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Burden of Health Care Costs for Persons with Alzheimer's Disease and Related Dementia

Adee Athiyaman¹

Abstract

What is the typical out-of-pocket spending on healthcare for individuals afflicted with Alzheimer's Disease and Related Dementia? This paper addresses this and other related questions using microdata from the Health and Retirement Study. Results of data analysis indicate that the average out-of-pocket spending is around \$2,383 per month and the patient's social security income covers less than one half of this cost.

Introduction

Healthcare costs are higher for sufferers of Alzheimer's Disease and Related Dementia (ADRD)²; in fact, ADRD is one of the costliest diseases to society³. In an earlier paper, I estimated the healthcare cost of dementia for Illinois at \$76.9billion⁴. Given that 25% of ADRD healthcare cost is out-of-pocket spending (OOP)⁵, it is essential to catalogue the type of ADRD-related out-of-pocket costs incurred by individuals. This paper is a step in that direction; it addresses questions such as:

- (i) What is the average OOP for ADRD patients?
- (ii) Does OOP vary by demographic segments, for example, sex?
- (iii) What constitutes OOP, for example, nursing home expenditures?

¹ Professor, Illinois Institute for Rural Affairs, Western Illinois University.

² Leibson, C. L., Long, K. H., Ransom, J. E., Roberts, R. O., Hass, S. L., Duhig, A. M., ... & Petersen, R. C. (2015). Direct medical costs and source of cost differences across the spectrum of cognitive decline: A population-based study. *Alzheimer's & Dementia*, 11(8), 917-932.

³ Wimo, A., Seeher, K., Cataldi, R., Cyhlarova, E., Dielemann, J.L., Frisell, O., Guerchet, M., Jönsson, L., Malaha, A.K., Nichols, E. and Pedroza, P., 2023. The worldwide costs of dementia in 2019. *Alzheimer's & Dementia*.

⁴ Athiyaman, A. (2023). Cost of Dementia in Illinois: Metro versus Nonmetro. *Research Brief*, 5(12), June 9. Available: http://www.iira.org/wp-content/uploads/2023/05/RB5_12-Cost-of-Dementia-in-Illinois-Metro-versus-Nonmtro.pdf.

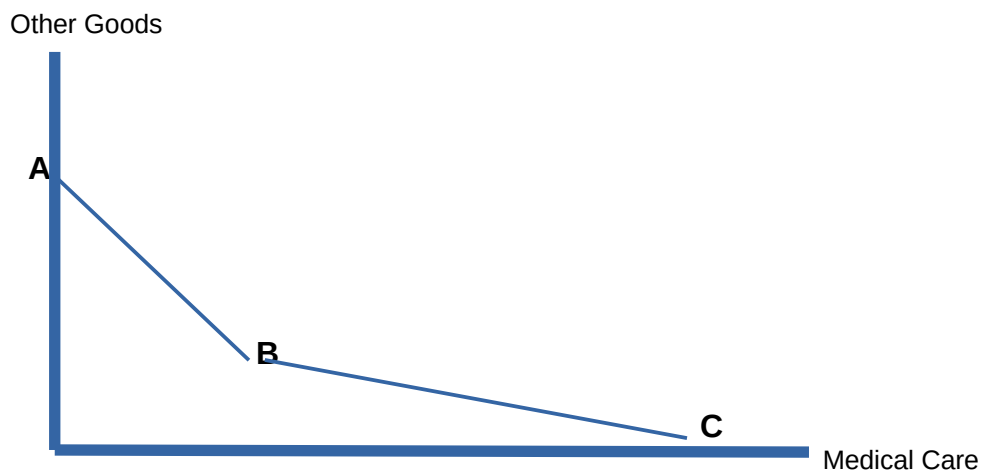
⁵ Alzheimer's Association. 2023 *Alzheimer's Disease Facts and Figures*. *Alzheimer's Dement* 2023;19(4). DOI 10.1002/alz.13016.

Concepts that Explain Medical Costs, for Both Healthy Individuals and ADRD Patients

Most health insurance plans require the patient to pay the first few hundred dollars of the annual cost of healthcare, called deductible; the insurance company pays

the rest or balance of the healthcare cost. This arrangement produces a kink in the consumer's budget line (Figure 1).

Figure 1: Budget Line Depicting Deductibles and OOP in Health Insurance



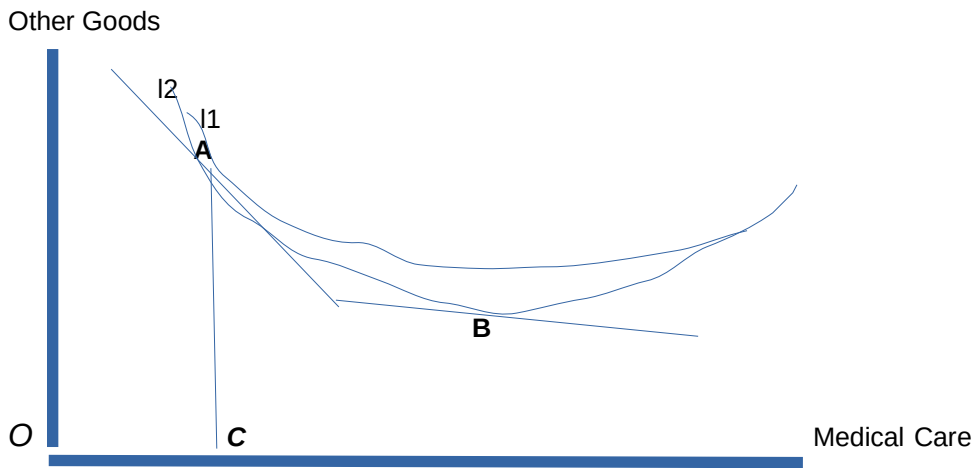
In Figure 1, the budget line is *ABC*; the point *B* is where the deductible is reached. In theory, the budget line should be horizontal from *B*, since the insurance company pays from *B*. But in reality, the patient incurs OOP costs such as transportation to the healthcare facility hence the kink in the budget line.

To deduce the consumer's equilibrium, we need indifference curves. However, the indifference curves are different for healthy and sick individuals, ADRD

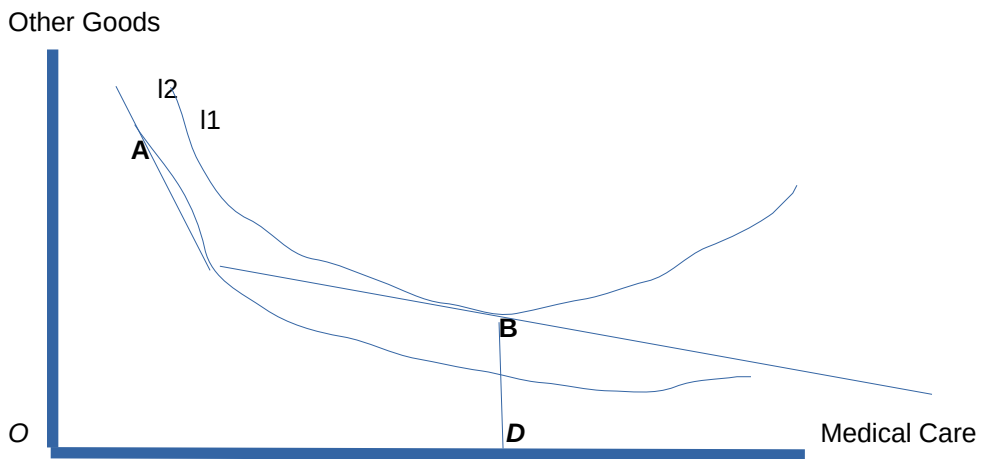
sufferers. Figure 2(a) shows indifference curves for healthy individuals. There are two points of tangency, *A* and *B*. Point *A* is on the higher indifference curve; the quantity of healthcare demanded is *OC*. In contrast, for ADRD sufferers (Figure 2(b)), the amount of healthcare demanded is much higher than the healthy individuals, *OD*. The point is, it is theoretically expected that healthcare costs including OOP will be higher for sick individuals.

Figure 2: Effects of Deductibles and OOP on Demand for Medical care

(a). Healthy Individuals



(b). ADRD Patients



Methodology

Data are from the Health and Retirement Study, 2020⁶. Respondents were from a set of seven sub-samples and comprised of people who were born between 1931 and 1965⁷; they were interviewed during March 2020 through May 2021. Data analysis were constructed using

“respondent level files”, H20A_R, H20B_R, H20C_R, H20F_R, H20G_R, H20J3_R, and H20N_R; “household level files”, H20E_H; and “pension level files”, H20J2_P. Table 1 lists the variables used in data analysis.

Table 1: Variables and their Definitions

Variable ⁸	Definition
RZ261	Respondent suffers from Alzheimer's; binary, 1 = Yes
RZ262	Respondent has dementia; binary, 1 = Yes
RZ123	Currently working; binary, 1 = Yes
RZ124	Retired; binary, 1 = Yes
RZ156	Value of main home, maximum value; ratio level measure
RZ162	Amount owed on home; ratio level measure
RZ216	Years of education; ratio measure
RZ266	Total wealth; ratio measure
RZ190	Total debt, ratio level
RZ216	Years of education; ratio measure
RX060_R	Sex of the respondent; binary, 1 = Yes
RB020	Family financial situation; rating, ordinal measure
RB028	Hispanic / Latino race; binary, 1 = Yes
RB049	Lived in rural area during school; binary, 1 = Yes
RE112	Amount of financial help from relatives; ratio measure
RN404	Monthly health insurance premiums; ratio measure
RN100	Number of overnight hospital stays; ratio
RN106	OOP amount, hospital costs; ratio
RN119	OOP amount, nursing home costs; ratio
RN139	OOP amount, outpatient surgery; ratio
RN156	OOP amount, for doctor visits; ratio
RN168	OOP amount, dental; ratio
RN180	OOP amount, prescription drugs per month; ratio
RN194	OOP amount, home health services; ratio
RN211	OOP amount, total for major medical costs; ratio

⁶ This analysis uses Early Release data from the Health and Retirement Study, 2020 HRS Final Core, sponsored by the National Institute on Aging (grant number NIA U01AG009740) and conducted by the University of Michigan. These data have not been cleaned and may contain errors that will be corrected in the Final Public Release version of the dataset.

⁷ See data description on <https://hrsdata.isr.umich.edu/data-products/2020-hrs-core>.

⁸ The variable labels are from HRS, see Health and Retirement Study, 2020 HRS Final Core public use dataset. Available, https://hrs.isr.umich.edu/sites/default/files/meta/2020/core/codebook/h20_00.html.

Data were analyzed using crosstabulations of variables; associations among variables were assessed using correlation coefficients. Differences among means, for example, annual income levels of female and male Respondents, were tested using group comparison procedures, *t* Test.

Findings

The data files contained 421 records of AD & RD patients. A typical respondent was a US-born female, 58%⁹. A majority has retired from work (61%); most of the ‘currently working’ respondents were US-born individuals (Table 2).

Table 2: Impact of Birthplace and Gender on Work Status

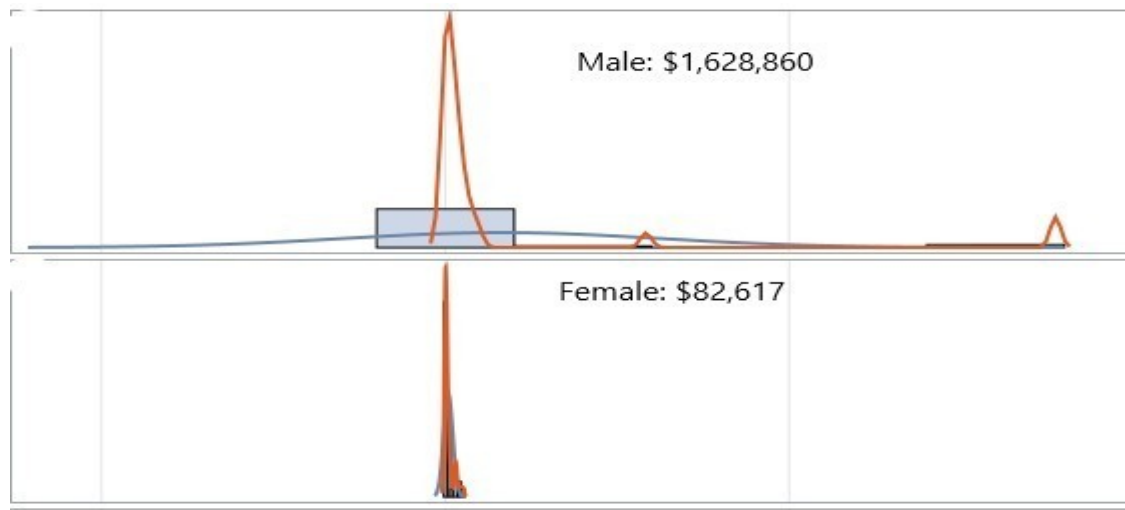
Attribute	Currently Working	χ^2	<i>p</i>
US Born	71% (n = 24)	3.2	<.1
Male	54% (n = 28)	1.57	ns

Note: ns = not significant.

Figure 3 shows the total wealth of the ADRD patients, by gender. The average wealth of a male is 20 times greater than that of a female ($t_{\text{mean difference}} = 2.24$, $p < .05$). The question is whether this difference in wealth is associated with the amount of debt that they carry; in other

words, do females have a higher debt burden than males? Data in Table 3 show that although females have a higher wealth-to-debt ratio, the average amount of debt does not differ between male and female.

Figure 3: Total Wealth by Sex



⁹ Modal values are reported; classification of respondent’s sex was based on interviewer’s observation. For more on demographics of ADRD patients, see the reference stated in footnote 4.

Table 3: Respondent's Wealth and Amount of Debt

Variable	Male	Female	Results of Statistical Tests
Amount of debt	\$3,655 ($\sigma^2 = 10,920$)	\$3,398 ($\sigma^2 = 11,600$)	$t = .19, p = ns$
Value of main home	\$228,750 ($\sigma^2 = 711,073$)	\$74,354 ($\sigma^2 = 280,157$)	$t = 2.62, p = <.05$
Total wealth	\$1,628,860 ($\sigma^2 = 4,590,802$)	\$82,617 ($\sigma^2 = 132,300$)	$t = 2.24, p = <.05$

Out-Of-Pocket (OOP) Spending

OOP spending averaged around \$57,183, for both male and female¹⁰. Outpatient surgery contributed the most to the total spending, 88%; nursing home expenses were a distant second (Table 4).

Table 4: OOP Spending, Mean Values

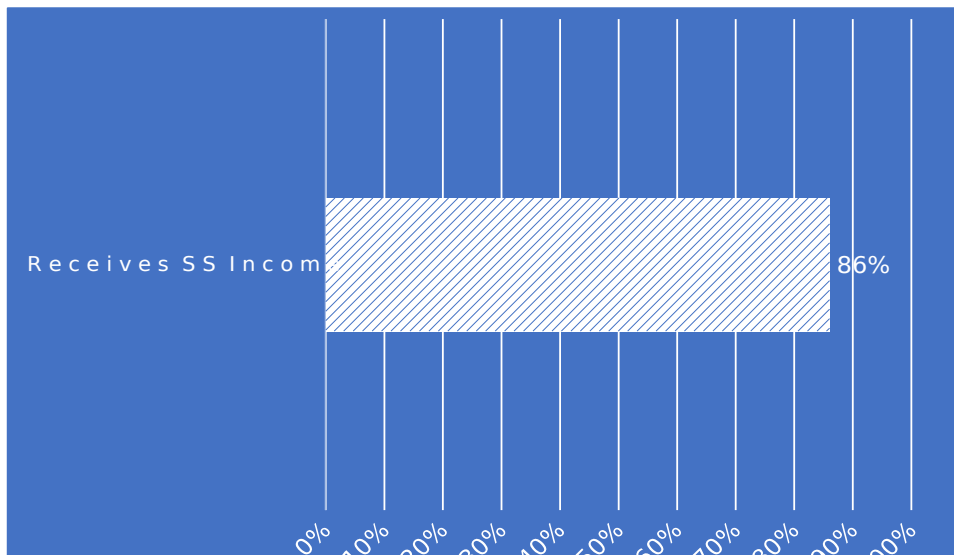
OOP Category	Mean Value	Lower 95%	Upper 95%
Nursing Home	\$2,902	\$504	\$5,301
Outpatient Surgery	\$41,701	\$17,231	\$66,170
Doctor Visits	\$267	\$226	\$309
Dental	\$597	\$374	\$820
Drugs per month	\$909	\$637	\$1181
Other Health Services	\$807	\$600	\$2214

¹⁰ The costs are for the last two years, except for drugs.

To further understand financial hardship, if any, responses to questions about social security income and financial help from relatives were analyzed. As shown in Figure 4, 86% receive social security income; its median value is \$1,200 per month. Less than one half percent of the

respondents receive financial support from relatives. Finally, 22 respondents stated that they lack health insurance and gave reasons such as, “lost coverage due to changes in employment”, 64%, and “cost is high”, 14% (Table 5).

Figure 4: Social Security Income, Proportion of Recipients and Monetary Value of the Income



Note: n = 418

Table 5: Reasons for Lack of Health Insurance

Reason	Male	Female
Lost job or changed employer	70%	58%
Cost is high	10%	17%
Lost Medicaid	20%	17%
Other	0%	8%
n	10	12

Summary and Conclusion

This paper highlights the out-of-pocket medical expenses of AD / ADRD patients using survey data from the Health and Retirement Study. A cross-sectional analysis of 421 records or responses indicates that:

- i. The average OOP spending for An AD / ADRD patient is around \$2,383 per month;
- ii. Female patients have less wealth than their male counterparts, \$82617 is the typical monetary value of wealth for females compared to \$1,628,860 for males;
- iii. Outpatient surgery costs account for the majority of the total OOP spending, and
- iv. Social security income would cover less than one half of the monthly OOP spending of an AD / ADRD patient.

The conclusion is simple: OOP spending is greater than respondents' monthly social security income, so public and private action is needed to reduce them. The National Institute of Health's initiative to develop measures of financial hardship associated with ADRD patients is a right step in this direction¹¹.

¹¹ NIH's RFA-AG-24-036.

References

- [1] Arapakis, K., Brunner, E., French, E., & McCauley, J. (2021). Dementia and disadvantage in the USA and England: population-based comparative study. *BMJ open*, *11*(10), e045186.
- [2] Aranda, M. P., Kremer, I. N., Hinton, L., Zissimopoulos, J., Whitmer, R. A., Hummel, C. H., ... & Fabius, C. (2021). Impact of dementia: Health disparities, population trends, care interventions, and economic costs. *Journal of the American Geriatrics Society*, *69*(7), 1774-1783.
- [3] A Athiyaman, A. (2023). Cost of Dementia in Illinois: Metro versus Nonmetro. *Research Brief*, *5*(12), June 9. Available: http://www.iira.org/wp-content/uploads/2023/05/RB5_12-Cost-of-Dementia-in-Illinois-Metro-versus-Nonmetro.pdf.
- [4] Favreault, M. M., & Johnson, R. W. (2021). Risks and Costs of Severe Cognitive Impairment at Older Ages: Literature Review and Projection Analyses. *Risk*, *2*, 01.
- [5] 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.
- [6] Kufenko, V., Prettnner, K., & Sousa-Poza, A. (2019). The economics of ageing and inequality: Introduction to the special issue. *The Journal of the Economics of Ageing*, *14*, 100195.