Family Burden in Caregivers of Elderly with Cognitive Impairment residing in Rural and Tribal Population of a District in Western India – A Baseline Study

Shobha Misra, Rajat Oswal, Mehul Patel
Department of Community Medicine, Medical College Baroda, Department of Psychiatry, Medical College Baroda and Attached Hospital, SSGH, Vadodara, Gujarat, India

Abstract

Study Objectives: The objective was to assess cognitive impairment (CI) in adults older than 59 years, residing in rural and tribal population and to assess family burden of those who had significant CI. Materials and Methods: This cross-sectional study was conducted among adults residing in the rural population of a block in a district located in Western India in 2015. A total of 240 households from 12 villages of the block were selected by multistage and random sampling method. Mini-mental state examination and Zarit Burden Interview tools were used to assess CI and burden. Data were entered in MS Excel 2007 and analyzed with descriptive statistics and Chi-squared test. Results: A total of 212 adults aged over 59 years were studied. The overall prevalence of CI was 42.92%. There was a statistically significant difference seen in CI among females as compared to males. Interview of primary care taker showed that 32 (35.16%) caregivers had little or no burden, 53 (58.24%) had mild-to-moderate burden, and 6 (6.59%) had moderate-to-severe burden, while none had a severe burden. Conclusions: Enabling caregivers to provide at home care for longer periods before hospitalization would decrease the burden of CI.

Keywords: Aged people, caregivers, cognitive impairment, family burden

Introduction

Mental health is one of the critical health requirements that society needs to address in the present century. According to the World Health Organization, around 450 million people suffer from a mental or behavioral disorder globally, and one in four will be affected by mental or neurological disorders at some point in his/her life.[1] As the world is going through “demographic transition,” the aging leads to cognitive impairment (CI) – a risk factor for dementia that has serious clinical and public health consequences.[2]

Very often, the family has to face significant and serious physical and psychological burden, as the family is a part of the care system for a person with chronic mental illness. In such conditions, the family has to provide extra care to the person than usual. It involves taking care of personal hygiene of patients, emotional support such as listening, counseling, and companionship, and informational caring such as learning how to change the living environment of the patients. Various studies have shown a high degree of subjective and objective burden on family members.[3-5] The burden of care can be classified into two categories: subjective and objective. Objective burden of care includes “social disturbances” caused by the patients themselves, while subjective burden refers to “distress” actually experienced by them.[6] Burden of care was defined by Zarit,[7] an American Gerontologist, as “the discomfort experienced by the principal caregiver of an older family member, including the caregiver’s health, psychological well-being, finances, and social life.

There is scarce information on the prevalence of CI in adults and burden experienced by their caregivers from rural and tribal population of India. Hence, the current study was carried out among adults residing in rural and tribal population of a district located in Western India in 2015.
out; to assess CI in adults older than 59 years, residing in rural and tribal population and to assess the family burden of those who had significant CI.

**Materials and Methods**

A cross-sectional study was carried out among adults residing in rural and tribal population of a block in a district located in Western part of India, between March 2015 and June 2015. There are six primary health centers (PHCs) in the block, catering to approximately 120 villages and 30,000 households (HHs). Each PHC caters to six subcenters (SCs). The villages have a mixed population of rural and tribal inhabitants. The sampling was carried out in stages: at stage 1, one SC from each of the six PHCs was selected for study by simple random sampling method; at stage 2, two villages from each of the selected SC were selected, also by random sampling, therefore in this way, 12 villages were selected; at stage 3, 20 HHs based on the feasibility of available time, money, and workforce were surveyed from each of the selected village. To include participants from all over the village, the same was divided into four quadrants to visit five HHs from each quadrant, thus in this way, 240 HHs were selected.

The approval of the Institutional Ethical Committee for Human Research of the institution was obtained before starting the data collection (approval dated March 20, 2015). Adults 60 or > 60 years of age willing to give informed written consent were included in the study for interview using mini-mental state examination (MMSE) and Zarit Burden Interview. The MMSE is an 11-question measure that tests five areas of cognitive function: orientation, registration, attention and calculation, recall, and language. The maximum score is 30. A score of 22 or lower is indicative of CI in literate participants while a score of 20 or lower in illiterate participants. The MMSE takes only 5–10 min to administer and is therefore practical to use repeatedly and routinely. The Zarit Burden Interview tool was administered to persons whose MMSE score was ≤ 22 in literate, whereas 20 in illiterate participants. The Zarit Burden Interview was administered to the primary caretaker of the cognitive impaired person. If the caretaker was older than 59 years, the MMSE was administered to that person also. If husband and wife both were found to have CI, then any person taking care of them (including a neighbor) was interviewed. The Zarit Burden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire. The revised version contains 22 items. Each item on the interview is a statement, which the caregivers are asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). Interpretation of Zarit Burden Interview scores were as follows: 0–21 indicating little or no burden, 21–40 indicating mild-to-moderate burden, 41–60 indicating moderate-to-severe burden, and 61–88 indicating severe burden.

These tools were administered to the participants after explaining the purpose and ensuring that appropriate instructions were given and understood individually for both the tests. A 2 h training session for the persons involved in data collection was conducted by a psychiatrist. The obtained data were entered in MS Excel 2007 and analyzed with descriptive statistics and Chi-squared test.

**Results**

This cross-sectional study was conducted in 2015 among adults residing in rural and tribal population of a block located in central India to assess CI in them and family burden experienced by their caregivers. A total of 212 adults older than 59 years from 240 HHs were studied using MMSE. Of these 212 adults, 125 (58.96%) were males and 87 (41.04%) were females. Most of the participants were in the age group of 60–65 years (72.17%). There were only 42 literate adults out of the 212 studied (20%), of whom three were females and 39 were males. The overall prevalence of CI was 42.92% (91/212). Of the 87 females in the study group, 63 (72.4%) of them were found to have CI, whereas out of 125 males, 28 (22.4%) had CI. There was a statistically significant difference seen in CI among females ($\chi^2 = 52.37; P < 0.01$) as compared to males as shown in Table 1.

The Zarit Burden Interview administered to the primary caretaker of the 91 cognitive impaired participants showed that 32 (35.16%) caregivers had little or no burden, 53 (58.24%) had mild-to-moderate burden, and 6 (6.59%) had moderate-to-severe burden, while none had a severe burden. Moreover, most of the adults (59.34%) were from the age group of 60–65 years as shown in Table 2.

**Discussion**

The present study conducted to assess CI and family burden of those who had significant CI used MMSE tool and Zarit Burden Interview. The overall prevalence of CI was 42.92%, and significantly higher CI was seen in females as compared to males. Similar findings are reported by Tsolaki et al. who in their study conducted in Greece observed a prevalence of 35.15% for CI in people aged over 65 years, they found that the prevalence of mild CI increased with age ($P < 0.001$), and women had a higher prevalence. Increasing age of cognitive impaired person was not a responsible factor for severity of caregivers’ burden in our study. This may be due to small sample size in the higher age groups. Ortiz et al. conducted their study in Mexico and found an overall prevalence of CI to be 13.8%.

### Table 1: Prevalence of cognitive impairment among study participants

| Gender | Cognitive impairment | Total, n (%) |
|--------|----------------------|--------------|
|        | Present, n (%)       | Absent, n (%)|
| Male   | 28 (22.4)            | 97 (77.6)    | 125 (58.96) |
| Female | 63 (72.4)*           | 24 (27.6)    | 87 (41.04)  |
| Total  | 91 (42.92)           | 121 (57.08)  | 212 (100)   |

* $\chi^2 = 52.37, P<0.01$
which is lower than that found in our study but they also found a higher proportion of CI in women as compared to men, although not statistically significant. Whereas we found a statistically significant difference in CI among females ($P < 0.01$) as compared to males. In our study, 35.16% of caregivers had little or no burden, 58.24% had mild-to-moderate burden, and 6.59% had moderate-to-severe burden, while none had a severe burden. Similar findings are reported by Paradise et al.,[12] who found that 36% of mild CI caregivers reported clinically significant levels of burden. Hayashi et al.[13] found that about 20% of the caregivers reported a clinically significant burden in Japan. Whereas in community-based studies conducted in Latin America, China, and India by Sosa et al.,[14] the prevalence of mild CI ranged from 2.1% to 11.5%. The results from these studies pose questions as to how much assistance can a family member provide to the patient before he/she feels burdened and seek professional help. These issues need more exploration in the form of more community-based studies from the country. As most of the studies carried out are among patients and caregivers of patients, there is lack of information on the same from community-based studies in India. Community-based health workers can be empowered with proper training to collect baseline data about the prevalence of CI, which would help in planning interventions. Identification of CI and appropriate tailored community-based multicomponent interventions for male and female caregivers, including a diversity of services can improve the quality of life and promote the mental health of patients and well-being of caregivers. To minimize the effect of literacy on the scoring system, the scoring system was modified, and appropriate training was imparted to the investigator involved in data collection.

**Conclusions**

The study findings clearly suggest that significantly higher CI was seen in females as compared to males, and different levels of burden were experienced by caregivers of cognitively impaired. These issues need more exploration in the form of more community-based studies from the country. Enabling caregivers to provide at home care for longer periods before hospitalization can decrease the burden of CI.

**Financial support and sponsorship**

Nil.

**Conflicts of interest**

There are no conflicts of interest.

**References**

1. Mental Disorders Affect One in Four People – WHO. Available from: http://www.who.int/mediacentre/newsroom/releases. [Last accessed on 2020 May 02].

2. Patel RM, Singh US. Prevalence study of cognitive impairment and its associated sociodemographic variables using mini-mental status examination among elderly population residing in field practice areas of a medical college. Indian J Community Med 2018;43:113-6.

3. Maurin JT, Boyd CB. Burden in chronic mental illness in the family; a critical review. Arch Psychiatr Nurs 1990;4:99-107.

4. Loukissa DA. Family burden in chronic mental illness. J Adv Nurs 1995;21:248-55.

5. Provencher HL. Objective burden among primary caregivers of person with chronic schizophrenia. J Psychiatr Ment Health Nurs 1996;3:181-7.

6. Hoening J, Hamilton MN. The schizophrenic patient in the community and his effect on the household. Int J Soc Psychiatry 1966;12:165-76.

7. Zarit SH, Reever KE, Back-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist 1980;20:649-55.

8. Kurlowicz L, Wallace M. The mini-mental state examination (MMSE). J Gerontol Nurs 1999;25:8-9.

9. Herbert R, Bravo G, Previle M. Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. Canadian J Aging 2000;9:494-507.

10. Tsalaki M, Kakoudati T, Tsalaki A, Verykouki E, Pattakou V. Prevalence of mild cognitive impairment in individuals aged over 65 in a rural area in North Greece. Adv Alzheimers Dis 2013;4:111-9.

11. Ortiz GG, Arias-Merino ED, Flores-Saiffe ME, Velazquez-Brizuela IE, Macias-Islas MA, Pacheco-Moises FP, et al. Prevalence of cognitive impairment and depression among a population aged over 60 years in the metropolitan area of Guadalajara, Mexico. Curr Gerontol Geriatr Res 2012;2012:353-61.

12. Paradise M, McCade D, Hickie IB, Diamond K, Lewis SJ, Naismith SL. Caregiver burden in mild cognitive impairment. Aging Ment Health 2015;19:72-8.

13. Hayashi S, Terada S, Nagao S, Ikeda C, Shindo A, Oshima E, et al. Burden of caregivers for patients with mild cognitive impairment in Japan. Int Psychogeriatr 2013;25:1357-63.

14. Sosa AL, Albanese E, Stephan BC, Dewey M, Acosta D, Ferri CP, et al. Prevalence, distribution, and impact of mild cognitive impairment in Latin America, China, and India: A 10/66 population-based study. PLoS Med 2012;9:e1001170.