Associations Between Dysfunctional Behaviors, Gender, and Burden in Spousal Caregivers of Cognitively Impaired Older Adults

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Progressive deterioration, such as observed in patients with Alzheimer's disease (AD), negatively impacts on caregivers, a problem described as "caregiver burden". Caring for these individuals may be more stressful than caring for the physically disabled (Grad & Sainsbury, 1965, 1973; Isaacs & Livingstone, 1972). Patient characteristics such as mood, dysfunctional behaviours, and reduced independence in activities of daily living (ADL) are associated with burden (Grafstrom et al., 1992; Molloy et al., 1996; Newens et al., 1995; Swearer et al., 1988). On the other hand, cognitive impairment itself is not associated with caregiver burden (Molloy et al., 1996).

Caregivers of cognitively impaired patients are often depressed (Saad et al., 1995; Schulz et al., 1995) and use fewer community services than caregivers of nonimpaired patients (Canadian Study of Health and Aging, 1994). Caregiver health, burden, and exhaustion are predictors of institutionalization (Cohen et al., 1993; Gold et al., 1995; McFall & Miller, 1992; Tsuji et al., 1995).

Burden represents caregivers* perceived situation and is the appropriate target for interventions. Most interventions to reduce burden in caregivers have focused on caregivers themselves. Satisfaction with social support has beneficial effects on caregiver burden (McNaughton et al., 1995; Reis et al., 1994; Thompson et al., 1993) and reduces the likelihood of institutionalization (Boaz & Muller, 1994). Respite and day-care interventions can produce short-term reductions in burden and delay institutionalizations (Adler et al., 1993; Larkin & Hopcroft, 1993; Mittelman et al., 1993; Wimo et al., 1993), but it is not clear that these interventions result in long-term reductions in caregiver burden.

Although these interventions highlight the psychosocial component of burden, the medical component has been more difficult to assess. Caregiver burden can be associated with patient characteristics (e.g., behavior) that can be targeted by healthcare practitioners (Molloy et al., 1996; Ten et al., 1988). However, the options available to healthcare practitioners to treat cognitively impaired patients are limited. In general, cognitive abilities and independence in ADL continue to deteriorate over the course of the disease. Mood and behavior, on the other hand, vary and can be improved with appropriate diagnosis and treatment (Cummings & Miller, 1990; O*Connor, 1987; Rab ins et al., 1982). Healthcare practitioners can have a positive impact on caregiver burden by managing patients* depression and dysfunctional behaviors but also by ensuring appropriate and timely referral to community supports.

To gain better insight into determinants of caregiver burden, we asked three questions: (a) what changes in patients* conditions and caregivers* burden are obtained following our standardized medical intervention in cognitively impaired patients, (b) what variables account for any pre-post variability recorded in burden, and (c) what baseline measurements predict burden at follow-up and pre-post changes in burden. We hypothesized that our intervention would not affect cognition and independence in ADL, which would continue to decline over the course of the study, but that symptoms of depression, dysfunctional behaviors, and care-giver burden would be reduced. We also hypothesized that changes in patients* mood, independence in ADL, and dysfunctional behaviors would be associated with changes in caregivers* burden. Finally, we hypothesized that baseline variables predicting burden at follow-up would be different from variables that predict the differential effect of the intervention.

Methods

Subjects

Subjects were chosen at random from all patients referred to a geriatric clinic between July 1, 1990, and June 30, 1995. Inclusion criteria were as follows: community-dwelling, had a spousal care-giver available to give information, and patients and caregivers came to the clinic for at least one follow-up visit. All participants had been referred to the clinic for memory problems by general practitioners or specialists.

Design

Participants and caregivers were seen first for a standardized baseline assessment, which took approximately 2 hours. The standardized assessment documented presenting complaints from patients and caregivers, past medical history, social history, drugs taken, and systems review, and a comprehensive physical assessment was performed. Caregiver burden was determined. Caregivers were educated about cognitive impairment, and interventions to reduce burden were suggested (e.g., change in medication regimen, day care, respite care, support groups). Depending on the problem, the follow-up visit was scheduled for I to 12 months after the initial visit. At follow-up, patients* conditions and caregivers* burden were reevaluated. All data were collected by a geriatric assessment team composed of geriatricians, nurse clinicians, physiotherapists, and/or occupational therapists. Caregiver information was gathered in a separate area from the patient.

Measures

Several measures included in this report documented the status and progression of the condition, and were required at baseline only. These included: Reisberg stage (1-7; Reisberg et al., 1982), gradual onset (yes/no), step-like progression (yes/no), communication problem (yes / no), judgment problems (yes/no), and difficulties with word finding (yes/no).

Other measures were obtained at baseline and follow-up. Four instruments were used to measure the patients* mood, cognition, behavior, and function: the Geriatric Depression Scale (GDS; Brink et al., 1982), the Standardized Mini-Mental State Examination (SMMSE; Molloy et al.,

1991), the Dysfunctional Behavior Rating Instrument (DBRI; Molloy et al., 1991), and an assessment tool developed by Lawton and Brody measuring self-maintaining and instrumental ADL ("Lawton"; Lawton & Brody, 1969). Data regarding caregivers* own health, time demands from caregiving, and support from other caregivers were obtained. Caregiver burden was measured by the Zarit Burden instrument (Zarit et al., 1985).

Statistical Analyses

We used mixed-design analyses of variance (ANOVAs) and McNemar tests to compare baseline and follow-up results and diagnostic groups. The ANOVAs* repeated factor was time (baseline versus follow-up) and between factor was diagnostic group (AD versus non-AD). Regression analyses examined the relationship between caregiver burden and independent variables. Univariate analyses were conducted for all variables. To control for these variables, we entered variables with p values of less than .10 into multivariate analyses using stepwise, forward, and backward methods to produce models. It is generally accepted that greater confidence in a model is achieved if all three methods produce the same results (Afifi & Clark, 1990).

Results

Demographics

In total, 111 patients were included. The mean age of patients at baseline was 70.6 (95% CI = 69.0 to 72.1), and 61% were male (95% CI = 52 to 70). The mean duration of symptoms prior to this initial visit was 3.4 years (95% CI = 2.8 to 3.9), and 47% (95% CI = 37 to 57) of patients had a diagnosis of AD. The mean SMMSE score was 20.6 (95% Cl = 19.3 to 21.9). Complete demographic information is displayed in Table 1.

TABLE 1. Demographics of Participants at Baseline

Variable	Baseline*
Age	70.6 (69.0-72.1)
% Male	61 (52-70)
Duration of symptoms (years)	3.4 (2.8-3.9)
% Alzheimer*s diagnosis	47 (37-57)
Reisberg score (max = 7)	3.6 (3.3-3.8)
SMMSE (max 30)	20.6 (19.3-21.9)
GDS (max = 30)	8.7 (7.5-10.0)
ADL (max = 60)	49.1 (47.3-51.0)
DBRI (max = 125)	22.7 (19.8-25.6)
Burden (max 88)	18.8 (16.2-21.4)
% Gradual onset	89 (84-95)
% Step-like disease progression	10 (4-16)
% Communication problems	53 (43-63)
% Judgment problems	65 (55-75)
% Difficulties with word finding	61 (51-71)
Weekly hours spent with patient	107.3 (93.4-121.2)
% CG with medical problem	71 (62-80)
% Receiving support from other CGs	13 (7-19)

Note: SMMSE = Standardized Mini-Mental State Examination; GDS = Geriatric Depression Scale; ADL = activities of daily living; DBRI = Dysfunctional Behavior Rating Instrument; CG = caregiver.

*Values represent mean or percentage 95% confidence interval).

Change From Baseline

Patients were seen at follow-up after a mean interval of 7.3 months (95% CI = 6.1 to 8.5). Cognitive abilities and ADL significantly declined between visits. Overall scores on the SMMSE

declined by 1.46 (95% CI = 0.5 to 2.4; $F(1,96)$ 11.27, $p = .001$), but this effect was dependent on the diagnostic group, with AD patients having larger declines in cognition than non-AD patients. Scores on the Lawton declined by 2.22 points overall (95% CI = 0.7 to 3.7; $F(1,103) = 10.58$, $p = .002$). The time-by-treatment interaction approached, but did not reach, statistical significance ($F(1,103) = 3.62$, $p = .060$). Statistically significant reductions were observed on depression symptomatology irrespective of the diagnostic group, although depression symptoms, overall, were lower in AD patients ($F(1,92) = 7.25$, $p = .008$). Scores on the GDS decreased 1.41 (95% CI = 0.4 to 2.5; $F(1,92) = 6.25$, $p = .014$). An average deterioration of 1.96 (95% CI = -1.0 to 4.9) was recorded for dysfunctional behaviors but failed to reach statistical significance ($F(1,93) = 2.07$, $p = .153$). At follow-up, caregivers spent an average of 18 hours more per week with the patient than at baseline ($F(1,54) = 5.44$, $p = .023$), but no differences between diagnostic groups were obtained. No significant change in the proportion of caregivers with medical problems from baseline was recorded ($p = .238$), but significantly more caregivers reported the involvement of other caregivers in the care of the patient at follow-up compared to baseline (25% versus 14%; $p = .013$). This increased involvement was solely accounted by an increase in the proportion of non-AD caregivers receiving extra help. The proportion of AD patients* secondary caregivers remained stable at 11%, whereas the proportion of non-AD secondary caregivers increased to 33% from 15% ($p = .039$).

Caregiver burden remained stable overall with a nonsignificant overall increase of 0.12 (95% CI = -2.7 to 3.0; $F(1,90) = 0.08$, $p = .775$). However, examination of frequency data revealed that caregiver burden was not static, but displayed considerable variability; 45% of caregivers reported less burden at follow-up, whereas 47% reported more burden. Forty-eight percent of caregivers had changes of 10 points or more in burden scores.

To determine the factors associated with these changes in burden, we conducted univariate linear regressions with prepost change scores and biological variables (age, gender, and duration of symptoms) as independent variables. These results are displayed in Table 2.. In regard to the patients* condition, only changes in the frequency of dysfunctional behaviors predicted changes in care-giver burden; changes in cognition, ADL, and mood did not predict changes in burden. Changes in dysfunctional behaviors recorded by the DBRI accounted for 24% of the variance in changes in caregiver burden. Gender differences approached the conventional significance threshold ($p = .057$). A multivariate analysis with variables with p values of less than .10 included dysfunctional behaviors and gender. The model yielded an R value of .55 (adjusted $R^2 = .28$, $F(2,85) = 18.28$, $p = .001$). Dysfunctional behaviors ($p = .001$) and gender ($p = .011$) both related significantly to changes in burden. Reductions in dysfunctional behaviors and male caregivers were associated with reduced burden at follow-up.

TABLE 2. Univariate Analyses With Change in Caregiver Burden Score as Dependent

Variable	R	Coefficient	p
Age (patient)	.07	0.11	.537
Duration of symptoms (patient)	.11	0.21	.288
Gender (patient)	.20	-5.58	.057

SMMSE	.10	0.29	.360
GDS	.03	0.09	.781
ADL	.10	0.18	.338
DBRI	.49	0.44	.001
Weekly hours spent with patient	.06	0.02	.665
CG with medical problem	.13	-3.71	.235
Receiving support from other CGs	.01	-0.22	.957

Note: *R* = correlation between variables; coefficient = regression coefficient; *p* = probability value (two-tailed). Other abbreviations as in Table 1.

Predictors of the Intervention Effect and of Burden at Follow-Up

To predict who would benefit from the intervention, univariate regressions were conducted with baseline information as independent variables and changes in burden as the dependent variable (see Table 3). Baseline burden ($p = .001$), Reisberg stage ($p = .028$), and GDS scores ($p = .042$) were significantly associa ted with changes in burden at follow-up. Gender ($p = .057$) and a pattern of gradual deterioration ($p = .084$) were added to the multivariate analysis. Stepwise, forward, and backward methods produced the same statistically significant model ($R = .49$, adjusted $R^2 = .20$, $F(3,59) = 6.32$, $p = .001$). Gender ($p = .012$), burden ($p = .002$), and Reisberg stage ($p = .020$) contributed significantly to the model. High burdens in caregivers of female patients with a low Reisberg stage were predictive of declines in burden at follow-up.

TABLE 3. Univariate Regressions With Baseline Information for Burden Scores at Follow-Up and Differential Benefit From Intervention

Variable	Differential Effect			Follow-Up		
	R	Coefficient	*p*	*R*	Coefficient	*p*
Age	.06	0.10	.590	.06	-0.12	.532
Male	.20	-5.58	.057	.23	-7.35	.022
Duration of symptoms	.07	0.34	.510	.05	0.28	.637
Alzheimer*s diagnosis	.08	-2.18	.473	.07	2.13	.525
Reisberg score	.27	2.71	.028	.37	4.55	.002
SMMSE	.12	-0.22	.266	.14	-0.30	.174
G DS	.22	-0.45	.042	.09	-0.22	.371
ADL	.10	0.14	.348	.33	-0.51	.001
DBRI	.01	0.01	.926	.45	0.46	.001
Burden	.37	-0.37	.001	.56	0.63	.001
Gradual onset	.19	-7.59	.084	.01	0.52	.915
Step-like disease progression	.12	-4.96	.310	.02	0.90	.870
Communication problems	.01	-0.36	.913	.05	-1.67	.650
Judgment problems	.02	-0.69	.842	.29	-9.91	.009
Difficulties with word finding	.10	3.00	.370	.00	-0.15	.967

Weekly hours spent with patient	.07	0.02	.582	.01	.00	.928
CG with medical problem	.00	-0.03	.993	.05	-1.70	.639
Receiving support from other CGs	.01	0.53	.908	.22	-9.57	.033

Note. R = correlation between variables; coefficient = regression coefficient; p = probability value (two-tailed). Other abbreviations as in Table 1.

The variables predicting changes in burden at follow-up were slightly different from the variables predicting actual burden scores at follow-up (Table 3). The model for predictors of actual burden scores at follow-up was composed of baseline burden, dysfunctional behaviors, and Reisberg scores (R = .70, adjusted R^2 = .46, $F(3,54)$ = 17.51, p = .001). High burden at baseline (p = .005), high frequency of dysfunctional behaviors (p = .006), and high Reisberg stage (p = .006) were predictive of high burden scores at follow-up.

Discussion

The deterioration of patients over the course of this study followed predicted patterns. Cognition and independence in ADL, which cannot be improved by present therapeutic means in this population, declined over the course of the study. On the other hand, depression symptoms, which can be ameliorated, were reduced as predicted. Dysfunctional behaviors and caregiver burden did not improve overall as we hypothesized, but varied considerably.

Given the short interval between baseline and follow-up and an effect size of 0.3, the deterioration in cognition and ADL was clinically significant. Yesavage and colleagues (1988) used the MMSE to show a 4-point deterioration in 1 year in their AD patients. Our data suggest a yearly deterioration of about 2.5 points. This discrepancy is explained by our inclusion of patients with cognitive impairment of other origin than AD; patients with dementias of other origin than AD remained stable during our follow-up period. The mean SMMSE change for AD patients only was 2.64 over an average interval between visits of 8.15 months, for a projected yearly decline of 3.9 points. Thus, the cognitive decline observed in our AD patients was consistent with previous reports, and greater confidence in our diagnosis can be derived from these data.

The improvement in mood seen in our patients may reflect a genuine treatment effect, a nonspecific effect, or a measurement problem. Because depression is often confounded with increased cognitive impairment (Albert & Moss, 1984), clinicians are especially attentive to depression symptoms and attempt to devise treatment plans accordingly. The higher level of depression symptoms in our non-AD patients attests to this potential problem. The improvement on the GDS may also have been a nonspecific effect. For example, the deterioration in cognition may result in a reduction of patients* insight into their condition with a consequent reduction in depression symptomatology. However, a recent report failed to show a relationship between depression symptoms and self-awareness of cognitive impairment (Cummings et al., 1995). A third possibility is that of measurement error. The validity of the GDS with increasingly impaired patients is unclear. As our patients become more impaired the GDS scores may become less

reliable; the use of a third-party rating instrument is indicated.

We have shown that dysfunctional behaviors and caregiver burden are highly variable within individuals. Even though overall pre-post differences were negligible, substantial variation was observed in dysfunctional behaviors and burden. Roughly half of the patients* caregivers experienced burden changes in excess of 10 points. Given the progressive nature of dementia, our hypothesis concerning reductions in dysfunctional behaviors and burden may have been overly optimistic. Whereas some patients and caregivers may benefit from our intervention, the situation in others may deteriorate sufficiently to negate any beneficial effects of the intervention. An alternative and less desirable explanation is that the intervention made some patients/caregivers worse. Although we find it difficult to accept the latter explanation, it is possible that nonspecific effects such as informing patients and caregivers of the diagnosis (i.e.. labeling) had detrimental effects.

Changes at follow-up observed in some patients and caregivers are informative but do not constitute proof that our intervention was responsible for these changes. This study aimed primarily at identifying correlates of changes in caregiver burden. The pre-post design, with the absence of a control group, does not lend itself to inferences from the data regarding the actual impact of the intervention. We cannot conclude that our intervention produced the changes observed or that it failed to reduce burden. Valuable information can, however, be derived to better understand factors that may explain not only burden but also changes in burden.

This study shows that changes in the frequency of dysfunctional behaviors are associated with corresponding changes in caregiver burden. Dysfunctional behaviors alone accounted for approximately one quarter of the caregiver burden variance. Given the multitude of factors that may impact on burden, this is a considerable proportion. A limitation of these data concerns the qualitative nature of behaviors. In this model, all dysfunctional behaviors had equal weight, when in reality, all dysfunctional behaviors are not equal. Some dysfunctional behaviors (e.g., aggression) create more burden than others (e.g., repeating over and over; Molloy et al., 1996; Swearer et al., 1988). This may explain why the frequency of dysfunctional behaviors alone did not account for the same proportion of the variance in this study as in previously reported ones. Future studies could examine the differential effects of changes in specific behaviors on burden.

Using multivariate models, we found that male caregivers were more likely to report reductions in burden than female caregivers. We had an unusually high proportion of male patients in our sample (61%) because we limited our study to spousal caregivers, but it is unlikely that this could explain the gender effect. Our intervention may address more successfully male caregiver concerns or male caregivers may be more likely to use resources at their disposal. The burden literature shows a reluctance from care givers to use services (Ganzer & England 1994), but some data suggest that male caregivers may be more likely to use services than female caregivers (Biegel et al., 1993). Similarly, female caregivers may be more reluctant to use services because of a sense of obligation created by societal norms regarding caregiving and gender (Office of Technology Assessment, 1990). Alternatively, Lutzky and Knight (1994) hypothesized that female caregivers use less effective coping skills than male caregivers. This explanation appears too simplistic. Dysfunctional behaviors exhibited by male patients may be of an aggressive nature,

and little, short of institutionalization, is likely to reduce the burden associated with such behaviors. It is impossible to determine the cause of this gender difference until the influence of specific dysfunctional behaviors has been examined.

Qur best model explained 28% of the variance in burden changes. What explains the remaining 72% is unclear. It appears unlikely that other patient variables will explain substantial proportions of the burden score. However, caregiver variables or factors outside their control could influence burden. Caregivers* health, economic status, and geographical location with respect to support system may affect burden. The psychological disposition of caregivers may also explain burden differences between individuals (Gallagher et al., 1994; Reis et al., 1994) and also between genders. External factors such as support from relatives and friends and availability of day care or respite services may also impact on burden in the long run.

Unfortunately, this study could not properly capture the impact of external factors on changes in caregiver burden. Although we reported an increased number of hours spent with patients, this rise likely reflects the progressive nature of the disease and increased demands on caregivers without increased burden. It is also difficult to interpret the increased involvement of other caregivers at follow-up without a concomitant reduction in burden. One explanation is that this increased involvement is reactive to increasing burden on the primary care-giver as opposed to proactive. We have difficulties explaining the increased involvement of secondary caregivers in non-AD cases but not in AD cases. It is possible that some stigma might be attached to the AD diagnosis, rendering caregivers less likely to seek external help.

The relationship between dysfunctional behaviors and caregiver burden is often construed in causal terms (Vitaliano et al., 1993). Although it is tempting to conclude that dysfunctional behaviors cause burden, association alone does not establish causality (Susser, 1991). Briefly, to establish causality, (a) we must demonstrate an association between the variables of interest, (b) we must demonstrate a time-order effect; changes in the causal agent should precede changes in the dependent variable, and (c) we must be able to show that changes in the dependent variable directly result from changes in the antecedent factor. Here it is especially critical to establish that a third variable is not involved in causing changes in the two variables of interest.

If we examine our caregiver data, we find that Criteria b and care not fulfilled. We cannot prove that changes in dysfunctional behaviors preceded changes in burden, and we cannot conclude that changes in burden were the direct result of changes in behavior. This observation is critical for future work. Our intervention targeted both patients and caregivers, and we are unable to dissociate cause and effect. Reducing caregiver burden will require the identification of causal agents as opposed to correlates. Until now the emphasis in this research area has been to understand the factors associated with burden. Future studies will have to address the issue of causality if effective interventions to reduce burden are to be developed.

One limitation of the present study is that our results apply to a short-term follow-up. We showed that changes in dysfunctional behaviors and gender were predictive of changes in burden after an average interval of 7 months. Long-term studies may reveal a different pattern and must be conducted. At a later stage in the disease, other factors (e.g., heavy ADL care, incontinence) may

supplant dysfunctional behaviors as determinants of burden, requiring different interventions. Furthermore, the long-term effects of some factors may start to cumulate and increase burden (Biegel et al., 1991).

Nonetheless, at the early stages of the condition, dysfunctional behaviors are closely associated with caregiver burden. They must be assessed, treated, and monitored. However, the treatment of dysfunctional behaviors may negatively impact on cognition and ADL function. The decision to follow this course must be evaluated carefully, but the evidence presented in this and many other reports suggests that changes in cognition do not affect the burden of caregivers. Nonetheless, medications that reduce dysfunctional behaviors while minimizing the impact on cognition and ADL would be welcome, and would represent a better pharmacological treatment to those presently available. Drugs to improve cognition, however attractive the idea, may not provide tangible benefits to caregivers unless the disease process was actually reversed. If cognitionwere improved and patients were overstimulated, an increase in dysfunctional behaviors might occur in response to these treatments and increase the burden on caregivers.

We need to reduce burden in caregivers for three reasons: (a) burden affects caregivers* quality of life, (b) burden has the potential to increase health problems in caregivers, and (c) burden increases the likelihood of institutionalization. We need to improve our understanding of the relationship between dysfunctional behaviors and burden, develop effective interventions that address this problem, and improve our knowledge of the health consequences of caregiving.