

Abstract

Introduction Epilepsy is not simply a seizure disorder. It is a condition, which has a significant impact on a poor psychosocial outcome of the Principal Care Givers (PCG). For the better management of epilepsy, the psychosocial problems among the PCGs and their knowledge on epilepsy have been identified as priority factors in the recent past.

The objectives of this research was to assess the effectiveness of an intervention to improve the 'knowledge on epilepsy' and 'coping with psychosocial problems' among the PCGs, having Children With Epilepsy (CWE) aged 3-12 years, attending state hospitals, in the Colombo District.

Methods. The study consisted of two phases. In phase 1 of the study, the instrument Children with Epilepsy- Caregiver Questionnaire Sinhala [CWE-CGQ(S)] was developed and validated to assess the knowledge on epilepsy among the PCGs of CWE and to describe the psychosocial problems among them. This instrument was translated into the Tamil Language [Children with Epilepsy -Caregiver Questionnaire -Tamil [CWE-CGQ (T)] and validated. A convenient sample of 378 PCGs was selected from the state hospital clinics in the Colombo district. Their knowledge was assessed and their psychosocial problems were identified using the CWE-CGQ(S) and CWE-CGQ (T).

A quasi-experimental intervention was carried out to improve the knowledge on epilepsy and coping with their psychosocial problems. Knowledge on epilepsy and psychosocial problems of PCGs were obtained from the baseline survey. Coping strategies were assessed using Revised Ways of Coping Checklist (RWCC) Sinhala in the intervention group (IG) and the control group (CG). Based on the above results the intervention module was prepared. The intervention was carried out over a period of two months and the assessment was done six months after the intervention using the knowledge assessment section of the CWE-CGQ(S), which was used at the baseline survey. Coping strategies were assessed using the RWCC Sinhala. The

selected psychosocial problems were assessed using a checklist. Monitoring was done in the IG.

Frequency distribution and cross tabulation were done to analyze the baseline survey. The intervention was analyzed before and after the study and within the study groups.

Results The survey found that almost 98% of the PCGs of CWE were the mother of the epileptic child. More than three quarter of them had their school education beyond grade five. Approximately 40% of them had poor levels of knowledge on epilepsy. The common psychosocial problems experienced by the PCGs were their perception of deterioration of their social status because of their child's epileptic condition (49%), the perception of discrimination by the society because of their child's epilepsy (26%) and financial difficulties (44%) due to the child's epilepsy. Frustration (27.5%), depressed mood (30.4%), anger (34.9%) and hopelessness (41.0%) were the psychological problems experienced by the PCG within the previous two weeks. With regard to their spouses support, 36% stated that they were always helped by their spouse in caring for their epileptic child while 23.4% were provided with emotional support all the time by their spouses.

Following the intervention, a significant improvement of knowledge on general information of epilepsy ($p < 0.05$), management of epilepsy ($p < 0.05$) and overall knowledge on epilepsy ($p < 0.05$) was observed among the PCGs in the IG compared to the control group at six months follow up.

A significant reduction of the psychosocial problems was found in the IG compared to the CG six months after the intervention. A significant reduction of the PCGs' perception of deterioration of their social status because of the child's epilepsy ($p < 0.05$) and societal discrimination of the PCG ($p < 0.05$) was also observed. Their financial difficulties due to the child's epilepsy were reduced significantly ($p < 0.05$) following the intervention. The PCGs psychological problems such as frustration ($p < 0.05$), depressed mood ($p < 0.05$), anger ($p < 0.05$) and hopelessness ($p < 0.05$) reduced significantly after the intervention.

A significant improvement of planful problem solving ($p < 0.05$, accepting responsibility ($p < 0.05$), reduction of escape- avoidance ($p < 0.05$) and positive reappraisal ($p < 0.05$) coping strategies were observed in the IG compared to the CG six months after the intervention.

Conclusion and recommendation This study found that CWE-CGQ(S) and CWE CGQ (T) were valid and reliable instruments to assess knowledge on epilepsy and to identify psychosocial problems. A significant percentage of the PCG of CWE were found to have lack of knowledge on general information and management of epilepsy and also to suffer from a range of psychosocial problems. With effective intervention targeting these problems, one could improve their knowledge on epilepsy and also give answers to cope with their psychosocial problems. It is recommended that the CWE-CGQ(S), CWE-CGQ (T) and the intervention module be used in community and hospital settings in Sri Lanka.

Key words Epilepsy, Principal care giver, children with epilepsy, children with epilepsy- caregiver questionnaire