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Psychological experiences of informal caregivers of patients with dementia

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Background: Dementia is a chronic deteriorating condition of older adults with the symptoms of cognitive and functional decline, behavioural problems, lack of insight, and personality changes. Hence, patients with dementia need caregivers to assist their daily living activities. Most caregivers are family members; known as informal caregivers whose tasks often influence their psychological wellbeing.

Objective: This study explored the psychological experiences of informal caregivers of people with dementia at the Neuropsychiatric clinic in the National Hospital of Sri Lanka.

Method: Twenty informal caregivers with more than six months of caregiving experiences as caregivers of people with dementia were purposively recruited for this phenomenological study at the Neuropsychiatric clinic in the National Hospital of Sri Lanka. Ethical clearance was obtained from the National Institute of Mental Health. Data were collected by semi-structured interviews and data analysis was done using Colalizzi’s analysis method.

Results: Three themes that emerged from the data were, caregivers’ helplessness, stressful caregiving process, and stress due to deficiency of healthcare services. Lack of support from family in caregiving, lack of proper training to handle people with dementia, and stress due to financial instability created caregivers’ helplessness. Stress due to poor prognosis of people with dementia and the time-consuming caregiving process was identified as stressful caregiving process. Lack of proper health education and unavailability of social support groups for caregivers generated stress due to deficiency of healthcare services.

Conclusion: The caregivers of people with dementia have faced many negative psychological experiences due to caregivers’ helplessness, stressful caregiving challenges, and inadequate healthcare services that further lead to a decrease in their psychological wellbeing. Hence, it is recommended to ensure the importance of arranging counseling sessions, proper health education and training programs, and community and social support services for informal caregivers of people with dementia.