

Quantitative Measures of the Effects of Caregiving

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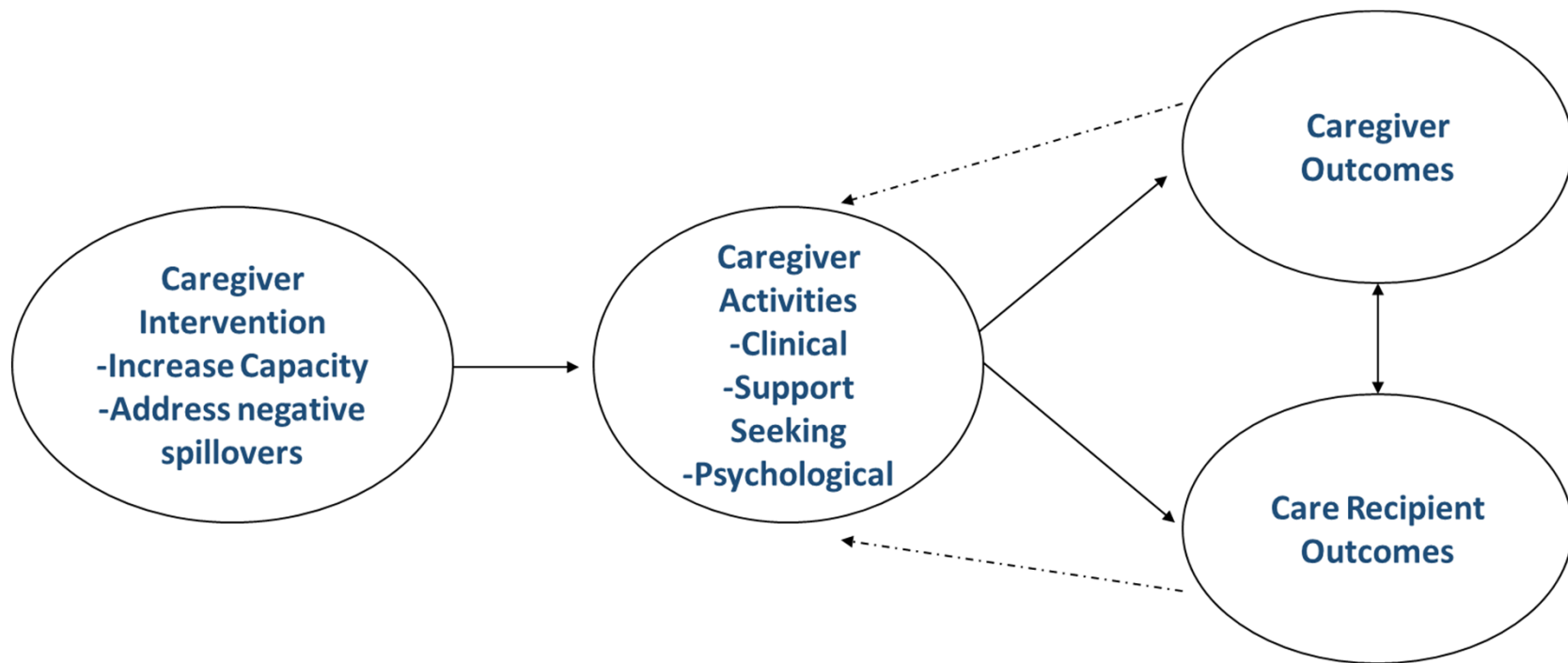
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Importance of the Caregiver Perspective

- Caregivers play a critical role in managing the care of persons with complex health needs like dementia
- The American Medical Association (AMA) has recommended more purposeful support and inclusion of caregivers by the healthcare community
- In 2016, the NASEM (2016) proposed a national policy strategy to support caregivers of older adults.

The Contribution of Family Caregivers



Van Houtven, Voils, Weinberger, 2011

Key Knowledge Gaps

1. How do caregivers perceive themselves to be recognized and valued by health care professionals?
2. What is the impact on caregivers of maximizing time at home for people with chronic conditions?
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How can quantitative data help us to fill these gaps?

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CAPACITY: CAregiver *Perceptions* About Commun/cation with clinical *Team* Members

Rationale

In order to optimize care of the patient in the home, providers need to understand the caregiver's abilities and knowledge, as well as any physical, cognitive, or emotional limitations

Long-term Goal

To better understand the extent to which caregivers experience person- and family-centered care

Van Houtven CH, KEM Miller, EC O'Brien et al. *Med Care Res Rev.* 2017:1077558717747985.

CAPACITY Instrument

- Initial list included 14 items covering caregiver perception of two dimensions:

Communication

Quality of communication between healthcare team and the caregiver about the patient's care needs and care plan

Capacity

Extent to which the healthcare team assessed his/her capacity to provide care and his/her preferences in providing care

CAPACITY Design and Participants

- Instrument mailed in January 2015 to a sample of caregivers who applied to the PCAFC
 - Program to provide support to caregivers providing care to Veterans who sustained a serious or aggravated injury in the line of duty on or post-9/11
 - 30% TBI, 70% PTSD
- Also collected information on:
 - Perceived quality of VA Health care
 - Zarit Burden Inventory
 - Positive Aspects of Caregiving
 - CES Depression Scale
 - Veterans IADL scale
 - Caregiver Demographics
 - Caregiver Health Status
 - VR-12 Quality of life measure

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CAPACITY Results

- N=929 with complete data retained for analysis
- *Caregiver demographics*
 - Mean age = 40.8 years
 - 92.1% female
 - 69.6% spouses
 - 62.5% white
- *CAPACITY Instrument*
 - Internal consistency (communication domain): 0.90
 - Internal consistency (capacity domain): 0.93
 - Confirmatory factor analysis supported a two-factor solution
 - Convergence between subscales, other measures provided evidence of convergent and discriminant validity

CAPACITY Results

Measure	Average(SD)	Possible Score Range
<i>Perceived quality of veteran's care</i>	6 (3)	0-10, with 10=best quality of care
<i>Positive Aspects of Caregiving</i>	34 (8)	Maximum score =45; higher scores=more positive experience
<i>Zarit Burden score</i>	18 (10)	Higher scores = higher burden; >16 = clinically significant burden
<i>VR-12 Mental Health</i>	32 (11)	Maximum score = 75; lower scores = worse health
<i>VR-12 Physical Health</i>	30 (10)	Maximum score = 72; lower scores = worse health

Van Houtven CH, et al. *Med Care Res Rev.* 2017:1077558717747985.

Early Learnings: Cognitive Impairment and CAPACITY

Among 1746 care partners and 1746 persons with cognitive impairment:

1. CAPACITY items fit the expected two-factor structure (communication and capacity)
2. Higher cognitive function (patients) and health literacy (care partners) → lower domain and overall scores
3. Poor care partner well-being was associated with lower CAPACITY scores

Future Directions for CAPACITY

Do higher scores lead to more satisfaction with the health care team?

What is the association between CAPACITY and medication adherence and clinical outcomes?

Do higher scores indicate more clinical, support-seeking, or psychological skills?

Do higher scores indicate better caregiver emotional or physical well-being?

Key Knowledge Gaps

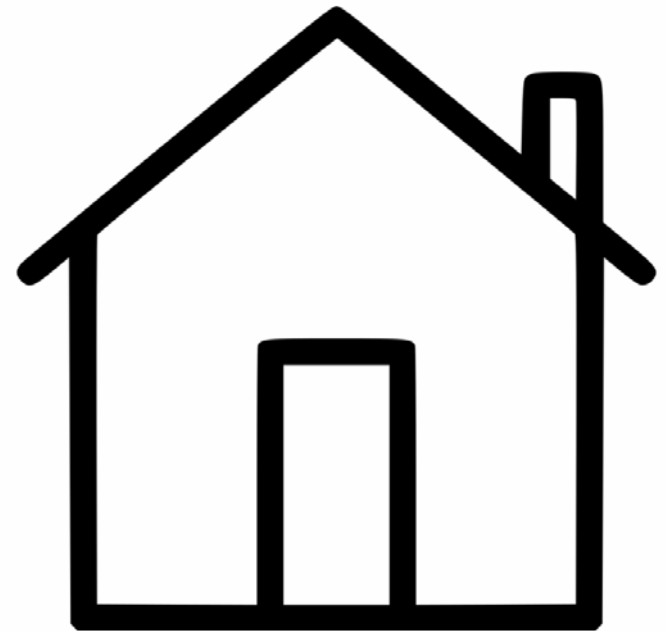
1. How do caregivers perceive themselves to be recognized and valued by health care professionals?
2. **What is the impact on caregivers of maximizing time at home for people with chronic conditions?**

Home-time

Definition: A person-centered outcome representing days alive and out of a healthcare institution

Methods: Calculated using administrative claims data (inpatient, outpatient, and skilled nursing facility days)

Prior applications: comparative effectiveness, hospital variation in cardiovascular disease



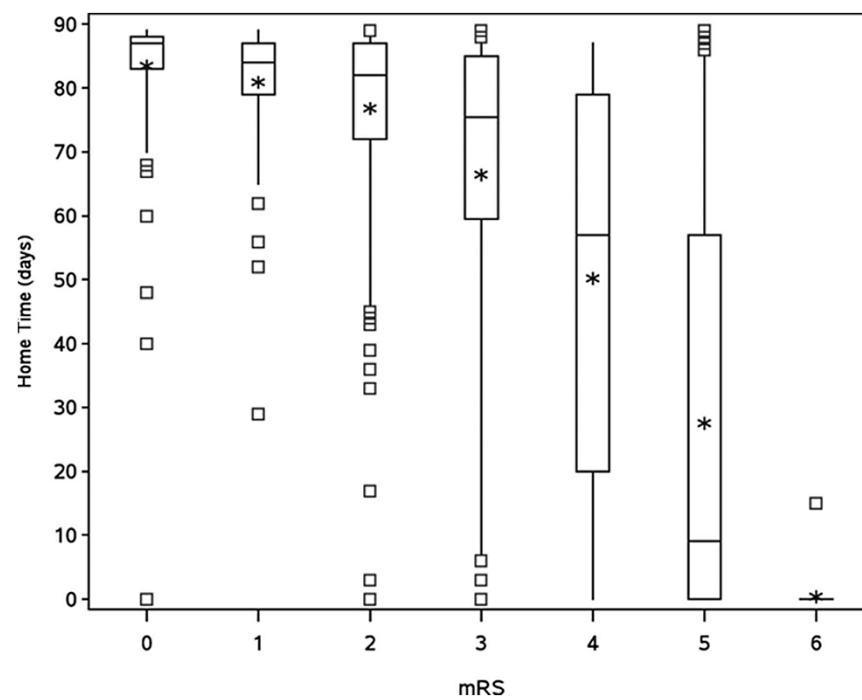
Hospital Characteristics by Home Time Quartiles

Variable	Q1 (N=39174)	Q2 (N=38432)	Q3 (N=28209)	Q4 (N=51072)
Academic hospital	60.3	58.4	58.4	57.0
No. of beds, median (SD)	370 (260, 559)	368 (258, 545)	365 (258, 545)	363 (253, 544)
Rural location	3.4	3.3	3.9	4.3
Region				
Midwest	24.5	22.7	25.5	24.4
Northeast	26.8	25.8	23.0	21.8
South	36.1	36.8	35.4	37.9
West	12.6	14.7	16.1	16.0

Home Time for Comparative Effectiveness Research

	Statin (n=54,991)	No Statin (n=22,477)	Unadjusted HR (95% CI)	Adjusted HR (95% CI)
MACEs, %	48.9%	57.9%	0.78 (0.76, 0.80)	0.91 (0.87, 0.94)
P <.001				
	Statin (n=54,991)	No Statin (n=22,477)	Unadjusted Difference (99% CI)	Weighted Difference (99% CI)
Home time, days mean (SD)	544 (255)	475 (285)	71 (65, 77)	28 (21, 34)
*Weighted by proportion of follow-up; †Differences in days P <.001				

Home Time and Functional Outcomes



Fonarow GC, et al. *Stroke*. 2016;47(3):836-842.

Home Time and PROs / Patient-centered outcomes

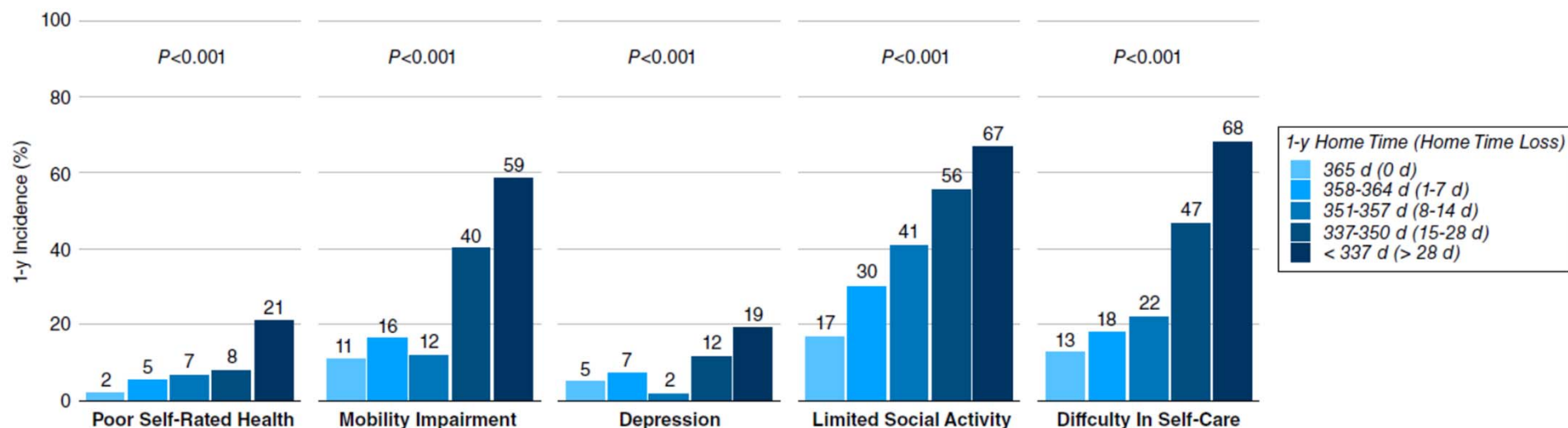


Figure 2. Home time and 1-year incidence of worsening patient-centered outcomes in the Medicare Current Beneficiary Survey 2011.

Lee H, Shi S, Kim D. Home time as a patient-centered outcome in administrative claims data. *JAGS*. 2018.

Is home-time caregiver-centered?

Home-time may be patient-centered,
but how do increased days at home
translate to caregiver quality-of-life?

ASPIRE Home

Goal: To directly obtain caregiver and Veteran perspectives on the person-centeredness of *home time* measures

- Development of home time measure based on caregiver and veteran definition
- Evaluation of relationship between Veteran and caregiver definition(s) and outcomes known to reflect high QOL
- Development of User's Guide for home time measures.



Project Dates: July 2019 – July 2024
PI: Van Houtven

Challenges with scaling caregiver outcome measures

Linking patient
days from claims
data to caregiver
PROs

Lack of standardized
assessments of
caregiver cognitive
function and strain

Identifying
caregivers in
large, real-world
datasets

Thank you!

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