US Dementia Care Spending by State, 2010–2019

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BACKGROUND

- Dementia is a costly disease, leading to as much health spending as cardiovascular disease.[1]
- The cost of dementia cannot simply be characterized by direct spending as a large portion of dementia care cost is the indirect cost of informal care.[1,2]
- These indirect costs are important but also challenging to measure.
- In 2013, Hurd and colleagues[1] provided the first estimates of total societal cost attributable to dementia in the US, including the financial burden of informal care.
- Hurd and colleagues estimated the total cost of dementia in 2010 to range from $215 billion using a replacement cost valuation to $159 billion using a foregone wage valuation. Accounting for an aging population, Hurd projected that costs would reach $379 to $511 billion by 2050.[1]
- We update and expand on the informal care estimates created by Hurd by combining caregiving data from three national surveys.
- Many health care policies are set at the state level, but no study has estimated dementia costs at the state level to our knowledge. This study aims to fill this gap by estimating the cost of informal dementia care at the US state level.

METHODS

Cost

$$Cost_{LY} = prevalent\ cases_{LY} * \left(\frac{hours}{case}\right)_{LY} * \left(\frac{cost}{hour}\right)_{LY}$$

→ 1) Replacement cost

→ 2) Foregone wage

L: Location (state)
Y: Year (2010–2019)

- The number of prevalent dementia cases come from the Global Burden of Disease 2019.[3]*
- The average number of care hours per dementia case by state and year are estimated using the survey data outlined below.

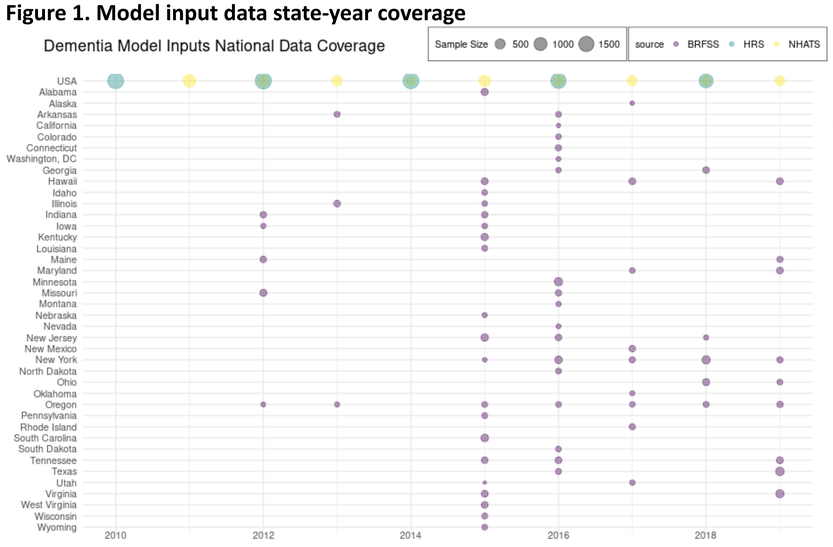
**The Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) is the most comprehensive effort to date to measure epidemiological levels and trends worldwide.*

- Cost per hour is calculated using two methods:
  1. **Replacement cost method:** cost per hour is the average cost of a home health aide
  2. **Foregone wage method**: cost per hour in this method is the expected wage based on the caregiver's age, sex, education, state, and year, scaled by the labor force participation rate for each demographic group

Caregiving data

- The Behavioral Risk Factors Surveillance System (BRFSS) survey is conducted by individual states and offers an optional caregiver module. We collected data from 68 state-years from 2012 to 2019.
- The National Health and Aging Trends Study (NHATS) is a nationally representative panel study of Medicare recipients aged 65 and older. We used NHATS rounds 1–9, representing 2011–2019.
- The Health and Retirement Study (HRS) is a nationally representative survey of US adults aged 50 and older. HRS is conducted biennially. We used all waves of HRS available from 2010 to 2018.
- The data we collected do not represent all state-year combinations from 2010 to 2019 (see Figure 1). To fill in the missing state-years, we used spatiotemporal Gaussian process regression (ST-GPR). This involves a two-step process:
  1. Caregiving hours for each state-year are predicted with linear regression
  2. Predictions are smoothed over space and time

Figure 1. Model input data state-year coverage



Forecasting

- Forecasts in Table 1 hold the per-case cost of informal care constant. Costs increase due to forecasted increase in dementia prevalence.

Attributable fraction

- Not all caregiving hours provided to a person with dementia are attributable to the dementia. We use a log-linear model of caregiving hours and comorbidities[4] to estimate the fraction of care hours attributable to dementia:

$$\log(Hours_i) = \alpha + \sum_j \beta_j I(X_j) + \epsilon$$

$$AF_j = p_j(e^{\beta_j} - 1)$$

- The following comorbidities were considered: heart disease, high blood pressure, arthritis, diabetes, lung disease, stroke, cancer, anxiety and depression.
- We found **73%** of care time is attributable to dementia.

RESULTS

Figure 2. US map of dementia care costs by state in 2019: replacement and foregone wage costs

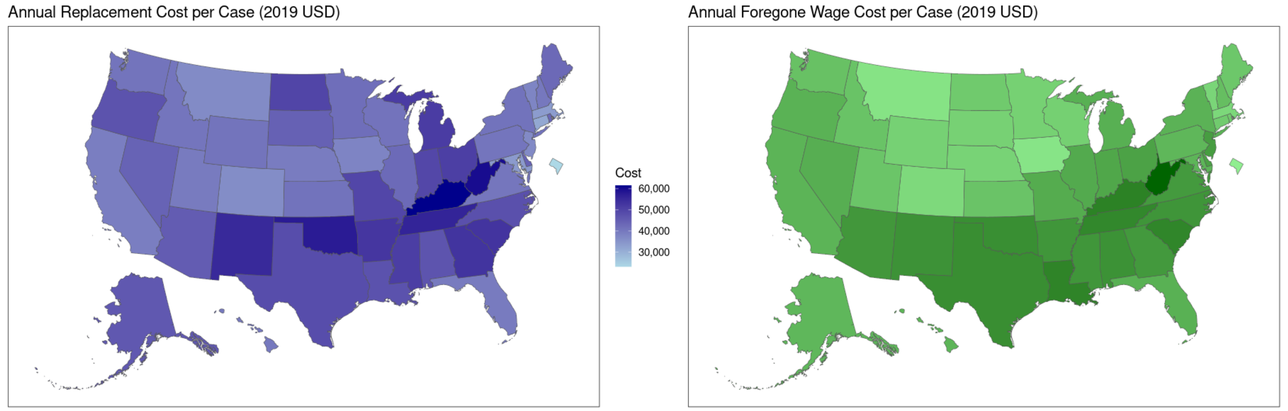


Figure 3. US dementia care costs, 2010–2019

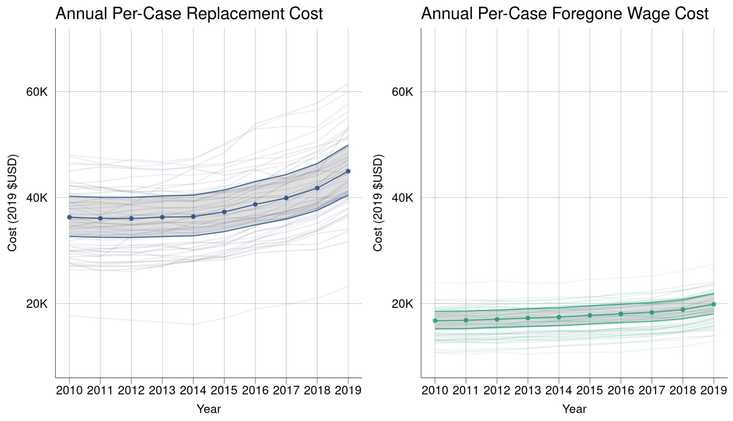


Table 1. Forecasting total costs through 2050

Cost and year	Replacement cost (95% CI)	Foregone wage (95% CI)
Total cost (billions of $)		
2019	244 (204–293)	108 (91–128)
2030	276 (228–336)	128 (107–155)
2040	358 (291–440)	166 (137–203)
2050	404 (319–505)	188 (149–233)
Total per capita cost ($)		
2019	990 (828–1,188)	438 (370–521)
2030	1,037 (858–1,262)	482 (402–581)
2040	1,303 (1,062–1,604)	605 (497–739)
2050	1,458 (1,151–1,825)	677 (539–841)

IMPLICATIONS AND CONCLUSIONS

- After adjusting for comorbidities, the national estimate for cost of informal care per patient in 2019 was $44,983 (40,475–49,933) using replacement cost and $19,889 (18,067–21,892) using foregone wages. This was an increase from the estimates by Hurd and colleagues, which were $32,456 (in 2019 dollars) for replacement cost and $15,403 for foregone wages.
- There is significant variation in cost across US states, with costs per case for the most expensive states (Kentucky and West Virginia) being more than twice as high as costs for the least expensive states (District of Columbia and Iowa). The primary driver of variation was the age profile of the state, followed by the age-standardized dementia prevalence.
- Estimates of the financial burden of dementia care will enable policymakers to allocate resources appropriately as dementia cases grow.

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