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Health Impacts of Caring for a Spouse With Dementia: Rural Versus Urban

Settings

Joy Creese ©

Supervisor: Dr. M. Bedard

Second Reader: Dr. D. Mazmanian

External Reader: Dr. K. Brazil

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Abstract

Adverse mental and physical health outcomes in caregivers of persons with dementia are well documented, particularly for spouse caregivers. However, geographical setting may affect the caregiving experience. The main objective of this study was to investigate potential differences between rural and urban spouse caregivers in the health impact of caregiving, as well as identifying correlates of health status, health behaviors, and sleep disruptions. A sample of 33 spouse caregivers for persons with dementia in Northwestern Ontario was recruited, including 26 from an urban setting (population 109,000), and 7 from rural settings (populations < 9,000). Rural caregivers rated the amount of information about how to access support services significantly poorer than did urban caregivers ($t(31) = 16.76, p < .001$). No other statistically significant differences were found across residential settings in terms of caregiver health or health behaviors. However, different correlates of health status and health behaviors emerged for the two settings. For rural caregivers, lower levels of physical health were associated with higher levels of depressive symptoms ($r(5) = -.938, p = .002$), higher levels of role burden ($r(5) = -.938, p = .002$), and poorer care recipient functioning in basic activities of daily living ($r(5) = .895, p = .007$). These associations were not significant for urban caregivers. It was also hypothesized that healthy behaviors would be positively associated with health status, but this hypothesis was not supported. Sleep disruptions and depressive symptoms were reported by both groups. Results suggest that the impact of caregiving may be different for rural and urban spouse caregivers. More research is needed, with larger and more representative samples, to further investigate these potential rural-urban differences.

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Health Impacts of Caring for a Spouse With Dementia: Rural Versus Urban Settings

Background

In Canada, approximately 8% of Canadians over the age of 65, and 35% of those over age 85, suffer from dementia (Canadian Study of Health and Aging Working Group, 1994a). By 2031, it is estimated that over 750,000 Canadians will have some form of dementia, such as Alzheimer's disease (Canadian Study of Health and Aging Working Group, 1994a). Most people with dementia live at home, supported by their spouses, relatives, or friends (Canadian Study of Health and Aging Working Group, 1994b; Stone, Cafferata, & Sangl, 1987).

It is generally acknowledged that caring for someone with dementia is more demanding than caring for other older frail adults (Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2000; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Dementia caregiving is thought to be particularly challenging due to the combination of progressive physical and cognitive impairments, disruptive behaviors, emotional outbursts, and personality deterioration associated with the course of dementia (Haley, Levine, Brown, Berry, & Hughes, 1987). Informal caregivers of persons with dementia provide care for a greater number of hours each day compared not only to noncaregivers but also to caregivers of individuals with Parkinson's and cancer (Teel & Press, 1999). Dementia caregivers report higher levels of physical and emotional strain than nondementia caregivers (Ory et al., 1999), and are at greater risk of psychiatric and physical morbidity compared to population norms and control groups (Canadian Study of Health and Aging, 1994).

Over the past few decades, a great deal of research has focused on the substantial role played by family members in caring for relatives with dementia. The central focus of caregiving research has been the negative consequences of caring, the concept of “caregiver burden”. Caregiver burden is typically conceptualized in terms of subjective aspects such as feelings of stress or strain (Pearlin, Mullan, Semple, & Skaff, 1990) and objective aspects such as task burden and financial burden (Biegel, Song, & Chakravarathy, 1994). For caregivers, this burden may manifest itself in terms of transient negative reactions or more long-lasting consequences such as depression and illness (Biegel, Sales, & Schulz, 1991).

Primary caregivers, and especially those living with the care recipients, may experience a higher level of burden than other caregivers (Bedard et al., 2001b). Over 70 % of informal caregivers are women (Canadian Study of Health and Aging Working Group, 1994b; Stone et al., 1987), mainly consisting of wives and daughters. In Canada, 37% of the caregivers are spouses, who are elderly themselves and often have health problems of their own (Canadian Study of Health and Aging Working Group, 1994b). Furthermore, spouses appear to be more adversely affected, both mentally and physically, than adult children caring for a parent (Baumgarten et al., 1992; Brodaty & Hadzi-Pavlovic, 1990; Cohen et al., 1990; George & Gwyther, 1986; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Zarit & Whitlatch, 1992).

The health impact of caregiving

Caregiving is associated with elevated levels of depressive symptoms as measured by self-report instruments (Baumgarten et al., 1992; Cattanach & Tebes, 1991; Hooker, Monahan, Shifren, & Hutchinson, 1992; Schulz & Williamson, 1991; Shields, 1992).

Compared to noncaregivers, caregivers of dementia patients report significantly higher levels of depressive symptoms (Baumgarten et al., 1992; Haley et al., 1987; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). In addition, some studies indicate that caregivers are at risk of experiencing clinical depression (Cattanach & Tebes, 1991; Gallant & Connell, 1997; Schulz & Williamson, 1991; Williamson & Schulz, 1993). Also, psychotropic drug use is higher among caregivers than noncaregivers (Schulz, O'Brien, Bookwala, & Fleissner, 1995).

Spouse caregivers demonstrate greater distress than other family caregivers (Baumgarten et al., 1992; Grafstrom et al., 1992; Zarit & Whitlatch, 1992). Gender differences have been found in several studies, with female caregivers demonstrating significantly higher levels of depressive symptoms than males (Baumgarten et al., 1992; Grafstrom et al., 1992; Schulz & Williamson, 1991; Yee & Schulz, 2000) although other studies have not replicated these findings (Neundorfer, 1991; Shields, 1992). Such negative mental health outcomes may compromise the ability of the family caregiver to continue providing care: caregiver depression is a significant predictor of institutionalization of the care recipient with dementia (Arai, Sugiura, Washio, Miura, & Kudo, 2001; Whitlatch, Feinberg, & Stevens, 1999).

Findings regarding the physical health impact of caregiving are mixed. In the majority of caregiving studies, caregivers' self-ratings of overall health are consistently lower than population norms, and caregivers generally perceive their health to be worse than that of their same-age peers (Canadian Study of Health and Aging Working Group, 1994b; Schulz et al., 1995). However, some studies have found no significant differences between caregivers and demographically-matched controls in terms of self-rated health

(Fuller-Jonap & Haley, 1995; George & Gwyther, 1986). Several cross-sectional studies have shown that when compared to noncaregiving controls, caregivers report a greater number of physical symptoms (Deimling, Bass, Townsend, & Noelker, 1989; Haley et al., 1987; Stone et al., 1987) and more chronic illnesses (Baumgarten et al., 1992; Haley et al., 1987; Pruchno & Potashnik, 1989), but not necessarily more frequent visits to physicians (Fuller-Jonap & Haley, 1995; Grafstrom et al., 1992; Pruchno & Potashnik, 1989).

Spouse caregivers in particular may be at risk for health declines. Compared to other family caregivers, spouse caregivers of patients with dementia report significantly more physician visits and poorer self-rated health (George & Gwyther, 1986). Baumgarten and colleagues (1992) found that on physical symptoms the difference between dementia caregivers and noncaregivers was substantially larger among spouses than children. At least two cross-sectional studies have reported higher rates of respiratory symptoms in male spouse caregivers compared to demographically-matched controls (Fuller-Jonap & Haley, 1995; Pruchno & Potashnik, 1989). Another study (Pruchno & Potashnik, 1989) found that spouse caregivers reported higher rates of diabetes, arthritis, ulcers, and anemia compared to population-based norms. In addition, it has been demonstrated that illness episodes of spousal caregivers are of longer duration, and result in more physician visits, than the episodes of noncaregivers (Kiecolt-Glaser et al., 1991).

More objective measures of health status have also demonstrated the heightened vulnerability of spouse caregivers to negative health outcomes. These include hypertension (Shaw et al., 1999), higher levels of insulin production (Vitaliano, Scanlan,

Krenz, Schwartz, & Marcovina, 1996), and increased risk of cardiovascular problems (Uchino, Kiecolt-Glaser, & Cacioppo, 1992). Additionally, spouse caregivers mount poorer immune responses to viral challenges (Esterling, Kiecolt-Glaser, & Glaser, 1996; Glaser & Kiecolt-Glaser, 1997), and evidence slower rates of wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995) than do age-matched controls. Thus it is not surprising that spouse caregivers have been referred to as the “hidden patients” (Fengler & Goodrich, 1979).

Further evidence comes from longitudinal studies. Kiecolt-Glaser and colleagues (1991) reported that spouse caregivers showed significant decreases in cellular immunity compared to controls over a 13-month period. Also, caregivers reported significantly more days of infectious illness, primarily upper respiratory tract infections, than controls. A longitudinal study comparing spouse caregivers of Alzheimer’s disease patients and married control participants reported a trend for caregivers to experience a greater risk for developing a serious illness over a three-year period (Shaw et al., 1997). In a second, related study, caregivers had an elevated risk for developing mild hypertension over a six-year interval (Shaw et al., 1999). Such changes in physiology can become risk factors for disease or chronic illness over time, particularly among elderly caregivers (Schulz et al., 1995). Finally, caregiving may even place individuals at risk for mortality; a recent population-based study (Schulz & Beach, 1999) found that caregiving spouses who report caregiving strain were 63% more at risk of dying within 4 years of the initial interview than noncaregivers.

These longitudinal studies of spouse caregivers have demonstrated consistent support for the “wear and tear” hypothesis, which suggests that role demands accumulate

to create caregiver burden, ultimately reaching a level at which caregivers cannot cope. Thus it appears that while caregivers may subjectively rate their own health as remaining relatively constant over time, more objective measures of chronic illness and immune function indicate that physiological processes may mediate caregivers' risk of physical morbidity.

The role of health behaviors

Although a growing body of evidence links caregiving with adverse health outcomes, the mechanism of this relationship remains unclear. One possible explanation is that changes in lifestyle and health behaviors, such as poorer diets and lack of sleep and exercise, may contribute to adverse health outcomes for caregivers.

Recently, caregiving studies have begun to investigate the role of health behaviors, and there is a growing body of evidence that document negative health behavior patterns and changes among dementia caregivers. The link between health behaviors and health status is based on empirical findings from studies in the general population. A number of studies have demonstrated that physical health status, physical functioning, and mortality are related to physical activity, sleep patterns, proper nutrition, cigarette smoking, alcohol consumption, and maintenance of appropriate body weight (Belloc & Breslow, 1972; Buchner, Beresford, Larson, Lacroix, & Wagner, 1992; Habte-Gabr et al., 1991; Lacroix & Omenn, 1994; Palmore, 1970; Posner, Jette, Smith, & Miller, 1993; Wagner, Lacroix, Bucher, & Larson, 1992). Empirical evidence also suggests that stress can negatively influence the performance of health behaviors. Stress, which has been operationalized in various ways, has been associated with increased smoking (Cohen, Schwartz, Bromet, & Parkinson, 1991), increased alcohol consumption

(Finney & Moos, 1984), increased calorie and fat intake (McCann, Warnick, & Knopp, 1990) and increased body mass index (Rookus, Burema, & Frijters, 1988). Thus it is possible that increased levels of stress may lead to negative health behavior changes, ultimately affecting physical health status.

The relationships between stress, health behaviors and health outcomes may be particularly salient for caregivers. The demands of caregiving may lead to changes in health behaviors; for instance, caregivers may not have enough time to include self-care activities, such as exercise, in their daily lives. The unique demands posed by dementia caregiving may restrict the time available for self-care activities to the extent that some positive health behaviors become almost impossible; for example, getting a good night's sleep. Indeed, the most consistently cited health behavior change among caregivers is a decrease in amount of sleep (Burton, Newsom, Schulz, Hirsch, & German, 1997; Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997; Kiecolt-Glaser et al., 1991; Schulz et al., 1997; Teel & Press, 1999). Compared to age and gender-matched controls, caregivers report greater problems getting adequate rest and sleep (Acton, 2002; Burton et al., 1997; Fuller-Jonap & Haley, 1995). One study found that dementia caregivers reported decreased sleep since caregiving began, with half of the caregivers currently reporting less than seven hours of sleep per night (Gallant & Connell, 1997).

Although many studies report the sleep duration of caregivers, little empirical attention has been devoted to caregiver sleep quality and the nature and frequency of sleep disruptions. For many dementia caregivers, sleep disruptions occur as a result of care recipient nocturnal awakenings. Care recipient nocturnal disruptions are related to poorer overall sleep quality for caregivers (Wilcox & King, 1999), and these disruptions

are the most problematic sleep complaint among family caregivers (McCurry et al., 1999). In addition, disturbances in sleep and nocturnal behavior of dementia patients have been cited by caregivers as a reason for patient institutionalization (Pollak & Perlick, 1991). However, more research is needed to clarify the frequency and severity of these disruptive nocturnal care recipient behaviors.

Caregiving is also associated with inadequate exercise, not having enough time to rest when sick, and not finding time for doctor appointments (Acton, 2002; Burton et al., 1997; Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997; Schulz et al., 1997). Dementia caregivers report a significantly higher use of psychotropic medications than noncaregivers (Baumgarten et al., 1992; Clipp & George, 1990; Grafstrom et al., 1992; Mort, Gaspar, Juffer, & Kovarna, 1996; Pruchno & Potashnik, 1989). One study reported that 30% of the dementia caregiving sample used prescribed psychotropic drugs (antianxiety, antidepressant, and sedative/hypnotic) on at least an occasional basis (Clipp & George, 1990). In addition, psychotropic drug use was most common among female spouse caregivers who have more stress symptoms, most of whom are elderly (Clipp & George, 1990). Older female caregivers are also more likely than other caregivers to take sleep aids (Clipp & George, 1990). In a study of male dementia caregivers, no significant differences were found between caregivers and noncaregivers' use of psychotropic drugs (Fuller-Jonap & Haley, 1995). Most men in the study, when questioned about sleeping medication, were reluctant to take any medication that would prevent them from being alert at all times, especially if their spouse got up and wandered during the night (Fuller-Jonap & Haley, 1995).

Other health behaviors that have received attention in the caregiving literature include changes in weight, alcohol consumption and cigarette smoking. Weight gain has been reported by caregivers in some studies (Gallant & Connell, 1997; Vitaliano, Russo, Scanlan, & Greeno, 1996), while other studies report both weight gains and losses among caregivers (Connell, 1994; Fredman & Daly, 1997). Empirical evidence to date reveals that caregivers consume similar or lower amounts of alcohol than age-matched controls (Baumgarten et al., 1992; Fuller-Jonap & Haley, 1995; Schulz et al., 1997). Although male caregivers may consume more alcohol than female caregivers (Gallant & Connell, 1997), the majority of caregivers do not report drinking heavily or an increased use of alcohol since caregiving began (Burton et al., 1997; Gallant & Connell, 1997). As with alcohol consumption, caregivers report similar or lower tobacco consumption than do age-matched controls (Burton et al., 1997; Fuller-Jonap & Haley, 1995; Scharlach, Midanik, Runkle, & Soghikian, 1997; Vitaliano et al., 1996). Thus caregiving does not necessarily have a deleterious impact on all health behaviors.

The evidence to date suggests that dementia caregivers are at risk for sleep problems, declines in physical activity, changes in weight, and increased psychotropic medication use. Contrary to the general findings from the literature linking stress to health behaviors, caregivers do not appear to be at risk for increased alcohol consumption or smoking. More research is needed to further investigate the role of health behaviors as potential determinants of health declines in caregivers.

Minimizing the negative impact of caregiving

In addition to health behaviors and psychological distress, there are other factors that contribute to the negative impact of caregiving. In order to minimize the negative

impact of caregiving, we need to understand its determinants. These determinants of caregiver burden and negative health outcomes can be broadly categorized into three categories: 1) care recipient characteristics (e.g., frequency/severity of problem behaviors), 2) caregiver characteristics (e.g., resilience), and 3) external variables (e.g., external supports).

Among care recipient characteristics, empirical evidence reveals that care recipient problem behaviors, but not level of cognitive and functional impairment, are predictive of negative physical and mental health outcomes among caregivers (Bedard, Molloy, Pedlar, Lever, & Stones, 1997; Schulz et al., 1995). Such problem behaviors can range from being repetitive to physically aggressive. Indeed, the presence of problem behaviors is likely the most important determinant of caregiver burden (Bedard, Pedlar, Martin, Malott, & Stones, 2000), often explaining 50% of the variability in caregiver burden (Bedard et al., 2000). There is also empirical evidence that problem behaviors are associated with poorer caregiver general health status (Wijeratne & Lovestone, 1996) and greater health problems (Baumgarten et al., 1992), but the magnitude of these associations is unclear. A longitudinal study of spousal dementia caregivers found that spouses who were most distressed by problem behaviors and who also showed lower levels of social support demonstrated the greatest and most uniformly negative changes in immune function over time (Kiecolt-Glaser et al., 1991). Dependence in activities of daily living (ADL) is also associated with higher caregiver burden (Bedard et al., 2000), but its relationship with health status is unclear. Cognitive impairment by itself is neither associated with caregiver burden (Bedard et al., 2000) nor health status (Wijeratne & Lovestone, 1996).

The contributions of caregiver and external variables have also been documented, but their roles appear less substantial than that of care recipient characteristics. Many studies reveal an association between poorer physical health in caregivers and greater psychological distress (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992), anxiety (Neundorfer, 1991), and depression (Hooker et al., 1992; Moritz, Kasl, & Ostfeld, 1992; Neundorfer, 1991; Pruchno, Kleban, Michaels, & Dempsey, 1990). In addition, caregiver burden has also been linked to caregiver health status (Draper et al., 1992; Pruchno & Resch, 1989; Vitaliano, Russo, Young, Becker, & Maiuro, 1991) as well as to negative health behavior changes (Gallant & Connell, 1997; Sisk, 2000)

External variables such as social support are also predictors of the impact of caregiving. A recent review of caregiver outcomes found a consistent relationship between lower levels of social support and poorer physical health among caregivers (Schulz et al., 1995). However, there is growing evidence that it may be caregivers' satisfaction with their social network and the perceived availability of social support that is more important than the actual amount of informal help received (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Schulz & Williamson, 1991). Similarly, caring for a spouse with whom the premorbid relationship was warm and positive has been found to be less stressful than if the premorbid relationship was strained or more difficult (Morris, Morris, & Britton, 1988; Schulz & Williamson, 1991).

Although the contribution of care recipient, caregiver, and external variables have been documented, their specific roles in determining the impact of caregiving remain to be established. In addition, although it is hypothesized that health behaviors and health status are related, this has not actually been confirmed among dementia caregivers. Thus

more research is needed to establish preliminary evidence that health behavior practices are associated with physical health status for caregivers, as well as to clarify the role of potential determinants of caregiver health outcomes.

The rural/urban dichotomy

One other external variable that may influence the caregiving experience is geographical setting. The incidence of dementia in rural areas is likely to be similar to that in urban areas, although methodological differences among prevalence studies make it difficult to draw any firm conclusions (Coogle, 2002; Keefover et al., 1996). Dementia may even be underdiagnosed in rural areas, mainly due to the limited availability of comprehensive geriatric assessments in such areas (Buckwalter, Smith, & Caston, 1993; Coogle, 2002). Unfortunately, there are very few studies investigating potential differences in the caregiving experience for urban and rural dwellers. Some data suggest that urban dwellers may be referred to specialized clinics earlier than rural dwellers (Wackerbarth, Johnson, Markesbery, & Smith, 2001), and that urban residents receive patterns of home care typical of long-term care support while the pattern for rural residents is more consistent with post-acute care (Nyman, Sen, Chan, & Commins, 1991). Although one study reported that older adults from rural areas may be institutionalized prematurely in comparison with their urban counterparts (Greene, 1984), these findings have not been replicated in other urban/rural samples (Duncan, Coward, & Gilbert, 1997; Penrod, 2001).

Very few studies have examined differences in caregiver burden, depression, health status, or healthy behaviors of rural and urban caregivers. One study conducted by Dwyer and Miller (Dwyer & Miller, 1990) investigated residential differences in

caregiver burden and stress; they found that urban caregivers reported a higher level of burden, yet also a higher rating of self-perceived health than rural caregivers. However, the care recipients in the study by Dwyer and Miller (1990) were not restricted to dementia sufferers, which may limit the generalization of the findings to the experiences of dementia caregivers. Findings from general studies of the health status of rural and urban elders are mixed; some claim that rural elders report a higher number of medical conditions and more functional limitations than urban residents (Coward, McLaughlin, Duncan, & Bull, 1994), whereas others have found no significant difference in health status for urban and rural elders (Penning & Chappell, 1993). Of the few studies to date, no significant differences have been found between urban and rural residents on measures of depression (Bull & Aucoin, 1975; Johnson et al., 1988; Ortega, Metroka, & Johnson, 1993). However, one study found that rural residents made fewer specialty care visits for depression, had 3.06 times higher risk of admission to hospital for mental health problems than urban residents, and reported significantly more suicide attempts during the period of one year as compared to urban residents (Rost, Zhang, Fortney, Smith, & Smith, 1998).

The varying availability of supports across settings may also result in different experiences for urban and rural caregivers. Researchers generally agree that there are fewer formal services available to caregivers in rural settings than in urban areas (Glasgow, 2000; McCabe, Sand, Yeaworth, & Nieveen, 1995; O'Reilly & Strong, 1997; Wenger, Scott, & Seddon, 2002). However, a study by McCabe and colleagues (McCabe et al., 1995) found that although more services were available and used more frequently in urban areas, comparing the proportional utilization of services indicated that rural

caregivers' use of available services was significantly greater than that of urban caregivers. In other words, despite the limited availability of services, rural caregivers effectively used the services that were available to them. Other studies have reported low use of available formal services by rural caregivers (O'Reilly & Strong, 1997; Wenger et al., 2002). More research in this area is required in order to clarify any differences in formal service use by urban and rural caregivers of cognitively-impaired older adults.

Including a sample of both rural and urban caregivers, Bowd and Loos (Bowd & Loos, 1996) identified the support factors rated most important by caregivers. In decreasing order of importance, these supports included information about the care recipient condition (>90%), informal support (>60%), and formal support (>30%). Despite the importance of such services, both urban and rural caregivers may face challenges in accessing them. Bruce and Paterson (Bruce & Paterson, 2000) described potential barriers to community support for urban caregivers of dementia sufferers. These barriers included late referral of dementia sufferers to community care by general practitioners, problems with health care agencies, and lack of information regarding the diagnosis of dementia, how to deal with problem behaviors, and how to access support services. These challenges may also be faced by rural caregivers, and are compounded by additional limitations in accessing services due to living in a rural area. Having to travel long distances, lack of public transportation, and for some elderly spouses, an inability to drive (O'Reilly & Strong, 1997) create difficulties for rural residents in accessing some services. Thus rural caregivers may be at a particular disadvantage compared to their urban counterparts when it comes to accessing the limited services available to them.

Spouse caregivers living in rural areas may be particularly at risk for negative mental and health outcomes, not only because of their age and isolation, but also their reluctance to use available formal support services. The finding that spousal caregivers are less likely than adult children caregivers to use formal support services (Canadian Study of Health and Aging, 1994; McCabe et al., 1995) has also been reported in a study of rural dementia caregivers in Wales (Wenger et al., 2002). Although the main source of help for spousal caregivers in rural Wales was reported to be the adult children of the caregivers who lived nearby, caregiving spouses were more likely than other caregivers to claim that they did not need help (Wenger et al., 2002). This finding is of concern, as over half of the caregivers reported that they were in less than good health.

At present it is difficult to evaluate whether there are any consistent differences between rural and urban caregivers in the psychological and physical impact of caregiving. Although the evidence is fairly consistent with regards to the lower availability of formal support services in rural areas, it remains unclear whether or not this affects caregiver burden and other caregiving outcome measures. It is important to clarify and understand potential differences between urban and rural settings, as such differences may have implications for the health of caregivers and the planning of service provision.

In addition, it is important to extend these preliminary studies to include residents from diverse rural populations in Canada. The majority of research examining urban and rural differences has been conducted in the United States. Among rural environments, there is a great diversity in a number of dimensions that influence the provision of care, including population density, proximity to metropolitan/urban areas, regional culture,

economic base, and migration patterns (Palo Stoller & Lee, 1994). Thus findings from studies conducted in the rural United States may not generalize to the experience of caregivers living in rural Canada, especially in rural Northwestern Ontario. A study by Bowd and Loos (1996) indicated that there are indeed demographic similarities between a sample of caregivers from Northwestern Ontario and others from less isolated and urban areas in North America, with the majority of caregivers being women and reporting a moderate to high level of burden arising from their caregiving experience. However, community based services varied considerably throughout the region, and this variation may influence accessibility to and use of formal services for rural caregivers. In particular, isolated areas of Northwestern Ontario have limited in-home respite services, respite day care, education and social support services (Bowd & Loos, 1996).

Preliminary data

A pilot study was conducted by Bedard and colleagues (Bedard, Koivuranta, & Stuckey, in press) in order to address some of the afore-mentioned issues. Using a sample of urban and rural dementia caregivers in Northwestern Ontario, no significant differences were found between the two caregiving groups on measures of burden, health status, or prevalence of healthy behaviors. However, higher burden among rural caregivers was associated with fewer healthy behaviors. The authors suggested that differences in service/support availability may explain why over-burdened rural caregivers engaged in fewer healthy behaviors, although further study needs to be conducted to clarify the issue. Limitations of the study included a small sample size (20 rural caregivers and 17 urban caregivers) and a heterogeneous sample consisting of spousal and adult children caregivers.

Purpose

The purpose of the present study is fourfold. First, this study will extend the preliminary findings by investigating potential differences in the caregiving experience for rural and urban spouse caregivers of individuals with dementia. In particular, the health status, healthy behaviors, and depressive symptoms of spousal caregivers living in rural and urban settings will be compared. Although preliminary findings did not indicate the presence of any significant residential differences, the sample was not composed exclusively of spousal caregivers. Based on the evidence that spouses are at increased risk for negative health outcomes, and that rural spouses may be more limited in the availability and accessibility to appropriate health services, it is anticipated that rural spouses will demonstrate poorer health status, engage in fewer healthy behaviors, and exhibit higher levels of depressive symptoms than urban caregivers. However, it is also hypothesized that caregivers in both settings will report elevated levels of depressive symptoms.

Second, the relationship between healthy behaviors and health status will be examined. In the majority of caregiving studies, changes in healthy behaviors and health status are not assessed consistently in tandem. Since the proposed causal linkage is that negative health behaviors lead to poorer health outcomes, it is important to demonstrate an association between these variables to warrant future studies. Based on the empirically demonstrated associations between health behaviors and health status in noncaregiving samples, it is hypothesized that engaging in a greater number of health behaviors will be positively associated with better health status for caregivers.

The third purpose of this study is to examine the contribution of other determinants such as depression, burden, problem behaviors, dependence in ADL, sex, external supports, and quality of the premorbid relationship towards health and behaviors in rural and urban spouse caregivers. There are little data regarding the determinants of health status in rural caregivers. In order to intervene effectively with rural caregivers, this knowledge needs to be developed.

Finally, there are little data regarding the nature and frequency of sleep disruptions in dementia caregivers. Following the suggestion of others (Pollak & Perlick, 1991; Wilcox & King, 1999), correlates of caregiver sleep quality and the nature and frequency of sleep disruptions will also be investigated.

Method

Participants

The participants were 33 spouse caregivers of individuals with possible or probable Alzheimer's Disease or other forms of dementia. Seven caregivers were from rural settings and 26 were from an urban setting. Participation was limited to caregivers who currently resided with the care recipient. Caregivers and care recipients lived in Northwestern Ontario, Canada. The Northwest region consists of the region bounded by the border between the provinces of Manitoba and Ontario in the West, and the Northern shore of Lake Superior in the East. Northwestern Ontario covers an area (525,193 sq. km.) that is approximately 60% of the landmass of the province with only 2.3% of its total population (Northwestern Ontario District Health Council, 2000). Almost half of the regional population resides in or immediately around the City of Thunder Bay. In the

Kenora District, 60.5% of the population resides in rural areas, while 46.5% of the population in the Rainy River District resides in rural areas (Statistics Canada, 2001).

The urban setting was defined as living within the city limits of Thunder Bay (population: 109,000). The urban setting had the typical amenities of larger centers, including an acute hospital, a rehabilitation chronic care hospital, a psychiatric hospital and several services for older adults and their caregivers. The rural setting was defined as living at least one hour outside the city limits of Thunder Bay and Kenora. Individuals living in the Kenora district were excluded because the size of the agglomeration (10,000) warrants services beyond those normally found in rural settings.

Materials

The variables of interest were operationalized by means of self-report measures and incorporated into a questionnaire (see Appendix A). The variables can be categorized as follows: caregiver variables, care recipient variables, and external supports.

Caregiver Variables

Demographic information was obtained from caregivers, including their date of birth, sex, community of residence, and current employment status (see Appendix A - Part A). The questionnaire asked caregivers to indicate the length of time caring for the care recipient. Caregivers were also asked to indicate the presence of any diagnosed medical conditions, and current prescription medication use.

Caregiver variables also included measures of sleep, health status, health behaviors, depression, caregiver burden, quality of the premorbid marital relationship, and leisure activities. These measures are listed below.

Sleep. Quality of sleep was measured with five items (see Appendix A – Part B). The first item was “During the past month, how would you rate your sleep quality overall?”, with five possible responses (excellent, very good, good, fair, or poor). To measure change in sleep quality over the past year, participants were asked, “Compared to one year ago, how would you rate your quality of sleep now?”, also with five possible responses (much better, somewhat better, about the same, worse, or much worse). A third item determined whether caregivers slept in the same bed, in the same room but not the same bed, or in another room than their spouse. Sleep disturbances due to disruptive behaviours of the individual with dementia were also assessed; the questionnaire asked caregivers to indicate both the nature of the disruptive behaviors, as well as the frequency of sleep disruption due to these behaviors. Three of the above items (items 1, 3, and 5) were modified from the Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Finally, a sixth item that was not written in the questionnaire but was asked verbally of all participants, was “During the past month, how many hours of sleep did you get at night, on average?”.

Health status. The health status of caregivers was measured using the Short Form-12 Health Survey (SF-12; see Appendix A – Part B), a 12-item generic measure of health status (Ware, Kosinski, & Keller, 1998). The SF-12 is the short version of the 36-Item Short-Form Health Survey (SF-36) (Ware, 1988) but retains the validity, reliability and responsiveness of the longer version (Ware et al., 1998). The SF-12 can be divided into physical and mental health domains, yielding separate Physical Component Summary (PCS-12) and Mental Component Summary (MCS -12) scale scores. This instrument includes one or two items from each of eight health concepts commonly

represented in widely used surveys. Four of the eight health concepts comprise the domain of physical health (PCS-12) and the other four concepts relate to the domain of mental health (MCS-12). The four concepts comprising the domain of physical health include: physical functioning (2 items), role limitations due to physical health problems (2 items), bodily pain (1 item), and general health (1 item). The concepts comprising the mental health domain (MCS-12) are as follows: vitality (energy/fatigue; 1 item), social functioning (1 item), role limitations due to emotional problems (2 items), and mental health (psychological distress and psychological well-being; 2 items).

The PCS-12 and MCS-12 summary scale scores are scored using norm-based methods. There are four steps involved in scoring the PCS-12 and MCS-12 summary scales: (1) Four items (items 1,8,9,10) are reverse scored so that a higher score indicates 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), aggregated, and (4) A constant (regression intercept) is added, and the aggregate PCS-12 and MCS-12 scores are standardized to have the same mean as SF-36 versions in the general U.S. population. Both the PCS-12 and MCS-12 scales are transformed to have a mean of 50 and a standard deviation of 10 in the general U.S. population.

The SF-12 was chosen for the present study on the basis of its brevity, the availability of normative data allowing comparisons with the general population, as well as its strong psychometric properties. Test - retest reliability coefficients of .88 and .89 have been reported for the physical summary scale, and coefficients of .76 and .78 have been reported for the mental health summary scale (Brazier, Jones, & Kind, 1993;

McHorney, Kosinski, & Ware, 1994). The items of the SF-12 are relatively heterogeneous in content, hence internal consistency reliabilities are not generally reported. In the 16 tests of validity performed to date, the SF-12 has demonstrated favorable construct and predictive validity (Ware, Kosinski, & Keller, 1996). Normative data are also available for the SF-12, allowing comparisons with the general population.

Health behaviors. Caregiver health behaviors were measured using 42 items from the Health-Promoting Lifestyle Profile (HPLP; see Appendix A – Part B) (Walker, Sechrist, & Pender, 1987). In the development of this instrument, based on the Health Promotion Model proposed by Pender (Pender, 1982), health-promoting lifestyle was viewed as a “multidimensional pattern of self-initiated actions and perceptions that serve to maintain or enhance the level of wellness, self-actualization, and fulfillment of the individual” (Walker, Sechrist, & Pender, 1987; p. 77). Six dimensions of health-promoting lifestyle identified through factor analysis are generally used as subscales: self-actualization, health responsibility, exercise, nutrition, interpersonal support, and stress management (Walker et al., 1987).

The original HPLP consists of 48 items. In the present study, only 42 of the 48 original items were used; six items were not used because they were not relevant to a sample of older adults. Respondents are asked to rate on a 4-point scale (1 = never, 2 = sometimes, 3 = often, 4 = routinely) their frequency of engaging in various health behaviours. Each item is worded as desirable or positive actions or perceptions. A total HPLP score was obtained by calculating a mean of the individual’s responses to the 42 items, with possible total scores ranging from 0 to 168. Higher scores indicate greater frequency of engaging in health-promoting behaviors.

The HPLP has demonstrated content validity and excellent internal consistency (Cronbach's alpha = .92) in large ($N > 450$) samples of community-dwelling adults (Walker et al., 1987; Walker, Volkan, Sechrist, & Pender, 1988), as well as high test-retest reliability ($r = .93$ for two-week interval). The HPLP has been used extensively in research studies, including samples of elderly persons (age 65 years and older) (Coulson, Marino, & Minichiello, 2001; Lucas, Orshan, & Cook, 2000; Walker et al., 1988) as well as rural elderly (Pullen, Walker, & Fiandt, 2001; Speake, Cowart, & Stephens, 1991).

Depression. The Center for Epidemiologic Studies - Depression Scale (CES-D; see Appendix A – Part B) (Radloff, 1977) was used to assess caregiver depression. This screening instrument is a 20-item self-report depression scale designed to identify current depressive symptomatology in the general population. The emphasis of the CES-D is on affective components of depression, including depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, and disturbances of sleep and appetite. Respondents are asked to rate the frequency with which they experienced various affective symptoms during the past week. For each item, possible responses range along a 4-point Likert-type scale from 0 = rarely or none of the time to 3 = most or all of the time. Four of the 20 items cover positive affect, and are reverse-scored. Possible total scores range from 0 to 60 with higher scores indicative of greater depressive symptomatology. Individuals scoring 16 or greater are generally considered to be at risk for developing clinical depression (Canadian Study of Health and Aging, 1994; Radloff & Teri, 1986).

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). It has also been validated in a rural sample (Husaini, Neff, Harrington, Hughes, & Stone, 1980). 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 demonstrated good reliability and validity. For instance, high internal consistency values ranging from .88 to .90 have been reported in caregiver samples (Canadian Study of Health and Aging, 1994; Pruchno & Potashnik, 1989; Pruchno & Resch, 1989; Schulz & Williamson, 1991; Williamson & Schulz, 1993).

Burden. Caregiver burden was measured with the Short version of the Zarit Burden Interview (S-ZBI; see Appendix A – Part B) (Bedard et al., 2001a). The 22-item Zarit Burden Interview (Zarit, Orr, & Zarit, 1985) is the most consistently used instrument in caregiving research (Bedard et al., 2000). The S-ZBI is a 12-item questionnaire that retains the two-factor structure (role strain and personal strain) of the original 22-item version (Bedard et al., 2001a; O'Rourke & Tuokko, 2003). Role strain refers to the demands of the caregiving role (e.g., time constraints), whereas personal strain refers to caregivers' sense of adequacy in their role. Item responses are scored on a scale ranging from 0 = never to 4 = daily; higher scores indicate greater burden. Nine items assess role burden (possible total score varies from 0 to 36) while three items assess personal burden (possible total score ranges from 0 to 12).

The S-ZBI has excellent internal consistency ($\alpha = .77$ to $.89$) and is highly correlated with the longer version ($r = .92$ to $.97$) in different situations (Bedard et al., 2001a; Hebert, Bravo, & Preville, 2000; O'Rourke & Tuokko, 2003; Whitlatch, Zarit, & von Eye, 1991).

Quality of the premorbid relationship. The quality of the pre-morbid marital relationship between the caregiver and care recipient was assessed using the Social Interaction Scale (see Appendix A – Part B) (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984). This scale asks the respondent to rate the quality of the relationship between him/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 scale consists of six items regarding the past frequency of certain social interactions. For each item the possible responses are 0 = never, 1 = sometimes, or 2 = much of the time. 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 of the items refers to a positive social interaction; "Did you laugh and joke together?". The one positive item is reverse scored, and scale scores range from a low of 0 to a high of 12. Higher scores indicate more negative perceptions of the premorbid relationship.

Leisure activities. For the measurement of leisure activities, a questionnaire used in the Canadian Study on Health and Aging (Canadian Study of Health and Aging Working Group, 1994a) was employed (see Appendix A – Part B). The questionnaire asks respondents to rate the frequency of their participation in seven different leisure activities. Each question referred to the previous summer to keep the reference season constant. Specifically, respondents were asked, "Last summer, how often did you...visit friends, go shopping, work in the garden, golf or do other sports, go for a walk, go to clubs or church, play cards?" Possible answers for each item are 0 = not at all, 1 = less than weekly, 2 = once a week, or 3 = two or more times a week.

Care recipient variables

Given the potential lack of insight among care recipients, all information about them was obtained from caregivers. The age of care recipients was obtained, as well as information about any diagnosed medical conditions and current prescription medications (see Appendix A – Part A).

Furthermore, standardized instruments were used to determine care recipients' independence in activities of daily living (ADL), frequency of problem behaviors, and level of cognitive decline. These instruments are listed below.

Dependence in ADL. Dependence in ADL was measured with the instrument developed by Lawton and Brody (see Appendix A – Part C) (Lawton & Brody, 1969). This instrument assesses dependence in “basic” (e.g., grooming; BADL) and “instrumental” ADL (e.g., using the phone; IADL). Six items comprise the BADL scale, and 8 comprise the IADL scale. The minimum and maximum scores are respectively 6 and 29 for BADL and 8 and 30 for IADL; higher scores indicate greater independence.

Behavior problems. For care recipient behavior problems the Cohen-Mansfield Agitation Inventory for Relatives (CMAI-R; see Appendix A – Part C) (Cohen-Mansfield, Werner, Watson, & Pasis, 1995) was used. This instrument is a 34-item caregiver-rated questionnaire designed to assess the frequency of manifestations of agitated behaviors in elderly persons. The CMAI-R is an expanded version of the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, Marx, & Rosenthal, 1989), also an informant rating questionnaire. Agitation has been operationally defined as “inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual” (Cohen-Mansfield

& Billig, 1986, p. 712). Agitation is not a diagnostic term, but rather a term used by clinicians for a group of symptoms that may reflect an underlying disorder (Cohen-Mansfield & Billig, 1986).

The CMAI-R consists of 34 agitated behaviors, selected on the basis of previous literature, nurses' perceptions, and input from day-care staff. The scale rates the frequency of each behavior in the preceding two weeks, using a 7-point scale as follows: 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, and 6 = several times an hour. Factor-analytic studies of the CMAI in community-dwelling elderly (Koss et al., 1997) have found the instrument to be comprised of four factors as follows: Physically nonaggressive behaviors (PNAB; e.g., general restlessness, performing repetitious mannerisms, hiding or hoarding things, inappropriate dressing or undressing), verbally nonaggressive behaviors (VNAB; e.g., relevant and irrelevant verbal interruptions, repetitive sentences or questions, constant requests for attention or help), verbally aggressive behaviors (VAB; e.g., making verbal sexual advances, cursing or verbal aggression, temper outburst, strange noises, and screaming or shouting), and physically aggressive behaviors (PAB; e.g., grabbing onto people, hitting, kicking, throwing things, intentional falling, hurting self or others). Scores for these four factors were calculated by summing the ratings for the items comprising each factor, as listed above. Maximal scores for the four factors were 48, 42, 30, and 84, respectively. Higher scores indicate greater agitation.

Inter-rater agreement rates for the CMAI range between .71 and .81 (Cohen-Mansfield et al., 1995). Also, the CMAI has demonstrated good test-retest reliability

over one month ($r = .74$ to $.92$) in a sample of community-dwelling Alzheimer's disease patients (Koss et al., 1997).

Cognitive decline. In order to approximate the level of cognitive impairment of the care recipient, an instrument was needed that could be completed by the caregiver over the telephone, without requiring the participation of the care recipient. A short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; see Appendix A – Part C) (Jorm, 1994) met this criteria. The IQCODE evaluates the presence or absence of declines by asking questions regarding the declines in 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, informants are asked to rate the subject's change in cognitive capabilities in relation to performance 10 years ago, rating change on a 5-point scale (1 = much improved, 2 = somewhat improved, 3 = not much change, 4 = a bit worse, 5 = much worse). Ratings are averaged over the 16 items to give a total score; thus total scores can range from 1 to 5. Higher scores indicate a greater decline in cognitive function over the past ten years.

The original IQCODE has 26 items, and has demonstrated high internal consistency in a general population sample ($alpha = .95$) and reasonably high test-retest reliability over one year in a dementing sample ($r = .75$) (Jorm & Jacomb, 1989). The shortened 16-item version has shown to be as effective as the longer version, with a correlation between versions of $.98$ (Jorm, 1994; Jorm, Christensen, Korten, Jacomb, & Henderson, 2000). The IQCODE has been found to discriminate well between the general population and dementing samples (Jorm & Jacomb, 1989), and has also

demonstrated sensitivity for detecting early dementia (Louis, Harwood, Hope, & Jacoby, 1999). The IQCODE has demonstrated comparable sensitivity and specificity to the Mini Mental State Exam (Jorm, 1994; Jorm, Scott, Cullen, & MacKinnon, 1991). Individuals who score in the range indicating moderate or severe cognitive decline in everyday cognitive abilities show deteriorating performance on directly administered cognitive tests after a period of 7 to 8 years, suggesting that knowledgeable informants are able to identify subtle changes in everyday abilities that precede future decline (Jorm et al., 2000).

External supports

External supports were divided according to formal (e.g., home care, respite) and informal (e.g., other family caregivers, friends) lines. The questionnaire asked the caregiver about the type of help most often received by the care recipient (formal vs. informal), and the average number of hours that the caregiver received help (from both formal and informal sources) in caring for his/her spouse (see Appendix A – Part A). The following questions and instruments were also used to assess formal and informal supports:

Formal supports. Formal supports were evaluated with general questions relevant to the setting. Caregivers were asked about the type and availability of formal supports, and the access to diagnosis and information about Alzheimer's disease in their community. The questionnaire asked about the availability of, and the caregiver's satisfaction with, facilities, services, and people in the community that could provide information and services regarding the diagnosis of Alzheimer's disease and how to deal with problem behaviours. In addition, caregivers were asked to rate the amount of information available to them about how to access support services in the area.

Caregivers were also asked about the availability of care facilities or services (such as respite and homecare) in their community, how often they used such services, and their satisfaction with the services they had received.

Informal supports. Informal supports were evaluated with the Perceived Social Support-Family (PSS-Fa) and Friends (PSS-Fr) Scales (Procidano & Heller, 1983). The PSS scales were designed to assess whether the individual perceives that his or her needs for support, information, and feedback are being met by his or her family and friends (Kane & Kane, 2000). In addition, some items measure the reciprocity of social support that the respondent provides to individuals in his or her social network (e.g., “Members of my family get good ideas about how to do things or make things from me”) (Lindsey, 1997). Validation studies have confirmed that the two measures reflect related but separate constructs, supporting the distinction between family support and friend support (Procidano, 1992). Individuals may rely on or benefit from family or friend support to different extents at different times and in different situations (Procidano & Heller, 1983), and identifying differences in the two forms of support for spousal caregivers was of particular interest in the present study.

The self-report PSS measures are composed of 20 declarative statements each. For each statement the respondent must answer “Yes”, “No”, or “Don’t know”. Many items on the PSS-Fa scale are also on the PSS-Fr scale, simply replacing “family” with “friends” (e.g., “My family gives me the moral support I need”, “My friends give my the moral support I need”). However, some items are unique to only one scale: for example, “Members of my family seek me out for companionship” is unique to the PSS-Fam scale, while “I feel that I’m on the fringe in my circle of friends” is unique to the PSS-Fr scale.

Each item is a declarative statement. For each item, the response indicative of perceived social support was scored as +1, and the responses indicative of a lack of perceived social support were scored as 0 (The “Don’t know” category was not scored). Thus, possible scores range from 0 to 20, with higher scores indicating greater levels of perceived support.

A meta-analysis of studies employing the PSS scales demonstrated support for the internal consistency of both the PSS-Fa and PSS-Fr scales, with Cronbach’s alpha values ranging from .88 to .91, and .84 to .90, respectively (Procidano, 1992). In addition, a number of studies have shown that the two scales appear to measure valid constructs that are distinct from one another (Procidano, 1992).

Design and Procedure

Participants were identified through local and regional service delivery agencies, a geriatrician, advertising, and media releases. Service delivery agencies included respite services, day programs for individuals with Alzheimer’s Disease, the Alzheimer Society, and other homecare and support services (e.g., Community Care Access Centre). Service providers identified and approached potential participants, explaining the study briefly and determining whether the participant would consent to having a research assistant contact him/her. Caregivers who agreed to have their names released were then contacted by the study investigator by phone. The study was described in more detail and informed consent was obtained verbally. Upon informed consent, the investigator and caregiver agreed to a mutually acceptable time to conduct the phone interview. A copy of the questionnaire was mailed to the caregiver in advance of the phone interview, accompanied by a cover letter providing details of the study as well as assurance

regarding confidentiality, the voluntary nature of this study, and the right to withdraw without penalty (see Appendix B).

Telephone interviews lasted just over one hour ($M = 1.12$ hours, $SD = 0.43$) minutes, although interview times ranged from 30 minutes to 2.25 hours. The researcher marked responses on the interview booklet as she conducted the interview. Following completion of the questionnaire, the researcher asked the participant an open-ended question, "Is there anything else that you would like to add that we have not already covered?". At the end of the interview, the researcher thanked the participant for his/her willingness to participate in the study. Four of the participants requested returning the completed questionnaire by mail rather than conducting the interview over the phone. The researcher contacted each of these 4 participants by phone upon receipt of the completed questionnaires to provide an opportunity for participants to ask questions or make additional comments.

A cross-sectional design was used to document differences across settings, to document the association between health status and healthy behaviors, and to investigate potential determinants of health and behaviors. These variables cover care recipient characteristics, caregiver characteristics and the health impact of caregiving, and external supports.

Results

Data screening and analyses

All data analyses were conducted using the Statistical Package for the Social Sciences (SPSS).

Missing items. There were no missing items or variables.

Outliers. Prior to analyses, univariate outliers, or extreme scores (scores more than 3.29 standard deviations above or below the mean) on each measure were identified. Only two outliers were identified: one score on the verbally aggressive behaviors (VAB) subscale of the CMAI that had a standardized score of 3.63, and one score on the physically aggressive behaviors (PAB) subscale of the CMAI with a standardized score of 3.83. Considering the expected high frequency of agitated behaviors in the population sampled, these scores were not unreasonable. As these two scores were not inordinately extreme considering the nature of the sample, they were retained and no changes were made to the raw scores. In addition, the analyses to be performed using these variables (independent samples *t*-tests and Pearson product-moment correlations) are fairly robust to the presence of one or two slightly extreme scores (Howell, 1987).

Independent t-tests. Comparisons of rural and urban residents on variables of interest were conducted using independent samples *t*-tests. Due to the number of *t*-tests performed, a significance level of .01 was used in order to minimize potential Type I errors (i.e., rejecting the null hypothesis when it is true). Levene's test for equality of variances was conducted prior to all *t*-test analyses; in cases where Levene's test was significant at the .05 level, independent *t*-values and associated significance values were reported according to calculations using unequal variances.

Chi-square tests. Comparisons of rural and urban residents on categorical variables of interest were conducted using Chi-square tests. For cases in which the contingency tables were 2 x 2, combined with small expected frequencies, the Yates correction for continuity was used. In all other cases, the reported Chi-square values are Pearson Chi-square values.

Bivariate analyses. Bivariate analyses involved assessing the predicted relationships between care recipient characteristics, caregiver characteristics, caregiver depression, and measures of general mental and physical health and health behaviors using zero-order Pearson product-moment correlation coefficients. In some cases, a point-biserial Pearson correlation was required (i.e., when correlating a dichotomous variable such as sex with a continuous variable). A significance level of .01 was used in order to minimize potential Type I errors that might result from a large number of correlations tested.

Separate correlations were performed for rural and urban caregivers so as not to contaminate the results by normal differences that might exist between the two residential settings. Because the level of one independent variable may be significantly associated with another only in one subgroup (e.g., depression may be significantly correlated with health behaviors in rural but not urban caregivers), formal comparisons of the correlation coefficients (Howell, 1987) were obtained across the two subgroups. Such formal comparisons were made only in the case where a correlation was significant at the .01 level in at least one of the subgroups. In addition, only formal comparisons that yielded significant results for two-tailed tests at the .01 level were reported, again to minimize Type I errors.

General characteristics and group descriptions

Caregiver characteristics. The sample was composed of 26 urban and 7 rural spousal caregivers. The rural caregivers resided in communities ranging in populations from less than 500 to just over 8,300. All of the urban caregivers resided in the City of Thunder Bay. However, 4 of the urban caregivers had recently moved to the City of

Thunder Bay from rural areas; these four caregivers moved to the urban area in order to be closer to family as well as to have better access to available services.

Demographic characteristics of caregivers in both rural and urban settings are presented in Table 1. There were no significant differences across settings on any of the demographic variables. The majority of caregivers in both settings were female (76 %). Caregivers ranged in age from 49 to 89 years of age ($M = 73.27$, $SD = 8.92$). All but one of the caregivers was retired. The typical caregiver had been assuming this role for an overall average of 5.11 years ($SD = 3.50$), although length of care ranged from 5 months to 15 years.

The majority of caregivers reported the presence of medical conditions (84.85 % overall) as well as current use of prescription medications (84.85 % overall). The most frequently reported medical conditions in both settings included arthritis, back problems, diabetes, heart conditions, high cholesterol levels, hypertension (high blood pressure), anxiety, and osteoporosis. No significant differences were found across settings in terms of prevalence rates of these various medical conditions.

Most caregivers participated in some form of leisure activities at least once a week. The most frequently reported leisure activities for caregivers included going shopping (87.88 %), going for a walk (72.73 %), working in the garden (63.64 %), attending clubs or church (60.61 %), and visiting friends (57.58 %). Very few caregivers participate in recreational sports such as golf; only 15.38 % of urban caregivers reported golfing or doing other sports at least once a week. Very few caregivers played cards- 61.54 % of urban caregivers, and 57.14 % of rural caregivers reported that they never

play cards. No significant differences in the frequency of leisure activities was found across settings.

Care recipients. Demographic information regarding care recipients is presented in Table 2. No significant differences were found across settings on any of the care recipient variables. The majority of the care recipients (76 % overall) were male. Care recipients ranged in age from 54 to 85 years ($M = 76.15$, $SD = 7.60$). More than 90 % of the care recipients had another serious medical condition in addition to the probable diagnosis of AD. The most frequently reported medical conditions for care recipients included arthritis, cancer, heart conditions or stroke, hypertension, and Parkinson's disease. Over 85 % of care recipients were currently taking prescription medications, either for dementia or other existing medical conditions.

The care recipients in both settings were similar regarding independence in basic and instrumental ADL, level of cognitive decline, and frequency of agitated behaviors. For ADL, the overall mean scores were 21.82 ($SD = 4.78$, range 10 to 29) for basic ADL (BADL) and 13.30 ($SD = 5.11$, range 8 to 27) for instrumental ADL (IADL). Cronbach's alpha was .87 for BADL and .85 for IADL.

The average level of cognitive decline among care recipients was 4.53 ($SD = 0.49$; range 3.25 to 5.00) out of a possible maximum score of 5, which corresponds to a rating of "severe decline" over the last ten years. There was a ceiling effect for the IQCODE scores: 84.85 % of scores were above the cutoff score of 4 indicating "severe decline". Of the remaining IQCODE scores, 6.10 % were in the range of "slight decline", and 9.09 % were in the range of "moderate decline". In the present sample, Cronbach's alpha was .93 for the IQCODE.

Overall, the frequency of reported agitated behaviors was relatively low, particularly for aggressive behaviors; the overall mean scores were 0.91 ($SD = 1.65$; range 0 to 6) out of a maximum possible 84 for the physically aggressive subscale (PAB), and 1.70 ($SD = 2.58$; range 0 to 12) out of a maximum possible 30 for the verbally aggressive subscale (VAB). For the nonaggressive behaviors, average scores were 6.36 ($SD = 6.94$, range 0 to 30) out of a maximum possible 48 for the physically nonaggressive subscale (PNAB), and a mean of 8.06 ($SD = 6.94$, range 0 to 23) out of a possible total score of 42 for the verbally nonaggressive subscale (VNAB). Cronbach's alpha for the overall CMAI scale was 0.81; alpha coefficients for the PNAB, VNAB, PAB, and VAB subscales were 0.76, 0.71, 0.55, and 0.75, respectively. The most frequently reported agitated behaviors included repetitive sentences or questions (69.69 %), general restlessness (39.39 %), relevant verbal interruptions (36.36 %), unrelated verbal interruptions (36.36 %), and hiding or hoarding things (33.33 %). These behaviors were generally rated as occurring at least once or twice a week.

Formal external supports. Availability, caregiver use of, and satisfaction with, external supports are presented in Table 3. Over 85 % of caregivers in both settings reported that formal services were available. Just over a third of caregivers used available services once or twice a week; 45.5 % of caregivers overall used services three or more times a week. However, 21.3 % of caregivers were not currently using any formal services. Rural caregivers rated the amount of information available about how to access support services significantly lower than urban caregivers, $t(31) = 16.76, p < .001$. No other significant differences emerged across settings with regard to formal supports. The most frequently reported services used in urban settings included day programs for

the care recipient, in-home day respite, and homecare services. Also, two caregivers attended a weekly support group at the Alzheimer's Society. In rural settings, services were more limited, and caregivers typically only used in-home respite services and where available, homecare services.

Caregivers were generally satisfied with the services they have received; approximately 85% of caregivers reported that they were either "satisfied" or "very satisfied" with the quality of service they have received. Approximately 73 % of caregivers were also satisfied with the amount of information they received concerning their spouse's diagnosis of probable dementia. However, 43 % of caregivers expressed uncertainty or dissatisfaction with the quality of the information they had received about how to deal with problem behaviors that might arise through the progression of their spouse's dementia. Many caregivers commented on the lack of information they had received about problem behaviors that might arise during the progression of dementia.

Overall, caregivers reported receiving a range of 0 to 29 hours of help per week ($M = 10.18$, $SD = 8.30$) from both formal and informal sources. Although there were no significant differences across settings on the amount of help received, there was a trend for male caregivers ($M = 16.44$ hours, $SD = 8.19$; range 5 to 26.50) to receive more hours of help per week than female caregivers ($M = 8.18$ hours, $SD = 7.42$; range 0 to 29), $t(31) = 2.68$, $p = .012$, although this difference was not quite significant at the .01 level. All male caregivers received at least 5 hours of help per week, while 12 % of female caregivers received 0 hours of help per week. In both settings, informal help from family and friends was the type of help most often received. However, 8 % of urban caregivers,

and 14 % of rural caregivers reported that they do not receive any help from either formal or informal sources.

Urban and rural comparisons of variables measuring the impact of caregiving

Means, standard deviations, and ranges of quantitative variables measuring the impact of caregiving are presented in Table 4. There were no significant differences between urban and rural caregivers on any of these variables. In general, most caregivers reported good health; approximately two-thirds of caregivers rated their health as *good* or *very good*. The overall average score on the healthy behaviors scale was 101.45 ($SD = 16.96$) out of a possible maximum score of 128. Cronbach's alpha was .90 for the HPLP scale in the present sample.

No significant differences were found across settings on mean scores of depressive symptoms. However, overall 13 (39.39 %) caregivers had CES-D scores greater than 16. A greater proportion of rural caregivers (57.14 %) than urban caregivers (34.62 %) had CES-D scores greater than 16, but this difference was not statistically significant, $\chi^2 (df = 1, N = 33) = 0.42, p = .518$. The value of Cronbach's alpha was .91 for the CES-D in the present sample. There was also a trend for female caregivers to report higher levels of depressive symptoms than male caregivers, $t(31) = 2.47, p = .019$, although this was not significant at the .01 level.

In general, caregivers reported receiving similar levels of support from family and friends. Overall, the average scores were 15.00 ($SD = 5.26$) on the PSS-Fa, and 12.94 ($SD = 5.93$) on the PSS-Fr. In the present sample, the value of Cronbach's alpha was .91 for the PSS-Fa and .92 for the PSS-Fr.

Caregivers reported a generally positive view of their premorbid marital relationship. Higher scores on the SIS represent more *negative* views of the premorbid relationship; in the present sample, the overall SIS mean was 3.21 ($SD = 1.93$) out of a possible 12. Although there were no significant differences across settings on ratings of the premorbid relationship, there was a significant gender difference among caregivers. Male caregivers ($M = 1.63$, $SD = 1.41$) rated their premorbid marital relationship as being significantly more positive than did female caregivers ($M = 3.72$, $SD = 1.81$), $t(31) = 2.98$, $p = .006$.

Both urban and rural caregivers reported relatively low levels of personal burden ($M = 2.76$, $SD = 2.81$ overall out of a possible 12). The mean score for role burden was 12.55 ($SD = 8.53$) out of a possible 36, representing 35 % of the possible range. However, these values for role and personal burden were comparable to those reported in the pilot study (Bedard et al., in press).

Comparisons of caregivers' ratings of physical and mental health with Canadian norms

One-sample t-tests were used to compare the means of urban and rural, as well as male and female caregivers' physical health ratings with age- and gender-matched Canadian population norms (see Table 5a). Neither urban nor rural caregivers reported significantly different ratings of physical health compared to age-matched Canadian population norms. In addition, no significant differences were found between male and female caregivers with age- and gender-matched norms of physical health scores.

Comparisons of mental health component scores with Canadian norms are presented in Table 5b. Urban caregivers reported significantly poorer mental health compared to Canadian norms, $t(25) = 3.87$, $p < .001$. There was also a trend for rural

caregivers to report poorer mental health compared to Canadian norms, but this difference was not significant at the .01 level, $t(6) = 3.46, p = .014$. Both male and female caregivers reported significantly poorer mental health ratings compared to Canadian norms, $t(7) = 3.69, p = .008$, and $t(24) = 3.97, p < .001$, respectively.

Caregiver sleep characteristics

Caregiver sleep characteristics are presented in Table 6. The typical caregiver reported an average of 6.29 ($SD = 1.59$) hours of sleep at night; the lowest reported sleep duration was 3.5 hours, and the greatest was 10 hours. The average rating of current sleep quality was 3.45, where 3 represented “good” and 4 represented “fair”. Approximately 58 % of caregivers reported that their sleep quality was “fair” or “poor”. Approximately 25 % of caregivers reported that their sleep had worsened over the past year, while just over half reported no change in their sleep quality.

Almost half of the caregivers share a bed with their spouse, while 12 % sleep in the same room, but not the same bed, and 42 % have separate rooms. Two-thirds (66.6 %) of caregivers reported that their sleep is disrupted by their spouse’s behaviors during the night. Over half of caregivers reported that their sleep is disturbed at least once a week by their spouse’s disruptive behaviors; 36 % of those caregivers actually report disruptions in their sleep three or more times a week.

The most commonly reported nocturnal problem behaviors that disrupt caregiver’s sleep are presented in Table 7. These disruptive behaviors include the care recipient needing to use the washroom (and in most cases requiring the assistance of the caregiver to do so), wandering around the house or trying to sneak out of the house, purposely awakening the caregiver with requests for attention or help during the night,

talking in his/her sleep, restlessness, disturbing dreams or nightmares, and wanting to get dressed in the middle of the night. One significant difference emerged across settings: rural caregivers were significantly more likely to have their sleep disrupted by the care recipient wandering during the night than urban caregivers, $\chi^2(1, N = 33) = 9.86$, $p = .002$.

Bivariate analyses

Healthy behaviors and health status. The third hypothesis predicted that engaging in a greater number of healthy behaviors would be positively related to physical health status. Table 8 presents the correlations among health behaviors, physical and mental health status, and depression. For both rural and urban caregivers, there was no statistically significant association between physical health status and healthy behaviors, $r(5) = .475$, $p = .281$, and $r(24) = .311$, $p = .122$, respectively. However, for urban caregivers, there was a significant association between higher levels of depressive symptoms and lower healthy behaviors, $r(24) = -.638$, $p < .001$. Formal comparisons revealed no significant differences across settings for this correlation.

For rural caregivers, higher levels of depressive symptoms were significantly associated with lower ratings of physical health, $r(5) = -.938$, $p = .002$ (see Figure 1). No significant association was found between depressive symptoms and physical health for urban caregivers, $r(24) = -.299$, $p = .137$, and formal comparisons revealed a significant difference between rural and urban caregivers for these two correlation coefficients. Finally, there was a significant association between higher levels of depressive symptoms and lower mental health ratings for both rural, $r(5) = -.901$, $p = .006$, and urban caregivers, $r(24) = -.636$, $p < .001$.

Relationship of caregiver characteristics with health behaviors and health status.

Pearson correlations among caregiver characteristics with health behaviors, health status, and depression are presented in Tables 9a and 9b, for rural and urban caregivers, respectively. For the rural sample, higher levels of role burden were significantly associated with lower ratings of physical health, $r(5) = -.938, p = .002$ (see Figure 2), and higher ratings of depressive symptoms, $r(5) = .888, p = .008$. No significant associations between role burden, physical health, and depressive symptoms were found in the urban sample. Formally comparing correlation coefficients across settings revealed a significant difference for the correlation between role burden and physical health. The correlation coefficients for role burden and depressive symptoms did not differ significantly across settings. No other caregiver characteristics were significantly correlated with health behaviors, health status, or depression for either rural or urban caregivers.

Relationship between care recipient characteristics, healthy behaviors, and health status. For the rural sample, there was a significant association between more functional limitations in basic ADL of care recipients and lower ratings of caregiver physical health, $r(5) = .895, p = .007$, as well as higher ratings of caregiver depressive symptoms, $r(5) = -.893, p = .007$. No such association was significant for urban caregivers, and no significant differences existed across subgroups for this correlation.

In the rural sample, more functional impairments in both care recipient basic and instrumental ADL were significantly associated with poorer caregiver mental health ratings, $r(5) = .909, p = .005$, and $r(5) = .939, p = .002$, respectively. None of these associations were significant for urban caregivers. Formal comparisons revealed

significant differences between rural and urban caregivers for the correlation coefficients between both basic and instrumental ADL and caregiver mental health ratings.

Caregiver sleep characteristics. Correlations among sleep variables for rural and urban caregivers were calculated. For rural caregivers, no significant correlations emerged among sleep variables. For urban caregivers, however, a number of significant bivariate associations emerged. Having more hours of sleep was significantly associated with fewer sleep disruptions, $r(24) = .621, p < .001$, and higher ratings of current sleep quality, $r(24) = -.633, p < .001$. Lower ratings of current sleep quality were significantly associated with more frequent nocturnal disruptions, $r(24) = .646, p < .001$, and more frequent care recipient verbally aggressive behaviors, $r(24) = .494, p < .010$. In addition, greater care recipient functional impairment in basic ADL was significantly related to a greater frequency of sleep disruptions for urban caregivers, $r(24) = -.507, p = .008$. No other significant correlations emerged, and no significant differences were found across settings.

Other significant bivariate relationships. A number of other significant bivariate associations emerged for urban caregivers. Higher levels of role burden were significantly associated with higher levels of physically nonaggressive, $r(24) = .523, p = .006$, and verbally nonaggressive agitated behaviors, $r(24) = .492, p = .011$, as well as more negative views of the premorbid marital relationship, $r(24) = .499, p = .009$. None of these associations were significant for rural caregivers, nor were there any significant differences across settings for these correlation coefficients.

Also in the urban sample, a significant association was found between higher levels of verbally aggressive agitated care recipient behaviors and lower levels of

perceived social support from friends, $r(24) = -.533, p = .005$, as well as poorer caregiver sleep quality, $r(24) = .494, p = .010$. These associations were not significant in the rural sample, and no significant differences were found across settings.

Among care recipient characteristics, several intercorrelations emerged for the urban sample. Higher levels of verbally nonaggressive behaviors were significantly associated with higher levels of physically aggressive behaviors, $r(24) = .520, p = .006$. Also, greater levels of cognitive decline were significantly associated with lower levels of independence in instrumental ADL, $r(24) = -.648, p < .001$. No significant correlations emerged among care recipient characteristics for the rural sample, and no significant differences were found across settings when the correlation coefficients were formally compared.

Detection of a multivariate outlier. Screening for univariate outliers prior to data analysis did not reveal the presence of a potential multivariate outlier that emerged during correlational analyses. The magnitude of the correlation coefficients for rural caregivers were exceptionally high (r 's exceeding .90) for some of the analyses performed. A closer look at the data revealed that outlying data points on scores of physical health, depressive symptoms, and role burden were all attributable to one particular rural caregiver.

Although these data points were found to be legitimate and were not detected as univariate outliers, they appeared to have a disproportionate influence on the resulting correlations. The regression analyses were run again excluding this case; although the statistical significance levels of the correlations decreased, the magnitude of the correlation coefficients was not substantially decreased. For example, the correlation between depressive symptoms and physical health, originally $r(5) = -.938, p = .002$, was

changed to $r(4) = -.766, p = .075$. As the inclusion of this potential outlier did not drastically affect the magnitude of the correlations, and increased the limited power for the small rural sample size, it was decided to retain the case in question, and no changes were made to the data analyses.

Discussion

The overall objective of the present study was to gather preliminary data in order to investigate potential differences in the caregiving experience of rural and urban spouse caregivers of individuals with dementia. In addition, potential correlates of caregiver health status, health behaviors, and sleep characteristics were examined for urban and rural caregivers. The results suggest the presence of some potentially significant differences in the impact of caregiving on rural and urban spouse caregivers. However, the results must be interpreted cautiously in light of the convenience sampling and small sample sizes. In addition, all of the rural caregivers were female, which may have confounded results. Nonetheless, the findings point to interesting issues.

Physical health and healthy behaviors

The first hypothesis, that rural caregivers would demonstrate poorer physical health and engage less frequently in healthy behaviors than urban caregivers, was not supported. In fact, no significant differences were found across settings for any caregiver, care recipient, or health variables. Overall, caregivers reported being in good physical health. Although other studies have found significant differences across residential settings, with rural residents typically reporting more chronic illnesses and poorer health than their urban counterparts (Dwyer, Lee, & Coward, 1990; Dwyer & Miller, 1990; Ortega et al., 1993), no such differences emerged in the present study. In

addition, although many studies report that caregivers generally rate their health as worse than that of noncaregivers (Baumgarten et al., 1992; Grafstrom et al., 1992; Haley, Levine, Brown, & Bartolucci, 1987), the present sample of caregivers reported physical health ratings comparable to those in an age-matched sample of Canadian elderly, in which over 75 % of elders aged 65 to 74 years rated their health as good to excellent (Rosenberg & Moore, 1997). Furthermore, no significant differences were found between caregivers' physical health ratings and age-matched Canadian norms.

Despite their generally positive ratings of physical health, however, the majority of caregivers reported the presence of chronic medical conditions. The most prevalent conditions reported were high blood pressure, arthritis, back problems, heart conditions, and diabetes. The presence of chronic conditions and aging, regardless of perceived health status, are associated with an increased use of professional healthcare services (Rosenberg & Moore, 1997). In turn, many chronic medical conditions may place elderly individuals at risk for health declines or even mortality. Hypertension in particular is a leading risk factor for coronary mortality (Dontas et al., 1993).

Overall caregivers in both settings engaged in healthy behaviors with similar frequency. At least one other study also found similar rates of healthy behaviors in rural and urban elderly residents (Speake et al., 1991). In the present sample, the overall average score on the healthy behaviors scale was 101.45, effectively representing 60 % of the possible range. This suggests that for both groups of caregivers, there remains room to improve on healthy behaviors. A recent study (Acton, 2002) found that caregivers practice significantly fewer health-promoting self-care behaviors than do noncaregivers. In addition, caregivers experience more barriers to health promotion than do

noncaregivers (Acton, 2002). This may be especially true for elderly rural caregivers. For rural older women, there is some empirical evidence that health care provider support may influence their engagement in healthy behaviors (Pullen et al., 2001) and the use of preventive (e.g., immunization) services (Pullen, Fiandt, & Noble Walker, 2001). However, the limited health care services available in rural communities may not be able to provide the support needed by these caregivers. In addition, while accessibility to health-promoting activities and programs has been cited as a barrier to engagement in healthy behaviors for elderly women (Lucas et al., 2000), it is possible that accessibility to such programs might be more limited for rural than for urban caregivers.

One of the most consistently cited health behavior changes linked to caregiving is an increase in sleep problems. Both rural and urban caregivers reported getting less than 7 hours of sleep per night, on average. This is comparable to rates reported in other caregiving studies (Gallant & Connell, 1997; Wilcox & King, 1999). Over half of caregivers rated their current sleep quality as “fair” or “poor”. In addition, 66 % of caregivers reported nighttime care recipient disruptions that occur 3 or more times per week. The most frequently reported disruptive behaviors included bathroom needs, wandering, requests for attention or help, talking in one’s sleep, restlessness, disturbing dreams and nightmares, and wanting to get dressed in the middle of the night. Rural caregivers were more likely than urban caregivers to have their sleep disrupted by the care recipient wandering during the night. The frequency of caregiver sleep disruption in both settings is of concern, as chronic sleep impairments are likely to have adverse effects on the caregiver’s physical and psychological health (Rosch, 1996), and may also

compromise the ability of the caregiver to continue providing care (Pollak & Perlick, 1991).

Thus caregivers in both settings report generally good physical health, and do not differ significantly from Canadian norms in terms of physical health. However, the presence of chronic medical conditions in both settings combined with the high frequency of sleep disruptions suggests that caregivers may be at risk for health decline. In addition, caregivers may not be engaging in an optimal number of health behaviors.

Depressive symptoms and mental health

No support was found for the hypothesis that rural caregivers would demonstrate higher levels of depressive symptoms than urban caregivers. It was also hypothesized that caregivers in both settings would demonstrate elevated levels of depressive symptoms (CES-D scores exceeding 16); overall, 39 % of caregivers had elevated levels of depressive symptoms. Other caregiving studies have also found similar rates of elevated depressive symptoms (Baumgarten et al., 1994; Canadian Study of Health and Aging Working Group, 1994b; Williamson & Schulz, 1993). In addition, urban caregivers reported significantly lower mental health scores compared to Canadian norms, and there was a similar trend for rural caregivers. These findings echo those of other caregiving studies (Schulz et al., 1995) indicating the negative mental health impacts associated with caregiving.

Both male and female caregivers had significantly lower mental health ratings than age and gender-matched norms. However, there was a trend for female caregivers to report higher levels of depressive symptoms than male caregivers, consistent with

findings from other caregiving studies (Baumgarten et al., 1992; Cohen et al., 1990; Gallant & Connell, 1997; Pruchno & Potashnik, 1989; Williamson & Schulz, 1993).

Formal external supports

Rural caregivers rated the amount of information available to them about how to access support services significantly poorer than did urban caregivers. Other studies have also cited lack of information about accessing formal and informal support services as a significant barrier for caregivers (Bowd & Loos, 1996; Bruce & Paterson, 2000; Morgan, Semchuk, Stewart, & D'Arcy, 2002). Caregivers are unable to access services if they do not know what services are available. Another study of rural caregivers in Canada (Morgan et al., 2002) emphasized the importance of having access to health care professionals who could diagnose an individual with dementia, as diagnosis is often a prerequisite for being informed about and accessing community resources. In Northwestern Ontario, community-based services for caregivers vary considerably throughout the region, and information regarding the availability of such services may only be available in certain larger communities. The majority of educational and support services are available only in Thunder Bay, making them relatively inaccessible to individuals living far away from the region's only urban center (Bowd & Loos, 1996). Combined with the barriers to accessing such services, such as distance, lack of public transportation, and poor road conditions in inclement weather (Bull, Krout, Rathbone-McCuan, & Shreffler, 2001; Neese, Abraham, & Buckwalter, 1999), rural caregivers in Northwestern Ontario likely have more difficulty in accessing both information and services than their urban counterparts.

There was also a trend for female caregivers to receive fewer hours of help than male caregivers. Other data on external supports have found that men receive more supports than women (Miller & Guo, 2000). Furthermore, the type of help received by male and female caregivers may differ: Miller and Guo (2000) also found that male caregivers, compared to female caregivers, received more emotional assistance from children, and more practical assistance from formal sources. The reasons for this differential support need to be investigated further.

Relationships among caregiver, care recipient, and health variables

The hypothesis that there would be a significant positive relationship between frequency of engaging in healthy behaviors and health status was not supported. Studies employing samples from the general population have demonstrated a significant relationship between healthy behaviors and perceived physical health status (Coulson et al., 2001; Lucas et al., 2000). In caregiving research, it is hypothesized that health behaviors may mediate the relationship between caregiver stress and long-term physical health outcomes. However, this causal relationship remains to be established among caregivers, although preliminary results do provide support for such a relationship (Gallant & Connell, 1997; Gallant & Connell, 1998). Due to the small sample size of the present study, the power to detect significant associations was limited. Longitudinal studies with larger sample sizes are required to assess these hypothesized relationships.

Although there were no significant differences across residential settings on any caregiver, care recipient, or health variables, significantly different patterns of bivariate relationships emerged among these variables for rural and urban settings. These findings

suggest some potentially important differences across residential settings; however, they must be considered in light of the convenience sampling and small sample sizes.

For rural caregivers, a number of significant correlates of physical health status emerged. No significant correlates of physical health were found for urban caregivers. Consistent with the findings from other caregiving studies, poorer ratings of physical health were associated with higher levels of depression (Hooker et al., 1992; Moritz et al., 1992; Neundorfer, 1991; Pruchno et al., 1990) and higher levels of role burden (Lawton et al., 1991; Pruchno & Resch, 1989) for rural caregivers.

The physical health ratings of rural caregivers were also significantly associated with one care recipient variable: independence in basic ADL. Lower levels of care recipient independence in basic ADL were correlated with poorer self-ratings of caregiver physical health. Although some cross-sectional studies have found no significant association between care recipient functioning and caregiver health status (Morrissey, Becker, & Rubert, 1990; Schulz et al., 1997; Schulz et al., 1995), there is some evidence that greater ADL responsibility is associated with accelerated health declines in caregivers over time (Shaw et al., 1997). In the rural sample, there was also a significant association between lower levels of care recipient functioning in both basic and instrumental ADL and lower ratings of caregiver mental health. Findings regarding the relationship of care recipient functioning and negative caregiver outcomes have been inconclusive; some document a weak association (Bedard et al., 1997; Kiecolt-Glaser et al., 1991; Russo, Vitaliano, Brewer, Katon, & Becker, 1995) while others report a stronger relationship (Baumgarten et al., 1992; Gallant & Connell, 1997).

These findings suggest that the determinants of physical and mental health of rural caregivers may differ from those of urban caregivers. It is difficult to explain why these associations exist for the rural, but not the urban, sample. The determinants of caregiver burden vary across residential settings (Dwyer & Miller, 1990), and thus perhaps so do those of caregiver physical and mental health. Perhaps differences in service and support availability and accessibility play a role in explaining why overburdened, depressed rural caregivers providing more support in ADL report poorer physical health.

However, these findings must be interpreted cautiously, as all the rural caregivers were female. Thus the determinants of caregiver health may be accounted for by a gender effect rather than a residential setting effect. A larger sample size, including male caregivers, would be required in order to further clarify these relationships.

For urban caregivers, a different pattern of correlations emerged among caregiver and health variables. Although none of these correlations were significant for rural caregivers, no significant differences existed across settings in terms of the magnitude of the correlations coefficients. This suggests the possibility of similar patterns in both settings. However, larger sample sizes would be needed to determine whether any significant differences do indeed exist.

In the urban sample, higher levels of caregiver depression were associated with lower frequency of healthy behaviors. Other studies have also found that caregivers reporting a greater number of depressive symptoms are at elevated risk for negative health behavior change (Gallant & Connell, 1997; Gallant & Connell, 1998). However,

no other variables were significantly correlated with caregiver health behaviors, nor with caregiver physical health status for urban caregivers.

Finally, for urban caregivers, a number of variables were correlated with role burden. Consistent with the findings from other studies (Gold et al., 1995; Morris et al., 1988; Williamson & Schulz, 1990; Zarit, Todd, & Zarit, 1986), urban caregivers reporting a more positive relationship with their spouse prior to the onset of the dementia reported less burden than those whose relationship had been more negative. In addition, male caregivers rated the quality of the premorbid marital relationship significantly more favourably than did female caregivers, also consistent with other studies (Shanks-McElroy & Strobino, 2001; Williamson & Schulz, 1990). The correlational and cross-sectional design of the present study precludes any statements regarding the direction of causality of these relationships. Nonetheless, these findings suggest that further study of the contributions of the prior marital relationship to caregiver burden, and in turn potential sex differences in these associations, may be useful.

Role burden in urban caregivers was also related to care recipient frequency of nonaggressive behaviors and dependence in ADL. The contributions of both ADL (Bedard et al., 2001b; Gaugler, 2000; Molloy, Lever, Bedard, Guyatt, & Butt, 1996) and especially that of behavioral problems to caregiver burden have been documented in a large number of studies (Bedard et al., 2000).

One other unexpected, but significant correlation emerged for urban caregivers between higher levels of verbally aggressive behaviors and lower levels of perceived support from friends. This relationship was not significant for rural caregivers. Many caregivers mentioned that their social life had suffered since the onset of their spouse's

illness; perhaps one reason for the decrease in socializing is a result of the increased frequency of verbally aggressive, and often unpredictable, behaviors of the care recipient. Verbally aggressive behaviors, such as making strange noises, temper outbursts, and verbal threats or insults, may understandably make even close friends feel uncomfortable. As a result, perhaps friends shy away from the care recipient (and caregiver), leading to decreased support for the caregiver from friends.

The results of the present study did not replicate the finding from the previous pilot study of a significant negative relationship between role burden and healthy behaviors for rural caregivers. However, some important differences exist between the two samples; the pilot study included adult child caregivers, while the present sample consisted only of spouse caregivers. In addition, the pilot study included male caregivers in the rural sample, while the present study did not. These results suggest that the experience of spouse caregivers in rural areas might differ from that of rural adult child caregivers. Many caregiving studies have documented significant differences in the impact of caregiving on spouse and adult child caregivers (Cohen et al., 1990; Harper & Lund, 1990; King, Atienza, Castro, & Collins, 2002; Mailick Seltzer & Li, 1996; Miller, McFall, & Montgomery, 1991; Pinquart & Sorensen, 2003). However, such direct comparisons were not made in the present study. More research is needed, comprising larger sample sizes and various sub-groups of family caregivers, in order to provide better answers to questions regarding these differential findings.

Correlates of caregiver sleep quality and disruptions

For urban caregivers, poorer sleep quality was associated with higher levels of care recipient verbally aggressive behaviors. Consistent with the findings from other

studies, greater frequency of nocturnal care recipient disruptions was associated with poorer sleep quality (Wilcox & King, 1999) and with lower levels of care recipient functioning in basic ADL (McCurry et al., 1999). In particular, providing care for basic ADL such as taking the care recipient to the bathroom may not be burdensome for caregivers during the daytime, but when their sleep is continually disrupted by having to perform such caregiving tasks during the night, these caregiving demands may take more of a toll on the caregiver's physical and psychological health.

Sleeping arrangements were not significantly associated with any other sleep variables; thus spouses sleeping in separate rooms may be just as likely as caregivers sharing a bed with their spouse to be awakened by the care recipient's behaviors. Although it has been suggested that caregivers sharing a bed with their spouse would have more sleep disruptions (McCurry, Logsdon, Vitiello, & Teri, 1998), the most frequently cited nocturnal disruptions are not those that are related to sharing a bed or a room (e.g., restlessness, talking in one's sleep), but rather demands that require the caregiver's assistance regardless of where he or she is sleeping (e.g., care recipient needing to use the bathroom, wandering, and requests for attention or help). These findings suggest that care recipient behaviors contribute to the sleep problems experienced by dementia caregivers, and that sleeping in a separate room is not necessarily a solution to sleep disruptions. Indeed, McCurry and colleagues (1998) recently examined the effects of a sleep intervention in family caregivers of individuals with dementia, and found that older female spouse caregivers were less likely to respond favourably to treatment than other caregivers. These findings suggest that older spouse caregivers may need different forms of intervention in order to improve their sleep.

Summary of present research

Spouse caregivers may represent a particularly vulnerable subgroup of caregivers. Although generally rating their physical health as good, caregivers in the present study report the presence of chronic medical conditions, as well as elevated rates of depression and lower ratings of mental health than their same-aged counterparts. In addition, frequent sleep disruptions are common. Not only are these findings of concern with respect to the impact on the caregiver's health, but these factors have also been cited as reasons for institutionalization of the care recipient (Arai et al., 2001; Brodaty & Hadzi-Pavlovic, 1990; Pollak & Perlick, 1991; Whitlatch et al., 1999).

Different correlates of physical and mental health emerged for rural and urban caregivers. For rural caregivers, higher levels of depression and burden, combined with more restricted care recipient functioning in ADL were associated with poorer physical and mental health ratings. In the urban sample, however, none of these correlations were significant. Instead, higher levels of depression were associated with a lower frequency of healthy behaviors for urban caregivers. Also, ratings of the premorbid marital relationship as poorer were associated with higher levels of role burden in urban caregivers. Caregiver sleep disruption was common in both settings. For urban caregivers, more frequent sleep disruptions were associated with poorer sleep quality and more functional impairment in care recipient basic ADL. The fact that some significant differences across settings existed despite the small sample size suggests the possibility that the caregiving experience may be different for rural than for urban caregivers.

Strengths and limitations

There are a number of strengths to the present study. First of all, using a homogeneous sample of spouse caregivers provided an opportunity to better understand the experience of this particular sub-group of caregivers. Second, few studies have investigated potential differences between rural and urban caregivers; the present study provides some evidence that further studies investigating residential differences may be warranted with larger sample sizes. Third, the present research provides preliminary data regarding the determinants of health status and health behaviors in rural caregivers, which is lacking in the empirical literature. Fourth, the present research investigated the nature and frequency of caregiver sleep disruptions due to care recipient behaviors in more detail than is typically studied.

A number of limitations to the present research must also be acknowledged. First of all, the group sample sizes were small, particularly for the rural sample. As a result of the small sample sizes, the power to detect significant differences was limited. Second, the present sample was one of convenience obtained from caregivers who are currently accessing support services. Thus the present sample may not be a true representation of the caregiver population in urban and rural areas of Northwestern Ontario. In particular, the results may not generalize to rural male caregivers. Convenience samples such as the present one often exhibit restricted variance with respect to caregiver distress, amount of care provision, and the level of impairment of the care recipient (Pinquart & Sorensen, 2003), and as a result tend to underestimate the size of association between variables. In addition, sampling caregivers from support groups and other services tends to inflate rates of depression (Malonebeach & Zarit, 1991; Neundorfer, 1991).

Third, the cross-sectional, correlational design of the present study, combined with the lack of a control group, prevents any assertions regarding causality, which would require longitudinal studies. Fourth, the use of self-report measures to assess caregiver physical and mental health may introduce reporting biases and recency effects (Wright, Clipp, & George, 1993). Also, caregiver-rated measures of care recipient functioning may not have been accurate depictions of the objective cognitive and functional status of the care recipient.

Finally, the use of a rural-urban dichotomy to identify differences among caregivers may not be the most useful distinction. Studies employing a rural-urban dichotomy have often failed to find significant differences across the two residential settings. Rural areas are very diverse, and as a result, it has been suggested that there may be as much variation within a category (e.g., rural) as between categories (Coward et al., 1994). In addition, rural-urban residence is not an accurate measure of geographic access (Fortney, Rost, & Warren, 2000), nor is it a significant predictor of the propensity to use available physical and mental health services (Fortney, Chumbler, Cody, & Beck, 2002). Utilizing residential distinctions that are more specific than the traditional rural-urban dichotomy, which take into account not only the residential location of the caregiver but also travel time to relevant formal medical and social support services may reveal more distinctions across residential settings for caregivers (Dwyer & Miller, 1990; Fortney et al., 2002).

Even in the present sample, rural caregivers resided in 4 different communities which ranged in population from less than 500 to just over 8,000. There was great variation among rural communities in terms of available services and travel time to such

services. These rural communities were also at varying distances from urban centers, or towns in which services were provided. The experience of an elderly rural caregiver living in a larger rural community with a population of approximately 8,000 with respite and social support services readily available in the community may be quite different from that of an elderly caregiver living in a rural community that has less than 500 residents and is 3-4 hours drive from the nearest urban center.

Clinical implications

Given the potential for excess physical and psychological morbidity among spouse caregivers, it is important to consider appropriate and effective interventions. It has been suggested that elderly caregivers, particularly those with health problems, may need interventions that are tailored to their unique needs (McCurry et al., 1998). Primary care physicians, other health care professionals, and support service providers may all play an important role in identifying the unique needs of individual caregivers.

Physicians and other health care professionals should routinely screen caregivers for depressive symptoms and sleep problems in addition to examining their general physical health. Providing information concerning available services and interventions for caregivers and individuals with dementia, and ensuring timely referrals to support systems are also important interventions.

However, the paucity of both health care and formal caregiver support services in rural areas means that effective intervention programs, as well as regular contact with health professionals or service providers, are not always feasible. In addition, distance and other accessibility issues may exacerbate the situation for rural caregivers and service providers. To surmount the barriers preventing rural caregivers' access to all services we

may need to use new technologies. For example, telephone conference calls have been used successfully with caregivers of individuals with traumatic brain injuries, demonstrating improvement in caregiver outcomes, including burden, comparable to “in-person” meetings (Brown et al., 1999). Tele-psychiatry has been successful with nursing homes in dealing with residents’ issues (Johnston & Jones, 2001), and along with video-conferencing and other forms of telephone technologies, may provide additional approaches to increasing support to rural caregivers, both by informing them about caregiver-relevant aspects and supporting the maintenance of physical health and healthy behaviors.

Directions for future research

The present research suggests that further study of potential differences in the health impact of caregiving for rural and urban spouse caregivers is warranted. Potential differences among male and female caregivers should also be further explored in both rural and urban settings. However, better sampling methodology is needed in order to clarify whether such differences do indeed exist. First, it would be beneficial to replicate the present study to ensure the accuracy and predictability of results by including more caregivers living in rural areas. In particular, male spouse caregivers living in rural areas should be included. In turn, more representative samples of caregivers are needed, rather than only samples of convenience. Including caregivers of various ethnic and cultural groups is also important, as caregiving may have different meanings and implications for different groups. Second, more objective measures of caregiver health status and care recipient level of cognitive and functional levels would improve the accuracy of results. Third, more refined distinctions and measures of geographic access would be useful.

Finally, longitudinal designs should be employed in order to effectively establish causal relationships among variables. This work would be an important step towards the development of new and effective models of service delivery for both urban and rural caregivers.

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Table 1

Caregiver Demographic Characteristics According to Residential Setting

Variable	Rural ^a (n = 7)	Urban ^a (n = 26)	<i>t</i> / χ^2 ^b	<i>p</i> -value ^c
Age	71.00 (10.58)	73.88 (8.55)	0.76	.456
Sex: Female	7 (100 %)	18 (69.23 %)	1.42	.234
Employment status:				
Retired	7 (100 %)	25 (96.15 %)	---	---
Years caring for spouse	5.43 (2.28)	5.03 (3.79)	0.27	.792
Medical conditions:				
Arthritis	1 (14.29 %)	10 (38.46 %)	2.74	.098
Back problems	1 (14.29 %)	5 (19.23 %)	---	---
Diabetes	2 (28.57 %)	2 (7.69 %)	0.72	.395
High cholesterol	1 (14.29 %)	3 (11.54 %)	---	---
Hypertension	4 (57.14 %)	13 (50.00 %)	---	---
“Nerves”/anxiety	2 (28.57 %)	2 (7.69 %)	1.64	.201
Osteoporosis	1 (14.29 %)	2 (7.69 %)	---	---
Prescription medication use	6 (85.71 %)	22 (84.62 %)	---	---
Leisure activities:				
Visit friends	5 (71.43 %)	14 (53.85 %)	5.34	.069
Go shopping	7 (100 %)	22 (84.62 %)	1.85	.397
Work in garden	4 (57.14 %)	17 (65.38 %)	1.63	.653
Golf/other sports	0 (0 %)	4 (15.38 %)	4.79	.188

Table 1 continued

Variable	Rural ^a (n = 7)	Urban ^a (n = 26)	t/χ^2 ^b	p -value ^c
Leisure activities (continued)				
Go for a walk	6 (85.71 %)	18 (69.23 %)	1.23	.746
Go to clubs/church	5 (71.43 %)	15 (57.69 %)	3.23	.357
Play cards	1 (14.29 %)	1 (3.85 %)	1.07	.586

^aValues are means (standard deviations) for continuous variables or frequencies (percents) for categorical variables.

^bValues are t -values (independent samples; $df = 31$) for continuous variables or Chi-square (Yates continuity correction for 2×2 contingency tables, $df = 1$) for categorical variables. Values with dashed lines (---) represent Chi-square values equal to 0.

^cProbability values (two-tailed) associated with the statistical tests.

Table 2

Care Recipient Characteristics According to Residential Setting

Variable	Rural ^a (n = 7)	Urban ^a (n = 26)	<i>t</i> / χ^2 ^b	<i>p</i> -value ^c
Age	76.43 (10.82)	76.08 (6.78)	0.11	.916
Sex: Male	7 (100 %)	18 (69.23 %)	1.42	.234
Other medical conditions	7 (100 %)	23 (88.46 %)	0.04	.840
Prescription medication use	4 (57.14 %)	25 (96.15 %)	4.64	.031
Activities of daily living				
Basic (BADL)	21.43 (5.53)	21.92 (4.67)	0.24	.812
Instrumental (IADL)	15.86 (6.52)	12.62 (4.58)	1.52	.139
Cognitive decline (IQCODE)	4.17 (0.68)	4.63 (0.38)	1.70 ^d	.133
Behavior problems (CMAI)				
Physically nonaggressive	10.43 (11.90)	5.27 (4.66)	1.12 ^d	.301
Verbally nonaggressive	8.14 (6.87)	8.04 (6.10)	0.04	.969
Physically aggressive	1.43 (2.51)	0.77 (1.37)	0.67 ^d	.525
Verbally aggressive	1.43 (1.51)	1.77 (2.82)	0.31	.762

^aValues are means (standard deviations) for continuous variables or frequencies (percents) for categorical variables.

^b Values are *t*-values (independent samples; *df* = 31) for continuous variables or Chi-square (Yates continuity correction; *df* = 1) for categorical variables.

^cProbability values (two-tailed) associated with the statistical tests.

^dReported *t*-values are those for unequal variances (Levene's test for equality of variances significant at .05 level).

Table 3

Caregiver Use of and Satisfaction With Formal External Supports

Variable	Rural ^a (n = 7)	Urban ^a (n = 26)	<i>t</i> / χ^2 ^b	<i>p</i> -value ^c
Formal supports available	6 (85.71 %)	26 (100 %)	0.51 ^d	.475
Used often (> three times a week)	3 (42.86 %)	12 (46.15 %)	1.07 ^e	.784
Satisfied with quality of service	5 (71.43 %)	23 (88.46 %)	4.21 ^e	.122
Satisfied with information about:				
Spouse's diagnosis of AD	3 (42.86 %)	21 (80.77 %)	4.35 ^e	.226
Dealing with problem behaviors	3 (42.86 %)	16 (61.54 %)	1.44 ^e	.695
How to access support services	2 (28.57 %)	24 (92.31 %)	16.76 ^e	.001
Informal help predominant	7 (100 %)	18 (69.23 %)	1.42 ^d	.234
Hours of help per week	6.86 (4.61)	11.08 (8.89)	1.71	.103

^aValues are means (standard deviations) for continuous variables or frequencies (percents) for categorical variables.

^b Values are *t*-values (independent samples; *df* = 31) for continuous variables or Chi-square values (see notes *d* and *e* below) for categorical variables.

^cProbability values (two-tailed) associated with the statistical tests.

^dChi-square values are Yates Continuity Correction values (for 2 x 2 contingency table).

^eChi-square values are Pearson Chi-Square values.

Table 4

Means (Standard Deviations), Ranges, and Independent Samples t-Tests of Caregiving Impact Variables According to Residential Setting

Variable	Rural (n = 7)		Urban (n = 26)		t-value	p-value ^a
	Mean (SD)	Range	Mean (SD)	Range		
Health status (SF-12)						
Physical health (PCS-12)	48.71 (6.64)	35.75 – 55.91	42.82 (13.60)	19.29 – 62.39	1.61 ^b	.123
Mental health (MCS-12)	35.77 (13.73)	17.38 – 55.87	45.24 (11.15)	22.32 – 64.19	1.90	.066
Health behaviors (HPLP)	95.57 (17.48)	67.00 – 124.00	103.04 (16.80)	55.00 – 129.00	1.04	.309
Depression (CES-D)	18.71 (12.55)	5.00 – 43.00	13.27 (9.37)	2.00 – 39.00	1.27	.213
Burden (SZBI)						
Role strain	15.43 (10.05)	0 – 33.00	11.77 (8.12)	0 – 28.00	1.01	.321
Personal strain	4.00 (4.28)	0 – 12.00	2.42 (2.27)	0 – 6.00	1.34	.191
Perceived social support						
Family (PSS-Fa)	15.71 (5.44)	4.00 – 20.00	14.81 (5.31)	3.00 – 20.00	0.40	.692
Friends (PSS-Fr)	11.86 (8.53)	0 – 20.00	13.23 (5.21)	0 – 20.00	0.41 ^b	.696
Quality of premorbid relationship (SIS)						
relationship (SIS)	3.43 (1.40)	1.00 – 5.00	3.15 (2.07)	0 – 7.00	0.33	.744

^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).

Table 5a

One-Sample t-Tests Comparing Caregiver Physical Health Mean Ratings With Canadian Population Norms by Residence and Sex

	Physical Component Scale (PCS)		t-value	p-value ^b
	Present Sample (SF-12)	Canadian Norms ^a (SF-36)		
Residential Setting:				
Rural ^c	48.70 (6.64)	47.20 (9.70)	0.60	.571
Urban ^d	42.82 (13.60)	47.20 (9.70)	1.64	.113
Sex:				
Male ^e	51.13 (7.79)	43.70 (10.30)	2.70	.031
Female ^f	41.81 (13.12)	46.50 (10.20)	1.79	.087

Note. For place of residence, using norms for age range = 65-74 years. For sex comparisons, using age range of ≥ 75 years for males, and 65-74 years for females.

^aSource: Hopman et al.(2000). Canadian normative data for the SF-36 health survey. *Canadian Medical Association Journal*, 163, 265-271.

^bProbability values (two-tailed) associated with the statistical tests.

^cn = 7; mean age = 71.00 years.

^dn = 26; mean age = 73.88 years.

^en = 8; mean age = 76.13 years.

^fn = 25; mean age = 72.36 years.

Table 5b

One-Sample t-Tests Comparing Caregiver Mental Health Mean Ratings With Canadian Population Norms by Residence and Sex

	<u>Mental Component Scale (MCS)</u>		<i>t</i> -value	<i>p</i> -value ^b
	Present Sample (SF-12)	Canadian Norms ^a (SF-36)		
Residential Setting:				
Rural ^c	35.77 (13.73)	53.70 (8.30)	3.46	.014
Urban ^d	45.24 (11.15)	53.70 (8.30)	3.87	.001
Sex:				
Male ^e	46.01 (6.80)	54.90 (8.00)	3.69	.008
Female ^f	42.34 (13.43)	53.00 (8.80)	3.97	.001

Note. For place of residence, using norms for age range = 65-74 years. For sex comparisons, using age range of ≥ 75 years for males, and 65-74 years for females.

^aSource: Hopman et al.(2000). Canadian normative data for the SF-36 health survey. *Canadian Medical Association Journal*, 163, 265-271.

^bProbability values (two-tailed) associated with the statistical tests.

^c $n = 7$; mean age = 71.00 years.

^d $n = 26$; mean age = 73.88 years.

^e $n = 8$; mean age = 76.13 years.

^f $n = 25$; mean age = 72.36 years.

Table 6

Caregiver Sleep Characteristics According to Residential Setting

Variable	Rural ^a (n = 7)	Urban ^a (n = 26)	<i>t</i> / χ^2 ^b	<i>p</i> -value ^c
Sleep duration (hours)	6.36 (1.63)	6.27 (1.61)	0.13	.899
Sleep quality	3.86 (1.07)	3.35 (1.09)	1.10	.279
Change in sleep quality	3.00 (1.41)	3.04 (0.77)	0.07 ^d	.947
Sleeping arrangements			1.54	.462
Same bed	3 (42.86 %)	12 (46.15 %)		
Separate beds	0	4 (15.38 %)		
Separate rooms	4 (57.14 %)	10 (38.46 %)		
Sleep disruptions due to spouse's behaviors:			3.11	.375
3 or more times a week	2 (28.57 %)	10 (38.46 %)		
1 – 2 times a week	2 (28.57 %)	5 (19.23 %)		
Less than once a week	2 (28.57 %)	2 (7.69 %)		
Not during past month	1 (14.29 %)	9 (34.62 %)		

^a Values are means (standard deviations) for continuous variables and frequencies (percents) for categorical variables.

^b Values are *t*-values (independent samples, *df* = 31) for continuous variables and Chi-square values for categorical variables.

^c Probability values (two-tailed) associated with the statistical tests.

^d Reported *t*-value is that for unequal variances (Levene's test for equality of variances significant at .05 level).

Table 7

Frequencies (Percentages) of Caregivers Citing Disruptive Nocturnal Care Recipient Problem Behaviors

	Rural (n = 7)	Urban (n = 26)
Disruptive Behavior		
Needs to use bathroom	2 (28.57 %)	10 (38.46 %)
Wandering	5 (71.43 %)	2 (7.69 %)
Requests for attention/help	1 (14.29 %)	4 (15.38 %)
Talks in sleep	1 (14.29 %)	2 (7.69 %)
Restlessness	1 (14.29 %)	3 (11.54 %)
Nightmares/bad dreams	0	2 (7.69 %)
Wants to get dressed	0	2 (7.69 %)

Table 8

Pearson Correlations Between Health Behaviors, Health Status, and Depressive Symptoms for Rural (n = 7) and Urban (n = 26) Caregivers

	<u>Physical Health</u>		<u>Mental Health</u>		<u>Depressive Symptoms</u>	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Rural Caregivers (n = 7)						
Health behaviors	.475	.281	.010	.983	-.358	.431
Health Status:						
Physical Health			.789	.035	-.938*	.002
Mental Health					-.901*	.006
Urban Caregivers (n = 26)						
Health behaviors	.311	.122	.343	.086	-.638**	.000
Health Status:						
Physical Health			-.261	.198	-.299	.137
Mental Health					-.636**	.000

Note. *r*- values are Pearson correlation values; *p*- values are two-tailed statistical significance values.

p* < .01, *p* < .001

*

Table 9a

Pearson Correlations of Caregiver and Care Recipient Variables With Health Variables for Rural Caregivers (n = 7)

	<u>Health Behaviors</u>		<u>Physical Health</u>		<u>Mental Health</u>		<u>Depressive Symptoms</u>	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Demographic Variables								
Age	.115	.806	.385	.393	.526	.225	.317	.488
Sex ^a	---	---	---	---	---	---	---	---
Caregiver Characteristics								
Role strain	-.267	.562	-.938*	.002	-.822	.023	.888*	.008
Personal strain	.568	.184	-.288	.532	-.459	.300	.350	.441
Perceived support:								
Family	.509	.244	-.258	.576	-.544	.207	.233	.615
Friends	.067	.887	-.321	.483	-.632	.128	.480	.275
Premorbid relationship	-.387	.391	-.751	.052	-.489	.266	.645	.118
Sleep duration	-.715	.071	.064	.892	.526	.226	-.211	.650
Sleep quality	.531	.220	-.332	.467	-.569	.182	.369	.415
Change in sleep quality	-.189	.685	-.623	.135	-.282	.540	.347	.445
Sleeping arrangements	.601	.153	.367	.418	-.074	.874	-.295	.521
Frequency of sleep								
Disruptions	.438	.325	-.503	.249	-.540	.211	.447	.315
Care Recipient Characteristics								
BADL	.299	.515	.895*	.007	.909*	.005	-.893*	.007
IADL	-.033	.944	.777	.040	.939*	.002	-.824	.023
Cognitive Decline	.167	.720	-.547	.203	-.371	.412	.372	.412

Table 9a (continued)

	<u>Health Behaviors</u>		<u>Physical Health</u>		<u>Mental Health</u>		<u>Depressive Symptoms</u>	
	r	p	r	p	r	p	r	p
Care Recipient Characteristics								
Agitated Behaviors:								
Physically nonaggressive	-.448	.314	-.692	.085	-.392	.384	.513	.239
Verbally nonaggressive	.620	.138	.042	.930	-.152	.744	-.079	.867
Physically aggressive	.214	.645	-.432	.332	-.605	.150	.619	.138
Verbally aggressive	.405	.367	-.323	.480	-.701	.079	.517	.235

^aAll caregivers in the rural sample were female; hence no correlations were computed between sex and other variables for rural caregivers.

* $p < .01$.

Table 9b

Pearson Correlations of Caregiver and Care Recipient Variables With Health Variables for Urban Caregivers (n = 26)

	<u>Health Behaviors</u>		<u>Physical Health</u>		<u>Mental Health</u>		<u>Depressive Symptoms</u>	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Demographic Variables								
Age	.125	.544	.156	.446	.174	.394	-.303	.132
Sex	-.322	.109	-.415	.035	-.047	.820	.437	.026
Caregiver Characteristics								
Role strain	-.309	.124	-.153	.456	-.232	.253	.347	.082
Personal strain	.160	.434	.337	.092	-.221	.278	.124	.545
Perceived support:								
Family	.136	.506	.282	.163	.016	.937	-.321	.110
Friends	.264	.193	.048	.816	.209	.305	-.171	.404
Premorbid relationship	-.352	.078	-.121	.555	-.107	.603	.189	.354
Sleep duration	.309	.124	-.107	.602	.423	.031	-.457	.019
Sleep quality	-.425	.030	-.126	.540	-.263	.195	.451	.021
Change in sleep quality	-.446	.022	.228	.264	-.328	.101	.341	.089
Sleeping arrangements	-.165	.420	.028	.893	-.288	.153	.254	.211
Frequency of sleep								
Disruptions	-.218	.285	.174	.395	-.350	.079	.311	.123
Care Recipient Characteristics								
BADL	.050	.808	.061	.766	-.008	.968	-.138	.500
IADL	.183	.372	-.015	.941	.173	.397	-.143	.486
Cognitive Decline	-.147	.473	.198	.332	-.338	.091	.189	.354

Table 9b (continued)

	<u>Health Behaviors</u>		<u>Physical Health</u>		<u>Mental Health</u>		<u>Depressive Symptoms</u>	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Care Recipient Characteristics								
Agitated Behaviors:								
Physically nonaggressive	-.035	.866	-.241	.236	.089	.667	.142	.489
Verbally nonaggressive	.027	.895	-.184	.368	.003	.990	.232	.253
Physically aggressive	.084	.683	.108	.601	-.113	.583	.164	.422
Verbally aggressive	-.077	.710	-.350	.079	-.192	.348	.243	.231

* $p < .01$

Figure Caption

Figure 1. Correlation between depressive symptoms and physical health status for rural (n = 7; top panel) and urban (n = 26; bottom panel) caregivers.

*

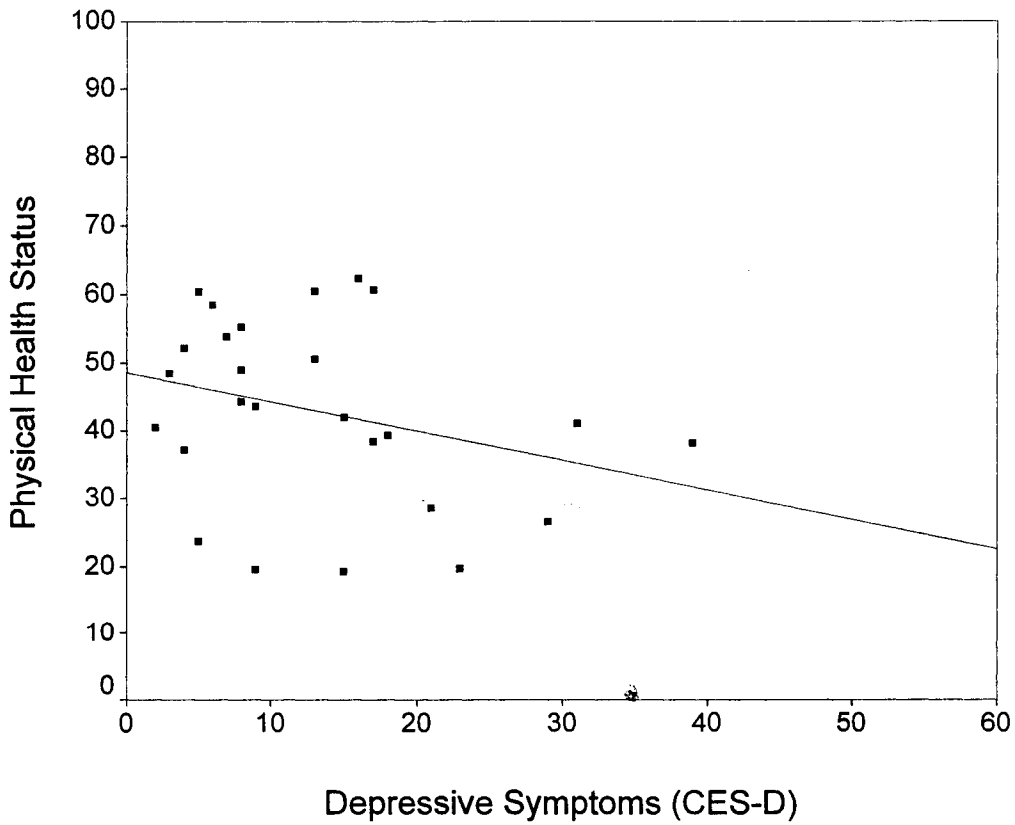
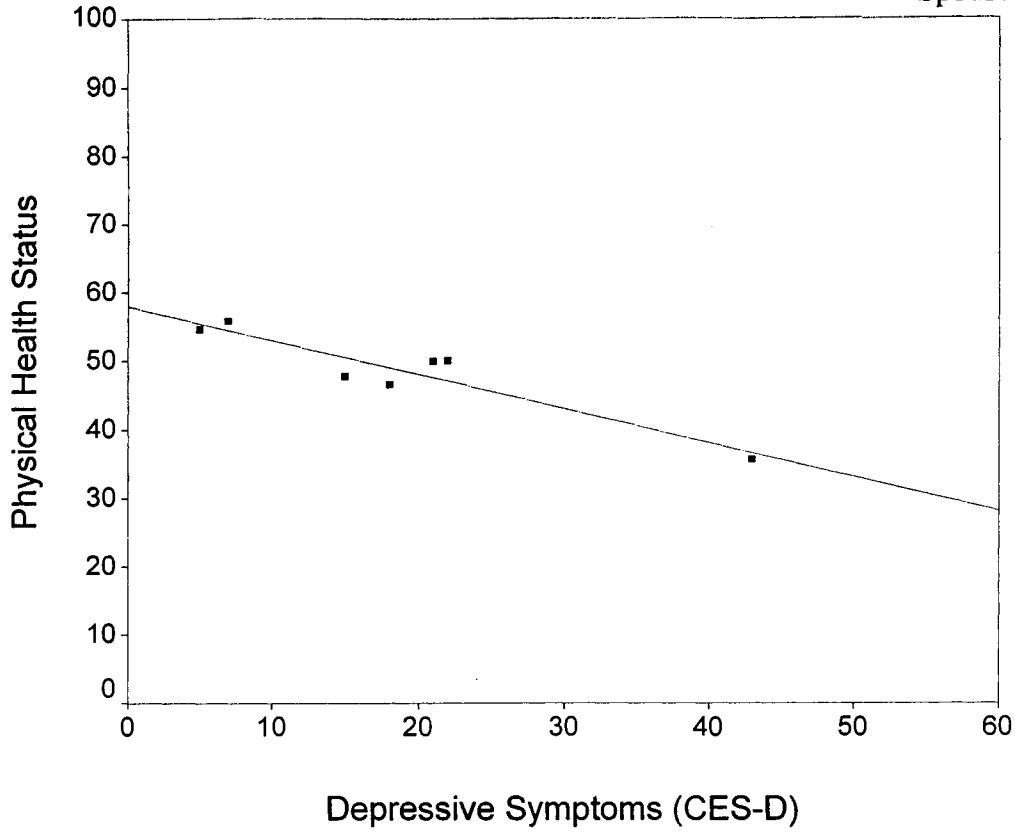
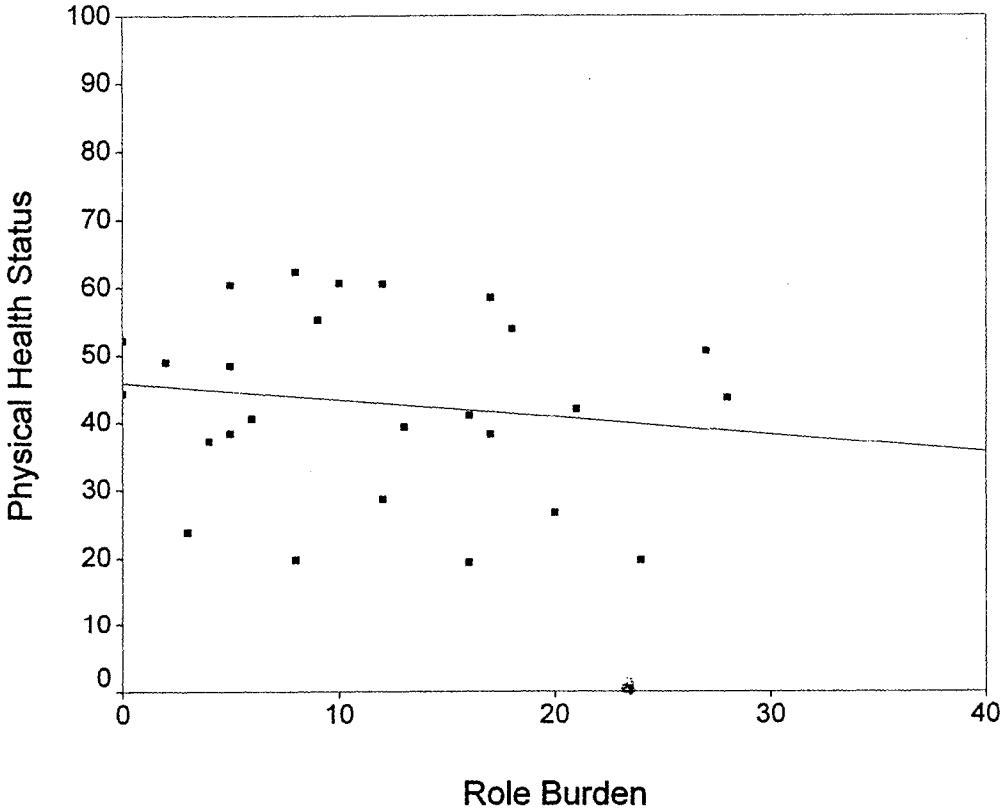
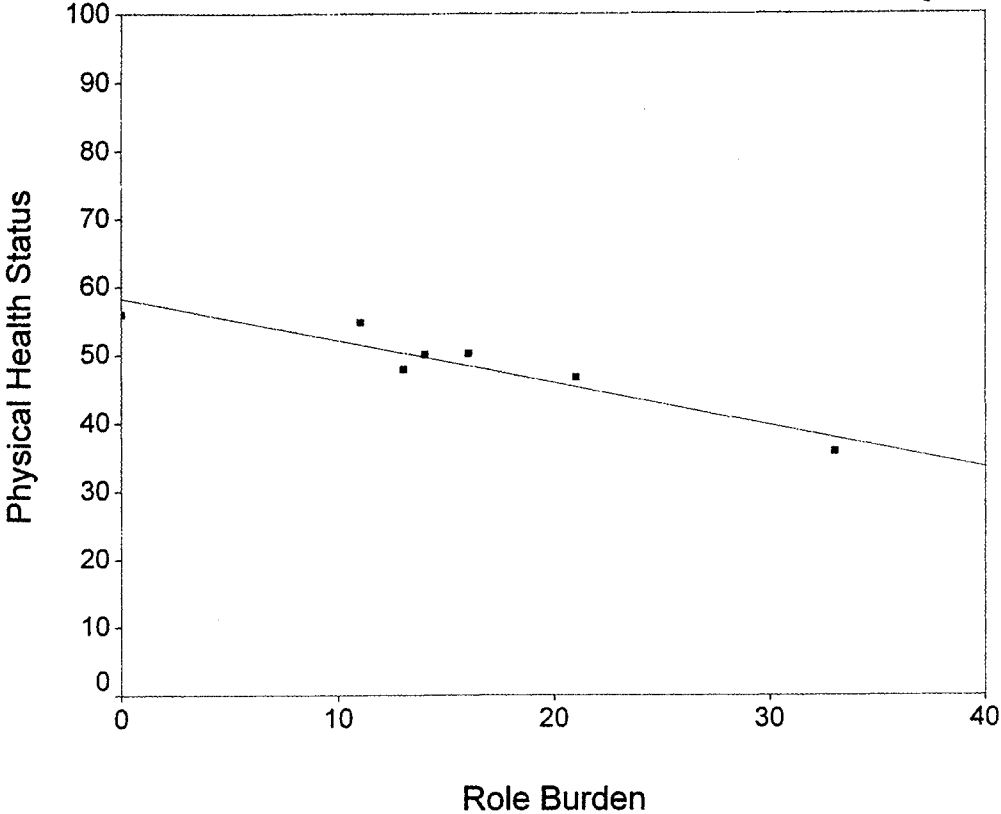


Figure Caption

Figure 2. Correlation between role burden and physical health status for rural (n = 7; top panel) and urban (n = 26; bottom panel) caregivers.

*



Appendix A
Questionnaire



ID: _____

Date: _____

Spouse Caregiving and Health: Urban and Rural Realities Study

Part A: The first set of questions I'd like to ask you addresses general information about yourself and your spouse.

Caregiver

Please provide us with the following information about yourself:

1. What is your date of birth?

_____ (dd/mm/yyyy)

2. Please indicate your sex:

₁ Male

₂ Female

3. Where do you live? (e.g. Thunder Bay, Kenora, etc.)

4. Check your current employment status:

₁ Full-time

₂ Part-time

₃ Unemployed

₄ Retired

5. How long have you been caring for the care recipient? (specify years or months)

*

6. Are there facilities, services, or people that can provide information about Alzheimer's disease available in your community?

- ₁ Yes
₂ No
₃ Don't Know

7. How satisfied are you with the amount of information you received about your spouse's diagnosis of dementia?

- ₁ Very satisfied
₂ Satisfied
₃ Not sure
₄ Dissatisfied
₅ Very dissatisfied

8. How satisfied are you with the quality of the information you received about how to deal with problem behaviours?

- ₁ Very satisfied
₂ Satisfied
₃ Not sure
₄ Dissatisfied
₅ Very dissatisfied

9. How would you rate the amount of information available to you about how to access support services in your area?

- ₁ Excellent
₂ Good
₃ Fair
₄ Poor

10.a) Are there care facilities or services (such as respite or home care) available in your community?

- ₁ Yes
- ₂ No
- ₃ Don't Know

b) If "Yes", please specify what types:

11. How often do you make use of these care facilities or 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

12. How satisfied are you with the quality of service you have received from these care facilities/ services?

- ₁ Very satisfied
- ₂ Satisfied
- ₃ Not sure
- ₄ Dissatisfied
- ₅ Very dissatisfied

13. Check the type of help that the care recipient *most* often receives:

- ₁ Formally based (professional services)
- ₂ Informal (friends and family)

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

_____ Hours

15. a) Has a healthcare professional diagnosed you with any medical conditions?

₁ Yes

₂ No

b) If “Yes”, please list any medical conditions below:

16.a) Are you currently taking any prescription medications?

₁ Yes

₂ No

b) If “Yes”, please list the medications:

Care Recipient

Please provide us with the following information about your spouse:

17. What is his/her date of birth?

_____ (dd/mm/yyyy)

18.a) Does the care recipient have any other medical conditions?

₁ Yes

₂ No

b) If “Yes”, please list his/her medical conditions below:

19.a) Is the care recipient currently taking any prescription medications?

₁ Yes

₂ No

b) If “Yes”, please list the medications:

*

Part B: The following sets of questions address topics such as your health status and health behaviours, the emotional impact of caregiving, as well as social support available to you.

Below are some questions that ask you to rate your **quality of sleep**; please check the response that best applies to you:

1. **On average, how many hours of sleep do you get at night?** _____ hours

2. **During the past month, how would you rate your sleep quality overall?**

- ₁ Excellent
- ₂ Very good
- ₃ Good
- ₄ Fair
- ₅ Poor

3. **Compared to one year ago, how would you rate your quality of sleep now?**

- ₁ Much better
- ₂ Somewhat better
- ₃ About the same
- ₄ Worse
- ₅ Much worse

4. **Does your spouse sleep:**

- ₁ In the same bed
- ₂ In the same room, but not the same bed
- ₃ In another room

5. **a) Do any of your spouse's behaviours (e.g. restlessness, wandering) disrupt your sleep during the night?**

- ₁ Yes
- ₂ No

b) If “Yes”, please specify the behaviours that disrupt your sleep:

6. During the past month, how often have you had trouble sleeping because of your spouse’s disruptive behaviours?

- ₁ Not during the past month
- ₂ Less than once a week
- ₃ Once or twice a week
- ₄ Three or more times a week

SF-12 HEALTH SURVEY (STANDARD)

INSTRUCTIONS: 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:

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Excellent | Very good | Good | Fair | 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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Climbing several flights of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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 | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Were limited in the kind of work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |

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 | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Didn't do work or other activities as carefully as usual | <input type="checkbox"/> | <input type="checkbox"/> |
8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 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? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Did you have a lot of energy? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Have you felt downhearted and blue? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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.)?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| All of the time | Most of the time | Some of the time | A little of the time | None of the time |

Healthy Lifestyle

Instructions: 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:

	Never	Sometimes	Often	Routinely
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 food containing sugar (sweets).	1	2	3	4
7. Read or watch TV programs about improving health.	1	2	3	4
8. Exercise vigorously for 20 or more minutes at least three times a week (such as brisk walking, 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 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 vegetables each day.	1	2	3	4

	Never	Sometimes	Often	Routinely
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 nuts group 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

CES-D Scale

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:

- 1 = Rarely or none of the time (Less than 1 day)**
2 = Some or a little of the time (1-2 days)
3 = Occasionally or a moderate amount of time (3-4 days)
4 = Most or all of the time (5-7 days)

During the past week:

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

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:

- 0 = NEVER**
1 = NOT IN PAST WEEK
2 = 1 OR 2 TIMES IN PAST WEEK
3 = 3 TO 6 TIMES IN PAST WEEK
4 = DAILY

DO YOU FEEL:

- | | | | | | |
|---|---|---|---|---|---|
| *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 |

Questions with a star (*) can be used as the "screening" version

Social Interaction Scale

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

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

The Perceived Social Support – Family Scale
--

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: (1) Yes, (2) No, (3) Don't know. Please circle the answer you choose for each item.

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

	Yes	No	Don't Know
15. Members of my family get good ideas about how to do things or make things from me.	1	2	3
16. When I confide in members of my family, it makes me uncomfortable.	1	2	3
17. Members of my family seek me out for companionship.	1	2	3
18. I think that my family feels that I'm good at helping them solve problems.	1	2	3
19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.	1	2	3
20. I wish my family were much different.	1	2	3

The Perceived Social Support – Friends Scale

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: (1) Yes, (2) No, (3) Don't know. Please circle the answer you choose for each item.

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

	Yes	No	Don't Know
17. I think that my friends feel that I'm good at helping them solve problems.	1	2	3
18. I don't have a relationship with a friend that is as intimate as other people's relationships with friends.	1	2	3
19. I recently got a good idea about how to do something from a friend.	1	2	3
20. I wish my friends were much different.	1	2	3

Leisure Activities During the Summer

Last summer, how often did you:

	Two or more times a week	Once a week	Less than once a week	Not at all	Don't Know
1. Visit friends:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. Go shopping:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. Work in the garden:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. Golf or do other sports:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
5. Go for a walk:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
6. Go to clubs, church:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
7. Play cards:	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Part C: Finally, we would like to ask you to answer some questions about how your spouse functions every day.

Lawton 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 Maintains the house alone, or with occasional assistance, e.g. “heavy work-domestic help”.
- ₅ 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. RESPONSIBILITY 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 dosages 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.

COHEN-MANSFIELD AGITATION INVENTORY - Relatives

We would like to ask about specific behaviors. We have listed behaviors 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 behaviors will apply to your relative. Read each of the behaviors, and circle how often (from 1 - 7) each applied to your relative over the last 2 weeks:

FREQUENCY: 1 - Never

2 - Less than once a week

3 - Once or twice a week

4 - Several times a week

5 - Once or twice a day

6 - Several times a day

7 - Several times an hour

1.	General restlessness, fidgeting, always moving around	1	2	3	4	5	6	7
2.	Performing repetitious mannerisms (tapping, rocking, rubbing)	1	2	3	4	5	6	7
3.	Pacing, aimless wandering, constantly walking back and forth (include wandering while in wheelchair)	1	2	3	4	5	6	7
4.	Trying to get to a different place (sneaking out of room, out of the house, off property)	1	2	3	4	5	6	7
5.	Handling things inappropriately (rummaging through drawers, moving furniture)	1	2	3	4	5	6	7
6.	Hiding or hoarding things	1	2	3	4	5	6	7
7.	Grabbing things from others (food from other's plate)	1	2	3	4	5	6	7
8.	Tearing things or destroying property	1	2	3	4	5	6	7
9.	Inappropriate dressing or undressing (put on clothes in strange way or take off when in public)	1	2	3	4	5	6	7
10.	Spitting, including at meals	1	2	3	4	5	6	7
11.	Eating/drinking inappropriate substances	1	2	3	4	5	6	7
12.	Grabbing onto people	1	2	3	4	5	6	7
13.	Hitting (including self)	1	2	3	4	5	6	7
14.	Kicking	1	2	3	4	5	6	7
15.	Pushing, shoving	1	2	3	4	5	6	7
16.	Throwing things, hurling, flinging	1	2	3	4	5	6	7

FREQUENCY:

- 1 - Never
 2 - Less than once a week
 3 - Once or twice a week
 4 - Several times a week
 5 - Once or twice a day
 6 - Several times a day
 7 - Several times an hour

Biting people or things	1	2	3	4	5	6	7			
Scratching people or self				1	2	3	4	5	6	7
Intentional falling (including from wheelchair or bed)	1	2	3	4	5	6	7			
Hurting self (burns, cuts, etc.)	1	2	3	4	5	6	7			
Hurting others (burns, cuts, etc.)				1	2	3	4	5	6	7
Making physical sexual advances, exposing self				1	2	3	4	5	6	7
Relevant verbal interruptions (i.e., cut short others who are speaking to relative; being rude - even if it does not seem to be intentioned)				1	2	3	4	5	6	7
Unrelated verbal interruptions (i.e., having nothing to do with ongoing conversation or activity)	1	2	3	4	5	6	7			
Repetitive sentences or questions (do not include complaining)				1	2	3	4	5	6	7
Constant requests for attention or help (nagging, pleading, calling out)				1	2	3	4	5	6	7
Verbal bossiness or pushiness				1	2	3	4	5	6	7
Complaining, whining				1	2	3	4	5	6	7
Negativism, bad attitude, doesn't like anything, nothing is right (uncooperative, refusing)				1	2	3	4	5	6	7
Cursing or verbal aggression; threatening, insulting				1	2	3	4	5	6	7
Temper outburst (verbal or non-verbal expression of anger)				1	2	3	4	5	6	7
Strange noises (weird laughter, moaning, crying)				1	2	3	4	5	6	7
Screaming, shouting, howling				1	2	3	4	5	6	7
Making verbal sexual advances				1	2	3	4	5	6	7

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Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE – Short Form)
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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 1993. 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 ten 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

Compared with ten years ago how is this person at:

	Much improved	A bit improved	Not much change	A bit worse	Much worse
15. Handling other everyday arithmetic problems, e.g., knowing how much food to buy, knowing how long between visits from family or friends	1	2	3	4	5
16. Using his/her intelligence to understand what's going on and to reason things through	1	2	3	4	5

Appendix B

Cover letter accompanying questionnaire

SPOUSE CAREGIVING AND HEALTH: URBAN AND RURAL REALITIES

Dear _____:

Thank you for agreeing to participate in a study of caregivers of adults with a memory impairment. As mentioned in the initial letter you received (and/or during our phone conversation), the researchers want to compare the experiences of caregivers who live in rural and urban areas. Some of the issues that we are interested in are the health status of you and the person you care for, support services you may use, different activities of your daily life and problems you might have caring for your family member.

As I mentioned to you over the phone, the assessment will consist of a telephone interview using tools and questionnaires. The interview will explore the issues of caregiving discussed above. Enclosed please find a copy of the questionnaires that you will be completing over the phone. As we discussed over the telephone, I will be phoning you on _____ at _____ to complete the interview. It will take approximately 1 hour for you to complete the interview.

Your participation is voluntary and you may terminate your participation at any time without affecting the quality of services you and your family member receive.

The information you provide will be treated in a confidential manner. There will be no disclosure of data to anyone other than the researchers conducting the study. In any scientific presentation or publication 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 required by ethics guidelines.

When the study has been completed, you can receive a copy of the findings by contacting the principal investigator listed below (Dr. Michel Bedard). We may contact you in coming years to see how your situation has changed.

Thank you for agreeing to participate.

Sincerely,

Joy Creese, H.B.Sc.
M.A. Candidate

Dr. Michel Bedard
Assistant Professor

Department of Psychology, Lakehead University

FOR INFORMATION OR QUESTIONS CALL:

JOY CREESE

(807) 346-4799

DR. MICHEL BEDARD, LAKEHEAD UNIVERSITY

(807) 343-8630