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Dimensions of Caregiver Burden in Dementia: Impact of Demographic, Mood, and Care Recipient Variables

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Abstract

Objectives—While typically examined as a unitary construct, there is evidence that caregiver burden may be comprised of several dimensions. The purpose of this study was to examine the factor structure of the Zarit Burden Interview (ZBI) in a sample of dementia caregivers and to explore the relationship between these factors and demographic, mood, and care recipient variables.

Design—Cross-sectional

Setting—Academic medical center

Participants—206 spousal or adult child caregivers for patients with mild to moderate dementia residing in the community.

Measurements—Caregiver measures included the ZBI, Center for Epidemiologic Studies Depression Scale, and the Burns Relationship Satisfaction Scale. Patient measures included scores on the Dementia Rating Scale, Lawton-Brody Activities of Daily Living scale, and Revised Memory and Behavior Problems Checklist

Results—Factor analysis revealed three dimensions of caregiver burden: direct impact of caregiving upon caregivers' lives, guilt, and frustration/embarrassment. Caregiver depression and age emerged as unique predictors of the first two factors. Caregivers' satisfaction with their relationship with the patient and patients' functional independence also uniquely predicted the direct impact of caregiving upon caregivers' lives. Patients' behavioral problems and caregivers' level of relationship satisfaction with the care recipient served as unique predictors of frustration/embarrassment.

Conclusions—Findings demonstrate the multidimensionality of caregiver burden among dementia caregivers. Given the unique predictors of each dimension of burden, caregivers may benefit from different types of tailored interventions specific to the subtype of burden they are experiencing.

Keywords

Caregiving; Burden; Dementia

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Many older adults with dementia are cared for at home, primarily by spouses and adult children. Providing care for patients with dementia can have significant consequences caregivers, including poorer physical health, increased rates of emotional distress and depression, and a higher risk of mortality than non-caregiving individuals¹⁻⁴.

The Zarit Burden Interview (ZBI)⁵ is one of the most widely used measures of caregiver burden. The most commonly used version of the ZBI contains 22 items assessing burden associated with patients' behavioral and functional impairments and covering the impact of caregiving upon caregivers' lives in areas such as their health, relationships, and finances. The ZBI has shown good internal consistency across multiple studies⁶⁻⁹.

While the ZBI measures caregiver burden as a unitary construct, some authors have argued that caregiver burden is multidimensional and that single, global scores may not accurately capture the experiences of burdened caregivers. As a result, the factor structure of the ZBI has been examined by several groups. Hebert, Bravo, and Preville⁹ proposed a 12-item, 2-factor version of the ZBI after testing several alternative models using confirmatory factor analysis (CFA) in a sample of Canadian dementia caregivers. Their two factors included Personal Strain (3 items; e.g., feel strained, losing control of one's life) and Role Strain (9 items – e.g., lack privacy, negative impact upon social life and health, insufficient time for self, stress balancing caregiving with other responsibilities). Similarly, Bedard et al¹⁰ found a two-factor model for the ZBI after conducting an exploratory factor analysis (EFA) in a sample of caregivers for cognitively impaired older adults referred to a memory clinic. Although their two factors, Personal Strain and Role Strain, are conceptually similar to those in found by Hebert et al (2000), the composition of the factors across both studies was not the same. O'Rourke and Tuokko⁸ provided additional support for the psychometric properties of the 12-item, 2-factor model proposed by Bedard et al (2001) in a sample of Canadian dementia caregivers.

In contrast, Knight, Fox, and Chou⁷ did not find support for a two-factor model, instead proposing a three-factor model using 14 ZBI items in two separate dementia caregiver samples. Their three factors were Embarrassment/Anger (9 items – e.g., feel embarrassed, feel angry, negative impact upon health and social life, feel strained), Patient's Dependency (3 items – e.g., patient is dependent, insufficient time for self), and Self-criticism (2 items – should be doing more, could do a better job). Flynn-Longmire and Knight⁶ tested this 14-item 3-factor model in two separate samples (one African American and one Caucasian) using CFA and found good model fit in both groups, providing support for this factor structure across racial groups. Ankri et al¹¹ also proposed a 3-factor model for the ZBI using EFA in a sample of dementia caregivers. Their factors included social consequences for the caregiver (6 items – e.g., negatively impacts relationships with others, health has suffered, lost control of life), psychological burden (6 items – e.g., feel embarrassed, feel angry, feel strained), and guilt (4 items – e.g., should be doing more, could do a better job).

Despite studies supporting either a two- or three-factor structure in the ZBI, only Ankri et al (2005) examined the relationships between these factors and caregiver characteristics (spouse vs. child) and patient characteristics (e.g., age, global cognition, functional independence, behavior, and mood). They found increased scores on the factor representing social consequences for caregivers to be related to increased functional dependence, aggressiveness, wandering, and communication problems in patients, as well as relationship status, with spouses scoring higher than children on this factor. Scores on this factor were unrelated to dementia severity. Increased scores on the psychological burden factor were associated with increased patient aggressiveness and anger and unrelated to relationship status, dementia severity, and functional impairments. Increased guilt factor scores were associated with increased patient aggressiveness, sadness, and depression as well as

relationship status, with children reporting significantly greater scores than spouses. However, this study did not examine relationships with other constructs known to impact caregiver burden, including caregiver depression and relationship satisfaction.

The purpose of this study was to explore the dimensions of the ZBI in a sample of dementia caregivers experiencing high levels of distress due to their caregiving role and to examine different predictors of these dimensions of caregiver burden. We sought to explore the relationships between the various aspects of caregiver burden and demographic variables, caregiver depression, and patients' behavioral symptoms and cognitive and functional status.

METHODS

Caregivers completed self-report measures of their perceived burden, mood, and relationship satisfaction as part of their baseline assessment for a longitudinal caregiver psychosocial intervention study. In addition, caregivers rated patients' functional abilities and mood and behavioral problems, and most patients also completed an assessment of their global cognitive status. Informed consent was obtained from all participants prior to participating in this IRB approved study.

Participants

Participants were spousal ($n = 114$) or adult child ($n = 92$) caregivers of patients with mild to moderate dementia residing in the community (see Figure 1 for a depiction of N's for screening and enrollment). Participants self-identified as caregivers and were recruited in the greater Providence, RI area through memory disorders centers, geriatricians, and community advertising. To be eligible for participation in the larger intervention study, caregivers were required to have been in the primary caregiver role for at least 6 months, be providing at least 4 hours of assistance per day, and endorse significant distress. Significant distress was defined as endorsing two or more of the following: feeling overwhelmed or stressed, sad mood/depression, anger or frustration, loss of contact with family or friends, conflict in family or family stress, neglecting their own health, demands/pressures of caregiving are too much, exhaustion and fatigue, or not taking care of their own needs. Most patients were diagnosed with Alzheimer's disease (78.7%), with the other most common dementia etiologies including frontotemporal dementia (3.2%), vascular dementia (2.8%), and Lewy Body dementia (1.9%). The majority of caregivers (87.7%) were female, and 82.0% of caregivers lived with the care recipient. See table 1 for additional description of the sample.

Measures

Zarit Burden Interview (ZBI)⁵—The ZBI is a 22-item self-report measure of perceived caregiver burden. Caregivers were asked to rate their degree of burden on a Likert scale, with higher scores indicating higher levels of burden.

Center for Epidemiologic Studies Depression Scale (CES-D)¹²—The CES-D was used to measure caregivers' depressive symptoms. This 20-item self-report measure assesses the extent to which caregivers experienced various symptoms of depression during the past week, with higher scores indicating higher levels of depression.

Burns Relationship Satisfaction Scale (BRSS)¹³—The BRSS is a 7-item self-report questionnaire assessing caregivers' satisfaction with several aspects of their relationship with care recipients which has been used in several studies of individuals caring for older adults^{14–16}. Caregivers are asked to rate the degree of communication and openness, conflict resolution, degree of caring/affection, intimacy/closeness, satisfaction with relationship

roles, and overall relationship satisfaction on a 7-point Likert scale. Higher scores indicate greater relationship satisfaction.

Revised Memory and Behavior Problem Checklist (RMBPC)¹⁷—The RMBPC is a 24-item caregiver-report measure of behavioral problems in dementia patients observed by the caregiver during the past week. This measure provides scores on 3 subscales (disruptive behaviors, depression, and memory), and higher scores indicate a greater frequency of problematic behaviors.

Lawton-Brody Activities of Daily Living Questionnaire¹⁸—This questionnaire, completed by caregivers, measures the degree of care recipients' independence in basic (e.g., grooming, eating) and instrumental (e.g., medication and financial management) daily activities. Each item is scored on a 3-point scale, reflecting independence, need for assistance, or dependence. Higher scores reflect greater functional independence.

Dementia Rating Scale-2 (DRS)¹⁹—The DRS is a widely used measure of global cognition in older adults. Lower scores are indicative of poorer cognitive functioning, and a total score below 123 is typically considered to be within the range suggestive of dementia.

Statistical Analysis

An exploratory principal component factor analysis (EFA) using Oblimin rotation to allow factors to correlate with each other was conducted to examine the factor structure of the ZBI. Regression-based factor scores were also calculated during the EFA. Next, Pearson correlations and univariate analyses of variance were used to examine the relationship between caregivers' scores on these ZBI factors and caregivers' demographic variables, mood, and their perceived relationship satisfaction with the care recipient as well as relationships with care recipients' cognition, behavioral problems, and activities of daily living (given the number of analyses, significance was set at $p < .01$). Variables with significant relationships were then entered into linear multiple regressions to identify significant predictors of caregiver burden for each of the ZBI factor scores. All analyses were performed using SPSS 11.0.

RESULTS

Overall, 83.9% of caregivers reported clinically significant burden (ZBI = 21). A review of the distributions of each item revealed the distributions did not depart substantially from normality, and the full range of answers was endorsed on all items. Chronbach's alpha reliability of the whole scale indicated good internal consistency reliability ($\alpha = 0.90$).

In order to examine the ZBI's factor structure, an exploratory factor analysis was conducted using oblimin rotation. Five factors with an eigenvalue greater than 1 were extracted and accounted for 61.99% of the variance. The first three factors were retained; the fourth factor consisted of only one item (financial difficulties related to caregiving) and the fifth consisted of two items which were conceptually unrelated. The first factor, accounting for 35.00% of the variance, described the direct impact of caregiving upon caregivers lives (e.g., lost control of life, health suffered, social life suffered). The second factor reflected feelings of guilt (e.g., should do more, could do better job) and accounts for 8.81% of the variance. The third factor was characterized by frustration and embarrassment (e.g., care recipient asks for too much help, caregiver is embarrassed or angered by the care recipient) and accounted for 7.37% of the variance (Table 2). A significant correlation between factors was found only for factors one and three ($r = 0.38$, $df = 184$, $p < .001$).

Factor scores reflecting the direct impact of caregiving upon caregivers' lives were positively correlated with caregivers' depressive symptoms and inversely correlated with caregivers' age and relationship satisfaction (Table 3). Factor scores were also significantly associated with caregiver gender, with women scoring significantly higher on this factor than men (0.16 vs. -0.53; $F(1,184) = 17.31, p < .001$). In addition, these scores were significantly correlated with multiple patient variables, including positive correlations with patients' age and mood/behavioral problems and negative associations with patients' functional abilities. When all of these variables were entered as predictors in a multiple regression, only caregiver age ($\beta = -0.17, t = -2.86, df = 163, p < .01$), patients' age ($\beta = 0.20, t = 3.27, df = 163, p = 0.001$), patients' dependence for instrumental ADLs ($\beta = -0.17, t = -2.09, df = 163, p < .05$), caregiver CES-D scores ($\beta = 0.36, t = 6.04, df = 163, p < .001$), and caregiver BRSS scores ($\beta = -0.16, t = -2.64, df = 163, p < .001$) emerged as significant predictors (model fit: $R^2 = 0.52, F(10,163) = 17.54, p < .001$).

Guilt factor scores were positively correlated with both caregivers' and patients' depressive symptoms. Guilt was negatively correlated with caregivers' age. In addition, caregivers living separately from care recipients scored significantly higher on this factor than those living with the care recipient (0.42 vs. -0.09, $F(1,184) = 7.60, p < .01$). Guilt was not associated with patients' global cognition, behavioral problems, or functional abilities. When all variables having significant relationships with guilt were entered as predictors of guilt in a multiple regression, only caregiver age ($\beta = -0.27, t = -3.49, df = 179, p = .001$) and CES-D scores ($\beta = 0.22, t = 3.15, df = 179, p < .01$) emerged as significant predictors (model fit: $R^2 = 0.20, F(4,179) = 11.34, p < .001$).

Frustration/embarrassment was positively correlated with caregivers' level of depression and patients' behavioral problems, and inversely associated with caregivers' relationship satisfaction. Frustration/embarrassment not associated with patients' global cognition or functional abilities. When the 3 variables that significantly correlated with frustration/embarrassment were entered into the regression equation, only patients' behavioral problems ($\beta = 0.30, t = 4.34, df = 172, p < .001$) and caregivers' level of relationship satisfaction ($\beta = -0.36, t = -5.13, df = 172, p < .001$) emerged as significant predictors (model fit: $R^2 = .30, F(3,172) = 23.96, p < .001$).

DISCUSSION

Our study identified three dimensions of caregiver burden: direct impact of caregiving upon caregivers' lives, guilt, and frustration/embarrassment. These findings mirror those of Ankri et al (2005) and Knight et al (2000) who found 3 conceptually similar factors, although the exact items loading on each factor did vary somewhat across studies. The slight differences across these studies may be related to differences in composition of the caregiver sample and data analysis techniques. Furthermore, previous studies have also found the most variance to be explained by a factor assessing the direct impact of caregiving upon caregivers' lives, likely because caregivers are constantly reminded of the time and energy they are diverting from their own lives on a daily basis to provide care to their loved one.

Caregiver depression served as a unique predictor of the factors describing the direct impact of caregiving on caregivers' lives as well as guilt, with increased depression associated with increased scores on these two factors. This finding is consistent with a large body of literature showing a relationship between caregiver burden and increased depression²⁰⁻²².

Not surprisingly, caregivers of patients with greater IADL dependence reported greater direct impact of caregiving upon their lives. However, no association was seen between caregiver burden and patients' cognitive abilities. These findings are consistent with results

of previous studies^{11,23} and emphasize the deterioration in patients' ability to care for themselves as their dementia progresses, rather than cognitive deterioration, serves as an important predictor of caregiver burden. In addition, patients' behavioral problems were a unique predictor of frustration/embarrassment in this sample. Behavioral problems, in particular disinhibited behaviors, have been associated with caregiver burden in several other studies^{24–26} and are also a strong predictor of nursing home placement²⁵. Taken together, these findings suggest caregiver interventions teaching skills to manage patients' behaviors may be particularly effective in reducing caregiver burden, in particular frustration/embarrassment.

Caregiver age was associated with the first two factors, with younger caregivers reporting both a greater direct impact of caregiving upon their lives as well as increased guilt. This finding suggests that significant differences between spousal and adult child caregivers may exist on these two ZBI factors. Indeed, when mean factor scores for spousal and adult child caregivers were compared, spouses reported significantly less burden than adult children related to the direct impact of caregiving upon their lives (-0.34 vs. 0.41 ; $F(1,184) = 29.88$, $p < .001$) as well as guilt (-0.26 vs. 0.32 ; $F(1,184) = 16.54$, $p < .001$). This suggests the caregiving experience may be different for these two groups of caregivers, consistent with other studies illustrating differences between spousal and adult children caregivers^{26–28}. Adult children caregivers are often balancing the demands of caring for both their parents as well as their own children and are more likely to be working outside the home, and differences in spousal relationships vs. parent-child relationships may also be playing a role in the differences observed between these two groups of caregivers.

Limitations of this study include a predominantly Caucasian female caregiver population caring largely for patients with Alzheimer's disease who enrolled in a psychosocial intervention study for distressed caregivers, so the generalizability of findings to other caregiver populations is unknown. In addition, this study did not examine associations between caregiver burden and positive aspects of caregiving, which have been shown to protect against caregiver burden in other studies²⁷. Replication of these ZBI factors in an independent sample would also be informative.

Nevertheless, these results have important implications for our understanding of burden among dementia caregivers. Taken together with findings from other studies, results of this study suggest that although the ZBI is typically utilized as a single measure of caregiver burden, it likely reflects several different dimensions of burden, including the direct impact of caregiving upon caregivers' lives (e.g., declines in health and social life), feelings of guilt, and frustration/embarrassment, which has implications for the assessment and treatment of dementia caregivers. Given the complexity of burden, it is possible that particular intervention approaches may impact one dimension of burden but not others, and that development of tailored interventions specific to various subtypes of caregiver burden may be a useful line of future research.

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Figure 1.
Participant Flow Chart

Table 1

Sample Characteristics

	Mean	SD
Caregiver Characteristics		
Age (years)	62.88	12.69
Education (years)	14.90	2.71
Months of Caregiving	45.29	35.50
ZBI Total Score	38.03	14.18
CES-D	16.22	10.19
Burns Total Score	25.76	11.60
Patient Characteristics		
Age (years)	78.34	9.87
Education (years)	12.69	4.59
DRS	102.45	23.62
RMBPC	35.12	12.47
RMBPC-M	19.45	5.96
RMBPC-B	6.59	5.06
RMBPC-D	9.14	6.32
Basic ADLs	9.10	2.46
Instrumental ADLs	5.12	3.76

Note: ZBI = Zarit Burden Interview; CES-D = Center for Epidemiological Studies Depression Scale; DRS = Dementia Rating Scale; RMBPC = Revised Memory and Behavior Problems Checklist (M = memory, B = behavioral problems, D = depression); ADL = activities of daily living

Table 2

Pattern Matrix from the Principal Component Analysis with Oblimin Rotation

ZBI Item	Factor		
	Impact on Caregiver's Life	Guilt	Frustration/ Embarrassment
Do you feel you don't have as much privacy as you would like because of your relative?	.866		
Do you feel that your social life has suffered because you are caring for your relative?	.832		
Do you feel your health has suffered because of your involvement with your relative?	.725		
Do you feel that you have lost control of your life since your relative's illness?	.708		
Do you feel that because of the time you spend with your relative you don't have enough time for yourself?	.696		
Overall, how burdened do you feel in caring for your relative?	.675		
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	.550		
Do you feel your relative currently affects your relationship with other family members or friends in a negative way?	.524		
Do you feel strained when you are around your relative?	.527		
Do you wish you could leave the care of your relative to someone else?	.458		
Do you feel you should be doing more for your relative?		.900	
Do you feel you could do a better job in caring for your relative?		.845	
Do you feel angry when you are around your relative?		.616	
Do you feel uncertain about what to do about your relative?		.441	
Do you feel your relative asks for more help than he/she needs?			.786
Do you feel embarrassed over your relative's behavior?			.745
Do you feel uncomfortable about having friends over because of your relative?			.590
Do you feel your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?			.481
<i>Percent Variance Explained</i>	<i>35.00</i>	<i>8.81</i>	<i>7.37</i>

Note: To facilitate interpretation variables are ordered and grouped by the size of their loading. Factor loadings < 0.35 were left blank.

Table 3

Pearson Correlations between Caregiver and Care Recipient Characteristics and ZBI Factors

	ZBI Factor		
	Impact on Caregiver's Life	Guilt	Frustration/Embarrassment
Caregiver Characteristics			
Age (df = 184)	-.24**	-.33***	-.06
Education (df = 184)	.17	.17	-.02
CES-D (df = 193)	.52***	.29***	.21**
Burns Total Score (df = 186)	-.37***	-.02	-.48***
Care Recipient Characteristics			
Age (df = 183)	.28***	-.08	.05
Education (df = 184)	-.08	.02	-.04
DRS (df = 116)	-.19	.04	.03
RMBPC-M (df = 193)	.23**	-.06	-.04
RMBPC-B (df = 193)	.33***	.02	.40***
RMBPC-D (df = 193)	.24**	.22**	.08
Basic ADLs (df = 193)	-.37***	.01	-.05
Instrumental ADLs (df = 193)	-.36***	.07	-.02

Note:

**
p<.01,***
p<.001**Degrees of freedom are noted for each correlation; differences in degrees of freedom across correlations are due to missing data points.**

ZBI = Zarit Burden Interview; CES-D = Center for Epidemiological Studies Depression Scale; DRS = Dementia Rating Scale; RMBPC = Revised Memory and Behavior Problems Checklist (M = memory, B = behavioral problems, D = depression); ADL = activities of daily living