

EFFICACY OF THE SEIZURES AND EPILEPSY (S.E.E.) PROGRAM ON QUALITY OF LIFE, SEIZURE MANAGEMENT, AND COST SAVINGS FOR ADOLESCENTS WITH EPILEPSY AND THEIR PARENTS

Cheryl P. Shore¹, PhD, RN; Susan M. Perkins², PhD; and Joan K. Austin¹, DNS, RN

¹ Indiana University School of Nursing ² Indiana University School of Medicine

Rationale

Previous research suggests that children with epilepsy and their parents experience stressors related to the child's health condition. Attending the Seizures and Epilepsy Education (SEE) program has increased knowledge and reduced fears in adults with epilepsy. Adolescents with epilepsy and parents have been attending in increasing numbers. The purpose of this study was to investigate the efficacy of the SEE program on quality of life, seizure condition management, and health care costs for adolescents with epilepsy and parents of children with epilepsy.

Methods

Design: A quasi-experimental design was used.

Measures were completed prior to, 1 month after, and 6 months after program attendance.

Subjects: Parents of children with epilepsy and children aged 12 to 19 years were invited to take part. Representatives of 17 families participated. Each participant served as his or her control. Participants attended the SEE program, a two-day intensive psycho-educational program covering the medical and social/emotional aspects of having epilepsy. Data were collected using self-report questionnaires.

Data Analyses: Statistical analyses were completed using SAS Version 9.1. Repeated measures ANCOVA, McNemar's tests and Wilcoxon signed-rank tests were utilized.

Results

Parents significantly improved on many variables both one month and six months after program attendance. Outcomes with continued improvement six months after the program included parental perceptions of child behavior, child mental health, and family activities. Parents showed improved knowledge of epilepsy, had less worry about the seizure condition, reported fewer unscheduled health care visits for their children, and reported fewer child absences from school. Children's scores that remained significantly improved six months after the program included perceptions of their behavior, mental health, self-esteem, and family activities. Children also maintained significantly lower levels of depressive symptoms and had fewer fears about epilepsy six months after program attendance.

Demographics

Mothers (n=12)		
Mean Age		42.2 years
Education Completed		
High School	3 (25%)	
College	3 (25%)	
Graduate School	6 (50%)	
Marital Status		
Married	10 (83.4%)	
Single/Never Married	1 (8.3%)	
Not Reported	1 (8.3%)	
Race		
White	11 (91.7%)	
Black	1 (8.3%)	
Fathers (n=6)		
Mean Age*		45.0 years
Education Completed		
High School	2 (33.3%)	
College	3 (50.0%)	
Not Reported	1 (16.7%)	
Marital Status		
Married	3 (50%)	
Not Reported	3 (50%)	
Race		
White	5 (83.3%)	
Not Reported	1 (16.7%)	
Children (n=10)		
Mean Age		15.5 years
Mean Age at Seizure Onset**		8.9 years
Gender		
Female	4 (40%)	
Male	6 (60%)	
Current Education Level		
Middle School	5 (50%)	
High School	5 (50%)	
Race		
White	10 (100%)	

*one father did not report age
**as reported by the primary caregiver

OUTCOME	INSTRUMENT	PARTICIPANT	NUMBER OF ITEMS
Quality of Life	CHQ Quality of Life Scale	Child	87
	CHQ Quality of Life Scale	Parent	50
	Child Depression Inventory	Child	27
	Multiple Affect Adjective Checklist	Parent	46
Seizure Condition Management	Child Psychosocial Care Scale	Child	24
	Parent Psychosocial Care Scale	Parent	27
	Seizure Self Efficacy Scale for Children	Child	15
	Confidence in Seizure Mgmt Scale	Parent	12
	S.E.E. Pre-Program Survey/S.E.E. Post-Program Survey	Child & Parent	60/80
Medical Costs, Missed Work/School	Account of Health Care Visits and Absences	Child & Parent	6/7

Parent Outcomes

Variable	Baseline	1 month	6 months	Sig. Diff.
Quality of Life				
Child/Parent Health Questionnaire				
	n=16	n=14	n=16	
Global Health	70.3 (23.9)	66.4 (24.5)	80.6 (13.3)	B,6 & 1,6
Physical Functioning	87.2 (21.2)	90.1 (12.6)	90.3 (16.8)	NS
Role Emotional-Behavioral	65.3 (32.4)	84.9 (24.1)	84.0 (25.3)	B,1 & B,6
Role Functioning-Physical	83.3 (25.8)	85.7 (20.5)	88.5 (19.0)	NS
Bodily pain**	70.6 (24.3)	79.3 (21.3)	83.1 (19.6)	B,1 & B,6
Behavior	60.7 (16.7)	67.9 (13.9)	66.5 (18.3)	B,1 & B,6
Global Behavior	57.8 (30.8)	62.5 (21.0)	59.7 (32.9)	NS
Mental Health	61.3 (15.1)	71.1 (16.9)	67.8 (14.0)	B,1 & B,6
Self-esteem	54.4 (20.0)	64.0 (20.8)	60.2 (20.5)	NS
General Health	52.3 (17.7)	52.7 (17.7)	56.1 (15.4)	NS
Change in Health	3.1 (1.1)	3.2 (0.8)	3.7 (1.1)	B,6
Parental Impact-Emotional	31.3 (26.8)	47.0 (20.8)	51.0 (26.0)	B,1 & B,6
Parent Impact-Time**	59.3 (32.2)	70.1 (24.6)	73.0 (25.3)	NS
Family Activities	54.7 (23.0)	72.2 (17.8)	67.2 (16.4)	B,1 & B,6
Family Cohesion	60.3 (23.8)	61.1 (26.6)	67.0 (23.3)	NS
Multiple Affect Adjective Checklist				
	n=15	n=13	n=15	
Anxiety	4.3 (2.9)	3.2 (2.9)	4.0 (3.4)	NS
Depression	4.2 (5.5)	2.8 (2.9)	3.7 (4.2)	NS
Hostility**	1.7 (1.4)	2.0 (1.6)	2.2 (2.0)	NS
Seizure Condition Management				
Parent Response to Illness				
	n=15	n=13	n=15	
Family Life/Leisure Management	3.2 (0.5)	3.4 (0.3)	3.3 (0.5)	NS
Confidence in Seizure Management**	3.9 (0.6)	4.4 (0.5)	4.2 (0.5)	B,1
Parent Psychosocial Care				
	n=15	n=13	n=15	
Information Received	3.6 (0.8)	3.4 (0.8)	3.8 (0.8)	4,6
Unmet Needs for Information	2.2 (0.5)	1.7 (0.6)	1.6 (0.4)	B,1 & B,6
Worry	2.5 (1.0)	1.8 (0.6)	1.7 (0.7)	B,1 & B,6
Pre/Post Knowledge				
	n=14	n=12		
Total Correct**	32.4 (3.7)	36.1 (2.1)	35.3 (2.5)	B,1 & B,6
Fears Total Correct**	11.5 (2.7)	13.3 (1.1)	13.6 (0.7)	B,1 & B,6
Hazards Total Correct	8.1 (1.3)	9.5 (0.8)	9.2 (0.7)	B,1 & B,6
Costs (in last eight months)**				
	n			
More than two scheduled clinic visits	11	8 (72.7%)	4 (36.3%)	NS
At least one unscheduled clinic visit	9	6 (66.7%)	2 (22.2%)	.0455
At least one emergency-room visit	10	3 (33.3%)	1 (10.0%)	NS
At least one hospital visit	7	0 (0%)	0 (0%)	NS
Number of parent absences	10	3.8 (3.5)	1.3 (1.3)	NS
Number of child absences	9	6.3 (5.7)	1.8 (1.5)	.0469

NOTE: Sample sizes reported are the maximum for each instrument at each visit. There was occasionally 1 fewer value due to missing data, and once there were 2 fewer values.
Sig. Dif. = significant differences. B = Baseline, 1 = 1 month after program, 6 = 6 months after program
**Models do not include a random effect for family.
***As reported by the primary caregiver.

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Child Outcomes

Variable	Baseline	1 month	6 months	Sig. Diff.
Quality of Life				
Child Health Questionnaire/Child				
	n=9	n=8	n=9	
Global Health	63.9 (19.3)	66.9 (30.9)	85.6 (11.6)	B,6
Physical Functioning	93.4 (8.0)	93.5 (11.5)	95.5 (5.8)	NS
Role Functioning-Emotional	65.4 (32.6)	86.1 (27.1)	72.2 (36.2)	NS
Role Functioning-Behavioral	81.5 (26.3)	95.2 (12.6)	87.7 (26.9)	NS
Role Functioning-Physical	79.0 (27.5)	95.2 (8.7)	81.5 (26.6)	NS
Bodily Pain	74.4 (25.5)	76.3 (23.3)	81.1 (22.0)	NS
Behavior	67.6 (21.5)	79.8 (17.4)	80.5 (16.2)	B,1 & B,6
Global Behavior	70.6 (22.3)	84.4 (16.6)	88.8 (6.9)	B,1 & B,6
Mental Health	66.4 (16.6)	75.4 (13.3)	77.9 (14.9)	B,1 & B,6
Self-Esteem	65.9 (26.7)	83.3 (22.6)	82.9 (12.5)	B,1 & B,6
General Health	56.9 (20.2)	65.7 (17.3)	67.6 (19.9)	B,6
Change in Health	2.8 (1.0)	3.6 (0.9)	4.2 (1.1)	B,1 & B,6
Family Activities	59.7 (21.7)	76.6 (20.2)	72.7 (22.9)	B,1 & B,6
Family Cohesion	53.9 (26.2)	78.8 (11.6)	56.7 (28.2)	B,1
Child Depression Index				
	n=9	n=8	n=9	
	11.3 (11.9)	5.7 (9.4)	4.7 (4.8)	B,1 & B,6
Seizure Condition Management				
Child Psychosocial Care				
	n=9	n=7	n=9	
Information Received	2.1 (0.5)	2.3 (0.6)	2.3 (0.5)	NS
Unmet Needs for Information	1.6 (0.7)	1.7 (0.4)	1.3 (0.3)	B,6
Worry	2.5 (1.1)	2.1 (1.0)	2.3 (1.1)	NS
Seizure Self-Efficacy				
	n=9	n=8	n=9	
	62.7 (11.0)	60.6 (20.5)	68.3 (8.9)	NS
Pre/Post Knowledge				
	n=8	n=8	n=7	
Total Correct	29.9 (4.0)	29.9 (5.9)	32.6 (3.3)	NS
Fears Total Correct	10.1 (3.6)	11.3 (2.4)	12.4 (1.5)	B,6
Hazards Total Correct	7.3 (1.2)	7.5 (2.1)	7.9 (2.0)	NS
Costs (in last eight months)				
	n			
More than two scheduled clinic visits	8	4 (50%)	2 (25%)	NS
At least one unscheduled clinic visit	5	4 (80%)	0 (0%)	.0455
At least one emergency-room visit	5	2 (40%)	0 (0%)	NS
At least one hospital visit	3	0 (0%)	0 (0%)	NS
Number of child absences	5	7.8 (7.8)	2.4 (1.8)	NS

Limitations

The major limitation was the lack of a control group.

Although we had originally intended to include a control group, recruitment challenges resulted in a quasi-experimental design. The small sample size was a related limitation.

Conclusions

SEE program attendance resulted in improved quality of life and seizure condition management, in addition to reduced health care and other costs for adolescents with epilepsy and parents of children with epilepsy. The results are consistent with those from a previous study with adult participants (Helgeson et al., 1990). Health care providers can recommend the SEE program and reasonably expect that attendance will result in improved quality of life and seizure condition management.