

## ABSTRACT

Schizophrenia is a major mental illness. It is characterized by auditory hallucinations, delusions and disorganized speech. Chronic nature of this disease needs long term rehabilitation. Once these patients are discharged from the hospitals long term rehabilitation is provided mainly by unpaid informal caregivers who are family members, relatives, friends and neighbours. Due to the chronic nature of the illness, long term caring may lead to psychosocial problems among these caregivers.

The main objective of this study was to identify psychosocial problems and knowledge of caregivers involved in the long term care for patients with schizophrenia and to develop, implement and assess the effectiveness of an intervention to improve emotional well being of caregivers of patients with schizophrenia.

This study was conducted under two phases. Phase 1 was a descriptive cross sectional study and 226 caregivers of patients with schizophrenia in the Gampaha district identified in the community on the details of their schizophrenia patients. Patient details identified from the selected hospitals with psychiatric treatment facilities.

The study instrument was an Interviewer Administered Questionnaire developed after literature review, discussions with experts and Focus Group Discussion with caregivers. Translated, pretested Sinhala version of Interviewer Administered Questionnaire was recommended by experts using Delphi Technique. Data collection was done by trained data collectors.

Phase 1 of present study revealed that 54.1% of caregivers were aged between 30-39 years and mean age was 38.5. Females (61.5%) were higher than males (38.5%). Majority (88.1%) of caregivers were married. Of the caregivers 54.9% had Grade 6 to G.C.E (O/L) education. Approximately 80% of caregivers did not have satisfactory family relationships while 49.5% caregivers were family members. Majority (75.2%) of caregivers were not engaged in leisure time activities. Only 5.8% of caregivers had adequate rest while caring and 68.8% of caregivers were sad to see their loved one was

suffering. Of the caregivers 68.6% were found to be not having adequate money for their own needs while 93.8% did not have adequate money for their family needs. Majority (85.8%) of caregivers reported that they were not receiving due respect. Of the 14.2% who received due respect 28.1% received by service providers. Caregiver life satisfaction at the end of the day, irritability with the patient and neglected caregiver own health were not significantly associated with the severity of schizophrenia. Caregiver social contacts and sharing feelings with others found to be significantly associated with severity of patient illness. Severity of schizophrenia was significantly associated with caregiver sleep pattern and sharing feelings with others. Type of the family, duration of care giving and sex of caregivers were significantly associated with caregiver knowledge on schizophrenia and home based rehabilitation. Financial assistance (34.1%) was the most prioritized need of caregivers.

Phase 2 was an intervention study to improve emotional well being of caregivers of patients with schizophrenia. Referring to the definition of emotional well being, Ways of Coping instrument was identified to assess the coping strategies of caregivers and selected items of Interviewer Administered Questionnaire of Phase 1 identified, to assess managing emotions of caregivers in the intervention. Ways of Coping was translated and validated into Sinhala language to assess coping strategies of 127 caregivers of patients with schizophrenia in Colombo district. Ways Of Coping (Sinhala) instrument found to be a reliable and valid instrument for screening of caregivers coping strategies of patients with schizophrenia. Validity of the Ways of Coping instrument was satisfactory with sensitivity of 85.8% and specificity of 71.8%. Cut off point (30) recognized in this study can be used in the community surveys.

Based on the results of phase 1 and expert opinion, intervention modules were developed by the Principal Investigator with guidance of Consultant Psychiatrist. Developed modules were pre tested and recommended by a panel of experts prior to implementation. Implementation of intervention was done by experts in the relevant fields. Thirty six caregivers of patients with schizophrenia selected for each intervention and control group. Intervention group had eight intervention sessions and control group had two

general health oriented sessions. Socio demographic factors were similar in both intervention and control groups.

It is concluded that intervention has improved emotional wellbeing of caregivers of patients with schizophrenia. Ways of coping, family relationships, leisure time activities, social contacts, rest during caring, share own feelings, caregiver and family satisfactory feeling and knowledge of caregivers showed significant association in the intervention group prior to and after intervention.