

Caregiving: Predicting At-Risk Status*

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RÉSUMÉ

Malgré l'accent mis, lors de la recherche en gérontologie, sur les obligations en matière de prestation de soins, des études ont démontré que peu de dispensateurs de soins sont soumis à un trop lourd fardeau. Le présent article compare les prévisions des obligations particulières aux rôles et deux mesures de la qualité de vie chez les dispensateurs de soins soumis à des exigences importantes en matière de soins de santé afin d'évaluer les effets du rôle de chacun. L'étude a porté sur 92 dispensateurs communautaires de soins dans l'île de Vancouver, en Colombie-Britannique. Les prédicteurs comprenaient des facteurs primaires de stress, des ressources personnelles, et des facteurs socio-démographiques. Les exigences en matière de prestation de soins ont été la corrélation la plus significative des obligations particulières aux rôles, et elles avaient une importance indirecte en raison des obligations liées au bien-être général. La résilience avait un rapport important avec les trois résultats. Au cours de l'année de l'étude, les dispensateurs de soins se sont améliorés dans les trois résultats, mais ils n'ont pas réussi à prévoir ce changement. Les résultats suggèrent que les dispensateurs de soins peuvent être à la fois accablés et faire simultanément l'expérience d'un bien-être appréciable ou élevé, ce qui exige de ne pas généraliser à partir d'études limitées uniquement aux obligations des dispensateurs de soins lorsqu'il s'agit de présenter des recommandations sur l'ensemble de la vie de chacune de ces personnes.

ABSTRACT

Despite the focus on burden of caregiving in gerontological research, studies have shown that few caregivers are overly burdened. This article compares predictors of role-specific burden and two quality-of-life measures among caregivers experiencing heavy care demands to assess role-impact on each. The study included 92 community-based caregivers on Vancouver Island. Predictors included primary stressors, personal resources, and socio-demographic factors. Demands of caregiving emerged as the most significant correlate of role-specific burden and was important for overall well-being indirectly, through burden. Resilience was an important correlate of all three outcomes. Over the year of the study, caregivers improved in all three outcomes examined, but we were unsuccessful in predicting that change. Findings suggest caregivers can both be burdened and simultaneously experience *good* or *high* well-being, pointing to the importance of not generalizing from studies restricted only to caregiver burden in making recommendations about these people's overall lives.

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Introduction

Gerontological research has a long tradition of studying the stresses and burdens experienced by caregivers to older adults (George, 1987; Vitaliano,

Young, & Russo, 1991; Zarit, Johansson, & Jarrott, 1998). Despite an emphasis on the burden of this role, findings indicate that, at any one time, the majority of caregivers are not overly burdened

(Vitaliano, Young, & Zhang, 2004). Schulz & Williamson (1991) found that most caregivers are able to meet the demands of caregiving without becoming dysfunctional. Further, caregivers can experience burden and, at the same time, have a good quality of life or high overall well-being. That is, being burdened in the caregiver role does not translate into lower quality of life for everyone (Chappell & Reid, 2002).

The variation in caregiver burden together with the finding that caregiver burden does not necessarily mean a lower quality of life raises the question: What are the predictors of being “at risk”—in this instance, of a lower quality of life? If most informal caregivers are coping despite the demands, who is at risk? This article examines primary stressors, personal resources (social support, resilience and hardiness, and coping), and socio-demographic factors among a sample of 92 caregivers, all under heavy demands of caregiving, to identify those at risk of lower quality of life, distinguishing between role-specific and overall outcomes. Change in quality of life over a 1-year period is also examined.

Review of the Literature

Burden has enjoyed a long history of attention in gerontology research, defined over 20 years ago by George and Gwyther (1986) as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (p. 253). This popular concept is “concrete”, tied directly to the impact of caregiving on the caregiver (Chappell & Reid, 2002; Parks & Pilisuk, 1991). *Burden* is conceptualized as distinct from overall well-being or quality of life; caregivers can experience burden while reporting reasonable and even high levels of well-being (Chappell & Reid, 2002; Yates, Tennstedt, & Chang, 1999). *Overall well-being* or *quality of life* is a broader, more generic concept, encompassing major domains of life, including but not restricted to the caregiving role.

Not surprisingly, different predictors emerge as important to risk, depending on the outcome examined (specific mental and physical health outcomes, such as depression, self-perceived health, and various morbidities) and the sample of caregivers included (caring for persons with dementia, who have family members that are institutionalized, who are spouses or adult children, etc.). Nevertheless, significant predictors of caregiving outcomes fairly consistently refer to personal resources of the caregiver, the demands of caregiving, and demographic factors. Research using other outcomes is not reviewed here because our interest is in burden and well-being

(measured in terms of life satisfaction and overall stress). It is to be noted, however, that the same general findings hold (DiBartolo, 2003; Huang, Musil, Zauszniewski, & Wykle, 2006; Savage & Bailey, 2004; Sussman, 2003).

The *personal resources* of the caregiver include *social support*, which has been related to less burden and higher life satisfaction (Clayburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Goode, Haley, Roth, & Ford, 1998). Among spousal caregivers to seniors, Spaid and Barusch (1991) found helpful support alleviates caregiver stress, while adverse social contacts are associated with more strain. O’Rourke and Tuokko (2000) report that it is the perception of satisfaction with social supports rather than the amount of social support that is important. Among caregivers to seniors generally, social support from family and friends is significantly associated with caregiver ability to manage stress (Parrish & Adams, 2003) and Savage and Bailey (2004) report social support as a moderator between caregiving stress and the mental health of the caregiver. On the other hand, Barber (1988) did not find measures of social support correlated with feelings of burden among son and daughter caregivers to seniors. Among in-home spouse caregivers, Knight (1991) reports that neither quantitative nor qualitative social support is related to life satisfaction. However, Chappell and Reid (2002) found social support strongly associated with well-being but not burden.

Personality characteristics are another type of personal resource. *Resilience* has been related to caregiver outcomes (Hooker, Frazier, & Monahan, 1994), but research on resilience seldom focuses on caregivers to seniors. The few studies that have this focus measure resilience as a “good” score on outcome measures such as depression or life satisfaction or managing the role well (Ross, Holliman, & Dixon, 2003) rather than measuring it as a facet of personality (as the ability to withstand and rebound from crisis and adversity or the ability to transform disaster into a growth experience and move forward; Bergeman & Wallace, 1999) using resilience scales developed for that purpose. Some research is available on the personality characteristic of *hardiness* (commitment denoting involvement rather than detachment, control involving pro-activity rather than passivity, and challenging experiences). However, most of this research also focuses on younger persons and not caregivers to seniors (Maddi, 2002). Among caregivers to home-bound seniors, hardiness is related to having less burden (Henkle, 1994). Among caregivers to older adults, it is related to higher life satisfaction (Clark, 2002; Clark & Hartman, 1996).

Coping is a personal resource that captures how people respond to stress, such as through seeking help or problem solving. *Problem-focused* and *emotion-focused* coping are the two types most frequently cited, often as co-occurring (Baez, 2000). Less frequently reported but also popular is *seeking social support*, which is differentiated from *receiving social support*. Among caregivers to persons with Parkinson's disease, Sanders-Dewey, Mullins, and Chaney (2001) conclude that emotion-focused coping is related to distress. In a review of 16 cross-sectional and 4 longitudinal studies on coping among caregivers, Kneebone and Martin (2003) conclude that problem solving is likely advantageous to caregivers of people with dementia, but outcomes for caregivers vary from study to study. Savage and Bailey's (2004) review of the literature on the mental health of caregivers to seniors concludes that coping strategy, in general, moderates the impact of caring. This is not to deny that there are studies, such as Morano (2003), that had no findings or negative findings.

There is intuitive appeal to the hypothesis that the *demands of the role* itself have an impact. Research on the characteristics and needs of the care recipient often supports this thinking. Lévesque, Ducharme, and Lachance (1999) found that caregivers to those who are demented experience more stressors than do caregivers to those who are cognitively intact, a difference reflected in poorer outcomes. Others report that it is disturbing behaviours rather than the diagnosis of dementia per se that are most problematic (Chappell & Penning, 1996; Clayburn et al., 2000). In a review of the literature, Pinquart and Sorensen (2003) found behaviour problems more strongly related to caregiver outcomes than other stressors. Disruptive behaviour has also been found to be more stressful than co-morbidity (Parrish & Adams, 2003).

More hours of caregiving is associated with mental and psychological health problems (Wagner, 1997). Redinbaugh, Baum, Tarbell, and Arnold (2003) report that caregivers of the terminally ill using home hospice programs have greater strain when involved with recipients with more ADL needs. Hooker, Manoogian-O'Dell, Monahan, Frazier, and Shifren (2000) found that the disease of the care recipient matters differentially for wives and husbands: Wives caring for those with Alzheimer's disease have significantly worse mental health outcomes than husbands, but there is no difference in the case of those caring for persons with Parkinson's disease.

In terms of relationship with the care recipient, Barber (1988) reports that daughters have higher levels of burden than do sons who are caregiving. However,

Chumbler, Grimm, Cody, and Beck (2003) found that daughters have burden scores comparable to those of wives, sons, and husbands. Bookwala and Schulz (2000) found husbands experience fewer stressors than wife caregivers. Health of the caregiver is also potentially important. Knight (1991) finds that the caregiver's symptomatology is moderately and inversely related to life satisfaction.

Demographic factors are often insignificant as predictors of burden and/or well-being. This is the case despite the fact that women caregivers are more likely to engage in typically female tasks (preparing meals, housework, personal care, etc.) and men in more traditionally male tasks (yard work, household repairs, etc.). As an exception, Bookwala and Schulz (2000) found male spouses highly engaged in personal care. Women are considered more *social*, whether due to biological or socialization influences or both; they are believed to seek social support as a response to stress and to befriend and support others in need. Despite these differences, Chumbler et al. (2003) report no gender differences in the burden of caregivers to those with cognitive impairment.

Findings on the relevance of age are contradictory. Older caregivers often experience worse health problems of their own but may also have fewer competing demands in their lives. Henkle (1994) found older age related to burden and stress, but Spaid and Barusch (1991) report that, among spouse caregivers to seniors, the older the caregiver, the less the sense of strain because older caregivers have, in part, accepted the aging process.

Given the inconclusiveness among existing studies, the purpose of this article is to identify the predictors of caregiver at-risk status using both role-specific and general outcome measures among a sample of caregivers providing heavy care. Those providing heavy care were targeted as the most likely to be experiencing burden from caregiving and thus most likely to demonstrate a relationship between role-specific quality of life and overall quality of life. We hypothesize that personal resources and the demands of the caregiving role will differentiate those at-risk. Although we anticipate demands of the role will have greater impact on role-specific burden because of their immediacy, existing research does not provide sufficient evidence to suggest whether we are correct. Change in these outcome measures over 1 year and the predictors of that change are also examined.

Methods

Data were collected in face-to-face interviews averaging 2 hours, using structured questionnaires.

All respondents were caregivers to persons age 65 and older who were living in the community (i.e., not in an institution) at the time of referral. Data collection occurred from April 2003 to January 2004, in greater Victoria, B.C., and communities up to 1.5 hrs drive "up island" from greater Victoria. The sample was purposive, selecting caregivers providing *heavy* care (see below) through referrals from a variety of health service agencies, such as the Family Caregivers Network and the Geriatric Outreach program in the local area. Agencies were asked to refer those who met specific criteria; each referral was then screened by study personnel to ensure s/he met study criteria.

The eligibility criteria were providing a minimum of 4 hours of direct care for at least 3 days per week to a care recipient who was residing in the community (not in a facility). The criteria were established by an expert steering committee that included community caregivers as well as health care service providers who worked with seniors. The criteria exceeded the cut-off of over three (3) hrs/week that Keefe and Rosenthal (2000) found differentiated employed caregivers to elderly relatives from those providing no help, on both cultural and structural dimensions. In total, there were 103 referrals; 11 did not meet study criteria and 3 withdrew their consent due to personal circumstances, such as death of the care recipient shortly after the screening interview for the caregiver. In total, 92 caregivers were included; 52 (56.5%) resided in the Greater Victoria area and 40 (43.5%) up island.

Caregivers were re-interviewed 1 year later. Of the original 92 caregivers, at t_2 87 per cent of the original sample was interviewed; 12 caregivers did not participate at t_2 due to caregiver death, family stress, move from area, personal health, and refusal to comment. At t_2 , caregivers were providing 2 more hours of care per week on average than at t_1 ; the proportion of those living with the care recipient decreased from 63.0 per cent to 48.8 per cent; at t_2 , 21.0 per cent of care recipients were in an institution, 14.0 per cent were deceased, and 65.0 per cent remained living in the community.

Three outcomes are of primary interest: *burden* is role-specific and *life satisfaction* and *overall perceived stress* are quality-of-life measures. Burden was measured using the highly popular short Zarit Burden Inventory (ZBI), consisting of 12 items, demonstrated as being as reliable as the longer 22-item version and recommended as adequate to measure change over time (Bedard et al. 2001). On a 5-point scale, with response ratings from 0 (*never*) to 4 (*daily*), respondents are asked to rate how well the statements reflect their feelings (e.g., "Do you feel that because of the time

you spend with _____, you don't have enough time to yourself?"; "Do you feel you should be doing more for _____?"). In this study, the Cronbach's $\alpha = 0.90$ was slightly better than in previous studies (0.77 to 0.89) (O'Rourke & Tuokko, 2003).

Life satisfaction was measured with Andrews and Withey's (1976) life satisfaction scale (the Terrible Delightful scale) as modified by Michalos (1980, 1985). Respondents are asked to indicate their satisfaction with 10 potentially salient areas of their lives: health, finances, family relations, friendships, housing, partner, recreation activity, religion, self-esteem and transportation, and life as a whole. Response categories range from 1 (*terrible*) to 7 (*delightful*) for each question (range 11–77; our range 35–71). Scores are summed and divided by the number of questions answered. The Cronbach's $\alpha = 0.74$ in this present study was similar to that in other studies ($\alpha = 0.75$) (Chappell & Reid, 2002).

Perceived stress was measured using MacArthur and MacArthur's scale (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988), consisting of four questions, tapping overall stress, not caregiving-specific stress. The intent was to measure how unpredictable, uncontrollable, and overloaded respondents found their lives. For example, one question is, "In the last month, how often have you felt that you were able to control the important things in your life?" Responses range from 0 (*never*) to 4 (*very often*); scores are obtained by reverse scoring the positive items. The possible range of scores is 0 to 16; our range was 4 to 11. The Cronbach's $\alpha = 0.78$ was somewhat lower than for previous studies (0.84–0.86) but still reasonable (Cohen et al., 1983).

Social support was measured with several items. A single item asked whether respondents received unpaid assistance from anyone and if so, from how many people; it was coded as 0, 1, 2 or 3+. Another question asked whether they received emotional support from family (0 = *no*; 1 = *yes*), what their living arrangements were (number of people in household) and what their marital status was (married or not). They were asked whether their relationship with the care recipient had changed since they had begun caregiving and if so, how? Change was coded as *primarily negative* (1), *no change* (2), or *primarily positive* (3). No one said that it had not changed. The relationship of the caregiver to the care recipient was also recorded (*husband, wife, daughter, son, other*).

Coping was measured using the brief Ways of Coping scale (WOC). The WOC scale is used extensively in coping research; the brief version correlates highly

with the long version (Folkman, Lazarus, Pimley, & Novacek, 1987). It is a 31-item scale, with four response categories, 0 = *not used* to 4 = *used a great deal*. Eight separate coping strategies can be calculated: confrontive coping, seeking social support, planful problem solving, positive reappraisal, distancing, self-controlling, escape avoidance, and accepting responsibility. The number of items per scale varies. In the present study, the three most common styles of coping were computed. Problem-solving coping consisted of summing the items for confrontive coping and planful coping ($\alpha = 0.69$). An emotion-focused scale combined distancing coping, control, accepting responsibility, escape, and reappraisal ($\alpha = 0.72$). Because emotion-focused coping includes both negative- and positive-focused emotions, separate scales also measured each: negative emotion-focused coping included distancing, control, and escape ($\alpha = 0.62$); positive emotion-focused coping included accepting responsibility and reappraisal ($\alpha = 0.64$). Seeking social support consisted of the original 5 items comprising this scale in the WOC scale ($\alpha = 0.75$). Items include, for example, "talked to someone to find out more about the situation" and "I accepted sympathy and understanding from someone". The alphas obtained for the scales used here were typical of these measures, which the originators of the scales argue appropriately reflect their conceptualization.

Wagnild & Young's (1990, 1993) resilience scale has excellent psychometric properties and is applicable to most population samples (Ahern, Kiehi, Sole, & Byers, 2006). It is a 25-item measure of the positive emotional stamina people rely on to manage difficult life events. It uses a 7-point scale from 1 (*disagree*) to 7 (*agree*); a higher score indicates more resilience. The alpha reported here (0.92) is within the range found in other studies (Humpreys, 2003; Hunter & Chandler, 1999). The Family Hardiness Index (McCubbin & Thompson, 1991) is a 20-item scale with four subscales (commitment, confidence, challenge, and control), but the overall score has been shown to be the best indicator of hardiness. It uses a 4-point scale from 0 (*false*) to 3 (*totally true*). The scale has been reported to have excellent internal consistency (0.85 in this sample) and test/re-test reliability (Giallo & Gavidia-Paynbe, 2006).

Demands of caregiving were measured in terms of the health of the caregiver, the health of the care recipient, and other characteristics of the caregiving task. Health of the caregiver included chronic conditions. Each respondent was asked, "For each problem that I read, please tell me if this health issue is something that you are currently managing or facing in your life?" Conditions read to them included high blood pressure

or hypertension (with or without medication), coronary heart disease, stroke or effects of stroke, paralysis or paraplegia, Parkinson's disease, other neurological problems, eye trouble not relieved by glasses, ear trouble including hearing loss, and so on, with a total of 36 health problems. The results were summed. Perceived health was measured with the standard question, "For your age, would you say, in general, your health is excellent, good for your age, fair for your age, poor for your age or bad for your age?" *Poor* and *bad* response categories had so few responses that they were combined.

Functional disability of the care recipient was measured in terms of the level of assistance s/he required with her or his daily activities, coded as *no assistance required* or *requires assistance* for a list of 14 activities of daily living, such as bathing, toileting, using the telephone, transportation, and financial responsibilities ($\alpha = 0.78$). Chronic conditions of the care recipient were asked using the same question as above but in reference to the care recipient. Behavioural problems of the care recipient were coded into three categories: verbal agitation, physically non-aggressive, and physically aggressive behaviour (*no* = 0; *yes* = 1 for each). The mental health of the care recipient was solicited with the question, "Are there any mental health issues facing the care recipient?" (*no* = 0; *yes* = 1).

In addition, caregivers were asked how many years they had been providing care (coded in years), how many hrs/week they spent caregiving, and whether they had given up any recreational activities due to their caregiving (0 = *no*; 1 = *yes*).

Sex (male, female) and age (left continuous) were also included.

Analyses

Multiple regression analyses were conducted with each of the three outcomes as dependent variables (DV). Because of the small sample size, relative to the number of independent and control variables, each group of independent variables (IVs) was entered into a separate regression (for each of demographic factors, social support, personality, and demands of caregiving), thus meeting acceptable standards for ratios of observations to independent variables (Bartlett et al., 2001; Miller & Kunce, 1973). Only those variables that were statistically significant at the 0.05 level were entered into a final regression for each DV, shown here. Data were examined for co-linearity, linearity, homoscedasticity, and normality.

Change was computed using the Reliability Change Index (RCI) consisting of $t_2 - t_1 / SE_{meas}$. This classical

approach is suitable when there is no known intervening variable between t_1 and t_2 ; it does not require uniform distribution of the data and rules out a high probability of measurement error. It provides an assessment of whether the change in scores is reliable (Maassen, 2004; Wu & Hart, 2002).

Regression analyses were also conducted to assess the predictors of change, wherein t_2 of the DV was the dependent variable, with t_1 entered first into the equation. Variance explained after the removal of t_1 refers to change. t_1 independent and control variables were entered in blocks as per above. Then t_2 IVs were added as a block after those significant at t_1 were entered. The t_2 IVs included care recipient status at t_2 (*remains in the community, now institutionalized, deceased*) and change in care recipient's behavioural problems, ADLs, and chronic conditions; as well as caregiver's chronic conditions, resilience, and hardiness. All other change variables were removed from the assessment because they did not demonstrate significant and reliable change as assessed using the RCI.

Results

Females constituted the majority of the sample (68.5%), with male caregivers comprising less than a third (see Table 1). At t_1 , most caregivers were married (83.3%); half were caring for a spouse (50.0%). These caregivers were relatively highly educated, with 28.3 per cent having a bachelor degree or more and 23.9 per cent a college diploma or associate degree. Their average age was 60.7 years and the average age of the

care recipient was 80.1 years. On average, caregivers in this study had been providing care for 8 years and provided 86 hours of care per week, representing full-time—often 24/7—care, far exceeding the minimum set for the study. Almost two thirds (63.0%) lived with the person to whom they were providing care. This non-representative sample included only caregivers who were experiencing heavy demands, as intended.

The three dependent variables are related but are different. Perceived stress and life satisfaction share 20 per cent of the variance ($r=0.45$), leaving 80 per cent that is different. Burden and perceived stress share 19 per cent ($r=0.44$) and burden and life satisfaction share 14 per cent ($r=0.38$).

Table 2 shows the final regression analyses for burden, life satisfaction, and perceived stress at t_1 . The strongest predictors of caregiver burden are demands emanating from the recipient of care—their behavioural problems and their mental health issues. These primary stressors are both significant at the 0.01 level, explaining 8 per cent and 7 per cent of the variance respectively. Also significant, but less strongly correlated, are two personal resources of the caregiver: having less resilience and using negative emotion-focused coping are related to experiencing more burden. For each, 4 per cent of the variance ($p<0.05$) is explained. That is, the burden of caregiving is predicted largely by the demands consequent on the care recipient's condition but is also correlated with the personal resources of the caregiver. Overall, 26 per cent of the variance is explained.

The results for the overall well-being measures are different, confirming the conceptual distinction between role-specific outcomes and general quality-of-life measures. For life satisfaction, resilience, seeking social support, and self-rated health (all characteristics of the caregiver) are strong correlates ($p<0.001$; explaining 17%, 8%, and 12% of the variance, respectively). Burden, another characteristic of the caregiver, is also significant ($p<0.05$; explaining 3% of the variance). It should be noted that no demands of caregiving emanating from the condition of the recipient are significantly related to life satisfaction. Overall, 57 per cent of the variance is explained. The results are the same when burden is not added to the equation (minus the relationship with burden, of course).

Table 2 also shows the results for perceived stress. Like life satisfaction, a caregiver characteristic is the stronger predictor; this time it is burden (explaining 12% of the variance, $p<0.001$). A demand of the role, specifically hrs/week of caregiving, explains 6 per cent of the variance ($p<0.01$), and a personal resource of the caregiver, resilience, explains 4 per cent of the

Table 1: Selected sample characteristics t_1 (N = 92)

Sex	%
Male	31.5
Female	68.5
Marital Status	%
Married	83.3
Divorced/Separated	6.7
Other	9.8
Relation To Care Recipient (Caregiver is ___)	%
Wife	38.0
Husband	12.0
Daughter	35.9
Son	10.9
Other	3.0
Education	%
≤ High School	26.1
Trade Diploma/Some University	18.5
College Diploma/assoc. Degree	23.9
≥ Bachelor Degree	28.3
Caregiver Lives with Care Recipient	%
Yes	37.0
No	63.0

Table 2: Final regression analyses—Outcomes t_1

A) Burden			
IVs	B	beta	t
Neg Emotion Focused	0.41	0.20	2.16*
Resilience	-0.12	-0.21	-2.20*
Emotional Support	2.19	0.06	0.64
Behavioural Problems	6.51	0.28	2.91**
Mental Health Issues	6.46	0.27	2.79**
Adj $R^2 = 0.26$; $F = 7.34$; $df = 5$; $p < 0.000$			
B) Life Satisfaction Scale			
IVs	B	beta	t
Emotion Focused Coping	-0.08	-0.09	-1.23
Resilience	0.15	0.41	5.43***
Seeking Social Support	0.59	0.28	3.88***
Emotional Support	2.82	0.11	1.52
CG Health Changes	-1.34	-0.09	-1.10
Self Rated Health	-3.03	-0.34	-4.54***
Burden	-0.11	-0.16	-1.99*
Adj $R^2 = 0.57$; $F = 17.88$; $df = 7$; $p < 0.000$			
C) Perceived Stress Scale			
IVs	B	beta	t
Emotion Focused	0.02	0.09	1.00
Resilience	-0.02	-0.19	-2.00*
Chronic Conditions of CG	-0.51	-0.15	-1.70
Emotional Support	-0.90	-0.17	-1.86
Hours/Week Caregiving	0.01	0.24	2.63**
Burden	0.05	0.34	3.52***
Adj $R^2 = 0.28$; $F = 6.84$; $df = 6$; $p < 0.000$			

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Table 3: Change in outcomes

	t_1 SD	t_2 SD	Change (%)	RCI
Burden	16.95 (1.22)	12.19 (0.942)	-5.17 (30.5)	-5.66
Life Satisfaction	56.38 (0.802)	58.89 (0.755)	2.15 (3.8)	4.38
Perceived Stress	6.91 (0.174)	6.18 (0.204)	-0.77 (11.1)	-3.44

variance ($p < 0.05$). Overall, 28 per cent of the variance is explained. The results are the same when burden is not included (minus burden and therefore explaining little of the variance).

The strongest predictors of role-specific burden are the primary stressors of the role itself, with a lack of personal resources also important but less so. However, the primary predictors of overall quality of life are the personal resources of the caregiver. A primary stressor is related to one but not both of the overall quality-of-life measures. Further, burden is significantly related to quality of life. Resilience and only resilience is related to all three outcomes. Importantly, social support, gender, and age are

unrelated to any of the outcome measures examined here.

Over 1 year, caregivers improved on all three outcomes (see Table 3). Their mean burden score improved the most, by 30.5 per cent (from 16.95 to 12.19); their perceived stress also improved but by less, 11.1 per cent (from 6.91 to 6.18); their life satisfaction improved by only 3.8 per cent (from 56.38 to 58.89). It is to be noted that well-being improved far less than burden. These improvements occurred despite the fact that their caregiving increased on average 2 hrs/week.

The predictors of change in burden, life satisfaction, and perceived stress are shown in Table 4.

Table 4: Final regression analyses—Outcomes t_2

A) Burden			
IVs	B	β beta	t
Burden t_1	0.50	0.73	7.72***
Neg Emotion Focused	0.02	0.01	0.14
Resilience	-0.03	-0.05	-0.65
Emotional Support	-2.58	-0.09	-1.12
Behavioural Problems	1.18	0.07	0.81
Mental Health Issues	-1.76	-0.10	-1.13
Adj $R^2 = 0.54$; $F = 15.90$; $df = 6$; $p < 0.000$			
B) Life Satisfaction Scale			
IVs	B	β beta	t
Life Satisfaction t_1	0.66	0.68	9.21***
Emotional Support	2.36	0.10	1.50
Self Rated Health	-1.66	-0.21	-2.89**
Adj $R^2 = 0.67$; $F = 53.08$; $df = 3$; $p < 0.000$			
C) Perceived Stress Scale			
IVs	B	β beta	t
Perceived Stress t_1	0.30	0.27	2.57*
Emotion Focused Coping	0.03	0.12	1.09
CG Health Changes	0.94	0.26	2.47*
CG Health Improvements	-0.03	-0.17	-1.61
Adj $R^2 = 0.22$; $F = 6.44$; $df = 4$; $p < 0.000$			

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Importantly, few significant predictors emerged. Overwhelmingly, the main predictors of burden and life satisfaction at t_2 are burden and life satisfaction, respectively, at t_1 ; since our interest is in change, it is the variables that are significant after the variance explained by the outcome that are of interest. After t_1 is removed, no variables significantly predict burden 1 year later. Only self-rated health of the caregiver predicts change in life satisfaction (explaining 4% of the variance, $p < 0.01$). For perceived stress at t_2 , perceived stress at t_1 is again a significant predictor, but interestingly, it explains relatively little of the variance (7%, $p < 0.05$). In terms of predictors of change, only change in the caregiver's health since s/he started caregiving is significant (explaining 7% of the variance, $p < 0.05$). Whether the care recipient was in a long-term care facility at t_2 is unrelated to change in outcome, regardless of outcome examined. That is, despite reliable change over the 1-year period in all three outcomes, we were unsuccessful in identifying predictors of that change.

Conclusions

This article began with the observation that, despite the burden, most caregivers cope with the demands. Furthermore, high burden does not necessarily mean

low quality of life. The question posed here was, among caregivers with heavy demands from this role, who are those at risk of low quality of life? To examine this question, a sample of informal caregivers providing very heavy care to seniors living in the community was sought—and obtained. The findings reveal differential effects depending on whether one is examining role-specific or overall outcomes. They show that the demands of the role are the best predictors of caregiver burden; personal resources of the caregiver are also significant but less so than the demands of the role. Overall quality of life, however, is best predicted by personal resources and burden. Role demands are much less important (not significant for life satisfaction and one variable for perceived stress). However, role demands are important for overall quality of life because they appear to act indirectly through burden.

Data from these caregivers show the importance of not generalizing from a focus on role burden to the entirety of these people's lives. The data remind us that caregivers are not only caregivers; they are also spouses, daughters, sons, friends, and so on. Importantly, caregivers can be burdened and still have good life satisfaction and little perceived stress in their lives. Burden is important for caregivers' quality of life but more so for some measures than

others; in this instance, more so for perceived stress than for life satisfaction. The differential findings for the two different quality-of-life measures also reinforce the concern expressed by O'Rourke & Tuokko, (2000) that there is an over-reliance on single outcomes.

The data also suggest that it is timely for caregiver researchers to turn their attention to resilience, a personal resource that emerged as the only significant predictor for all three of the outcomes examined and that would appear to have both direct and indirect (through burden) effects on quality of life. This is particularly interesting given the lack of incorporation of this factor in caregiving studies to date. The measure used here purports to capture the ability to transform disaster into growth and move forward, to withstand and rebound from crisis and adversity—positive emotional stamina.

Improvement occurred in all three outcomes over a 1-year period, especially in burden, but we were singularly unsuccessful in identifying correlates of that change other than to note the importance of the caregivers' own health (either their self-rated health or their perceived improvements in their health). The reasons for this failure are unknown. It may be that, over time, the effects of heavy caregiving responsibilities are mitigated by the caregiver's gaining experience. The improvement in outcomes found in this study is different from the findings of other studies conducted over time that reported either no change or deterioration (Gaugler, Kane, Kane, & Newcomer, 2005; Powers, Gallagher-Thompson, & Kraemer, 2002).

Also notable are the non-findings that there are no gender or age differences in burden or overall quality of life. Further research is needed to determine whether this is an effect of sample size or an issue of heavy burden's having levelled the experience. Other than the coping strategy of seeking social support as a predictor of life satisfaction, none of the social support variables are related to the outcomes. Rather, it is domain specific demands and personal resources that appear, among this sample of caregivers, to predict burden, life satisfaction, and perceived stress. It may be that, when you are providing care equivalent to two full-time jobs, gender differences disappear; it becomes the individual management of the role that is important and personal resilience helps determine the extent to which those role demands effect overall well-being.

This study included specific sample criteria in order to recruit those under heavy caregiving demands. Further research needs to test the applicability of these findings to other samples. For example, is caregiver

burden less relevant for the well-being of caregivers providing considerably less care than among those studied here? Those who are less well educated and those who live in large metropolitan areas may differ from those studied here. Research should also pursue the importance of resilience; if resilience is as protective as these data suggest, studies on facilitating this characteristic might prove helpful. Factors that effect *change* in caregiver outcomes need to be identified. If they are different from the predictors at one point in time, this adds to the need for longitudinal research.

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