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Exploring the Other Side of Alzheimer’s Disease and Related Dementia: Informal Caregivers

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Abstract

This paper investigates metro-nonmetro differences in caregiving for sufferers of Alzheimer’s Disease and Related Dementia. Based on the reasoning that caregiving is learned vicariously, for example, through observation, differences in both observer characteristics and external reinforcement were analyzed for both the geographies. Data are from the National Health and Aging Trends Study. Data analysis suggests that a typical caregiver is a female age 50 and above with a high school education. On average, caregivers in the metro work for longer hours, 6hours per day in the metro compared to 4hours in the nonmetro.

Introduction

In an earlier *Research Brief* I documented the prevalence of Alzheimer’s Disease and Related Dementia (ADRD) in Illinois²; Table 1 shows its prevalence in the nation, by geography or metro / nonmetro, gender, race, and age; typical values are shown.

Table 1: Demographics of ADRD Sufferers, Modal Values (n = 351)

Demographic Variable	%	χ^2	p
Metro residents	79%	5.51	<.10
Female	62%	7.74	<.05
White, Non-Hispanic	62%	16.83	<.05
Age, 90+	35%	15.50	<.05

Source: National Health and Aging Study; Round 11, November 2022; see www.NHATS.org

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² 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-Non-metro.pdf.

The average annual income for this segment is \$40,700³ and a majority (69%) live in the 'community'⁴. More than one in ten get financial help from family and one in ten receive food stamps⁵. In spite of the community living status, a majority of the respondents used a proxy to respond to the NHATS survey⁶, 53%; typically, the proxies were the target respondent's son or daughter⁷.

In this paper, the focus is on the caregivers of the ADRD sufferers. Research questions that are of interest include:

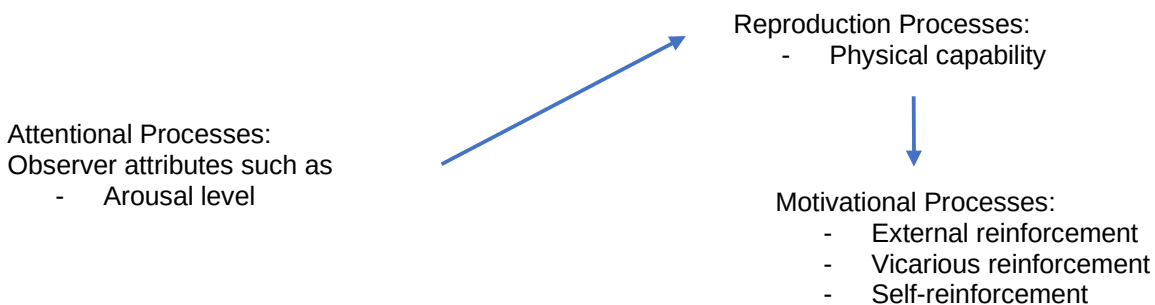
1. What proportion of ADRD sufferers have caregivers?
2. What is the demographic profile of a typical caregiver?
3. What is the average number of hours of care per day?

4. What kind of help do caregivers provide, for example, help with shopping?
5. Do caregivers get paid for their services?
6. What is the typical monthly pay for a caregiver?
7. Does caregiver pay differ between the metro and the nonmetro?

Conceptual Framework

Informal caregiving is the provision of health and care needs for a relative or friend with a chronic illness or disability⁸. It is learned vicariously, through observing or modeling another person engaged in caregiving or reading about it or viewing pictures of it. The mechanisms required for observational learning include attentional processes, reproduction processes, and motivational processes (Figure 1).

Figure 1: Processes Governing Observational Learning⁹



³ Mean values of income did not differ between the metro (Mean = \$44,357.7; SE = 21,589.5) and the nonmetro (Mean = \$26,774.3; SE = 4,537.7); $t = 0.8, p > .42$.

⁴ Community living indicates people living outside of nursing homes.

⁵ Almost 13% of the respondents receive financial help from family and 11% receive food stamps.

⁶ The survey gathers information from a nationally representative sample of Medicare beneficiaries ages 65 and older; see "Methodology" for information about NHATS.

⁷ Two to three children were typical; modal value for the number is 50%, frequency.

⁸ <https://www.hopkinsmedicine.org/health/caregiving/being-a-caregiver>.

⁹ Adapted from, Bandura, A., & Walters, R. H. (1977). *Social learning theory* (Vol. 1). Prentice Hall: Englewood cliffs.

Attention to the model stimulus is a function of observer characteristics and her arousal level; research question 2 above explores these characteristics. In addition, the arousal level of the observer is indicated by research question 3, number of hours spent on care.

The *reproduction process* shows what is to be done; typical activities of care include bathing, grooming, dressing, and eating¹⁰. Research question 4 explores these activities and the moderating role of caregiver’s physical capabilities (for example, holding a full-time job) in performing caregiving.

The role of reinforcement in caregiving involves the *motivational processes*; the an-

icipation of reinforcement is the motivational factor determining expression of behaviors learned earlier. Research questions 5-7 highlight the role of external reinforcement in caregiving.

Methodology

Data are from the National Health and Aging Trends Study (NHATS), round 11¹¹. The study population is Medicare beneficiaries ages 65 and older; the survey was first administered in 2011.

Microdata relating to 3,819 respondents or their proxies were analyzed. Table 2 shows the variables extracted to address the research questions.

Table 2: Variables and their Definitions¹²

Variable	Definition
demC1	Dementia classification; 1 = respondent has dementia; 0 = no dementia
r11dmetnonmet	Respondent resides in the metro (value = 1) or nonmetro (value = 2)
op11dage	Caregiver’s age at interview
op11dgender	Caregiver’s gender; 1 = male; 2 = female
is11prxyrelat	Proxy’s relationship to the target respondent; 2 = spouse/partner; 3 = daughter; 4 = son; 5 & 6 = daughter/son-in-law; 7 = sister; 8 = brother; 9 = friend; 10 = priest
op11ishelper	Helped with one or more activities such as bathing, laundry, shopping, etc. In all, 17 items were listed; yes = 1
op11paidhelpr	Is helper paid? 1 = yes; 2 = no
op11monthlypy	Monthly pay for the helper
op11payunit	Payment unit for helper; 1 = hourly; 2 = weekly; 3 = monthly
op11numdayswk	Number of days of help per week
op11numhrsday	Number of hours of help per day

¹⁰ See, <https://www.caringinfo.org/planning/caregiving/caregiver-duties-and-activities/>.

¹¹ Vicki A. Freedman, Jennifer A. Schrack, Maureen E. Skehan, and Judith D. Kasper. 2022. National Health and Aging Trends Study User Guide: Rounds 1-11 Final Release. Baltimore: Johns Hopkins University School of Public Health.

¹² A more comprehensive list of variables can be obtained from <https://nhats.org/researcher/nhats/methods-documentation>.

Crosstabulations of variables were used to test for independence among variables, for example, prevalence of dementia in the metro / nonmetro geographies. Group comparison procedures were used to test differences between means, for example, differences in caregiver pay between the metro and the nonmetro.

Findings

Proportion of ADRD sufferers with caregivers

One in five metro and nonmetro ADRD sufferers get help, mostly from relatives. Informal caregiving by daughters and sons is more prevalent in the nonmetro than the metro (Table 3).

Table 3: Informal versus Formal Care, Metro and Nonmetro

Caregiver	Metro	Nonmetro
Spouse / partner	3%	3%
Daughter	14%	15%
Son	11%	16%
Grand-daughter / son	11%	8%
Other relatives	3%	4%
Friend	14%	15%
Other, nonrelative	9%	9%
Paid employee / housekeeper	5%	4%
n	3,032	787

Note: Only categories $\geq 3\%$ are listed, so column will not sum to 100; $\chi^2 = 74.75$; $p \leq .05$.

Typical Caregiver

Table 4 shows the demographics of the caregivers, by metro and nonmetro. Three in five are females in both the geographies. The modal age of the caregiver is 50-59 in the metro and 60-69 in the nonmetro. One in three has a bachelor's degree or master's degree, but high school education is the typical educational level of the caregiver. A majority of the caregivers in both the geographies state their marital status as "married".

Table 4: Demographics of the Caregivers by Geography

Variable	Metro	Nonmetro	χ^2	<i>p</i>
Gender				
- Male	40%	41%		
- Female	60%	59%		
n	2,344	592	.24	ns
Age				
- < 30	LT .5%	2%		
- 30-39	2%	7%		
- 40-49	13%	12%		
- 50-59	25%	22%		
- 60-69	22%	30%		
- 70-79	23%	14%		
- 80-89	11%	11%		
- ≥ 90	5%	3%		
n	231	103	11.83	<.1
Education				
- < HS	6%	11%		
- HS diploma	35%	26%		
- Vocational education	7%	10%		
- Some college	12%	10%		
- Associate degree	8%	5%		
- Bachelor's degree	20%	23%		
- Master's degree	12%	15%		
n	826	261	19.91	<.05
Marital Status				
- Married	54%	66%		
- Living with partner	7%	5%		
- Separated	5%	2%		
- Divorced	15%	13%		
- Widowed	7%	6%		
- Never married	12%	8%		
n	770	245	12.62	<.05

Note: The term “ns” signifies that the crosstabulation is not statistically significant; the variables are independent.

Type of Care and Total Hours of Caregiving

The typical care involves preparing “hot meals”, the modal value is 12%. Other often cited caregiving tasks include help with shopping, doing laundry, and medications (Figure 2). On average, caregivers in the metro work for longer hours, 6 hours per day in the metro

compared to 4 hours in the nonmetro. Other than the number of hours of work, little or no variability exists in types of caregiving between the geographies; caregivers work for five days per week in both the regions, provide the types of care shown in Figure 2, and are paid around \$1,063 to \$1,448 per month (Table 5).

Figure 2: Types of Caregiving, Metro and Nonmetro

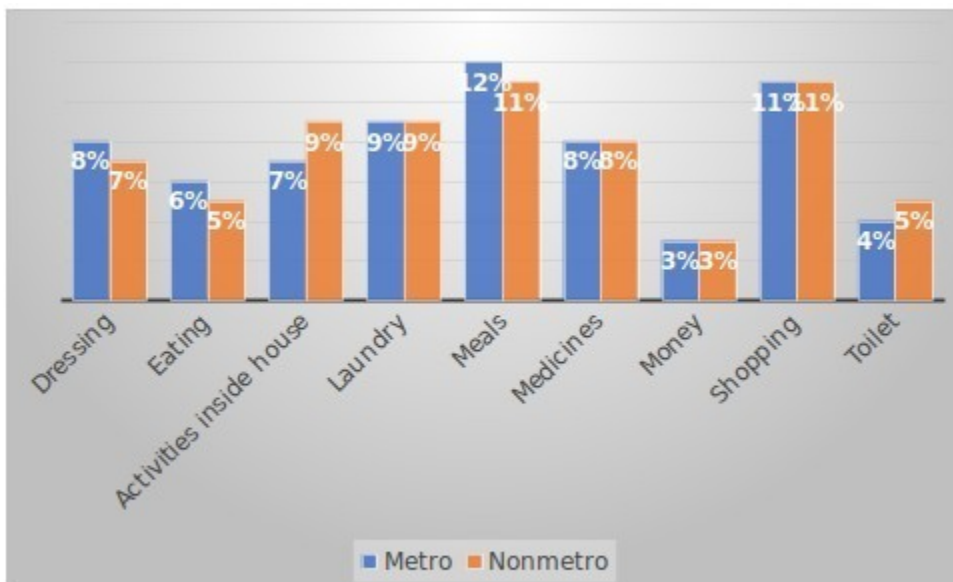


Table 5: Metro-Nonmetro Differences in Mean Values: Hours of Help Per Day, Days Per Week, and Monthly Compensation

Variable	Metro	Nonmetro	Pooled Difference	Box Plot (Metro versus Nonmetro)
Hours of help provided per day	5.51	4.10	1.40*	
Days per week	5.12	5.27	-.1488	
Monthly pay	\$1,063	\$1,448	-\$385.5	

Note: * = significant at $p < .05$ level.

Summary and Conclusion

This paper profiles metro-nonmetro differences in caregiving of ADRD sufferers or patients. Microdata on 3,819 caregivers were extracted from the National Health and Aging Trends Study, round 11. The focus was on ‘informal’ caregivers, that is, relatives and friends.

Results of data analysis reveal that:

1. One in five metro and nonmetro ADRD sufferers get help, mostly from relatives.
2. A typical caregiver is a female, age 50-59 in the metro and 60-69 in the nonmetro, with a high school education.
3. Caregivers in the metro work for longer hours, 6 hours per day in the metro compared to 4 hours in the nonmetro.
4. The typical care involves preparing “hot meals”, and
5. caregivers work for five days per week in both the metro and the nonmetro.

An ageing population places considerable demands on informal caregivers, particularly in the nonmetro. Although informal caregiver motivations were not explored in this paper, data suggest love and emotional attachments are motives for caregiving in both the geographies. Future research should explore norms and expectations around informal care.