

Caregiver Burden: Measurement Approaches, Scientific Gaps, and Promising New Approaches

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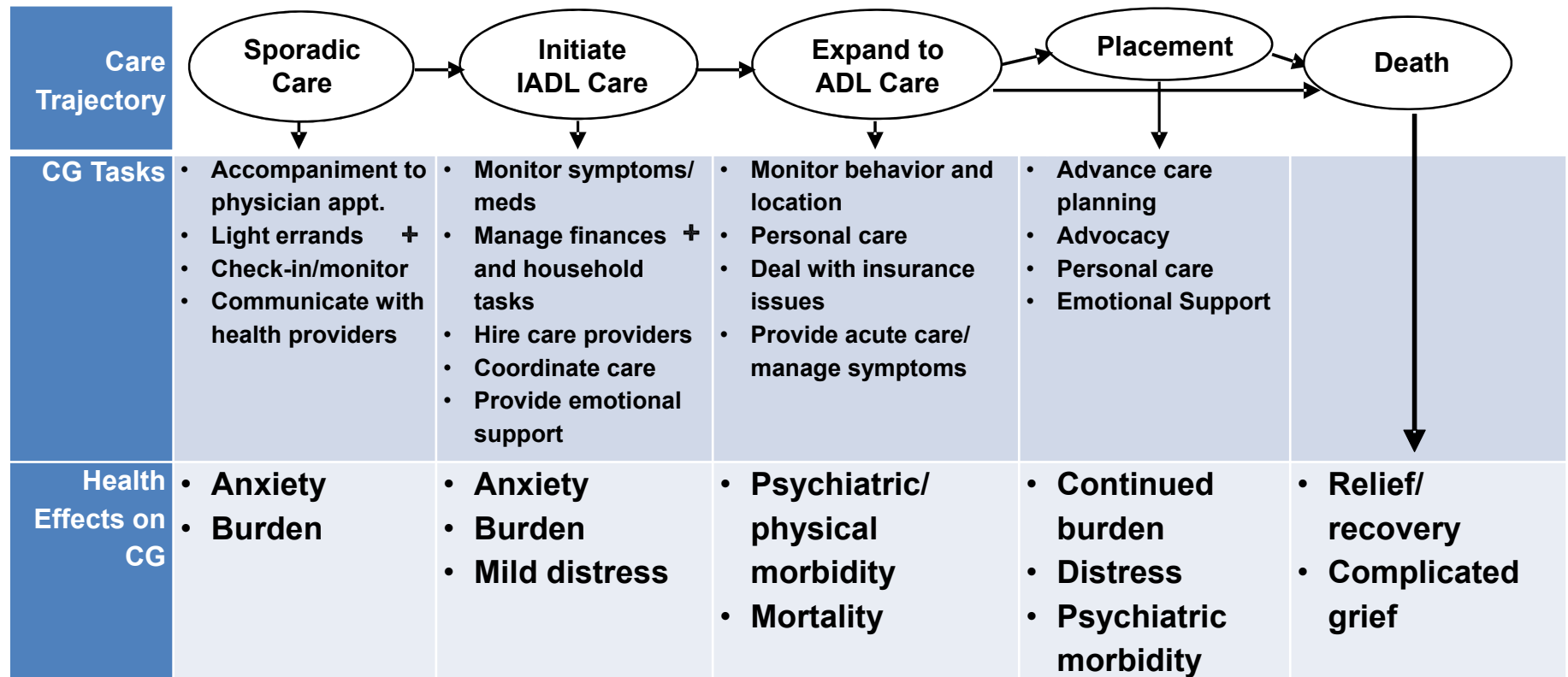
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Overview

- Caregiver Burden: Overview and Current Measurement
- Scientific Gaps I – Broadening (and Sharpening) Conception and Measurement of Caregiver Burden
- Scientific Gaps II – Caregiver Burden and Quality of Care Provided
- Methodological Approaches to Caregiving Research

Care Trajectory: Tasks and Health Effects



Caregiver Burden: Overview and Measurement

"Caregiver Burden"	Additional / Global Caregiver Outcomes
OBJECTIVE BURDEN	Quality of Life / Well-Being (<i>SF-36; SF-12; Euro-Qol</i>)
<ul style="list-style-type: none"> Number and types of IADL / ADL tasks 	Mental Health (depression; anxiety)
<ul style="list-style-type: none"> Hours per week / day spent caregiving 	Physical Health (self-reported and objective indicators; chronic conditions; physical symptoms; mortality)
<ul style="list-style-type: none"> "Heavy / physical" ADL lifting, moving 	
<ul style="list-style-type: none"> ADRD patient "problem behaviors" / Behavioral and Psychological Symptoms of Dementia (BPSD) <p>(<i>Revised Memory & Behavior Problems Checklist [RMBPC]; Neuropsychiatric Inventory Questionnaire [NPI]</i>)</p>	Social Impacts (social activity restrictions; family conflict)
SUBJECTIVE BURDEN	Economic / Financial Impacts (financial strain; out-of-pocket costs; work impacts)
<ul style="list-style-type: none"> "Personal Strain" 	
<ul style="list-style-type: none"> "Role Strain" 	
(<i>Zarit Burden Interview [ZBI]</i>)	

Broadening the Caregiver Burden Concept

Perceived Patient Suffering

- The degree to which the caregiver believes that the care recipient is suffering – psychologically, physically.
- Independent of “objective” burden indicators (# and variety of ADL / IADL tasks; hours, problem behaviors, etc.).
- Significant independent negative effects on AD caregiver depression and increased anti-depressant medication use (*Schulz et al., 2008, Alzheimer Disease and Associated Disorders, 22, 170-176*).
- Findings replicated in other samples, caregiver populations.
- Standardized measures developed.
- Important target for caregiver interventions.

Measuring Care Recipient Suffering

Physical symptoms (9 items)

“Please give us your best estimate of how often your loved one experienced each of the following symptoms during the past 7 days: (e.g., lack of energy/fatigue, pain, nausea, shortness of breath).”

Overall

“I’d like to ask you to the degree to which you think CR has been suffering physically during the past 7 days on a scale from 1-10 where 1 equals “CR has not been suffering physically,” and 10 equals “CR has been suffering terribly.”

Psychological symptoms (15 items)

“Please indicate how often your loved one has experienced the feelings listed below during the past 7 days: (e.g., afraid, depressed, cheerful, angry, calm/peaceful, hopeless).”

Overall

“Now, please rate the degree to which you think CR has been suffering psychologically or emotionally during the past 7 days on a scale from 1 to 10 where 1 equals “CR has not been suffering psychologically/emotionally,” and 10 equals “CR has been suffering terribly.”

Broadening the Caregiver Burden Concept

- AD Patient Resistiveness to Care during ADL Assistance
- Degree to which the patient struggles, resists, or engages in other uncooperative behaviors *during* caregiver efforts to assist with ADLs (bathing, eating, dressing).
- How upsetting this is to the caregiver.
- Related to, but independent of more global “agitation,” which operates independent of interactions with others.
- Struggling, resisting, refusing to bathe / shower, eat, dress.
- Trouble sitting still to eat.
- Wearing inappropriate clothes; taking off clothes inappropriately.
- Resistiveness to care upset significantly and independently predicted caregiver burden - role overload, role captivity; and depression.
- Also, important target for caregiver interventions.

Resistiveness to Care During ADL Assistance

	Behavior	Did the behavior occur in the past week?		If Yes, How many times did it occur?				On average, how long did the behavior last?	To what extent was this behavior upsetting to you?
		YES	NO	1-2 times	3-6 times	Once or twice a day	Many times a day	Minutes	
Eating	Struggled, refused, or resisted to eat	1	0	1	2	3	4		1 2 3 4 5
	Had trouble sitting at a meal	1	0	1	2	3	4		1 2 3 4 5
Bathing	Struggled, resisted, or refused to bathe or shower	1	0	1	2	3	4		1 2 3 4 5
Dressing	Struggled/resisted dressing	1	0	1	2	3	4		1 2 3 4 5
	Wore inappropriate clothes	1	0	1	2	3	4		1 2 3 4 5
	Took off clothes at inappropriate times	1	0	1	2	3	4		1 2 3 4 5

Broadening the Caregiver Burden Concept

What caregivers do: Assist with...

- Household tasks
- Personal care and mobility
- Operating in home medical equipment
- Medical care-injections, catheters
- Care coordination and navigation of Long-term Services and Supports (LTSS)
- Often with NO FORMAL TRAINING....
- Need to expand caregiver burden conception and measurement approaches to incorporate specific stresses and burdens associated with medical / nursing tasks, and navigation of complex LTSS system

Complementing the Caregiver Burden Concept

Positive Aspects of Caregiving

- Vast majority of caregiving research focused on risk factors for negative CG outcomes – burden, depression, etc.
- Most interventions focus on reduction of negative outcomes.
- *Positive aspects of caregiving* approaches focus on benefit finding, finding meaning, possible gains.
- Recent review of positive aspects of AD caregiving literature (Yu et al., 2018) found four key domains:
 - A sense of personal accomplishment and gratification
 - Feelings of mutuality in a dyadic relationship
 - An increase in family cohesion and functionality
 - A sense of personal growth and purpose in life
- Positive and negative dimensions may be independent – co-occur; *caregiver ambivalence*.
- Interventions to increase positive aspects of CG in addition to reducing negative aspects.

Caregiver Burden and Quality of Care Provided

- Most research on caregiver burden examines burden as an outcome – levels and risk factors.
- Little research on caregiver burden as a risk factor for other outcomes.
- What is the impact of high levels of caregiver burden on patient outcomes?
- How does caregiver burden affect the caregiver's ability to provide high quality care?
- Linkages between caregiving and potential elder neglect / abuse.
- These questions reflect the caregiver stress theory – stressed caregivers can't (neglect) or won't (abuse) provide adequate care.
- Frequently cited, but very little data!

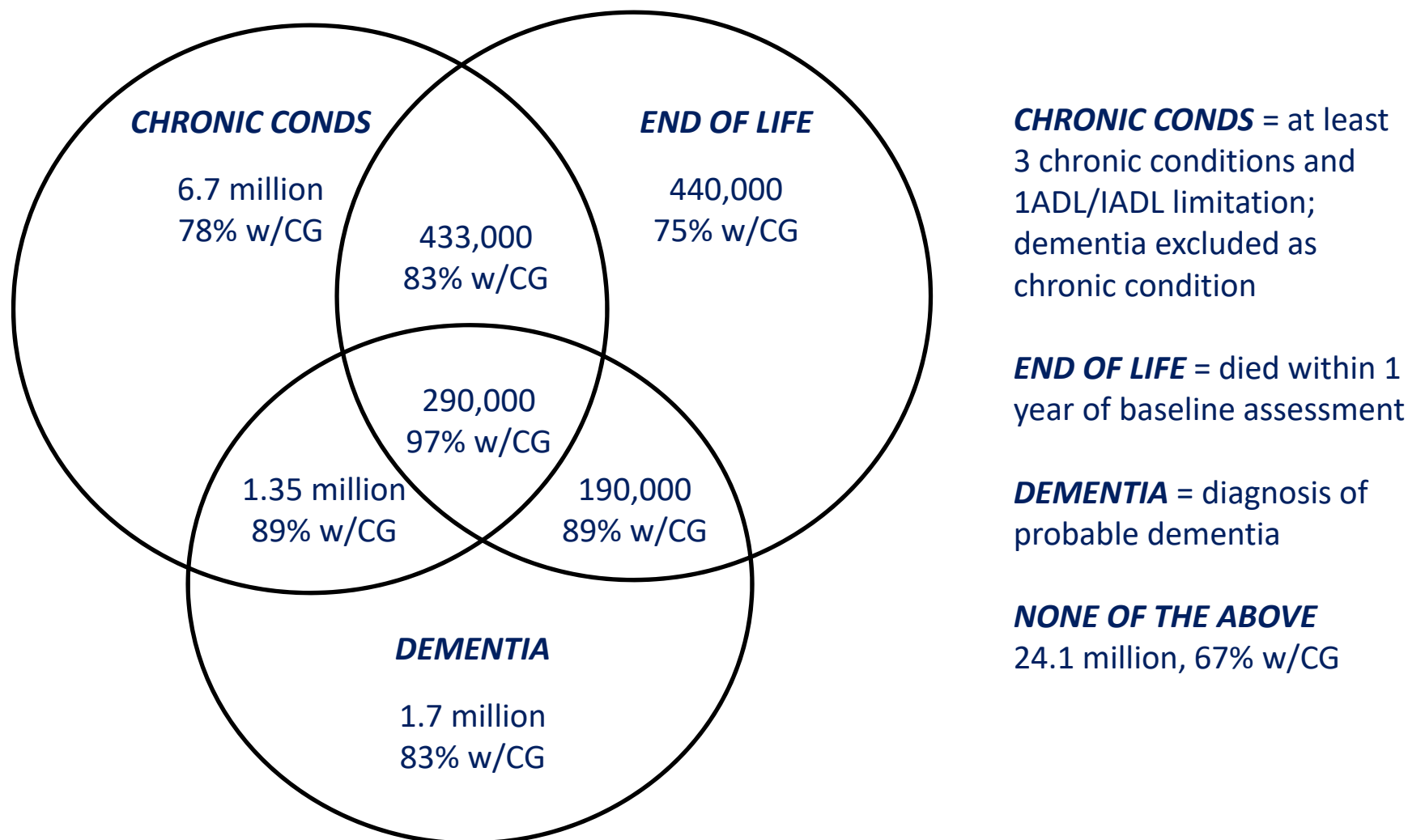
Caregiver Burden and Quality of Care Provided

Profile of Caregivers with Care Recipients who Reported Zero, One, and Two or More Unmet Needs in Past Month, National Study of Caregiving (NSOC), 2011. (*Beach et al., 2017; JAGS, 65, 560-566*)

	Zero UN (n=1,060)	One UN (n=477)	Two or more UN (n=459)
> 100 hours per month of caregiving	14.7	17.3	29.0***
Helps to lift CR from a seated position every day / most days	5.7	7.5	15.4***
Helps manage medical tasks	8.0	11.9*	14.9**
Helps with care of feet	22.8	29.8**	33.6**
Helps with skin care and wounds	16.9	27.4***	32.6***
CR has only one caregiver	30.2	25.5	17.7**
Pain limits CG every day or most days	10.2	12.9	17.7**
Caregiving financially difficult	19.7	20.3	32.3**
Caregiving emotionally difficult	39.5	44.6	54.8***
Caregiving physically difficult	19.3	21.9	31.7***
CG has restricted social participation	17.6	23.5	32.9***

High Need/High Cost Patients and Their Caregivers

Figure 1. Three Overlapping Patient Populations and Proportion w/at Least One Unpaid Caregiver (CG)*



Source: National Health and Aging Trends Study (NHATS, 2011, N=7609); non-institutionalized U.S. older adults aged 65 and over, 35.3 million, weighted population estimates.

High Need/High Cost Patient Caregiver Impacts

Unmet needs by high need category. National Health and Aging Trends Study (NHATS, 2011). Includes 4,024 adults age 65 and older who report difficulty with/or receive help with at least one IADL/ADL.
(Beach et al., in press, *Journal of Gerontology: Social Sciences*)

	TOTAL	LOW NEED	Chron Conds (MCC)	Dementia (DEM)	Died (EOL)	Chron Conds+ Dementia	Chron Conds+ Died	Dementia+ Died	Chron Conds+ Dementia +Died
Sample Size (unweighted)	4,024	1,379	1,564	359	66	396	98	66	96
Any unmet need	31.8	21.4	31.6 ^a	39.6 ^a	48.7 ^a	53.4 ^a	53.2 ^a	46.2 ^a	65.6 ^a
Any IADL unmet need	13.4	11.4	13.9	13.4	15.5	18.2 ^b	25.7 ^a	5.6	6.0
Any mobility unmet need	19.3	10.4	20.0 ^a	23.1 ^a	31.8 ^a	36.5 ^a	42.9 ^a	28.1 ^a	43.4 ^a
Any ADL unmet need	12.6	5.6	12.3 ^a	17.8 ^a	12.7 ^c	28.6 ^a	26.6 ^a	26.9 ^a	41.2 ^a

Caregiving Research Methodology

- Majority of observational caregiving research is cross-sectional, conducted with non-probability clinic-based samples of caregivers (no care recipient).
- Need more longitudinal dyadic (both CG and CR) studies with population-based samples to capture caregiver transitions and impacts on both the caregiver and care recipient outcomes.
- More detailed mixed methods assessment of caregiver tasks and burdens; micro-longitudinal (ecological momentary assessments; time diaries).
- Intervention research – shift from efficacy to implementation!