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BRIEF REPORT

A Composite Measure of Caregiver Burden in Dementia: The Dementia Burden Scale—Caregiver

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OBJECTIVES: To better capture the scope of caregiver burden by creating a composite of 3 existing measures that assess different health domains.

DESIGN: Prospective follow-up study.

SETTING: University-based dementia care management program.

PARTICIPANTS: Caregivers of persons with dementia (PWD) (N=1,091).

MEASUREMENTS: The composite measure (the Dementia Burden Scale—Caregiver (DBS-CG)) was based on the Modified Caregiver Strain Index, Neuropsychiatric Inventory Questionnaire Distress Scale, and Patient Health Questionnaire (PHQ-9). Alternative factor structures were evaluated using 2 confirmatory factor analysis (CFA) models: a bifactor model and a 3 correlated factors model. Good model fit was defined as a root mean square error of approximation (RMSEA) of less than 0.06 and comparative fit index (CFI) value greater than 0.95. Coefficient omega was used to estimate scale reliability. Minimally important 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 (RMSEA = 0.04, CFI = 0.95). Based on this model, a DBS-CG scale was created wherein all items were transformed to a possible range of 0 to 100 and then averaged. Higher scores indicate higher burden. Mean DBS-CG score was 27.3. The reliability was excellent (coefficient omega=0.93). MID estimates ranged from 4 to 5 points (effect sizes: 0.20–0.49).

CONCLUSION: 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. **J Am Geriatr Soc 2018.**

Key words: dementia; Alzheimer's; caregiver burden; patient-reported outcome

As of 2017, 10% of Americans aged 65 or older had 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.[2–4] Not only the affected persons, but also those who provide their care, feel the effects of dementia, which may result in social restrictions, financial strain, and emotional distress.[5,6]

Because of this adverse effect on caregivers, there is a need for caregiver-focused clinical interventions to reduce 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. We describe the development and evaluation of the 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 1,091 primary caregivers of individuals recruited from UCLA's ADC program between July 2012 and December 2014. The ADC serves community-dwelling individuals diagnosed with any type

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of dementia 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 institutional review board approved this protocol (#13–001480-AM-00014).

Survey and Measures

Caregiver measures

Measures of caregiver experience captured the strain of caregiving, the distress caused to the caregiver by the PWD's behavioral symptoms, and depressive symptoms measured using 3 existing instruments. The Modified Caregiver Strain Index[12] (MCSI; 13 items) asks about types of strain and are rated as "on a regular basis," "sometimes," or "no" (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"). The Neuropsychiatric Inventory Questionnaire (NPI-Q) Distress scale[2] assesses whether PWD are experiencing any of 12 symptoms: delusions, hallucinations, agitation or aggression, depression or dysphoria, anxiety, elation or euphoria, apathy or indifference, disinhibition, irritability or lability, motor disturbance, nighttime behaviors, and problems with appetite or eating. For each symptom that the individual is experiencing, the caregiver is asked to rate how much distress that symptom causes them (the caregiver), from "not distressing at all" to "extreme or very severe." Finally, caregiver depressive symptoms were measured using the 9-item version of the Patient Health Questionnaire (PHQ-9),[13] which asks how often 9 depressive symptoms (e.g., "little interest in doing things," "poor appetite or over-eating") have bothered the person, 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. The DBS-CG is also available upon request.

PWD measures

PWD measures included the Functional Activities Questionnaire (FAQ),[14] which asks how often the PWD 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, and was used to measure the functional ability of the PWD. Questions were also asked about caregiving self-efficacy, including confidence in managing dementia-related problems, knowing where to turn to obtain answers about dementia-related problems, and confidence in managing frustrations from caregiving. Caregivers rated each self-efficacy statement using "strongly agree" to "strongly disagree" response options.

Statistical Analyses

First, Pearson product moment correlation coefficients were estimated between each candidate scale. The criteria for magnitude of correlation coefficients was defined using Cohen's cut-offs (small: 0.100–0.242; medium: 0.243–0.370; large: ≥ 0.371).[15] Next, for scales that had at least a medium correlation with the other candidate scales, the

dimensional structure of a potential combined scale was examined using confirmatory factor analysis (CFA). Two CFA models were examined—a bifactor model and 3 correlated factors model.

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

The fit of both models was compared with the comparative fit index (CFI) and root mean square error of approximation (RMSEA). CFI values greater than 0.95[16] and RMSEA less than 0.06[16] were evidence of good model fit. In addition, the model chi-square value was examined; nonsignificant values indicate better fit. The appropriateness of the bifactor model was examined by testing the unidimensionality assumption (determining the extent to which there is a general underlying factor). To do so, the ratio of the first to second eigenvalues from an exploratory factor analysis was examined. Ratios greater than 3 suggest unidimensionality.[17] CFA models were estimated assuming categorical responses (polychoric correlations) and used the weighted least-squares mean and variance adjusted (WLSMV) estimator. Coefficient omega was estimated to determine the 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 1 year later for several variables tracking caregiver self-efficacy in managing the care of the person with dementia, including confidence in managing dementia-related problems, knowing where to obtain answers to problems, and confidence in managing 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." We also examined change in the functional ability of the PWD from program entry to year 1 using FAQ change scores, which were categorized as "decrease in or same functional ability" or "increase in functional ability." For each anchor, categories capturing clinically relevant change were defined, and differences in DBS-CG change scores (year 1 score–baseline score) were evaluated using independent-sample t-tests. Standardized effect sizes were calculated as the DBS-CG change score difference divided by the baseline pooled standard deviation. Cohen conventions for magnitude of effect were adopted (small: 0.20–0.49; medium: 0.50–0.79; large: ≥0.80).[15]

For all statistical tests, p<.05 was considered statistically significant, and statistical analyses were conducted using Mplus version (Muthén & Muthén, Los Angeles, CA) 8 and R version 3.4.1.

RESULTS

Caregiver characteristics are provided in Table 1. Correlations between the MCSI, NPIQ Distress, and PHQ-9 were

Table 1. Participant Characteristics

Characteristic	Value
Caregiver age, mean ± standard deviation (range)	63 ± 14 (22–99)
Relationship to person with dementia, n (%)	
Child	540 (49)
Spouse or partner	379 (35)
Friend	27 (2)
Paid or hired caregiver	36 (3)
Other family	104 (10)
Caregiver lives with person with dementia, n (%)	
Yes	595 (55)
No	369 (34)
Missing	127 (11)
Caregiver education, n (%)	
≤High school graduate	95 (9)
Some college	178 (16)
≥College graduate or more	441 (40)
Missing	377 (35)
Caregiver marital status, n (%)	
Single	113 (10)
Married or living with partner	489 (45)
Divorced, widowed	113 (10)
Missing	376 (35)
Sex, n (%)	
Female	730 (67)
Male	355 (33)
Caregiver ethnicity, n (%)	
Hispanic	107 (10)
Not Hispanic	550 (50)
Missing	434 (40)
Caregiver race, n (%)	
White	486 (44)
Black	69 (6)
Asian	54 (5)
Other	59 (5)
Missing	423 (39)
Diagnosis of person with dementia, n (%)	
Dementia type not specified	465 (43)
Alzheimer's dementia	413 (38)
Mixed dementia	88 (8)
Vascular dementia	44 (4)
Other dementia	71 (6)

all at least medium in magnitude, with product moment correlation coefficients (r) ranging from 0.34 to 0.54. The CFA models fit the data well, with the bifactor model having a slightly better fit (χ^2=1,580.69, degrees of freedom (df)=497, p<.001, RMSEA 0.05, CFI 0.95). The 3 correlated factors model fit almost as well (χ^2=1,848.94, df=557, p<.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. Because of its superior fit and theoretical appropriateness, we selected the bifactor model. In this model, only 5 items loaded on the general factor at less than 0.40, including 3 from the NPI-Q Distress Scale (caregiver distress caused by hallucinations, elation, appetite) and 2 from the PHQ-9 (trouble sleeping or sleep too much, self-harm).

We created a composite scale wherein all items were transformed linearly to have a range from 0 to 100 and then averaged, with higher scores indicating greater 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±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 coefficient omega was 0.93, indicating excellent reliability. (Table 2).

MID estimates for the DBS-CG generally ranged from 4 to 5 points. Significant differences in this range were found in change in confidence managing dementia-related problems, confidence managing frustrations from caregiving, and change in functional ability (Table 3). Each of these differences was associated with a small effect size. A MID estimate of 4 to 5 points is less than one-third of a standard deviation of the scale. All scales will have a standard deviation. In this case, the observed standard deviation of the mean is 17.2.

DISCUSSION

The results of this study provide evidence of the reliability and validity of the DBS-CG, which broadly captures the range of psychological symptoms that caregivers experience. This 34-item composite scale of 3 existing measures, retaining all items from each scale, indicates the effect 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 PWD and to efforts to manage caregiver burden. In addition, the DBS-CG has sufficient reliability to determine whether scores increase or decrease over time. It has been recommended that a measure have a reliability of at least 0.90 for use with individuals.[20] The DBS-CG exceeds this threshold. In addition, estimates of MIDs presented in this article can help clinicians determine how much change on the DBS-CG is likely to matter clinically (smallest amount of change that would be considered clinically relevant). Our results indicate that differences of 4 to 5 points are the smallest meaningful differences. That is, a decrease in score of 4 to 5 points reflects significant improvement, whereas an increase of this amount indicates cause for concern and that the individuals may be an appropriate candidate for intervention to reduce the rising burden of caregiving.[19]

Table 2. Dementia Burden Scale—Caregiver: Distribution and Reliability

Mean ± standard deviation	27.3 (17.2)
Median (interquartile range)	26.3 (14.8, 39.0)
Range	0–92.7
At floor, %	2%
At ceiling, %	0%
Coefficient omega	0.93

Table 3. Minimally Important Differences for the Dementia Burden Scale—Caregiver (DBS-CG)

Criterion Variable	DBS-CG Change Score		P-Value	Effect Size[b]
	Mean	Δ[a]		
Change in confidence of ability to handle patient's problems			.01	0.23
Increase in self-efficacy	−0.1	3.87		
Decrease in or same self-efficacy	3.8			
Change in knowing where to turn for answers about patient's problems			.16	0.13
Increase in self-efficacy	0.9	2.15		
Decrease in or same self-efficacy	3.1			
Change in confidence to manage frustrations of caregiving			.007	0.24
Increase in self-efficacy	−0.4	4.16		
Decrease in or same self-efficacy	3.7			
Change in functional ability			.005	0.27
Increase in ability	−1.40	4.62		
Decrease in or same ability	3.22			

[a]Estimate of minimally important difference.
[b]Effect sizes were calculated as DBS-CG change score Δ/pooled standard deviation of 17.2.
Note: Conventions for effect size are small = 0.20–0.49; medium = 0.50–0.79 large = $\geq$ 0.80.

Although the DBS-CG is not the first scale used to assess burden of caring for PWD, it broadens the range of dimensions captured. Two of the more widely used measures that are currently available include the Zarit Burden Interview[21] and the Caregiver Burden Inventory.[22] Although the DBS-CG has some content overlap with these measures, it has the advantage of containing 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 generic and condition-targeted measures is recommended for a measure's scores to be comparable between clinical 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 collected at the UCLA ADC (originally collected for clinical assessment). As a result, the amount of missing data on caregiver demographic characteristics (e.g., ethnicity, race, marital status) is greater than would be expected in research settings. Moreover, additional work should examine whether other constructs that the ADC does not measure would be appropriate to add to the scale. Second, the data used in this study were 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, comprehensive approach to measuring the effect of caregiving for PWD that may be valuable to clinicians and researchers.

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REFERENCES

1. Alzheimer's A 2017 Alzheimer's disease facts and figures. Alzheimers Dement 2017;13:325–373.
2. Kaufer DI, Cummings JL, Ketchel P et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci 2000;12:233–239.
3. Zekry D, Hauw JJ, Gold G. Mixed dementia: Epidemiology, diagnosis, and treatment. J Am Geriatr Soc 2002;50:1431–1438.
4. O'Brien JT, Thomas A. Vascular dementia. Lancet 2015;386:1698–1706.
5. Roland KP, Chappell NL. Caregiver experiences across three neurodegenerative diseases: Alzheimer's, Parkinson's, and Parkinson's with dementia. J Aging Health 2017:898264317729980.
6. Jennings LA, Reuben DB, Evertson LC et al. Unmet needs of caregivers of individuals referred to a dementia care program. J Am Geriatr Soc 2015; 63:282–289.
7. Gitlin LN, Winter L, Burke J, Chernett N, Dennis MP, Hauck WW. Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. Am J Geriatr Psychiatry 2008;16:229–239.
8. Ostwald SK, Hepburn KW, Caron W, Burns T, Mantell R. Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. Gerontologist 1999;39:299–309.
9. Akkerman RL, Ostwald SK. Reducing anxiety in Alzheimer's disease family caregivers: The effectiveness of a nine-week cognitive-behavioral intervention. Am J Alzheimers Dis Other Demen 2004;19:117–123.
10. Callahan CM. Alzheimer's disease: Individuals, dyads, communities, and costs. J Am Geriatr Soc 2017;65:892–895.
11. Reuben DB, Evertson LC, Wenger NS et al. The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. J Am Geriatr Soc 2013;61:2214–2218.
12. Thornton M, Travis SS. Analysis of the reliability of the modified caregiver strain index. J Gerontol B Psychol Sci Soc Sci 2003;58B:S127–S132.

13. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9—validity of a brief depression severity measure. J Gen Intern Med 2001;16:606–613.

14. Pfeffer RI, Kurosaki TT, Harrah CH, Jr., Chance JM, Filos S. Measurement of functional activities in older adults in the community. J Gerontol 1982;37:323–329.

15. Cohen J. Statistical Power Analysis for the Behavioral Sciences. New York: Academic Press; 1988.

16. Hu Lt, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Struct Equ Modeling 1999;6:1–55.

17. Slocum-Gori SL, Zumbo BD. Assessing the unidimensionality of psychological scales: Using multiple criteria from factor analysis. Soc Indic Res 2011; 102:443–461.

18. McDonald RP. Test Theory: A Unified Treatment. New York: Taylor & Francis; 1999.

19. Revicki D, Hays RD, Cella D, Sloan J. Recommended methods for determining responsiveness and minimally important differences for patient-reported outcomes. J Clin Epidemiol 2008;61:102–109.

20. Nunnally JC. Psychometric Theory, 2nd Ed. New York: McGraw-Hill; 1978.

21. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist 1980;20:649–655.

22. Novak M, Guest C. Application of a multidimensional caregiver burden inventory. Gerontologist 1989;29:798–803.

23. Cella D, Hahn EA, Jensen SE et al. Patient-Reported Outcomes in Performance Measurement. Research Triangle Park, NC: Research Triangle Institute; 2015.