Quantitative Measures of the Effects of Caregiving

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October 17, 2019
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

- Caregiver Intervention
  - Increase Capacity
  - Address negative spillovers

- Caregiver Activities
  - Clinical
  - Support Seeking
  - Psychological

- Caregiver Outcomes
- Care Recipient Outcomes

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?

How can quantitative data help us to fill these gaps?
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1. How do caregivers perceive themselves to be recognized and valued by health care professionals?
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How can quantitative data help us to fill these gaps?
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.

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

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

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

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) \(\rightarrow\) 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?
**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

<table>
<thead>
<tr>
<th>Variable</th>
<th>Q1 (N=39174)</th>
<th>Q2 (N=38432)</th>
<th>Q3 (N=28209)</th>
<th>Q4 (N=51072)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic hospital</td>
<td>60.3</td>
<td>58.4</td>
<td>58.4</td>
<td>57.0</td>
</tr>
<tr>
<td>No. of beds, median (SD)</td>
<td>370 (260, 559)</td>
<td>368 (258, 545)</td>
<td>365 (258, 545)</td>
<td>363 (253, 544)</td>
</tr>
<tr>
<td>Rural location</td>
<td>3.4</td>
<td>3.3</td>
<td>3.9</td>
<td>4.3</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwest</td>
<td>24.5</td>
<td>22.7</td>
<td>25.5</td>
<td>24.4</td>
</tr>
<tr>
<td>Northeast</td>
<td>26.8</td>
<td>25.8</td>
<td>23.0</td>
<td>21.8</td>
</tr>
<tr>
<td>South</td>
<td>36.1</td>
<td>36.8</td>
<td>35.4</td>
<td>37.9</td>
</tr>
<tr>
<td>West</td>
<td>12.6</td>
<td>14.7</td>
<td>16.1</td>
<td>16.0</td>
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</tbody>
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<table>
<thead>
<tr>
<th></th>
<th>Statin (n=54,991)</th>
<th>No Statin (n=22,477)</th>
<th>Unadjusted HR (95% CI)</th>
<th>Adjusted HR (95% CI)</th>
</tr>
</thead>
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<tr>
<td><strong>MACEs, %</strong></td>
<td>48.9%</td>
<td>57.9%</td>
<td>0.78 (0.76, 0.80)</td>
<td>0.91 (0.87, 0.94)</td>
</tr>
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*Weighted by proportion of follow-up; †Differences in days  \( P < .001 \)

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<tr>
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<th>Statin (n=54,991)</th>
<th>No Statin (n=22,477)</th>
<th>Unadjusted Difference (99% CI)</th>
<th>Weighted Difference (99% CI)</th>
</tr>
</thead>
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<tr>
<td><strong>Home time, days mean (SD)</strong></td>
<td>544 (255)</td>
<td>475 (285)</td>
<td>71 (65, 77)</td>
<td>28 (21, 34)</td>
</tr>
</tbody>
</table>

*Weighted by proportion of follow-up; †Differences in days  \( P < .001 \)
Home Time and Functional Outcomes

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

Is home-time caregiver-centered?

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

**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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