QUANTIFYING OUT-OF-POCKET COSTS IN DEMENTIA CARE PARTNER RESEARCH: THE COSTS OF BEHAVIORS

Walter Dawson, DPhil, Sarah Gothard, BA, Nora Mattek, MPH, Jeffrey Kaye, MD, Allison Lindauer, PhD, APRN

Oregon Health & Science University, Portland, Oregon USA

ILPN International Conference, London, United Kingdom, September 9, 2022
DISCLOSURES

• Funding for this study was provided by the National Institutes of Health (NIA) and the Oregon Roybal Center for Care Support Translational Research Advantaged by Integrating Technology (ORCASTRAIT)

• Award # NIA P30 AG024978-18

• No other relevant disclosures
• Care Partners for persons living with dementia experience both positive and negative health outcomes due to their caregiving effort.

• Measuring these outcomes is difficult due to biases.

• Understanding the effect of an intervention could be finessed by assessing objective outcomes to complement subjective findings.

• Little is known about the interaction between costs and objective outcomes for Care Partners who receive a psychoeducational intervention.
• Dementia care related costs are high – societal and personal / family levels
• Total dementia-related costs: $377,621 lifetime, per individual (2021 dollars) Alzheimer’s Association 2022)
• 70% of those costs are carried by family care partners resulting in high out-of-pocket expenses (Jutkowitz et al, 2015).
• What are the links between behaviors and out-of-pocket costs and how do we mitigate?
INTERVENTION

• Support via Telehealth: Living and Learning with Advancing AD (STELLA)
  • Videoconference-based multicomponent intervention designed to facilitate effective management of the upsetting behavioral symptoms that often accompany the progression of dementia.

• Goal: reduce upsetting behaviors that are common in the later stages of dementia, and thus reduce care partner burden including out-of-pocket costs incurred by families.
INTERVENTION

• STELLA developed from STAR-C (Teri et al., 2005)
• Modified to be administered via telehealth (Lindauer et al, 2018; 2019)
• Adapted to address Care Partner behaviors and Care Partner isolation (Lindauer et al, 2021)
• 14 family members caring for individuals with dementia participated in an 8-week intervention with a guide.

• Sensors and other technologies used in participants’ homes to monitor and detect early changes in health, cognitive function, activity, and behavioral-functional signatures of patients and Care Partners.

• Goal: assess the relationship between behavioral symptom frequency, care partner reactivity, and out-of-pocket costs for care partners.

• We are then comparing the objective and subjective findings to identify trends that correlate with burden and cost.
STELLA INTERVENTION

Figure 3. Nova Component of Tele- STELLA
METHODS

• Weekly online surveys of care partners living with a person with dementia

• Measure weekly out-of-pocket costs reported by CPs
  
  • Costs: Hospitalizations, ED visits, PCP visits, medications (prescription and over the counter), in-home care, respite services

  • Time: measure time devoted to care-related activities ($27 per hour rate) including travel time

  • Do expenditures and time change while participating in STELLA?
<table>
<thead>
<tr>
<th>Variable</th>
<th>Care Partner</th>
<th>Care Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
<td>n=14</td>
<td>n=14</td>
</tr>
<tr>
<td>Age, years</td>
<td>71.9 (7.0)</td>
<td>75.3 (8.8)</td>
</tr>
<tr>
<td>Female, sex</td>
<td>62%</td>
<td>38%</td>
</tr>
<tr>
<td>Education, years</td>
<td>16.3 (1.9)</td>
<td>15.5 (2.5)</td>
</tr>
<tr>
<td>White non-Hispanic, race</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Mean (standard deviation) or percentage as appropriate.
FINDINGS

POSITIVE

• Participants like the intervention
• "I feel like I got a little more attuned to how things affect him."
• Early improvement:
  • "I already feel progress."

NEGATIVE

• Difficult enrollment
• Many adverse events
• Staff changes
• Tech issues
### EXPENSE-RELATED FINDINGS

Table 11. STELLA participant out-of-pocket expenses

<table>
<thead>
<tr>
<th>Expense Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenses (any)</td>
<td>13 (93%)</td>
</tr>
<tr>
<td>ED Visit / Hospitalization</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>Primary care</td>
<td>9 (64%)</td>
</tr>
<tr>
<td>Prescription drugs</td>
<td>12 (86%)</td>
</tr>
<tr>
<td>In-home assistance</td>
<td>8 (57%)</td>
</tr>
<tr>
<td>OTC drugs / care items</td>
<td>9 (64%)</td>
</tr>
</tbody>
</table>
ED/hospitalizations
- 70% of CPs spent over $100
- 70% spent 3 or more hours assisting with the visit.

Primary care assistance
- 44% spent > $100
- 63% spent more than 1 hour

In-home assistance weekly
- 57% spent over $200 (30% spent over $500)
- 38% spent more than 1 hour

Prescription drug assistance:
- 83% spent between $1-$100.
- 58% spent more than 30 minutes on the task.

Over the counter medication assistance
- 53% spent one hour or more on the task
- 86% spent between $1-$100.
SUMMARY & CONCLUSIONS

• Initial evidence on the implementation of a technology-based intervention, and the potential resulting impacts on family-level costs related to BPSD frequency, CP reactivity, and burden.

• Findings so far support existing literature on out-of-pocket expenses and time dedicated to care-related activities by CPs.

• Next steps: to look at expense changes pre/post intervention

• Additional research is needed on out-of-pocket costs of dementia

• Policies need to be tailored to better support car partners
  • e.g., training on medication management, funding for paid in-home care supports.


REFERENCES


Thank you!

Email: dawsonw@ohsu.edu