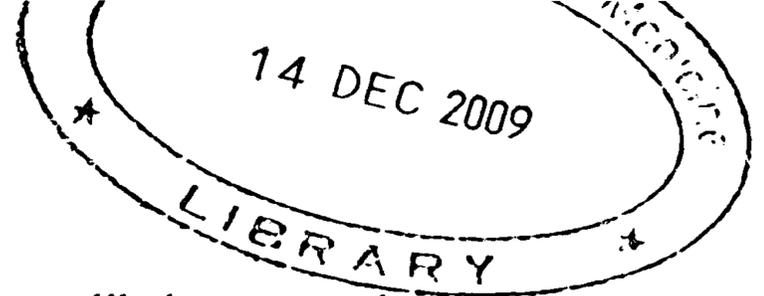


## ABSTRACT



**Introduction:** The caregivers of children with disabilities are likely to experience a wide range of health problems due to the burden of caregiving. Therefore, assessment of the level of burden experienced by the caregivers and its impact on their health and well-being is of importance to ensure optimum benefits for both the caregivers and care recipients.

The objectives of this research were to develop a valid and a reliable instrument to assess the caregiver burden experienced by caregivers of children with cerebral palsy and to assess the caregiver burden of principal caregivers of such children in the Galle District, their psychological problems and the predictors of the psychological problems.

**Methods:** Phase I of the study developed and validated a self administered, 25 item, multidimensional scale - the Caregiver Difficulties Scale (CDS) - to assess the level of caregiver burden experienced by the principal caregivers of children with cerebral palsy, in a hospital setting.

Phase II of the study assessed the level of caregiver burden experienced by a sample 375 principal caregivers attending the Teaching Hospital (TH), Karapitiya, using the CDS. The prevalence of psychological problems of these caregivers was calculated using the General Health Questionnaire (GHQ). The predictors of psychological problems in caregivers were determined using a logistic regression analysis, with a special emphasis on caregiver burden.

**Results:** The content validity of the CDS was established through the process of item generation and the multidimensionality of the CDS was confirmed by an exploratory factor analysis. The construct validity of the CDS was confirmed by demonstration of a moderate to good correlation with two hypothetical constructs, namely the caregiver quality of life and severity of the disease in the care recipient. Both internal consistency and the reliability of the CDS, assessed using Cronbach's alpha and test-retest reliability, were found to be satisfactory.

The caregiver characteristics that demonstrated a significant association with a high level of burden included, rural residence ( $p < 0.001$ ), low level of education ( $p < 0.001$ ), low family income ( $p < 0.001$ ) and being in an extended family ( $p < 0.001$ ). Having less siblings ( $p = 0.05$ ), spastic quadriplegic cerebral palsy ( $p = 0.004$ ), longer duration of illness ( $p = 0.003$ ), presence of co-morbidities ( $p < 0.001$ ) and more associated problems ( $p < 0.001$ ) were also significantly related to a high level of caregiver burden. The treatment related variables associated with a high burden of caregiving included having more treatment types ( $p = 0.002$ ) and a higher expenditure for the child ( $p < 0.001$ ). The spousal support ( $p < 0.001$ ) and practice of coping methods were associated with a low level of caregiver burden ( $p = 0.001$  or  $p < 0.001$ ).

Fifty six percent of the caregivers had psychological problems according to the GHQ (95% confidence interval=51.0%-61.0%). The presence of psychological problems was significantly related to a high level of caregiver burden ( $p < 0.001$ ). Other factors associated with the caregiver psychological problems included, low educational level of the caregiver ( $p = 0.005$ ), being in an extended family ( $p = 0.02$ ), younger age of the child ( $p = 0.04$ ), non-schooling states of the child ( $p = 0.04$ ), presence of co-morbidities ( $p < 0.001$ ), a higher number of associated problems ( $p < 0.001$ ) and treatment types ( $p = 0.004$ ), lack of spousal support ( $p = 0.01$ ) and not seeking support from a trusted person to look after the child ( $p < 0.001$ ).

The logistic regression analysis identified 5 predictors of psychological problems in the caregivers. The strongest predictor for presence of psychological problems was the level of caregiver burden ( $p < 0.001$ ). The educational level of the caregiver and the age of the child ( $p < 0.001$ ) were also predictive of the psychological problems ( $p < 0.001$ ). The other predictors included the number of treatment types ( $p = 0.02$ ) and not seeking caregiving support as a coping method. ( $p = 0.04$ ).

**Conclusions:** The CDS demonstrated good psychometric properties as a caregiver assessment instrument, during the preliminary appraisal of validity and reliability. It can be used to predict psychological problems in the principal caregivers of children with cerebral palsy in a hospital setting. There are a number of factors associated with caregiver burden and caregiver psychological problems, which needs to be considered when developing long term care plans for children with cerebral palsy.