

EMERGING INFORMAL CAREGIVER BURDEN DOMAINS IN THE NEW NATIONAL STUDY OF CAREGIVING: RESULTS, RELIABILITY, & APPLICATIONS

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Presenter Disclosures

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Steven A. Cohen, DrPH, MPH

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No relationships to disclose.



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Defining “caregiver burden”

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- **Definitions:**
 - The set of psychological, behavioral, and physiological effects that may influence health¹⁻³
 - The physical, psychological, emotional, social and financial, stresses that individuals experience due to providing care⁴
- **Objective vs. subjective burden⁵**
 - “Objective” burden: The physical or instrumental provision of aid to care-recipients
 - “Subjective” burden: The emotional or psychological toll that ‘objective burden’ has on caregivers

1. Gouin JP, Hantsoo L, Kiecolt-Glaser JK. Neuroimmunomodulation. 2008;15(4-6):251-259.

2. Lee S, Colditz GA, Berkman LF, Kawachi I. Am J Prev Med. 2003;24(2):113-119.

3. Schulz R, Beach SR. JAMA. 1999 Dec 15;282(23):2215-2219.

4. George LK, Gwyther LP. The Gerontologist. 1986;25:3-259.

5. Baslawrous M. Int J Nursing Studies. 2013;60(3):431-441.



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Research challenges

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- **Measuring “caregiver burden” is an ongoing challenging in aging research**
 - No singular or uniform conceptualization of the term
 - Multidimensionality
 - Inconsistency across caregiver population subgroups (e.g. culture, age, sex)



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Research challenges: Existing scales

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- Burden Scale for Family Caregivers¹
- Caregiver Burden Inventory²
- Modified Caregiver Strain Index³

1. <http://www.caregiver-burden.eu>
2. <http://www.fullcirclecare.org/caregiverissues/health/burden.html>
3. http://consultgerm.org/uploads/File/trythis/try_this_14.pdf



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Objectives

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1. Identify latent domains of caregiver burden found in a comprehensive new data source for information on informal caregivers: The National Study of Caregivers.
2. Analyze the validity and reliability of those latent caregiver domains.



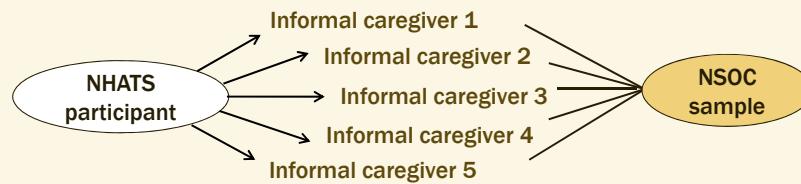
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Data: National Study of Caregiving

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- National study of people who help older family members and friends with their daily activities
- Supplementary data from the larger National Health and Aging Trends Study (NHATS)



Additional information available about NHATS and NSOC at www.nhats.org.



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Data: Burden variables

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Felt down, depressed or hopeless	Paid for in-home assistance
Felt nervous, anxious, or on edge	Worked for pay
Felt little interest in life	Volunteered
Felt lonely	Participated in group activities
Felt worried	Attended religious services
Felt upset	Thought life had meaning and purpose
Felt bored	Feels confident in CG abilities
Felt peaceful	Adapts to change easily
Felt full of life	Is able to recover quickly from challenges
Felt cheerful	Went out for enjoyment
Gave CR monetary gift	Visited family and friends
Paid for CR's medicine and/or med care	



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Statistical analysis

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- Exploratory factor analysis (EFA) used to obtain latent factors of caregiver burden
 - Multiple models examined (4–7 factors)
- Sensitivity analysis conducted to determine if factors are consistent across caregiver groups
 - By sex, relationship to care recipient, and, “sandwiched” caregiver status
- SAS v. 9.3 used for analyses



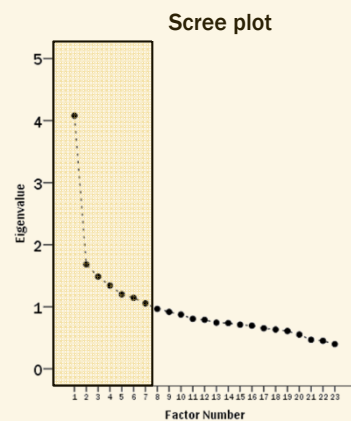
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Factor loadings: 7 factors

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	Factor						
	1	2	3	4	5	6	7
Cronbach's α	0.715	0.790	0.485	0.487	0.457	0.468	0.332
Down & depressed	0.711						
Nervous	0.671						
Little interest	0.570						
Upset	0.567						
Worried	0.566						
Lonely	0.566						
Bored	0.468						
Peaceful		0.820					
Full of life		0.800					
Cheerful		0.763					
Paid for meds/medical care			0.743				
Gave CR gift			0.692				
Paid for in-home help			0.615				
Volunteered				0.716			
Group activities				0.696			
Religious services				0.619			
Life has meaning					0.791		
Feels confident					0.714		
Adapts to change						0.836	
Recovers quickly						0.733	
Out for enjoyment							0.724
Visit family & friends							0.688
Worked for pay							0.380



Percent variance explained:
52.1%



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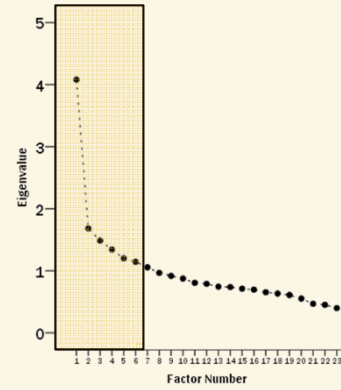
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Factor loadings: 6 factors

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	Factor					
	1	2	3	4	5	6
Cronbach's α	0.715	0.790	0.510	0.461	0.457	0.468
Down & depressed	0.711					
Nervous	0.670					
Little interest	0.568					
Upset	0.568					
Worried	0.564					
Lonely	0.562					
Bored	0.470					
Peaceful		0.820				
Full of life		0.796				
Cheerful		0.754				
Group activities			0.700			
Volunteered			0.591			
Religious services			0.530			
Visit family & friends			0.482			
Out for enjoyment			0.464			
Paid for meds/medical care				0.739		
Gave CR gift				0.701		
Paid for in-home help				0.591		
Worked for pay				0.416		
Life has meaning					0.752	
Feels confident					0.645	
Adapts to change						0.836
Recovers quickly						0.732

Scree plot



Percent variance explained:
47.5%



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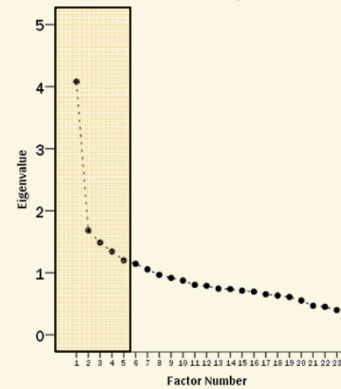


Factor loadings: 5 factors

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	Factor				
	1	2	3	4	5
Cronbach's α	0.715	0.790	0.510	0.422	0.461
Down & depressed	0.714				
Nervous	0.674				
Worried	0.574				
Lonely	0.567				
Upset	0.559				
Little interest	0.559				
Bored	0.462				
Peaceful		0.816			
Full of life		0.791			
Cheerful		0.748			
Group activities			0.700		
Volunteered			0.592		
Religious services			0.531		
Visit family & friends			0.483		
Out for enjoyment			0.466		
Adapts to change				0.657	
Recovers quickly				0.650	
Feels confident				0.553	
Life has meaning				0.450	
Paid for meds/med care					0.739
Gave CR gift					0.699
Paid for in-home help					0.591
Worked for pay					0.416

Scree plot



Percent variance explained:
42.5%



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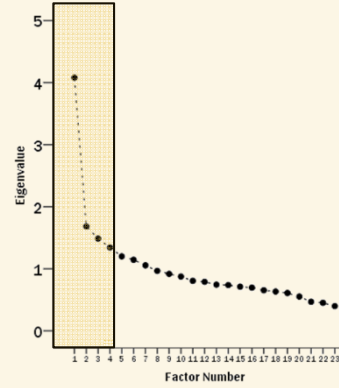


Factor loadings: 4 factors

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	Factor			
	1	2	3	4
Cronbach's α	0.563	0.584	0.510	0.461
Down & depressed	0.720			
Nervous	0.697			
Worried	0.587			
Little interest	0.549			
Lonely	0.531			
Upset	0.516			
Bored	0.455			
Recovers quickly	-0.326			
Peaceful		0.821		
Full of life		0.798		
Cheerful		0.763		
Feels confident		0.354		
Adapts to change		0.236		
Life has meaning		0.208		
Group activities			0.691	
Volunteers			0.581	
Religious services			0.527	
Visiting family & friends			0.496	
Out for enjoyment			0.478	
Paid for meds/med care				0.738
Gave CR gift				0.699
Paid for in-home help				0.593
Worked for pay				0.413

Scree plot



Percent variance explained:
37.4%



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Factor loadings: 4 factors (modified)

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	Factor			
	1	2	3	4
Cronbach's α	0.710	0.790	0.510	0.461
Down & depressed	0.756			
Nervous	0.745			
Worried	0.642			
Little interest	0.574			
Upset	0.522			
Lonely	0.504			
Peaceful		0.819		
Full of life		0.803		
Cheerful		0.766		
Group activities			0.713	
Volunteers			0.601	
Religious services			0.536	
Visiting family & friends			0.496	
Out for enjoyment			0.483	
Paid for meds/med care				0.759
Gave CR gift				0.748
Worked for pay				0.504

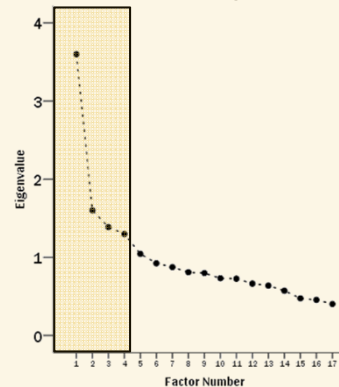
Negative emotional

Positive emotional

Social

Financial

Scree plot



Percent variance explained:
46.4%



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Sensitivity analysis: Caregiver groups

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	Factor loadings			
	Overall	Factor 1	Factor 2	Factor 3
Down & depressed	0.756			
Nervous	0.745			
Worried	0.642			
Little interest	0.574			
Upset	0.522			
Lonely	0.504			
Peaceful	0.819			
Full of life	0.803			
Cheerful	0.766			
Group activities	0.713			
Volunteers	0.601			
Religious services	0.536			
Visiting family & friends	0.496			
Out for enjoyment	0.483			
Paid for meds/med care	0.759			
Gave CR gift	0.748			
Worked for pay	0.504			
Cronbach's alpha	0.710			
	0.790			
	0.510			
	0.461			
Percent of variance explained	46.4			



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Sensitivity analysis: Caregiver groups

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	Factor loadings			
	Overall	Males	Females	
Down & depressed	0.756	0.771	0.755	
Nervous	0.745	0.725	0.748	
Worried	0.642	0.575	0.671	
Little interest	0.574	0.553	0.588	
Upset	0.522	0.543	0.523	
Lonely	0.504	0.457	0.513	
Peaceful	0.819	0.810	0.819	
Full of life	0.803	0.810	0.795	
Cheerful	0.766	0.807	0.738	
Group activities	0.713	0.679	0.726	
Volunteers	0.601	0.667	0.601	
Religious services	0.536	0.635	0.501	
Visiting family & friends	0.496	0.446	0.487	
Out for enjoyment	0.483	0.416	0.460	
Paid for meds/med care	0.759	0.672	0.771	
Gave CR gift	0.748	0.669	0.663	
Worked for pay	0.504	0.539	0.502	
Cronbach's alpha	0.710	0.661	0.730	
	0.790	0.797	0.786	
	0.510	0.502	0.511	
	0.461	0.368	0.455	
Percent of variance explained	46.4	46.5	46.8	



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Sensitivity analysis: Caregiver groups

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	Factor loadings				
	Overall	Males	Females	Child of CR	Other relat.
Down & depressed	0.756	0.771	0.755	0.765	0.745
Nervous	0.745	0.725	0.748	0.758	0.681
Worried	0.642	0.575	0.671	0.645	0.606
Little interest	0.574	0.553	0.588	0.558	0.589
Upset	0.522	0.543	0.523	0.532	0.548
Lonely	0.504	0.457	0.513	0.517	0.381
Peaceful	0.819	0.810	0.819	0.825	0.815
Full of life	0.803	0.810	0.795	0.805	0.795
Cheerful	0.766	0.807	0.738	0.780	0.713
Group activities	0.713	0.679	0.726	0.713	0.683
Volunteers	0.601	0.667	0.601	0.588	0.625
Religious services	0.536	0.635	0.501	0.527	0.618
Visiting family & friends	0.496	0.446	0.487	0.500	0.407
Out for enjoyment	0.483	0.416	0.460	0.475	0.475
Paid for meds/med care	0.759	0.672	0.771	0.769	0.715
Gave CR gift	0.748	0.669	0.663	0.756	0.603
Worked for pay	0.504	0.539	0.502	0.473	0.529
Cronbach's alpha	0.710	0.661	0.730	0.731	0.678
	0.790	0.797	0.786	0.794	0.783
	0.510	0.502	0.511	0.496	0.503
	0.461	0.368	0.455	0.420	0.484
Percent of variance explained	46.4	46.5	46.8	46.6	46.7

Factor 1
Factor 2
Factor 3
Factor 4



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Sensitivity analysis: Caregiver groups

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	Factor loadings						
	Overall	Males	Females	Child of CR	Other relat.	Sandwiched	Non-sand
Down & depressed	0.756	0.771	0.755	0.765	0.745	0.745	0.762
Nervous	0.745	0.725	0.748	0.758	0.681	0.710	0.753
Worried	0.642	0.575	0.671	0.645	0.606	0.667	0.638
Little interest	0.574	0.553	0.588	0.558	0.589	0.541	0.570
Upset	0.522	0.543	0.523	0.532	0.548	0.425	0.560
Lonely	0.504	0.457	0.513	0.517	0.381	0.388	0.542
Peaceful	0.819	0.810	0.819	0.825	0.815	0.819	0.816
Full of life	0.803	0.810	0.795	0.805	0.795	0.818	0.806
Cheerful	0.766	0.807	0.738	0.780	0.713	0.780	0.780
Group activities	0.713	0.679	0.726	0.713	0.683	0.673	0.708
Volunteers	0.601	0.667	0.601	0.588	0.625	0.475	0.592
Religious services	0.536	0.635	0.501	0.527	0.618	0.571	0.509
Visiting family & friends	0.496	0.446	0.487	0.500	0.407	0.542	0.508
Out for enjoyment	0.483	0.416	0.460	0.475	0.475	0.455	0.477
Paid for meds/med care	0.759	0.672	0.771	0.769	0.715	0.731	0.769
Gave CR gift	0.748	0.669	0.663	0.756	0.603	0.683	0.752
Worked for pay	0.504	0.539	0.502	0.473	0.529	0.612	0.429
Cronbach's alpha	0.710	0.661	0.730	0.731	0.678	0.696	0.737
	0.790	0.797	0.786	0.794	0.783	0.809	0.792
	0.510	0.502	0.511	0.496	0.503	0.496	0.496
	0.461	0.368	0.455	0.420	0.484	0.503	0.384
Percent of variance explained	46.4	46.5	46.8	46.6	46.7	48.4	46.6

Factor 1
Factor 2
Factor 3
Factor 4



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Summary of findings

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- Several caregiver domains emerged
 - Fairly consistent domains: **Negative emotional**, **positive emotional**, **social**, and **financial**
- Reliability of factors varied from good to poor
- Measures were generally consistent throughout most caregiver groups



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Strengths and limitations

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Limitations

- Dichotomized burden questions
- Did not examine other demographic differences
- Exploratory factor analysis, by definition, is subjective– results open to interpretation
- Did not assess physical health questions

Strengths

- First study to explore caregiver domains in NSOC
- Burden domains consistent with previous studies
- Large sample; can be linked with other caregiver and care recipient information from NHATS



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Future directions

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- Incorporate physical health questions
- Analyze concordance and discrepancies with other caregiver burden scales
- Use the results to characterize caregiver burden:
 - Descriptive epidemiology of caregiver burden in US
 - Examine associations between caregiving intensity and caregiver burden (in 2 minutes)



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Acknowledgements

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Thank you for participating!



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Questions?

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