

Spouse and Adult Child Differences in Caregiving Burden*

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RÉSUMÉ

Cette étude a comparé les corrélats de la charge pour le conjoint et les soignants qui sont enfants adultes à deux moments dans le temps et a évalué si les corrélats de T₁ à T₂ prédit la charge. L'échantillon était constitué de 878 soignants pour les adultes plus âgés de la Colombie-Britannique auxquels on a prescrit des inhibiteurs de la cholinestérase. La charge a été mesurée six mois après la personne âgée a été prescrit le médicament et un an plus tard (*n* = 759). Les résultats suggèrent que les enfants adultes sentent plus fort la charge que les conjoints à T₁ et T₂, avec les enfants adultes, mais pas les conjoints, diminuant leur fardeau au fil du temps. Les corrélats de la charge de T₁ ont expliqué des quantités importantes de variance, révélant la corrélation différentielle pour les deux groupes et l'importance des caractéristiques des soignants sur les caractéristiques des patients. La charge au T₂ s'explique principalement par les facteurs de T₂, plus la charge de T₁, suggérant l'importance des facteurs relativement immédiats des effets directs sur la charge des soignants. Les effets indirects étaient opérationnels par la charge de T₁.

ABSTRACT

This study compared the correlates of burden for spouse and adult child caregivers at two points in time and assessed whether correlates at T₁ predicted burden at T₂. The sample consisted of 878 caregivers to older adults throughout British Columbia who were prescribed cholinesterase inhibitors. Burden was measured six months after the older adult was prescribed the medication and one year later (*n* = 759). Findings suggest that adult children experience more burden than spouses at both T₁ and T₂ with adult children but not spouses decreasing their burden over time. Correlates of T₁ burden explained significant amounts of variance, revealing differential correlates for the two groups and the importance of caregiver characteristics over patient characteristics. Burden at T₂ is explained mostly by T₂ factors, plus T₁ burden, suggesting the importance of relatively immediate factors for direct effects on caregiver burden. Indirect effects operated through T₁ burden.

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Considerable gerontological literature addresses caregiver burden, especially burden among those caring for persons with dementia. Some of this research distinguishes between spouse and adult child caregivers, although much does not. Yet caregiving can be different for these two groups; spouses are more likely to

be older, to be married, to be living with the care recipient, to have fewer competing responsibilities, and to have a different emotional relationship with the care recipient than do adult child caregivers (Pinquart & Sörensen, 2011). There is some suggestion that spouses view caregiving as normative, part of their marriage

vows (“in sickness and in health”; “until death do us part”) whereas adult child caregivers, in contrast, view caregiving as extra work and experience the burden of role reversal (caring for one’s parents) (Bastawrous, 2013; Lee & Smith, 2012). There are reasons, in other words, to suggest that the two groups differentially experience the burden of caregiving. Yet research findings are inconsistent, and Pinquart and Sörensen’s (2011) review of the literature reported no difference in overall burden but differential experiences depending on the specific type of burden (physical, relationship, emotional, etc.) examined.

Vellone, Piras, Talucci, and Cohen (2008) noted that different types of informal caregivers need to be investigated separately to better characterize differences that exist in their needs and in the challenges they encounter when caring for a relative with Alzheimer’s disease. Lee and Bronstein (2010) similarly argued that spouse and adult child caregivers should be analyzed as separate groups to better understand the role and influence of culture across these two groups. Less is known about how burden might evolve differentially over time for spouses and adult children and whether the factors affecting burden early on continue to have the same influence over time as the disease progresses. The vast majority of research on caregiver burden is cross-sectional. The few longitudinal studies that are available provide mixed results regarding change in burden over time (Garlo, O’Leary, Van Ness, & Fried, 2010). To further examine caregiver burden differences between spouses and adult children, we investigated them separately and over a 1-year period. Specifically, we considered the correlates of burden for both groups approximately six months after the care recipient was prescribed dementia medication (T_1) and one year later (T_2) and whether T_1 factors predicted burden at T_2 . Thus, the focus of our study was on a subset of those who care for persons with dementia.

Literature Review

Informal caregivers are often found to be more stressed than non-caregivers (Pinquart & Sörensen, 2003). The stresses of caregiving are well-researched, drawing on a plethora of concepts and operationalizations that are sometimes used differently and sometimes used to refer to the same concept (burden, depression, guilt, worry, anxiety, loneliness, emotional stress and strain, physical functioning, and social functioning) (Bastawrous, 2013). Nevertheless, there is now relative consensus that burden is distinct from broader concepts such as quality of life and overall well-being, and that it is specific to the caregiving role (Chappell & Reid, 2002). Burden is typically defined as the negative consequences (physical, psychological, emotional, social, and/or financial) of caregiving. Burden can be objective,

typically referring to factors such as disease or functional disability that require care (Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009), or it can refer to the physical or instrumental provision of care (such as hours of caregiving). It can be subjective, referring to the psychological and emotional strain of caregiving. Some researchers, such as Savundranayagam, Montgomery, and Kosloski (2011), have defined and measured several specific types of burden: stress burden, relationship burden, and objective burden (referring to time infringements).

The list of factors related to burden is long, yet researchers do not often distinguish the type of caregiver (spouse, adult child, child-in-law, etc.), or they study only one type of caregiver. Among the correlates are those emanating from and related to the disease itself or other objective health characteristics depicting worsening health of the care recipient. These characteristics include functional decline in terms of both activities of daily living (ADL) and independent activities of daily living (IADL) (Gallagher et al., 2011; Kim, Chang, Rose, & Kim, 2012; Lu et al., 2007;), cognitive decline (Ryan et al., 2010), and more-advanced disease stage (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Vetter et al., 1999). Some researchers suggest that, over time, caregivers may adapt and manage more effectively (Riedijk et al., 2008; Wong & Wallhagen, 2012). Other disease factors related to burden include any number of behavioural disturbances such as agitation, aggression, irritability, delusions, hallucinations, apathy, anxiety, dis-inhibition, and motor over-activity (Cheng et al., 2012; Cheng, Lam, & Kwok, 2012; Gómez-Gallego, Gómez-Amor, & Gómez-García, 2012; Leroi et al., 2012; Stella et al., 2009).

Which conditions of the disease are most relevant for burden is not clear. Gallagher et al. (2011) found that functional decline was most predictive of caregiver burden among those caring for persons with mild dementia whereas behavioural symptoms were most predictive among caregivers to those with moderate to severe dementia. However, others have found that cognitive deficit is the most burdensome in the early stages, with behavioural problems and poor IADL functioning becoming more stressful as the disease progresses (Germain et al., 2009; Ornstein et al., 2012; Yeager, Hyer, Hobbs, & Coyne, 2010; Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012). Still other researchers (Allegri et al., 2006; Zawadzki et al., 2011) have reported the greater importance of behavioural symptoms compared with cognitive or functional declines. Direct measures of the care provided, such as hours of care, have also been associated with burden (Kim et al., 2012; Pinquart & Sörensen, 2003).

Resources available to the caregiver can prevent or alleviate burden and can refer to external supports for the

caregiver, such as support from family and friends and services from the health care system, or they can refer to internal resources such as a lack of anxiety and viewing the situation more positively. External resources that are associated with more burden include a lack of informal supports (Clayburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Galvin et al., 2010), an inability to take breaks when needed (Goldsworthy & Knowles, 2008); poor relationship quality (Goldsworthy & Knowles, 2008), and the lack of receipt of formal services, including adult day services (Zarit et al., 2011).

Schoenmakers, Buntinx, and De Lepeleire's (2009) systematic review of eight studies concluded that pharmacological treatment of older adults with dementia (specifically the use of cholinesterase inhibitors [ChEI]) seems to lower caregiver burden irrespective of the actual effect of these drugs on the person with dementia. Lingler, Martire, and Schulz (2005) also revealed small benefits for burden after a review of four drug trials that included caregiver burden as an outcome. A better understanding of the differential effects and usefulness of pharmacological treatment, placebo or otherwise, on alleviating burden might have been obtained if these analyses had distinguished their results by type of caregiver.

Internal resources related to more burden include loneliness/social isolation (Mausbach, Coon, Patterson, & Grant, 2008), and what the original stress process model (Pearlin, Mullan, Semple, & Skaff, 1990) referred to as a lack of secondary intrapsychic strengths, such as competence and inner strength.

Caregiver socio-demographic factors are also important for burden. For example, when gender differences emerge, females report more burden than do males (Beeson, Horton-Deutsch, Farran, & Neundofer, 2000; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Kim et al., 2012). The same has been reported for those with fewer economic resources (Robinson, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Sun, Hilgeman, Durkin, Allen, & Burgio, 2009); less education (Navaie-Waliser et al., 2002); co-residence with the care recipient (Kim et al., 2012; Raccichini et al., 2009); and younger age (Andren & Elmstahl, 2007). The latter is often attributed to older caregivers being more likely to be spouses who have a greater commitment due to their marital vows. Information is lacking on whether differential types of resources are more important or effective for spousal compared with adult child caregivers.

Existing research comparing types of caregivers suggests such a distinction is important in characterizing caregiver burden. For example, spouses often experience less burden than others (Bookwala & Schultz, 2000), particularly spouses with more satisfying relationships

(Williams, 2011). Comparing adult child caregivers with other family caregivers, Andren and Elmstahl (2007) found that adult children are significantly more burdened, irrespective of age, and that low income is related to higher burden among adult children. Cho, Zarit, and Chiribaga (2009) found that, among women, social isolation is more of an issue for wives than daughters, but daughters experience more social disruption.

Specifically comparing spouse and adult child caregivers, Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2010) reported that spouses were less burdened than adult child caregivers, with a gender difference. From experiencing least to most burden, the order was as follows: husbands, wives, daughters, sons. Living with the care recipient results in more burden although only for adult children, but interestingly, age, physical health, or clinical characteristics of the care recipient are unrelated to burden. The lesser burden experienced by spouses may be attributed to their view of caregiving as part of their marital role whereas adult children view it as a significant change to their lives.

Other researchers report finding, however, that spouses experience more burden than adult child caregivers (Ott, Sanders, & Kelber, 2007; Hong & Kim, 2008). Kim et al. (2012) and Mohamed, Rosenbeck, Lyketsos, and Schneider (2010) reported higher burden among spouses compared with non-spousal caregivers. Based on their meta-analysis of 94 empirical studies, Pinquart and Sörensen (2011) concluded that there is no difference between spouses and adult children caregivers in overall burden but that spouses experience higher physical, financial, and relationship burden with no more emotional burden or social or job strain than do adult children. There is still much to understand about differences in burden between spouses and adult children.

Few studies have examined burden over time despite the value of longitudinal data in determining whether burden is primarily affected by more immediate circumstances or whether it is affected more or equally by distal factors and whether this differs for spouses and adult children. Garlo et al. (2010), however, found little change in caregiver burden over a 12-month period, with caregiver characteristics more strongly associated than patient characteristics with higher burden over time and the strongest association with needing more help with daily tasks. This supports Dunkin and Anderson-Hanley's (1998) conclusion, after a review of the literature, that patient characteristics are not particularly strong predictors of caregiver outcomes. To the contrary, though, Mohamed et al. (2010) reported a change in patient symptoms and behavioural problems

at six months to be the strongest correlates of change in caregiver burden.

The present article contributes to knowledge in this area by comparing levels of burden, and their correlates, among spouse and adult child caregivers, both cross-sectionally and over a 12-month period.

Methods

Data Source

Data in our study came from a larger program of research (the Alzheimer's Drug Therapy Initiative) involving five studies, one of which is the Caregiver Appraisal Study (CAS). Data reported here are from the CAS, a province-wide study in British Columbia that recruited caregivers to those with dementia as diagnosed by a physician and taking ChEI of which there are three (Aricept, Reminyl, Exelon); all are covered by the B.C. Ministry of Health's PharmaCare program. The main goal of the CAS is to assess caregivers' perceptions of the effectiveness of these drugs. In this article, we report on the burden experienced by these caregivers. The sample was recruited through referral (self, staff, physician) and through calls made by PharmaCare to notify individuals that the medications were approved for coverage for the care recipient and to inform them of the study. The caregivers were asked whether they wished to be linked by phone to the study office, to be sent a letter regarding the study, or, otherwise, to indicate that they were not interested. The sample therefore is not representative of all family caregivers caring for those with dementia or even whose care recipients are taking ChEI.

After contact was made with study personnel, potential respondents were informed about the study and asked whether they were willing to be included in a triage phone call after the care recipient had been taking the drug for at least six months. Eligibility for the triage included two conditions: caregivers were a family member providing at least three hours of care per week, and the care recipient was taking a ChEI. Of the 1,300 triages completed, 1,243 or 95.6 per cent agreed to participate in the T₁ interview; 29 were not eligible (patient deceased, not diagnosed with dementia, infrequent contact, etc.), and 28 declined the invitation for the full interview (too busy, patient too sick, caregiver too sick, etc.).

Of the 1,243 caregivers, 24.2 per cent ($n = 301$) were not interviewed (because, e.g., the patient had died, the caregiver interviewed at triage was no longer the caregiver at the time of the interview, etc.); that is, 942 caregivers were interviewed in-person at T₁, approximately six months after the care recipient had been taking the medication. Six months was chosen because that is the

time when physicians assess cognitive performance and provide a recommendation to the family on whether the individual should continue, stop, or switch the medication. Caregivers were asked to make their own assessment of the ChEI at this time as well. Subsequently, when re-contacted approximately one year later (i.e., the care recipient had been taking the ChEI for 18 months) for the T₂ interview, another 36 (2.3%) withdrew from the research (the caregiver was deceased, too ill, no longer involved, etc.) requesting removal of their T₁ data, leaving 906 as the final T₁ sample. The average length of T₁ interviews was 97.26 minutes.

For this study, we included only spouse and adult child caregivers ($n = 878$ or 96.9% of the T₁ sample). The vast majority, 69.8 per cent, were spouses; 30.2 per cent were adult children. Caregivers were interviewed again in-person one year after the first interview; 760 caregivers completed the second interview (that is, 83.8% of the T₁ sample). The T₂ interview lasted an average of 85 minutes. We began the T₁ interviews in 2008 and completed the T₂ interviews in 2012.

Measures

The dependent variable, burden, was measured using a revised version of the well-established short Zarit Burden Interview (Bédard et al., 2001), a measure of subjective burden. It consisted of 12 questions such as "Do you feel that because of the time you spend with _____, you don't have enough time to yourself?" and "Do you feel strained when you are around _____?", scored from 0 = never, 4 = daily. In this data set, internal consistency was excellent ($\alpha = 0.89$).

Independent variables referring to dementia included these: (a) disease stage (whether memory loss of the care recipient was mild or moderate/severe); (b) type of dementia (Alzheimer's, vascular, other); (c) care recipient's disability in terms of basic ADLs (bathing, dressing, toileting, transfers, continence, feeding, and phoning, $\alpha = 0.80$) and IADLs (shopping, food preparation, housekeeping, laundry, transportation, medication management, and banking, $\alpha = .83$); (d) care recipient's chronic conditions (high blood pressure/hypertension, arthritis/rheumatism, ear trouble including hearing loss, stomach/digestive problems, feet/ankle problems, depression, leg problems, allergies/sinus problems, back problems, chronic pain, thyroid problems, fatigue/sleep problems, and weight loss/gain – summed); and (e) whether s/he had incontinence problems (no, yes), sleep/fatigue problems (no, yes), or engaged in verbally agitated behaviour (no, yes).

We measured caregiving in terms of hours per week of care provided and length of time providing care in years.

External resources of the caregiver included (a) whether the caregiver received help with the care from family or friends (no, yes), (b) whether the caregiver needed family or friends to be more involved (no, yes), (c) whether s/he could take a break when needed (no, sometimes, yes), and (d) whether s/he received emotional support (no, yes). We measured expressive support with Pearlin's Expressive Support Scale. (One of the original eight items – "There is really no one who understands what you are going through" – was deleted because doing so raised α from 0.79 to 0.91). Other items included "You have someone you feel you can trust" and "There are people in your life who help you keep your spirits up" (1 = strongly agree, 4 = strongly disagree; items were summed, $\alpha = 0.91$). Also included were questions about whether the care recipient received emotional support (no, yes), and the caregiver's assessment of having a prior relationship with the care recipient (on a scale of 1 to 5, the higher the number the closer the relationship). Caregivers were asked the number of formal services received by the care recipient (0, 1, 2, 3, or more), the type of ChEI (Aricept, Reminyl, Exelon) being taken, and drug history (continuing same ChEI or switched type).

Internal caregiver resources included (a) caregiver's perceptions of their own health (scale of 1–3), (b) the number of chronic conditions the caregiver had (high blood pressure/hypertension, arthritis/rheumatism, ear trouble including hearing loss, stomach/digestive problems, feet/ankle problems, depression, leg problems, allergies/sinus problems, back problems, chronic pain, thyroid problems, fatigue/sleep problems, and weight loss/gain; these were summed), and (c) anxiety measured using the anxiety subscale of the Hospital Anxiety and Depression Scale (Mykletun, Stordal, & Dahl, 2001; Zigmond & Snaith, 1983). The latter consisted of six items asking respondents how often (coded 0–3) they experienced feelings such as "I feel tense or wound up" and "Worrying thoughts go through my mind"; $\alpha = 0.83$). Additional measures assessed whether they felt alone or isolated as a result of providing care (no, yes), and whether they felt appreciated ("On a scale of 1 to 10, with one being not appreciated at all and 10 being very appreciated, how much do you feel appreciated by the care recipient for what you do to support them?"). Caregivers were also asked about 10 pleasures or satisfactions that they might potentially derive from their caregiving (such as "Become more aware of inner strengths", "Gained personal satisfaction", and "Made new social connections"). Responses to these items were summed ($\alpha = 0.79$).

Socio-demographic variables referred to caregiver gender, age, education, how well their income satisfied their needs (coded 1–3), marital status (married/common-law, other), geographic distance (in miles) from the care

recipient, and religiosity (0–3, sum of three items, "Are you affiliated with any organized religion?", "Do you engage in spiritual or religious activities on a regular basis?", and "Do you think religious or spiritual beliefs have an impact on your caregiving?"; $\alpha = 0.81$).

Analysis Procedures

We began analyses by examining frequencies and bivariate correlations. Multivariate regression analyses (OLS [ordinary least squared]) were then used to assess the correlates of burden at T_1 and predictors of burden at T_2 . At both T_1 and T_2 , analyses were conducted for the sample as a whole, and for spouses separately and adult children separately. When burden at T_2 was the DV (dependent variable), burden at T_1 was forced into a stepwise regression before any of the independent variables (Cohen, Cohen, West, & Aiken, 2003). The data were checked for multicollinearity, linearity, and homoscedasticity. When collinearity was evident, the variables were entered into separate regression models; results appear in the tables in brackets immediately following the variable with which they are multicollinear. When skewness was evident, variables were either truncated or categories collapsed (log transformations did not remove sufficient skewness). Listwise deletion was used in all cases (in no case did missing values total more than 5%). All scales were created by summing, then dividing by the number of items answered to take into account any missing data. Only significant variables are shown in the tables.

Results

The sample was primarily Caucasian (95.7%). Table 1 shows selected characteristics of the sample at T_1 . The sample as a whole consisted primarily of spouse caregivers (69.8%) and, not surprisingly, mostly women (68.9%). However, care recipients were split evenly between men and women (49.0% women). Over half of care recipients had Alzheimer's disease (59.0%); 12.8 per cent had vascular dementia; and just over a fifth (21.9%) had a diagnosis of dementia of unknown type. In most instances, the caregiver and care recipient lived together (75.2%) which was not surprising given the number of spouses in the sample, almost all of whom (90.1%) were married. Incomes were fairly equally distributed from low (less than \$2,249 per month) to high (\$4,750 or more per month). Caregivers were, on average, 10 years younger than the person they cared for, and they provided, on average, over 24 hours of care per week.

Spouse and adult child caregivers differed in expected ways. The differences between spouse and adult child caregivers displayed in Table 1 were significant in all instances ($p < .000$) except in terms of the sex of the

Table 1: Sample caregiver characteristics at T₁

Characteristics	All Caregivers	Spouses	Adult Child
	<i>n</i> = 878	<i>n</i> = 613	<i>n</i> = 265
Caregiver is adult child	30.2		
Caregiver is husband/wife	69.8		
Sex of caregiver (female)	68.9	67.2	72.8
Sex of care recipient (female)	49.0	33.6	84.5
Alzheimer's disease diagnosis	59.0	63.4	49.3
Vascular dementia diagnosis	12.8	10.2	18.8
Caregiver and care recipient live together	75.2	92.0	36.4
Caregiver marital status (married/common-law/widowed)	90.1	99.2	69.1
Caregiver monthly income			
Less than \$2,249 per month	20.7	20.3	21.8
\$2,250 to \$3,499 per month	27.8	31.0	19.9
\$3,500 to \$4,749 per month	24.6	26.1	20.8
\$4,750 or more per month	26.9	22.6	37.5
	Range, Mean		
Hours per week caregiving	0–165, 24.74	0–165, 25.12	1–160, 23.99
Caregiver age at time of interview	28–93, 69.05	42–93, 74.27	28–87, 56.92
Care recipient age at time of interview	48–100, 79.62	48–93, 77.44	58–100, 84.64

* Spouses and adult children were significantly different on each of the characteristics ($p < .000$) except for sex of the caregiver.

caregivers; for both groups, about 70 per cent were female. Spouse caregivers were more likely to be caring for a male and for someone with a diagnosis of Alzheimer's disease, to be living with the care recipient, to be married, to have moderate income (i.e., not especially poor or wealthy), to be providing more hours of care, and to be older but caring for someone younger than were adult children caregivers (suggesting the parent care recipient was widowed).

As shown in Table 2A, adult child caregivers were significantly more likely to experience medium and high burden at T₁ whereas spouse caregivers were more likely to report low or somewhat low burden. Interestingly, over the 1-year period from T₁ to T₂, burden among adult child caregivers as a group decreased. This finding remains when restricting the analyses only to those with scores at both time periods, excluding those who dropped out after T₁ who could potentially inflate the difference since those with higher burden scores at T₁ were the adult child caregivers who tended to drop out (see Tables 2B and C) (the score is higher at T₁ [14.41] if everyone who participated at T₁ is included). Among spouses, the mean burden score does not increase significantly, from 10.24 to 10.40, if we include only those who participated at both time periods; nor does their score decrease significantly (from 10.44 to 10.40) if we take everyone from T₁ into account. Overall, the burden scores for spouses remained the same (i.e., the difference was not statistically significant).

Of note, none of the burden scores were inordinately high. The total possible score was 48. Unfortunately,

there are no theoretically or empirically established thresholds for what constitutes high burden (Garlo et al., 2010). Nevertheless, in comparative terms, adult child caregivers experienced more burden than did spouse caregivers in our sample, and adult children but not spouses experienced a change in their burden over time. Using our cut-offs (see Table 2A), determined to provide relatively equal categories, the means for spouses fell in the medium burden range. At T₁, adult children either came close (in the restricted sample) or scored within the high burden range (all T₁ participants). The decrease among adult children could reflect regression towards the mean, but the scores to begin with were relatively low.

The results of the multivariate analyses for burden at T₁ appear in Table 3. When examining the total sample, whether the caregiver was a spouse or an adult child is not significant when other factors are controlled for. However, when examining spouse and adult child caregivers separately, there are some important differences in the correlates. For the total sample, the strongest predictors were (a) needing the family to be more involved, (b) feeling lonely or isolated, (c) not feeling appreciated, (d) having to deal with the care recipient's agitated behaviours, and (e) being younger (all predictors except agitated behaviours refer to caregiver and not care recipient characteristics). Significant but less strong predictors were (a) having a prior relationship with the care recipient that was less close and (b) receiving more formal services (perhaps indicating greater care need on the part of the care recipient as well as having to co-ordinate the services and have them come into their

Table 2: Level of Burden by type of caregiverT₁ Burden by type of caregiver (%)

Burden	Caregiver: Spouse	Caregiver: Adult Child
Low (0–2)	22.0	13.8
Somewhat low (3–7)	25.9	17.7
Medium (8–13)	22.6	26.6
High (14–48)	29.5	42.3

 $\chi^2 = 24.38; df = 3; p < .001$ **T₁ Burden by type of caregiver (means)**

Caregiver	T ₁	T ₂
Spouses	10.44(.38)	10.40(.42)
Adult children	14.41(.68)	11.94(.63)

T₁ Burden, restricted sample of participants still in at T₂ (means)

Caregiver	T ₁	T ₂
Spouses	10.24(.40)	10.40(.42)
Adult children	13.78(.69)	11.94(.63)

Difference between spouses (T₁ and T₂), n.s.Difference between adult children (T₁ and T₂), $p < .001$ Difference between spouses and adult children at T₁, $p < .001$ Difference between spouses and adult children at T₂, $p < .001$

personal space, i.e., the home). Also significantly but only weakly correlated were (a) caregivers having more chronic conditions, (b) caring for someone with more chronic conditions, and (c) receiving more expressive support. In total, 43 per cent of the variance in burden at T₁ is explained.

Because over two-thirds of the sample consisted of spouses, spouses and adult children were examined separately. Spouse and adult child caregivers shared the following significant correlates: needing more family involvement, feeling lonely, feeling underappreciated, and being younger. Then they parted company. A prior relationship that was less close was significantly related to burden among spouses, as was having to care for someone with agitation or someone with sleep and fatigue problems, and who was receiving more-formal services, none of which were significant among adult child caregivers. Adult child caregivers (and only this group) were more burdened when the caregiver had fewer chronic conditions and when they could not take breaks when they believed they needed them. Taking breaks was not significantly related to burden either in the total sample or among spouse caregivers. Thus, among spouses, more caregiver characteristics were associated with burden, but three care recipient characteristics were also.

Table 3: Burden at T₁, multivariate regression analyses (betas)

IV	Total ^a	Spouse ^b	Adult Child ^c
Need family more involved	.22****	.23****	.16****
Lonely	.28****	.25****	.31****
Appreciated	-.16****	-.17****	-.20****
Caregiver chronic conditions	.07*	n.s.	-.19****
Expressive support	.07*	n.s.	n.s.
Prior relationship	-.09**	-.10	n.s.
Care Recipient chronic conditions	.06*	n.s.	n.s.
Agitated behaviour	.12****	.15****	n.s.
Formal services	.07**	.12****	n.s.
Caregiver age	-.15****	-.09**	-.17****
Breaks	n.s.	n.s.	-.19****
Care Recipient fatigue/sleep problems	n.s.	.09**	n.s.

* $p < .05$; ** $p < .01$; *** $p < .001$; **** $p < .0005$ ^a $R^2 = .43; df = 10 \text{ \& } 851; p < .0005$ When stage of dementia is included, it is significant ($r = .09; p < .01$), expressive support and care recipient chronic conditions are not; n reduces to 580^b $R^2 = .41; df = 8 \text{ \& } 578; p < .0005$ When stage of dementia is included, it is significant ($r = .15; p < .000$), care recipient fatigue/sleep problems are no longer significant; n reduces to 393^c $R^2 = .45; df = 6 \text{ \& } 264; p < .0005$

IV = independent variable.

Among adult child caregivers, however, all of the correlates refer to caregiver characteristics. In all, 41 per cent of the variance is explained among spouses; 45 per cent among adult children. Both internal and external resources emerge as important for all groups of caregivers.

For an assessment of whether these T₁ correlates also predicted burden at T₂, see the results shown in Table 4. As expected, burden at T₁ was highly correlated with burden one year later, explaining 11 per cent of the variance at T₂ in the total sample, 8 per cent among spouses, and 14 per cent among adult children. Burden at T₁ was less predictive of later burden among spouses than among adult child caregivers. For all groups, there was considerable variance left to be explained. Perhaps most noticeable is the fact that none of the correlates of burden T₁ explained change in burden over time. This does not mean that the correlates of burden at T₁ were unimportant for burden at T₂ but rather that they affected burden at T₂ indirectly, through the influence of T₁ burden. In addition, the fact that, other than T₁ burden, it was T₂ variables that were related suggests that burden may be more affected by proximate factors (other than burden at T₁).

For the sample as a whole, three care recipient or disease condition characteristics were significant although only

Table 4: Burden at T₂, multivariate regression analyses

IV	Total Sample ^a	Spouse ^b	Adult Child ^c
Burden at T ₁	.33****	.28****	.37****
Hours per week caregiving at T ₂	.07**	n.s.	n.s.
Changing caregiving demands at T ₂	.20****	.26****	.19****
Caregiver feels isolated or alone at T ₂	.12****	.10**	.14**
Caregiver feels appreciated at T ₂	-.11****	-.12****	n.s.
Caregiver can take breaks at T ₂	-.12****	-.13****	-.15**
Care recipient has sleep problems	.07**	n.s.	n.s.
Caregiver anxiety at T ₂	.26****	.26****	.22****
Care recipient chronic health problems at T ₂	n.s.	.08*	.11*

p* < .01; **p* < .0005

^a *R*² = .56; *df* = 8 & 661; *p* < .0005

^b *R*² = .54; *df* = 7 & 449; *p* < .0005

^c *R*² = .59; *df* = 6 & 238; *p* < .0005

IV = independent variable.

at the .01 level: (a) caregivers providing more hours of care per week, (b) those perceiving care demands to be increasing, and (c) those caring for persons with sleep problems at T₂ were more likely to experience more burden at T₂. All other predictors referred to caregiver characteristics, all of which explained more of the variance than any of the care recipient characteristics except perceiving increasing demands. Two internal resources – feeling isolated or lonely, and feeling unappreciated and being anxious – were associated with experiencing more burden. One external resource, being unable to take breaks when needed, was also related to more burden.

Among spouses and adult children separately, neither hours of caregiving nor sleep problems of the care recipient was significant, but perceiving increasing demands and number of care recipient chronic health conditions was; the more conditions, the more burden. Feeling more isolated and being unable to take a break remained significant for both spouses and adult children. Feeling underappreciated was significant for spouses but not adult children.

Conclusions

The fact that burden among this group of caregivers was not especially high is of note and supports earlier research indicating that, despite the attention paid to the area, most were not at the point of burn-out (Chappell & Hollander, 2013; Chappell, McDonald, & Stones, 2008). Nevertheless, among the caregivers we studied, adult children emerged as significantly more burdened than

adult spouses at both T₁ and T₂. Even though their subjective burden decreased over time while that of spouses remained stable, it did not decrease sufficiently to reduce the difference to non-significance. This finding in itself suggests the caregiving experience is very different for the two groups. The differences at T₁ confirm past research reporting lower burden for spouses (Bookwala & Schultz, 2000; Conde-Sala et al., 2010); the difference over time adds to this knowledge. The fact that the two groups differed in terms of their stage of life, relationship with the care recipient, and a number of other characteristics as demonstrated here, supports the need to examine the groups separately, which was confirmed in the differential findings for the two groups. This research supports past arguments that adult children are more likely to have multiple demands of home, interests, work, and caregiving roles which all contribute to their burden (Leggett, Zarit, Taylor, & Galvin, 2011; Williams, Skirton, Barnette, & Paulsen, 2012).

In terms of the correlates at T₁, those examined here explained a substantial amount of the variance in burden, among both groups but especially among adult children. The correlates common to both groups all referred to caregiver characteristics (i.e., the need for family to be more involved, feeling lonely as a result of the caregiving, feeling underappreciated, being younger) and referred primarily to the caregiver's internal resources. This supports Garlo et al.'s (2010) contention that efforts directed towards helping the caregivers cope with their role may well reduce burden and improve caregiver outcomes. Also found in previous research (Vetter et al., 1999; Kim et al., 2012), we found that particular to spouses, however, are several disease characteristics (agitation, sleep problems, more formal services) – and their prior relationship with the care recipient (also noted by Goldsworthy and Knowles, 2008). For adult children, only two other caregiver characteristics were significant – the caregivers' own chronic health status (they experienced less burden if they had fewer chronic conditions) and being able to take breaks when they felt they needed them. Some of the contradictory findings in past research might be attributable to not taking type of caregiver into account.

Perhaps most noticeable about the multivariate analyses conducted at T₂ is the total lack of influence of T₁ variables other than T₁ burden scores, either those correlated with T₁ burden (except indirectly through T₁ burden) or others. This suggests that burden is most directly affected by relatively immediate factors. Indeed, T₂ variables explain a significant amount of the variance on their own, suggesting the influence of the here and now experience of caregiving. Those wishing to assist caregivers to persons with dementia would be well-advised to focus on the current demands on the caregiver

and the current resources (both internal and external) available for him or her to draw upon.

While this study offers new knowledge in terms of the correlates and predictors of caregiver burden, and in terms of the distinctiveness and similarities of spouse and adult child caregivers, the sample is not representative. As such, the findings need verification in other samples of caregivers. A representative sample may find greater burden; our sample seems skewed on the basis of income. For example, caregivers of individuals with lower incomes and those belonging to ethnic minorities might well report having less access to resources; among adult children, less access to taking breaks and to accommodating employment. Furthermore, caregivers lost to attrition were those experiencing higher levels of burden over the course of the year from the first to the second interview.

How unique this sample is given that the care recipients have all been prescribed ChEI is unknown. The many randomized controlled trials (Hansen, Gartlehner, Lohr, & Kaufer, 2007; Kaduszkiewicz, Zimmermann, Beck-Bornholdt, & van den Bussche, 2006; Ringman and Cummings, 2006) carried out on the effectiveness of these drugs are inconclusive, suggesting that any benefit is small and applicable to only some for whom it is prescribed. The latter finding suggests that the sample may not be distinctive as a result of taking ChEI. No data were collected on employment of the caregiver or number of children, areas to be explored in further research. Nevertheless, the findings reported here suggest important leads for follow-up with other samples of caregivers and indicate the importance of launching more longitudinal research to increase our understanding of how burden changes over time and across types of caregivers.

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