ORIGINAL ARTICLE

Economic burden in patients with dementia attending a geriatric care clinic in chennai - a cost of illness study

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Abstract:

Background: Dementia is one of the major causes of dependency and disability among the elderly. With an increase in life expectancy, the burden of dementia is also on the rise especially in countries like India. There are economic concerns to the family as health expenses are majorly borne by them. There are few cost of illness studies for dementia from low- and middle-income countries. Our study aims to estimate the burden of costs of dementia in patients attending a geriatric clinic in a private hospital setting.

Methods: This retrospective observational study assessed the economic burden of dementia by estimating both direct and indirect costs of illness from the caregiver's perspective.

Results: Direct costs from medical services and social costs are higher when compared to indirect costs. Not all people have incurred social costs as many are provided care by the families and their inputs are not paid or accounted. The costs of informal care were under evaluated in the study.

Conclusion: The direct health care cost of illness of Dementia from caregiver perspective is more than one seventh of the per-capita income of Indian population provided indirect costs and direct social costs are not included. Evaluating various costs incurred in various health care settings is important to understand the economic burden of Dementia. There is a need for well-designed prospective studies to inform policy decisions towards better service development for persons with dementia.

Keywords: *Direct medical costs, Social costs, Indirect costs, LMIC nation*

INTRODUCTION

Dementia is a chronic progressive neurodegenerative disease that affects one or more cognitive processes of memory, thinking, comprehension, learning ability, calculation, language, and judgement and leads to functional impairment.[1] Dementia is the leading cause of dependency and disability among the elderly and poses significant health and economic burden to society.[2] Dementia is not only devastating to individuals who have it, but also to families and society. The huge cost of disease poses challenges to health systems in terms of currently available resources and future ability to handle the predicted increase in disease burden.[3] There is a growing body of evidence on the costs of dementia globally suggesting that dementia is already imposing a huge economic burden.[4] However, most of the epidemiological cost of illness studies for dementia are conducted in high-income countries with better healthcare resources and the data remains sparse in low and middle-income countries(LMIC), where costs tend to be higher than global average and affordability is lesser.[5]

There is a need to estimate costs of dementia in various settings as it is crucial to understand its impact on families, governments, and their health and social care systems, which is fundamental for raising awareness, achieving proper prioritisation, and focusing efforts toward improving the lives of people with dementia and of their caregivers.[6,7] This cost-of-illness study aimed to analyze the total, direct, and indirect costs of dementia in a population of patients suffering from the illness, attending a tertiary specialty clinic in the private setting in Chennai, India.

METHODS

Study setting

This study was conducted in a Geriatric Care Clinic (GCC) in Chennai. The clinic is run by a multi-disciplinary team of Neuropsychiatrists, Psychologists and Psychiatric social workers. The study was approved by the Institutional Ethics Committee.

Study design

A retrospective cohort design was used to collect data of outpatients with dementia who had attended the GCC from January 2019 to December 2019. GCC maintains records of patients evaluated with documentation of socio-demographic information, clinical details, and investigations necessary for evaluation of the disease along with information on the functional ability of the patient and caregiver support available.

Procedure

The medical records in the GCC were screened for diagnosis of Dementia. The information on the utilization of health care and non-healthcare resources was extracted from the records. Some information about non-health resources was also obtained from the patient's caregiver through telephonic interviews after taking informed verbal consent.

Cost estimation

Costs of illness considered for this study were the standardized unit costs of services used to diagnose and manage dementia in the last year. The total costs include direct and indirect costs. Direct costs refer to money used for medical care (doctor consultation, investigations, medications) and social costs (nursing care, meals, rehabilitation care). Indirect costs refer to productivity loss secondary to illness (early retirement, decreased work productivity, excess leaves, etc) and unpaid inputs from caregivers (loss of wage days, lost leisure time, and caregiver burden).

Data collection

Data were collected through a structured proforma from the extracted medical records data. Demographic details (age, gender, and education), medical care costs, social costs, and indirect costs related to loss of wage days were collected in a semi-structured format, using the data available. Overall costs were calculated by adding direct and indirect costs incurred for the individual with dementia in the previous year from the caregiver perspective.

Data analysis

Descriptive statistics like frequency distribution for qualitative variables, central tendency (mean), and statistical variability (standard deviation) for quantitative variables were performed.

RESULTS

The analysis of the cost of illness in patients who had visited GCC in the previous year with the diagnosis of dementia was done from the caregiver perspective.

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Table 1 shows the socio-demographic and clinical characteristics of patients with Dementia. Of the 30 patients, 22 were males,19 had primary school level or less education. Majority of them lived with their families and were retired from formal employment.

SD variable	Mean (SD)	Range	N (%)
Age of the patient	71.06(9.7)	52-87 years	
Age at diagnosis of Dementia	67.5(8.3)	54-82 years	
Gender of the patient		Male	22(71%)
		Female	9(29%)
Education of the patient		Primary school or less	19(61.3%)
		Higher secondary school or more	12(38.7%)
Occupation of patient		Retired from work	22(71%)
		Informal work	9(29%)
Source of income		Absent	24(77.4%)
		Present	7(22.6%)
Living with spouse		Yes	25(80.6%)
		No	6(19.6%)
No. of children		less than or equal to one	16(51.6%)
		Two or more	15(48.4%)
Living arrangement		With family	28(90.3%)
		In rehabilitation home	3(9.7%)

Table 1: Sociodemographic and clinical characteristics of patients with Dementia

Table 2 shows resource consumption for patients with Dementia attending GCC in the last one year. Among indirect costs, productivity loss secondary to illness (early retirement, decreased work productivity etc) and unpaid inputs from caregivers (lost leisure time and caregiver burden) couldn't be computed due to non-availability of the data. Only loss of wage days for the caregiver was assessed in this study.

Cost of resources in a year consumed in Indian rupees		Mean(S.D)
Direct health care costs	Antidementia drugs	6939.13(6224.42)
	Medical tests-Haematological	2374.42(420.28)
	Medical tests-Imaging	7903.23(20880.94)
	Physician consultation	7290.32(502.89)
	Total direct medical costs	22720(7081)
Direct social costs	Meal	44593.55(7759)
	Transport	17224(21410)
	Nursing care	210000(42426)
	Rehabilitation	220000(34641)
	Total direct social costs	96101(96771)
Indirect costs	Wage loss for caregiver	12480(7078)

Table 2: Resource consumption for patients with Dementia attending GCC in one year

DISCUSSION

The study is one of the very few that is done in India, which has looked at the health care costs of dementia. Low- and middle-income countries (LMIC) have a different care pathway for people with dementia compared to advanced economies, and the support services are non-existent in most cases.8,9 The current study covered a population that visited a tertiary care treatment centre in the private sector. The direct health care total cost incurred in lieu of physician consultation, investigations, medication was around rupees 22720/-, which comes to one-seventh of the annual per capita income of an individual in India.10 The direct costs emerged to be most expensive category in this study, similar to the findings from another study done in a LMIC nation, Thailand.11 Notably, in our study, direct social costs exceeded direct medical costs for dementia patients, suggesting that the financial burden of non-medical care and support services could impede patients access to continued rehabilitation, nursing, and day care services. These findings highlight the need for targeted interventions and policy measures aimed at alleviating the economic burden on families and facilitating improved access to essential care services for individuals with dementia. While the medications and most of the basic investigations are provided free of cost in government settings, inconsistency in care and non-availability of resources lead to many seeking more expensive private care, escalating costs.

The direct social costs in dementia are seldom considered in public health policies in Indian setting, as most of the burden of care is borne by the immediate relatives, and it is considered as part of the routine expenses of care for the aged. Our study shows a wide discrepancy in this, primarily because of the difference in the socio-economic backgrounds of the family accessing care. Affluent families were more likely to keep additional specialized personnel for the care of the patient at home, where as lower- and middle-income families bore the entire burden on themselves, directly leading to increased care giver burden. The details of care giver burden were not however available for this study, as this was a retrospective review from the clinical records of the patient alone.

Wage loss for the caregiver in this study appears to be lesser than expected, but this is due to the fact that caregivers had regular salaried employment in most cases (especially children of the patients) and they could avail carer’s leave. Spouses of the majority of the patients were retired and providing most of the day-to-day support. This assumes huge significance when it comes to daily wage earners form the primary carer, and is not reflected in the current study.

However, this study also throws light into the unique characteristics of the population under study. It shows how a serious condition like dementia impacts the society, with all the characteristics intrinsic to the urban population in India, where traditional family attitudes and care giving still form the back bone of care for the patients. This comes with a huge cost on physical and psychological wellbeing of the carers and it remains unnoticed and unpaid for. Introduction of carers pension is an important social support initiative that could be taken up by the government to mitigate this burden.

The study also highlights the urgent need for dementia care services in the public sector like day care centres, respite homes and nursing homes to cater to the escalating costs of care and diminishing supportive care from families for people with dementia.

Our study has many limitations. The sample studied is small, not representative of the full spectrum of persons with dementia in the society, as it was conducted in a tertiary care institution rather than in the community. The study being a retrospective record review, not all information were redeemable, especially related to caregiver burden, and indirect costs related to unpaid work. There is a wide variation in socio-economic backgrounds of the patients and their families. Provision of care by close family members makes it impossible to standardize costs incurred. The stage of dementia and utilization of existing support services from government were not evaluated in the study.

CONCLUSION

The availability and accessibility of support services for persons with dementia are minimal in LMIC like India. There is a huge variation in the costs incurred as affordability decides utilization when the services are not state sponsored. The cultural norms and attitudes towards elderly play a huge role in determining the societal costs and indirect costs in a country like India. There is a need for prospective epidemiological studies to understand the cost estimates of dementia to direct future service development and fund allocation for provision of care for persons with dementia.

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CONFLICT OF INTEREST

Nil.

Competing interests

Authors have declared that no competing interests exist.

Authors' contributions

This work was carried out in collaboration among all authors. All authors have read and approved the final manuscript.

Consent

As per international standard or university standard, patients' written consent has been collected and preserved by the author(s).

Ethical approval

As per international standard written ethical approval has been collected and preserved by the author(s)

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