

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

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DISCLOSURES

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BACKGROUND

- 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.



BACKGROUND

- 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)



ORCATECH PLATFORM

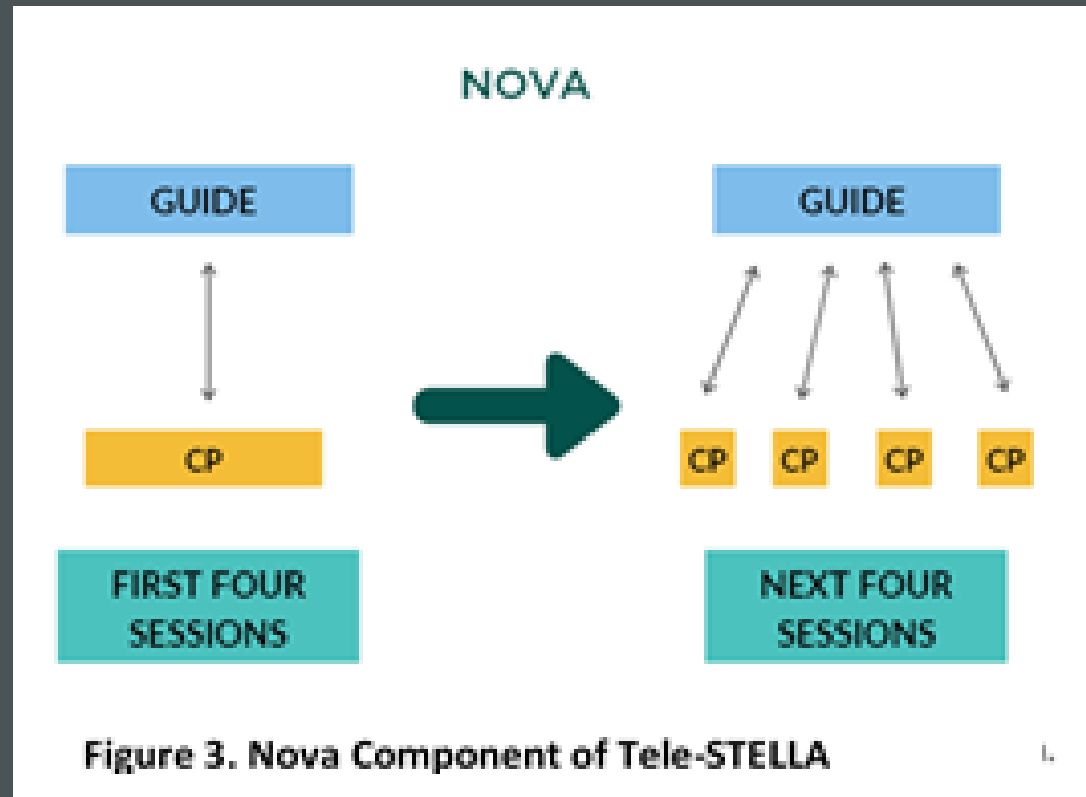


DESCRIPTION

- 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



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?



DEMOGRAPHICS

Table 1. STELLA participant demographics

	Care Partner	Care Recipient
Variable	n=14	n=14
Age, years	71.9 (7.0)	75.3 (8.8)
Female, sex	62%	38%
Education, years	16.3 (1.9)	15.5 (2.5)
White non-Hispanic, race	100%	100%

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 II. STELLA participant out-of-pocket expenses

Expense Variable	n (%)
Expenses (any)	13 (93%)
ED Visit / Hospitalization	5 (36%)
Primary care	9 (64%)
Prescription drugs	12 (86%)
In-home assistance	8 (57%)
OTC drugs / care items	9 (64%)



FINDINGS

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.



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Thank you!

Email: dawsonw@ohsu.edu

