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Caring for dementia: a burden? A cross sectional study on the primary caregivers who are in contact with the Mental Health Unit at Teaching Hospital Jaffna

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Introduction In par with the increasing prevalence of dementia, the responsibility of providing appropriate care also increases. In low- and middle-income countries, in the absence of organized services, it is the family members who take on the role of primary caregivers to their beloved. In the present context, the satisfying and joyous process of caregiving may, in fact, become a burden for the caregivers.

Objective This study aimed to assess the perceived burden and its association with selected demographic characteristics among the primary caregivers of people with dementia.

Methodology A cross-sectional descriptive study was conducted among 99 primary caregivers who are connected with the Mental Health Unit, Teaching hospital, Jaffna. An interviewer-administered questionnaire consisting of sociodemographic section and the translated Zarit Burden Inventory scale was filled over the telephone call. Student's T-test and one-way ANOVA were performed by using SPSS 25 software.

The study was approved by the Ethics Review Committee of Faculty of Medicine, Jaffna.

Results The overall caregiver burden was found to be 73.7% (95% CI, 65.0%-82.4%). While majority of the caregivers (65.6%) were found to have mild burden, a small portion (8.1%) were found to be moderately burdened by the demands of caregiving. Though female sex, low or no formal education, married status, no formal employment, and increased caregiving time were found to be associated with increased caregiver burden, the statistical analysis did not show these to be statistically significant.

Conclusion Caring for the people with dementia does seem a burden to the primary caregivers, even though this burden is mild or moderate in many. The results show the impact of culture, which reinforces the perception of caregiving not as a burden but as a duty, a responsibility, returned.