# Best Evidence Statement (BESt)

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***Topic and/or question as originally asked*** What effect inpatient support groups can have on families/parents of children with intractable epilepsy?

**Clinical Question**

P (population/problem) Families with children diagnosed with intractable epilepsy
I (intervention) does the implementation of inpatient mutual support groups versus
C (comparison) standard care
O (outcome) decrease psychosocial stress for the family

**Target Population** parents of children age 0-18 years hospitalized with intractable epilepsy

**Recommendation(s)** It is recommended that mutual support groups for parents/families of vulnerable pediatric patients (i.e. children with intractable epilepsy) in the inpatient care setting be developed, implemented and evaluated (*AndersonButcher, D., Khairallah, A. O., & RaceBigelow, J., 2004-Level 4b; Aytch, L. S., Hammond, R., & White, C. 2001-Level 4b; Lewis, M. H., Hatton, C., Ines, S., Leake, B., & Chiofalo, N., 1991-Level 2b; O'Brien, P. J., 2002-Level 4b).* The evidence demonstrates that parent support groups can:

i. Improve parental attitudes
ii. Increase parental knowledge
iii. Decrease parental anxiety

**Note:** An evaluation of mutual support groups would include a measurement of the intervention's effectiveness and address any potential adverse effects.

**Discussion/summary of evidence**

Of the 11 (see References 1-11) studies found, only 4 *(AndersonButcher, D., Khairallah, A. O., & RaceBigelow, J., 2004-Level 4b; Aytch, L. S., Hammond, R., & White, C. 2001-Level 4b; Lewis, M. H., Hatton, C., Ines, S., Leake, B., & Chiofalo, N., 1991-Level 2b; O'Brien, P. J., 2002-Level 4b)* focused on mutual support groups for vulnerable populations. Of the remaining 7 articles, 5 *(Austin, J.K., McNelis, A.M., Shore, C.P., Dunn, D.W., & Musick, B., 1988-Level 4a; Buelow, J.M., 2007-Level4b; Buelow, J.M., McNelis, A., Shore, C.P., & Austin, J.K., 2006-Level 4b; Mu, P., 2005- Level 4a; O'Dell, C. Wheless, J.W., & Cloyd, J., 2007-Level 5)* discussed background information that would support the intervention and 2 *(Austin, J.K. McNelis, A.M., Shore, C.P., Dunn, D.W., & Musick, B., 2002-Level 4a; Shore, C.P., Perkins, S.M., & Austin, J.K., 2008-Level 4a)* studies focused more on educational interventions. One of the 4 articles *(AndersonButcher, D., Khairallah, A. O., & RaceBigelow, J., 2004-Level 4b)* was a qualitative study which discussed themes from the feedback of participants involved in a mutual support group (parents receiving Temporary Assistance for Needy Families). Themes including mutual support (received support, helped others, provided leadership in group, participated in outreach and advocacy, provided respite, experienced stress relief, socialized with others, had positive outcomes) and tangible outcomes (acquired knowledge, learned skills, enhanced self efficacy) were all identified *(AndersonButcher, D., Khairallah, A. O., & RaceBigelow, J., 2004-Level 4b).*

There was also evidence found to support the intervention of support groups for another vulnerable population (parents of adolescents admitted to an inpatient psychiatric unit). In this article, there was

discussion about the subjective feedback from parents who took part in the intervention. The feedback provided some significant findings. Parents reported feeling less alone, increased feelings of self esteem and confidence concerning the future *(O'Brien, P. J., 2002-Level 4b).*

In a randomized control trial involving support groups, there were significant results found when a 90-minute parent support program utilizing a counseling model and education interventions was implemented. The program was designed to help family members cope, increase knowledge, reduce anxieties, and enhance decision making skills. It was compared to standard education lecture sessions that were 2 hours in length facilitated by a physician *(Lewis, M. H., Hatton, C., Ines, S., Leake, B., & Chiofalo, N, 1991-Level 2b).* With this study, there were significant improved results in parent's knowledge level for needs such as acute seizure management. There was also a significant decrease in anxiety scores among parents per the Taylor's Manifest Anxiety Scale *(Lewis, M. H., Hatton, C., Ines, S., Leake, B., & Chiofalo, N., 1991-Level 2b)* when the experimental intervention was utilized.

In a study examining the effects of seizures on the family, parents raised concern for the child's safety and had an increased sense of vigilance in protecting their child from harm (*Aytch, L. S., Hammond, R., & White, C. 2001-Level 4b*). In this same study, there was further discussion about the family needs for information and support. Some common themes included the need for information about the seizures' effect on early development and learning and the need for accurate and easy to understand information about seizures. Many parents reported that opportunities to talk to other parents of children with a seizure disorder would be helpful. Further discussion included preferences of these parents, if given the opportunity to speak with other parents. Preferences were participating in a parent support group or even communication with an individual family (*Aytch, L.S., Hammond, R., & White, C., 2001-Level 4b*).

**Health Benefits, Side Effects and Risks**

Health Benefits - Increased social support, stress relief, and positive attitude change for parents and families participating in this specific intervention. Further literature goes on to report improved/increased knowledge including seizure management as well as decreased anxiety.

Side Effects - A possible adverse effect of a parent support group may occur if it is not effective in providing the support and attention needed. Some factors that may cause this includes how the support group is facilitated as well as the overall environment of the meeting.

Other Risks - Other risks to consider includes cost for the support group (i.e. location, staff), time involvement of both staff and parents, ability of parents to be able to attend the meetings and if able to have that devoted time away.

**References/citations**

1. AndersonButcher D, Khairallah AO, RaceBigelow J. Mutual support groups for long-term recipients of TANF. *Soc Work*. 2004; 49(1):131-140. Level 4b

2. Austin JK, McDermott N. Parental attitude and coping behaviors in families of children with epilepsy. *J Neurosis Nurs*. 1988; 20(3):174-179. Level 4a

3. Austin JK, McNelis AM, Shore CP, Dunn DW, Musick B. A feasibility study of a family seizure management program: 'be seizure smart'. *J Neurosci Nurs*. 2002; 34(1):30-37. Level 4a

 

4. Aytch LS, Hammond R, White C. Seizures in infants and young children: An exploratory study of family experiences and needs for information and support. *J Neurosci Nurs*. 2001; 33(5):278-285. Level 4b

5. Buelow JM. An intervention for parents of children with epilepsy and significant learning problems; lessons learned from a feasibility study. *Journal of American Psychiatric Nurses Association*. 2007; 13(3):146-146-152. Level 4b

6. Buelow JM, McNelis A, Shore CP, Austin JK. Stressors of parents of children with epilepsy and intellectual disability. *J Neurosci Nurs*. 2006; 38(3):147-54, 176. Level 4b

7. Lewis MH, Hatton C, Ines S, Leake B, Chiofalo N. Impact of the children's epilepsy program on parents. *Epilepsia*. 1991; 32(3):366-366-374. Level 2b

8. Mu P. Paternal reactions to a child with epilepsy: Uncertainty, coping strategies, and depression. *J Adv Nurs*. 2005; 49(4):367-376. Level 4a

9. O'Brien PJ. Reflections of a facilitator for a parent support group in an adolescent in-patient psychiatric program. *Family Therapy*. 2002; 29(3):141-151. Level 4b

10. O'Dell C, Wheless JW, Cloyd J. The personal and financial impact of repetitive or prolonged seizures on the patient and family. *Journal of Child Neurology*. 2007; 22(5 SUPPL):61S-61S-70S. Review Article Level 5

11. Shore CP, Perkins SM, Austin JK. Seizures and epilepsy education (SEE) program for families of children with epilepsy: A preliminary study. *Epilepsy and Behavior*. 2008; 12:157-157-164. Level 4a

12. Teeters JA. List serve support groups, 3/24/08; from NACHRI List Serve. Level 5

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Note: Full tables of evidence grading system available in separate document:

- Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality (abbreviated table below)
- Grading a Body of Evidence to Answer a Clinical Question
- Judging the Strength of a Recommendation (abbreviated table below)

**Table of Evidence Levels** (see note above)

| ***Quality level*** | ***Definition*** |
|---|---|
| 1a† or 1b† | Systematic review, meta-analysis, or meta-synthesis of multiple studies |
| 2a or 2b | Best study design for domain |
| 3a or 3b | Fair study design for domain |
| 4a or 4b | Weak study design for domain |
| 5 | Other: General review, expert opinion, case report, consensus report, or guideline |

†a = good quality study; b = lesser quality study

**Table of Recommendation Strength** (see note above)

| ***Strength*** | ***Definition*** |
|---|---|
| "Strongly recommended" | There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations). |
| "Recommended" | There is consensus that benefits are closely balanced with risks and burdens. |
| No recommendation made | There is lack of consensus to direct development of a recommendation. |

***Dimensions:*** In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.

1. Grade of the Body of Evidence (see note above)
2. Safety / Harm
3. Health benefit to patient *(direct benefit)*
4. Burden to patient of adherence to recommendation *(cost, hassle, discomfort, pain, motivation, ability to adhere, time)*
5. Cost-effectiveness to healthcare system *(balance of cost / savings of resources, staff time, and supplies based on published studies or onsite analysis)*
6. Directness *(the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome])*
7. Impact on morbidity/mortality or quality of life

## Supporting information

### Introductory/background information

Selected patients with intractable epilepsy conditions undergo an inpatient evaluation on the Epilepsy Monitoring Unit (EMU). The purpose of the inpatient admission is to evaluate the patient's potential as a neurosurgical candidate to treat intractable epilepsy. It was anecdotally reported and confirmed in the literature that parents and families have increased stress and anxiety during hospital admissions while caring for a child with intractable epilepsy. The increased stress and anxiety can be related to factors including: seizure medications being held or changed, possible changes in seizure type and intensity, worries of how increased seizures will affect their child's cognitive abilities, lack of predictibility, financial burdens, and extended hospitalization *(O'Dell, C. Wheless, J.W., & Cloyd, J., 2007-Level 5).* One review article reported the degree of parental anxiety over the children's seizures was almost twice what a physician noted it would be *(O'Dell, C., Wheless, J. W., & Cloyd, J., 2007-Level 5).* Another study focused solely on identifying stressors of parents of children with epilepsy. Some major stressors included consequences of seizures including cognitive and physical decline, future concerns about what will happen to their child as they get older, and changes in family relationships including poor family support and sibling relationships *(Buelow, J. M., McNelis, A., Shore, C. P., & Austin, J. K., 2006-Level 4b).*

### Group/team members

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### Search strategy

OVID Medline, OVID CINAHL, OVID EBM Reviews, PubMed, Scopus, PsychInfo., NACHRI list serve, and hand searching the selected articles for references

Search terms included families, psychosocial stress, intractable epilepsy, intervention, advocacy, inpatient support groups, family satisfaction, coping mechanisms, perception, seizures, pediatric

## Applicability issues

The plan to disseminate the evidence and implement a practice change of includes initial steps of providing education to appropriate staff and the unit's Family Centered Care committee. Education will include a synthesis of the evidence found to support the intervention of an inpatient parent support group. Also included in the education will be some of the components that facilitate an effective support group based on the evidence found. The plan also includes the development of an evaluation tool for staff and the committee to complete regarding the education of the proposed intervention (inpatient parent support group). Institutional Review Board (IRB) proposal will need to be accepted if an evaluation tool is developed for the education of staff.



*Additionally for more information about CCHMC Best Evidence Statements and the development process, contact the Health Policy & Clinical Effectiveness office at: 513-636-2501 or* ***HPCEInfo@chmcc.org***.

### Note

**This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.**

## Reviewed by Clinical Effectiveness