

# Burden and Well-Being Among Caregivers: Examining the Distinction

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**Purpose:** This study assessed overall quality of life of caregivers, using a path model in which burden was conceptualized as distinct from well-being. **Design and Methods:** Data were drawn from a representative sample of caregivers to dementia and nondementia care receivers in British Columbia, Canada ( $N = 243$ ). The model used was based on a previously proposed stress/appraisal path model and used multiple regression path estimates. Primary stressors were care receiver cognitive status, physical function, and behavioral problems; the primary appraisal variable was hours of caregiving during the previous week. Mediators were perceived social support, frequency of getting a break, and hours of formal service use; secondary appraisal was subjective burden. The outcome measure was generalized well-being. **Results:** Well-being was directly affected by four variables: perceived social support, burden, self-esteem, and hours of informal care. Burden was affected directly by behavioral problems, frequency of getting a break, self-esteem, and informal hours of care and was not affected by perceived social support. **Discussion:** The finding that perceived social support is strongly related to well-being but unrelated to burden reinforces the conceptual distinctiveness of the latter two concepts. This suggests that quality of life of caregivers could be improved even with burden in their lives and that the overwhelming focus in caregiving research on burden should be supplemented with an emphasis on quality of life.

**Key Words:** Well-being, Quality of life, Burden, Path analysis

Despite the amount of research on caregivers, and specifically on their burden, our understanding of their psychological well-being is not well advanced. Although the amount of research might suggest most

caregivers are at risk of collapse, most cope and seem to cope fairly well (Vitaliano, 2000; Chappell, 2001). Furthermore, despite early suggestions that burden and quality of life are opposite sides of the same coin (Montgomery, 1989), the terms *burden* and *well-being* among caregivers are, more often than not, treated as distinct concepts, with burden a predictor of overall well-being (Pearlin, Mullan, Semple, & Skaff, 1990; Stull, Kosloski, & Kercher, 1994; Yates, Tennstedt, & Chang, 1999). This suggests caregivers can be burdened while also experiencing high/adequate levels of well-being. To further understanding of the psychological well-being of caregivers, we assessed the distinction between the two concepts, burden and well-being, using a path model in which burden is conceptualized as distinct from well-being. (A version of the caregiver stress/appraisal model proposed by Yates et al., 1999, is drawn on.) Data come from a random sample of caregivers to both cognitively impaired and unimpaired persons in British Columbia, Canada.

Definitions of quality of life vary widely. At its broadest, the concept includes spirituality, health, activity level, social support, resources, satisfaction with personal accomplishments, and life situations (Diener & Suh, 1997). It includes both affective dimensions (feelings) and cognitive dimensions (Lawton, Kleban, & DiCarlo, 1984; Mayring, 1991; Ranzijn & Luszcz, 2000). Affect includes positive affect, negative affect, and affect balance. Most researchers, however, incorporate a somewhat narrower definition such as health-related quality of life (Ciuipers & van Lammeren, 2001), depression (Schulz, O'Brien, Bookwala, & Fleissner, 1995; Tennstedt, Cafferata, & Sullivan, 1992), anxiety, physical morbidity (Schulz et al., 1995), health behaviors (Gallant & Connell, 1998), or self-care (Gallant & Connell, 1997). Even those who do use more inclusive measures such as Hughes, Giobbie-Hurder, Weaver, Kubal, and Henderson (1999), who used the Short Form 36 Health Status Questionnaire, do not cover all of the domains of quality of life noted previously. Caregiver burden is likewise variously defined and measured, although it is less conceptually broad than is quality of life. Montgomery (1989) identified several terms commonly encountered in the literature that capture the essence of the meaning of burden (i.e., a consequence of caregiving), including stress effects, caregiving consequences, and

Funding for this study was received from the Social Sciences and Humanities Research Council of Canada.

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caregiving impact. George and Gwyther (1986, p. 253) defined caregiver burden as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults.” Burden is commonly understood to be composed of both objective and subjective components (Vitaliano, Young, & Russo, 1991), although conceptual clarity has been elusive (Montgomery, 1989).

Burden is often studied as an outcome in its own right (Kramer & Kipnis, 1995; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999) as well as a predictor of other caregiving outcomes (Gallagher-Thompson & Powers, 1997; Hughes et al., 1999). Distinguishing between burden and quality of life, Montgomery (1989) argued that burden refers to experiential differences among caregivers, whereas the more generic concept of well-being is useful for comparing caregivers and noncaregivers. Stull et al. (1994) empirically examined burden and well-being (in terms of health, finances, and social activity domains). Viewing each as outcome variables, the burden measures were more highly correlated with their antecedents (elder activities of daily living [ADLs], instrumental ADLs, and cognitive impairment) than were the well-being measures, and when treated as independent variables, the burden measures were more effective predictors of service use outcomes (use of chore/homemaker services, use of adult daycare and recency of consideration of nursing home placement) than were well-being measures. They concluded that burden is a unique domain of the caregiving experience and that it is not captured in more generic indicators. Indeed, the most widely used conceptual models of the predictors of caregiving outcomes incorporate burden as an endogenous variable, an intermediate predictor of other outcomes.

One such model, the stress process model (Pearlin et al., 1990), treats burden as a subjective primary stressor, affected by background variables such as caregiving history and socioeconomic characteristics. In turn, burden affects outcomes such as depression and physical health directly, as well as indirectly through secondary role strains (e.g., family conflict, economic problems) and secondary intrapsychic strains (e.g., self-esteem, competence). Coping and social support mediators explain different outcomes experienced by caregivers in seemingly similar caregiving situations. The model is specific to care recipients with Alzheimer’s disease and has received some support (see, e.g., Gallagher-Thompson & Powers, 1997; Hughes et al., 1999; Noonan & Tennstedt, 1997).

Yates and colleagues (1999) built on the stress process model of Pearlin and colleagues (1990), incorporating adaptations derived from the appraisal model of Lawton, Kleban, Moss, Rovine, and Glicksman (1989) and Lawton, Moss, Kleban, Glicksman, and Rovine (1991). One adaptation consists of treating overload (burden) as a secondary appraisal variable rather than as a primary stressor, based on the argument that it is the equivalent of subjective burden assessment. A second adaptation sees the primary stressor caregiving

assistance in the Pearlin and colleagues model designated a primary appraisal variable. Measured by hours of informal care, they argued that the caregiver makes an assessment of how much care the care recipient requires, although it is recognized that hours of care will also be a function of the objective needs of the care recipient. They find that the primary stressors (cognitive impairments, functional disability, and problem behaviors) lead indirectly to caregiver depression through hours of informal care and overload (subjective burden). This indirect relationship is mediated by one of the four mediator variables: caregiver/care receiver relationship.

This article follows in this tradition, using Yates and colleagues’ (1999) model to further explore the relationship between burden and well-being in the search for a greater understanding of the experience of caregiving. We chose an overall measure of quality of life that captures self-assessed well-being in seven essential areas of a caregiver’s life (health, finances, housing, partner, recreation, religion, and transportation) because of an interest not in a domain of quality of life but in overall quality of life.

Among the contextual variables, gender is important, with female caregivers typically experiencing more burden than male caregivers (Barusch & Spaid, 1989; Stuckey & Smyth, 1997), although not all researchers have come to the same conclusion (Miller & Cassafo, 1992). Kramer and Kipnis (1995) found that age of caregiver and burden were inversely related among employed informal caregivers. Jutras and Veilleux (1991) reported an increase in burden with age of caregiver. They also found that unemployed caregivers experienced higher levels of burden than did employed caregivers. Whether or not the caregiver lives with the care recipient is also important (Hughes et al., 1999; Knight, Williams, McGee, & Olan, 1998), with coresident caregivers experiencing higher levels of burden. Higher caregiver education has been associated with greater burden (Cooney & Di, 1999), as well as with reduced burden (Hughes et al., 1999).

Primary stressors identified in the research literature include care recipient’s health (Clarke, 1997; Peters-Davis, Moss, & Pruchno, 1999) and behavioral problems or dysfunctional behaviors (Nagatomo et al., 1999). Level of dependence in the care recipient’s activities of daily living has been positively linked with burden (Newens, Forster, & Kay, 1995), although at least one study found that reported burden was lower among caregivers of persons with total dependence than among those who were partially dependent (Arai & Washio, 1999). The greater level of burden experienced by dementia compared with nondementia caregivers is generally acknowledged (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz et al., 1995).

Turning to primary appraisal variables, Call, Finch, Huck, and Kane (1999) found that the number of hours spent caregiving, following hospital discharge of the care recipient, was positively related to burden for nonfamily and extended family caregivers, but not for spouse and child caregivers. A positive association

of burden with length of caregiving has been found (Donaldson & Burns, 1999).

Mediators have likewise been identified. A number of studies have shown that respite and day care use can lead to a reduction in burden (Mittleman et al., 1993; Wimo, Mattsson, Adolfsson, Eriksson, & Nelvig, 1993). In a review of 29 studies, McNally, Ben-Shlomo, and Newman (1999) found, however, that these effects are short term and that evidence of long-term effects has not been reported. The perception of the adequacy of, or satisfaction with, social support is inversely associated with burden (Gold, Cohen, Shulman, Zuccherro, Andres, & Etezadi, 1995; Knight et al., 1998; Stuckey & Smyth, 1997). These same researchers also found satisfaction with social support to be positively associated with caregiver health. Yates et al. (1999) likewise reported a negative relationship between emotional support and overload, but the relationship was indirect and very small. At the same time, emotional support was directly and moderately strongly related to their measure of well-being, depression.

Other than social support, predictors of both burden and well-being largely overlap, causing interpretive confusion, despite relative consensus that burden and well-being are distinct concepts. The literature suggests the conceptual model shown in Figure 1 and that each preceding variable will be related to the outcome. The present study sought to investigate this conceptual distinction and to contribute to understanding the caregiving experience in general, using a sample of caregivers to both those who suffer from cognitive impairment and those who do not.

## Design and Methods

Participants were recruited from a randomly generated sample of residential telephone numbers in the

greater Victoria area of British Columbia, Canada, in 1998. Of the 5,595 contacted, the overwhelming majority (79.9%) had no caregiver within the household; 10.2% refused to participate in the screen; and 9.9% identified caregivers within the household ( $N = 554$ ). Of these 554, 18.1% declined to be contacted again for participation in the study, leaving 454 potential participants. Of these, 32.8% were excluded because they had moved or were no longer a caregiver by the time of the interview, and 2.4% could not be contacted after nine tries. It is unknown why so many (almost a third) had moved on or were no longer a caregiver by the time they were contacted. The listing was obtained in March. Screening telephone calls were made in April and May. Individuals were contacted to be interviewed starting in June. Interviewing took place throughout the summer and early fall, so for some participants, 4 months could have elapsed before they were contacted for an interview. The high percentage who were no longer eligible still seems high. Of the final eligible sample ( $n = 294$ ), 82.7% agreed to be interviewed. The final sample consisted of 243 participants. Interviews were conducted face-to-face and for an average of 1 hr, 17 min. A structured face-to-face interview was administered.

The measure of well-being was based on the Andrews and Withey (1976) Life Satisfaction Scale, as modified by Michalos (1980, 1985). Respondents were 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. An 11th statement asked respondents to rate an overall assessment of their lives "right now." Because the model specified in the present study contains a measure of perceived social support as a mediator, the two items measuring satisfaction with friends and

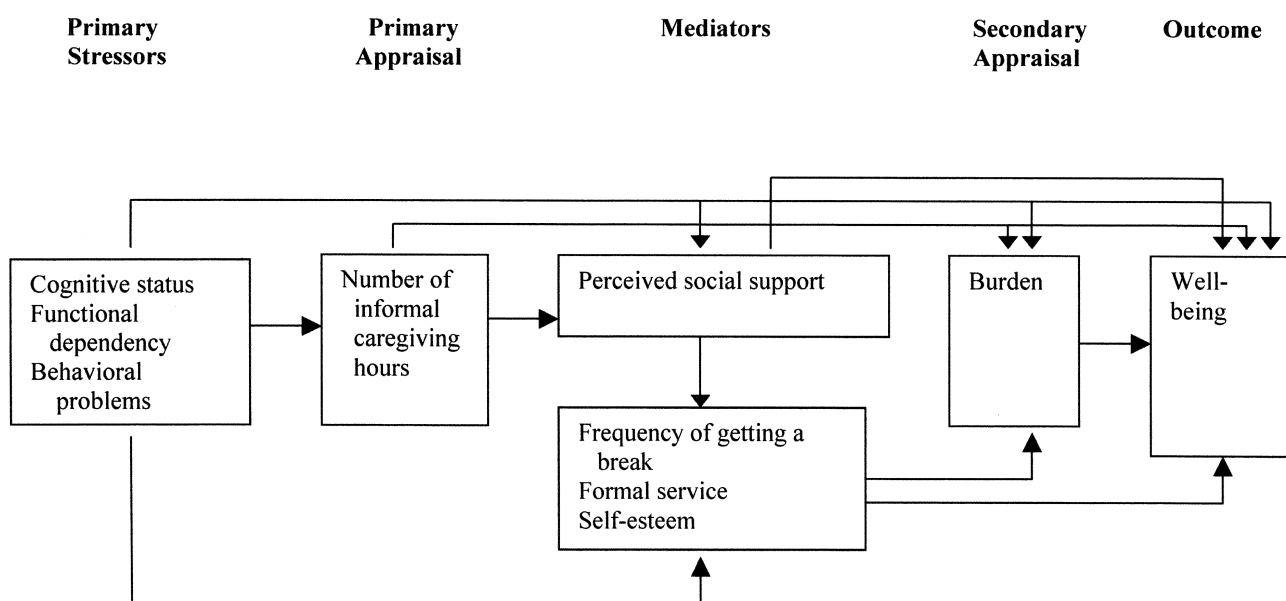


Figure 1. Conceptual model. Based on Yates et al. (1999). Conceptual or background variables, including caregiver and care receiver characteristics, were used as control variables but were not the central focus of this model and are therefore not shown. Detailed explanations are provided in the Design and Methods section. Table 3 shows the betas for these variables.

families were deleted from the overall well-being measure. Likewise, because self-esteem is included as a mediator, it was removed from the measure of well-being. Response categories ranged from 1 (terrible) to 7 (delightful) for each of the eight items. Religion and partner statements were not applicable for 42 and 33 respondents, respectively. Therefore, scale scores for well-being were calculated by adding individual scale items and dividing by the number of questions answered. Cronbach's alpha was .75.

Eight background or contextual variables were included in the model. These included care recipient's age in years, gender (0 = male, 1 = female), and marital status (0 = married, 1 = other) and caregiver's age, gender (0 = male, 1 = female), employment status (0 = not employed, 1 = employed), and education (number of years) and whether the caregiver and care recipient lived in the same dwelling (1 = no, 0 = yes).

Three primary stressors were included. Cognitive status of care recipient was obtained from caregiver assessments that indicated whether the care recipient had Alzheimer's disease, other dementia, or other serious memory loss problems. Care recipient activities of daily living were measured by asking the caregiver to rate the recipient's level of dependence on a 3-point scale (0 = independent, 1 = some help required, 2 = completely dependent) for 15 items including eating, dressing/undressing, getting about the house, getting in and out of bed, taking a bath or shower, using the toilet, using the telephone, going shopping for groceries or clothes, preparing meals, doing heavy housework and laundry, doing light housework, doing yard work, taking medication, managing money day-to-day, and handling long-term finances. Items were summed and divided by the total number of valid responses for each respondent ( $\alpha = .93$ ). For care recipient behavioral problems, the caregiver was asked to indicate the frequency of occurrence on a 5-point scale (0 = never, 4 = all the time) of 10 common behavioral problems including physical attacks, day wandering, night wandering, noncooperation when taking medications, requires constant supervision, is incontinent, makes unwarranted accusations, loses/misplaces/hides things, sleeps excessively during the day, and asks the same questions over and over. Individual item scores were added to create a total behavioural problem score ranging between 0 and 40, with 40 representing the greatest number and frequency of occurrence of these problems ( $\alpha = .66$ ).

Primary appraisal was measured as the number of hours caregiving in the previous week reported by the caregiver (logged for statistical purposes due to a strong positive skew). The question asked, "During the past week, about how many hours have you spent providing care?" thus leaving it to each respondent to define what constituted their caregiving. Caregivers reported providing a mean of 26.1 hr ( $SD = 41.4$ ) of informal care per week, with a range of 0 to 168. The mean of the logged variable was 1.07 ( $SD = 0.54$ ), with a range of 0 to 2.23.

Four mediator variables were included in the model. Formal service use consisted of the natural log

of the number of hours of formal services currently received whether inside (e.g., homemaker services) or outside (e.g., adult day care) the home. The mean of the unlogged variable was 4.7 hr ( $SD = 9.9$ ) and ranged from 0 to 95. It showed a strong positive skew. The range of the logged variable was 0 to 4.56. Perceived support for the caregiver was measured with the Perceived Social Support Scale (Pearlin, Lieberman, Menaghan, & Mullan, 1981). This is an eight-item scale that requires a response on a 4-point scale (1 = strongly disagree, 4 = strongly agree). Items include, for example, "There is really no one who understands what you are going through" and "The people close to you let you know that they care about you." One item is reverse coded. Possible scale scores range from 8 to 40. Cronbach's alpha in the present study was .73. A variable measuring the frequency that each caregiver reported having a break from caregiving was included as a fourth mediator variable. Caregivers were asked whether they got a break from each of 20 common activities that a caregiver might take part in as a matter of their daily or weekly routine (such as running errands, doing things around the house, doing hobbies, informal socializing, spiritual activities, or resting/sleeping). If they responded that they did receive a break from caregiving through these activities, they were asked to estimate how often they received a break in this way. Factor analysis using orthogonal, Varimax rotation produced one main factor (eigenvalue = 4.12) including doing things for yourself, exercise or other activities, doing hobbies, listening to radio/TV, informal socializing, and having time alone/to yourself. To create a scale variable, valid responses were added and then divided by the number of nonzero responses given for each caregiver. Possible scale scores ranged from 0 to 7 ( $\alpha = .71$ ). Self-esteem was measured with the Rosenberg (1965) Self-Esteem Scale. This scale consists of 10 items, each rated on a 4-point scale. The scale can range from 10 to 40, with 40 being the strongest measure of an individual's self-esteem ( $\alpha = .86$ ). Self-esteem is analogous to mastery. The data in the present study did not include measures of quality of the relationship between caregiver and care recipient.

The secondary appraisal variable, caregiver burden, was measured with the Zarit Caregiver Burden Inventory (Zarit, Reever, & Bach-Peterson, 1980). This scale consists of 22 items. The first 21 items are questions designed to measure specific areas of subjective caregiver burden. For example, "Do you feel your social life has suffered because you are caring for [the care recipient]?" Responses are on a 5-point scale (0 = never, 4 = always). The final item is a summary statement that asks how burdened overall the caregiver feels. One question is specific to caregivers who reside with the care recipient—a minority of the cases—necessitating standardization of the summed scale. Responses to the 22 items were summed and divided by the number of valid responses for each respondent. Possible scale scores range from 0 to 4 ( $\alpha = .91$ ). The means, standard deviations, and coding schemas for all of the variables in the analyses can be found in Table 1.

Table 1. Variable Means, Standard Deviations, and Coding

Variable Name	%	M	SD	Coding
Care recipient age		80.35	7.25	Age in years (65–99)
Care recipient gender (female)	67.9			0 = male; 1 = female
Care recipient marital status (married)	37.0			0 = married; 1 = other
Care recipient resides with caregiver? (yes)	28.4			0 = lives with caregiver; 1 = does not live with caregiver
Caregiver age		51.12	14.1	Age in years (21–85)
Caregiver gender (female)	69.1			0 = male; 1 = female
Caregiver employment status (employed)	56.0			0 = not working for pay; 1 = working for pay
Caregiver education		14.19	3.30	Years of schooling completed (5–26)
Cognitive status (have dementia or other serious memory problem)	45.70			Does care recipient have dementia or other serious memory problem (caregiver assessment)? 0 = no; 1 = yes
Physical disability		0.78	0.54	Level of dependency in activities of daily living—standardized to number of valid responses (0–2)
Behavior problems		7.60	5.50	Frequency of care recipient behavior problems observed by caregiver in previous week (0–40)
Log of informal hours of caregiving		1.07	0.54	No. hours reported by caregiver for previous week
Frequency of getting a break		3.27	1.81	How often the caregiver gets a break by personal things (0–6)
Log of service use hours		0.271	0.15	No. formal services ever used by caregiver or care receiver—standardized to number of valid responses (0–1)
Perceived social support		26.57	3.54	Pearlin’s Perceived Social Support Scale—higher = more perceived support (8–32)
Self-esteem		32.89	4.16	Rosenberg’s Self Esteem Scale—higher = greater self-esteem (10–40)
Burden		1.25	0.65	Zarit Burden Inventory—standardized higher = higher burden (0–4)
Well-being		5.17	0.64	Andrew & Withey Life Satisfaction Scale, modified by Michalos (1980, 1985)—standardized to number of valid responses—higher = more satisfied (0–7)

The conceptual model was tested using ordinary least squares regression coefficient estimates (standardized) in a path analysis. Ten regressions were estimated, with each of the 10 variables in Figure 1 entered as the dependent variable for each respective equation. Thus, cognitive status, functional disability, behavioral problems, informal hours of care (logged), perceived social support, frequency of getting a break, hours of formal service use (logged), self-esteem, caregiver burden, and well-being were entered as dependent variables, in turn, for each regression. The variables preceding each dependent variable in the model (see Figure 1), in addition to the contextual variables, were entered as independent variables. Regressions in which the primary stressors—cognitive status, functional disability, and problem behaviors—act as dependent variables do not include caregiver characteristics as contextual variables because they are not expected to have any influence on these dependent variables (Yates et al., 1999). Tests for linearity, collinearity, and homoscedasticity were performed before all analyses, and when necessary, adjustments were made. A power analysis shows that when the sample size is 243, the multiple linear regression test of  $R^2 = 0$  ( $\alpha = .05$ ) for 17 normally distributed covariates will have 99% power to detect an  $R^2$  of .5.

## Results

The mean age of caregivers in this study was 51.1 years ( $SD = 14.1$ ) and ranged from 21 to 85 years. Care recipients were 80.4 years old on average ( $SD =$

7.25) and ranged between 65 and 99 years old. The majority of caregivers (69.1%) and care recipients (67.9%) were female. Almost half (45.7%) of care recipients were reported by the caregiver to have Alzheimer’s disease or dementia or other serious memory loss problems. This figure is high. Yates et al. (1999) reported 29.9% with cognitive impairment with older care recipients (86 vs 80 years old). Their definition of cognitive impairment was similar. The mean number of informal hours of care provided weekly by each caregiver was 26.1 hr ( $SD = 41.5$ ), with a range of 0 to 168.

Bivariate correlations are presented in Table 2, and standardized correlation coefficient estimates for the 10 regression equations are presented in Table 3. The final path model is shown in Figure 2. When controlling for contextual variables, and simultaneously controlling for all other variables in the model, four independent variables had statistically significant direct effects on well-being. Burden ( $r = -.15, p < .05$ ) and informal hours of care ( $r = -.19, p < .05$ ) were negatively associated with well-being, with lower burden scores and lower number of informal hours of care leading to higher well-being scores. Perceived social support ( $r = .19, p < .01$ ) and self-esteem ( $r = .39, p < .001$ ) were positively related to well-being. None of the primary stressors (cognitive status, functional dependency, and behavioral problems) was directly associated with well-being.

Burden was directly affected by four variables. Increased behavioral problems ( $r = .30, p < .001$ ) of the care receiver led directly to higher reported burden.

Table 2. Bivariate Correlations

	1	2	3	4	5	6	7	8	9	10
1. Cognitive status	—	.29***	.54***	-.09	-.02	.01	-.08	-.08	.26***	-.11
2. Activities of daily living		—	.45***	.13*	.01	.05	.14*	.06	.07	.04
3. Behavior			—	-.03	.00	.06	.04	.01	.36***	-.09
4. Informal hours				—	-.18**	.24***	.05	.02	.16*	-.14*
5. Perceived social support					—	.02	.03	.29***	-.06	.34***
6. Frequent breaks						—	-.01	.01	.20**	.01
7. Formal service hours							—	.04	.07	.06
8. Self-esteem								—	-.17*	.50***
9. Burden									—	-.29***
10. Well-being										—

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

Likewise, an increase in informal hours of care ( $r = .30, p < .001$ ) led to increased burden. The more frequently a caregiver reported getting a break ( $r = .15, p < .05$ ) and the higher a caregiver's self-esteem ( $r = -.14, p < .05$ ), the less the probability of increased burden scores.

Among the mediators, perceived social support ( $r = .16, p < .05$ ) and formal service use ( $r = .16, p < .05$ ) were directly and positively influenced by greater care recipient functional dependency. Formal service use was also associated with care recipient's cognitive status, with caregivers of persons without dementia or serious memory problems reporting a greater number of formal service use hours. Informal hours of care had a direct positive effect on the frequency a caregiver received a break ( $r = .24, p < .01$ ). In direct contrast to Yates and associates' (1999) find-

ings, the primary appraisal variable, hours of informal care, was not predicted by any of the primary stressors. Among the primary stressors, behavioral problems were predicted by functional dependency ( $r = .32, p < .001$ ) and cognitive status ( $r = .43, p < .001$ ), with caregivers to cognitively impaired and more functionally dependent care recipients reporting more care recipient behavioral problems. Functional dependency was predicted by care recipients' cognitive status ( $r = .28, p < .001$ ): Those with dementia exhibited higher levels of ADL dependency.

Perceived social support and self-esteem had direct positive influences on well-being. Caregivers to care receivers with greater physical dependency tended to perceive greater levels of social support, which led directly to increased caregiver well-being. Caregivers to care receivers with dementia or serious memory

Table 3. Regression Estimates (betas) and R<sup>2</sup>

Independent Variables	Dependent Variables									
	Cognitive Status	Activities of Daily Living	Behavior	Informal Hours	Perceived Social Support	Frequent Breaks	Formal Service Hours	Self-Esteem	Burden	Well-Being
Control										
CR age	.11	.07	.05	.00	.16*	.03	.16*	-.03	-.10	.13*
CR sex	-.03	.05	-.03	.03	-.01	.01	-.04	.11	-.07	.07
CR marital status				-.09	-.02	-.09	-.03	-.07	.16*	-.10
Live together?				-.58***	-.03	-.02	-.06	.10	.13	-.06
CG age				.06	-.21**	-.11	-.09	.19*	.01	.14
CG sex				.05	.26***	.13	.01	-.11	.07	.01
CG employment status				-.15*	.17*	-.04	-.10	-.01	.16*	.10
CG education				-.05	.17**	.03	.11	.13	.05	-.03
Main Independent Variable										
CR cognitive status		.28***	.43***	-.06	-.06	.00	-.16*	-.11	.12	-.02
CR activities of daily living			.32***	.02	.16*	.00	.16*	-.01	-.06	.01
CR behavior				.08	-.08	.05	.04	.07	.30***	-.05
Informal hours					-.06	.24**	.02	.08	.30***	-.19*
Perceived social support						.01	-.01	.35***	-.06	.19**
Frequent breaks							-.03	.01	.15*	.07
Formal service hours								-.00	.10	-.04
Self-esteem									-.14*	.39***
Burden										-.15*
R <sup>2</sup>	.01	.09	.38	.48	.25	.09	.08	.16	.28	.38

Notes: N = 243. Missing values replaced with mean.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

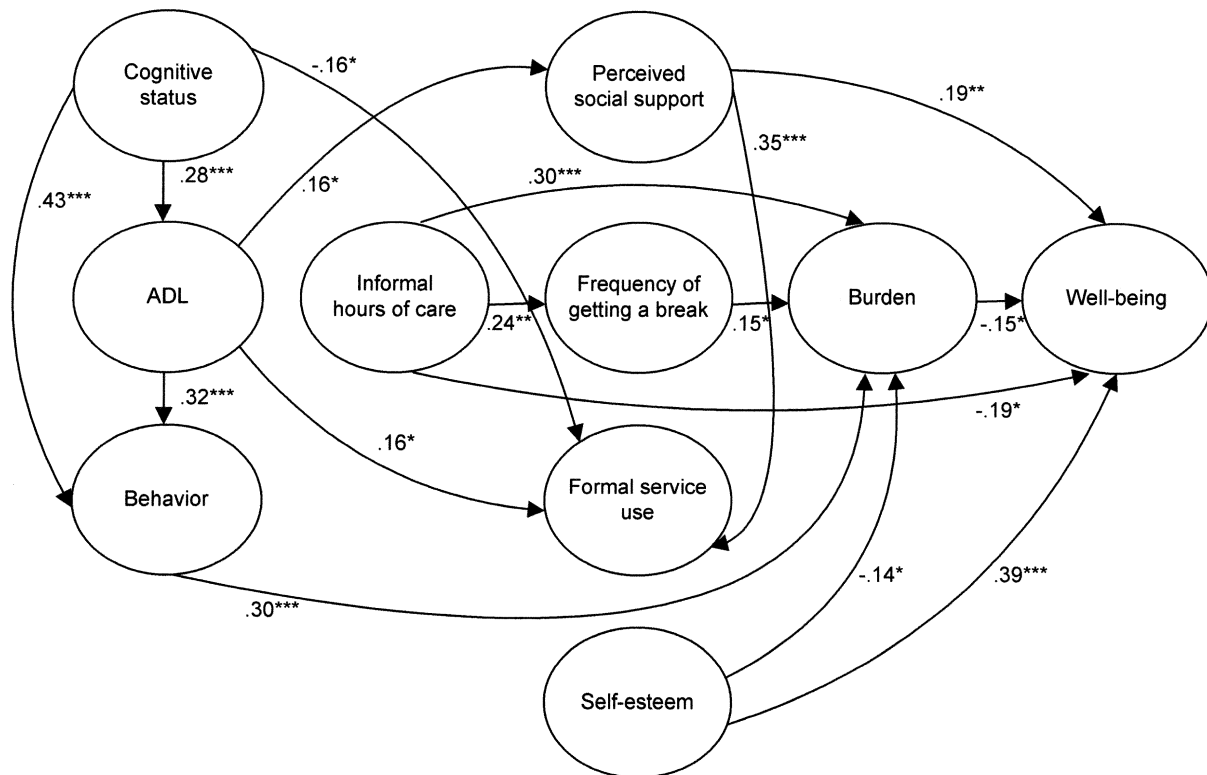


Figure 2. Path model. Only significant betas are shown. Conceptual or background variables, including caregiver and care receiver characteristics, were used as control variables but were not the focus of this model and are therefore not shown. Detailed explanations are provided in the Design and Methods section. Table 3 shows the betas for these variables. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

loss used fewer formal service hours, and caregivers to those whose physical needs were greater tended to use more formal service hours. Formal service itself has no effect on self-esteem, burden, or well-being. Care receivers with dementia or other serious memory loss, and those with lower levels of physical dependence, also had more behavioral problems. Behavioral problems were directly and positively related to burden scores but were not directly related to well-being. Perceived social support was directly and positively related to well-being but not to burden.

Three critical general relationship configurations can be identified within this model. First, well-being was directly affected by perceived social support, burden, self-esteem, and informal hours of care. All other effects on well-being were indirect. Second, burden was directly affected by frequency of getting a break, informal hours of care, care recipient behavior, and caregiver self-esteem. Although burden and well-being were both affected by informal hours of care and self-esteem, the difference in effect sizes was noteworthy. The relationship between informal hours of care and burden ( $r = .30, p < .001$ ) was stronger than the one between the former and well-being ( $r = -.19, p < .05$ ). Similarly, self-esteem was more strongly related to well-being ( $r = .39, p < .001$ ) than to burden ( $r = -.14, p < .05$ ). Third, perceived social support had a direct and relatively strong impact on well-being but no direct impact on burden

## Discussion

This study examines the relationships between a series of variables identified as central to the caregiving process and their effects on caregiver's well-being. It attempts to capture the complexities involved in caregiving through the use of a path model and to measure the effects of the variables in that model on a general quality-of-life indicator. In doing so, it has sought clarification between the concepts of burden and well-being.

Care recipient's cognitive status is not directly or indirectly related to hours of informal care but is directly related to formal service use. This implies that whether a care recipient has dementia is less critical in the caregiver's determination of need for formal services than how functionally dependent the care recipient is. This could be related to the type of services that are available. Greater formal service use, however, is unrelated to higher levels of burden or caregiver well-being.

Again using care recipient cognitive status as the starting point, care recipients with dementia exhibit higher levels of functional dependency, which also results in greater perceived social support among caregivers. Perceived social support is directly and positively related to well-being. This path suggests that those caregivers whose charges have dementia or serious memory loss and resultant higher levels of functional dependency tend to see their social support as

more adequate than do caregivers to those without dementia and who have lower levels of functional dependency. This may be due to the fact that caregivers to nondemented care recipients (and their networks) do not see themselves as being in need of assistance, that they can and should handle things on their own to a greater degree, suggesting the potential for educating caregivers about the beneficial effects of social support for their well-being. If caregivers to care recipients with dementia and greater levels of functional dependency can experience relatively good quality of life, the benefits for other caregivers are potentially available via the improvement of the perception of social support. Of the four variables proposed, only perceived social support acted as a mediator between the primary stressors represented by the care recipient's cognitive and physical condition and the caregiver's well-being.

Those with dementia and those who had greater levels of functional dependency also tend to exhibit increased levels of behavioral problems. Consistent with previous research, behavioral problems are a primary determinant of caregiver burden (Schulz et al., 1995). Thus, it is not the cognitive status of the care recipient per se that determines the associated burden and well-being experienced by the caregiver; it is the functional and behavioral manifestations engendered, and possibly exacerbated, by the disease process that ultimately result in the erosion of caregiver quality of life. This implies that an intervention aimed at slowing the progression of the disease—whether biophysically or through the use of effective psychosocial interventions—may have as one positive effect an improvement in caregiver quality of life.

The primary appraisal variable, number of hours of informal care, has a direct positive effect on burden. Not surprisingly, an increase in informal hours of care leads directly to greater burden. However, an increase in informal hours of caregiving is associated with an increased frequency in breaks for the caregiver, which in turn is associated with an increase in burden and a decrease in well-being. It does not appear that an increased propensity to take breaks from caregiving is of any value in mediating the relationship between hours of informal care and burden. Rather, it appears that taking breaks is simply part of the caregiving lifestyle and not an especially effective means of lowering burden and improving quality of life. On the other hand, perhaps the breaks that a caregiver does report getting prevent burden scores from going even higher. That is, in the absence of these breaks, the propensity for the caregiving situation to become overwhelming may increase accordingly. This suggests that the current understanding of respite requires reassessment (see Chappell, Reid, & Dow, 2001).

The lack of an observed relationship between the primary stressors and informal hours of care is unusual and in fact counter to most research in this area. It may be due to the single indicator question that left it to caregivers to define for themselves what constituted caregiving. There may have been considerable

variability in terms of what was included (e.g., the inclusion of cooking and laundry).

This research adds further support to the view that burden and well-being are separate though related concepts. The fact that social support is strongly related to well-being but unrelated to burden affirms this view. These findings are consistent with those of Yates and associates (1999), who report that perceived emotional support from family and friends is directly related to depression but not to overload (burden). This suggests that caregivers' quality of life could be improved even with burden in their lives and that the overwhelming focus in caregiving research on burden should be supplemented with an emphasis on quality of life. This study also provides evidence of the robustness of the model proposed by Yates and associates (1999), and thus its potential usefulness for further research.

This study has several notable strengths, not the least of which are the random community sample and the empirically tested model on which it is based. However, one important limitation relates to its use of cross-sectional rather than longitudinal data. The care requirements of the care recipient and the ability of the caregiver to correspondingly provide adequate care are subject to change over time. It is precisely the *dynamics* involved in this evolutionary process that need to be researched before caregiver experience can be adequately understood. For example, cross-sectional data analyses are not the most effective strategy for evaluating the effect of factors such as speed of cognitive decline among those with dementia or the effect of change in caregiver health status on the relationship between burden and well-being. These relationships can be detected only by tracking individuals over time. Notwithstanding a strategy to obtain a representative sample, a high ineligible rate and characteristics of the resultant sample (such as a high proportion caring for those with impaired cognition) suggest the sample may not be totally representative of caregivers within the community. We also note that the model is recursive and not interactive.

Previous research has identified the overall effect of the primary stressors—cognitive status, functional dependency, and behavioral problems—on caregiver well-being. Dementia or serious memory loss, increased functional dependency, and an associated increase in care recipient behavioral problems typically result in the decline of quality of life for the caregiver. It is only by identifying the mechanisms through which these primary stressors work to affect quality of life that appropriate and effective intervention policies can be developed. This study suggests that the perception of social support, regardless of the care recipient's cognitive or functional status, may be a fruitful area for intervention. Although burden and well-being are not independent concepts, they are highly correlated and, when controlling for other factors, burden is not a strong predictor of well-being. Caregivers can be burdened and still maintain a reasonable quality of life. The caregiving process is clearly an inherently complex one and is in need of more study.



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Received December 20, 2001

Accepted May 30, 2002

Decision Editor: Laurence G. Branch, PhD