



Published in final edited form as:

J Am Geriatr Soc. 2018 September ; 66(9): 1785–1789. doi:10.1111/jgs.15502.

A Composite Measure of Caregiver Burden in Dementia: The Dementia Burden Scale – Caregiver (DBS-CG)

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Abstract

Background/Objectives: Caregiving for persons with dementia (PWD) results in a variety of psychological symptoms ranging from strain to depression. To better capture the scope of caregiver burden, we created a composite from 3 existing measures that assess different domains.

Design: Prospective follow-up study.

Setting: University-based dementia care management program

Participants: 1091 caregivers of PWD.

Measurements: The Dementia Burden Scale - Caregiver (DBS-CG) composite measure was based on the Modified Caregiver Strain Index, Neuropsychiatric Inventory Questionnaire Distress Scale, and Patient Health Questionnaire (PHQ-9).

Analysis: Alternative measure structures were evaluated with two confirmatory factor analysis (CFA) models: 1) bifactor model and 2) a correlated 3 factor model. Good model fit was defined as a root mean squared error of approximation (RMSEA) value of < 0.06 and comparative fit index (CFI) value of >0.95. ω was calculated as an estimate of the scale reliability. Minimally important

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Author Contributions. JDP performed statistical analyses and lead the manuscript draft. LAJ and RDH analyzed data and helped draft the manuscript. NSW and EK provided critical revisions and edits to the manuscript. DBR conceived of the study, analyzed data, and helped draft the manuscript.

Impact Statement: We certify that this work is novel. This work provides a new outcome measure of burden for caregivers of persons with dementia.

Conflict of Interest. None of the authors have conflicts relevant to this manuscript.

differences (MIDs) were estimated by anchoring the magnitude of DBS-CG change to change in caregiver self-efficacy and functional ability of PWD.

Results: The bifactor CFA model fit best, with RMSEA = 0.04 and CFI = 0.95. Based on this model, a DBS-CG scale was created wherein all items were transformed to a 0–100 possible range and then averaged. Higher scores indicate higher burden. The mean DBS-CG score was 27.3. The ω reliability was 0.93, indicating excellent reliability. MID estimates ranged from 4–5 points (effect sizes: 0.20 $d < 0.50$).

Conclusions: This study provides support for the reliability and validity of the DBS-CG. It can be used as an outcome measure to assess the effect of interventions to reduce dementia caregiver burden.

Keywords

Dementia; Alzheimer's; Caregiver Burden; Patient-Reported Outcome

Introduction

As of 2017, 1 in 10 Americans age 65 or older has Alzheimer's disease, approximately 5.3 million people.¹ Persons with Alzheimer's disease and other dementias often experience severe neuropsychiatric and behavioral symptoms including hallucinations, delusions, and aggressive behaviors.^{2, 3, 4} The impact of dementia is felt not only by the affected persons but also by those who provide their care, and may result in social restrictions, financial strain, and emotional distress.^{5, 6}

Because of this adverse impact on caregivers, there is a need for caregiver-focused clinical interventions to help with the strain of caregiving.^{7–9} Comprehensive dementia care management programs have been developed to address these needs,¹⁰ including the University of California, Los Angeles's (UCLA) Alzheimer's and Dementia Care (ADC) program.^{6, 11} To assess the benefit of this program and others, a reliable and valid outcome measure that captures the multidimensional aspects of burden due to caregiving is needed. In this paper, we describe the development and evaluation of a comprehensive Dementia Burden Scale - Caregiver (DBS-CG) using existing measures of caregiver strain, depression, and distress due to dementia-related neuropsychiatric symptoms.

Methods

Study Sample

Participants in the study were 1091 primary caregivers of patients recruited from UCLA's ADC program between July 2012 and December 2014. The ADC serves community-dwelling patients diagnosed with any type of dementia who are referred by a UCLA provider. Caregivers are surveyed during routine care for the person with dementia (PWD) at the ADC. The data for this study were taken from surveys at time of program entry and 1 year later. The UCLA IRB approved this protocol (#13–001480-AM-00014).

Survey and Measures

Caregiver measures: Measures of caregiver experience captured the strain of caregiving, the distress caused by behavioral symptoms, and depressive symptoms measured by 3 existing instruments. The Modified Caregiver Strain Index¹² (MCSI; 13 items; e.g., “My sleep is disturbed,” “It is upsetting to find the person I care for has changed so much from his/her former self,” “Caregiving is a financial strain”) items ask about types of strain and are rated as “Yes, on a regular basis,” “Yes, Sometimes,” or “No.” The Neuropsychiatric Inventory Questionnaire (NPI-Q) Distress scale² assesses whether persons with dementia are experiencing any of 12 symptoms: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviors, and appetite/eating. For each symptom that the patient is experiencing, the caregiver is asked to rate how much distress that symptom causes from “not distressing at all” to “extreme or very severe”. Finally, caregivers’ depressive symptoms were measured with the 9-item version of the Patient Health Questionnaire (PHQ-9).¹³ The PHQ-9 asks how often one has been bothered by 9 depressive symptoms (e.g., “little interest in doing things,” “poor appetite or over-eating”) from “not at all” to “nearly every day”. Each of these measures is available to the public at no cost. Use of the NPI-Q should be registered at <http://npitest.net/about-npi.html>. In addition, the composite measure created in this paper is available upon request.

PWD measures: PWD measures included the Functional Activities Questionnaire (FAQ),¹⁴ which was used to measure the functional ability of the person with dementia. The FAQ asks how often the person needed help over the past 4 weeks with 10 activities (e.g., “writing checks, paying bills, or balancing a checkbook”, “preparing a balanced meal”), rated from “normal” to “dependent”. In addition, questions were asked about caregiving self-efficacy, including about confidence to handle dementia-related problems, knowing where to turn to get answers about dementia-related problems, and confidence to deal with frustrations from caregiving. Caregivers rated each self-efficacy statement using “strongly agree” to “strongly disagree” response options.

Statistical Analyses

First, Pearson’s product moment correlation coefficients were estimated among the candidate scales. The criteria for magnitude of correlation coefficients was defined with Cohen’s cut-offs: small: $0.10 < r < 0.243$; medium: $0.243 < r < 0.371$; large: $r > 0.371$.¹⁵ Next, among scales that were correlated at a medium or larger magnitude, the dimensional structure of a potential combined scale was examined with confirmatory factor analysis (CFA). Two CFA models were examined – the bifactor model and correlated 3 factor model.

The bifactor model tests the hypothesis that each scale is an indicator of a more general factor representing caregiver burden. This model includes both a general factor for caregiver burden and specific factors for MCSI, NPI-Q Distress, and the PHQ-9. This model assumes that the specific factors are not correlated with the general factor and not correlated among one another. The correlated factor model estimates 3 factors (MCSI, NPI-Q Distress and PHQ-9) that are allowed to be correlated.

The fit of both models was compared with the comparative fit index (CFI) and root mean square error of approximation (RMSEA). Good model fit was evidenced by CFI values of above 0.95,¹⁶ and RMSEA of less than 0.06.¹⁶ In addition, the model χ^2 value was examined; non-significant values indicate better fit. The appropriateness of the bifactor model was also examined by testing the unidimensionality assumption (i.e., determining the extent to which there is presence of a general underlying factor). To do so, the ratio of the 1st to 2nd eigenvalues from an exploratory factor analysis was examined. Ratios of >3 are suggestive of unidimensionality.¹⁷ CFA models were estimated assuming categorical responses (polychoric correlations) and used the weighted least-squares mean and variance adjusted (WLSMV) estimator. ω was estimated for reliability of the scale.¹⁸

After the DBS-CG was created, minimally important differences (MIDs) were estimated using the anchor method wherein change in the scale of interest is mapped to another clinically important change. MIDs are defined as the smallest amount of clinically-relevant change on a scale.¹⁹ Anchors included changes from program entry to one year later in several variables tracking caregivers' self-efficacy to manage the person with dementia's care, including confidence to handle dementia-related problems, knowing where to turn to get answers to problems, and confidence to deal with frustrations of caregiving. These variables were categorized as "increase in self-efficacy from program entry to year 1" and "Decrease or same self-efficacy from program entry to year 1". In addition, we examined change in the functional ability of the person with dementia from program entry to year 1 using FAQ change scores. FAQ change scores were categorized as "decreased or same functional ability" or "increased functional ability". For each anchor, categories capturing clinically relevant change were defined and then differences in DBS-CG change scores (year 1 score – baseline score) were evaluated using independent samples t-tests. Standardized effect sizes were calculated as the DBS-CG change score difference divided by the baseline pooled standard deviation. Cohen's conventions for magnitude of effect were adopted: small = 0.20 $d < 0.50$; medium = 0.50 $d < 0.80$; large = $d \geq 0.80$.¹⁵

For all statistical tests, p-values of <0.05 were considered statistically significant and statistical analyses were conducted using Mplus version 8 and R version 3.4.1.

Results

Characteristics of caregivers are provided in Table 1. Correlations between the MCSI, NPIQ Distress, and the PHQ-9 were all at least medium in magnitude, with product moment correlation coefficients (r) ranging between 0.34–0.54. The CFA models fit the data well, with the bifactor model showing a slightly better fit: χ^2 , df, p-value: 1580.69, 497, <0.001; RMSEA: 0.05; CFI: 0.95. The 3 correlated factors model fit almost as well: χ^2 , df, p-value: 1848.94, 557, <0.001; RMSEA: 0.05; CFI: 0.94. The ratio of the first to second eigenvalue from an exploratory factor analysis was 3.8, indicating unidimensionality and offering support for the bifactor model. Due to its superior fit and theoretical appropriateness, we selected the bifactor model. In this model, only 5 items loaded on the general factor at <0.40, including 3 from the NPI-Q Distress Scale (items regarding caregiver distress caused by hallucinations, elation, and appetite), and two items from the PHQ-9 (items regarding trouble sleeping/sleep too much and self-harm).

We created a composite scale wherein all items were transformed linearly to be on a 0–100 possible range and then averaged with higher scores indicating higher caregiver burden. This scoring reflects the presence of a single underlying construct representing caregiver burden. We also examined an alternative scoring approach that omits respondents who do not have responses to all the component measures of the DBS-CG, and results were unchanged from the scoring described above. Table 1 shows the distribution and characteristics of the DBS-CG. The mean score was 27.3 (standard deviation = 17.2). The scores were distributed across the entire scale, with only 2% of scores at the possible minimum (0) and none at the possible maximum (100). The reliability of the scale (ω) was 0.93. (Table 2.)

MID estimates for the DBS-CG generally ranged between 4–5 points. Significant differences in this range were found in change in confidence to handle dementia-related problems, confidence to deal with frustrations from caregiving, and change in functional ability (Table 3). Each of these differences was associated with a small effect size. An MID estimate of 4–5 points is less than one third of a standard deviation of the scale.

Discussion

The results of this study provide evidence of the reliability and validity of the DBS-CG, which more broadly captures the range of psychological symptoms experienced by caregivers. This 34-item composite scale of 3 existing measures, retaining all items from each scale, represents the impact of caregiving in a single score that is easy to calculate. This instrument may be used to measure the benefit of programs aimed at improving dementia care.

Perhaps the most beneficial aspect of the DBS-CG is its usefulness in clinical assessment. First, the DBS-CG covers several critical elements of caregiving burden that are likely to indicate response to clinical changes in patients, as well as in response to efforts to manage caregiver burden. In addition, the DBS-CG has sufficient reliability to determine if scores increase or decrease among individuals over time. It has been recommended that a measure have at least a reliability of 0.90 for use with individuals.²⁰ The DBS-CG exceeds this threshold, though many measures do not. In addition, estimates of MIDs presented in this paper can help clinicians determine how much change on the DBS-CG is likely to matter clinically (i.e., the smallest amount of change that would be considered clinically relevant). Our results indicate that differences of 4–5 points on the scale are the smallest meaningful differences. That is, persons whose scores decrease by 4–5 points reflect significant improvement and those whose scores increase by this amount show cause for concern and may be appropriate candidates for intervention to reduce the rising burden of caregiving.¹⁹

Although the DBS-CG is not the first scale used to assess burden of caregiving for patients with dementia, it broadens the range of dimensions captured. Two of the more widely used measures that are currently available include Zarit's Burden Interview²¹ and Novak and Guest's Caregiver Burden Inventory.²² While the DBS-CG has some content overlap with these two other multidimensional measures, the DBS-CG has the advantage of featuring a generic assessment of emotional distress through the PHQ-9, as well as more targeted assessments of the financial, physical, psychological, and social dimensions of caregiver

burden through the MCSI, and behavioral symptom-specific assessments of distress through the NPI-Q Distress scale. Use of both generic and condition-targeted measures is recommended in order for a measure to be both comparable to other populations while still specific enough to be responsive.²³

When interpreting these results, the limitations of this study must be considered. The DBS-CG was created from secondary data already collected at the UCLA ADC (i.e., the data were originally collected for clinical assessment). As a result, the amount of missing data on caregiver demographics (e.g., ethnicity, race, and marital status) is higher than would be expected in research settings. Additional work should examine whether other constructs not currently measured by the ADC would also be appropriate to add to the scale. Second, the data used in this study are from a single, urban, academic health system, and the results may not generalize to the national dementia caregiver population. Future studies with broader caregiver samples should attempt to replicate these psychometric analyses.

In summary, the DBS-CG presents an updated, more comprehensive approach to measuring the impact of caregiving for patients with dementia that may be valuable to both clinicians and researchers.

Acknowledgements

All individuals who contributed significantly to this manuscript are listed as authors, and all authors have consented to submit this manuscript to JAGS.

Sponsor's Role. Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Numbers R21AG054681 and P30AG028748. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. This research was also supported by The Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health care issues and makes grants to improve health care practice and policy. The views presented here are those of the author and not necessarily those of The Commonwealth Fund, its directors, officers, or staff.

List of abbreviations

CFI	Comparative fit index
CFA	Confirmatory factor analysis
DBS-CG	Dementia Burden Scale - Caregiver
FAQ	Functional Activities Questionnaire
MID	Minimally important difference
MCSI	Modified Caregiver Strain Index
NPI-Q	Neuropsychiatric Inventory Questionnaire
PHQ-9	Patient health questionnaire 9 item version
PWD	Person with dementia
RMSEA	Root mean square error of approximation

WLSMV	Weighted least-squares mean and variance adjusted estimator
UCLA	University of California, Los Angeles

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Table 1.

Participant Characteristics

Caregiver's Age in Years, mean (sd, range)	63 (14, 22–99)
Relationship to Person with Dementia, % (n)	
Child	49% (540)
Spouse/Partner	35% (379)
Friend	2% (27)
Paid/hired caregiver	3% (36)
Other family	10% (104)
Caregiver Lives with Person with Dementia, % (n)	
Yes	55% (595)
No	34% (369)
Missing	11% (127)
Caregiver Education, % (n)	
High school graduate or less	9% (95)
Some college	16% (178)
College graduate or more education	40% (441)
Missing	35% (377)
Caregiver Marital Status, % (n)	
Single	10% (113)
Married/Living with Partner	45% (489)
Divorced/Widowed	10% (113)
Missing	35% (376)
Gender, % (n)	
Female	67% (730)
Male	33% (355)
Caregiver Ethnic Group, % (n)	
Hispanic/Latino	10% (107)
Not Hispanic/Latino	50% (550)
Missing	40% (434)
Caregiver Race, % (n)	
White	44% (486)
African-American	6% (69)
Asian	5% (54)
Other	5% (59)
Missing	39% (423)
Diagnosis of Person with Dementia, % (n)	
Dementia type not specified	43% (465)
Alzheimer's dementia	38% (413)
Mixed dementia	8% (88)

Vascular dementia	4% (44)
Other dementia	6% (71)

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Table 2.

Dementia Burden Scale – Caregiver (DBS-CG) Distribution and Reliability

Mean (SD)	27.3 (17.2)
Median (IQR)	26.3 (14.8, 39.0)
Range	0–92.7
% at Floor	2%
% at Ceiling	0%
Reliabilities	
ω total	0.93

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Table 3.

Minimally Important Differences for the Dementia Burden Scale – Caregiver (DBS-CG)

	DBS-CG Change Score Mean	DBS-CG Change Score ^a	p-value	Effect Size (d) ^b
Change in confidence to handle patient's problems				
Increase in self-efficacy	-0.1	3.87	0.01	0.23
Decrease/same in self-efficacy	3.8			
Change in knowing where to turn to get answers about patient's problems				
Increase in self-efficacy	0.9	2.15	0.16	0.13
Decrease/same in self-efficacy	3.1			
Change in confidence to deal with frustrations of caregiving				
Increase in self-efficacy	-0.4	4.16	0.007	0.24
Decrease/same in self-efficacy	3.7			
Change in Functional Ability				
Decrease/same dependence	-1.40	4.62	0.005	0.27
Increase in dependence	3.22			

^aThe DBS-CG change score gives an estimate of the minimally important difference.

^bEffect sizes were calculated as DBS-CG change score / a pooled SD of 17.2.

Note: Conventions for effect size are small = 0.20 d < 0.50; medium = 0.50 d < 0.80; large = d ≥ 0.80