The Cost-Effectiveness of Caregiver Support Interventions for People Living with Dementia

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Study Objectives

- Determine the cost savings and cost-effectiveness of nondrug interventions that support people living with ADRD and their care partners.

Cost-effectiveness and Net Cost of Interventions

- Model structure
  - Measures
  - Data
  - Estimate model parameters
- Modeling treatment effects

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY

Clinical Investigation

Societal and Family Lifetime Cost of Dementia: Implications for Policy

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Bryan Dowd PhD

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THE GERONTOLOGICAL SOCIETY OF AMERICA

OXFORD

Research Article

Effects of Cognition, Function, and Behavioral and Psychological Symptoms on Medicare Expenditures and Health Care Utilization for Persons With Dementia

Eric Jutkowitz,[1] Robert L. Kane,[1] Bryan Dowd,[1] Joseph E. Gaugler,[2] Richard F. MacLeh

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RESEARCH ARTICLE

Cost effectiveness of non-drug interventions that reduce nursing home admissions for people living with dementia

Eric Jutkowi
Katherine N

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Featured Article

Effects of cognition, function, and behavioral and psychological symptoms on out-of-pocket medical and nursing home expenditures and time spent caregiving for persons with dementia

Eric Jutkowitz, Karen M. Kuntz, Bryan Dowd, Joseph E. Gaugler, Richard F. MacLehose, Robert L. Kane

First published: 01 February 2017 | https://doi.org/10.1016/j.jalz.2016.12.011 | VIEW METRICS

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Microsimulation Model Calibration with Approximate Bayesian Computation in R: A Tutor

Peter Shewmaker

Volume 42, Issue 5

Jutkowitz et al. BMC Geriatrics (2026) 26:23
https://doi.org/10.1186/s12877-025-06532-1

BMC Geriatrics

RESEARCH Open Access

The cost of non-drug interventions that improve function and reduce dementia-related behaviors

Eric Jutkowitz[1*],
Joseph E. Gaugler

The Journals of GERONTOLOGY SERIES A

Volume 72, Issue 2
1 February 2017

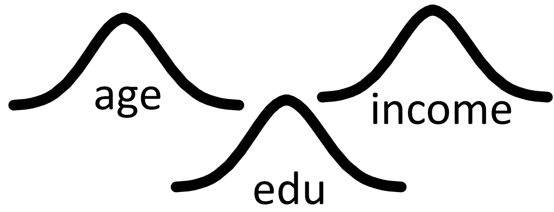
JOURNAL ARTICLE

Risk Factors Associated With Cognitive, Functional, and Behavioral Trajectories of Newly Diagnosed Dementia Patients Get access

Eric Jutkowitz, Richard F. MacLehose, Joseph E. Gaugler, Bryan Dowd, Karen M. Kuntz, Robert L. Kane

The Journals of Gerontology: Series A, Volume 72, Issue 2, 1 February 2017, Pages 251–258, https://doi.org/10.1093/gerona/glw079

Model Structure



Cognition, Function, and Behavior
(predict 1)

Transition Place of Residence,
Medicaid Status, Dead
(predict 2)

Costs Associated with Disease Status,
Place of Residence, Medicaid Status
(predict 3)

Community
Medicare

Community
Medicare
Medicaid

Long Term Care
Medicare

Long Term Care
Medicare-
Medicaid

Measures of Dementia Symptoms

Domain	Instrument	Scoring
Cognition	Mini-Mental State Examination (MMSE)	Lower scores more cognitive impairment
Function	Investigator-modified Functional Activities Questionnaire	Higher scores more functional difficulties
Behavior	Neuropsychiatric Inventory (NPI-Q)	Higher scores more behavioral symptoms

Data Sources

Predict	Data Source	Brief Description
1. Cognition, Function, and Behavior (predict 1)	National Alzheimer's Coordinating Center (NACC) Uniform Data Set	Clinical diagnosis and longitudinal data on clinical features

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1. Cognition, Function, and Behavior (predict 1)	National Alzheimer's Coordinating Center (NACC) Uniform Data Set	Clinical diagnosis and longitudinal data on clinical features
2. Transition Place of Residence, Medicaid Status, Dead (predict 2)	• NACC Uniform Data Set; calibrated against Medicare data • Medicare enrollment data • Literature	• Longitudinal data on clinical features and place of residence • Estimates from literature

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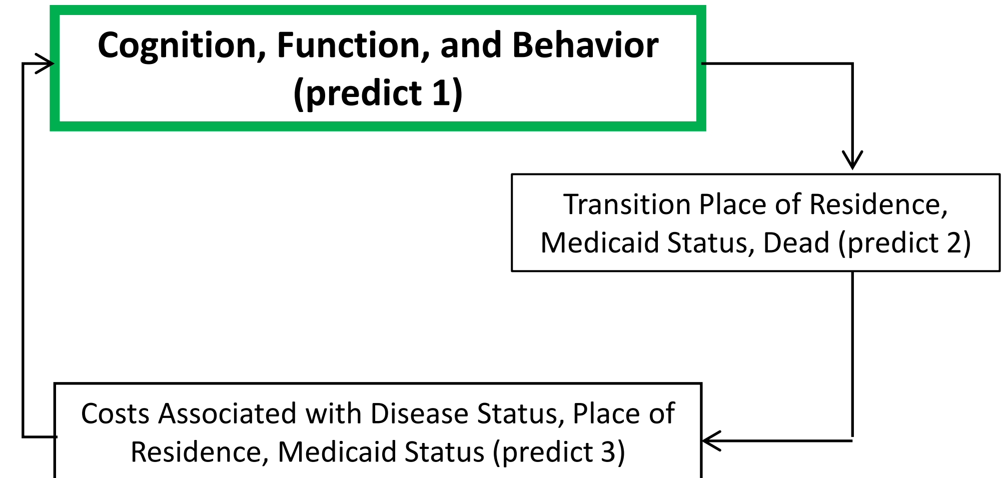
2. Transition Place of Residence, Medicaid Status, Dead (predict 2)	• NACC Uniform Data Set; calibrated against Medicare data • Medicare enrollment data • Literature	• Longitudinal data on clinical features and place of residence • Estimates from literature
3. Costs Associated with Disease Status, Place of Residence, Medicaid Status (predict 3)	Aging, Demography, and Memory Study (ADAMS) linked to the Health and Retirement Study (HRS) and CMS Medicare	ADAMS clinical diagnosis and cross-sectional data on clinical features and time caregiving, HRS data on out-of-pocket expenditures.

Clinical Trajectories

- Objective: Describe clinical trajectories
- Method: Linear-mixed effects models
  - NACC-UDS
  - Time, Time-squared and random intercepts and slopes
  - Sociodemographic and clinical risk factors associated with decline
  - Model building process



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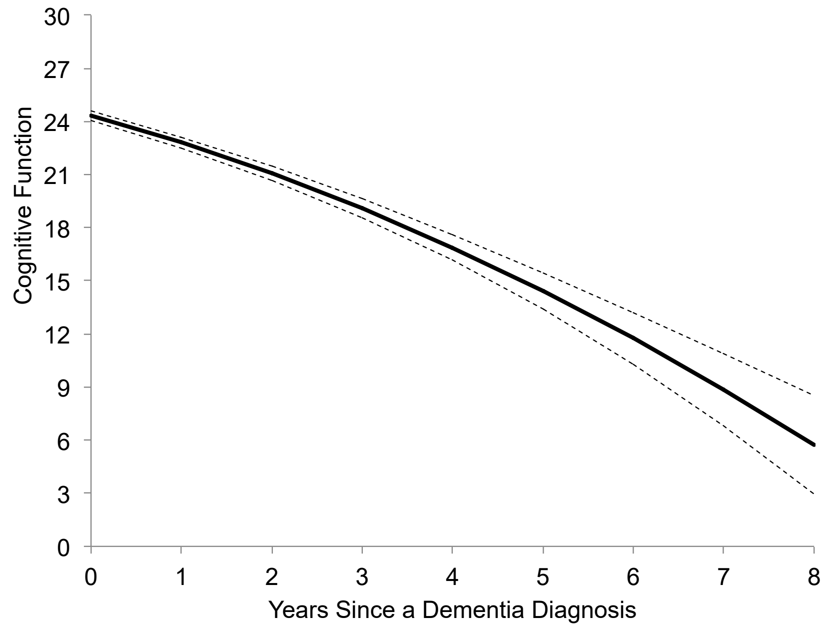
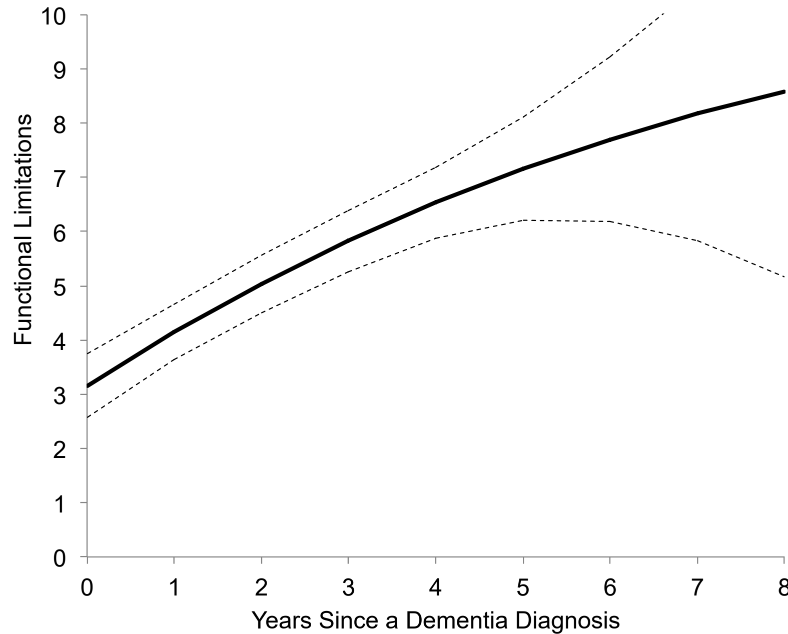
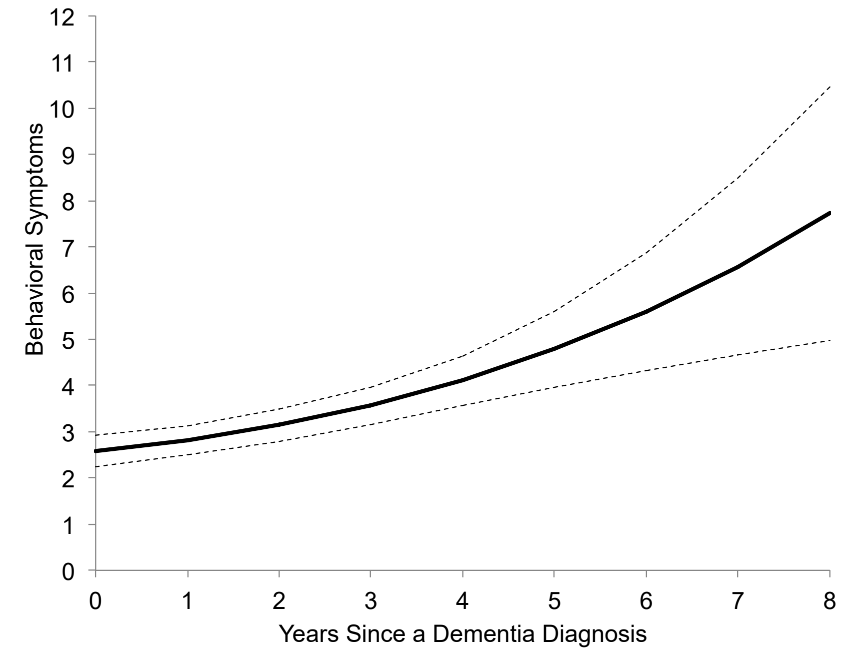
Clinical Trajectories



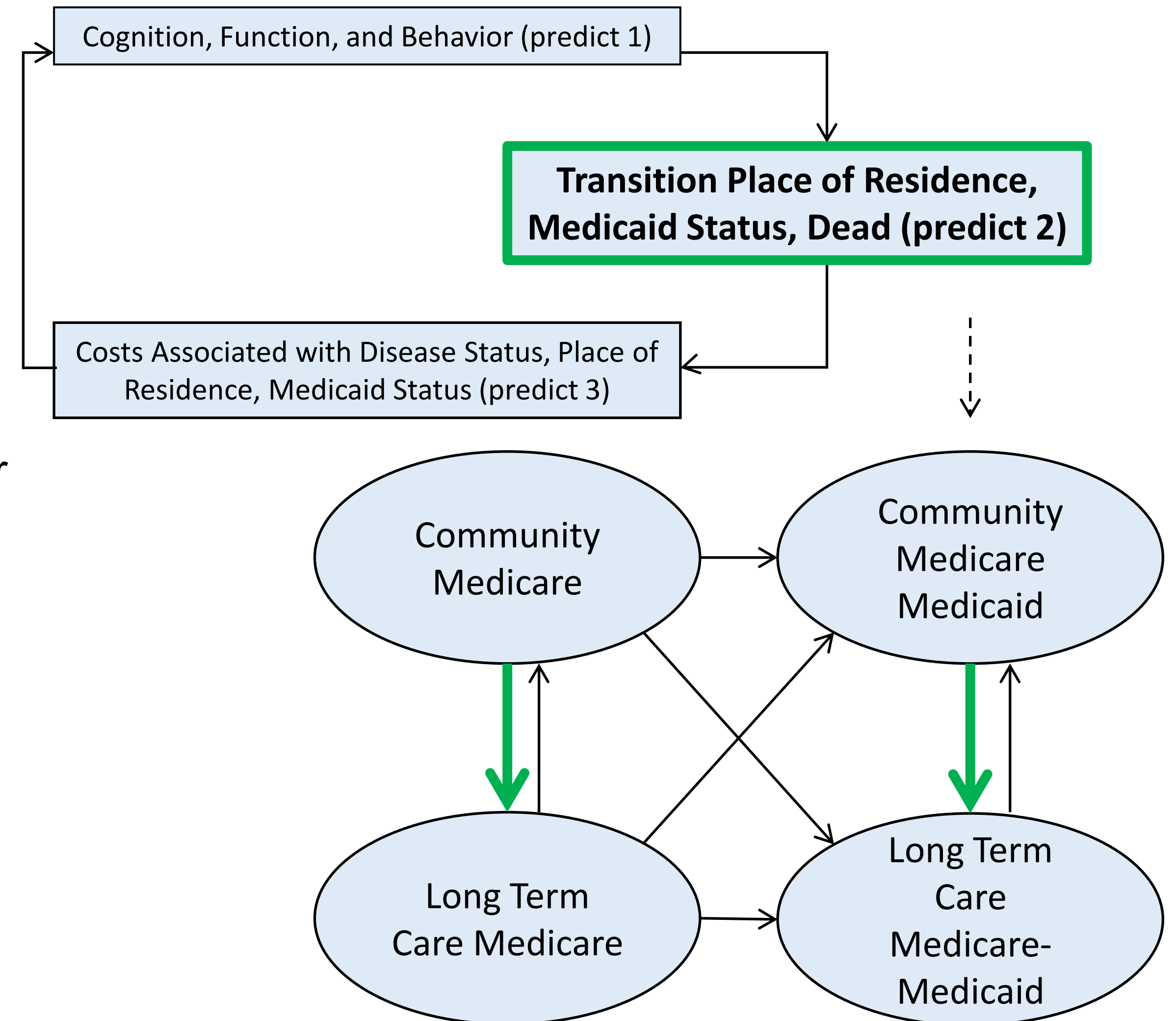




1. Jutkowitz et al. Risk Factors Associated With Cognitive, Functional, and Behavioral Trajectories of Newly Diagnosed Dementia Patients. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences. 2017

Transitions Between Place of Residence

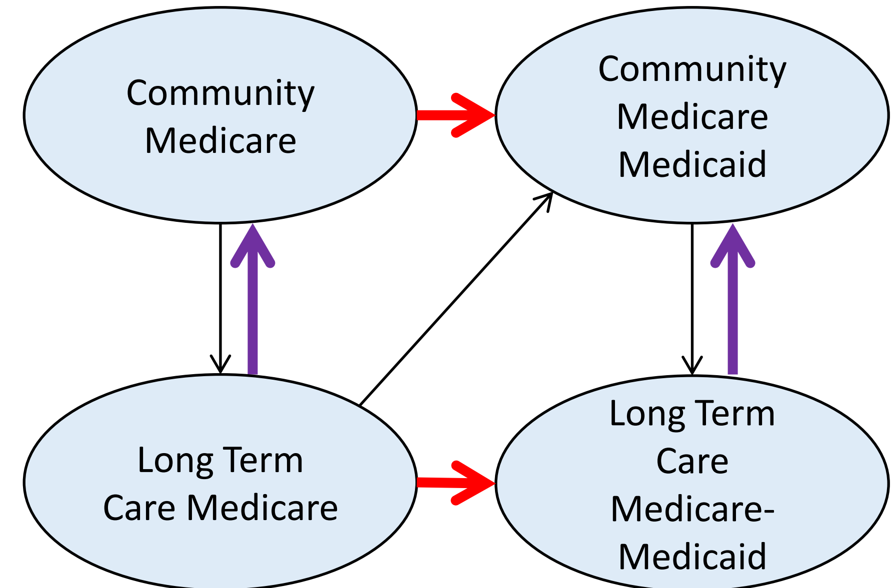
- Objective: Probability of transition from community to nursing home.
- Method: Weibull survival model
  - NACC-UDS
  - Main effects prior cognition, function, and behavior
- Average difference (months) between the predicted time in NH and values observed in Medicare data (Shewmaker et al MDM 2022).
  - Before calibration: 3.74 months
  - After Calibration 1.47 months



Other Transitions

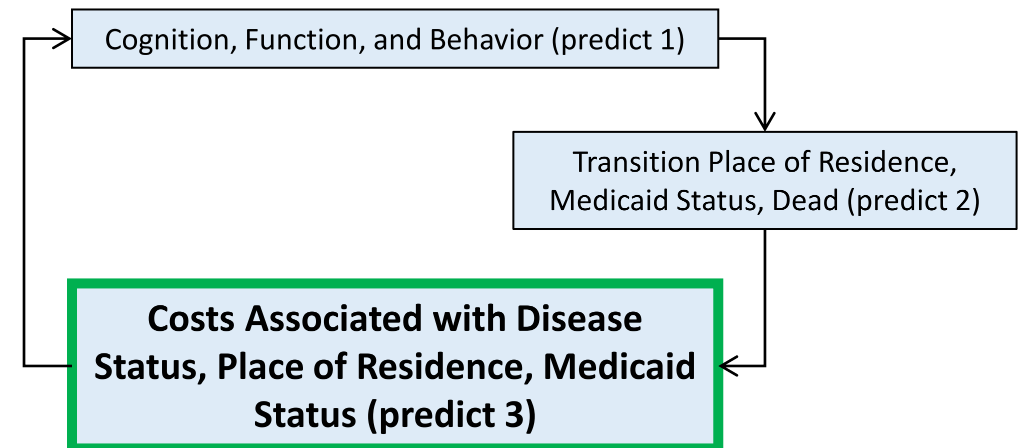
- Objective: Probability of transition from NH to community, Medicaid, and death

- Method: Estimates obtained from Medicare data or literature
  - Arling et al. “Targeting Residents for Transition from Nursing Home to Community” → updated based on Medicare data
  - Medicaid transitions obtained from MBSF and Residential History File
  - US Lifetables with HR for dementia specific mortality



Cost Inputs

- Objective: Describe relationship between clinical features and cost
  - out-of-pocket medical
  - informal care (family caregiving time)
  - formal community based care
  - Medicare
- Method: Two-part modeling approach
  - ADAMS + HRS+ CMS
  - Main effects for clinical features
  - Control for confounders



Cost Inputs

Cost Type	Payer	Brief Description
1. Informal Caregiving	Family	• $19.71/hr
2. Formal community care	Family	• $22.26/hr
2. Out-of-pocket long-term care facility	Family	• Facility monthly rate $7,270
3. Medicaid long-term care facility	Medicaid	• Facility monthly rate $6,236

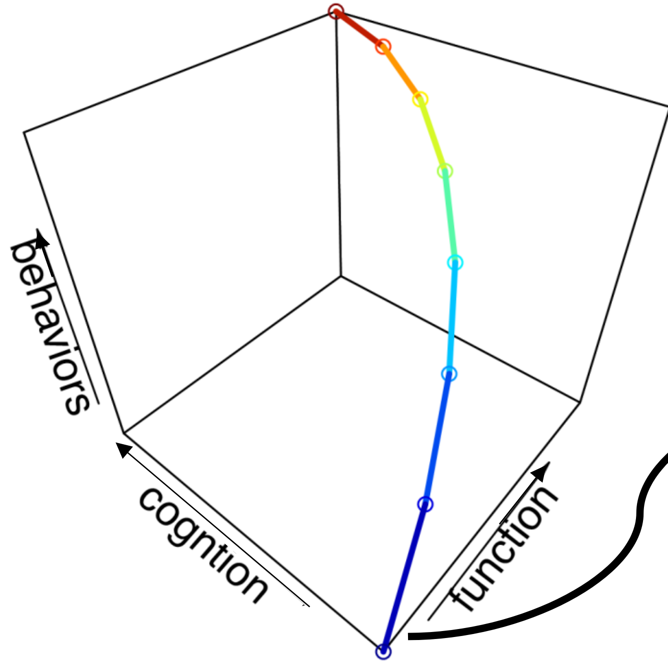
1. Jutkowitz E et al. Effects of Cognition, Function, and Behavior on Out-of-Pocket Medical and Nursing Home Expenditures and Time Caregiving For Persons with Dementia. *Alzheimer's and Dementia*. 2017.
2. Jutkowitz E et al. Effects of Cognition, Function, and Behavior on Medicare Expenditures For Persons with Dementia. *Journals of Gerontology Series A*. 2017.

Preference Weights

Stage	Community	NH
1. Mild (MMSE 21-25)	0.68	0.71
2. Moderate (MMSE 11-20)	0.54	0.48
2. Severe (MMSE 0 - 10)	0.37	0.31

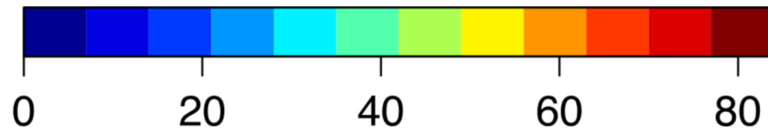
1. Preference weights obtained from Neumann et al.

Simulation



Months Since Diagnosis	Risk of Long-term Care Facility Admission	Risk of Medicaid	Cost
Diagnosis	Low	Low	$
12	Medium	Medium	$$
36	High	High	$$$
60	High	High	$$$$

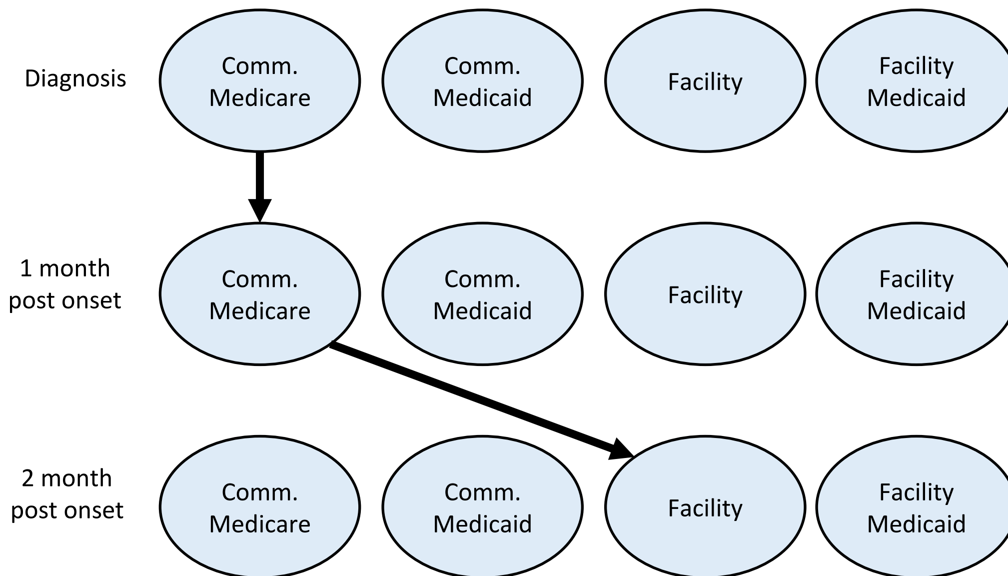
Months Since Dementia Diagnosis

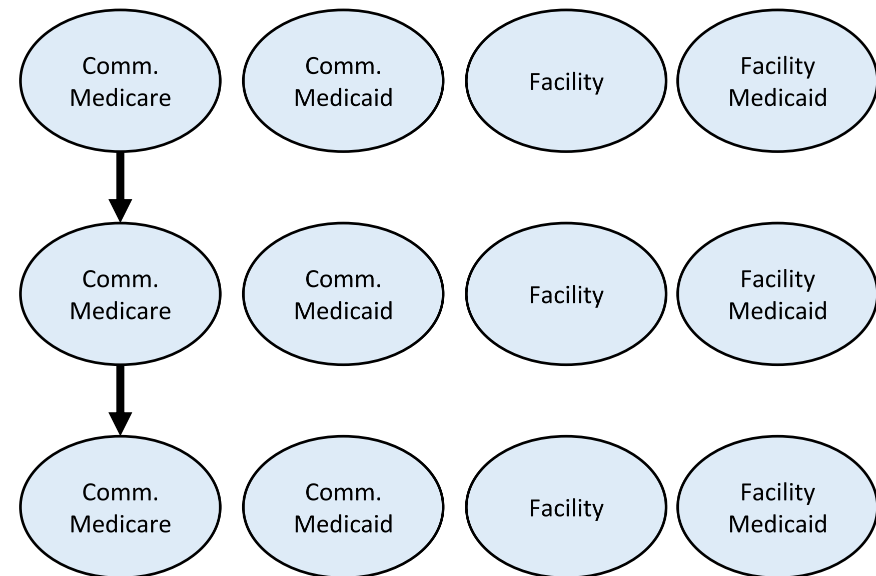


Simulating Usual Care vs. Intervention

Dementia Usual Care

Intervention





Identifying Interventions to Improve Care

- We searched the Best Practice Caregiving Registry on August 3rd 2021
- "Study Findings" filter for "Nursing Home Admission Long/Short-Term-Quantity." This search identified two interventions that reduce nursing home admissions.

Identifying Interventions to Improve Care

Intervention Setting	Caregiver Outcome Domain Categories								Person with Dementia Outcome Domain Categories								
	Mental Health	Stress/Strain/Burden	Physical Health	Psychosocial Resources	Quality of Life/Well-being	Social Support	Dyad Relationship	Knowledge	Mental Health	Physical Health	Neuropsychiatric Symptoms	ADL/IADL/Functional Dependence	Community Resource Utilization	Healthcare Resource Utilization	Quality of Life	Long-term Care/Nursing Home Placement	Psychosocial Resources
Home	7	8	4	8	6	1	3	0	4	4	8	4	2	2	6	3	1
Hospital/ Medical Center	7	7	4	4	2	2	1	1	5	4	5	3	1	4	4	1	0
Telephone/ Web-based	16	19	10	10	6	7	0	3	3	4	13	5	0	5	4	4	0
Community Space (Library, School etc.)	19	18	15	11	4	7	3	3	4	4	9	2	0	0	2	2	2
Adult Day Service	4	4	3	3	1	1	0	0	1	1	2	0	1	0	1	1	0
Retirement Communities/Independent Living / Assisted Living	2	2	1	2	0	1	1	0	0	1	1	0	0	0	0	0	0
Nursing Home/ Long-term Care	1	1	0	1	0	0	0	0	1	0	1	0	0	0	1	0	0

1: NIA IMPACT - Dissemination & Implementation Core

Identifying Interventions to Improve Care

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Nursing Home/ Long-term Care	1	1	0	1	0	0	0	0	1	0	1	0	0	0	1	0	0

1: NIA IMPACT - Dissemination & Implementation Core

Interventions to Support Caregivers and People Living with ADRD

Intervention	Setting	Cost	Duration of Tx Effect	Behaviors	Function	NH	Other
Collaborative Care	Primary Care	$1,500	18mo	Y			
COPE	Home	$2,050	12mo	Y	Y		Medicare Cost
TAP	Home	$1,000	4mo	Y	Y		Time caregiving
Skills2Care	Home	$1,000	3mo	Y			
MIND	Home	$1,224	18mo			Y	Time caregiving
NYU Caregiver	Primary Care	$3,500	42mo			Y	
Alzheimer's and Dementia Care	Primary Care	$1,200	36mo			Y	Medicare Cost
ADSPlus	Adult Day	$888	12mo			Y	

Defining the Interventions and Core Studies

- Intervention Name and Description
- Comparison Name and Description
- Setting
- Target Population
- Intervention Intensity
- Study Design / Unit of Randomization
- Outcome Measure(s) Modeled
- Cost of Delivering the Intervention
- Structural Assumption

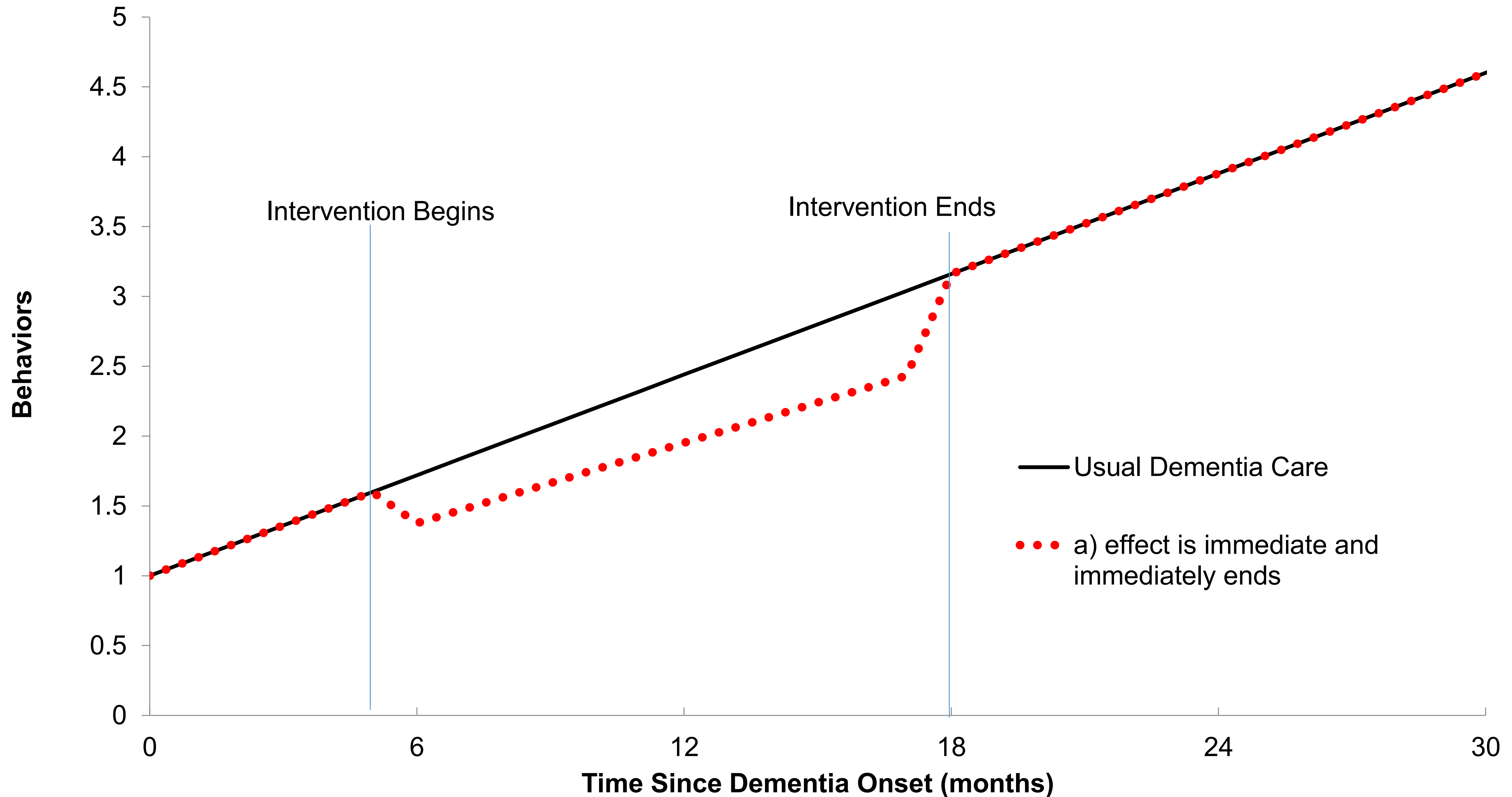
Examples of Interventions to Support Caregivers and People Living with ADRD

- Tailored Activity Program – VA (Gitlin et al. JAGS 2018)
  - 8 in-home occupational therapist led intervention over 4 months
  - Fewer behavioral symptoms at 4 month follow up
  - Fewer assistance for functional activities
- Collaborative Care for Older Adults with AD (Callahan et al. JAMA 2006)
  - Care management by primary care physician and geriatric nurse care manager delivered to the person with dementia and primary caregiver up to 12 months
  - Fewer behavioral symptoms (NPI) at 18 month follow up
  - Mean Difference: -0.90 (95% CI: -1.7, -0.2)

Treatment Effect Assumptions

- Timing of intervention
  - Modeling the time to start an intervention for a simulated person is important because outcomes (e.g., transitioning to a nursing home or costs) are not accumulated at a constant rate.
  - We modeled the time a simulated person receives an intervention based on months since a dementia diagnosis.
- Duration of effect
  - Immediately starts & ends at last reported follow up

Treatment Effect Assumptions



Additional Modeling Assumptions

- We did not compare interventions against each other.
  - Target different settings and different enrollment criteria.
- Cost-minimization analysis
  - Model was not designed to evaluate health-related quality of life, all interventions we evaluated demonstrated improved health outcomes compared to usual care, a cost-minimization analysis provides a conservative approach to evaluating these interventions.

Example of MIND - RCT

- MIND (Samus et al. JAGP 2014)
  - Participants, care partners, and primary care physician receive results of care needs assessment and 18 months of care coordination.
  - The care coordination team is comprised of a non-clinical community worker (Coordinator), RN, and geriatric psychiatrist.
  - Care coordination is manualized and aims to identify needs, care planning, dementia education, skill building, coordination/referral/linkage to services, and care monitoring.

Example of MIND

- RCT reported: 18-month HR of leaving the home: 0.63 (95% CI: 0.42, 0.94).

- We applied a HR to the background hazard of entering a nursing home.

Example of MIND

- Time caregiving: change in usual care - change in intervention from baseline to 18 months in time spent with care recipient: – 16.90 hours/week (95% CI: −33, −0.72) or -73.43 hours/month.

  - The microsimulation model predicts hours of family caregiving based on a two-part regression model.
    - Part 1 is a logistic regression model that predicts whether a person receives any family caregiving.

    - Part 2 is a log-link gamma distribution regression that predicts the amount of family caregiving among those who received any caregiving.

Example of MIND

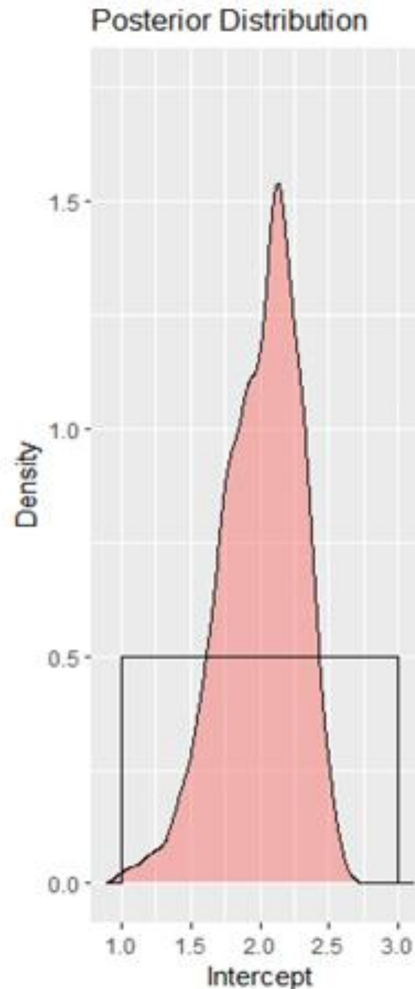
- We modeled the effect of MIND on time spent caregiving using a sample importance replacement calibration (SIR) approach.

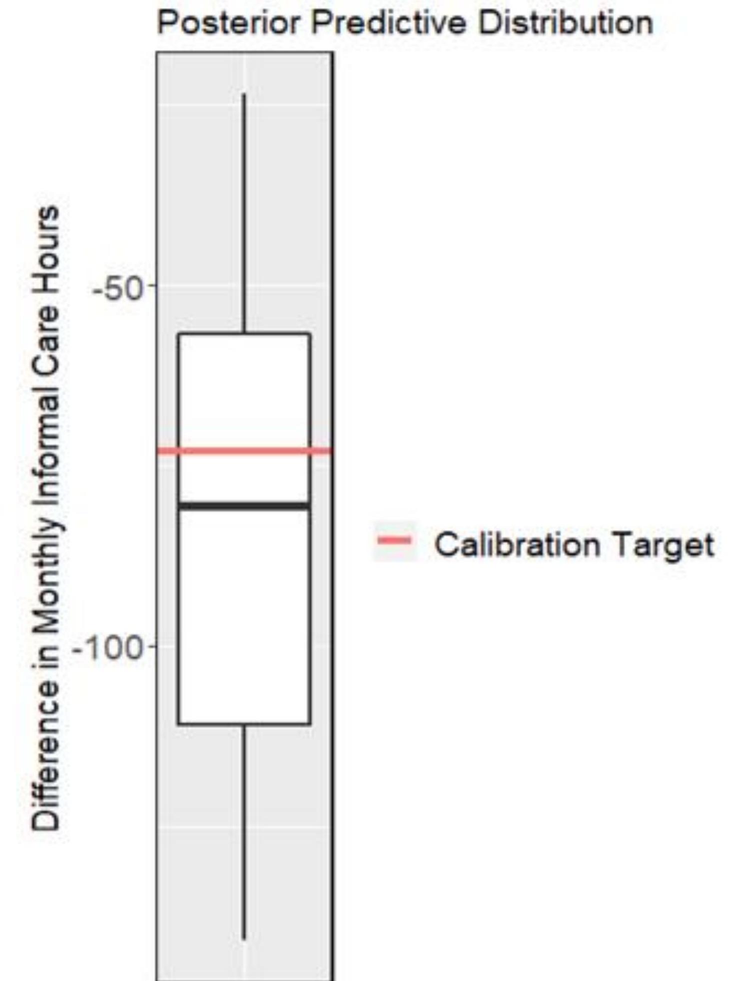
Calibration Parameter	Original Parameter Value	Prior Distribution	Target Outcome from Trial Difference in Caregiving Hours*
Intercept of part 2 of the informal caregiving regression	2.53	Unif(1,3)	-73.43 hours/month

- RCT reports 18-month difference. We assume the difference was constant for the duration of the trial.

Example of MIND

- Time caregiving: change in usual care—change in intervention from baseline to 18 months in time spent with care recipient: – 16.90 hours/week (95% CI: −33, −0.72).





Alzheimer's and Dementia Care (quasi-experimental)

- Intervention Description: Participants with dementia were co-managed by NP, dementia care managers and physicians.
- Intervention included a needs assessment, individual care plans, monitoring and updating care plans, 24/7/365 access to a dementia care manager.

- 3-year hazard ratio (HR) of being admitted to a long-term care facility: 0.60 (95% CI: 0.59, 0.61).

- In sensitivity analysis we applied Turner et al.'s method to adjust for internal bias.

Alzheimer's and Dementia Care (quasi-experimental)

- We answered the following question for each domain (selection bias, performance bias, attrition bias, detection bias).
  - Even if there were no intervention effect in this study, what apparent effect might be induced by this bias? Risk lower in intervention group [or higher in control group] or risk lower in control group [or higher in intervention group].
- Each reviewer is asked to mark a 67% range on elicitation scale for each type of bias. The following correspondence between qualitative judgments of severity and the range limits are given: none (1), low (0.9–1), medium (0.7–0.9), and high (less than 0.7).
- The aggregated results from each reviewer are used to calculate a total bias.

	Original Hazard Ratio	Bias Adjusted Hazard Ratio
Alzheimer’s and Dementia Care (ADC)	0.60 [0.59, 0.61]	0.76 [0.71, 0.82]

Modeling Results From Different Measures

- Some studies used different measures of function and behavioral symptoms than those used in the ADRD microsimulation model.

- To model the intervention effects, we calculated a standardized mean difference (Cohen's D) with a confidence interval for each intervention.

- We calibrated the parameters that predicted change in function and behaviors towards this standardized mean difference, using a diffuse uniform prior distribution.

COPE

- 12-month in-home 10 session occupational therapist led intervention. Structured assessments are used to inform tailored skill building for caregivers with written action plans.

- Meta-analysis to combine results from two trials.

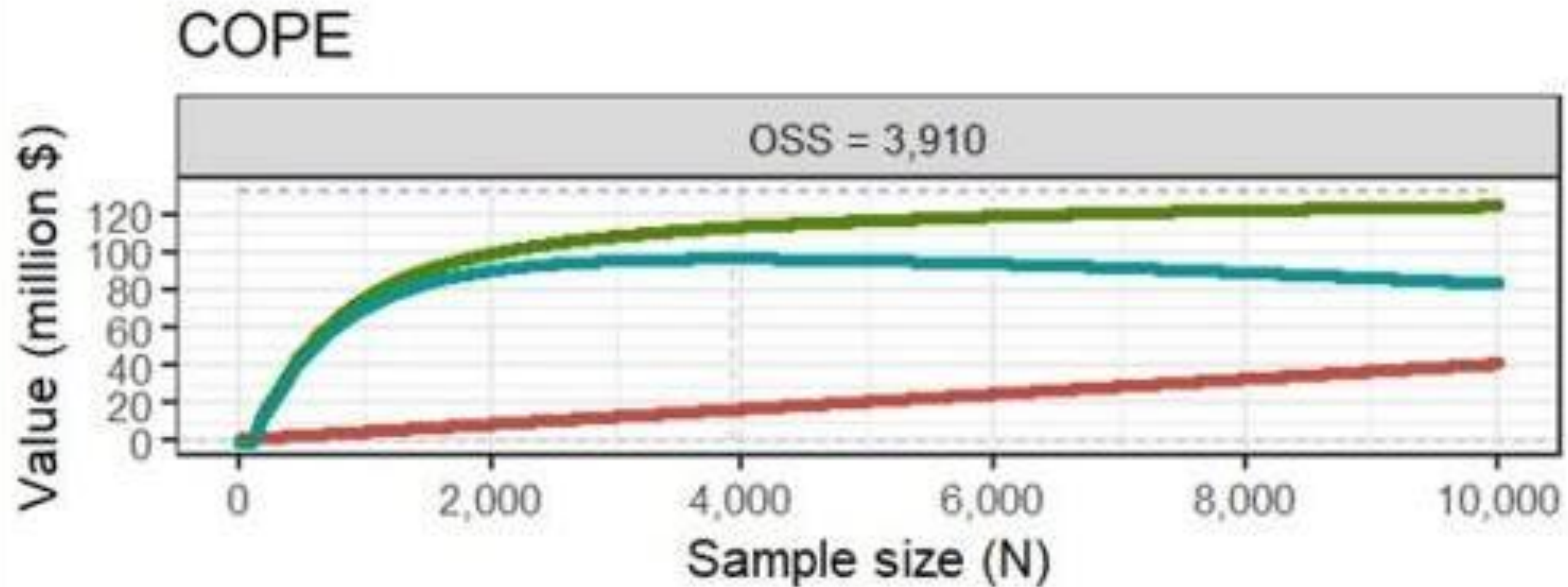
- In modeling found a -$5,262 net cost savings to society.

- Used a value of information analysis to determine the value of conducting a new randomized trial to reduce uncertainty on the cost-savings of non-drug interventions.

COPE

Intervention	Effective Sample	Population Assumption	ENBS Assumptions
COPE	209	Prevalence population eligible for intervention: 1,033,333 Incident population that would be eligible: 600,600	Fixed cost of an NIH funded randomized trial: $1,050,000 Cost per patient enrolled in the trial: $2,000 Willingness-to-pay: $0

COPE



Sensitivity Analysis

- One-way: no major changes to conclusions.
- Two-way: for some interventions results sensitive to effect size and number of people who participate in the intervention (ie., compliant).
- Structural: overall conclusion did not change when we modeled 12 months for tx to reach max effectiveness and effect extended 12 months after last reported follow up.

Questions

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