International Journal of Research in Medical Sciences
Mishra AK et al. Int J Res Med Sci. 2016 Sep;4(9):3675-3678
www.msjonline.org
pISSN 2320-6071 | eISSN 2320-6012
DOI: http://dx.doi.org/10.18203/2320-6012.ijrms20162900

Review Article

Financial burden of stroke on family and caregiver in India: a literature review

Anil K. Mishra[1]*, Neeti Mishra[2], Khushbu Gajjar[1]

[1]Department of Physiotherapy, Shrimad Rajchandra College of Physiotherapy, Uka Tarsadia University, Bardoli, Surat-394350, India
[2]Department of Physiotherapy, SPB College of Physiotherapy, Ugat-Bhesan road, Surat-395009, India

Received: 13 July 2016
Accepted: 08 August 2016

***Correspondence:**
Dr. Anil K. Mishra,
E-mail: anilmpt@gmail.com

Copyright: © the author(s), publisher and licensee Medip Academy. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ABSTRACT

As life expectancy increases, India will face enormous socioeconomic burden to meet the costs of integrated rehabilitation of subjects with stroke. Caring for stroke patients leads to caregiver (CG) strain and financial burden. The CG burden is perceived differently in the Indian background depending on the society and culture. Caregiving stress has the potential to hamper rehabilitation of the patients and is of vital importance both as a research topic and the focus of clinical care. Cost and burden of informal care giving are high rural Indian community. Financial stress was prominent and common among the socioeconomically weaker division. The financial costs associated with family caregiving were a significant factor in caregiving burden, both for the male and female caregivers. Despite the high financial burden, limited recent studies have focused on costs associated with stroke in the India. Establishing total stroke-related costs is essential to evaluate and support the health economic research on stroke systems of care. Stroke care giving studies may help to better understand care giving impact, and also to find the most effective interventions to improve the quality of life of stroke patients and their caregivers, reduce the burden and depression of caregivers. Policies and programs to alleviate the financial burden and to provide social and financial support for these family caregivers are equally important for both family caregivers and their care receivers.

Keywords: CG, Financial burden, Older adults, Stroke

INTRODUCTION

Stroke is a global health problem. It is the second commonest cause of death and fourth leading cause of disability worldwide.[1] It causes functional impairments, with 20% of survivors requiring institutional care after 3 months and 15% - 30% being permanently disabled.[2] It is recognised that the negative motor impairments following stroke, eg, loss of strength and dexterity, contribute most to disability.[3]

The high incidence and high prevalence of stroke have a major impact on society.[4] Stroke patients require intensive as well as early physiotherapy to enhance recovery, which require high amount of cost for the treatment.[5] A larger number of studies have identified risk factors for greater caregiver burden. Stroke is a life-changing event that affects not only the person who may be disabled, but their family and caregivers. Physical, cognitive, and behavioural dysfunctions are associated with stroke, which causes necessity of caregiver (CG) support for rehabilitation and general care. Caregivers play an important role in supporting people with illness either acute or chronic.

The importance of addressing the burden of care givers involved in care of patients with neurological disorders has been recommended. In spite of neurological conditions being one of the most common causes of disability very few studies have addressed the impact of

these conditions on the care givers in Indian setting especially of financial burden. It has been well documented that the family members are affected by the patient's illness from the outset. This burden of care can lead to a breakdown among the care givers themselves. The patients experience long-term impairments in physical, psychosocial, and cognitive function and rely mainly on the caregivers for practical and emotional support concerning activities of daily living which again leads to financial burden.

Most studies carried out in India show that about 10% to 15% of strokes occur in the population below 40 year, which is a higher proportion compared with other countries. Organized provision of care in a stroke unit have been found to increase the number of patients who survive, return home, and regain functional independence in their everyday activities.[6] However, implementation of such organized care for stroke is limited and inadequate in low and middle income countries, especially in a country like India where resources for rehabilitation are scarce.[7]

A similar scenario is expected in India because of increasing stroke incidence and minimal social support. Moreover, report on this issue is lacking in India.[8] Despite the high prevalence of stroke and the potentially high burden of family caregiving for the stroke survivors, few studies have systematically addressed the financial consequences of stroke on family members and other informal caregivers. Thus, the purpose of this article is to provide a review and analysis of published empirical studies that have examined the outcomes of care giving for stroke caregivers on financial aspect.

Full-text papers were identified on the basis of a literature search in PubMed/ MEDLINE and Ovid/ EMBASE databases from January 1995 to July 2015. Only published research articles were included in this review. A computer search was conducted to review the databases by using the following key words: caregivers of stroke patient's care for stroke survivors, and stroke care giving, financial burden on caregiver.

FAMILY CARE GIVING FOR PATIENTS WITH STROKE

One study by Bhattacharjee M, et al on factors affecting burden on caregivers of stroke survivors: Population-based study in Mumbai (India) describes that nearly one-third of the stroke survivors stay at home and take domiciliary care, which in reality is a burden on the CG.[9]

In oriental countries including India, the joint family system prevails, wherein in a small apartment, family members stay together sharing infrastructural facilities. Therefore, any patient with a major illness like stroke is preferable sent to a nearby health care facility, but this may not always be possible on account of economic constraints, deficient infrastructure facilities, etc. This again increases financial burden on care givers. Another study that used the survey of burden among stroke care givers in 2010 found that financial stress was prominent and common among the socioeconomically weaker section. These findings highlight the need for better financial facilities, such as wide coverage of medical insurance and upgrading of the social support system.[8]

Other study provide evidence about the prevalence of stroke and related burden among older people living in India reported that the prevalence of stroke was higher among men, increased with age and among the 904 stroke survivors, severe disability and dependence were common and were associated with comorbid dementia, depression and physical impairments.[10] Carers often reported giving up work to care which causes financial burden among care givers.

One study done by Kumar R et al. on Needs, Burden, coping and quality of life in stroke caregivers in 2015 found that the pattern of burden experienced by the caregivers under each domain shows that caregivers had higher burden in term of financial constraints compared to other factors (Figure 1).[11]

In addition to literature, care giving affects a caregiver's work and family financials, such as balancing a job and providing care to family members, also family caregivers had to take more time off work, were interrupted at work more often regarding family matters, missed more days at work, took more time off without pay, and ultimately worked fewer hours than desired.[12,13] This again leads to financial burden on care givers.

The finances of family caregivers can also be affected by the daily costs of care giving.[14] Other related care giving expenses such as transportation, non-prescription medications, medical supplies, prescription medications, equipment, and homemaking supplies can also affect financial adequacy.[15]

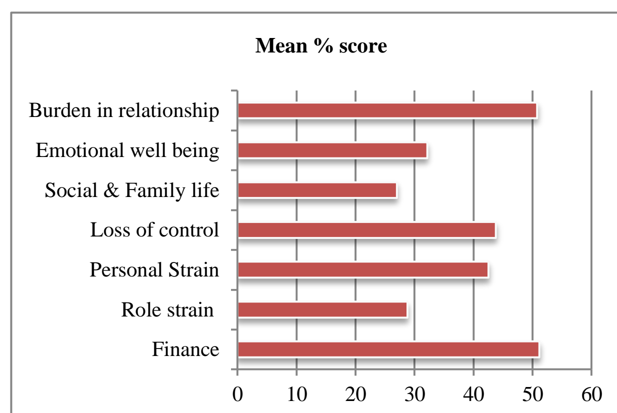

Figure 1: Pattern of burden experienced by caregivers of stroke survivors.

This literature review has presented the available evidence on the financial burden related to stroke care-givers in developing country like India. Stroke continues to be a leading cause of death and long term disability in adults worldwide. India is a developing economy, where ageing population, changes in lifestyle and rapid urbanization have contributed to a rise in non-communicable diseases, including stroke.[16] In India and other developing countries, an alarming increase in the incidence of stroke has been observed.

Stroke prevalence among the elderly in rural India was 1.1% and urban India was 1.9%. Men are more likely to have a stroke than women: the male/female sex ratio for India is 7:1.[17] Stroke can occur at any of age. Childhood disability entails economic costs that ate to some extent measurable.[18] Stroke is a crisis for the family because of sudden onset nature and multiple impairments in survivors. Usually after the hospitalization, the survivors become partially or completely depended on caregivers.

As there are more than five million dependent older people in India, the estimation of annual national cost on informal care giving can be very high.[19] The economic burden caused by stroke has not been explored in India.[20] If action is not taken now against this avoidable disease, it will have an adverse effect on economic development of the country.[21]

The present study proved that providing care for stroke patients is stressful and burdensome task. Early recognition and diagnosis of stroke using validated tools outside hospital environment can help save life and limit disability. Specifically the face arm speech and time (FAST) test is a lay approach to diagnose stroke and is widely used to raise awareness about early recognition of stroke among the public in developed countries.[22]

CONCLUSION

As given in all literatures that we reviewed financial consequences of stroke on care givers in India. Nonetheless, there are limitations to generalization of these findings due to methodological challenges as well as lack of study on financial burden of stroke care giver in India. Well-founded estimates of the average costs of stroke will require random samples with controls to account for people who have costly and less costly treatments, and what would have happened in the absence of the diseases. On the other hand, significantly, this review suggests that it is equally as important to focus on people who could not seek care for stroke due to financial reasons.

Policies and programs are needed to address the financial needs and security of these family caregivers. Insight into their health-related need would provide valuable inputs for the development of new strategies to sustain caregivers in their vital roles. It is particularly important to address the context of the family caregivers who are female, who in addition to their care giving challenges, often face multiple demands in employment and caring for their own family, when attempting to secure gainful employment and financial stability.

The push to develop health-financing systems that improve financial risk protection and help achieve universal health coverage in developing country is promising. However, policymakers need to ensure that the health as well as the financial burden from any long term disease is adequately addressed in future reforms, while at the same time improve access and financial protection for all other health services needed by the population.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: Not required

REFERENCES

1. Strong K, Mathers C, Bonita R. Preventing stroke: saves lives around the world. Lancet Neurol. 2007;6:182-7.
2. Steinwachs DM, Collins-Nakai RL, Cohn LH, Garson A Jr, Wolk MJ. The future of cardiology: utilization and costs of care. Am CollCardiol. 2000;35(5 Suppl B):91B-8B.
3. Burke D. Spasticity as an adaptation to pyramidal tract injury. Advances in Neurology. 1988;47:401-18.
4. Stineman MG, Maislin G, Fiedler RC, Granger CV. A prediction modelfor functional recovery in stroke.Stroke.1997;28:550-6.
5. Gajjar K. 'To assess the outcome of Intensive Physiotherapy given in Early Stage of Stroke' International Journal of sciences and applied research. 2015;2(6):68-72.
6. Langhorne P. Stroke Unit Trialists' Collaboration. How do stroke units improve patient outcomes? A collaborative systematic review of the randomized trials. Stroke. 1997;28:2139-44.
7. Langhorne P, Villiers LD, Pandian JD. Applicability of stroke-unit care to low-income and middle-income countries Lancet Neurol. 2012;11:341-8.
8. Das SK, Banerjee TK, Biswas A, Roy T, Raut DK, Mukherjee CS, et al. A prospective community-based study of stroke in Kolkata, India. Stroke. 2007;38:906-10.
9. Bhattacharjee M, Vairale J, Gawali K, Dalal PM. Factors affecting burden on caregivers of stroke survivors: Population-based study in Mumbai (India), Ann Indian Acad Neurol. 2012;15(2):113-9.
10. Ferri CP, Schoenborn C, Kalra L, Acosta D, Guerra M, Huang Y, et al., Prevalence of stroke and related burden among older people living in Latin America, India and China, J Neurol Neurosurg Psychiatry. 2011;82:1074-82.
11. Kumar R, Kaur S, Reddemma K. Needs, Burden, Coping and Quality of Life in Stroke Caregivers A

Pilot Survey, Nursing and Midwifery Research Journal. 2015;11(2):57-67.

12. Haddock SA, Zimmerman TS, Lyness KP, Ziemba SJ. Practices of dual earner couples successfully balancing work and family. Journal of Family and Economic Issues. 2006;27:207-34.
13. Grunfeld E. Caring for elderly people at home: The consequences to caregivers. Canadian Medical Association Journal. 1997;157:1101-5.
14. Fast JE, Williamson DL, Keating NC. The hidden costs of informal elder care. Journal of Family and Economic Issues. 1999;20:301-26.
15. Decima Research. National profile of family caregivers in Canada: Final report. Ottawa, Ontario: Health Canada. 2002.
16. Dalal PM, Bhattacharjee M, Vairale J, Bhat P. UN millennium development goals: Can we halt stroke epidemic in India? Ann Indian Acad Neurol. 2007;10:130-6.
17. Lutz BJ, Young ME, Cox KJ, Martz C, Creasy KR. The crisis of stroke: experiences of patients and their family caregivers. Topics in Stroke Rehabilitation. 2011;18:1-14. doi: 10.1310/tsr1806-786.
18. Mishra AK, Mishra N. A review on childhood disability and its direct and indirect cost to families, International Journal Of Management. 2014;5(11):96-102.
19. WB: Data: Population ages 65 and above. 2012.http://data.worldbank.org/ indicator/ SP.POP.65UP.TO.ZS.
20. Pandian J, Srikanth V, Read S, Thrift A. Poverty and stroke in India: a time to act. Stroke. 2007;38:3063-9.
21. Beaglehole R, Epping-Jordan J, Patel V, Chopra M, Ebrahim S, Kidd M, et al. Improving the prevention and management of chronic disease in low-income and middle-income countries: a priority for primary health care. Lancet. 2008;372:940-49.
22. Mishra AK, Mishra N. To study the impact of physical disability on mental health and economic status of caregivers in southern Gujarat, journal of Social science & humanities. 2015;2(7). ISSN : 2278 – 859X.

Cite this article as: Mishra AK, Mishra N, Gajjar K. Financial burden of stroke on family and caregiver in India: a literature review. Int J Res Med Sci 2016;4: 3675-8.