A Cross sectional study on caregiver needs, perceived burden, coping and health related quality of life (HRQoL) among caregivers of stroke patients with a view to develop ‘care-guidelines’ for the caregivers in selected community settings, Punjab

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Abstract

**Introduction & Background:** Stroke entails the sudden death of brain cells resulting from a problem with the blood supply. The patient is subsequently left with varying degrees of disability, and usually requires the assistance of a caregiver. Long-term caregiving expose caregiver to face enormous amount of burden and subsequently compelled to adopt negative coping strategies in order to maintain good quality of life. The aim of the study was to identify caregiving needs, perceived burden, coping strategies and health related quality of life among caregivers and development of ‘care-guidelines’ to meet caregiving needs of caregivers.

**Material & Methods:** A cross sectional descriptive correlational survey was carried out by recruiting 100 caregivers purposively. Caregiver Need Questionnaire (CNQ), Zarit Burden Interview Schedule (ZBIS), Coping Checklist (CCL) and World Health Organization Quality of Life– BREF (WHOQOL–BREF) scale was used to identify caregiving needs, perceived burden, coping strategies and quality of life in caregivers. Data was collected through self-administration (paper-pencil) technique. The ‘Care-Guidelines’ was developed through Delphi technique to the caregivers of stroke patient. Data was analyzed by using descriptive and inferential statistics and is presented thorough tables and figures.
**Results:** The mean age of caregivers was 41.79 years (SD± 14.12, range 21-79 years. In terms of caregiving, 36% caregivers were sons/daughter, followed by 33% spouses and 58% providing care round the clock with mean duration of 2.68±1.89 months. 94% of caregivers reported availability of another person at home to take care of patient and 85% were found healthy. 86% of caregivers agreed for availability of family support in the care of patients. CNQ findings evidenced that need related to professional support(86.67%) were more frequently reported by the caregivers followed by health information (85.14%) and involvement in care needs (81.50%). Further, 63% caregivers faced moderate to severe burden. Acceptance (77%) was most frequently used coping strategies by the caregivers. Good quality of life was in social relations aspects (69.91%) followed by psychological (64.24%) and environment quality of life (62.93%). The burden was negatively related with psychological (p<0.05), social (p<0.01), and environment (p<0.01) quality of life. Acceptance coping strategy had statistical significant relationship with satisfaction with quality of life (p<0.01), physical (p<0.05) and psychological quality of life (p<0.01) in caregivers. Denial coping strategy had statistical significant relationship with burden (p<.01) and other different types of burden (p<.01) in caregivers. Total burden had statistical significant association with family history of stroke (p=0.008), secondary education status (p=0.039), short caregiving time at home (hrs/day) (p=0.011) and lack of support in care (p=0.000). The extent of burden had statistical significant association with caregivers’ employment status (p=.030), relationship with patient (p=.045), availability of another person at home (p= 0.049), past family history of stroke (p=0.020) and availability of support (p=0.002) in care. Problem focused coping strategies had statistical significant association with age (p=0.004) and gender of the caregivers (p=0.001), education status (p=.001) and caregiving total time (hrs./day) (p=0.008). Time of care (day or night) (p=0.031) and healthy life style (p=0.023) of caregivers were had statistical significant association with emotional
and seeking social support coping strategies by caregivers respectively. Physical quality of life found statistical significant association with family structure ($p=0.048$) and availability of support in care ($p=0.032$). Psychological quality of life was statistical significant association with gender ($p=0.013$), marital status ($p=0.012$), employment status ($p=0.014$), and total caregiving time/day ($p=0.027$). Social relation quality of life found statistical significant association with family history of stroke ($p=0.004$), availability of support in care ($p=0.004$) and caregiving total time (hrs./day) ($p=0.024$) in care of patient at home. Environmental quality of life found statistical significant association with caregivers’ family history of stroke ($p=0.001$), availability of support ($p=0.019$), family structure ($p=0.044$), health status of caregiver ($p=0.025$), and caregiving total time (hrs./day) ($p=0.003$).

**Conclusion & Recommendations:** Caregivers of stroke survivors felt varied types of caregiving needs to meet the patient demands at home. Unmet home needs consequently put enormous burden and subsequently worsen health related quality of life in caregivers. Study recommended to provide hands on training or to devise specific target interventions for caregivers to enhance their quality of life and successful stroke home rehabilitation.

**Keywords:** Stroke, caregivers, needs, burden, coping, quality of life