Original Article

Effects of Nursing Intervention on Knowledge and Family Functioning among Parents of Epileptic Patients

Rukhsana Kousar[1], Hajra Sarwar[1], Kousar Perveen[1] and Sadia Khan[2]

ABSTRACT

Objective: To evaluate the effect of educational interventions on knowledge, and family functioning of parents regarding the epileptic patient's management.

Study Design: Qausi experimental study

Place and Duration of Study: This study was conducted at the Department of Neurology Faculty of Allied Health Sciences, The University of Lahore from June 2021 from October 2021.

Materials and Methods: 36 parents of epileptic patients were enrolled. The parents of epileptic patients who visited in the neurology clinic (OPD) were included and the parents who were already in the health profession and whose children without seizures in the last year were excluded. Family functioning was assessed by using the Family Assessment Device (FAD).

Results: Majority of patients were more than 35 years old (63.9%), females (66.7%), have secondary education (36.1%) and belongs to rural area (58.1%). After intervention it was observed a statistical significant difference in domain of FAD like problem solving, Defining Roles, Affective involvement, behavior Control and general function of family (P<0.05).

Conclusion: The nurse plays a vital role in improving the family functioning of epileptic family's. They are the key essentials for training parents. The Nursing intervention has positive impact on the family functioning of epileptic patients especially in problem solving, defining roles, affective involvement, behavior control and general function of family.

Key Words: Epilepsy, Family Functioning, Intervention programme, Education

INTRODUCTION

Epilepsy is chief neurological illnesses among the children that affect approximately 50,000,000 individuals around the globe.[1] Among all the epileptic cases in the world, 80% of the population with epilepsy is from the developing countries. However, in spite of all these facts, epilepsy happen at any stage of life but half of the epileptic cases appeared in youth or adolescent. A recent survey on epilepsy conducted in the twenty three Asian nations including specially Bangladesh explored that the ratio of epilepsy is 1.5 to 14.0 % out of 1000 people in these Asian countries.[2]

1. Department of Lahore School of Nursing / Physical Therapy[2], Faculty of Allied Health Sciences, The University of Lahore.

Correspondence: Rukhsana Kousar, MS Scholar, Lahore School of Nursing, Faculty of Allied Health Sciences, The University of Lahore.
Contact No: 03030-7518195
Email: rukhsanakusar9909@gmail.com

The prevalence of active epilepsy in Pakistan was 0.98% with 98.1% epilepsy treatment gap in the rural area.[3]

Epilepsy is often misunderstood and not taken seriously as compare to other diseases the reason behind it is lack of health related knowledge, poor economic condition, shortness of health facilities in the remotes areas. So that, the ratio of epilepsy is very high in the developing countries and treatment gap is very difference than the developed countries.[4] Epilepsy is an old common neurological condition. It occurs due to unprovoked spontaneous seizures. The prevalence rate in elderly people and children is 0.7-1.0%, where some patients have more signs and symptoms like jerky movements and unsatisfied behavior.[5]

Parents do not have enough knowledge to access epilepsy just like medical professionals. Sudden onset of epilepsy has strong effect on family routine life. Sometimes parents' emotional supports delay the initial diagnosis.[6] Moreover, delay and mishandling of these problems from parents can be life threatening for epileptic patients. Especially children need more attention in this condition, because they can encounter worse complications during seizure. The combination of fever and seizure in children, develop severe anxiety in their parents as the time of despair sometimes they proclaimed that their children are dying. However, it is

important for the parents or attendants should be aware for management of this disease during the critical time to save the child from developing epileptic complications. It is necessary to educate parents to manage this problem at home care.[7] Epilepsy in individual not only affects their perception and good behavior, but also effect on caregivers, involving employment and work at home, physical and emotional health, relations of health care providers with partner, other age fellows, friends, and self-confidence for caregiving.[8]

Epilepsy has significant influence on family functioning. Epilepsy can cause psychological difficulties in terms of stress, stigmatization, marital issues, low self-esteem, and social anxiety in family members. Family functioning is an important factor for intervening patient's condition and outcome.[9] It is essential that the parents maintain their coping strategies because the psychological well-being of a parent is directly related to family functioning. If a family is not able to function, there may be a profoundly negative impact on the child's psychosocial adjustment to living with a chronic condition.[10] Training of parents for improving family functioning and effective self-management behaviors are very essential. Several training programs have been developed and available for patient's self-management.[11] Parents need sufficient knowledge and awareness regarding epilepsy. It was observed that there was a direct relation between parents' knowledge and their practice.[12,13]

Due to poor knowledge of epilepsy family functioning suffers badly. Parents of epileptic patients cannot participate in active decision making, role and relationship, effective communication, due to lake of knowledge. They cannot manage actively epileptic seizure at home because they have no training and knowledge regarding epilepsy. Sufficient knowledge helps the families of epileptic patients to improve the family functioning. Therefore, there is a need educational intervention programs at community level which will be improved the knowledge and family functioning of parents with epileptic patients. The objective of the current study was to evaluate the effect of educational interventions on knowledge, and family functioning of parents regarding the epileptic patient managemen.

MATERIALS AND METHODS

This quasi experimental study was conducted at public sector hospital, Neurology Department. The study duration was from 1st June 2021 to 31st October 2021. Ethical approval was obtained from Institutional Review Board of University of Lahore. Thirty-six parents of epileptic patients were enrolled in current study after taking informed consent. The parents of epileptic patients who visited in the neurology clinic

(OPD) were included and the parents who were already in the health profession and whose children without seizures in the last year were excluded. Data regarding Socio demographic characteristics for parents with epileptic patients was collected through a self-administered questionnaire. Parent's knowledge about epileptic patient care will be assessed through questionnaire developed by Joan Austin[14] "Knowledge of parents toward epilepsy". The questionnaire had questions which were of the close ended type and comprised of true/false answers. Family functioning was assessed by using the Family Assessment Device(FAD) developed by Epstin et al.[15] The scale have 7 domains including, Communication (6 items), Problem solving(5 items), Affective response(6 items), Affective Involvement(7 items), General Functioning (12 items) and Role (8 items). Responses of each items were graded as strongly agree' to 'strongly disagree' based on how the participant's family reacts most of the time. Scores on the 12 items are summed to produce a total ranging from 4 to 48. Lower scores indicate healthy functioning in terms of communication and problem solving, and higher scores reflect unhealthy family functioning.

Intervention:

Phase I: Parents were introducing about the program after the self-introduction then written consent will be taken to participate in the study. Pre-test was conducted through structured schedule questionnaire. Demographic data was collected through face-to-face interview; parent's knowledge about epileptic patient care was" Knowledge of parents toward epilepsy" questionnaire. And family functioning was assessed by using the Family Assessment Device (FAD)

Phase II: The education program was implemented over 16 weeks. The study participants attended 5 sessions, 2 sessions for theory (6 weeks) which includes epilepsy knowledge, self-management skills and social support and 3 sessions for practice of seizer management, coping with problems, improving family functioning (10 weeks). The duration of each session ranged between 30-45 minutes. At the beginning of each session researcher starts by giving a summary about previous session and explaining the objective new one. Different strategies were used including brain storming, instructions, lectures, role playing and group discussions.

Phase III: After 4 month of intervention Post-test was conducted. Post-test data was collected by using same questioners.

Statistical analysis was performed using the SPSS-26. The frequencies, proportions and comparisons of means using a paired t-test will analyze. Differences were considered statistically significant if $p < 0.05$.

RESULTS

There were 13 (36.1%) participants having age less than 35 years and remaining 23 (63.9%) were having age above 35 years. Among those 13 participants; 3 (8.3%) were having poor, 4 (11.1%) average level and 6 (16.7%) good levels of knowledge. Whereas from participants above 35 years of age; 3 (8.3%) were having poor, 8 (22.2%) average and 12 (33.3%) were having good levels of knowledge. There were females 24 (66.7%) and 12 (33.3%) were males. There were 7 (19.4%) males who achieved good level of knowledge post-test and 11 (30.6%) were females. Majority of the participants were having secondary level of education 13 (36.1%). Twenty-four (66.7%) were employed and remaining 12 (33.3%) were employed. From employed participants 2 (5.6%) were having poor knowledge, 4 (11.1%) were having good knowledge and 6 (16.7%) were having good level of knowledge. Twenty-one (58.3%) from rural area while remaining 15 (41.7%) were from urban area. There was statistically insignificant (P>0.05) relationship between demographic characteristics and level of knowledge at post-test (Table 1).

It has been observed that there were statistically significant (P<0.001) changes in all dimensions except communication and affective responsiveness between pre and post intervention session. The pre-intervention mean score regarding problem solving was 2.66±0.43 and post intervention mean score was 2.00±0.42 with a mean difference of 0.66±0.63 (p<0.001). Regarding communication, the pre-study mean score was 2.38±0.22 and post-study session mean score was 2.34±0.64 (p=0.782). Concerning roles dimension the pre-intervention mean score was 2.48±0.56 and post-intervention was 2.13±0.50 (p<0.003). The affective responsiveness the mean score was observed as 2.45±0.61 before study and after 2.26±0.48 (p=0.140). The affective involvement the pre-study mean score was 2.62±0.64 and post-study the mean score decreased to 1.93±0.45 (p<0.001). The behaviour controls the mean score before 2.68±0.49 and after 1.90±0.35 (p-value < 0.001) and concerning general functioning the mean score before 2.32±0.59 and post study was 1.93±0.40; with a mean difference of 0.39±0.67 (p<0.001) [Table 2].

There was statistically significant (P<0.001) difference regarding pre-post knowledge levels. According to pre-intervention sessions there were almost 18 (50.0%) participants having poor knowledge, 12 (33.3%) participants having average knowledge and remaining only 6 (16.7%) participants having good knowledge. As far as post-intervention session is concerned there were only 6 (16.7%) participants who were having poor knowledge regarding epilepsy, 12 (33.3%) participants were having average knowledge and 18 (50.0%) participants were having good knowledge regarding epilepsy (Table3).

Table No.1: Relationship of demographic characteristics of parents and their knowledge at post intervention

Variable	Level of Knowledge				χ2	P value
	Poor	**Average**	**Good**	**Total**		
Age (years)						
< 35	3 (8.3%)	4 (11.1%)	6 (16.7%)	13 (36.1%)	0.602	0.740
≥ 35	3 (8.3%)	8 (22.2%)	12 (33..3%)	23 (63.9%)		
Gender						
Male	2 (5.6%)	3 (8.3%)	7 (19.4%)	12 (33.3%)	0.625	0.732
Female	4 (11.1%)	9 (25%)	11 (30.6%)	24 (66.7%)		
Education						
Primary	1 (2.8%)	2 (5.6%)	6 (16.7%)	9 (25%)	5.300	0.506
Secondary	4 (11.1%)	3 (8.3%)	6 (16.7%)	13 (36.1%)		
Bachelor	1 (2.8%)	5 (13.9%)	4 (11.1%)	10 (27.8%)		
Masters	-	2 (5.6%)	2 (5.6%)	4 (11.1%)		
Employment Status						
Employed	2 (5.6%)	4 (11.1%)	6 (16.7%)	12 (33.3%)	0.000	1.000
Unemployed	4 (11.1%)	8 (22.2%)	12 (33.3%)	24 (66.7%)		
Residential Area						
Rural	5 (13.9%)	7 (19.4%)	9 (25%)	21 (58.3%)	2.057	0.358
Urban	1 (2.8%)	5 (13.9%)	9 (25%)	15 (41.7%)		

Table No.2: Comparison of means scores regarding family functioning domains among participants

Domains	FAD Scores			t	P value
	Before Study	**After study**	**Mean Difference**		
Problem solving (Cutoff=2.20)	2.66±0.43	2.00±0.42	0.66±0.63	6.348	<0.001*
Communication (Cutoff=2.20)	2.38±0.22	2.34±0.64	0.03±0.70	0.279	0.782

Roles (Cutoff=2.30)	2.48±0.56	2.13±0.50	0.35±0.65	3.242	0.003*
Affective responsiveness (Cutoff=2.20)	2.45±0.61	2.26±0.48	0.19±0.77	1.509	0.140
Affective involvement (Cutoff=2.10)	2.62±0.64	1.93±0.45	0.69±0.85	4.902	<0.001*
Behavior Control (Cutoff=1.90)	2.68±0.49	1.90±0.35	0.78±0.59	7.960	<0.001*
General Functioning (Cutoff=2.00)	2.32±0.59	1.93±0.40	0.39±0.67	3.550	0.001*

* Statistically significant

Table No.3: Knowledge of epilepsy levels

Knowledge level	Level of Knowledge			Test	P value
	Before the Study	After the study	Mean Difference		
Poor knowledge	18 (50%)	6 (16.7%)	12 (33.3%)	Wilcoxon Signed Rank Test	0.001*
Average knowledge	12 (33.3%)	12 (33.3%)	-		
Good knowledge	6 (16.7%)	18 (50%)	12 (33.3%)		

DISCUSSION

Epilepsy is an old common neurological condition. It occurs due to unprovoked spontaneous seizures. Epilepsy is often misunderstood and not taken seriously as compare to other diseases the reason behind it is lack of health related knowledge, poor economic condition, shortness of health facilities in the remotes areas. In current study majority of patients were more than 35 years old (63.9%), females (66.7%), have secondary education (36.1%) and belongs to rural area (58.1%). In a study conducted in an Arab experience shows that if the caregiver was female, less educated, and parent of epilepsy patients had significant effect on their QOL. Females have to face more social, emotional and physical problems.[16] In another cross-sectional study on burden of caregivers shows that majority of the caregivers were females and have tertiary education which also supports the results of current study.[17] In this study majority of the participants belong to rural area. This would be the reason behind poor management and family functioning as they have not much knowledge about epilepsy, medications, nutrition, access to medical services and treatment methods. These findings were supported by different studies which showed that majority of participants were from rural area.[18,19]

The current study focuses on the management of family functioning and coping strategies among families of epileptic patient's. After intervention it was observed a statistical significant difference in domain of FAD like problem solving, Defining Roles, Affective involvement, behavior Control and general function of family (P<0.05). It was also observed that there was significant difference between pre and post intervention results. The findings show that the families who have underwent the intervention programme, follow the instruction of nurses, follow the coping strategies to improve their family functioning, define the responsibility of each family member, how to control and avoid causes the creates problems, make their own decisions and obtain information about self-management shows that the intervention programme was effective and worthy.

The study conducted in India on the effectiveness of educational programme among epileptic patients shows significant difference in mean scores of each domain.[20] In a study conducted in Sweden also shows that the intervention programme has significant effect on the self-management support scales and subscales.[21]

Another study conducted on the effect of nursing intervention programme on self-management and social support in epileptic patient's reported that the nursing intervention plays a vital role in the improvement of management skills of patient. There was significant difference in pre and post intervention.[22] The results of current study also supported by the study conducted on nurse led self-management intervention programme shows significant difference physical role limitations, medication and health issues.[23]

The role of family functioning is very important. A study was conducted to compare the family functioning of pseudoseizures and epilepsy patients. There was significant difference was observed in affective involvement, communication and general functioning among both groups. pseudoseizures thought that they have more dysfunctional families as compared to epileptic patients. It was also suggested that the intervention programs should be conducted so that lacking in family function should be improved.[24].

CONCLUSION

The nurse plays a vital role in improving the family functioning of epileptic family's. They are the key essentials for training parents. The Nursing intervention

has positive impact on the family functioning of epileptic patients especially in problem solving, defining Roles, affective involvement, behavior control and general function of family whereas communication and affective responsiveness shows lacking. Family education and interventions programme should focus on these domains which may lead to important aspects of treatment and improvement in their lives.

Author's Contribution:

Concept & Design of Study:	Rukhsana Kousar
Drafting:	Hajra Sarwar, Kousar Perveen
Data Analysis:	Kousar Perveen, Sadia Khan
Revisiting Critically:	Rukhsana Kousar, Hajra Sarwar
Final Approval of version:	Rukhsana Kousar

Conflict of Interest: The study has no conflict of interest to declare by any author.

REFERENCES

1. Asare RO. Knowledge, Attitude And Practice Regarding Epilepsy Among Nurses In Asutifi North District (Doctoral Dissertation).
2. Mohammad QD, Saha NC, Alam MB, Hoque SA, Islam A, Chowdhury RN, et al. Prevalence of epilepsy in Bangladesh: results from a national household survey. Epilepsia Open 2002;5(4): 526-36.
3. Mogal Z, Aziz H. Epilepsy treatment gap and stigma reduction in Pakistan: a tested public awareness model. Epilepsy Behavior 2020;102:106637.
4. Dhooria A, Gawalkar A, Santosh K, Bahl A, Mb A, Naidu G, Dhir V. Acute myocardial dysfunction in lupus: outcomes in Asian Indians. Clin Rheumatol 2020;39: 3661-7.
5. Kuroda N. Epilepsy and COVID-19: associations and important considerations. Epilepsy Behavior 2020; 108.
6. Jones C, Atkinson P, Memon A, Dabydeen L, Das KB, Cross JH, et al. Experiences and needs of parents of young children with active epilepsy: a population-based study. Epilepsy Behavior 2019; 90: 37-44
7. Lewis SA, Noyes J, Hastings RP. Systematic review of epilepsy self-management interventions integrated with a synthesis of children and young people's views and experiences. J Advan Nursing 2015;71(3):478-97.
8. Jain P, Subendran J, Smith ML, Widjaja E, Team PS. Care-related quality of life in caregivers of children with drug-resistant epilepsy. J Neurol 2018;265(10): 2221-30.
9. Ellis N, Upton D, Thompson P. Epilepsy and the family: a review of current literature. Seizure 2000; 9(1):22-30.
10. Thornton N, Hamiwka L, Sherman E, Tse E, Blackman M, Wirrell E. Family function in cognitively normal children with epilepsy: Impact on competence and problem behaviors. Epilepsy Behavior 2008;12:90-95.
11. Helde G, Brodtkorb E, Bråthen G, Bovim G. An easily performed group education programme for patients with uncontrolled epilepsy - a pilot study. Seizure 2003;12(7):497-501.
12. Hauser WA, Annegers JF, Elveback LR. Mortality in patients with epilepsy. Epilepsia 1980;21(4):399-412.
13. Gürhopur FDT, Dalgiç AI. The effect of a modular education program for children with epilepsy and their parents on disease management. Epilepsy Behavior 2018;78:210-18.
14. Austin JK, MacLeod J, Dunn DW, Shen J, Perkins SM. Measuring stigma in children with epilepsy and their parents: instrument development and testing. Epilepsy Behavior 2004; 5(4):472-82.
15. Epstein NB, Bishop DS, Levin S. The McMaster model of family functioning. J Marital Fam Therapy 1978;4(4):19-31.
16. Ohaeri JU, Awadalla AW, Farah AA. Quality of life in people with epilepsy and their family caregivers. Saudi Med J 2009;30(10):1328-35.
17. Lai ST, Tan WY, Wo MC, Lim KS, Ahmad SB, Tan CT. Burden in caregivers of adults with epilepsy in Asian families. Seizure 2019;71:132-9.
18. Ngugi AK, Bottomley C, Scott JA, Mung'ala–Odera V, Bauni E, Sander JW, et al. Incidence of convulsive epilepsy in a rural area in Kenya. Epilepsia 2013;54(8):1352-9.
19. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, Chandra PS, et al. Need for a national epilepsy control program. Ann Indian Acad Neurol 2012;15(2):89.
20. Seethalakshmi A, Shankar V, Samson R. Effectiveness of an epilepsy education programme on the self-management among patients with epilepsy. IOSR J Nursing Health Sci 2015;4(5):33-54.
21. Fraser RT, Johnson EK, Lashley S, Barber J, Chaytor N, Miller JW, et al. PACES in epilepsy: results of a self-management randomized controlled trial. Epilepsia 2015;56(8):1264-74.
22. Elnaser A, Gamal M, AbdAllah ES, Ali HH, Metwally SM. The Effect of Nursing Intervention Program on Self-Management and Social Support of Adult Epileptic Patients. Zagazig Nursing J 2018;14(2):134-52.
23. Helde G, Bovim G, Bråthen G, Brodtkorb E. A structured, nurse-led intervention program improves quality of life in patients with epilepsy: a randomized, controlled trial. Epilepsy Behavior 2005;7(3):451-7.
24. Krawetz P, Fleisher W, Pillay N, Staley D, Arnett J, Maher J. Family functioning in subjects with pseudoseizures and epilepsy. J Nervous Mental Dis 2001;189(1):38-43.