/moderator combination.

Table 3

Results of Multiple Regressions Testing Health Behaviours as a Mediator between Cognitive impairments and Physical Health for Dementia and Non-Dementia Caregivers

		B	Std. Error	*β*	*t*-value	*p*-value[a]	R^2
Dependent Variable: PCS							
Covariates	Gender	-7.88	2.91	-0.29	-2.71	0.01	--
	Age	-0.13	0.15	-0.09	-0.84	0.41	--
Path C:	IQCODE	1.32	1.99	0.07	0.66	0.51	0.09
Dependent Variable: HPLP							
Covariates	Gender	-6.50	4.37	-0.16	-1.49	0.14	--
	Age	0.06	0.22	0.03	0.26	0.79	--
Path A:	IQCODE	-1.86	2.98	-0.07	-0.62	0.53	0.03
Dependent Variable: PCS							
Covariates	Gender	-7.17	2.94	-0.26	-2.43	0.02	--
	Age	-0.14	0.15	-0.10	-0.91	0.37	--
Path B:	HPLP	0.10	0.07	0.14	1.35	0.18	--
Path c:	IQCODE	1.43	1.99	0.08	0.72	0.47	0.11

Note. PCS=Physical Component Summary; IQCODE=Informant Questionnaire on Cognitive Decline in the Elderly; HPLP: Health-Promoting Lifestyle Profile.

[a] Probability values (two-tailed) associated with the statistical tests.

Table 4

Results of Multiple Regressions Testing Health Behaviours as a Mediator between dependence in ADL and Physical Health for Dementia and Non-Dementia Caregivers

		B	Std. Error	*β*	*t*-value	*p*-value[a]	R^2
Dependent Variable: PCS							
Covariates	Gender	-7.52	2.91	-0.27	-2.58	0.01	--
	Age	-0.09	0.15	-0.06	-0.56	0.58	--
Path C:	ADL	0.10	0.15	0.07	0.66	0.51	0.09
Dependent Variable: HPLP							
Covariates	Gender	-6.67	4.39	-0.17	-1.52	0.13	--
	Age	0.04	0.23	0.02	0.17	0.86	--
Path A:	ADL	0.03	0.22	0.01	0.12	0.91	0.03
Dependent Variable: PCS							
Covariates	Gender	-6.83	2.95	-0.25	-2.32	0.02	--
	Age	-0.10	0.15	-0.07	-0.63	0.53	--
Path B:	HPLP	0.13	0.07	0.18	1.68	0.10	--
Path c:	ADL	0.14	0.14	0.10	0.96	0.34	0.11

Note. PCS=Physical Component Summary; ADL=Activities of Daily Living; HPLP=Health-Promoting Lifestyle Profile.

[a] Probability values (two-tailed) associated with the statistical tests.

A series of hierarchical regression analyses were conducted for each moderator variable separately. The potentially confounding effects of caregiver gender and age were controlled for in the moderator analyses. Covariates were entered into the equation prior to the main effects, which were followed by the interaction term. Moderation occurs when the interaction term of predictor (i.e., appraised burden) and moderator variable (i.e., social support or quality of the pre-illness relationship) significantly contributes to the variance in health outcomes beyond that already accounted for by their independent contributions (Baron & Kenny, 1986). The moderator model is illustrated in Figure 6 by the path from support or quality of the pre-illness relationship (moderator) that intersects the path between caregiver burden (predictor) and physical health (outcome). For each significant interaction term, post-hoc procedures suggested by Aiken and West (1991) were followed. Specifically, the interaction model was analyzed at 3 levels of appraised burden: high (1 SD above the mean value of burden), medium (mean value), and low (1 SD below the mean value of burden), respectively (see also Weaver (submitted) for a description of procedures for plotting and post hoc probing of interactions between continuous variables). The same methods were followed in cases where a significant main effect of the moderator variable was found.

Perceived social support as the moderator variable

Two multivariate outliers were identified based on the Mahalanobis distance with a chi-square criterion $\underline{p} < .001$ and were removed from their respective moderator analysis. Visual inspection of residuals indicated that normality, linearity, and homoscedasticity between predicted outcome scores and errors of prediction were adequate. Examination of multicollinearity among the independent variables indicated no

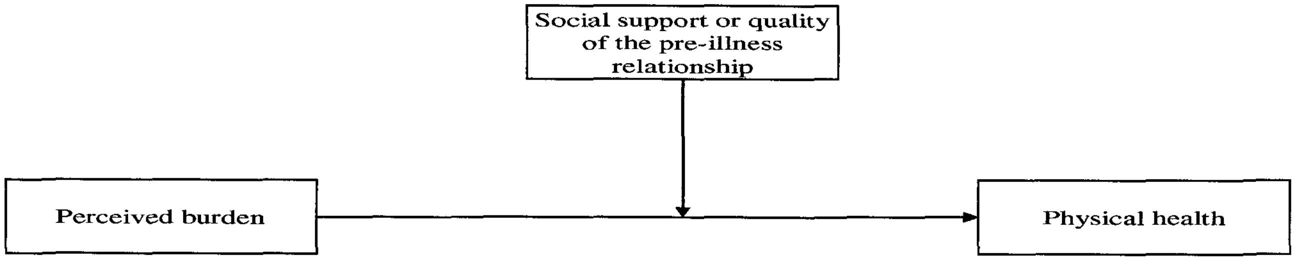

Figure 6. Model of the moderating effect of social support and quality of the pre-illness relationship on the association between burden and physical health.

problems evident, with explanatory variables sufficiently independent of one another.

Table 5 presents the main and interaction effects of perceived support on physical health, controlling for caregiver gender and age. Contrary to hypothesis, family support did not moderate the relationship between subjective burden and physical health. The interaction term was not statistically significant, R^2 *Change* = .004, *F Change* (1, 77) = 0.35, $p = .56$. However, there was a significant main effect for family support, R^2 *Change* = .084, *F Change* (2, 78) = 3.95, $p < .05$. Figure 7 depicts the main effect of family support at varying levels of burden. Results indicated that greater family support was associated with better physical health, regardless of the level of burden associated with caregiving. The covariates, gender and age, significantly contributed to the variance in physical health, *adjusted* $R^2 = .07$, $F(2, 80) = 3.89$, $p < .05$. The individual regression coefficient for gender shows that females report poorer physical health than their male counterparts, while age was not a significant independent predictor of health. Support from friends and burden did not interact in their prediction of physical health, R^2 *Change* = .005, *F Change* (1, 77) = 0.44, $p = .51$. Furthermore, there was no main effect for support from friends, R^2 *Change* = .04, *F Change* (2, 78) = 1.76, $p = .18$. The covariates accounted for 5% of the variance in physical health, $F(2, 80) = 3.32$, $p < .05$ (see Table 5).

Quality of the pre-illness relationship as the moderator variable

Table 6 displays the results of the regression analyses testing quality of the pre-morbid relationship as a moderator of the relationship between burden and physical health, with caregiver gender and age as covariates.

Table 5

Results of Multiple Regressions Testing Main and Interaction Effects of Support from Family and Friends on Physical Health for Dementia and Non-Dementia Caregivers

Independent Variable	*B*	Std. Error	*β*	*t*-value	*p*-value[a]
Covariates					
Gender	-8.15	11.56	-0.30	-2.78	0.01
Age	-0.04	0.16	-0.03	-0.24	0.81
Main effects					
Support from Family	0.74	0.28	0.27	2.60	0.01
Burden	-0.16	0.15	-0.11	-1.04	0.30
Interaction					
Family Support x Burden	0.02	0.03	0.06	0.59	0.56
Covariates					
Gender	-7.36	2.88	-0.28	-2.56	0.01
Age	-0.06	0.15	-0.04	-0.40	0.69
Main effects					
Support from Friends	0.44	0.25	0.20	1.80	0.08
Burden	-0.08	0.15	-0.06	-0.51	0.61
Interaction					
Friend Support x Burden	0.02	0.03	0.08	0.66	0.51

[a] Probability values (two-tailed) associated with the statistical tests.

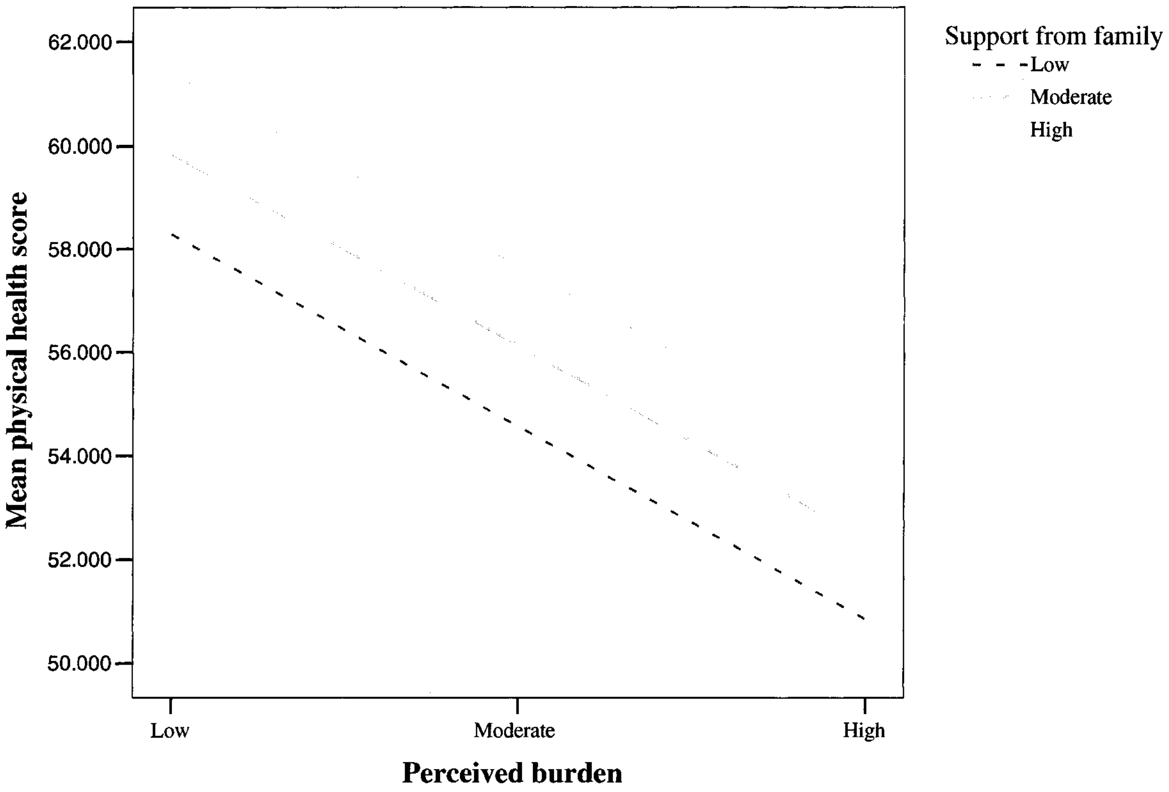

Figure 7. Main effect of social support controlling for caregiver age and gender: Physical health improved as support from family members increased from low to high levels, regardless of the amount of burden experienced.

The prediction that the quality of the premorbid relationship would buffer the association between subjective burden physical health was not substantiated. As can be seen in Table 6, the addition of the interaction term to the regression equation did not significantly add to the variance in physical health over and above their independent contributions, R^2 *Change* = .021, *F Change* (1, 78) = 1.84, $p = .18$. Furthermore, no main effect for quality of the pre-morbid relationship was observed, after controlling for gender and age, R^2 *Change* = .020, *F Change* (2, 79) = 0.88, $p = .42$. The covariates significantly contributed to the prediction of physical health, *adjusted* $R^2 = .05$, $F(2, 81) = 3.33$, $p < .05$, with a unique contribution provided by gender.

To summarize, support from family and friends, as well as appraisals of the pre-illness relationship did not attenuate the negative effect of caregiver burden on health. However, greater family support had a positive influence on physical health, irrespective of burden levels. Furthermore, findings indicated that gender was an important independent predictor of health.

Dataset 2

Participants

A total of 833 caregivers ($N = 349$ dementia, $N = 484$ non-dementia) of community-dwelling care-recipients were interviewed as part of the CSHA-1. Of these participants, 177 (dementia: $N = 105$, non-dementia: $N = 72$) were eligible for inclusion in the subsequent analyses.

Table 6

Results of Multiple Regressions Testing Main and Interaction Effects of Quality of the Premorbid Relationship on Physical Health for Dementia and Non-Dementia Caregivers

Independent Variable	*B*	Std. Error	*β*	*t*-value	*p*-value[a]
Covariates					
Gender	-7.23	2.88	-0.27	-0.25	0.01
Age	-0.10	0.15	-0.07	-0.68	0.50
Main effects					
Quality of the Premorbid Relationship	-0.85	0.81	-0.13	-1.05	0.30
Burden	-0.05	0.17	-0.04	-0.30	0.78
Interaction					
Quality of Relationship x Burden	0.12	0.09	0.15	1.36	0.18

[a] Probability values (two-tailed) associated with the statistical tests.

Caregiver demographics

The majority of dementia caregivers were female (76.2%), and they were on average 74 years old (range = 45 to 90, *SD* = 7.53). Sixty percent of non-dementia caregivers were female, and the average age was 75 years (*SD* = 9.18), with ages ranging from 30 to 90. Chi-square analysis indicated that the groups differed in terms of gender distribution, $\chi^2(1, N = 177) = 5.46, p < .05$, with the proportion of females to males being higher in the dementia group. However, no significant group differences were observed for caregiver age, $t(174) = -1.18, p = .24$.

Care-recipient demographics and functioning

No group differences were observed for care-recipient age, $t(175) = 1.60, p = .11$. Dementia care-recipients were on average 79 years old (range = 67 to 94, *SD* = 6.09), while the mean age of non-dementia care-recipients was 78 (range = 65 to 93, *SD* = 5.68). Table 7 shows the means and standard deviation for caregiver and care-recipient variables for both dementia and non-dementia groups. Analyses revealed that dementia caregivers exhibited greater cognitive impairments than their non-dementia counterparts, $t(129) = -13.29, p < .001$. Furthermore, they were more dependent in both basic and instrumental ADLs compared to non-dementia care-recipients, $t(173) = -3.63, p < .001$ and $t(165) = -8.56, p < .001$, respectively. The average frequency of disruptive behaviours among dementia caregivers was relatively low ($M = 14.96$ out of a maximum of 112, see Table 7).

Table 7

Means and (Standard Deviations) of Care-recipient and Caregiver Variables for Dementia and Non-Dementia Caregivers

Variables	Dementia $n = 105$	Non-Dementia $n = 72$
Care-recipient functioning		
Cognition	18.48 (5.42)	26.73 (2.23)
Instrumental ADL	6.43 (4.71)	11.14 (2.53)
Basic ADL	12.28 (2.60)	13.43 (1.63)
Disruptive behaviours	14.96 (12.84)	--
Caregiver variables		
Physical health	5.85 (1.59)	5.48 (1.51)
Depression	12.65 (9.58)	7.74 (7.96)
Burden	10.34 (9.58)	--
Formal service use	0.98 (1.20)	0.92 (0.99)

Note. Disruptive behaviours and caregiver burden were not assessed among non-dementia caregivers.

Objective 1: Analyses of group differences

Physical and psychological health

Given that caregivers differed with respect to gender, one-way analyses of covariance (ANCOVA) were conducted to compare dementia and non-dementia caregivers on health outcomes, controlling for the possible confounding effects of gender on physical and psychological health. Assumptions relevant to ANCOVA were tested. Homogeneity of regression was assessed using hierarchical regression procedures. Results indicated that the interaction between group and the covariate (caregiver gender) did not significantly contribute to the prediction of the dependent variables (both physical health and depression) over and above their independent contributions, indicating homogeneity of regression between group and gender. Inspection of residuals plotted against fitted values indicated that the assumptions of normality, linearity and homoscedasticity were within acceptable limits. Levene's test of equality of error variances indicated homogeneous variances for physical health, $F(1, 162) = 0.56, p > .05$. However, Levene's test indicated heterogeneous variances for depression, $F(1, 171) = 5.07, p < .05$. This violation may be due to the large sample size as the null hypothesis (for the Levene's test) is more likely to be rejected with larger samples. Given this possibility, and that ANCOVA is robust to violations of homogeneity of variances (Tabachnick & Fidell, 2001), no transformations were made to the data.

Results indicated that dementia and non-dementia caregivers did not differ in terms of physical health, even after the effect of gender was removed from the dependent variable, $F(1, 163) = 1.99, p = .16$, partial $\eta^2 = 0.01$, (dementia: $M = 5.84, SE = 0.16$; non-dementia: $M = 5.49, SE = 0.20$). However, group differences did emerge for depression, $F(1, 172) = 10.44$, $p < .001$, partial $\eta^2 = 0.06$. Dementia caregivers reported more depressive symptoms than non-dementia caregivers, (dementia: $M = 12.49$, $SE = .89$; non-dementia: $M = 7.97$, $SE = 1.06$).

Other stress process variables

Dementia and non-dementia caregivers did not differ with respect to the number of community services used within the last year, $t(174) = .37$, $p = .71$ (see Table 7). Group comparisons could not be performed on burden as only dementia caregivers were assessed. In this sample, dementia caregivers reported relatively low levels of burden, with a mean score of 10.34 (out of a maximum of 48).

Objectives 2 and 3: Test of mediator and moderator hypotheses

The mediator and moderator hypotheses could not be evaluated as health behaviours, perceived social support, and appraisal of the pre-illness relationship were not measured in this dataset.

Dataset 3

Participants

Caregiver demographics

Overall, 1,283 caregivers were interviewed as part of the 1999 ICS. However, applying the current study's eligibility criteria yielded a total of 341 caregivers ($N = 101$ CI caregivers, $N = 240$ NCI caregivers). Approximately 65% of CI caregivers were female, and they were on average 75.3 (range = 49 to 93, $SD = 8.20$) years old. Over half of the NCI caregivers were female (54.2%), with an average age of 74.0 years (range = 38 to 90, $SD = 7.38$). Seventeen percent of CI and 16.6% of NCI caregivers were providing care for less than 1 year, while 35.9% of CI and 32.2% of NCI caregivers spent between 1 to 4 years caring. About 31.5% of CI and 27% of NCI care-providers had been caring for their spouses between 4 to 10 years, and 15.2% of CI and 24.2% of NCI spent 10 years or more caregiving. No significant group differences were observed for caregiver gender, $\chi^2(1, N = 307) = 2.98, p = .08$, age, $t(339) = -1.50, p = .13$, or for length of caregiving, $\chi^2(7, N = 303) = 5.47, p = .60$.

Care-recipient demographics and functioning

Care-recipients significantly differed with respect to age, with CI care-recipients ($M = 78.42, SD = 7.13$) on average 3 years older than their NCI counterparts ($M = 75.79, SD = 6.72$), $t(339) = -3.25, p < .01$. Means and standard deviations for care-recipient functioning and caregiver variables are presented in Table 8 for both CI and NCI groups. Analyses indicated that CI care-recipients were more dependent in instrumental ADL than their NCI counterparts, $t(339) = -3.87, p < .001$. There was a trend for CI care-recipients to exhibit greater dependence in basic ADL, $t(339) = -2.22, p = .03$. Finally CI care-recipients exhibited greater frequency of disruptive behaviours than NCI care-recipients, $t(144) = -4.24, p < .001$.

Objective 1: Analyses of group differences

Physical health and other stress process variables

Results from independent t-tests revealed that CI and NCI caregivers did not differ with respect to physical health, $t(339) = -.78, p = .44$. However, CI caregivers reported more burden than NCI caregivers, $t(339) = -3.75, p < .001$. Caregivers did not substantially differ in their perceptions of support from family and friends, $t(339) = -.87, p = .38$. Furthermore, caregivers did not differ with respect to the number of services ever used, $t(339) = -1.16, p = .25$ (see Table 8).

Table 8

Means and (Standard Deviations) for Care-recipient Functioning and Caregiver Variables for Caregivers of Cognitively Impaired (CI) and Non-Cognitively Impaired (NCI) Caregivers

	Cognitively Impaired (CI) *n* = 101	Non-Cognitively Impaired (NCI) *n* = 240
Care-recipient Functioning		
Instrumental ADL	6.20 (2.46)	5.10 (2.37)
Basic ADL	2.62 (2.25)	2.06 (2.09)
Disruptive behaviours	15.21 (4.54)	13.37 (3.22)
Caregiver Variables		
Physical health	2.37 (0.88)	2.30 (0.75)
Burden	2.57 (1.98)	1.74 (1.82)
Support from family and friends	24.55 (4.54)	24.05 (4.94)
Service use	1.56 (1.35)	1.39 (1.30)

Objective 2: Test of mediator hypothesis

The mediator hypothesis could not be evaluated as health behaviours were not measured in this dataset.

Objective 3: Test of moderator hypotheses

Quality of the premorbid relationship was not assessed in this dataset; therefore, perceived social support was the only moderator variable examined. Unlike dataset 1, moderator analyses were performed for CI and NCI caregivers separately as a larger sample size permitted the division of groups. The interaction tests followed the same procedures described in dataset 1.

Perceived social support as the moderator variable

One to 5 multivariate outliers were found and subsequently removed from their respective analysis. All other assumptions relevant to multiple regression were met.

Tables 9 and 10 display the results of the regression analyses testing the interaction between perceived support and subjective burden for both CI and NCI caregivers, controlling for caregiver gender and age.

As can be seen from Table 9, the prediction that perceived social support would interact with appraised burden in their prediction of physical health was not supported among CI caregivers, R^2 *Change* = .005, *F Change* (1, 84) = 0.45, $p = .50$. However, the main effect model was significant, R^2 *Change* = .07, *F Change* (2, 85) = 3.11, $p < .05$. Figure 8 illustrates the main effect of support at different levels (i.e., high, medium, and low) of burden. There was a trend for greater perceived support to predict better physical health, irrespective of burden levels. Caregiver gender and age were not successful predictors of physical health among CI caregivers, *adjusted* R^2 = .02 $F(2, 87) = 0.27$, p =

Table 9

Results of Multiple Regressions Testing Main and Interaction Effects of Support from Family and Friends on Physical Health for Caregivers of Cognitively Impaired (CI) Care-recipients

Independent Variable	*B*	Std. Error	*β*	*t*-value	*p*-value[a]
			CI Caregivers		
Covariates					
Gender	0.18	0.24	0.09	0.74	0.46
Age	0.01	0.01	0.04	0.38	0.72
Main effects					
Support from family and friends	-0.04	0.02	-0.20	-1.94	0.06
Burden	0.07	0.05	0.16	1.52	0.13
Interaction					
Support x Burden	-0.01	0.01	-0.08	-0.67	0.50

[a] Probability values (two-tailed) associated with the statistical tests.

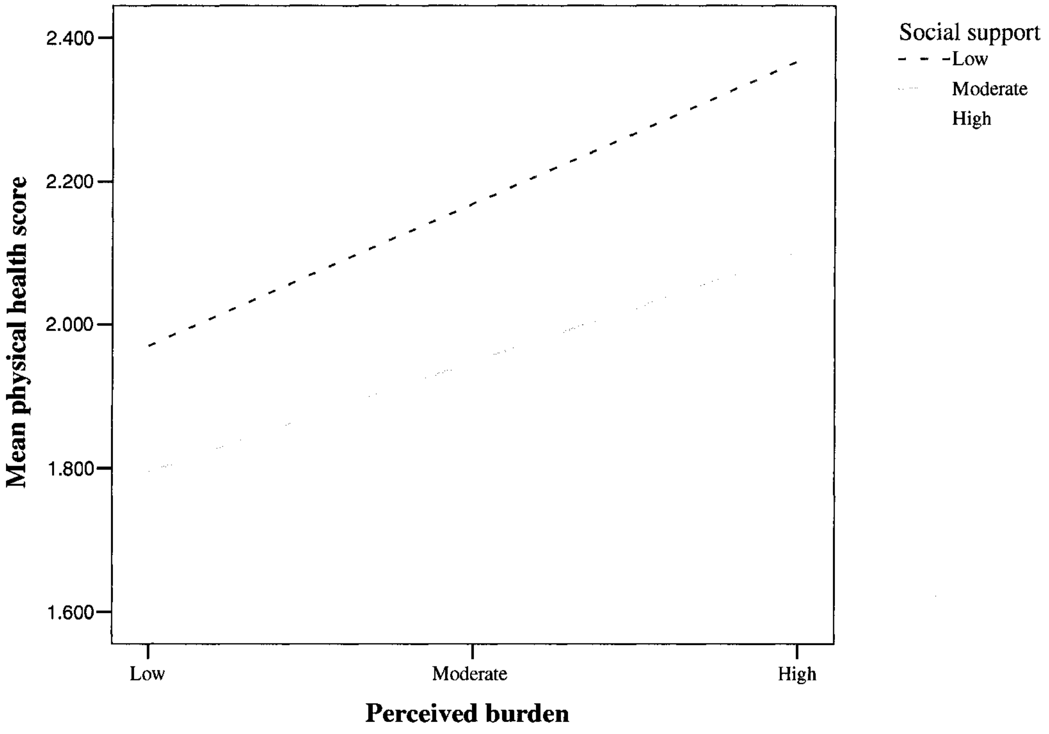

Figure 8. Main effect of social support controlling for caregiver age and gender: Physical health improved as perceived support increased from low to high levels, regardless of the amount of burden experienced.

.76. Among NCI caregivers, however, perceived support and burden contributed jointly to the variance of self-reported physical health among NCI over and above their independent contributions, R^2 *Change* = .02, *F Change* (1, 206) = 3.90, $p < .05$ (see Table 10). As can be seen in Figure 9, when burden is at a high or medium level, caregivers who perceived greater support experienced better physical health than those who had less support. But under conditions of low burden, support was not related to caregiver health. Thus, the hypothesis of a stress-buffering effect of social support was supported among NCI caregivers. The covariates, gender and age, significantly contributed to the variance in physical health, *adjusted* R^2 = .02, $F(2, 209) = 3.47$, $p < .05$. The individual regression coefficient for gender shows that NCI females report poorer physical health than their male counterparts. Age, however, was not a significant independent predictor of health (see Table 10).

In sum, results were consistent with the stress-buffering model for NCI caregivers. However, among CI caregivers, support was found for a main effect model, with a trend for perceived support to exert a positive effect on physical health, regardless of burden levels. Furthermore, female NCI caregivers, but not female CI caregivers, reported poorer physical health than their male counterparts.

Longitudinal analyses (Time 2)

Dataset 1

Participants

Attrition from Time 1 (initial assessment) to Time 2 (follow-up interview)

A follow-up interview was completed with 39 of the 66 dementia caregivers, yielding a 59% participation rate (Time 2 data was not collected for non-dementia

Table 10

Results of Multiple Regressions Testing Main and Interaction Effects of Support from Family and Friends on Physical Health for Caregivers of Non-Cognitively Impaired (NCI) Care-recipients

Independent Variable	*B*	Std. Error	*β*	*t*-value	*p*-value[a]
			NCI Caregivers		
Covariates					
Gender	0.26	0.11	0.17	2.36	0.02
Age	-0.004	0.01	-0.04	-0.57	0.57
Main effects					
Support from family and friends	-0.01	0.01	-0.08	-1.26	0.21
Burden	0.11	0.03	0.25	3.75	0.00
Interaction					
Support x Burden	-0.02	0.01	-0.16	-1.97	0.05

[a] Probability values (two-tailed) associated with the statistical tests.

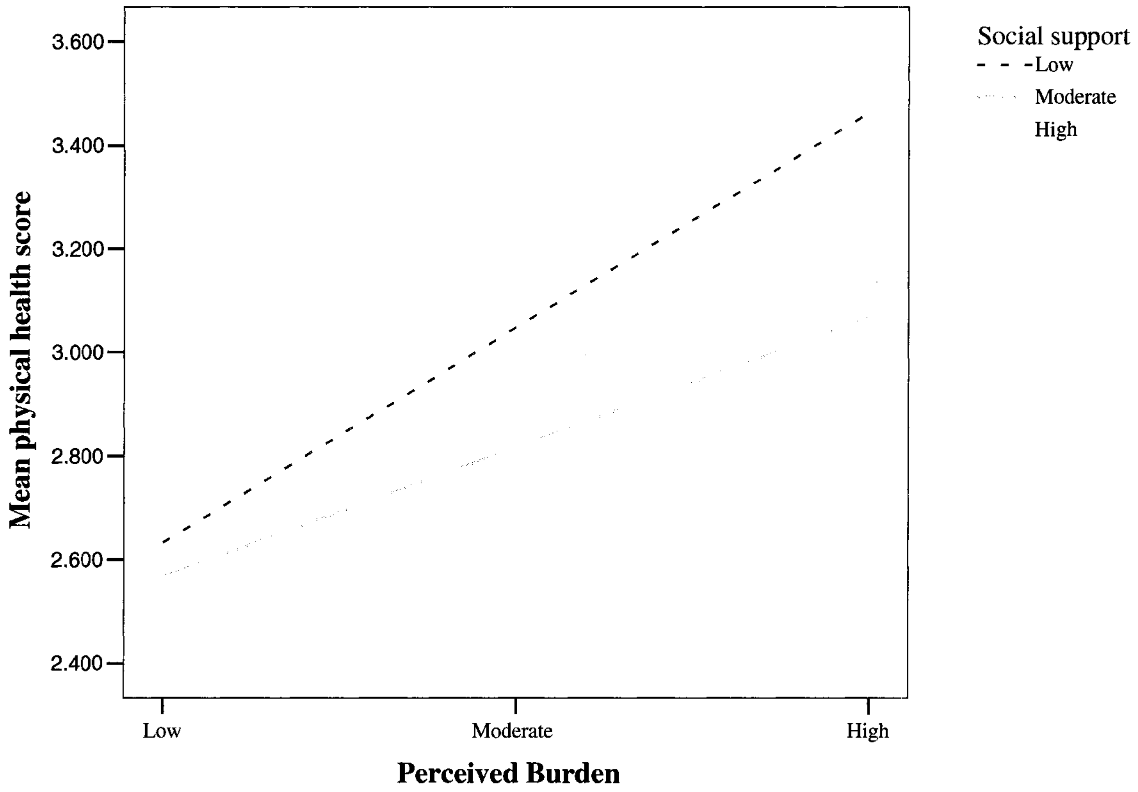

Figure 9. Burden x support interaction for physical health, controlling for caregiver age and gender: The interaction reveals when burden is at a high or medium level, caregivers who perceived greater support experienced better physical health compared to those who had less support. But under conditions of low burden, no health differences were observed between those with varying levels of support.

caregivers and non-caregivers). The assessments were conducted an average of 2.1 years (*SD* = 0.40) after the initial assessment. Telephone interviews lasted on average 61 minutes (*SD* = 21.6). Three participants chose to return the completed questionnaire by mail rather than conducting the interview over the phone. Of the 27 participants who did not complete the follow-up interview, 13 (48%) could not be contacted, 1 (4%) had died, 4 (15%) were too ill to participate, 3 (11%) refused to participate citing the recent death of the care-recipient, and 6 (22%) declined to complete the follow-up interview without giving any reasons.

Completers vs. Non-Completers

In comparing caregivers who completed both the initial and follow-up interviews to those who completed only the initial interview, no significant differences were revealed on care-recipient variables (all *t*s < 0.60, *ns;* see Appendix K). In addition, completers and non-completers did not differ by age, length of time spent caregiving, and hours of help received per week from informal and formal sources (all *t*s < -1.09, *ns;* see Appendix L). No significant differences were observed between groups on the remaining outcome variables (all *t*s < -0.62, *ns*). However, there was a trend for non-completers to have less support from friends than completers, $t(41) = -2.48$, $p = .02$ (see Appendix L). Chi square analyses revealed no significant gender differences across groups, $\chi^2(1, N = 66) = .57$, $p = .45$, with 72% of completers and 63% of non-completers being female.

Analyses of completers

Subsequent analyses are based on the 39 dementia caregivers for whom both initial and follow-up interviews were conducted. Data were analyzed for subgroups characterized by care-recipient status at follow-up. These analyses compared care-recipients who were still receiving care at home (continuous care group), those who were institutionalized (institutionalized group), and care-recipients who were deceased (deceased group).

Demographic description of the sample at Time 1

Between the initial assessment and follow-up interview, 39% of the caregivers ($N = 15$) continued to provide in-home care, 26% ($N = 10$) placed their spouses in long-term care, 36% ($N = 14$) were no longer serving as caregivers due to the death of the care-recipient. Caregivers placed their spouses in long-term care an average of 18.0 months ($SD = 10$) before the follow-up interview. Among widowers, an average of 19.21 months ($SD = 16.97$) had elapsed since the death of care-recipients.

Caregiver demographics

Of 39 dementia caregivers who completed follow-up interviews, 28% ($N = 11$) were male and 72% ($N = 28$) were female. The typical caregiver was approximately 72 years old ($SD = 10.02$) at study entry. At the time of the initial interview, caregivers had been providing care for an average of 5.43 years ($SD = 3.60$), and they received on average 13.70 ($SD = 13.21$) hours of help per week.

Comparisons between transition groups (continuous care versus institutionalized versus deceased at follow-up) on demographic variables assessed during the initial interview were conducted using one-way analysis of variance for the continuous measures and chi-square tests for discrete measures. Demographic characteristics for each group are presented in Table 11. Results indicated that groups did not differ systematically with respect to caregiver age, $F(2, 38) = 1.86, p = .17$, years spent caregiving, $F(2, 38) = 0.97, p = .39$, frequency of service use, $\chi^2(2, N = 38) = 0.87$,

Table 11

Means and (Standard Deviations) or Percentages for Demographic Characteristics of Dementia Caregivers, Separated by Transition Status (Continuous Care, Institutional Care, and Deceased)

	Continuous Care *n* = 15	Institutional Care *n* = 10	Deceased *n* = 14
	Means (Standard Deviations)		
Caregiver age	69.27 (11.49)	71.20 (10.04)	76.14 (7.37)
Care-recipient age	70.40 (10.53)	73.50 (8.06)	81.43 (4.88)
Duration of caregiving (years)	4.54 (3.79)	5.40 (3.50)	6.41 (3.47)
Help with caregiving (hours/week)	13.40 (13.52)	14.13 (13.26)	13.75 (13.84)
	Percentages		
Sex (% females)	60.00	50.00	100.00
Frequency of service use[a]	93.00	80.00	86.00

[a] Percent using services at least once per week.

$p = .65$, and hours of help with caregiving received per week, $F(2, 38) = 0.01$, $p = .99$. However, the proportion of females to males differed across groups, $\chi^2(2, N = 39)=8.87$, $p < .05$. For caregivers who were still providing in-home care, the proportion of females to males was higher (60% female), while among caregivers who placed their spouses in long-term care, the proportional split was even (50% female). All of the caregivers of deceased care-recipients were female (100% female).

Care-recipient demographics

Significant group differences were found for care-recipient age, $F(2, 38) = 6.75$, $p < .01$. Fisher's LSD revealed that care-recipients who were deceased at follow-up were on average 7.9 years older than care-recipients who were institutionalized, and 11 years older than community-dwelling care-recipients. However, the latter two groups were similar in age (see Table 11).

Objective 1: Analyses of group differences

This hypothesis could not be tested as non-dementia caregivers were not assessed at Time 2.

Objectives 2 and 3 (Tests of the mediator and moderator hypotheses)

These objectives could not be evaluated using follow-up data due to insufficient sample size.

Objective 4: Analyses of change over time by transition group

A 2X3 mixed-design ANOVA with time of testing (initial versus follow-up) as the within-subjects factor and transition status (continuous care versus institutionalized versus deceased at follow-up) as the between-subjects factor was conducted to determine whether transition groups differed in caregiver outcomes and care-recipient functioning over time. The small sample size precluded the ability to control for gender differences between groups. Means and standard deviations of Time 1 and Time 2 caregiver and care-recipient variables are presented in Tables 12 and 13, respectively.

Changes in physical and psychological health

Physical health

Caregiver physical health status remained relatively unchanged between Time 1 and Time 2, $F(1, 36) = 0.06, p = .81$, partial $\eta^2 = .002$. However, a significant main effect of transition status, $F(2, 36) = 5.21, p < .05$, partial $\eta^2 = .22$, was found. Fisher's LSD revealed that caregivers who institutionalized their spouses reported better physical health ($M = 51.09$, $SE = 3.18$) than caregivers whose spouses were deceased ($M = 38.08$, $SE =$ $SE = 2.69$) and compared to caregivers who were still providing home care at follow-up ($M = 40.85$, $SE = 2.59$), while the latter two groups did not differ. The time-by-transition status interaction was not significant, $F(2, 36) = 0.69, p = .51$, partial $\eta^2 = .04$, which suggests that changes in physical health did not depend on transition group.

Mental health

Mental health remained stable over time, $F(1, 36) = 0.51, p = .48$, partial $\eta^2 = .01$, and transition groups did not differ with respect to mental health, $F(2, 36) = 0.97, p = .39$, partial $\eta^2 = .05$. However, the time-by-transition status interaction approached, but failed to reach statistical significance, $F(2, 36) = 3.10, p = .06$, partial $\eta^2 = .15$. Post hoc tests revealed that changes in mental health did not significantly differ between continuing caregivers ($M_{time2\text{-}time1} = 3.92$, $SE = 2.69$) and bereaved caregivers ($M_{time2\text{-}time1} = 6.34$, SE

Table 12

Means and (Standard Deviations) for Time 1 and Time 2 Caregiver Variables for Continuous Care, Institutionalized, and Deceased Groups

	Time 1			Time 2		
	Continuous *n* = 15	Institution *n* = 10	Deceased *n* = 14	Continuous *n* = 15	Institution *n* = 10	Deceased *n* = 14
Physical health	42.58 (11.90)	49.68 (11.01)	38.52 (13.29)	39.12 (11.63)	52.49 (8.01)	37.64 (13.87)
Mental health	39.22 (11.96)	45.70 (12.90)	43.77 (14.61)	43.15 (13.38)	39.76 (14.34)	50.11 (10.68)
Depression	20.67 (13.11)	11.50 (8.97)	17.64 (10.70)	19.73 (14.19)	14.56 (8.87)	12.71 (9.09)
Burden	17.47 (11.99)	15.60 (10.44)	20.36 (10.03)	16.93 (9.87)	19.44 (13.92)	17.61 (12.81)
Family support	15.80 (5.26)	15.20 (3.82)	12.93 (6.58)	16.13 (4.91)	16.67 (3.68)	15.36 (5.36)
Friend support	13.53 (4.37)	13.50 (4.50)	14.21 (6.39)	13.73 (5.17)	13.00 (5.34)	14.21 (6.05)
Quality of premorbid Relationship	2.67 (1.95)	4.10 (1.20)	3.57 (2.17)	3.20 (2.36)	4.00 (2.06)	2.57 (1.60)
Health behaviours	106.67 (20.24)	100.80 (10.73)	103.57 (14.48)	107.00 (18.26)	102.00 (15.11)	110.43 (13.51)

Table 13

Means and (Standard Deviations) for Time 1 and Time 2 Care-recipient Variables for Continuous Care, Institutionalized, and Deceased Groups

	Time 1			Time 2		
	Continuous *n* = 15	Institution *n* = 10	Deceased *n* = 14	Continuous *n* = 15	Institution *n* = 10	Deceased *n* = 14
IQCODE	4.56 (0.50)	4.64 (0.24)	4.73 (0.32)	4.72 (0.40)	4.70 (0.36)	4.67 (0.43)
IADL	13.76 (6.30)	12.68 (4.65)	11.08 (3.67)	12.35 (4.16)	11.37 (3.21)	10.41 (2.45)
BADL	21.00 (5.84)	21.90 (4.61)	18.21 (5.15)	18.40 (5.74)	19.22 (4.60)	16.15 (5.74)
CMAI	27.47 (30.65)	21.50 (22.77)	27.93 (20.92)	26.73 (19.61)	25.56 (25.50)	27.23 (30.72)

Note. IQCODE=Informant Questionnaire on Cognitive Decline in the Elderly; IADL=Instrumental Activities of Daily Living; BADL=Basic Activities of Daily Living; CMAI=Cohen-Mansfield Agitation Inventory.

= 3.84). However, both groups differed from caregivers who placed their spouses in long-term care ($M_{time2-time1}$ = -5.94, SE = 3.82). Table 12 shows that while improvements were observed among the deceased and continuing care group, the institutional group experienced declines in mental health.

Depression

Depression scores did not change between initial and follow-up assessments, $F(1, 35) = 0.58$, $p = .45$, partial $\eta^2 = .02$, and transition groups did not differ with respect to depression symptoms, $F(2, 35) = 1.48$, $p = .24$, partial $\eta^2 = .08$. Furthermore, the time x transition status interaction was not statistically significant, $F(2, 35) = 1.74$, $p = .19$, partial $\eta^2 = .09$.

Changes in other stress process variables

Dependence in ADL

Analyses revealed a significant effect for time, $F(1, 34) = 15.41$, $p < .001$, partial $\eta^2 = .31$, indicating that dependence in basic ADL increased between Time 1 and Time 2 assessments ($M = 20.3$, $SE = .90$ versus $M = 17.9$, $SE = .93$). However, transition groups did not differ with respect to basic ADL, $F(2, 34) = 1.13$, $p = .34$, partial $\eta^2 = .06$, nor was there a significant time-by-transition status interaction, $F(2, 34) = 0.06$, $p = .94$, partial $\eta^2 = .003$.

Furthermore, results indicated care-recipients became more dependent in instrumental ADL over time ($M = 12.62$, $SE = .80$. versus $M = 11.38$, $SE = .58$), $F(1, 34) = 5.53$, $p < .05$, partial $\eta^2 = .14$, irrespective of transition status. Transition groups did not differ with respect to dependence in instrumental ADL, $F(2, 34) = 1.19$, $p = .32$, partial η^2

= .06, and the trajectory of change in instrumental ADL was similar across transition groups, $F(2, 34) = 0.15$, $p = .85$, partial $\eta^2 = .01$.

Disruptive behaviours

No main effects for time, $F(1, 34) = 0.001$, $p = .98$, partial $\eta^2 = .00$, transition status, $F(2, 34) = 0.13$, $p = .88$, partial $\eta^2 = .01$, or time by transition status interaction, $F(2, 34) = 0.17$, $p = .85$, partial $\eta^2 = .01$, were found for disruptive behaviours.

Cognition

Similar null findings were observed for cognitive functioning. Specifically, there were no significant main effects for time, $F(1, 34) = 0.29$, $p = .59$, partial $\eta^2 = .01$, transition status, $F(2, 34) = 0.13$, $p = .88$, partial $\eta^2 = .01$, or time x transition status interaction, $F(2, 34) = 0.86$, $p = .42$, partial $\eta^2 = 0.05$.

Burden

Caregiver burden levels remained stable over time, $F(1, 34) = 0.08$, $p = .78$, partial $\eta^2 = .00$, and transition groups did not differ in their perceptions of burden, $F(2, 34) = 0.15$, $p = .86$, partial $\eta^2 = .01$. Furthermore, the trajectory of change in burden was similar across groups, $F(2, 34) = 0.85$, $p = .44$, partial $\eta^2 = .05$.

Perceived social support

Caregivers' perception of support from family, $F(1, 35) = 2.51$, $p = .12$, partial $\eta^2 = .07$, or friends, $F(1, 35) = 0.01$, $p = .91$, partial $\eta^2 = .00$, did significantly change over time. Furthermore, transition groups did not differ with respect to perceived support from family, $F(2, 35) = 0.81$, $p = .45$, partial $\eta^2 = .04$, or friends, $F(2, 35) = 0.12$, $p = .89$, partial $\eta^2 = .01$. Finally, the interaction between time and transition status did not reach statistical significance for support from family or friends, $F(2, 35) = 0.72$, $p = .49$, partial $\eta^2 = .04$, and $F(2, 35) = 0.06$, $p = .94$, partial $\eta^2 = .00$, respectively.

Quality of pre-illness relationship

While the non-significant main effects of time, $F(1, 35) = 0.68$, $p = .41$, partial $\eta^2 = .02$, and transition status, $F(2, 35) = 1.14$, $p = .33$, partial $\eta^2 = .06$, suggested that appraisals of the pre-illness relationship did not change over time, and that transition groups did not differ with respect to their ratings, a significant time-by-transition status interaction revealed an interesting pattern of change among transition groups, $F(2, 35) = 4.36$, $p < .05$, partial $\eta^2 = .20$. Fisher's LSD found significant differences between the deceased ($M_{time2-time1} = -1.00$, $SE = 0.39$) and continuing care groups ($M_{time2-time1} = 0.53$, $SE = 0.31$) with respect to changes in premorbid relationship appraisals. However, no differences were observed between these two groups and the institutional group ($M_{time2-time1} = -0.11$, $SE = 0.54$). As can be seen in Table 12 (on page 128), caregivers whose spouses were deceased had poorer initial appraisals than continuing caregivers; however, by follow-up, their appraisals were more positive, while opposite was observed for continuing caregivers.

Health behaviours

No significant main effects were found for either time, $F(1, 35) = 1.44$, $p = .24$, partial $\eta^2 = .04$ or transition status, $F(2, 35) = 0.39$, $p = .68$, partial $\eta^2 = .02$. The time by transition status interaction was also non-significant, $F(2, 35) = 1.24$, $p = .30$, partial $\eta^2 = .07$ for health promoting practices.

Dataset 2

Participants

Attrition from Time 1 (initial assessment) to Time 2 (follow-up interview)

While new caregivers of community-dwelling care-recipients (i.e., those who did not take part in the Time 1 assessment) were interviewed in CSHA-2 (Time 2), they were not included in the current analyses. Follow-up interviews were completed with 108 of the 177 caregivers who took part in the initial assessment, yielding a 61% participation rate. Of the 105 dementia caregivers who completed the Time 1 assessment, 65 completed the second interview (62% participation rate). Of the 72 non-dementia caregivers who completed Time 1 assessments, 43 completed the follow-up interview (60% participation rate). Thus, the remaining sample included 65 dementia caregivers and 43 non-dementia caregivers who completed both Time 1 and Time 2 interviews.

Completers vs. Non-Completers

In comparing dementia caregivers who completed both the initial and follow-up interviews (i.e., completers) with those who completed only the initial interview (i.e., non-completers), no significant differences were observed for caregiver and care-recipient characteristics (all ts < 1.91, *ns*; see Appendices M and N). However, comparisons of non-dementia completers with non-completers revealed that care-recipients of the former group were significantly younger than the latter, $t(67) = 3.32$, $p < .01$. However, no significant differences were revealed on the remaining variables (all ts < 1.94, *ns*; see Appendices O and P).

Analyses of completers

Subsequent analyses are based on the 108 caregivers for whom both initial and follow-up interviews were conducted. Data were analyzed for subgroups characterized by transition status (i.e., care-recipient status at follow-up) and by caregiver type (dementia versus non-dementia). These analyses compared dementia and non-dementia care-recipients who were still receiving in-home care (continuous care group), those who were institutionalized (institutionalized group), and care-recipients who were deceased at follow-up (deceased group).

Between Time 1 and Time 2, 35% ($N = 37$) of caregivers were still providing in-home care (dementia: $N = 9$; non-dementia: $N = 28$), 21% ($N = 23$) placed their spouses in institutions (dementia: $N = 19$; non-dementia: $N = 4$), and 44% ($N = 48$) were no longer serving as caregivers due to the death of the care-recipient (dementia: $N = 37$; non-dementia: $N = 11$). Caregivers placed their spouses in long-term care an average of 25.05 months ($SD = 14.33$) before the follow-up interview. No significant group differences were found between dementia ($M = 27.0$, $SD = 14.51$) and non-dementia caregivers ($M = 14.0$, $SD = 7.21$) with respect to duration of institutionalization, $t(18) = 1.50, p = .15$). For widowers, an average of 29.8 months ($SD = 17.4$) had elapsed since the death of care-recipients. Dementia ($M = 29.41$, $SD = 16.74$) and non-dementia widowers ($M = 31.09$, $SD = 20.31$) did not differ with respect to duration of bereavement, $t(46) = -.28, p = .78$.

Demographic description of the sample at Time 1

Caregiver and care-recipient demographics

Of 108 caregivers who completed follow-up interviews, 23% ($N = 25$) were male and 77% ($N = 83$) were female. The typical caregiver was approximately 73.21 ($SD =$

6.81) years old at study entry, while care-recipients averaged 78.1 years of age (SD = 6.11) at the time of the initial assessment. Comparisons between transition groups (continuous care versus institutionalized versus deceased at follow-up) on demographic variables assessed at Time 1 were performed for dementia and non-dementia caregivers separately. Demographic characteristics of transition groups are presented in Table 14 for dementia and non-dementia caregivers. Among the dementia group, there was a trend for transition groups to differ with respect to care-recipient age, $F(2, 64) = 4.13$, $p = .02$; however, no significant differences were observed for caregiver age, $F(2, 63) = 0.93$, $p = .40$. Furthermore, transition groups did not differ in gender distribution, $\chi^2(2, N = 65) = 3.55$, $p = .17$. Within the non-dementia group, transitions groups did not differ with respect to caregiver and care-recipient age, and gender distribution, $F(2, 42) = 1.18$, $p = .32$, $F(2, 42) = 0.28$, $p = .76$, and $\chi^2(2, N = 43) = 1.10$, $p = .58$, respectively.

Objective 1: Analyses of group differences

Results of this objective are embedded in the analyses conducted to address Objective 4 (see below). Of main importance is the time x caregiver type x transition status interaction.

Objectives 2 and 3 (Tests of the mediator and moderator hypotheses)

These objectives could not be evaluated as the relevant measures were not included in this dataset.

Objective 4: Analyses of change over time by transition group

A 2X3X2 mixed design ANOVA with time of testing (initial versus follow-up) as the within-subjects factor, and transition status (continuous care versus institutionalized versus widowed at follow-up) and caregiver type (dementia versus non-dementia) as the

Table 14

Means and (Standard Deviations) for Demographic Characteristics of the Continuous Care, Institutional Care, and Deceased Groups as a Function of Caregiver Type (Dementia and Non-Dementia Caregivers)

	Demographic Variables		
	Caregiver Age	Care-recipient Age	Sex*
	Dementia Group		
Continuous Care	75.00 (5.00)	79.22 (4.58)	89.00
Institutionalized	71.53 (6.28)	76.21 (5.50)	74.00
Deceased	73.25 (6.97)	80.84 (6.01)	92.00
	Non-Dementia Group		
Continuous Care	74.07 (6.85)	76.21 (6.54)	57.00
Institutionalized	68.25 (14.50)	78.50 (2.52)	75.00
Deceased	74.18 (4.51)	76.00 (5.50)	73.00

* Percent female.

between-subjects factors was conducted to determine whether the trajectory of change in caregiver outcomes and care-recipient functioning differed depending on caregiver type and transition status.

Comparable datasets were not available for all three transition groups; that is, burden and disruptive behaviours were not assessed among the deceased group and among non-dementia caregivers. Consequently, a 2X2 mixed design ANOVA with transition status (continuous care versus institutionalized at follow-up) as the between-subjects factor and time of assessment as the within-subjects factor was conducted to assess whether changes in burden and disruptive behaviours differed between dementia caregivers who continued to provide-in home care and dementia caregivers who placed their spouses in long-term care.

Only the continuous care group (i.e., other two transition groups were not assessed) were asked questions pertaining to formal service use; therefore, comparisons could only be made between caregivers type (dementia vs non-dementia). A 2X2 mixed design ANOVA with time as the within-subjects factor and care-recipient illness (dementia versus non-dementia) as the between-subjects factor was used to assess whether changes in formal service use differed between dementia and non-dementia caregivers who were still providing in-home care. Means and standard deviations of Time 1 and Time 2 caregiver and care-recipient variables for dementia and non-dementia caregivers are presented in Tables 15 and 16, respectively.

Table 15

Means and (Standard Deviations) for Time 1 and Time 2 Caregiver Variables for Dementia Continuous Care, Institutionalized, and Deceased Groups

	Time 1			Time 2		
	Continuous *n* = 9	Institution *n* = 19	Deceased *n* = 37	Continuous *n* = 9	Institution *n* = 19	Deceased *n* = 37
Physical health	5.44 (1.33)	5.94 (1.48)	5.80 (1.64)	6.78 (2.05)	6.05 (1.96)	5.59 (1.42)
Depression	9.22 (6.18)	12.44 (12.70)	14.22 (9.94)	9.78 (6.71)	16.95 (13.66)	9.76 (8.43)
Burden	4.11 (7.21)	11.89 (10.81)	12.77 (11.08)	6.56 (9.37)	9.53 (10.51)	--
Service Use	0.56 (1.01)	0.53 (0.90)	1.22 (1.42)	1.33 (1.32)	--	--
Instrumental ADL	10.33 (4.77)	7.94 (3.49)	4.81 (4.15)	11.22(2.28)	6.33 (4.13)	8.06 (4.43)
Basic ADL	12.55 (3.64)	13.26 (1.63)	11.54 (2.81)	6.78 (4.76)	0.94 (1.13)	2.14 (2.78)
Disruptive behaviours	7.89 (12.58)	13.94 (8.80)	17.65 (15.57)	10.67 (11.84)	22.89 (11.79)	--

Table 16

Means and (Standard Deviations) for Time 1 and Time 2 Caregiver Variables for Non-Dementia Continuous Care, Institutionalized, and Deceased Groups

	Time 1			Time 2		
	Continuous *n* = 28	Institution *n* = 4	Deceased *n* = 11	Continuous *n* = 28	Institution *n* = 4	Deceased *n* = 11
Physical health	5.42 (1.53)	5.50 (1.91)	6.18 (1.94)	5.61 (1.45)	5.75 (2.50)	5.82 (1.83)
Depression	6.00 (5.06)	9.50 (11.44)	12.36 (10.30)	10.70 (11.90)	7.75 (9.18)	9.73 (8.25)
Service Use	0.71 (0.98)	0.50 (0.58)	1.36 (1.28)	1.00 (1.19)	--	--
Instrumental ADL	11.75 (2.37)	10.50 (3.11)	9.73 (2.28)	12.68 (2.75)	7.25 (5.62)	10.82 (3.57)
Basic ADL	13.57 (1.03)	14.00 (0.00)	13.36 (0.68)	10.71 (4.08)	2.75 (3.77)	6.36 (5.77)

Note. Disruptive behaviours and caregiver burden were not assessed among non-dementia caregivers; formal service use not assessed among the deceased and institutionalized groups at Time 2.

Changes in physical and psychological health

Physical health

No significant main effects for time, $F(1, 97) = 1.45, p = .23$, partial $\eta^2 = .02$, caregiver type, $F(1, 97) = 0.54$, p = .46, partial $\eta^2 = .01$, and transition status, $F(2, 97) = 0.01, p = .99$, partial $\eta^2 = .00$, were observed for physical health. Furthermore, the time x caregiver type interaction failed to reach statistical significance, $F(1, 97) = 0.96, p = .33$, partial $\eta^2 = .01$. However, there was a trend for the time-by-transition status interaction to approach significance, $F(2, 97) = 2.85, p = .06$, partial $\eta^2 = .06$, suggesting that the patterns of change in physical health were different among those in the transition groups. Fisher's LSD indicated that greater changes in physical health (Time 2 minus Time 1 scores) were observed among continuing caregivers ($M_{time2\text{-}time1} = 0.54$, $SE = 0.30$) compared to those whose care-recipients were deceased ($M_{time2\text{-}time1} = -0.28$, $SE = 0.25$). As can be seen in Table 17, there was a tendency for caregivers of deceased patients to exhibit improvements in physical health, while declines in physical health were observed for caregivers of community-dwelling care-recipients. No differences were observed between these two groups and the institutional group over time ($M_{time2\text{-}time1} = 0.38$, $SE = 0.42$). The interaction between caregiver type and transition group, as well as the three-way interaction were not significant, $F(2, 97) = 0.92, p = .40$, partial $\eta^2 = .02$, and $F(2, 97) = 0.58, p = .57$, partial $\eta^2 = .01$, respectively.

Depression

With respect to depression, no significant main effects for time, $F(1, 99) = 0.00$, $p = .96$, partial $\eta^2 = .00$, caregiver type, $F(1, 99) = 1.47, p = .23$, partial $\eta^2 = .02$, and

Table 17

Estimated Marginal Means and (Standard Errors) for Variables with Significant Time x Transition Status Interaction Effects

	Time 1			Time 2		
	Continuous	Institution	Deceased	Continuous	Institution	Deceased
Physical Health	5.43 (0.31)	5.72 (0.45)	5.99 (0.28)	6.24 (0.32)	6.05 (0.46)	5.69 (0.28)
IADL	11.04 (0.68)	9.31 (0.97)	7.29 (0.61)	11.95 (0.73)	6.79 (1.05)	9.44 (0.66)
BADL	13.06 (0.41)	13.63 (0.60)	12.45 (0.37)	8.75 (0.69)	1.85 (0.99)	4.25 (0.62)

Note. IADL=Instrumental Activities of Daily Living; BADL=Basic Activities of Daily Living.

transition status, $F(2, 99) = 0.83, p = .44$, partial $\eta^2 = .02$, were found. Furthermore, the time-by-caregiver type interaction and the time-by-transition status interaction failed to reach statistical significance, $F(1, 99) = 0.01, p = .92$, partial $\eta^2 = .00$, and $F(2, 99) = 2.53, p = .09$, partial $\eta^2 = .05$, respectively. Finally, the caregiver type x transition status interaction as well as the three-way interaction were not significant, $F(2, 99) = 0.38, p = .69$, partial $\eta^2 = .01$, and $F(2, 99) = 0.78, p = .46$, partial $\eta^2 = .02$, respectively.

Changes in other stress process variables

Dependence in ADL

Care-recipient dependence in basic ADL significantly increased between Time 1 ($M = 13.11$, $SE = 0.27$) and Time 2 ($M = 4.95$, $SE = 0.45$), irrespective of groups, $F(1, 101) = 292.6, p < .001$, partial $\eta^2 = .74$. A significant main effect of caregiver type was also found, $F(1, 101) = 15.4, p < .001$, partial $\eta^2 = .13$. Results indicated that dementia care-recipients ($M = 10.13$, $SE = 0.47$) exhibited greater dependence in basic ADL than their non-dementia counterparts ($M = 7.87$, $SE = 0.33$). The time x caregiver type interaction was significant, $F(1, 101) = 5.04, p < .01$, partial $\eta^2 = .05$, suggesting that these group differences persisted over time. Fisher's LSD indicated that dementia caregivers exhibited greater dependence in basic ADL over time ($M_{time2\text{-}time1} = -9.75$, $SE = 0.50$) compared to their non-dementia counterparts ($M_{time2\text{-}time1} = -4.70$, $SE = -0.76$), irrespective of transition group (see Table 18). Furthermore, there was a significant main effect of transition group, $F(2, 101) = 12.60, p < .001$, partial $\eta^2 = .20$. Post hoc tests revealed that community-dwelling care-recipients ($M = 10.91$, $SE = 0.44$) were more independent in basic activities of daily living than their counterparts who were institutionalized ($M = 7.74$, $SE = 0.63$) and deceased ($M = 8.35$, $SE = 0.39$), while the

Table 18

Estimated Marginal Means and (Standard Errors) for Basic Activities of Daily Living with Significant Time x Caregiver Type Interaction Effects

	Time 1		Time 2	
	Dementia	Non-Dementia	Dementia	Non-Dementia
BADL	12.45 (0.32)	13.65 (0.44)	3.28 (0.52)	6.61 (0.73)

Note. BADL=Basic Activities of Daily Living.

latter two groups did not differ. The time-by-transition group interaction also reached statistical significance, *F*(2, 101) = 18.8, $p < .001$, partial $\eta^2 = .27$. Post hoc tests indicated care-recipients in the institutional group exhibited greater declines independence in basic ADL ($M_{time2\text{-}time1} = -12.13$, *SE* = 0.50) than both deceased ($M_{time2\text{-}time1} = -8.83$, *SE* = 0.61) and continuing care groups ($M_{time2\text{-}time1} = -3.57$, *SE* = 0.68). Finally, the average amount of change in basic ADL differed between the latter two groups, with care-recipients who were deceased by follow-up becoming more dependent in basic ADL over time compared to those still residing in the community (see Table 17 on page 141). The caregiver type x transition status interaction and the three-way interaction were not significant, *F*(2, 101) = 0.70, $p = .50$, partial $\eta^2 = .01$, and *F*(2, 101) = 0.27, $p = .76$, partial $\eta^2 = .00$, respectively.

There was no significant main effect of time for instrumental ADL, *F*(1, 100) = 0.13, $p = .72$, partial $\eta^2 = .00$, which suggested that averaging across caregiver type and transition status, care-recipient dependence in instrumental ADL did not change over time. A significant main effect for caregiver type was found, *F*(1, 100) = 8.79, $p < .01$, partial $\eta^2 = .08$. Results indicated that dementia care-recipients (*M* = 8.15, *SE* = 0.45) exhibited greater dependence in instrumental ADL than their non-dementia counterparts (*M* = 10.4, *SE* = 0.63). However, there was no interaction between time and caregiver type, *F*(1, 100) = 1.39, $p = .24$, partial $\eta^2 = .01$. A significant main effect for transition group was found, *F*(2, 100) = 9.44, $p < .001$, partial $\eta^2 = .16$. Post hoc tests revealed that community-dwelling care-recipients (*M* = 11.50, *SE* = 0.59) were more independent in instrumental ADL than their counterparts who were institutionalized (*M* = 8.05, *SE* = 0.85) and deceased (*M* = 8.37, *SE* = 0.53), while the latter two groups did not differ. The time x transition status interaction also reached statistical significance, $F(2, 100) = 6.49$, $p < .05$, partial $\eta^2 = .12$, suggesting that, irrespective of caregiver type, care-recipients in the transition groups are changing in different ways over time. Post hoc tests revealed that the deceased ($M_{time2-time1} = 2.70$, $SE = 0.67$) and institutional groups ($M_{time2-time1} = -2.05$, $SE = 0.76$) differed with respect to changes in instrumental ADL, with care-recipients in the institutional group exhibiting greater dependence over time, while those who were deceased by follow-up experienced decreased dependence. Greater declines were observed among the institutional group compared to the continuing care group ($M_{time2-time1} = 0.92$, $SE = 0.54$), while changes in instrumental ADL did not differ between the latter group and those who were deceased by follow-up (see Table 17 on page 141). The interaction between caregiver type and transition status as well as the three-way interaction failed to reach significance, $F(2, 100) = 1.29, p = .28$, partial $\eta^2 = .03$, and $F(2, 100) = 0.56, p = .57$, partial $\eta^2 = .01$, respectively.

Disruptive behaviours

The findings regarding disruptive behaviours apply only to dementia caregivers who continued to provide in-home care and dementia caregivers who placed their spouses in long term care. A significant main effect of time was found, $F(1, 25) = 6.38, p < .05$, partial $\eta^2 = .20$, with disruptive behaviours significantly increasing between Time 1 ($M = 10.9$, $SE = 2.08$) and Time 2 ($M = 16.8$, $SE = 2.46$). A significant main effect of transition status was also found, $F(1, 25) = 5.51, p < .05$, partial $\eta^2 = .18$. Post hoc tests indicated that dementia care-recipients ($M = 18.4$, $SE = 2.26$) who were placed in long-term care exhibited a greater frequency of disruptive behaviours than their community-dwelling counterparts (*M* = 9.28, *SE* = 3.19). However, the time-by-transition status interaction was not statistically significant, $F(1, 25) = 1.78$, $p = .19$, partial $\eta^2 = .07$.

Burden

Results pertaining to changes in burden are only applicable to dementia caregivers who continued to provide in-home care at Time 2 and dementia caregivers who placed their spouses in long term care at Time 2. No significant main effects for time, $F(1, 25) = 0.01$, $p = .95$, partial $\eta^2 = .00$, and transition status, $F(1, 25) = 2.06$, $p = .16$, partial $\eta^2 = .08$, were found. Similarly, the interaction between time and transition status failed to reach statistical significance, $F(1, 25) = 2.12$, $p = .16$, partial $\eta^2 = .08$. Furthermore, the results remained unchanged when the full version of the ZBI was used.

Formal service use

There was a significant main effect of time, $F(1, 35) = 5.96$, $p < .05$, partial $\eta^2 = .15$, with the number of services used significantly increasing between initial (*M* = 0.64, *SE* = 0.12) and follow-up assessments (*M* = 1.17, *SE* = 0.23), irrespective of caregiver type. However, there was no main effect of caregiver type, $F(1, 35) = 0.06$, $p = .81$, partial $\eta^2 = .00$. The time x caregiver type interaction also failed to reach statistical significance, $F(1, 35) = 1.27$, $p = .27$, partial $\eta^2 = .04$, which suggests that the trajectory of change in service use is similar for both caregiver groups.

Discussion

In the current investigation, three datasets with varied methodological strengths were analyzed in order to address the following research objectives. The first goal of the present study was to assess whether or not caregiving negatively affected physical and psychological health. This investigation also examined whether or not dementia caregivers were at greater risk for poorer health outcomes compared to their non-dementia counterparts. Furthermore, select components of Martire and Schulz's (2001) stress process model of caregiving were addressed. Specifically, the mediational role of health behaviours on physical health, as well as the potential stress-buffering effects of social and personal resources were tested. Finally, to examine whether or not relinquishing the caregiving role had an effect on caregiver health, the current study compared health trajectories of those who experienced transitions in their caregiving career with those who have not.

Results of the present investigation are summarized and discussed in their respective sections. Furthermore, study limitations, directions for future research, as well as clinical and theoretical implications of the current findings are presented.

Objective 1: Analyses of group differences

Caregivers versus non-caregivers

Physical and psychological health

Results indicated that dementia caregivers experienced greater depressive symptoms compared to non-caregivers, while both caregiver groups experienced poorer mental health compared to their non-caregiving counterparts. Moreover, analyses revealed that caregiver groups did not differ from non-caregivers with respect to physical health. These findings are congruent with those found in a meta-analysis (Pinquart & Sorensen, 2003) citing larger differences between caregivers and non-caregivers with respect to psychological health compared to physical health.

A possible explanation for the lack of physical health differences between caregivers and non-caregivers could be attributed to caregiver selection factors. For example, physically robust individuals may be selected to become caregivers, and their good health could be maintained for a certain period of time, despite the stress associated with caregiving. The impact of caregiving on physical health may appear gradually and could initially only affect the caregiver's psychological health. Doubly prospective studies that compare changes in health in persons before and after they transition into the caregiving role with those of non-caregivers during the same period (Vitaliano, Young, & Zhang, 2004) would be needed to confirm these hypotheses.

Other stress process variables

In the present study, caregivers and non-caregivers were also contrasted on other stress process variables. Findings indicated a trend for both caregiver groups to perceive lower support from friends compared to their non-caregiving counterparts. No group differences, however, were observed for support from family members. It is possible that the chronic nature of caregiving stress is taxing on the supportive capacities of friends, but not of relatives. Indirect evidence consistent with this view is provided by studies in the general stress literature. For instance, Kutner (1987) and Horwitz (1978) reported that the family, as a support system, was best equipped to handle the long-term commitment required by individuals experiencing chronic stressors as the demands of their situation may place an inordinate strain on even the strongest friendships.

An alternative interpretation of the finding of less peer rather than family support among caregivers is that activities with friends may be more negatively affected by caregiving than activities with family members. This interpretation is supported by studies showing that caregivers often have to give up friends in order to provide care (Haley et al., 1987; Rabins, Mace, & Lucas, 1982). Less time to spend with peers may result in worsened perceptions of social support (Bergman-Evans, 1994). Isolation of the caregiver from peer support may be particularly detrimental to psychological health as participation in social activities is often vital to maintaining mental well-being (Reese et al., 1994).

Findings from the present study also indicated that caregivers engage in fewer health promoting practices than non-caregivers, which has been replicated in other studies (e.g., Burton et al., 1997). Caregiving responsibilities may leave little time for caregivers to engage in preventative health care activities as they have been found to report more barriers to health promotion practices in comparison to non-caregivers (Acton, 2002). We would expect that group differences in health promoting behaviours would also be accompanied by differences in physical health given the documented relationship between health behaviours and physical health outcomes (Buchner et al., 1992; Wiley & Camacho, 1980; Wingard et al., 1982); however, this was not the case in the current study. Instead, it appears that neglecting to engage in positive health behaviours may have a detrimental effect on caregiver psychological well-being.

Interpretation of results comparing caregivers with non-caregivers should be treated with caution as they were derived from a sample of convenience. These individuals may be more representative of caregivers who participate in support groups or use services rather than caregivers in general. Furthermore, comparison of results across datasets was not possible as only dataset 1 included a control group of non-caregivers. Thus, replication of these findings using a larger, more representative sample is needed.

Dementia versus non-dementia caregivers

Physical and psychological health

As predicted, findings were uniform across datasets 1 and 2 indicating that dementia caregivers experienced poorer psychological health compared to their non-dementia counterparts. These results corroborate those reported by Hooker and her colleagues (1998), who also found that spousal caregivers of individuals with cognitive impairments were more psychologically compromised than those caring for physically impaired, but cognitively intact, spouses. Other researchers, however, found no demonstrable differences in psychological health between dementia caregivers and non-dementia caregivers (Cattanach & Tebes, 1991; Draper et al., 1992). The absence of a significant group difference in these studies may be due to the use of samples with heterogeneous kin relationships between the care-recipient and caregiver (i.e., combining various kinships in one sample) or the focus on non-spouse caregivers. Because spouse caregivers experience poorer psychological health than other family caregivers (Baumgarten et al., 1992), combining these subgroups may lead to the dilution of statistical relations owing to increase error variance (Bédard et al., 2000). Further, the inclusion non-spousal caregivers (e.g., adult daughter caregivers; Cattanach & Tebes, 1991) may have diminished the chances of finding significant group differences as the effects of caregiving on psychological health are more likely to be attenuated in these samples compared to those comprising of only spouse caregivers.

It was also hypothesized that dementia caregivers would rate their physical health more poorly than non-dementia caregivers, however, none of the datasets found meaningful differences between dementia and non-dementia caregivers with respect to physical health. These results are at variance with those reported by others (CSHA Working Group, 1994b; Ory et al., 1999) who found poorer physical health among dementia caregivers compared to non-dementia caregivers. It is possible that group differences found in these studies were due to the influence of kinship on physical health. For example, researchers neglected to take into account differences in kinship tie in their group comparisons (CSHA Working Group, 1994b; Ory et al., 1999), despite finding that dementia caregivers in their sample were more likely to be spouses versus adult children (Ory et al., 1999). This difference in kin distribution may have contributed to findings of poorer health among dementia caregivers versus non-dementia caregivers as spouses are more likely to experience poorer physical health than adult children caregivers (Baumgarten et al., 1992; Pinquart & Sorensen, 2003). The current study, however, only included spouse caregivers to control for this potential confound.

On the basis of these findings, it appears that the nature of the care-recipient illness has a greater influence on caregiver psychological rather than physical health. These results were replicated using both convenience and population-based samples, thereby lending credence to their robustness and generalizability.

Other stress process variables

To understand what could be driving psychological health differences between dementia and non-dementia caregivers, groups were contrasted on stress process variables (e.g., caregiving stressors and resource variables). Findings indicated that dementia and non-dementia caregivers engaged in health promoting behaviours with similar frequency. Furthermore, they did not differ in their appraisals of the quality of the pre-illness relationship with the care-recipient, or in their perceptions of support from significant others. Collectively, these results suggest that healthy behaviours, relationship with the care-recipient and support may not be responsible for the poorer psychological health observed among dementia caregivers.

Findings with respect to service use were inconsistent across datasets. In dataset 1, the proportion of dementia caregivers who used formal services per week was significantly higher than that of non-dementia caregivers, while results from dataset 2 indicated no differences with respect to the number of formal services used in the past year. Finally, in dataset 3, dementia (CI) caregivers reported using more services than their non-dementia (NCI) counterparts; no anchoring time point was used in the assessment of service use. The lack of agreement across datasets may reflect differences in the operationalization of formal service use (i.e., frequency of service use versus number of services used).

However, results were generally consistent across datasets indicating that dementia care-recipients evidenced increased dependence in ADL, greater frequency of disruptive behaviours, and poorer cognitive functioning than non-dementia care-recipients. These results suggest that dementia caregivers contend with greater caregiving stressors than their non-dementia counterparts, which is consistent with findings of earlier studies (e.g., Hooker et al., 1998; Ory et al., 1999; Williamson et al., 2005). Furthermore, this study found that the nature of the care-recipient illness and caregiver burden were related, such that dementia caregivers experienced more subjective burden compared to their non-dementia counterparts. Several other investigations have also reported greater burden among caregivers of cognitively impaired individuals compared to those caring for patients with physical limitations (Kim et al., 2006; Reese et al., 1994). The greater caregiving demands experienced by dementia caregivers provide a plausible explanation for why they also perceived greater levels of burden relative to non-dementia caregivers, and consequently, exhibited poorer psychological health outcomes. This assumption is consistent with the stress process model advanced by Martire and Schulz (2001), which posits that greater caregiving stressors are associated with increased appraisals of burden, which in turn, lead to poorer health outcomes. Results from Clyburn, Stones, Hadjistavropoulos, & Tuokko's (2000) study provide further empirical support for this theory. Other variables not taken into account in the present study, such as loss of marital companionship (Barusch & Spaid, 1996), may further explain greater psychological morbidity among dementia caregivers in comparison to non-dementia caregivers.

Follow-up data from dataset 2 indicated that the physical health trajectory of dementia and non-dementia caregivers were comparable over time. Furthermore, changes in psychological health (i.e., depressive symptoms) did not differ between groups. However, the absence of significant group differences over time may reflect inadequate power to detect higher order interactions (e.g., 3-way interactions). Another plausible explanation for these null findings is that the time period between initial and follow up assessments may not have been long enough to observe an impact of the nature of the care-recipient illness on physical and psychological health outcomes. Perhaps a longer follow-up time would have borne out these relationships. Furthermore, differences between dementia and non-dementia caregivers may have emerged had different trajectories in care-recipient and other caregiver variables emerged. In other words, lack of group differences in health may have been due to similarities with respect to caregiving stressors, as well as other stress process variables over time. Future studies employing larger sample sizes with longer follow-up periods may help clarify the veridicality of these non-significant results.

With respect to the first objective, findings suggested that the consequences of caregiving are manifested by psychological distress but not by physical morbidity. The negative impact of caregiving on perceptions of peer support and health promoting activities may be responsible for the poor psychological health observed among caregivers. Furthermore, the present results suggest that the nature of the care-recipient's illness may not be a central aspect of the caregiving context in determining physical health outcomes. However, providing care to a spouse with dementia is related to poorer psychological outcomes compared to caring for a spouse with non-dementia. Greater caregiving stressors in the form of care-recipient impairments and greater perceptions of burden may translate into poorer psychological health for dementia caregivers compared to their non-dementia counterparts.

Objective 2: Test of mediator hypothesis

Mediating caregiving stressors: Health behaviours

Another objective of the current study was to examine health promoting behaviours as a possible mediator of the effects of caregiving stress on physical health. Gender and age were included as covariates on the basis of previous research which found relationships between these demographic variables and physical health (Pinquart & Sorensen, 2003). In general, findings from this study revealed that gender was a significant predictor of physical health, with female caregivers reporting poorer health than their male counterparts. Gender differences may exist because females often face greater levels of caregiving stressors (Pinquart & Sorensen, 2006). In fact, studies have found that compared with male caregivers, females performed higher number of caregiving tasks as well as contended with greater severity of care-recipient disruptive behaviours (Bédard et al., 1999; Pinquart & Sorensen, 2006). Age, on the other hand, was not a significant predictor of caregiver health in the present study. Because caregivers were relatively homogenous with respect to age, insufficient variation may have constrained the estimates of association between age and health.

The current study failed to find evidence supporting the mediating role of health behaviours. This finding is inconsistent with those of Vitaliano and his colleagues (2002) who reported an indirect influence of caregiving stressors on physical health via health behaviours. Differences in sample composition may account for these differential findings. The current study combined dementia and non-dementia caregivers in the mediator analyses, while in Vitaliano and others' (2002) investigation, only dementia caregivers were examined. Health behaviours may have functioned as a mediator had dementia and non-dementia caregiver been analyzed separately. Unfortunately in this study, sample sizes were not large enough for such an approach to be feasible. The lack of congruence between studies may also be due to the use of different measures of physical health, with metabolic indicators used in the study by Vitaliano and his colleagues (2002) versus self-report measures employed in the present investigation. Physiological measures may be more sensitive to the effects of stress compared to subjective measures (Vitaliano et al., 2003) and may therefore show associations with caregiving stress more readily. However, the use self-assessment of physical health status should not be discarded in favour of physiological measures as the former has been demonstrated to be a good indicator of current physical health and disability (Idler & Benyamini, 1997; Idler & Kasl, 1995). The finding that global self-rated health is strong predictor of mortality further highlights its importance (Idler & Kasl, 1991).

The lack of significant mediating effects of health behaviours may be explained by other mediator variables that were not assessed in the current study. That is, the relationship between stressors and physical health may be mediated by additional factors, such as immune function. As an example, persons under stress have been found to engage in less health promoting practices compared to those not under stress (Acton, 2002), and such practices may modulate immune response (Simon, 1991), which in turn, may influence the development of physical health problems (Cohen et al., 1995). Neuroendocrine factors provide another plausible pathway through which stressor exposure might result in physical health problems. Stress-elicited hormones, such as catecholamines and cortisol, have been postulated to result in immune alteration, which in turn, may affect the development of physical health illnesses (Cohen et al., 1995; Herbert & Cohen, 1993).

While the present study focused on reductions in healthy behaviours as possible consequences of stressful situations (i.e., pathway through which stress adversely affects physical health), health promoting practices could also be used as behavioural coping strategies to manage stress (Nowack, 1989). Traditional coping inventories include some items representing health behaviours as ways of coping; unfortunately, however, they are generally under-represented in these scales (Ingledew, Hardy, Cooper, & Jemal, 1996). Examining the role of healthy behaviours as a potential stress buffering resource would be a worthy avenue for future research.

In the present study, the mediator hypothesis could only be tested using cross-sectional data from a convenience sample of caregivers due to sample size constraints and the unavailability of instruments assessing health behaviours in the larger datasets. Testing mediation on data collected at one time of measurement severely limits the ability to make any causal arguments (i.e., that caregiving stress "caused" a change in health practices, rather than vice versa). In view of these limitations, we recommend that future studies employ longitudinal designs and population-based sampling strategies to examine mediator models.

Objective 3: Test of moderator hypotheses

Perceived social support as the moderator variable

The hypothesis of a buffering effect of social support received mixed support in this study. No stress buffering effect of support from family members was found in dataset 1. Instead, there was evidence for the main effect model, such that caregivers who perceived greater support from family members experienced better physical health irrespective of how burdened they felt. No main or buffering effects were found for support from friends. Findings from dataset 3 were consistent with the stress buffering hypothesis of social support, suggesting that the beneficial effect of social support derives primarily from its protective properties in the presence of high levels of burden. However, these findings applied only to non-dementia (NCI) caregivers. A main effect of social support was found among dementia (CI) caregivers. Differences in sample composition and instruments used to assess support may account for the discrepancy across datasets. In dataset 1, dementia and non-dementia caregivers were combined in moderator analyses, while in dataset 3, each caregiver group was analyzed separately.

Small sample size precluded the differentiation of groups in dataset 1. Furthermore, in dataset 1, a global measure of the supportive functions (i.e., informational, instrumental, emotional) provided by family and friends was used to measure perceived support. In dataset 3, however, a more specific assessment of the function of support (i.e., emotional support) was employed. Finally, only dataset 1 distinguished between sources of support (family versus peer support). Distinction between globality (i.e., combined functional indices) and specificity (i.e., differentiated functional indices) of supportive functions may be critical to the assessment of the stress buffering effects (Cohen & Wills, 1985). In fact, global functional measures of support have been found to be less successful in demonstrating buffering effects because the composite index may obscure the relevant function of support (Cohen & Wills, 1985). Therefore, the failure to find a buffering effect in dataset 1 may reflect the use of a global indicator of support that specified a broad range of functions.

Despite findings indicating a main effect of family support, no evidence of buffering or main effects was detected in the analyses of support from friends. It seems that support from friends does little to offset the adverse health impact associated with the provision of care, either in the presence of high or low caregiving stress. One explanation for our findings with regard to the importance of familial versus peer support derives from the notion of fitting support to the person or problem (Cohen & McKay, 1984). In other words, source of support (i.e., family or friends) may be an important consideration in the assessment of its effectiveness (Cohen & Wills, 1985). For stressors experienced in a given domain (i.e., providing care to family member), support provided by sources from that same domain (i.e., other family members) has been shown to be most beneficial

(Franks & Stephens, 1996). Hence, because caregiving involves stressors experienced in the family domain, it is likely that effective support would come from family members. Another plausible explanation for our findings is that perceived support from friends may have been ineffectual due to the quality of that support. That is, peers of caregivers may fail to mobilize support to their friend in need or may do so inappropriately (Leavy, 1983).

Findings in dataset 3 suggest that social support operates differently for dementia and non-dementia caregivers. Among dementia caregivers (CI), support had the same health effects, independent of the level of burden experienced. However, for non-dementia caregivers (NCI), social support exerted a buffering effect. The significantly greater level of caregiving stress (i.e., subjective burden) experienced among the dementia group (CI) compared to their non-dementia (NCI) counterparts (see Objective 1) may account for these differential findings. Specifically, perception of greater support may affect dementia (CI) caregivers similarly since they all feel considerably burdened by the needs of their highly impaired spouses.

The buffering effect observed among non-dementia (NCI) caregivers indicated that when caregivers experienced high levels of stress caring for their spouses, they were at higher risk for poorer physical health outcomes. However, if they received emotional support from significant others, caregiving stress had less of a negative impact. This finding can be interpreted in the context of the lower level of emotional support that may be available from the care-recipient. In the absence of emotional support from a spouse, caregivers may be particularly vulnerable to the corrosive effects of caregiving stress (Dean & Lin, 1977). Emotional support from others may compensate to some extent for the stress of the caregiving situation and the loss of spousal emotional support (Li, Seltzer, & Greenberg, 1997). In fact, the specificity hypothesis of social support postulates that when specific dimensions or functions of social support match the needs elicited by the stressor, they are more likely to buffer the effects of that stressor (Cohen & Wills, 1985). Support that does not match the particular need of the caregiver during stress may not be highly valued and therefore will have little beneficial effects on health (Cohen & McKay, 1984; Krause, 1987).

Collectively, our findings are generally consistent with studies of the moderating effects of social support in the caregiving literature, which have identified non-uniform effects of social support that depend on different sources or different types of support at different points in the stress process (Bass et al., 1996; Franks & Stephens, 1996; Li et al., 1997).

Both theoretical models and empirical studies have suggested possible pathways through which support may exert its positive influence on physical health. For instance, social support may alter the harmful biological responses to stress by increasing immune functioning or decreasing neuroendocrine responsivity (Cohen, 1988; Uchino et al., 1992). Further, support may promote health by facilitating healthy behaviours, altering appraisals of stressors, or by changing coping patterns (Cohen, 1988; Cohen & Mckay, 1984; Cohen & Willis, 1985). Future research examining the possible mechanisms by which social support exerts its effect on physical health for persons under stress is needed.

The present findings should be interpreted with the following caveats in mind. Some researchers have argued that effects that have been attributable to social support may be partially or entirely due to personality factors, such as social competence, neuroticism, or mood dispositions, that are highly correlated with perceptions of support (Bolger & Eckenrode, 1991; Wethington & Kessler, 1986). Conceivably, socially competent people may be more capable of developing strong support networks and of staying healthy by effectively coping with stressful events (Cohen & Wills, 1985). Furthermore, there has been evidence suggesting that perceptions of support and self-rated health may be confounded with negative affectivity and neuroticism (Bolger & Eckenrode, 1991). These variables may lead to lower perceptions of social support and poorer ratings of physical health status through a negativity bias (Watson & Pennebaker, 1989). Neuroticism could also impact reporting of stress, thereby yielding spurious associations between stress and physical health (Schroeder & Costa, 1984). These findings have led researchers to suggest the existence of a possible “neurotic contamination” for key constructs in the stress paradigm (Watson & Pennebaker, 1989). Studies that include these potential confounding variables are needed to rule out rival explanations for social support effects.

Quality of the pre-illness relationship as the moderator variable

Results from dataset 1 did not find a stress buffering effect of quality of pre-illness relationship. In addition, prior relationship appraisals did not exert an independent effect on physical health. Ratings of the quality of the pre-illness relationship had a fairly restricted range, with the majority of caregivers in this study reporting positive relationship appraisals with their spouses. Such restricted variance may partially explain these null findings as the probability of finding significant associations among variables diminishes as variability decreases. Another plausible explanation for our null findings may be that the quality of the present relationship is more important than pre-illness relations in determining the caregiving experience. Some researchers have suggested that the quality of the current (rather than past) relationship between caregiver and care-recipient may have a stress buffering effect on health (Lawrence, Tennstedt, & Assmann, 1998; Yates, Tennstedt, & Chang, 1999). Specifically, the negative effects of caregiving stress may be attenuated when the caregiver has a positive relationship with the care recipient. This emotional closeness may act like a coping mechanism by providing a perspective through which the situation is appraised in a less stress-inducing manner (Lawrence et al., 1998). Unfortunately, these hypotheses could not be verified as no quantification of the current relationship quality was available.

Results from this study suggest that the quality of pre-illness relationship may not be a particularly important personal resource variable as it did not have beneficial effects on health. However, because our findings were based on a convenience sample of caregivers, they need to be replicated in a larger, more representative sample.

In sum, results from the present investigation provided evidence for both main and buffering effects of social support, and these relationships emerged even after controlling for potential confounds, such as caregiver gender and age. The model that was supported depended on the composition of the caregiver sample as well as the type and source of social support that was assessed. Increased personal resources in the form of positive pre-morbid relationship appraisals did not confer health benefits, either in the presence or absence of stress.

Objective 4: Analyses of change over time by transition group

In order to provide a broad picture of the dynamics of caregiving, information about the role of different transition periods (i.e., care-recipient death or institutionalization) on caregiver physical health and psychological outcomes was investigated. More specifically, the current study examined the comparative changes in physical and psychological health between caregivers who continued to provide in-home care and those who ceased providing care either due to the institutionalization or death of the care-recipient. The percentage of caregivers who were still providing in-home care at Time 2 was similar across datasets, with approximately 39% in dataset 1 and 35% in dataset 2. Comparable percentages were found for those who placed their spouses in long-term care by Time 2 (dataset 1: 26%; dataset 2: 21%), and for those whose care-recipients were deceased by follow-up (dataset 1: 36%; dataset 2: 44%).

Changes in physical and psychological health

Data from this study presented a mixed picture of health outcomes following cessation of spousal caregiving. Findings from dataset 1 indicated that caregivers who institutionalized their spouses were in better physical health than continuing in-home caregivers and caregivers whose spouses were deceased, however, there was no change over time noted. These results differed from those of dataset 2, which found differences between transition groups with respect to physical health trajectories. Specifically, for caregivers whose care-recipients had died, the relinquishment of the caregiver role indicated improved physical health, while declines in health were found among continuing in-home caregivers. However, changes in physical health did not differ between the institutional and continuing care groups. Discrepant findings across datasets may be attributed to differences in time between initial and follow-up assessments. Perhaps the 2 year interval between assessments in dataset 1 (compared to 5 years in dataset 2) was not long enough for differential changes in physical health to emerge. Nonetheless, findings from dataset 2 suggest that the death of the care-recipient can have beneficial effects on the physical health, while such effects were not observed among those who institutionalized their spouses.

With respect to psychological health, findings from dataset 1 indicated a trend for the mental health of caregivers who institutionalized their spouses to undergo a different development in comparison to those who continued to provide in-home care. In particular, the institutional group on average experienced declines in mental health in the years following the cessation of in-home caregiving, while slight improvements in health was observed among the continuing care group. However, contrary to predictions, no significant differing effects on mental health were observed among bereaved caregivers. Our finding that mental health deteriorated over time among those who institutionalized their care-recipients relative to those who continued to provide in-home care is in contrast to earlier work that found the opposite pattern of change (Bond et al., 2003). The different trajectories of mental health found in caregivers after the institutional placement of their spouse might in part be due to study differences in duration of institutionalization. Caregivers in the present study (dataset 1) yielded to institutional care for a longer period of time (18.0 months) compared to those in a study by Bond and others (2003; 13.8 months). Mental health of those in the latter study may have shown a downward trend had greater time elapsed since placing their spouse in long-term care.

While comparative changes were observed in general mental health, the present study failed to find changes in depressive symptoms in relation to transition experiences. Thus, relative changes in psychological health over time do not appear to be explained by depressive symptoms. Instead, these finding suggest that scales measuring a wider range of mental health symptoms may be more effective in detecting change and in differentiating among groups who experience changes than instruments that only assess depressive symptoms (Pot et al., 1997).

Results also indicated that the trajectory of change in physical and psychological health did not differ depending on caregiver type (dementia versus non-dementia). Therefore, the nature of care-recipient illness may not be important in conditioning the effects of caregiving transitions. However, the lack of power to detect higher order interactions could explain these null findings.

Changes in other stress process variables

Transition groups were also contrasted on changes in other stress process variables. Results indicated that the trajectory of changes in care-recipient cognitive functioning and frequency of disruptive behaviours were similar across transition groups. However, findings differed across datasets regarding comparative changes in care-recipient dependence in ADL. Dataset 1 did not find differential changes in dependence in basic and instrumental ADL. On the other hand, results from dataset 2 suggested that the institutional and deceased groups became more dependent in basic ADL over time compared to the continuing care group. A different pattern emerged for dependence in instrumental ADL; only care-recipients in the institutional group exhibited increased dependence over time compared to the relatively stable patterns observed among the continuing care group. Part of the discrepancy across datasets may be due differences in the reference point for assessing functional status. That is, in dataset 1, caregivers who ceased in-home care by follow-up were asked to assess the functional status of their care-recipients in the context of the year they were still providing in-home care. In dataset 2, caregivers were asked to rate the functional status of their spouse as of 3 months before cessation of in-home caregiving. Regardless of these different methods, findings with respect to changes in care-recipient functioning among the institutional and deceased groups should be interpreted with caution given that they may be influenced by recall biases.

Our findings also indicated that cessation of in-home caregiving did not have an impact on changes in the frequency of engaging in healthy behaviours, perceptions of social support, or levels of burden. Because changes in these variables were not dependent on transition group, they are not likely responsible for the differential changes observed for physical and mental health. However, results indicated that patterns of change in premorbid relationship appraisals varied by transition group. Ratings of the quality of the pre-illness relationship became more positive over time for the deceased group, while the opposite trend was observed for the continuing care group. These findings may suggest some idealization of the deceased, a grief reaction commonly observed among bereaved non-caregivers (Futterman, Gallagher, Thompson, Lovett, & Gilewski, 1990). Increasingly positive relationship appraisals among bereaved caregivers relative to those continuing to provide in-home care are compatible with findings regarding improvements in mental health for the latter group.

Differential changes in stress process variables that were not assessed in the present study may also account for the physical health improvements observed among those who transitioned into widowhood. For instance, improvements in physical health may stem from relief from the chronic worry and physical demands of providing ADL assistance. Furthermore, after the death of the care-recipient, caregivers have been found to experience an increased sense of mastery, and such changes may promote health improvement (Skaff, Pearlin, & Mullan, 1996).

There may be several factors that explain the declines in mental health observed among those who placed their spouses in long-term care relative to continuing in-home caregivers. Caregivers who institutionalize their care-recipients may shift their responsibilities rather than completely exit the caregiving role. Instead of having to provide daily hands-on care, caregivers often visit their relative at the long-term care facility, as well as handle other care arrangements, such as ensuring quality of care in the institutional setting (Zarit & Whitlatch, 1992). From this viewpoint, the consequences of placement will depend on how institutionalization changes the caregiver's situation. To the extent caregivers remain involved with their spouses, they will continue to have other concerns (Zarit & Whitlach, 1992). Indeed, some researchers have speculated that those who placed their spouses in long term care may have a sense that their life is on hold despite fewer demands on their time (Skaff et al., 1996).

Collectively, our findings indicated that the physical and mental health trajectories of caregivers who continued to provide in-home care at follow-up differed from those of caregivers who experienced transition phases by the end of the study period. Specifically, those who were bereaved by follow-up experienced greater improvements in physical health compared to caregivers who were still providing residential care. In addition, the mental health of those who experienced the termination of the caregiving role through institutional placement deteriorated over time.

In the present study, health trajectories of caregivers who experienced transitions (i.e., long-term care placement and bereavement) were contrasted with those who did not undergo such transitions (i.e., continuing in-home caregivers). Future studies would be strengthened by the inclusion of a control group of non-caregivers. These individuals could serve as a reference group to determine if changes observed among former caregivers are clinically meaningful (i.e., return to levels comparable to those of non-caregivers after caregiving had ceased).

Some caveats are necessary concerning findings of this objective. Once the caregivers were classified into the three transition groups, the sample sizes became quite small. Low statistical power and large random sampling errors due to small sample size suggest that the present findings should be viewed with caution. The modest number of participants also precluded the ability to control for gender as a covariate. Larger samples are clearly needed to assure adequate power to detect statistical significance and provide opportunities for modeling covariates. Another limitation involves using only two time points to analyze change. Such an approach assumes linear development over time, which may not accurately capture the dynamics of caregiver health. Moreover, the aggregate change scores in two-wave designs often mask a considerable amount of individual variability (i.e., intra-individual change). In light of this shortcoming, future studies should conduct multiple assessments over time, and consider using statistical techniques, such as latent growth curve modeling (LGM), to test longitudinal trends from both inter-individual and intra-individual perspectives (see Gaugler, Kane, Kane, & Newcomer, 2005; Roth, Haley, Owen, Clay, & Goode, 2001, for application of LGM in caregiving research).

General study limitations

Other notable limitations to the present study centre on the sample composition, methods used to allocate caregivers into subgroups, as well as measurement of study variables. First, to ensure homogeneity of the study sample, only spouses of care-recipients were included. As a consequence, results cannot be generalized to caregivers who have some other relation with the care-recipient. Because spouses account for most of the caregivers of elderly persons with cognitive or physical impairments (Stone et al., 1987), this design feature does not severely limit generalizability of our findings. Furthermore, we were able to control for potential selection biases and variations due to kin relations by including only spouse caregivers. It is unlikely that selection into the caregiver role is a random process within the family; personality characteristics, for instance, may determine who takes on such a role (Anthony-Bergstone, Zarit, & Gatz, 1988). However, this type of selection bias is not likely to occur among spouse caregivers as many studies have documented that it is very unusual for a surviving spouse not to take on the caregiving role (e.g., Lawton, Brody, & Saperstein, 1989; Zarit, Birkel, & Malone Beach, 1989). The present study is also limited by the use of self-report measures, a practice that is common in caregiving research (e.g., Acton, 2002; Beach et al., 2000). Care-recipient functioning was also based solely on caregiver reports as there was no objective or corroborating assessments of care-recipient impairments.

Consequently, our findings partly reflect the shared method variance of caregiver perceptions regarding themselves and the persons for whom they care.

Because one of the goals of the present study was to compare the caregiving experience of dementia caregivers versus non-dementia caregivers, caregivers were separated based on the nature of their care-recipient's illness. The accuracy to which this subdivision was achieved varied across datasets. In dataset 1, group allocation was based on the caregiver's report of their spouse's diagnosis; unfortunately, however, medical records were not obtained to confirm these reports. We are more confident that individuals in dataset 2 actually had dementia as a more thorough procedure (i.e., consensus diagnosis by interdisciplinary teams) was used to differentiate between care-recipients with dementia and those with non-dementia. In dataset 3, less precise methods were used to separate groups. The main differentiating factors were presence or absence of AD, senility, or cognitive impairment based on a MMSE cut-off score. Therefore, we can not be certain that all individuals in the dementia (CI) group actually suffered from this disease. That is, some participants may have been cognitively impaired (based on their MMSE score) but not have a diagnosis of dementia. Nonetheless, the inclusive definition of dementia used in database 3 is likely to dilute rather than exaggerate differences between dementia and non-dementia caregivers. In addition, care-recipients in the dementia (CI) group exhibited greater functional impairments and disruptive behaviours than those in the non-dementia (NCI) group, findings that were consistent with those reported in datasets 1 and 2.

Clinical and research implications

Results from the current study have several practical implications. The finding that caregivers are more psychologically compromised than their non-caregiving counterparts should be a concern, not only for their well-being but also for that of their care-recipients. Poor caregiver psychological health may negatively influence the adequacy of care provided or the decision to seek long-term care placement for the care-recipient. Therefore, it may be worthwhile for caregivers to participate in psychotherapy or psychoeducational groups to reduce depression and promote general mental well-being (Gallagher-Thompson et al., 2000; Teri, Logsdon, Uomoto, & McCurry, 1997). Improving health behaviours is another potential focus for intervention given the finding that caregivers engage in fewer health promoting practices than non-caregivers.

Because results of the current study suggest that the negative psychological effects of caregiving are not homogenous across dementia and non-dementia caregivers, interventions should be tailored to these subgroups. In particular, educational interventions are needed to help dementia caregivers effectively manage and cope with care-recipient disruptive behaviours. Furthermore, providing formal or informal assistance to caregivers with ADL tasks may lessen the burden associated with these care demands (Schulz & Martire, 2004). Interventions aimed at alleviating caregiving stress may ultimate result in improved psychological health for dementia caregivers.

The findings of health benefits of perceived social support also have practical ramifications. Perceived support may be enhanced through individual counseling to develop skills to elicit desired emotional support from significant others, as well as strategies to re-evaluate their appraisals of support (Yates et al., 1999). Caregivers with low perceived family support may present a challenge for intervention efforts. Missing or non-supportive family members are not substitutable, which suggest that companionship programs for caregivers that increase peer contact still may be unable to compensate for absent family support (Thompson & Heller, 1990). Methods to strengthen the supportiveness of existing ties rather than focusing exclusively on building new ones should be considered. For example, one strategy for individuals already embedded in family networks but who lack family support would be to address the support-skill inadequacies of caregivers as well as their family members that prevent effective support seeking and provision (Thompson & Heller, 1990). These intervention strategies may be especially useful for non-dementia caregivers experiencing high levels of caregiving stress given the finding of a stress-buffering effect of support among this subgroup.

Results of the current study suggest that interventions should not only target caregivers of community-dwelling care-recipients, but also caregivers who have yielded to long-term care. That is, interventions should be developed to aid caregivers through the various transitions in their career (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Long-term care staff could become involved in monitoring the psychological health of these caregivers, and support groups similar to those that exist for caregivers in the community could be developed for caregivers of those in institutional settings (RIS MRC CFAS, 2000).

There are several implications from the present study for caregiving research and theory. On the basis of our findings, we recommend that future studies separate groups based on the nature of their care-recipients' illness when analyzing the psychological health effects of caregiving. Similarly, our results suggest that it may not be appropriate to generalize findings from studies of dementia caregivers to non-dementia caregivers.

Furthermore, results of the current study highlight the complexity of social support in the context of caregiving stress. In particular, our findings raise the need to use measures that separate the functions that the support is aiming to provide, as well as to consider the source and recipient of that support when examining its stress-buffering effects. Elaborate theoretical models that include associations between various types of caregiving stressors, diverse functions and sources of support, and their interactions are needed to advance our knowledge about the relationships between caregiving stress, social support, and health outcomes. Because our understanding of the stress process generally applies to the study of caregiving, and vice versa (Pearlin et al., 1990), results of the present study will not only inform caregiving research, but will also contribute to the general stress literature.

Overall summary of present research

The present study endeavored to gain a better understanding of the complex stress process of caregiving. Our findings have highlighted several issues, many of which warrant additional investigation. Results concerning differences between caregivers and non-caregivers led us to conclude that caregiving has a detrimental impact on perceived peer support and the frequency of engaging in healthy behaviours. Such negative effects may have contributed to the poorer psychological health observed among caregiver relative to their non-caregiving counterparts. Findings from the current study also suggested that being a dementia caregiver is an additional risk factor for poorer psychological outcomes by virtue of the greater levels of caregiver burden stemming from increased exposure to caregiving stressors in comparison to non-dementia caregivers. We also tested specific elements of Martire and Schulz's (2001) stress process model, and found that associations between caregiving stressors, in the form of care-recipient impairments, and physical health were unlikely to be mediated through changes in health promoting practices. With regard to moderating effects of personal and social resources, our data suggested that positive pre-illness relationship appraisals did not confer health benefits, either in the presence or absence of stress. The influence of social support on health was more complex. The stress-buffering effect of social support depended on the composition of the caregiver sample as well as the type of social support that was considered. Finally, we examined changes in caregiver health in the context of transitions in the caregiving career. Our results demonstrated that transitioning into widowhood was accompanied by improvements in physical health, while institutional placement of the care-recipient was associated with declines in mental health. The current findings offer new insight into the physical and psychological well-being of both caregivers and those in the process of disengaging from the caregiving role, and as such, may provide substantive contributions to the general stress literature. Furthermore, results from the present study highlight important caregiver intervention and research strategies.

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Appendix A

Consent Form (Verbal)

The following information will be read over the telephone and informed consent will be obtained verbally:

You have received an explanation about the nature of the study, its purpose and procedures, and you consent to participate.

You understand the following:

1. You can withdraw from the study at any time without affecting the type and quality of services that you or your spouse may receive.
2. The information collected will be confidential and only used for the stated research purposes. It will be stored for seven years in a secure filing cabinet in the Psychology Department at Lakehead University.
3. There are no known physical risks associated with participating in this study
4. You may experience psychological discomfort from some of the questions. However, should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling.
5. You also have the right to refrain from answering whatever questions you prefer to omit
6. The telephone interview will require approximately 1 hour of your time
7. The benefits of participating include being part of research that could advance knowledge about the effects of caregiving.
8. When the study is completed, you will be able to receive a summary of the research findings by contacting the principal investigator.

Do you understand and agree with the aforementioned information?

Appendix B

Consent Form (Written)

I have received an explanation about the nature of the study, its purpose and procedures, and I consent to participate.

I understand the following:

1. I can withdraw from the study at any time without affecting the type and quality of services that my spouse or I may receive.
2. The information collected will be confidential and only used for the stated research purposes. It will be stored for seven years in a secure filing cabinet in the Psychology Department at Lakehead University.
3. There are no known physical risks associated with participating in this study
4. I may experience psychological discomfort from some of the questions. However, should this arise, I may inform the researcher who can refer me to the appropriate resources for counseling.
5. I also have the right to refrain from answering whatever questions I prefer to omit
6. The telephone interview will require approximately 1 hour of my time
7. The benefits of participating include being part of research that could advance knowledge about the effects of caregiving.
8. When the study is completed, I will be able to receive a summary of the research findings by contacting the principal investigator.

My signature indicates that I understand and agree with the aforementioned information.

______________________________	______________________________
Signature	Print Name

Please send this completed form in the enclosed, self-addressed envelop:
Mun Tran
Department of Psychology, Lakehead University
955 Oliver Road
Thunder Bay, ON
P7B 5E1

Appendix C

Cover Letter for Dementia Group

Dear ________________,

Thank you for volunteering to participate in an investigation concerning caregiver health. This study is a follow-up to the one you took part in some time ago, entitled "Spouse caregiving and health: Urban and rural realities."

As mentioned to you during our phone conversation, the purpose of the study is to investigate the influence of caregiving on a broad range of pertinent issues, such as caregiver psychological and physical health, and social functioning.

The assessment will consist of a telephone interview using same questionnaires that you completed in the previous study, and it will take approximately 1hour to complete. The interview will explore the issues of caregiving described above. Enclosed, please find a copy of the questionnaires that you will be completing over the phone with me. As per our earlier conversation, I will be phoning you on __________ at _________ to conduct the interview.

There are no known physical risks associated with participating in this study. However, you may experience psychological discomfort from some of the questions. Should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling. Furthermore, you have the right to refrain from answering whatever questions you prefer to omit without penalty. I would also like to re-iterate that your participation is voluntary and you may terminate your participation at any time, without compromising the quality of services you and your spouse may receive.

The information you provide will be kept strictly confidential. There will be no disclosure of the data to anyone other than the researchers conducting the study. In any scientific publication or presentation, your name will not be used. The data that is recorded will be stored in a secure filing cabinet in the Psychology Department at Lakehead University for a period of seven years as stipulated by ethics guidelines.

After the study has been completed, you can receive a copy of the findings by contacting Dr. Michel Bédard (contact information listed below). We may need to contact you in the future for a follow-up, but your name and contact information will be kept in a list that is separate from the answers you give on the interview.

Thank you again for your continued cooperation.

Sincerely,

Mun Tran, PhD Candidate
mhtran@lakeheadu.ca
(807) 476-7234

Dr. Michel Bédard, Associate Professor
michel.bedard@lakeheadu.ca
(807) 343-8630

Appendix D

Recruitment Letter (Non-Dementia Group)

CAREGIVERS NEEDED TO PARTICIPATE IN RESEARCH:

Are you aged 65 years or older and providing care to a spouse with a chronic illness requiring assistance with activities of daily living (e.g., dressing, walking)?

I am a Ph.D. student in Clinical Psychology at Lakehead University conducting a study entitled "Caregiver Health" under the supervision of Dr. Michel Bédard. We are interested in examining the health status of you and the person you are caring for, different activities of your daily life, and any difficulties you may have caring for your spouse. The important information gained from this study will help guide the development of interventions for caregivers. Moreover, research in this area will further contribute to the understanding of the complex relationship between chronic stressors and physical illness. Through your participation in this study, you will help to address these issues.

Participation in the study involves completing a few brief questionnaires over the telephone. The interview, which will take approximately 1 hour, will explore the issues of caregiving described above. A research assistant will contact you and arrange a mutually convenient time to complete the questionnaires over the telephone. A copy of the questionnaire will be mailed to you prior to the interview.

There are no known physical risks associated with participating in this study. However, you may experience psychological discomfort from some of the questions. Should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling. Furthermore, you have the right to refrain from answering whatever questions you prefer to omit without penalty. Your contributions will remain completely anonymous and confidential. Only the researchers will have access to the data that you provide. No individual will be identified in any report of the results. The data will be stored in a secure filing cabinet in the Psychology Department at Lakehead University for a period of 7 years as required by ethics guidelines.

Your participation in the study is completely voluntary and you may withdrawal at any time without any negative repercussions (e.g., without affecting the quality of services you and your family member may receive). When the study has been completed, you may obtain a copy of the final results by contacting Dr. Michel Bédard.

If you are interested in participating, or would like to receive more information about the study, please do not hesitate to contact the investigators listed below. Thank you for your cooperation.

Sincerely,

Mun Tran, PhD Candidate	Dr. Michel Bédard, Associate Professor
mhtran@lakeheadu.ca	michel.bedard@lakeheadu.ca
(807) 476-7234	(807) 343-8630

Appendix E

Recruitment Letter (Non-Caregivers)

PARTICIPANTS NEEDED FOR RESEARCH STUDY:

Are you aged 65 years or older and living with your spouse?

I am a Ph.D. student in Clinical Psychology at Lakehead University conducting a study entitled "Caregiver Health" under the supervision of Dr. Michel Bédard. We are interested in comparing the experiences of caregivers with non-caregivers. Some of the areas we would like to explore include different activities of daily life, health, and social relationships. The important information gained from this study may benefit older adults in the future.

Participation in the study involves completing a few brief questionnaires over the telephone. The interview, which will take approximately 1 hour, will explore the issues described above. A research assistant will contact you and arrange a mutually convenient time to complete the questionnaires over the telephone. A copy of the questionnaire will be mailed to you prior to the interview.

There are no known physical risks associated with participating in this study. However, you may experience psychological discomfort from some of the questions. Should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling. Furthermore, you have the right to refrain from answering whatever questions you prefer to omit without penalty. Your contributions will remain completely anonymous and confidential. Only the researchers will have access to the data that you provide. No individual will be identified in any report of the results. The data will be stored in a secure filing cabinet in the Psychology Department at Lakehead University for a period of 7 years as required by ethics guidelines.

Your participation in the study is completely voluntary and you may withdrawal at any time without any negative repercussions (e.g., without affecting the quality of services you and your family member may receive). When the study has been completed, you may obtain a copy of the final results by contacting Dr. Michel Bédard.

If you are interested in participating, or would like to receive more information about the study, please do not hesitate to contact the investigators listed below. Thank you for your cooperation.

Sincerely,

Mun Tran, PhD Candidate	Dr. Michel Bédard, Associate Professor
mhtran@lakeheadu.ca	michel.bedard@lakeheadu.ca
(807) 476-7234	(807) 343-8630

Appendix F

Cover Letter for Non-Caregivers

Dear _________________,

Thank you for volunteering to participate in an investigation comparing the experiences of caregivers with non-caregivers.

As mentioned to you in the previous letter you received (and/or during our phone conversation), some areas we would like to explore include different activities of daily life, health, and social relationships.

The assessment will consist of a telephone interview using questionnaires, and it will take approximately 1hour to complete. The interview will explore the issues described above. Enclosed, please find a copy of the questionnaires that you will be completing over the phone with me. As per our earlier conversation, I will be phoning you on __________ at ________ to conduct the interview.

There are no known physical risks associated with participating in this study. However, you may experience psychological discomfort from some of the questions. Should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling. Furthermore, you have the right to refrain from answering whatever questions you prefer to omit without penalty. I would like to re-iterate that your participation is voluntary and you may terminate your participation at any time, without compromising the quality of services you and your spouse may receive.

The information you provide will be kept strictly confidential. There will be no disclosure of the data to anyone other than the researchers conducting the study. In any scientific publication or presentation, your name will not be used. The data that is recorded will be stored in a secure filing cabinet in the Psychology Department at Lakehead University for a period of seven years as stipulated by ethics guidelines.

After the study has been completed, you can receive a copy of the findings by contacting Dr. Michel Bédard (contact information listed below). We may need to contact you in the future for a follow-up, but your name and contact information will be kept in a list that is separate from the answers you give on the interview.

Thank you again for agreeing to participate.

Sincerely,

Mun Tran, PhD Candidate	Dr. Michel Bédard, Associate Professor
mhtran@lakeheadu.ca	michel.bedard@lakeheadu.ca
(807) 476-7234	(807) 343-8630

Appendix G

Cover Letter for Non-Dementia Group

Dear ___________________,

Thank you for volunteering to participate in an investigation concerning caregiver health.

As mentioned to you in the previous letter you received (and/or during our phone conversation), the purpose of the study is to investigate the influence of caregiving on a broad range of pertinent issues, such as caregiver psychological and physical health, and social functioning.

The assessment will consist of a telephone interview using questionnaires, and it will take approximately 1hour to complete. The interview will explore the issues of caregiving described above. Enclosed, please find a copy of the questionnaires that you will be completing over the phone with me. As per our earlier conversation, I will be phoning you on ___________ at _________ to conduct the interview.

There are no known physical risks associated with participating in this study. However, you may experience psychological discomfort from some of the questions. Should this arise, you may inform the researcher who can refer you to the appropriate resources for counseling. Furthermore, you have the right to refrain from answering whatever questions you prefer to omit without penalty. I would also like to re-iterate that your participation is voluntary and you may terminate your participation at any time, without compromising the quality of services you and your spouse may receive.

The information you provide will be kept strictly confidential. There will be no disclosure of the data to anyone other than the researchers conducting the study. In any scientific publication or presentation, your name will not be used. The data that is recorded will be stored in a secure filing cabinet in the Psychology Department at Lakehead University for a period of seven years as stipulated by ethics guidelines. This project has been approved by the Board Ethics Committee of St. Joseph's Care Group. Should you have any questions regarding the ethical protocol, please contact the Committee Chair, Susan Gerschwender at (807) 343-2450.

After the study has been completed, you can receive a copy of the findings by contacting Dr. Michel Bédard (contact information listed below). We may need to contact you in the future for a follow-up, but your name and contact information will be kept in a list that is separate from the answers you give on the interview.

Thank you again for agreeing to participate.

Sincerely,

Mun Tran, PhD Candidate
mhtran@lakeheadu.ca
(807) 476-7234

Dr. Michel Bédard, Associate Professor
michel.bedard@lakeheadu.ca
(807) 343-8630

Appendix H – Part A

Demographics and Service Use.

1. What is your date of birth (caregiver)?
   ____________________ (dd/mm/yyyy)

2. What is his/her date of birth (care-recipient)?
   ______________________ (dd/mm/yyyy)

3. Please indicate your sex (caregiver):
   ______1 Male
   ______2 Female

4. How long have you been caring for the care recipient? (in years or months)
   ____

5. How often do you make use of respite or home care services?
   _____1 Three or more times a week
   _____2 Once or twice a week
   _____3 Less than once a week
   _____4 Not during the past month

6. On average, how many hours a week do you receive help (from both formal and informal sources) caring for your spouse?
   _____________________ Hours

Appendix H - Part B

Caregiver Physical and Mental Health Status

Short Form-12 Health Survey (SF-12)

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

1. In general, would you say your health is:

______1 Excellent
______2 Very Good
______3 Good
______4 Fair
______5 Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	______1	______2	______3
3. Climbing several flights of stairs	______1	______2	______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 your physical health?

	Yes	No
4. Accomplished less than you would like	______1	______2
5. Were limited in the kind of work or other activities	______1	______2

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 any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like	______1	______2
7. Didn't do work or other activities as carefully as usual	______1	______2

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

______1	______2	______3	______4	______5
Not at All	A Little Bit	Moderately	Quite A Bit	Extremely

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 –

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time

9. Have you felt calm and peaceful? ______1 ______2 ______3 ______4 ______5 ______6

10. Did you have a lot of energy ______1 ______2 ______3 ______4 ______5 ______6

11. Have you felt downhearted and blue ______1 ______2 ______3 ______4 ______5 ______6

12. 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	______2	______3	______4	______5
All of the time	Most of the time	Some of the time	A little of the time	None of the time

Appendix H - Part C

Caregiver Depression.

The Centre for Epidemiologic Studies – Depression Scale (CES-D)

Below is a list of the ways you might have felt or behaved. Please indicate how often you have felt this way during the past week.

Frequency ratings:
0 = Rarely or none of the time (less than 1 day)
1 = Some or a little of the time (1 – 2 days)
2 = Occasionally or a moderate amount of time (3 – 4 days)
3 = Most or all of the time (5 – 7 days)

	FREQUENCY			
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating; my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help	0	1	2	3
4. I felt that I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3

13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3
18. I felt sad	0	1	2	3
19. I felt that other people dislike me	0	1	2	3
20. I could not get "going"	0	1	2	3

Appendix H - Part D

Caregiver Burden.

Short Zarit Burden Interview (S-ZBI)

The following is a list of statements which reflects how some people feel about taking care of another person. After each statement, please circle the number that best reflects how often you feel this way. The numbers correspond to the following scale:

Frequency ratings: 0 = Never
1 = Rarely (Not in past week)
2 = Sometimes (1 or 2 times in past week)
3 = Frequently (3 to 6 times in past week)
4 = Nearly always (daily)

How often do you feel....			FREQUENCY		
1. That because of the time you spend with your relative, you don't have enough time to yourself?	0	1	2	3	4
2. Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3. Angry when you are around your relative?	0	1	2	3	4
4. That your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5. Strained when you are around your relative?	0	1	2	3	4
6. Your health has suffered because of your involvement with your relative?	0	1	2	3	4
7. You don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8. Your social life has suffered because you are caring for your relative?	0	1	2	3	4
9. You have lost control of your life since your relative's illness?	0	1	2	3	4

10. Uncertain about what to do concerning your relative?	0	1	2	3	4
11. You should be doing more for your relative?	0	1	2	3	4
12. You could do a better job in caring for your relative?	0	1	2	3	4

Appendix H - Part E

Caregiver Perceived Social Support.

The Perceived Social Support - Family Scale (PSS-FA)

The following statements refer to feelings and experiences that occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, or Don't know. Please circle the answer you choose for each item.

1. My family gives me the moral support I need	Yes	No	Don't know
2. I get good ideas about how to do things or make things from my family	Yes	No	Don't know
3. Most other people are closer to their family than I am	Yes	No	Don't know
4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable	Yes	No	Don't know
5. My family enjoys hearing what I think	Yes	No	Don't know
6. Members of my family share many of my interests	Yes	No	Don't know
7. Certain members of my family come to me when they have problems or need advice	Yes	No	Don't know
8. I rely on my family for emotional support	Yes	No	Don't know
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later	Yes	No	Don't know
10. My family and I are very open about what we think	Yes	No	Don't kno

about things

11. My family is sensitive to my personal needs	Yes	No	Don't know
12. Members of my family come to me for emotional support	Yes	No	Don't know
13. Members of my family are good at helping me solve problems	Yes	No	Don't know
14. I have a deep sharing relationship with a number of members of my family	Yes	No	Don't know
15. Members of my family get good ideas about how to do things or make things from me	Yes	No	Don't know
16. When I confide in members of my family, it makes me uncomfortable	Yes	No	Don't know
17. Members of my family seek me out for companionship	Yes	No	Don't know
18. I think that my family feels that I'm good at helping them solve problems	Yes	No	Don't know
19. I don't have a relationship with a member of my family that is as close as other people's relationship with family members	Yes	No	Don't know
20. I wish my family were much different	Yes	No	Don't know

The Perceived Social Support – Friends Scale (PSS-FR)

The following statements refer to feelings and experiences that occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, or Don't know. Please circle the answer you choose for each item.

1. My friends give me the moral support I need	Yes	No	Don't know
2. Most other people are closer to their friends than I am	Yes	No	Don't know
3. My friends enjoy hearing what I think	Yes	No	Don't know
4. Certain friends come to me when they have problems or need advice	Yes	No	Don't know
5. I rely on my friends for emotional support	Yes	No	Don't know
6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself	Yes	No	Don't know
7. I feel that I'm on the fringe in my circle of friends	Yes	No	Don't know
8. There is a friend I could go to if I were just feeling down, without feeling funny about it later	Yes	No	Don't know
9. My friends and I are very open about what we think about things.	Yes	No	Don't know
10. My friends are sensitive to my personal needs	Yes	No	Don't know
11. My friends come to me for emotional support	Yes	No	Don't know
12. My friends are good at helping me solve problems	Yes	No	Don't know

13. I have a deep sharing relationship with a number of my friends	Yes	No	Don't know
14. My friends get good ideas about how to do things or make things from me	Yes	No	Don't know
15. When I confide in friends, it makes me uncomfortable	Yes	No	Don't know
16. My friends seek me out for companionship	Yes	No	Don't know
17. I think that my friends feel that I'm good at helping them solve problems	Yes	No	Don't know
18. I don't have a relationship with a friend that is as intimate as other people's relationship with friends	Yes	No	Don't know
19. I recently got a good idea about how to do something from a friend	Yes	No	Don't know
20. I wish my friends were much different	Yes	No	Don't know

Appendix H - Part F

Caregiver Health Behaviours.

Health-Promoting Lifestyle Profile (HPLP)

This questionnaire contains statements about your present way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behaviour by circling the appropriate number.

Frequency ratings:
1 = Never
2 = Sometimes
3 = Often
4 = Routinely

	FREQUENCY			
1. Choose a diet low in fat, saturated fat, and cholesterol	1	2	3	4
2. Report any unusual signs or symptoms to a physician or other health professional	1	2	3	4
3. Follow a planned exercise program	1	2	3	4
4. Get enough sleep	1	2	3	4
5. Feel I am growing and changing in positive ways	1	2	3	4
6. Limit use of sugars and foods containing sugar (sweets)	1	2	3	4
7. Read or watch T.V. programs about improving health	1	2	3	4
8. Exercise vigorously for 20 or more minutes at least three times a week (such as briskwalking, bicycling, aerobic dancing, using a stair climber)	1	2	3	4

9. Take some time for relaxation each day	1	2	3	4
10. Believe that my life has purpose	1	2	3	4
11. Eat 6-11 servings of bread, cereal, rice, and pasta each day	1	2	3	4
12. Question health professionals in order to understand their instructions	1	2	3	4
13. Take part in light to moderate physical activity (such as sustained walking 30-40 minutes 5 or more times a week)	1	2	3	4
14. Accept those things in my life for which I can not change	1	2	3	4
15. Look forward to the future	1	2	3	4
16. Eat 2-4 servings of fruit each day	1	2	3	4
17. Get a second opinion when I question my health care provider's advice	1	2	3	4
18. Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling)	1	2	3	4
19. Feel content and at peace with myself	1	2	3	4
20. Eat 3-5 servings of vegetable each day	1	2	3	4
21. Discuss my health concerns with health professionals	1	2	3	4
22. Do stretching exercises at least 3 times per week	1	2	3	4

23. Use specific methods to control my stress	1	2	3	4
24. Work toward long-term goals in my life	1	2	3	4
25. Eat 2-3 servings of milk, yogurt, or cheese each day	1	2	3	4
26. Inspect my body at least monthly for physical changes/ danger signs	1	2	3	4
27. Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking	1	2	3	4
28. Balance time between work and play	1	2	3	4
29. Find each day interesting and challenging	1	2	3	4
30. Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nut each day	1	2	3	4
31. Ask for information from health professionals about how to take good care of myself	1	2	3	4
32. Check my pulse rate when exercising	1	2	3	4
33. Practice relaxation or meditation for 15-20 minutes daily	1	2	3	4
34. Am aware of what is important to me in life	1	2	3	4

35. Read labels to identify nutrients, fats, and sodium content in packaged food	1	2	3	4
36. Attend to educational programs on personal health care	1	2	3	4
37. Reach my target heart rate when exercising	1	2	3	4
38. Pace myself to prevent tiredness	1	2	3	4
39. Feel connected with some force greater than myself	1	2	3	4
40. Eat breakfast	1	2	3	4
41. Seek guidance or counseling when necessary	1	2	3	4
42. Expose myself to new experiences and challenges	1	2	3	4

Appendix H - Part G

Quality of the Pre-morbid Relationship.

Social Interaction Scale (SIS)

Before the onset of your spouse's illness, did you:

	Much of the time	Sometimes	Never
1. Laugh and joke together	______0	______1	______2
2. Feel cross or angry with your spouse	______0	______1	______2
3. Feel he/she was possessive	______0	______1	______2
4. Feel he/she interfered too much (in your life, family affairs, household, etc)	______0	______1	______2
5. Feel any tension or strain in the relationship	______0	______1	______2
6. Have upsetting disagreements or arguments, or find yourselves not speaking	______0	______1	______2

Appendix H - Part H

Care-recipient Dependence in ADL.

Lawton and Brody ADL Scale

With regard to the following functions, which of the given statements best describes how your relative has functioned in the last week? Please check the appropriate response.

1. TOILETING He/She:
   - _____$_1$ Soils or wets while awake more than once a week
   - _____$_2$ Soils or wets while asleep more than once a week
   - _____$_3$ Needs to be reminded or given help in cleaning self or has rare accidents (weekly at most)
   - _____$_4$ Cares for self at toilet completely with no incontinence

2. FEEDING He/She:
   - _____$_1$ Does not feed self at all and resists efforts of others to feed him/her
   - _____$_2$ Requires extensive assistance at all meals
   - _____$_3$ Feeds self with moderate assistance and is untidy
   - _____$_4$ Eats with minor assistance at meal times and/or with special preparation of food, or helps with cleaning up after meals
   - _____$_5$ Eats without assistance

3. DRESSING He/She:
   - _____$_1$ Is completely unable to dress self and resists efforts of others to help
   - _____$_2$ Needs major assistance in dressing, but cooperates with efforts of others to help
   - _____$_3$ Needs moderate assistance in dressing or selection of clothes
   - _____$_4$ Dresses and undresses self with minor assistance
   - _____$_5$ Dresses, undresses and selects clothing from own wardrobe

4. GROOMING He/She:
   - _____$_1$ Actively resists or negates all efforts of others to maintain grooming
   - _____$_2$ Needs total grooming care, but can remain well groomed after help from others
   - _____$_3$ Needs moderate and regular assistance or supervision in grooming
   - _____$_4$ Grooms self adequately with occasional minor assistance (e.g., shaving)
   - _____$_5$ Is always neatly dressed, well-groomed, without assistance

5. WALKING He/She:
   - _____$_1$ Is bedridden more than half the time
   - _____$_2$ Sits unsupported in a chair or wheelchair, but cannot propel self

without help
____3 Walks with assistance of another person, or railing, or cane or walker or wheelchair. Needs help getting in and out of the house
____4 Walks within residence or about one block distance
____5 Goes about grounds or city

6. BATHING He/She:
____1 Cannot or will not try to wash self, and resists efforts to keep him/her clean
____2 Cannot or will not wash self, but is cooperative with those who bathe him/her
____3 Washes face and hands only, needs help with rest of body
____4 Bathes self with help getting in and out of tub
____5 Bathes self (tap, shower, sponge bath) without help

7. USING THE PHONE He/She:
____1 Does not use the phone at all
____2 Answers the telephone, but does not dial
____3 Dials a few well-known numbers
____4 Operates the telephone on own initiative, looks up and dials numbers, etc.

8. SHOPPING He/She:
____1 Is completely unable to shop
____2 Needs to be accompanied on any shopping trip
____3 Shops independently for small purchases
____4 Takes care of all shopping needs independently
____5 Does not apply – has never done this

9. FOOD PREPARATION He/She:
____1 Needs to have meals prepared and served
____2 Heats and serves prepared meals, or prepares meals but does not maintain adequate diet
____3 Prepares adequate meals if supplied with ingredients
____4 Plans, prepares and serves adequate meals independently
____5 Does not apply – has never done this

10. HOUSEKEEPING He/She:
____1 Does not participate in any housekeeping tasks
____2 Needs help with all home maintenance tasks
____3 Performs light daily tasks but cannot maintain an acceptable level of Cleanliness
____4 Performs light daily tasks, such as dishwashing and bed making.
____5 Maintains the house alone, or with occasional assistance, e.g., "heavy work-domestic help"
____6 Does not apply – has never done this

11. LAUNDRY He/She:
____1 Needs all laundry to be done by others
____2 Launders small items – rinses socks, stockings, etc.
____3 Does personal laundry completely
____4 Does not apply – has never done this

12. TRANSPORTATION He/She:
____1 Does not travel at all
____2 Has travel limited to taxi or automobile with assistance of another
____3 Travels on public transportation assisted or accompanied by another
____4 Arranges own travel via taxi, but does not otherwise use public transportation
____5 Travels independently on public transportation or drives own car

13. RESPONSIBILTIY FOR MEDICATION He/She:
____1 Is not capable of dispensing own medications
____2 Takes responsibility if medication is prepared in advance in separate dosages
____3 Is responsible for taking medication in correct dosage at correct time

14. ABILITY TO HANDLE FINANCES He/She:
____1 Is not capable of handling money
____2 Manages day-to-day purchases, but needs help with banking, major purchases, etc.
____3 Manages financial matters independently (budgets, writes cheques, pays rent and bills, goes to bank), collects and keeps track of income

Appendix HHH - Part I

Care-recipient Disruptive Behaviours.

Cohen-Mansfield Agitation Inventory for Relatives (CMAI-R)

We would like to ask about specific behaviours. We listed behaviours that are sometimes associated with elderly persons; they are arranged from physical to verbal and from benign to aggressive. We do not expect that all these behaviours will apply to your relative. Read each of the behaviours, and circle how often (from 1 – 7) each applied to your relative over the last 2 weeks.

Frequency ratings:
0 – Never
1 – Less than once a week
2 – Once or twice a week
3 – Several times a week
4 – Once or twice a day
5 – Several times a day
6 – Several times an hour

	FREQUENCY						
1. General restlessness, fidgeting, always moving around	0	1	2	3	4	5	6
2. Performing repetitious mannerisms (tapping, rocking, rubbing)	0	1	2	3	4	5	6
3. Pacing, aimless wandering, constantly walking back and forth (including wandering while in wheelchair)	0	1	2	3	4	5	6
4. Trying to get to a different place (sneaking out of room, out of the house, off property)	0	1	2	3	4	5	6
5. Handling things inappropriately (rummaging through drawers, moving furniture)	0	1	2	3	4	5	6
6. Hiding or hoarding things	0	1	2	3	4	5	6
7. Grabbing things from others	0	1	2	3	4	5	6

(food from other's plate)							
8. Tearing things or destroying property	0	1	2	3	4	5	6
9. Inappropriate dressing or undressing (put on clothes in strange way or take off when in public)	0	1	2	3	4	5	6
10. Spitting, including at meals	0	1	2	3	4	5	6
11. Eating /drinking inappropriate substances	0	1	2	3	4	5	6
12. Grabbing onto people	0	1	2	3	4	5	6
13. Hitting (including self)	0	1	2	3	4	5	6
14. Kicking	0	1	2	3	4	5	6
15. Pushing, shoving	0	1	2	3	4	5	6
16. Throwing things, hurling, flinging	0	1	2	3	4	5	6
17. Biting people or things	0	1	2	3	4	5	6
18. Scratching people or self	0	1	2	3	4	5	6
19. Intentional falling (including from wheelchair or bed)	0	1	2	3	4	5	6
20. Hurting self (burns, cuts, etc.)	0	1	2	3	4	5	6
21. Hurting others (burns, cuts, etc.)	0	1	2	3	4	5	6
22. Making physical sexual advances, exposing self	0	1	2	3	4	5	6
23. Relevant verbal interruptions (i.e., cut short others who are speaking to relative; being rude-even if it does not seem to be intentioned)	0	1	2	3	4	5	6
24. Unrelated verbal interruptions (i.e., having nothing to do with	0	1	2	3	4	5	6

ongoing conversation or activity)

25. Repetitive sentences or questions (do not include complaining)	0	1	2	3	4	5	6
26. Constant requests for attention or help (nagging, pleading, calling out)	0	1	2	3	4	5	6
27. Verbal bossiness or pushiness	0	1	2	3	4	5	6
28. Complaining, whining	0	1	2	3	4	5	6
29. Negativism, bad attitude, doesn't like anything, nothing is right (uncooperative, refusing)	0	1	2	3	4	5	6
30. Cursing or verbal aggression; threatening, insulting	0	1	2	3	4	5	6
31. Temper outburst (verbal or non-verbal expression of anger)	0	1	2	3	4	5	6
32. Strange noises (weird laughter, moaning, crying)	0	1	2	3	4	5	6
33. Screaming, shouting, howling	0	1	2	3	4	5	6
34. Making verbal sexual advances	0	1	2	3	4	5	6

Appendix H - Part J

Care-recipient Cognitive Functioning.

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE – Short Form)

We would like you to remember what your spouse was like 10 years ago and to compare it with what he/she is like now. 10 years ago was in 1996. Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same, or got worse in that situation over the past 10 years. Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered 'Hasn't changed much.' Please indicate the changes you have observed by circling the appropriate answer.

Compared with 10 years ago how is this person at:

	Much improved	A bit improved	Not much change	A bit worse	Much worse
1. Remembering things about family and friends e.g., occupations, birthdays, addresses	1	2	3	4	5
2. Remembering things that have happened recently	1	2	3	4	5
3. Recalling conversations a few days later	1	2	3	4	5
4. Remembering her/his address and telephone number	1	2	3	4	5
5. Remembering what day and month it is	1	2	3	4	5

6. Remembering where things are usually kept	1	2	3	4	5
7. Remembering to find things which have been put in a different place from usual	1	2	3	4	5
8. Knowing how to work familiar machines around the house	1	2	3	4	5
9. Learning to use a new gadget or machine around the house	1	2	3	4	5
10. Learning new things in general	1	2	3	4	5
11. Following a story in a book or on TV	1	2	3	4	5
12. Making decisions on everyday matters	1	2	3	4	5
13. Handling money for shopping	1	2	3	4	5
14. Handling financial matters e.g., the pension, dealing with the bank	1	2	3	4	5
15. Handling other everyday arithmetic problems, e.g.,	1	2	3	4	5

knowing how much food to buy, knowing how long between visits from family or friends					
16. Using his/her intelligence to understand what's going on and to reason things through	1	2	3	4	5

Appendix I – Part A

Demographics and Service Use.

1. When were you born (caregiver)?
   ____________________ (dd/mm/yyyy)

2. When were you born (care-recipient)?
   ____________________ (dd/mm/yyyy)

3. Sex of caregiver
   ______1 Male
   ______2 Female

Many services are available to help elderly people and those who care for them. Services may be provided by the government, hospitals, private agencies or volunteer agencies. You have probably heard of some of these: for example, Homemaker Services, In-Home Nursing, or Self-Help Groups.

4. Has a homemaker service or cleaning lady been used in (____)'s household in the past year (e.g., to help with cleaning, laundry, meal preparation)?
   1 Yes 0 No

5. Has (____) received home delivered meals (e.g., Meals on Wheels) in the past year?
   1 Yes 0 No

6. Has (____) received home help for personal tasks (e.g., bathing, dressing, grooming, toileting, etc.) in the past year?
   1 Yes 0 No

7. Has (____) received in-home nursing care (e.g., for changing dressings, checking blood pressure, medications, etc.) in the past year?
   1 Yes 0 No

8. Has (____) had physiotherapy, occupational therapy, podiatry or chiropractic treatments in the past year?
   1 Yes 0 No

9. Has (____) attended a day centre or a day hospital in the past year?
   1 Yes 0 No

10. Has (____) used a hospital or nursing home for respite care in the past year? (i.e., he/she was admitted temporarily to hospital or a nursing home to give relief to the family. Do not include admissions for assessment or treatment, etc.).
    1 Yes 0 No

11. Have you received counseling (e.g., from a social worker or psychologist) during the past year to support you in caring for (____)?

    1 Yes 0 No

Appendix I – Part B

<u>Caregiver Physical Health Status.</u>

1. 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?
   1 = very good   2 = pretty good   3 = not too good   4 = poor   5 = very poor

2. Is your health now better, about the same, or worse than it was one year ago?
   1 = better   2 = about the same   3 = worse

3. How much do your health troubles stand in the way of your doing the things you want to do?
   1 = not at all   2 = a little (some things)   3 = a great deal

Appendix I – Part C

Care-recipient Dependence in ADL.

1. Can (____) eat….
    2 without any help?
    1 with some help? (cutting food, identifying food for people with vision problems, etc)
    0 or is he/she completely unable to feed him/herself?

2. Can (____) dress and undress….
    2 without any help (pick out clothes, dress and undress self)?
    1 with some help (dressing or undressing)?
    0 or is he/she completely unable to dress and undress?

3. Can (____) take care of his/her own appearance, for example combing his/her hair and (for men) shaving….
    2 without help?
    1 with some help?
    0 or he/she completely unable to do this?

4. Can (____) walk….
    2 without help (except from a cane)?
    1 with some help (from a person or with the use of a walker, crutches, etc.)?
    0 or is he/she completely unable to walk?

5. Can (____) get in and out of bed….
    2 without help?
    1 with some help (from a person or device)?
    0 or is he/she unable to get out of bed unless someone lifts him/her?

6. Can (____) take a bath or shower….
    2 without help?
    1 with some help (from a person or device)?
    0 or is he/she completely unable to bathe?

7. Can (____) use the bathroom or toilet….
    2 without help?
    1 with some help?
    0 or is he/she unable to use the bathroom or commode unless someone moves him/her?

8. Can (____) use the telephone….
    2 without help (including looking up numbers and dialing)?
    1 with some help (can answer phone, dial operator in an emergency, but has a special phone or needs help in getting numbers or dialing)?

0 or is he/she completely unable to use the phone?

9. Can (____) get to places out of walking distance....
    2 without help (can travel alone on buses, taxis, or drive own car)?
    1 with some help (needs someone to help him/her or go with him/her when traveling)?
    0 or is he/she completely unable to travel unless special arrangements are made?

10. Can (____) go shopping for groceries or clothes....
(assuming he/she has transportation)
    2 without help (can take care of all shopping by him/herself)?
    1 with some help (needs someone to go with him/her on all shopping trips)?
    0 or is he/she completely unable to shop?

11. Can (____) prepare his/her own meals....
    2 without help (can plan and cook full meals)?
    1 with some help (can do some things but unable to cook full meals)?
    0 or is he/she completely unable to prepare any meals?

12. Can (____) do his/her housework....
    2 without help (can do heavy housework)?
    1 with some help (can do light work but needs help with heavy work)?
    0 or is he/she completely unable to do housework?

13. Can (____) take his/her own medicine....
    2 without help (in the right doses at the right time)?
    1 with some help (can take medicine if someone prepares it for him/her and or reminds him/her to take it)?
    0 or is he/she completely unable to take his/her own medicines?

14. Can (____) manage his/her own money....
    2 without help (write cheques, pay bills, etc.)?
    1 with some help (can manage day-to-day buying but has help with his/her cheque book and paying bills)?
    0 or is he/she completely unable to handle money?

Appendix I – Part D

Care-recipient Disruptive Behaviours.

Dementia Behaviour Disturbance Scale (DBD)

I am going to read you a list of common problems. Please tell me if (____) has had any of these problems generally these days (e.g., in the past week). If so, how often they occurred?

Frequency ratings: 0 = Never
1 = Rarely
2 = Sometimes
3 = Frequently
4 = All of the time

	FREQUENCY
1. (____) shows lack of interest in daily activities.	0 1 2 3 4
2. (____) makes unwarranted accusations.	0 1 2 3 4
3. (____) is verbally abusive, curses.	0 1 2 3 4
4. (____) empties drawers or closets.	0 1 2 3 4
5. (____) dresses inappropriately.	0 1 2 3 4
6. (____) exposes himself/herself indecently.	0 1 2 3 4
7. (____) screams for no reason.	0 1 2 3 4
8. (____) makes physical attacks (hits, bites, scratches, kicks, spits).	0 1 2 3 4
9. (____) makes inappropriate sexual advances.	0 1 2 3 4
10. (____) paces up and down.	0 1 2 3 4
11. (____) moves arms and legs in a restless or agitated way.	0 1 2 3 4
12. (____) gets lost outside.	0 1 2 3 4
13. (____) is incontinent of urine (wets himself/herself).	0 1 2 3 4
14. (____) is incontinent of stool (soils himself/herself).	0 1 2 3 4

15. (____) wakes up at night for no obvious reason. 0 1 2 3 4

16. (____) wanders in the house at night. 0 1 2 3 4

17. (____) sleeps excessively during the day. 0 1 2 3 4

18. (____) overeats. 0 1 2 3 4

19. (____) refuses to eat. 0 1 2 3 4

20. (____) cries or laughs inappropriately. 0 1 2 3 4

21. (____) refuses to be helped to personal care tasks such as bathing, brushing teeth. 0 1 2 3 4

22. (____) throws food. 0 1 2 3 4

23. (____) wanders aimlessly outside or in the house during the day. 0 1 2 3 4

24. (____) hoards things for no obvious reason. 0 1 2 3 4

25. (____) destroys property or clothing, breaks things. 0 1 2 3 4

26. (____) loses, misplaces, or hides things. 0 1 2 3 4

27. (____) asks the same question over and over again. 0 1 2 3 4

28. (____) repeats same action, (e.g., wiping table) over and over again. 0 1 2 3 4

Appendix J – Part A

Demographics and Service Use.

1. How old are you (caregiver)?

   ____

2. What is [sample person]'s date of birth?

   ____________________ (mm/dd/yyyy)

2. (Interviewer: Is caregiver male or female)?

   Male Female

3. How long ago did you start care of [sample person] because of [sample person]'s disability?

   1 = less than 3 months
   2 = 3 months – less than 6 months
   3 = 6 months – less than 1 year
   4 = 1 year – less than 2 years
   5 = 2 years – less than 4 years
   6 = 4 years – less than 7 years
   7 = 7 years – less than 10 years
   8 = 10 years or more

4. Have you ever received any respite or caregiver support services from a government source to assist you in providing care for [sample person]?

   1 Yes 0 No

5. Have you ever requested information about how to get financial help for [sample person]?

   1 Yes 0 No

6. Have you ever taken part in support groups for caregivers?

   1 Yes 0 No

7. Have you ever used a service to temporarily take care of [sample person] so that you get some time away?

   1 Yes 0 No

8. Have you ever enrolled [sample person] in a program outside the home such as an Adult Day Care or senior center?

   1 Yes 0 No

9. Have you ever had a service come help with personal care or nursing care at [sample person]'s home?

   1 Yes 0 No

10. Have you ever had a service come help you with housework at [sample person]'s home?

    1 Yes 0 No

11. Have you ever had an outside service deliver meals to [sample person]'s home?
    1 Yes 0 No

12. Have you ever had an outside service provide transportation for [sample person]?
    1 Yes 0 No

13. Have you ever obtained assistive devices, such as wheelchairs, walkers, etc., for [sample person]?
    1 Yes 0 No

Appendix J – Part B

Caregiver burden.

Now I am going to read some statements that describe some problems people sometimes have when taking care of another person. As I read each statement, please tell me if that statement is TRUE or FALSE for you, when you take care of [sample person].

1. Taking care of [sample person] limits my social life or free time.
   1 True 0 False

2. I have to give [sample person] almost constant attention.
   1 True 0 False

3. Taking care of [sample person] has caused my health to get worse.
   1 True 0 False

4. Care costs more than I can really afford.
   1 True 0 False

5. I have to take care of [sample person] when I don't feel well enough.
   1 True 0 False

6. Taking care of [sample person] is hard on me emotionally.
   1 True 0 False

Appendix J – Part C

Caregiver Perceived Social Support.

Let's turn now to the help and support you get from your friends and relatives. Thinking about your friends and family, other than [sample person], please indicate the extent to which you agree or disagree with the following statements:

Frequency ratings: 1 = Strongly disagree
2 = Disagree
3 = Agree
4 = Strongly agree

	FREQUENCY			
1. There is really no one who understands what you are going through.	1	2	3	4
2. The people close to you let you know that they care about you.	1	2	3	4
3. You have a friend or relative in whose opinion you have confidence.	1	2	3	4
4. You have someone whom you feel you can trust.	1	2	3	4
5. You have people around you who help you to keep your spirits up.	1	2	3	4
6. There are people in your life who make you feel good about yourself.	1	2	3	4
7. You have at least one friend or relative you can really confide.	1	2	3	4
8. You have at least one friend or relative you want to be with when you are feeling down or discouraged.	1	2	3	4

Appendix J – Part D

Care-recipient Dependence in ADL.

I am going to mention some activities for which a person might need help, and ask whether you helped [sample person] with them in the past week.

Did you –

1. Help [sample person] walk around inside or get around inside with a wheelchair or similar device?
   1 = Yes 2 = No 3 = Does not get around inside at all

2. Help [sample person] eat?
   1 = Yes 2 = No 3 = Does not eat at all

3. Help [sample person] get in or out of bed?
   1 = Yes 2 = No 3 = Does not get out of bed at all

4. Help [sample person] get dressed – by getting and putting on the clothes [he/she] wears during the day?
   1 = Yes 2 = No 3 = Does not get dressed at all

5. Help [sample person] bathe by helping [him/her] get into or out of the bathtub or shower, or by washing [him/her] in a bathtub or shower or at a sink or basin?
   1 = Yes 2 = No 3 = Does not bathe at all

6. Give [sample person] shots or injections?
   1 = Yes 2 = No 3 = Does not get shots or injections

7. Give [sample person] medicine, pills, or change [his/her] bandages?
   1 = Yes 2 = No 3 = Does not take medicine

8. Help [sample person] use the toilet by helping [him/her] get on or off the toilet, but arranging [his/her] clothes, or by cleaning [him/her]?
   1 = Yes 2 = No

9. Help [sample person] by preparing special foods or fixing extra meals?
   1 = Yes 2 = No

10. Help [sample person] by managing [his/her] money, like keeping track of bills or handling cash?
    1 = Yes 2 = No

11. Help [sample person] by making telephone calls for [him/her]?
    1 = Yes 2 = No

12. Help [sample person] by doing things around the house, such as straightening up, putting things away, or doing dishes?
    1 = Yes 2 = No

13. Help [sample person] by doing [his/her] laundry?
    1 = Yes 2 = No

14. Help [sample person] by shopping for [his/her] groceries?
    1 = Yes 2 = No

15. Help [sample person] by doing other small errands for [him/her] outside of the house?
    1 = Yes 2 = No

16. Help [sample person] get around outside, including helping [him/her] walk or use a wheelchair or walker?
    1 = Yes 2 = No

17. Help [sample person] get around the neighborhood or city by driving [him/her] or helping [him/her] use public transportation?
    1 = Yes 2 = No

Appendix J – Part E

Care-recipient Disruptive Behaviours.

In the past week, on how many days did you personally have to deal with the following behavior of [sample person]? How many days did [he/she]:

Frequency ratings:
1 = No days
2 = 1 – 2 days
3 = 3 – 4 days
4 = 5 or more days

	FREQUENCY			
1. Keep you up at night.	1	2	3	4
2. Repeat questions/stories.	1	2	3	4
3. Hide belongings and forget about them.	1	2	3	4
4. Cling to you or follow you around.	1	2	3	4
5. Become restless or agitated.	1	2	3	4
6. Become irritable or angry.	1	2	3	4
7. Swear or use foul language.	1	2	3	4
8. Become suspicious, or believe someone is going to harm [him/her].	1	2	3	4
9. Threaten people.	1	2	3	4
10. Show sexual behavior or interest at the wrong time/place.	1	2	3	4
11. Destroy or damage property.	1	2	3	4

Appendix K

Means (Standard Deviations) and t-values for Care-recipient Variables Used to Examine Group Differences between Participants who Completed Time 1 and Time 2 Assessments (Completers) and Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 1

	Completer (*n* = 39)	Non-Completer (*n* = 27)		
Care-recipient Variables	Mean (SD)	Mean (SD)	*t*-value	*p*-value[a]
Age	75.15 (9.41)	75.63 (8.90)	0.21	0.84
Disruptive Behaviours	26.10 (23.28)	24.08 (17.00)	-0.38	0.71
Cognitive Impairment	4.64 (0.38)	4.62 (0.47)	-0.23	0.82
Dependence in BADL[b]	20.23 (5.40)	21.00 (4.70)	0.60	0.55
Dependence in IADL[c]	12.52 (4.65)	12.25 (4.55)	-0.24	0.81

[a] Probability values (two-tailed) associated with the statistical tests.

[b] Dependence in basic activities of daily living.

[c] Dependence in instrumental activities of daily living.

Appendix L

Means (Standard Deviations) and t-values for Caregiver Variables Used to Examine Group Differences between Participants who Completed Time 1 and Time 2 Assessments (Completers) and Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 1

	Completer (*n* = 39)	Non-Completer (*n* = 27)		
Caregiver Variables	Mean (SD)	Mean (SD)	*t*-value	*p*-value[a]
Age	72.23 (10.02)	73.19 (9.81)	0.38	0.70
Duration of Caregiving	5.44 (3.61)	4.44 (3.72)	-1.09	0.28
Hours of Help Caregiving/Week	13.71 (13.21)	12.76 (11.35)	-0.31	0.76
Physical Health	42.94 (12.67)	43.79 (15.14)	0.25	0.81
Mental Health	42.51 (13.14)	40.71 (10.42)	-0.60	0.55
Depression	17.23 (11.61)	15.81 (9.73)	-0.52	0.61
Burden	18.03 (10.81)	17.89 (8.99)	-0.05	0.96
Health Behaviours	104.05 (15.83)	105.37 (22.09)	0.28	0.78

Appendix L (continued)

	Completer ($n = 39$)	Non-Completer ($n = 27$)		
Caregiver Variables	Mean (SD)	Mean (SD)	t-value	p-value[a]
Family Support	14.61 (5.26)	14.37 (5.34)	-0.19	0.85
Friend Support	13.77 (5.09)	9.66 (7.37)	-2.48[b]	0.02
Quality of Pre-morbid relationship	3.36 (1.93)	3.59 (2.15)	0.46	0.65

[a] Probability values (two-tailed) associated with the statistical tests.

[b] Reported t-values are those for unequal variances (Levene's test for equality of variances significant at .05 level).

Appendix M

Means (Standard Deviations) and t-values for Caregiver Variables Used to Examine Group Differences between Dementia Participants who Completed Time 1 and Time 2 Assessments (Completers) and Dementia Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 2

	Completer ($n = 65$)	Non-Completer ($n = 40$)		
Caregiver Variables	Mean (SD)	Mean (SD)	*t*-value	*p*-value[a]
Age	72.98 (6.53)	75.87 (8.77)	1.91	0.07
Physical Health	5.79 (1.54)	5.89 (1.69)	0.30	0.77
Depression	13.00 (10.39)	11.97 (8.24)	-0.51	0.61
Burden	24.37 (18.41)	21.19 (14.22)	-0.90	0.37
Service Use	0.92 (1.27)	1.13 (1.17)	0.83	0.41

[a] Probability values (two-tailed) associated with the statistical tests.

Appendix N

Means (Standard Deviations) and t-values for Care-recipient Variables Used to Examine Group Differences between Dementia Participants who Completed Time 1 and Time 2 Assessments (Completers) and Dementia Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 2

	Completer (*n* = 65)	Non-Completer (*n* = 40)		
Care-Recipient Variables	Mean (SD)	Mean (SD)	*t*-value	*p*-value[a]
Age	79.26 (5.98)	79.62 (6.28)	0.29	0.78
Disruptive Behaviours	15.16 (13.76)	14.38 (11.75)	-0.29	0.77
Dependence in BADL[b]	12.18 (2.73)	12.38 (2.42)	0.38	0.71
Dependence in IADL[c]	6.49 (4.59)	6.16 (5.05)	-0.35	0.73

[a] Probability values (two-tailed) associated with the statistical tests.

[b] Dependence in basic activities of daily living.

[c] Dependence in instrumental activities of daily living.

Appendix O

Means (Standard Deviations) and t-values for Caregiver Variables Used to Examine Group Differences between Non-Dementia Participants who Completed Time 1 and Time 2 Assessments (Completers) and Non-Dementia Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 2

	Completer (n = 43)	Non-Completer (n = 29)		
Caregiver Variables	Mean (SD)	Mean (SD)	t-value	p-value[a]
Age	73.56 (7.28)	77.92 (11.40)	1.94	0.07
Physical Health	5.63 (1.67)	5.19 (1.12)	-1.24[b]	0.22
Depression	7.95 (7.68)	7.96 (8.80)	0.004	0.99
Service Use	0.86 (1.06)	1.00 (0.94)	0.55	0.58

[a] Probability values (two-tailed) associated with the statistical tests.

[b] Reported t-values are those for unequal variances (Levene's test for equality of variances significant at .05 level).

Appendix P

Means (Standard Deviations) and t-values for Care-recipient Variables Used to Examine Group Differences between Non-Dementia Participants who Completed Time 1 and Time 2 Assessments (Completers) and Non-Dementia Participants who Completed only Time 1 Assessments (Non-Completers) in Dataset 2

	Completer (*n* = 43)	Non-Completer (*n* = 29)		
Care-recipient Variables	Mean (SD)	Mean (SD)	*t*-value	*p*-value[a]
Age	76.37 (5.97)	80.85 (4.34)	3.32	0.001
Dependence in BADL[b]	13.56 (0.91)	13.19 (2.45)	-0.89	0.38
Dependence in IADL[c]	11.12 (2.52)	11.00 (2.65)	-0.18	0.86

[a] Probability values (two-tailed) associated with the statistical tests.

[b] Dependence in basic activities of daily living.

[c] Dependence in instrumental activities of daily living.

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