Unique Contribution of Family Functioning in Caregivers of Patients with Mild to Moderate Dementia

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Abstract
The relationship between family functioning and dementia caregiving is complex. The present study examined the interrelationships between family functioning, caregiver burden, and patient characteristics. Participants were 72 live-in, family caregivers of patients with mild (n = 47) or moderate dementia (n = 25). Caregivers completed measures of burden, family functioning, depression, and anxiety. Ratings of patients’ memory/behavior problems and patients’ activities of daily living were also collected. Results indicated that higher levels of caregiver burden were significantly associated with increased caregiver depression and anxiety, greater frequency of memory and behavior problems in the dementia patient, worse activities of daily living, and poorer family functioning. Even after controlling for caregiver depression, caregiver anxiety, and frequency of memory/behavior problems in dementia patients, poorer family functioning continued to be associated with higher levels of caregiver burden. Caregivers with high levels of burden reported greater family dysfunction in communication and roles, regardless of their relationship to the patient (i.e., spouse or child). These findings suggest that including a family systems component in caregiver interventions may be beneficial in reducing burden in these very distressed individuals.

Introduction
Caregiver burden in dementia is known to negatively affect physical and emotional health, although little is known about how family functioning is affected. Several studies have examined the impact of family characteristics on burden and emotional distress in dementia caregivers. For example, criticism and emotional overinvolvement expressed by the family member toward the patient (i.e., expressed emotion) are associated with increased depression, greater burden, and fewer positive benefits from caregiving [1]. Low family cohesiveness, high family conflict, too rigid or too permeable family boundaries, low levels of family organization, lack of clear communication, and poor spousal support have also been associated with poor response to chronic disease such as dementia [2]. Primary caregivers who receive support from other family members experience lower levels of caregiver strain [3, 4]. Strawbridge and Wallhagen [5] found strong positive correlations between family conflict and caregiver burden and self-reported health. In contrast, several studies have found that families who use...
mechanisms to avoid family conflict and instead use guilt
tend to show declines in self-reported health, increased
caregiving distress, and less follow through with treatment
recommendations than families without these
characteristics [6]. There is also evidence that families of
dementia patients who use a focused decision making style,
positive conflict resolution methods, and focus on a pri-
mary caregiver provide significantly more help to the pa-
tient than those families who do not use this type of an
approach or try to divide resolution of the problem among
family members [7]. Although these studies have identi-
cified family characteristics associated with dementia care-
giving, none of the studies has examined the functioning
of the family unit as a system.

Recently, Heru et al. [8] found that perceived family
dysfunction was associated with increases in self-reported
caregiver strain and burden in 38 dementia caregivers.
This was the first study to use the Family Assessment De-
vice (FAD), a psychometrically sound measure of family
functioning based on the McMaster model of family func-
tioning [9]. The present study examined the interrelation-
ships between family functioning, caregiver burden, and
patient characteristics in a sample of live-in, family care-
givers of individuals with dementia. Given the complex
construct of burden, our aim was to understand the
unique contribution of family functioning as well as to
consider other variables that could explain some of these
relationships.

Method

Participants and Procedure

The participants were 72 caregivers of patients with dementia
who completed baseline assessment measures as part of a caregiver
intervention study. Caregivers were recruited from memory disor-
der clinics, support groups, and newspaper/television advertise-
ments in the Providence, Rhode Island region. All caregivers
resided with the care recipient and were providing a minimum of
4 h of daily care over at least 6 months. The majority of caregivers
were female (n = 56; 77%) and Caucasian (n = 69; 96%). Sixty-one
percent (n = 44) were spouses, and the remaining caregivers were
adult children. Caregivers had been providing care for an average
of 39.68 months (SD = 35.57), and the average length of dementia
diagnosis was 39.71 months (SD = 35.90). Caregivers’ average age
was 64.36 (SD = 11.66) and care recipients’ average age was 77.18
(SD = 9.47). Care recipient’s diagnosis of dementia was confirmed
by their primary physicians. Etiology of dementia in the care re-
cipient included probable Alzheimer’s disease (n = 42), vascular
dementia (n = 4), mixed dementia (n = 4), frontotemporal dement-
ia (n = 5), dementia with Lewy bodies (n = 4), Parkinson’s dement-
ia (n = 3), hydrocephalus (n = 2), progressive supranuclear palsy
(n = 1), dementia NOS (n = 2), and unknown (n = 5). Dementia
severity was determined by the Clinical Dementia Rating Scale
[10]. In addition to global scores, sums of box scores were also cal-
culated by summing ratings from each category. Caregivers com-
pleted the following measures as part of a baseline assessment of a
large-scale intervention study: Geriatric Depression Scale [11], Ac-
tivities of Daily Living (ADL) [12], Revised Memory and Behavior
Problems Checklist [13], Dementia Knowledge Test [14], State-
Trait Anxiety Inventory (State Form) [15], and the Zarit Burden
Interview [4]. Caregivers also completed the FAD [9]. The FAD is
a 60-item self-report questionnaire designed to assess the six di-
dimensions of the McMaster Model of Family Functioning, including
problem-solving, communication, roles, affective responsiveness,
affective involvement, behavioral control, and general functioning.
Psychometric properties of the scale support its reliability and va-
lidity in psychiatric, medical, and nonclinical samples [16]. Care-
givers were asked to rate statements about their families along a
4-point Likert Scale from strongly disagree to strongly agree. It was
emphasized to caregivers to answer according to their perceptions
of their family.

Results

Intercorrelations between all measures are presented in table 1. As can be seen, perceived burden was moder-
ately correlated with caregiver depression and anxiety,
frequency of patient behavior problems, and family func-
tioning. Weaker relationships were seen between burden
and severity of dementia (i.e., sum of boxes), length of
diagnosis, dementia knowledge, length of caregiving, and
total ADL, although this latter variable was statistically
significant. Interestingly, family functioning was signif-
cantly related to caregiver depression and caregiver situ-
tional anxiety. Length of caregiving, caregivers’ knowl-
edge of dementia, and length of diagnosis were not re-
lated to caregiver distress measures or family functioning.
Patient ADL were significantly related to caregiver de-
pression. To examine the unique contribution of family
functioning to burden, a partial correlation between fam-
ily functioning and burden removing the variance associ-
ated with caregiver depression, anxiety, and frequency of
memory and behavior problems in the patient was calcu-
lated. Findings showed a statistically significant relation-
ship, even after controlling for possible contributing vari-
ables (r = 0.24, p = 0.04).

To examine which aspects of family functioning are the
most important contributors to the relationship with bur-
den, caregivers were divided into low vs. high burden
groups based on a cut-off score on the Zarit Burden Inter-
view (high = a score of ≥ 35). Because relationship type
(spouse vs. child) could potentially impact family func-
tioning, we conducted burden (high vs. low) by caregiver
relationship (spouse vs. child) analysis of variance. None
of the interactions between relationship type and burden

Family Functioning in Dementia

Caregivers

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Dement Geriatr Cogn Disord 2006;21:170–174 171

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for any of the FAD subscale scores was significant. Furthermore, no significant main effects were found for relationship type for any of the FAD subscale scores, arguing against a significant effect of relationship type on family functioning. Average FAD subscale scores for the burden main effect are presented in Table 2. Based on published clinical cut-off scores [17], the high burden group shows dysfunctional scores in communication, roles, affective responsiveness, behavior control and general functioning domains. FAD scores for the low burden group were all within normal limits. To minimize the risk of type I error, only group differences significant at $p < 0.01$ were interpreted. As can be seen in table 2, FAD subscales of communication and roles were significantly higher (indicating greater dysfunction) in caregivers with high burden compared to those reporting low burden scores.

### Discussion

Results of this study show that family functioning is a significant contributor to perceptions of burden among a group of live-in dementia caregivers who met strict inclusion criteria. After removing the variance associated with caregiver depression and anxiety and patient behavior problems, a significant relationship between family functioning and burden was still found, providing support for the unique contribution of family functioning to caregiver burden. In addition, strong relationships were seen between poor family functioning and caregiver depression and anxiety. Aspects of family functioning have been shown to be dysfunctional in psychiatric disorders [16, 18], although our study is one of the few to demonstrate these relationships in dementia caregivers. Compared to

| Table 1. Intercorrelations between outcome measures |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                  | GDS             | ADL             | Sum of boxes    | Length of diagnosis | MBPC            | STAI            | DKT             |
| ZBI              | 0.40**          | –               | –               | 0.08              | 0.47**          | 0.34**          | 0.12            |
| GDS              | –               | –               | –               | –                 | –               | –               | –               |
| ADL              | –               | –               | –               | –                 | –               | –               | –               |
| Sum of boxes     | –               | –               | –               | –                 | –               | –               | –               |
| Length of diagnosis | –       | –               | –               | –                 | –               | –               | –               |
| MBPC             | –               | –               | –               | –                 | –               | –               | –               |
| STAI             | –               | –               | –               | –                 | –               | –               | –               |
| DKT              | –               | –               | –               | –                 | –               | –               | –               |
| FAD              | –               | –               | –               | –                 | –               | –               | –               |

ZBI = Zarit Burden Interview; GDS = Geriatric Depression Scale; ADL = Activities of Daily Living; MBPC = Memory and Behavior Problem Checklist; STAI = State Trait Anxiety Inventory; DKT = Dementia Knowledge Test; FAD = Family Assessment Device – General Functioning Subscale.

** $p < 0.01$, * $p < 0.05$.

| Table 2. Mean FAD scores for caregivers reporting high versus low burden (mean ± SD) |
|-------------------------------|---------------|--------------|---------------|
|                                | Low burden (n = 40) | High burden (n = 32) | F   | p     |
| Problem solving                | 1.90 ± 0.38   | 2.09 ± 0.48  | 1.75 | 0.190 |
| Communication                  | 2.07 ± 0.40   | 2.36 ± 0.38  | 9.53 | 0.003 |
| Roles                          | 2.00 ± 0.41   | 2.30 ± 0.39  | 7.06 | 0.010 |
| Affective responsiveness       | 1.92 ± 0.50   | 2.23 ± 0.56  | 5.07 | 0.028 |
| Affective involvement          | 1.82 ± 0.48   | 2.08 ± 0.32  | 3.91 | 0.052 |
| Behavioral control             | 1.71 ± 0.40   | 1.93 ± 0.38  | 5.70 | 0.020 |
| General functioning            | 1.82 ± 0.47   | 2.15 ± 0.51  | 5.23 | 0.025 |

Higher FAD scores indicate greater dysfunction. Low burden ≤ 34 and high burden ≥ 35 on Zarit Burden Interview.
previous studies of medical and psychiatric samples, our
dementia caregivers exhibited FAD subscale scores that
were somewhat worse than medical patients and better
than psychiatric samples, particularly for the problem-
solving, communication, and general functioning sub-
scales [16]. These findings suggest that dementia caregiv-
ers should be assessed for family difficulties within these
domains.

Our findings are consistent with those of Heru et al. [8]
as well as other studies showing a relationship between
family characteristics and dementia caregiver burden. We
add to results of previous studies by controlling for mod-
erating variables (e.g., depression, anxiety, patient behav-
ior problems), including measures of clinically-rated de-
mentia severity, and including a more homogenous group
of caregivers (i.e., those residing with the patient). Obvi-
ously, our findings do not address the direction of the re-
lationhip. That is, whether family dysfunction results in
greater caregiver burden or whether increased burden
causes greater family dysfunction. Studying family func-
tioning (and associated moderating variables) in a longi-
tudinal study may be more likely to identify causal rela-
tionships. Regardless of the direction, our findings high-
light the importance of including a family assessment and
intervention when working with dementia caregivers.

Zero-order correlations between burden and other
caregiver and patient variables revealed significant rela-
tionships between burden and caregivers’ emotional
function. In addition, a strong relationship was seen be-
tween burden and frequency of memory and behavior
problems in the patient. These findings highlight the com-
plexity of caregiver burden as a construct and argue for
identification of its unique contributors. After conducting
a meta-analysis of dementia caregiving interventions, Ac-
ton and Kang [19] concluded that burden was potentially
too global an outcome, and they called for use of precise
measures of caregivers’ functioning. Our findings suggest
the inclusion of family functioning as an important out-
come measure in caregiver intervention studies.

Interestingly, we found that family functioning was only
weakenly related to measures of patient functioning, includ-
ing severity of dementia, length of diagnosis, ADL, and
frequency of memory and behavior problems. Others have
found that subjective caregiver perceptions of problems,
satisfaction with and amount of social support, available
resources, coping skills, and feelings of self-efficacy are im-
portant predictors of caregiver depression and stress [20,
21]. Similarly, there is evidence that subjective caregiver
factors may be more important than patient factors to the
prediction of nursing home placement [22, 23].

Caregivers who were high in burden reported several
areas of family dysfunction that distinguished them from
those caregivers low in burden. We found that burden was
associated with perceived ineffective communication
among family members. In addition, caregivers who were
burdened described difficulty with distribution and fol-
low-through of family tasks. It is possible that these find-
ings reflect the changing role of patient with dementia
in the family. It is equally plausible that our findings reflect
the turmoil that can be created when there is disagree-
ment among family members about how to manage and
care for a family member with dementia. It is quite com-
mon for caregivers (especially live-in caregivers) to de-
scribe that other family members do not fully appreciate
either the level of care necessary or the stress and burden
associated with providing care. Our results suggest that
family therapy or supportive strategies early in the care-
giving process may reduce the risk for subsequent care-
giver burden. For example, family members may need
encouragement and support to express their feelings and
thoughts about the disease, as well as assistance in speci-
fying roles of family members and specific task assign-
ment.

As noted above, the cross-sectional nature of the cur-
rent study is a limitation. In addition, our sample size did
not allow for subgroup analyses of burden and family
functioning in dementia subtypes. There are clinical rea-
sions to believe that frontotemporal dementia and demen-
tia with Lewy bodies may be associated with different
levels of caregiver burden.

Overall, findings from the present study support the
unique contribution of family functioning to dementia
caregiver burden. The study establishes empirical sup-
port for the use of family assessment and family-based
treatments when working with dementia caregivers. Em-
phasizing the role of family functioning in these caregiv-
ers may ultimately lead to reduced burden and its associ-
ated negative consequences.

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