

The Economic Burden of Dementia in India

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ONLINE APPENDIX

Section A1: Additional information on variable construction, sample selection, and statistical models

Out-of-pocket medical spending

The measure of out-of-pocket medical spending aggregates out-of-pocket expenditures during hospital stays lasting more than one night (including care provider's fees, surgeries, medications, tests, and transportation), out-of-pocket expenditures associated with outpatient doctor visits, and out-of-pocket expenditures on medication or health supplements¹.

Hours of informal caregiving

“Informal” caregiving is defined as assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided by a relative or an unpaid nonrelative. Participants in the LASI study who reported experiencing difficulty with any activity from a list of 6 ADLs (dressing, walking across a room, bathing, eating, getting in or out of bed, using the toilet) and 6 IADLs (shopping, making phone calls, taking medications, doing chores, managing money, getting around) were asked if they received assistance with those difficulties. Those who reported receiving assistance were asked to identify their relationship with the person who most often helped them with those difficulties (a spouse, child, relative, friend, etc.). In what follows, we refer to this person as the “primary caregiver.”

Respondents whose relationship with the primary caregiver could be established (n = 2,812) were asked additional questions regarding how many days in the previous month they had

¹ Because public health care in India is heavily subsidized by the government, the time cost of the individual accompanying the person living with dementia to doctor visits may be a more significant component of healthcare costs than the treatment itself. We constructed a measure of hours lost by carers accompanying respondents during outpatient visits and found no statistical differences by dementia status. We found that the number of work days lost by carers accompanying respondents during hospitalizations was significantly higher when the respondent had dementia. However, hospitalizations were so infrequent (0.19 yearly visits, on average, for respondents with dementia and 0.10 for respondents without dementia) that adding this component to our measure of out-of-pocket medical expenditures did not change their value meaningfully. Thus, we do not consider these costs in the analysis.

received assistance and how many hours per day. Based on this information, we constructed a measure of the yearly hours of informal care received from the primary caregiver.

The 904 respondents who indicated receiving assistance with ADLs and IADLs but whose relationship with the primary caregiver could not be established were not asked questions about the frequency with which they received assistance. We imputed the number of yearly hours of informal care from the primary caregiver based on the average hours of care received by respondents of the same gender and dementia status for whom data on hours of care was available.

Hours of care provided by caregivers other than the primary caregiver were not recorded. To account for these, we multiplied the number of hours of informal care provided by the primary caregiver by 1.61, the average number of informal carers reported by LASI respondents who received assistance with ADLs and IADLs. This adjustment is based on the assumption that all caregivers contributed a similar number of hours of care as the primary caregiver.

Valuing informal care

The most common methods to value informal care are the replacement cost and the opportunity cost method (Engel et al. 2021). The replacement cost approach assigns values for informal care hours equal to the cost of replacing informal carers with professional care services. This method cannot be feasibly implemented in the Indian context due to the absence of a formal market for home care provision in most areas. Hence, in this study, we used the opportunity cost method, which aims to capture the value of the time the caregiver sacrifices.

Most applications of the opportunity cost method use some market wage to value caregiving time. While this approach is controversial when the caregiver is retired, it is worth pointing out that informal caregiving in India is most often provided by daughters and daughters-in-law, unlike in developed countries where the spouse is the most frequent provider of informal care. As a result, Indian informal caregivers tend to be much younger than their North American and European counterparts and hence more likely to be of working age (for example, 34% percent of dementia caregivers in the US are aged 65 or older (CDC 2023), versus 12% in our sample).

Research on caregivers of people with dementia in India has identified lost work income as the main financial cost for caregivers, as primary caregivers often become unable to supplement the family income through occasional casual work (Shaji et al. 2003, ARDSI 2010). Therefore, we use the wages of casual laborers to value informal caregiving hours.

Rural wages for casual workers were obtained from the LASI community survey, which asked village representatives about the minimum daily wages for casual female and male workers in their villages. The LASI community survey did not collect data on casual worker wages in urban areas. We were unable to locate a data source for urban wages at the city or town level. Therefore, we used state-level average wages of urban male and female casual workers from the

Periodic Labour Force Survey (PLFS). Like the Current Population Survey in the US, the PLFS is India's primary source of labor force statistics.

To verify the compatibility of the two data sources for wage data, we calculated the state-level average wage for rural male and female casual workers in LASI and compared them to the state-level figures reported by the PLFS. In states with more than 1,000 rural observations in LASI, the correlation between LASI and PLFS state-level wages was 0.97 for male workers and 0.86 for female workers. The correlations were lower in states with fewer than 1,000 rural observations in LASI (0.74 for males and 0.73 for females), with the largest discrepancies occurring in mostly urban states such as Delhi, which had only 3 rural male and 5 rural female observations.

We performed an additional robustness check where we used state-level wages from the PLFS to value informal care hours in both rural and urban areas, and the results were very similar to those reported in the paper.

Because we don't observe the gender of non-primary informal caregivers, we valued hours of informal care using a composite wage figure that reflects the gender composition of the sample of primary informal caregivers (69% female).

Sample selection

The LASI sample consists of 31,477 observations of individuals aged 60 and older. To construct the empirical sample, we excluded individuals with missing values for any of the variables used in the analysis, including demographics (7 cases), caste status (224), information on chronic condition diagnoses (136), and out-of-pocket costs (45). After excluding these observations, representing 1.3% of the initial sample, the analytical sample contained 31,065 observations.

Statistical analysis

In the empirical analysis, we estimated both unadjusted models and adjusted models. The former are regressions of the outcome variables on only the dementia indicator. The adjusted models are regressions of the outcome variables on the dementia indicator and controls for demographics (age, marital status, and education indicators), socioeconomic status (caste and rural/urban indicators), comorbid chronic conditions (indicators for existing diagnoses of high blood pressure, diabetes, cancer, lung disease, heart problem, stroke, arthritis, psychological disorder, and high cholesterol), and state fixed effects.

In the analysis, we relied on 20 multiple imputations of dementia status. The coefficients and standard errors reported in the empirical analysis were obtained using standard methods for handling multiple imputations using the **mi estimate** command in Stata 18.

Section A2: Full empirical results

Table A1: Hours of Informal Care

	Unadjusted		Adjusted	
	Coeff.	Std. error	Coeff.	Std. error
Dementia	444.92***	(64.79)	334.51***	(62.53)
Female			-16.35	(14.72)
Age 65-69			21.64	(15.96)
Age 70-74			32.56	(17.92)
Age 75-79			125.47***	(26.87)
Age 80-84			214.97***	(36.48)
Age 85+			394.82***	(45.24)
Divorced/never married			34.97	(56.98)
Widowed			11.25	(16.23)
Secondary education			-22.80	(17.60)
Tertiary education			3.95	(43.86)
Scheduled caste			46.97*	(23.70)
Scheduled tribe			-7.31	(24.57)
Other Backward Class			-6.92	(16.10)
Rural village			4.22	(16.00)
High blood pressure			35.87*	(16.98)
Diabetes			53.89*	(24.03)
Cancer			148.46	(102.55)
Lung disease			81.11	(47.82)
Heart problem			79.59	(46.03)
Stroke			719.43***	(96.95)
Arthritis			35.41	(19.82)
Psychological disorder			478.17**	(156.48)
High cholesterol			-23.88	(36.66)
State fixed effects			✓	
Observations	31,065		31,065	

All models include a constant. Observations were weighted using person-level sample weights. Regression results adjust for multiple imputations of dementia status. Standard errors clustered at the household level. ***, **, and * indicate significance at the 1 percent, 5 percent, and 10 percent level, respectively.

Table A2: Cost of Informal Care

	Unadjusted		Adjusted	
	Coeff.	Std. error	Coeff.	Std. error
Dementia	703.25***	(112.10)	517.63***	(108.51)
Female			-22.90	(24.71)
Age 65-69			50.43*	(24.68)
Age 70-74			44.94	(25.80)
Age 75-79			207.35***	(46.14)
Age 80-84			338.84***	(55.02)
Age 85+			648.92***	(80.88)
Divorced/never married			73.41	(104.04)
Widowed			16.68	(29.48)
Secondary education			-56.31*	(28.12)
Tertiary education			-16.12	(71.60)
Scheduled caste			74.99*	(36.58)
Scheduled tribe			3.27	(50.34)
Other Backward Class			-6.40	(27.36)
Rural village			-56.94*	(27.89)
High blood pressure			47.11	(27.41)
Diabetes			89.33*	(38.96)
Cancer			233.34	(179.01)
Lung disease			148.40	(79.60)
Heart problem			110.86	(65.13)
Stroke			155.34***	(176.94)
Arthritis			43.13	(30.82)
Psychological disorder			686.41**	(223.75)
High cholesterol			36.53	(92.41)
State fixed effects			✓	
Observations	31,065		31,065	

All models include a constant. Observations were weighted using person-level sample weights. Regression results adjust for multiple imputations of dementia status. Standard errors clustered at the household level. ***, **, and * indicate significance at the 1 percent, 5 percent, and 10 percent level, respectively.

Table A3: Out-of-pocket Spending

	Unadjusted		Adjusted	
	Coeff.	Std. error	Coeff.	Std. error
Dementia	11.19	(48.27)	53.79	(49.53)
Female			10.71	(31.98)
Age 65-69			-30.89	(32.83)
Age 70-74			11.85	(39.14)
Age 75-79			16.26	(36.10)
Age 80-84			-1.84	(48.10)
Age 85+			33.88	(73.11)
Divorced/never married			-156.57***	(30.00)
Widowed			-105.38***	(23.23)
Secondary education			124.94**	(46.26)
Tertiary education			276.96	(147.54)
Scheduled caste			-107.23**	(33.10)
Scheduled tribe			-170.47***	(37.46)
Other Backward Class			-105.41**	(40.25)
Rural village			-50.76	(28.08)
High blood pressure			83.54**	(30.60)
Diabetes			266.98***	(64.02)
Cancer			283.47*** ¹	(318.44)
Lung disease			220.70**	(80.16)
Heart problem			748.66***	(127.59)
Stroke			592.66***	(180.08)
Arthritis			85.46**	(31.15)
Psychological disorder			124.37	(95.74)
High cholesterol			213.01	(121.19)
State fixed effects			✓	
Observations	31,065		31,065	

All models include a constant. Observations were weighted using person-level sample weights. Regression results adjust for multiple imputations of dementia status. Standard errors clustered at the household level. ***, **, and * indicate significance at the 1 percent, 5 percent, and 10 percent level, respectively.

Table A4: Total Household Cost

	Unadjusted		Adjusted	
	Coeff.	Std. error	Coeff.	Std. error
Dementia	714.44***	(129.71)	571.43***	(121.39)
Female			-12.20	(45.50)
Age 65-69			19.53	(44.21)
Age 70-74			56.79	(48.93)
Age 75-79			223.61***	(60.72)
Age 80-84			336.99***	(74.73)
Age 85+			682.79***	(109.73)
Divorced/never married			-83.16	(112.24)
Widowed			-88.69*	(39.35)
Secondary education			68.63	(55.69)
Tertiary education			260.84	(195.70)
Scheduled caste			-32.24	(50.50)
Scheduled tribe			-167.20**	(63.89)
Other Backward Class			-111.81*	(50.77)
Rural village			-107.70**	(40.73)
High blood pressure			130.64**	(43.89)
Diabetes			356.31***	(77.66)
Cancer			516.81*** ¹	(376.45)
Lung disease			369.10**	(114.21)
Heart problem			859.52***	(149.30)
Stroke			748.00*** ¹	(289.41)
Arthritis			128.59**	(45.29)
Psychological disorder			810.78**	(261.08)
High cholesterol			249.54	(154.11)
State fixed effects			✓	
Observations	31,065		31,065	

All models include a constant. Observations were weighted using person-level sample weights. Regression results adjust for multiple imputations of dementia status. Standard errors clustered at the household level. ***, **, and * indicate significance at the 1 percent, 5 percent, and 10 percent level, respectively.

References not included in the main paper

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