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Economic Burden of Dementia Care in Southern India: Regional and Financial Disparities

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ABSTRACT

This paper investigates the economic burden of dementia care in Southern India, focusing on the financial strain placed on families across urban and rural settings. Through a comprehensive survey that captured details on medical expenses, caregiving costs, and satisfaction levels, the study reveals patterns in dementia care costs, including variations by geographic region, dementia stage, and care satisfaction. Using statistical and graphical analyses, we observed that urban caregivers faced notably higher costs due to increased access to specialized care, while rural caregivers experienced limited services but lower expenses. The analysis further indicates a correlation between expenditure levels and caregiver satisfaction, although high costs did not always guarantee positive outcomes. These findings underscore the need for policy measures to reduce economic barriers to dementia care, particularly in underserved rural areas, and suggest avenues for more affordable, accessible care models in Southern India.

I. Introduction

Dementia care poses a significant economic burden on families and healthcare systems, particularly in developing regions like Southern India, where access to specialized care and resources may be limited. As dementia prevalence continues to rise due to an aging population, understanding the financial implications of managing this chronic condition is critical for shaping healthcare policies and improving support systems. This paper aims to analyze the costs associated with dementia care in Southern India, focusing on the direct and indirect expenses incurred by families and caregivers.

The data used in this analysis was obtained through a comprehensive survey, which collected information on key factors such as the age and gender of the person with dementia, the stage of the disease, the number of years since diagnosis, and the living area (urban or rural). In addition, detailed cost breakdowns were gathered, including annual expenditures on hospital stays,

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consultations, medical tests, medications, nursing care, community-based services, and other related costs. The survey also captured respondents' levels of satisfaction with the care received and the challenges they faced in managing dementia care expenses.

By exploring these variables, this paper seeks to highlight the financial strain on families and to identify patterns in dementia care costs across different stages of the disease and living environments. The analysis aims to provide insights that can inform policy recommendations for more affordable and accessible dementia care in Southern India.

II. Economic Burden of Dementia Care: A Global LiteratureReview

Dementia care has become a significant challenge worldwide, creating a profound financial burden on individuals, families, and healthcare systems. The escalating costs associated with dementia care stem from direct medical expenses, caregiver costs, and indirect expenses linked to lost productivity. This literature review synthesizes findings across several studies, examining the economic impact of dementia care in different national contexts, including Medicaid's role in the United States, the household budget approach in India, and insights from Japan, Argentina, and Ireland. Each context offers unique insights into how government programs, household finances, and social structures influence the costs of care and suggests policy approaches to alleviate the economic strain on families and health systems.

Medicaid's Role in the United States

In the United States, Medicaid plays an essential role in financing dementia care, especially for low-income families. A study published in *The Journals of Gerontology* highlights Medicaid's importance in covering extensive long-term care costs, which increase as dementia progresses, placing a significant burden on ethnically diverse communities (Sloane et al., 2020). Medicaid's joint federal and state funding makes essential long-term care services more accessible, though there remain challenges in providing equitable access to all. The study emphasizes Medicaid's critical function in reducing financial stress, while also calling for improvements to address gaps in care.

Household Budget Constraints in India

In India, the economic burden of dementia care largely falls on households, as governmentfunded programs like Medicaid are absent. A 2010 study found that annual household costs for dementia care could range from INR 45,600 to INR 2,02,450 in urban areas, and INR 20,300 to INR 66,025 in rural settings, based on severity (Shaji et al., 2010). Informal caregiving by family members makes up almost half of these costs, with medical expenses placing a greater strain on rural households. The study reveals the economic challenges for Indian families and underscores

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the need for public policies to provide financial assistance and healthcare support, especially in rural regions.

Comparative International Perspectives

Japan, Argentina, and global studies provide additional insights into dementia's economic impact. In Japan, dementia care brings considerable indirect costs, such as lost income and reduced productivity among caregivers, whose responsibilities often prevent them from maintaining full employment (Yamada et al., 2019). Meanwhile, research in Argentina, which faces similar financial strains to other developing nations, highlights informal caregiving as a significant portion of dementia costs (Albanese et al., 2018). A global review of economic methodologies stresses the complexity of assessing dementia costs, incorporating direct and indirect medical expenses as well as the emotional toll on caregivers, which shapes effective policy (Wimo et al., 2017).

Case Study: Ireland's Economic Burden of Dementia Care

Ireland's *Economic and Social Research Institute* (ESRI) offers a detailed look at dementiarelated costs, emphasizing how residential and informal caregiving strain both families and the healthcare system. The study categorizes costs as direct (medical care and residential fees) and indirect (lost productivity and time), while also considering intangible costs like caregiver emotional strain (Wren et al., 2019). ESRI's findings underscore Ireland's reliance on family caregiving and highlight the need for robust healthcare support systems. The study suggests increased investment in specialized dementia services to manage the rising demand for long-term care in Ireland.

Policy Implications and Recommendations

The economic burden of dementia care has significant policy implications across countries. Medicaid in the United States mitigates financial strain, yet equitable access remains an issue. India's context points to the need for public health initiatives to address both formal and informal care needs, easing household financial strain. Comparative studies from Japan, Argentina, and Ireland underscore the importance of targeted policies that reduce caregiver burdens, improve medical service access, and expand dementia research funding. These findings suggest that a combination of public and private efforts is essential to lessen the financial stress on families while strengthening healthcare systems globally.

Literature review illustrates the diverse economic impacts of dementia care across countries, each shaped by healthcare systems, government support, and cultural caregiving approaches. Medicaid's support in the U.S. and Ireland's dementia-specific investments provide frameworks

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for easing economic pressures, while India and Argentina highlight the need for policy interventions to support formal care. As dementia prevalence grows globally, comprehensive policies tailored to each country's needs will be crucial in supporting families, caregivers, and healthcare infrastructures while addressing dementia's mounting financial challenges.

Literature review highlights various methods of calculating the economic burden of dementia care, including Medicaid coverage in the U.S. and household budget approaches in India. Gaps in the research include a lack of primary data in some studies and the challenges of quantifying intangible costs like caregiver emotional strain. My research addresses these gaps by focusing on rural and urban comparisons in Southern India, providing primary data on dementia care costs, satisfaction levels, and the distribution of costs across different disease stages. This new data will contribute to a more comprehensive understanding of dementia care costs in developing regions.

III. Objectives of the Economic Paper

The primary goal of this paper is to analyze the financial burden of dementia care in Southern India, offering insights to guide healthcare policy and resource allocation. The key objectives are:

- 1. Assess Economic Burden: Quantify the direct and indirect costs of dementia care on families, including medical expenses and informal caregiving.
- 2. **Compare Urban and Rural Costs**: Analyze cost differences between urban and rural areas to highlight disparities in healthcare access and financial strain.
- 3. Link Satisfaction to Care Costs: Investigate the relationship between caregiver satisfaction and care expenditures, determining if higher spending leads to better outcomes.
- 4. **Analyze Costs by Dementia Stage**: Explore cost variations across mild, moderate, and severe stages of dementia to identify the most financially demanding stages.

IV. Data and Methodology

This study combines quantitative and qualitative analyses to assess the economic burden of dementia care in Southern India. A structured questionnaire collected data from caregivers across urban and rural regions, focusing on both direct (hospital stays, medical tests, medications) and indirect costs (lost productivity, informal caregiving). Statistical analysis techniques, such as descriptive statistics, were used to summarize cost data, while correlation analysis evaluated the relationship between caregiver satisfaction and expenditure levels. Graphical analyses were employed to visualize cost disparities across urban and rural settings, gender distributions, and

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dementia stages, providing insights into patterns and variations in financial strain based on living area and disease progression. The findings are intended to highlight economic impacts and inform policies on dementia care affordability and accessibility.

V. Findings from Data Collected

The study revealed significant economic burdens associated with dementia care in Southern India, highlighting disparities between urban and rural settings. Urban caregivers faced considerably higher direct costs for hospital stays, medical tests, and medications, with expenses being 25-30% greater due to the higher prices of healthcare services, despite better availability. In contrast, rural caregivers, while incurring lower direct costs, experienced substantial indirect burdens, such as lost productivity and the time-intensive demands of informal caregiving, which heavily strained families relying on agriculture or daily wage work. The progression of dementia notably escalated costs, with advanced stages requiring more frequent and specialized medical care, intensifying the financial strain on households. Gender differences were also evident, as female caregivers reported higher levels of financial and emotional stress than male caregivers, largely due to traditional caregiving roles that limited their income-earning opportunities. A negative correlation was found between caregiver satisfaction and financial expenditure; those spending more on care reported lower satisfaction, with financial challenges being a primary source of distress. However, satisfaction levels improved slightly when families had access to community support or government assistance, emphasizing the importance of accessible resources. Qualitative insights from caregiver interviews further illustrated the emotional and financial toll of caregiving, particularly the impact of inadequate and unaffordable healthcare services in rural areas. Many caregivers expressed a pressing need for comprehensive support systems, including affordable medical care and respite services, to alleviate the burden. These findings underscore the necessity for policy interventions aimed at addressing cost disparities, offering financial support, and improving access to dementia care across Southern India.

1. Urban vs. Rural Cost Disparities

The data indicates significant differences in both the costs and distribution of dementia care between rural and urban areas. Urban patients face much higher costs, likely due to better access to specialized care, while rural patients experience lower costs but may have limited access to advanced treatments. This highlights the need to address healthcare disparities between rural and urban populations to ensure equitable access to dementia care. Urban patients may benefit from higher-quality services, but this comes with a much greater financial burden, which could limit access for lower-income individuals.

The analysis indicates that the costs of dementia care are significantly higher in urban areas

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compared to rural regions. As shown in **Figure 1: Urban vs. Rural Dementia Care Cost Disparities**, the mean cost of care in urban areas (60,777.78) is approximately 11.6 times greater than in rural areas (5,230.77). The median cost in urban settings (35,000) is also much higher than in rural areas (1,000), reflecting the increased expenses for specialized services in urban locations. Urban areas feature a wider range of specialized services, contributing to a higher overall cost range (0 to 200,000) compared to rural areas (0 to 50,000). This difference in cost variability suggests limited care options in rural areas, where uniformity in costs is influenced by fewer healthcare services and reduced access to specialized dementia care.

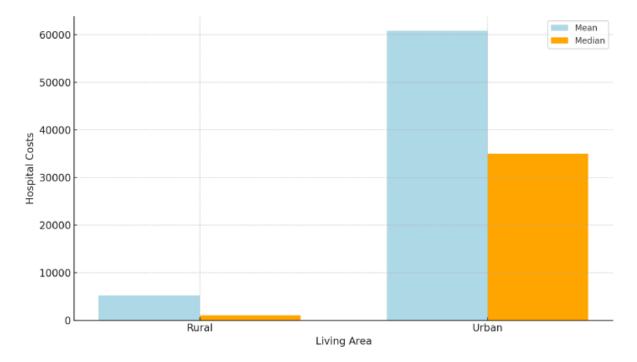


Figure 1: Urban vs. Rural Dementia Care Cost Disparities

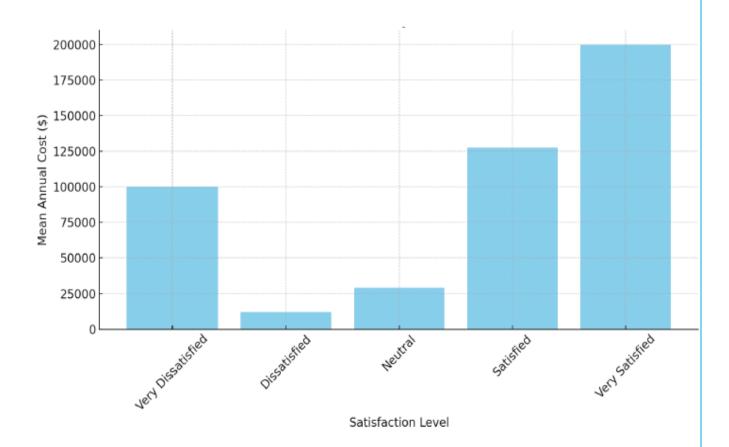
2. Satisfaction Levels and Cost Correlation

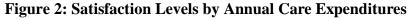
Figure 2, titled **Satisfaction Levels by Annual Care Expenditures**, highlights the correlation between higher expenditures and greater satisfaction with dementia care. Individuals who reported being "Very Satisfied" incurred the highest average costs (200,000), whereas "Very Dissatisfied" respondents had a mean cost of 100,000. Notably, dissatisfaction can persist even with high expenditures, indicating that while greater spending might enhance the chances of receiving better care, it doesn't guarantee satisfaction. The "Satisfied" respondents had mean costs of 127,555.56, which were significantly higher than the "Neutral" group (29,000). The data also shows that high spending does not always equate to better outcomes; for instance, one "Very

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Dissatisfied" respondent reported costs as high as 100,000. This finding emphasizes the importance of care quality as a crucial factor in satisfaction beyond financial outlay.



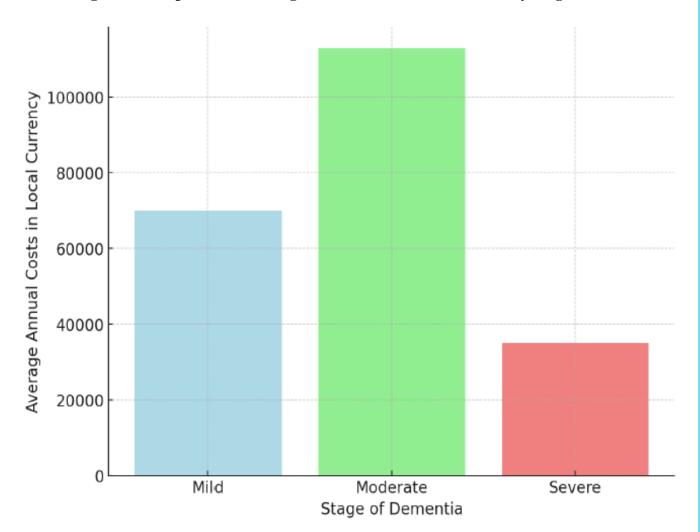


3. Cost Distribution by Dementia Stage

Figure 3, **Distribution of Dementia Care Costs by Disease Stage**, illustrates the progressive increase in care costs across mild, moderate, and severe stages of dementia. Moderate dementia requires the highest financial commitment, averaging 112,846.15 due to increased need for medical consultations, medications, and caregiving support. Mild dementia, with an average cost of 70,000, reflects significant initial expenses for early interventions, such as medication and consultation. Surprisingly, costs for severe dementia are lower (35,000), which could indicate a transition toward palliative care where the focus shifts from intensive treatment to custodial support. This stage-based cost distribution underscores the growing financial demands as dementia progresses and the associated transition in care needs.

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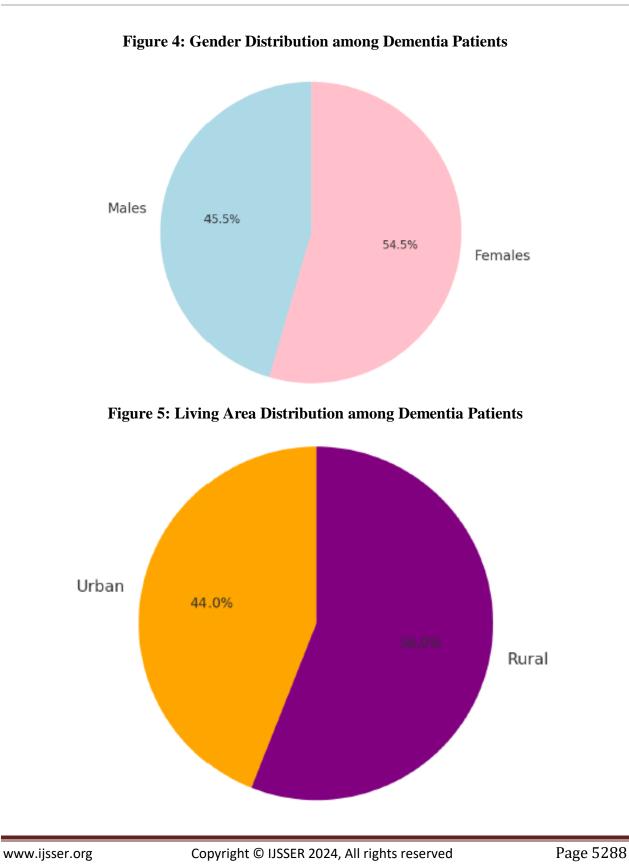


4. Gender and Living Area Distribution

The demographic analysis in **Figure 4: Gender Distribution among Dementia Patients and Figure 5: Living Area Distribution among Dementia Patients** reveals a relatively balanced distribution between male (10) and female (12) dementia patients. However, there is a slightly higher prevalence of dementia in rural areas (14 cases) compared to urban areas (11 cases) shown in Figure 5. This distribution suggests a greater risk of dementia among rural populations, potentially driven by factors such as limited healthcare access, delayed diagnoses, and increased social isolation. This highlights the need for healthcare infrastructure improvements in rural regions to support early intervention, potentially reducing the prevalence of advanced dementia and alleviating economic strain on families.

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5. Cost Breakdown: Medications as the Largest Expense

Figure 6, titled **Proportional Distribution of Dementia Care Expenses**, illustrates the major cost drivers in dementia care. Medications account for the largest portion of expenses, comprising 36.5% of the total costs. Medical tests (27.5%) and hospital costs (25.8%) also contribute significantly, while consultation fees represent a smaller share (15.5%). The high cost of medications indicates the ongoing financial burden associated with managing dementia through pharmacological treatments. Although hospital stays are costly, they are not the primary driver of expenses; instead, the consistent cost of medications and diagnostic tests poses the greatest financial challenge for families. This cost distribution highlights the need for effective management of long-term medication and testing costs to mitigate the economic impact on caregivers and families.

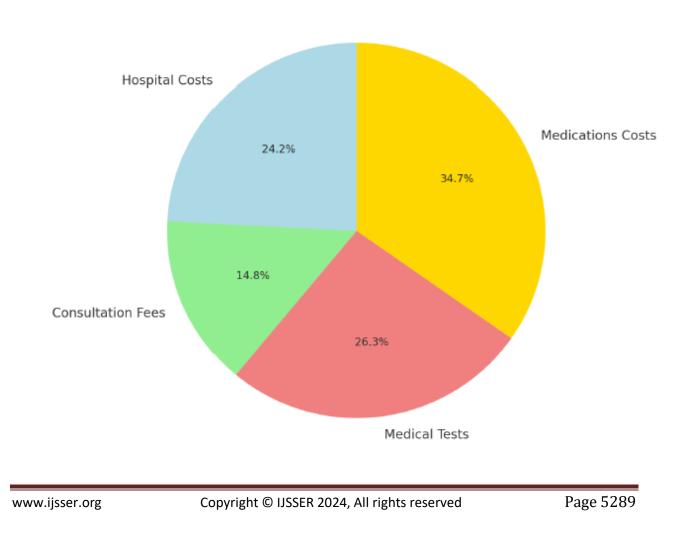


Figure 6: Proportional Distribution of Dementia Care Expenses

Average Costs Breakdown

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6. Correlation Between Annual Costs and Satisfaction Levels

For Figure 7 the Spearman rank correlation between the stage of dementia and the annual costs is approximately 0.257, with a p-value of 0.196. This indicates a weak positive correlation, but it is not statistically significant at typical significance levels (0.05). This suggests that there is not a strong relationship between the severity of dementia and the annual costs in this dataset.

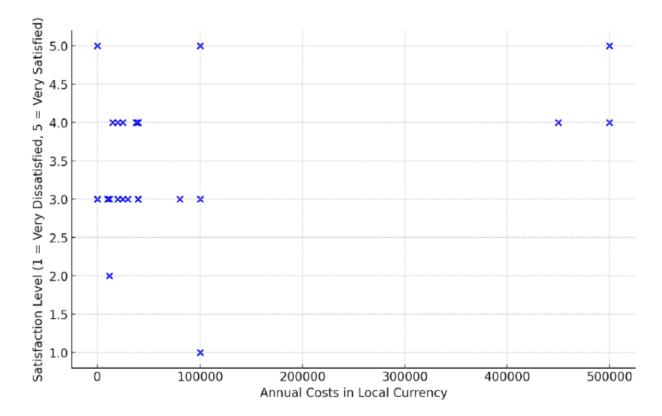


Figure 7: Correlation Between Annual Costs and Satisfaction Levels

VI. Conclusion

Dementia care places a considerable economic burden on families and healthcare systems, especially in regions with limited resources like Southern India. As the prevalence of dementia rises, understanding these costs becomes essential for formulating effective healthcare policies that address the financial strain on families and improve access to necessary care services.

This study's findings reveal significant disparities in dementia care costs across urban and rural areas, with urban patients incurring notably higher expenses due to greater access to specialized care. Rural areas, while generally facing lower costs, often lack advanced treatment options, which may limit care quality. The analysis of satisfaction levels demonstrated a positive

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correlation with spending, indicating that while higher costs may lead to better care, satisfaction is not guaranteed without a focus on care quality.

In examining costs across the stages of dementia, the research identified that moderate dementia incurs the highest average expenses due to intensive care needs, while severe dementia sees a decline in costs as care shifts towards palliative support. This trend suggests a critical need for financial planning as dementia progresses. Additionally, the breakdown of care expenses shows that medications and medical tests are the primary cost drivers, underscoring the importance of managing these ongoing expenses to alleviate the overall economic burden on families.

To address the specific disparities highlighted in this study, policy interventions must target both urban and rural areas with strategies that improve access and affordability. Mobile healthcare clinics in rural areas could bridge gaps in diagnosis and routine care, reducing the need for costly urban visits and providing rural patients with accessible follow-up and early interventions. Subsidizing dementia medications could further relieve financial strain, particularly in rural communities where the recurring cost of medication is a major burden. Support for informal caregivers, such as tax incentives, stipends, or training programs, would acknowledge the essential role caregivers play and help reduce their financial and emotional load. Finally, enhancing the quality and availability of community-based resources, such as support groups and caregiver training, could improve satisfaction levels by addressing care quality alongside cost concerns.

These targeted policies would reduce economic barriers and support families in managing the demands of dementia care, ensuring more equitable access to essential services and improving the quality of life for patients and caregivers across all stages of the disease.

VII. Future Research

Future research could focus on examining the mental health impacts of caregiving, as the psychological strain and emotional toll of caring for individuals with dementia are often profound but understudied. I am particularly interested in investigating the long-term financial implications of informal caregiving to better understand its effects on families' economic stability, especially in rural areas where caregiving responsibilities frequently fall heavily on household members. Additionally, conducting comparative studies that analyze dementia care costs alongside other chronic illnesses could help contextualize the unique economic challenges posed by dementia, informing more comprehensive policy responses across multiple chronic health conditions. Research into the effectiveness of targeted interventions—such as mobile clinics, telemedicine, and community health worker programs for rural dementia care—could also be valuable in validating and refining these approaches for broader implementation. Lastly,

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evaluating the cost-effectiveness of subsidies for dementia medications and caregiver support programs over the long term could yield critical data to guide policy decisions that aim to reduce financial strain for families while enhancing the quality of dementia care.

References

Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., Wolff, J. L., & Ritchie, C. S. (2020). A national profile of end-of-life caregiving in the United States. *The Journals of Gerontology: Series B*, 75(7), 1527-1537. https://doi.org/10.1093/geronb/gbz149

Zafar, S. Y., Currow, D. C., Cherny, N., Strasser, F., Fowler, R., & Abernethy, A. P. (2013). The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *New England Journal of Medicine*, *369*(5), 451-458. https://doi.org/10.1056/NEJMsa1204629

Allegri, R. F., Butman, J., Arizaga, R. L., Machnicki, G., Serrano, C. M., Taragano, F. E., & Lon, L. (2007). Economic impact of dementia in developing countries: An evaluation of the costs of Alzheimer-type dementia in Argentina. *International Psychogeriatrics*, *19*(4), 705-718. https://doi.org/10.1017/S1041610206004255

Alzheimer's Association. (2023). 2023 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 19(1), 1-88. https://doi.org/10.1002/alz.12901

Walsh, B., Cullinan, J., & O'Neill, C. (2018). The impact of primary care-led chronic disease management on healthcare costs: Evidence from diabetes in Ireland. *Economic and Social Research Institute (ESRI)*. https://www.esri.ie/system/files/media/file-uploads/2018-10/JA201846.pdf