Examining the Effects of Informal versus Formal Care in Dementia Patients

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Definitions

- Dementia
- Informal Care
- Formal Care
- Health and Retirement Study (HRS)

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What is the HRS?

- Longitudinal panel study launched by the University of Michigan in 1992.
- Surveys over 20,000 Americans who are age 50 or more every two years.
- Collects information on income, work, assets, pension plans, health insurance, disability, physical health and functioning, cognitive functioning, and healthcare expenditures.

Project Overview

- Examining the effects of informal versus formal care in Alzheimer’s and Related Dementia Patients (ADRD).
    - Aim 1: Provide an expanded profile of the supply of publicly and privately financed formal care markets in order to look at all the potential avenues of care substitution between informal and formal care.
    - Aim 2: Estimate the effect of informal versus formal care on health outcomes for persons with ADRD.
    - Aim 3: Estimate the effect of informal versus formal care on health care use and costs for persons with ADRD.

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Significance

- Among community-residing American elderly with long term care (LTC) needs, more than two thirds rely exclusively on informal care and over 90% rely on some form of informal care.[1]
- Dementia costs an estimated \$157- \$215B per year in the US.[2]
- In 2021, approximately 6.2 million people age 65 or older in the US are living with dementia.[3]
- Very little is known about the implications of receiving informal care over formal care and vice versa.
- Potential to drastically impact Medicare and Medicaid expenditures and policy.

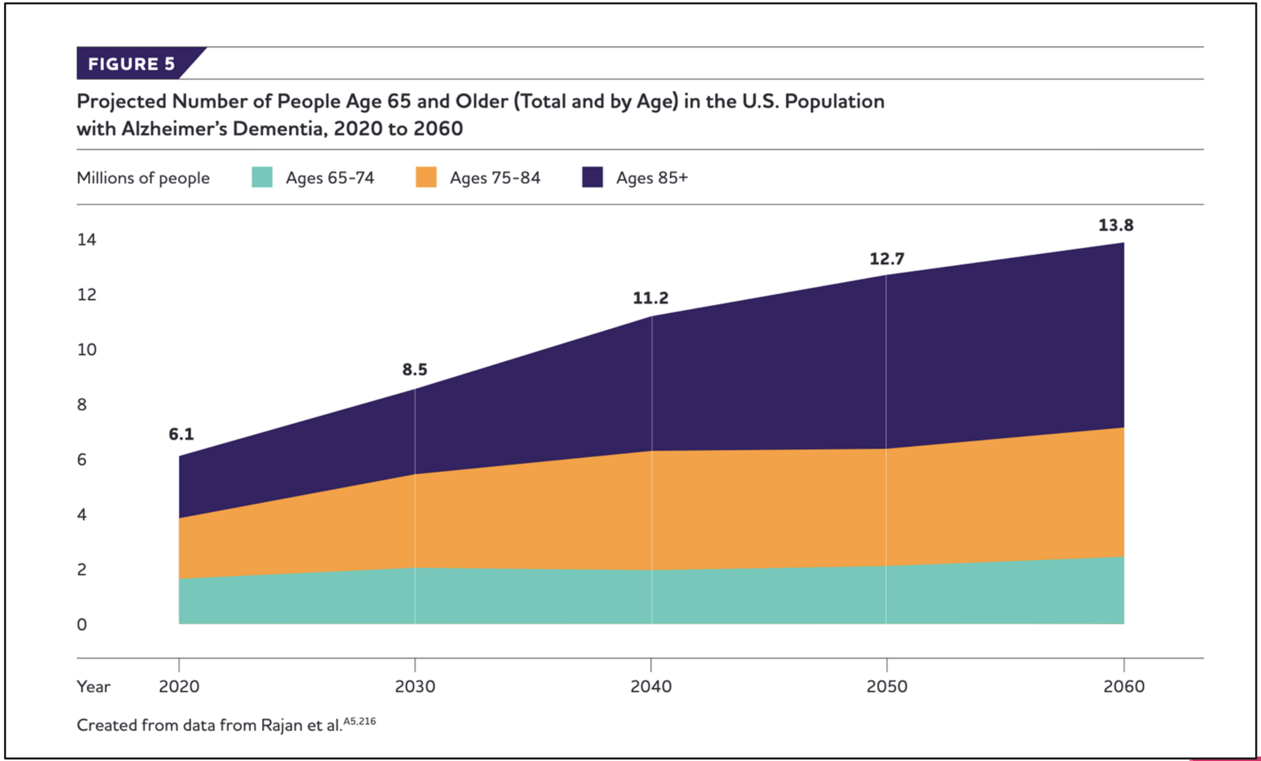


FIGURE 5

Projected Number of People Age 65 and Older (Total and by Age) in the U.S. Population with Alzheimer's Dementia, 2020 to 2060

Created from data from Rajan et al.[A5,216]

Source: Alzheimer's Association. (2021). *2021 Alzheimer's Disease Facts and Figures*.

https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Significance

- Medicare currently does not cover LTC.
- Medicaid covers LTC.
- Expensive self-pay.

Specific Aims

- Aim 2: Estimate the effect of informal versus formal care on health outcomes for persons with ADRD.
- Aim 3: Estimate the effect of informal versus formal care on health care use and costs for persons with ADRD.

Hypotheses

- H2
  - H.2.1: Physical health outcomes will be worse due to receiving informal care.
  - H.2.2: Emotional and mental health outcomes will be better due to receiving informal care.
  - H.2.3: These effects will vary by disease severity.
- H3
  - H.3.1: Informal care will lead to more preventable hospitalizations and ED visits.
  - H.3.2: Informal care will lead to lower Medicare and Medicaid costs, but higher individual financial burden.
  - H.3.3: These effects will be greater the more severe the disease

Methods

- Using the HRS (2004-2014) linked with Medicare (2004- 2012) and Medicaid (2005 - 2010) claims to run an instrumental variables estimation.
- Five main data sources:
    - HRS
    - Medicare claims
    - Medicaid claims
    - HRS Restricted geographic information
    - Market level data on public-pay, formal home care supply, and private-pay, market rate residential home care supply.

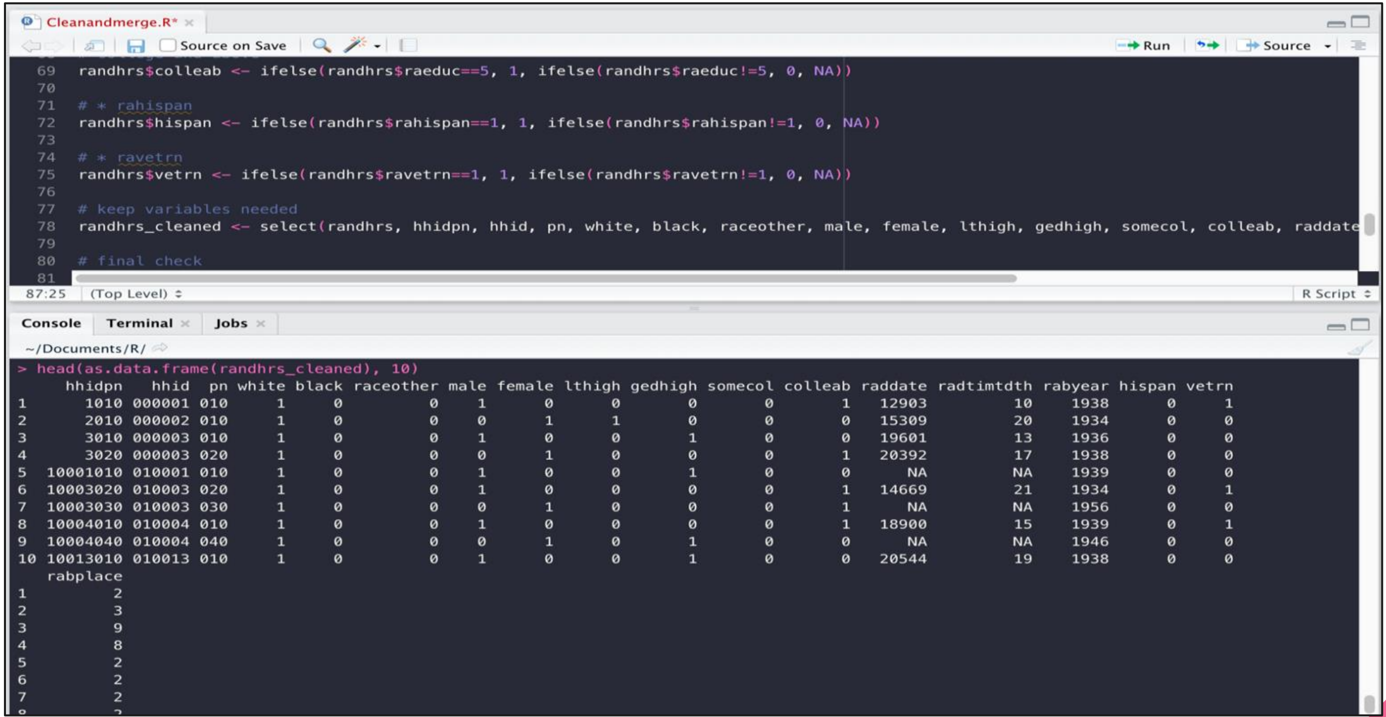
Methods continued

- Data Collection
  - Literature Reviews
    - Mostly utilizing Penn's Franklin search using MeSH terms and then filtering through relevant papers.
- Data Management
  - Downloading RAND Health and Retirement Study file into R
  - Extracted and recategorized variables of interest
  - Finalized three code files for future regression analysis

Literature Review Ex.

Title	d the Longitudinal Cost of Informal Care in the Cache County population	Closer Caregiver and Care-Recipient Relationships Predict Lower Informal Costs of Dementia Care: The Cache County Dementia Progression Study	Associations Between Informal Care Costs, Care Quality, Carer Rewards, Burden, and Subsequent Grief: The International, Access, Rights, and Empowerment Mortality Follow-Back Study of of the Last 3 Months of Life	Association of Sensory and Cognitive Impairment with Healthcare Utilization and Costs in Older Adults	Does Availability of Inform Hos
	2015	2016	2020	2019	
Authors	chwartz, C. Daniel Mullins, Chris Corcoran , Ilene H. ders, Maria C. Norton, Elizabeth B. Fauth, Jeannie- s, Constantine G. Lyketsos, JoAnn T. Tschanz	Gail B. Rattinger, Elizabeth B. Fauth, Stephanie Behrens, Chelsea Sanders, Sarah Schwartz, Maria C. Norton, Chris Corcoran, C. Daniel Mullins, Constantine G. Lyketsos, JoAnn T. Tschanz	Irene J Higginson, Deokhee Yi, Bridget M. Johnston, Karen Ryan, Regina McQuillan, Lucy Selman, Stephen Z. Pantilat, Barbara A. Daveson, R. Sean Morrison, and Charles Normand	Williams James Deardorff, Philip L. Liu, Richard Sloane, Courtney Van Houvten, Carl F. Pieper, Susan Nicole Hastings, Harvey J. Cohen, and Heather E. Watson	France M Wea
Exploits	etermine the effect of dementia severity on the iformal dementia care in this population-based ple of persons with dementia.	The purpose of this article is to extend previous findings related to the informal costs of dementia care [12,16,17] by examining whether care-related factors associated with slower disease progression (closeness, kin relationship, and problem-focused coping) also predict lower costs over time.	We aimed to determine and compare the informal care (IC) costs and their associations with self-reported caregiver burden, rewards and subsequent caregiver grief, taking account of care quality, as reported by informal carers (ICrs).	To examine how self-reported sensory impairments in the MCBS relate to healthcare utilization and cost in community-dwelling older adults with and without dementia.	
Outcome Variable		Healthcare costs of informal care	Informal care of older adults approaching their last three months of life	Healthcare Use and Costs in Older Adults with and without Dementia	He
Regression	No	Yes	Yes	Yes	
Covariates	N/A	Caregiver kin relationship (spouse, child, or other), caregiver age, caregiver sex, care-giver education, and whether or not the interviewed care-giver identified him/herself as the primary caregiver. Similarly, care-recipient factors tested as covariates included dementia severity at initial assessment as indicated by a global CDR score of mild (CDR of 0.5 or 1), moderate (CDR of 2), or severe (CDR of 3 or above); dementia dura-tion as indicated by the time interval from estimated demen-tia onset to the initial visit; age of dementia onset; education; and dementia type (AD, VaD, or other).	Age, gender, patient ' s cause of death (cancer or not), carer ' s relation-ship to patient, a religious faith of carer, carer ' s feeling about household financial status, carer ' s quality rating with care at hospital or home and informal and formal care costs. Country fixed effects were also included in the models.	Covariates included age, sex, race, annual income less than $10 000, and Medicaid insurance coverage eligibility. A variable indicating whether the participant lived alone was also included because several studies have demonstrated a relationship between living alone and healthcare utilization, albeit in different directions. 25,26 Chronic health conditions were divided into two groups: group A conditions were participants with and without dementia. 27,28 All statistical analyses were performed using SAS statistical software, ver-sion 9.0 (SAS Institute, Inc, Cary, NC). All hypothesis tests were two sided, with a signi fi cance level of P < .05.	Individual-level variables, X demographic characteristics, in regional fixed effects (i.e. can fi
Equation	N/A	No		Yes	
Abstract	tia costs are critical for influencing healthcare ongitudinal information exists. We examined care costs of dementia in a population-based sample. e Cache County Study included dementia onset, ssessed by the Mini-Mental State Examination entia Rating Scale (CDR), and Neuropsychiatric al costs of daily care (COC) was estimated based es. Mixed models estimated the relationship longitudinal COC in separate models for MMSE and CDR. and eighty-seven subjects (53% female, mean ge was 82.3 (5.9) years) participated. Overall per year. COC was 6% lower per MMSE-point d with very mild dementia, COC increased over d for moderate, and sixfold for severe dementia	**Introduction**: Identifying factors associated with lower dementia care costs is essential. We exam-ined whether two caregiver factors were associated with lower costs of informal care. **Methods**: A total of 271 care dyads of the Cache County Dementia Study were included. Estimates of informal costs were based on caregiver reports of time spent in care-related activities and inflation-adjusted 2012 Utah median hourly wages. Caregiver coping and emotional closeness with the care-recipient were assessed using the Ways of Coping Checklist–Revised and Relationship Closeness Scale, respectively. **Results**: Higher closeness was associated with 24% lower costs (exp b 5 0.763 [95% confidence in-terval: 0.583–0.999]) in linear mixed models controlling for demographics and baseline dementia severity and duration. Problem-focused coping was not associated with informal costs (P 5 .354). **Discussion**: Caregiver closeness, a potentially modifiable factor	**Background**: At the end of life, formal care costs are high. Informal care (IC) costs, and their effects on outcomes, are not known. This study aimed to determine the IC costs for older adults in the last 3 months of life, and their relationships with outcomes, adjusting for care quality. **Methods**: Mortality follow-back postal survey. Setting: Palliative care services in England (London), Ireland (Dublin) and the USA (New York, San Francisco). **Participants**: Informal carers (ICrs) of decedents who had received palliative care. Data: ICrs reported hours and activities, care quality, positive aspects and burdens of caregiving, and completed the Texas Revised Inventory of Grief (TRIG). **Analysis**: All costs (formal, informal) were calculated by multiplying reported hours of activities by country-specific costs for that activity. IC costs used country-specific shadow prices, e.g. average hourly wages and unit costs for nursing care. Multivariable logistic regression analysis explored the association of potential explanatory variables, including IC costs and care quality, on three outcomes: positive aspects and burdens of caregiving, and subsequent grief. **Results**: We received 767 completed surveys, 245 from London, 282 Dublin, 131 New York and 109 San Francisco. Most respondents were women (70%); average age was 60 years. On average, patients received 66 – 76 h per week from ICrs for ' being on call ' ,52 – 55 h for ICrs being with them, 19 – 21 h for personal care, 17 – 21 h for household tasks, 15 – 18 h for medical procedures and 7 – 10 h for appointments. Mean (SD) IC costs were as follows: USA $32,468 (28,578), England $36, 170 (31,104) and Ireland $43,760 (36,930). IC costs accounted for 58% of total (formal plus informal) costs. Higher IC costs were associated with less grief and more positive perspectiv es of caregiving. Poor home care was associated with greater caregiver burden.	**OBJECTIVES**: To examine the association between self-reported vision impairment (VI), hearing impairment (HI), and dual-sensory impairment (DSI), strati fi ed by dementia status, on hospital admissions, hospice use, and healthcare costs. DESIGN: Retrospective analysis. **SETTING**: Medicare Current Bene fi ciary Survey from 1999 to 2006. **PARTICIPANTS**: Rotating panel of community-dwelling Medicare bene fi ciaries, aged 65 years and older (N = 24 009). **MEASUREMENTS**: VI and HI were ascertained by self-report. Dementia status was determined by self-report or diagnosis codes in claims data. Primary outcomes included any inpatient admission over a 2-year period, hospice use over a 2-year period, annual Medicare fee-for-service costs, and total healthcare costs (which included information from Medicare claims data and other self-reported payments). **RESULTS**: Self-reported DSI was present in 30.2% (n = 263/871) of participants with dementia and 17.8% (n = 4112/23 138) of participants without dementia. In multivariable logistic regression models, HI, VI, or DSI was generally associated with increased odds of hospitalization and hospice use regardless of dementia status. In a general-ized linear model adjusted for demographics, annual total healthcare costs were greater for those with DSI	**Abstract:** This study assesse available at home on inpati contributions are to consider source, measured by multi examine this effect by type o support. A two-part model estimated to determine the im likelihood of hospitalisatio hospitalisation. The analysis i aged 18 1 from four waves (2004–2007). Overall, availabi likelihood of hospitalisation bu by 1.9 days. Available support 10 days), but has a significant i and longer stays. Additionall whether the source of informa other adults, or other adults changes leading to an expa households may incr

HRS File code in R



```r
randhrs$colleab <- ifelse(randhrs$raeduc==5, 1, ifelse(randhrs$raeduc!=5, 0, NA))

# * rahispan
randhrs$hispan <- ifelse(randhrs$rahispan==1, 1, ifelse(randhrs$rahispan!=1, 0, NA))

# * ravetrn
randhrs$vetrn <- ifelse(randhrs$ravetrn==1, 1, ifelse(randhrs$ravetrn!=1, 0, NA))

# keep variables needed
randhrs_cleaned <- select(randhrs, hhidpn, hhid, pn, white, black, raceother, male, female, lthigh, gedhigh, somecol, colleab, raddate

# final check

```

```
> head(as.data.frame(randhrs_cleaned), 10)
     hhidpn   hhid  pn white black raceother male female lthigh gedhigh somecol colleab raddate radtimtdth rabyear hispan vetrn
1      1010 000001 010     1     0         0    1      0      0       0       0       1   12903         10    1938      0     1
2      2010 000002 010     1     0         0    0      1      1       0       0       0   15309         20    1934      0     0
3      3010 000003 010     1     0         0    1      0      0       1       0       0   19601         13    1936      0     0
4      3020 000003 020     1     0         0    0      1      0       0       0       1   20392         17    1938      0     0
5  10001010 010001 010     1     0         0    1      0      0       1       0       0      NA         NA    1939      0     0
6  10003020 010003 020     1     0         0    1      0      0       0       0       1   14669         21    1934      0     1
7  10003030 010003 030     1     0         0    0      1      0       0       0       1      NA         NA    1956      0     0
8  10004010 010004 010     1     0         0    1      0      0       0       0       1   18900         15    1939      0     1
9  10004040 010004 040     1     0         0    0      1      0       1       0       0      NA         NA    1946      0     0
10 10013010 010013 010     1     0         0    1      0      0       1       0       0   20544         19    1938      0     0
   rabplace
1         2
2         3
3         9
4         8
5         2
6         2
7         2
```

Preliminary Findings (from Literature)

- People with higher levels of education are less likely to receive informal care.[4]
- Despite the growth in Medicare managed care enrollment, only 9 studies have reported the cost of Alzheimer disease and related dementias (ADRD) among private health plans now providing care to one-third of Medicare beneficiaries.[5]
- Increased caregiver relationship closeness (CRC) is associated with lower daily costs of informal dementia care, whereas coresidence of the caregiver with the care-recipient is associated with higher daily costs.[6]
- Informal care available at home does not impact the likelihood of hospitalisation but does significantly reduce length of stay by 1.9 days.[7]

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Implications

- Medicare policy
- Medicaid policy

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Summary/ Responsibilities

- Literature review on AIM 3
- Literature review for HRS and IRS data used to study dementia
- R Code from RAND HRS file
- Hospice Care Index 10 Indicators
- Weekly end of life care meetings

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References

1. O’Brien, E. (2005). Long-Term Care: Understanding Medicaid’s Role for the Elderly and Disabled. Kaiser Commission on Medicaid and the Uninsured.
2. Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine*, *368*(14), 1326-1334.
3. Alzheimer’s Association. (2021). *2021 Alzheimer’s Disease Facts and Figures*. https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf
4. Hu, B., & Ma, S. (2018). Receipt of informal care in the Chinese older population. *Ageing & Society*, *38*(4), 766-793.
5. Fishman, P., Coe, N. B., White, L., Crane, P. K., Park, S., Ingraham, B., & Larson, E. B. (2019). Cost of dementia in medicare managed care: A systematic literature review. *The American journal of managed care*, *25*(8), e247.
6. Rattinger, G. B., Fauth, E. B., Behrens, S., Sanders, C., Schwartz, S., Norton, M. C., ... & Tschanz, J. T. (2016). Closer caregiver and care-recipient relationships predict lower informal costs of dementia care: The Cache County Dementia Progression Study. *Alzheimer's & Dementia*, *12*(8), 917-924.
7. Weaver, F. M., & Weaver, B. A. (2014). Does availability of informal care within the household impact hospitalisation?. *Health Economics, Policy and Law*, *9*(1), 71-93.

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