Published in final edited form as:

J Neurosci Nurs. 2016 June ; 48(3): 166–174. doi:10.1097/JNN.0000000000000199.

A Randomized Controlled Trial Testing the Efficacy of the Creating Opportunities for Parent Empowerment (COPE) Program for Parents of Children with Epilepsy and Other Chronic Neurological Conditions

Lisa V Duffy, PhD, RN, CPNP-PC, CNRN, MSCN and

Pediatric Nurse Practitioner/Nurse Scientist, Boston Children's Hospital, Home Address: 104 King St. Norfolk, MA 02056, Work Address: Boston Children's Hospital 300 Longwood Ave Boston, MA 02115, Telephone: 508-528-5467 (home) 617-355-4611 (work) 617-355-4611, Fax: 617-730-0285

Judith A. Vessey, PhD, MBA, FAAN

Lelia Holden Carroll Professor, William F. Connell School of Nursing, Boston College, Home Address: 15 Fenmore Ave Wellesley, MA 02482, Work Address: 140 Commonwealth Ave Cushing Hall 427 Chestnut Hill, MA 02467, Telephone: 508-528-5467 (home) 781-237-0216 (work) 617-552-8817, Fax: 617-552-4250

Lisa V Duffy: lisa.duffy@childrens.harvard.edu; Judith A. Vessey: vessey@bc.edu

Introduction

Parents caring for children with neurological conditions face numerous challenges on a daily basis. Children with neurological diagnoses are living with conditions that often have an uncertain prognosis. This uncertainty produces stress, which leads to decreased parental belief in their caregiving skills, anxiety, and depression, ultimately altering parental functioning resulting in an increase in child behavioral problems (Duffy, 2011). The stress associated with caring for a child with neurological conditions is unlike caring for children with other chronic conditions. Neurological conditions are unpredictable and there are often no warning signs prior to an acute event. This produces an additional burden on the parents and family.

Although we know that parents live with these daily struggles, there is little to no existent literature that addresses these issues and helps facilitate coping in parents of children with neurological conditions. As healthcare providers, we need to help these parents learn how to facilitate coping in their child by helping them understand their new parenting role. By doing this, we will be able to decrease the incidence of psychosocial complications in parents, which will ultimately improve the health and functional outcomes in children with chronic neurological conditions.

Conflicts of Interest

The author has no conflicts of interest to declare.

The purpose of this study was to test the efficacy of the Creating Opportunities for Parent Empowerment (COPE) intervention for parents of children with neurological conditions.

Background

Parenting stress has a significant impact on the entire family. The negative consequences associated with the stress of parenting a child with a neurological condition are multifactorial. Most commonly these consequences include; depression, anxiety, decreased confidence in parenting skills, and increased behavior problems in children (Shatla et al., 2011; Wirrell et al., 2008; Buelow et al., 2006; Austin et al., 2004; & Melnyk et al., 2001). Unfortunately, in response to these findings, there have been few studies testing interventions aimed at helping these families learn to manage the day-to-day stress of caring for a child with a neurological condition.

The majority of intervention studies found in the literature including both children and their parents are educational programs for children with epilepsy (Jantzen, Muller-Godeffroy, Hallfahrt-Krisl, Aksu, Pust, Khol, et al., 2009; Snead et al., 2004; Austin et al., 2002; & Tieffenberg et al., 2000). The focus of these studies is on providing medical knowledge to parents and the limited psychosocial support that may have been offered to families by nursing as part of the intervention was not measured. This is an area where there is a significant need for further research. In order for a parental intervention to be successful, the intervention needs to address psychosocial implications, as we know that the parent's mental health can have a significant impact on the child's quality of life (Ferro & Boyle, 2014).

If parents can successfully manage the stress associated with their child's chronic neurological condition, they may be able to help their family adapt to living with such an uncertain illness trajectory. If parents can learn how to interpret their child's reactions to stressful situations, and be given information on how to appropriately respond to those reaction behaviors, then the child will be better equipped to cope with difficult situations. Therefore, it is crucial that an intervention provide parents with both medical information and coping strategies. Creating Opportunities for Parent Empowerment (COPE) is an intervention that teaches parents what behaviors they can expect in their children as a normal response to illness, and how to help their child cope with the illness experience. The COPE intervention has the potential to be successful with parents of children with neurological conditions.

COPE Intervention

COPE was initially developed to enhance the coping strategies of parents of previously healthy children who were admitted to an intensive care unit for the management of an acute condition (Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein, 1997). COPE teaches parents how their child might react to being hospitalized and then instructs parents on how to best respond to their child's needs. Evaluation of this intervention has been positive for parents of children who experience hospitalization for an acute condition. Parents who have participated in the COPE intervention have reported decreased levels of stress and anxiety, fewer depressive symptoms, and increased confidence in their parenting

abilities when compared to parents who did not participate in the intervention (Melnik et al., 2004; Melnik & Alpert-Gillis, 1998; Melnik et al., 1997). Families of children with neurological conditions need to learn how to adapt to the stress associated with living with an uncertain prognosis and repeat hospitalizations, procedures, and appointments. The role of the parent to facilitate coping in their child does not end with the hospitalization. Instead, parent education regarding how to facilitate coping in their child needs to be reinforced on an ongoing basis and each time the child is faced with additional hospitalizations or procedures. The COPE intervention has the potential to be useful among this chronically ill population because it teaches parents how to recognize and interpret their child's behavioral cues.

The strategies espoused in the COPE intervention have been shown to be successful when a child is hospitalized with an acute illness, but have yet to be implemented in facilitating the transition from hospital to home for children with chronic conditions. The transition from hospital to home is especially stressful for parents as there is a considerable amount of uncertainty related to the possible adjustments in their child's medical care as well as not knowing how to help children cope with experiences they may have had while in the hospital. This is an important area where information is lacking since children with chronic conditions will continue to experience repeated hospitalizations over the course of their condition. Although not introduced with parents whose children have a chronic condition, the past success and logical design of the COPE intervention offers an opportunity to replicate the intervention with parents of children with chronic conditions undergoing hospitalization as well.

This randomized controlled study was conducted to address the following research questions:

1. Will parents receiving the COPE intervention demonstrate more belief in their parenting skills post-treatment compared to parents receiving usual care?
2. Will parents receiving the COPE intervention demonstrate lower clinical depression scores post-treatment compared to parents receiving usual care?
3. Will parents receiving the COPE intervention demonstrate significantly less state anxiety post-treatment compared to parents receiving usual care?
4. Will the children of parents receiving the COPE intervention demonstrate fewer behavior problems compared to children of parents receiving usual care?

Methods

Study Design

This study was a randomized controlled trial.

Sample

Participants were recruited from a large urban pediatric teaching hospital in the northeast United States. Individuals were eligible for participation in the study if they were a parent of a child between the ages of 2 to 6 years who had previously been diagnosed with a chronic

neurological condition. Potential participants needed to be literate in English at a ninth grade reading level and have telephone access. Exclusion criteria included: parents of children who had been diagnosed with co-morbid conditions including, but not limited to; significant developmental delays, cancer, and mitochondrial or metabolic disorders.

Demographics for the complete parent sample are presented in table 1. The diagnoses of the children in this study varied. The majority of children had a diagnosis of seizures (76%), however, other diagnoses included; brain tumors, encephalitis, opsoclonus-myoclonus ataxia syndrome, neurofibromatosis, and pseudotumor cerebri.

The timing of the administration of the COPE intervention was modified to be implemented with parents of children with chronic neurological conditions (see table 2). Families of children with these conditions need to learn how to adapt to the stress associated with living with an uncertain prognosis and repeat hospitalizations, procedures, and appointments and the role of the parent to facilitate coping in their child does not end with the hospitalization. Therefore, the administration of the COPE intervention was divided into three phases--the first to be initiated during the hospitalization and the second and third phase to continue after the child was discharged home.

Phase I of the COPE intervention began within twenty-four hours of study enrollment and included oral and digitally recorded information regarding children's expected responses to illness and how caregivers could facilitate the child's adjustment to the experiences associated with the hospitalization. This information was reinforced throughout the hospitalization. Phase II of the COPE intervention consisted of a telephone call from a member of the research team three days after discharge from the hospital to reinforce information provided during Phase I of the program. The information was designed to help parents anticipate and respond to behavior changes that occurred when the child returned to his or her home environment.

Phase III of the COPE intervention included a parent-child activity workbook designed to teach parents how to use therapeutic play techniques to help the child cope with medical procedures and hospitalizations.

Usual Care Group

The Usual Care Group received standard nursing care and education regarding their diagnosis. In addition they received information, oral and written, that discussed tests to be administered during the hospitalization. The Usual Care Group also received a phone call within one week after discharge from a nurse who asked questions related to the hospital experience, and if they had any further needs or questions. Lastly, the Usual Care Group received a coloring book about being in the hospital four to six weeks after hospital discharge.

Instruments

Parental Beliefs Scale

This scale was developed by Melnyk (1994) to better characterize the extent to which child behavior and parental role confusion results in anxiety of the parent. The scale consists of 20 items divided into two subscales. The total scale scores range from 20 to 100 with a Cronbach's alpha of .86 for the total score. The first subscale consists of eight items that measure parent's beliefs about their hospitalized child. The second subscale consists of 12 items that address the parent's belief about their role during the hospitalization (Melnyk, 1994). Items are scored using a five point Likert scale, which ranges from "strongly agree" to "strongly disagree." The first subscale has a total score of eight to 40 with a Cronbach's alpha of .76. The second scale has a total score of 12 to 60 with Cronbach's alpha of .84. For each of these scales a higher score indicates positive beliefs.

Beck Depression Inventory II (BDI-II)

Beck et al. (1996) developed the BDI-II as an instrument to identify the presence or severity of depressive symptoms. The BDI-II is a 21 item self-report scale, which can be administered in a written or oral form in approximately 10–20 minutes. Each item is scored on a scale of 0–3 resulting in a total possible score ranging from 0–63. A higher score indicates more severe depression. Specific scores are as follows: 0–9 indicates minimal depression, 10–18 indicates mild depression, 19–29 indicates moderate depression and 30–63 indicates severe depression. Initial psychometric testing was done with a population of 500 psychiatric outpatients and 120 college students. Cronbach's alpha for the two groups was 0.92 and 0.93 respectively. Test-retest reliability was conducted with 26 outpatients resulting in a correlation of 0.93 (Beck et al., 1996).

State-Trait Anxiety Inventory (STAI-Y)

Spielberger (1983) developed STAI-P to measure state and trait anxiety levels. This measure consists of two self-report scales. The first scale, measuring state anxiety, consists of 20 items related to the level of anxiety at the present time. The second scale, measuring trait anxiety, consists of 20 items that indicate proneness to anxiety. Each scale has a possible score ranging from 20 to 80 and high scores indicate a greater level of anxiety. Initial psychometric properties for the scale were tested using a population of college students for test-retest intervals. Cronbach's alphas for the state scale ranged from 0.86–0.95, and 0.89–0.91, for the trait scale. Test-retest resulted in correlations ranging from 0.16–0.62 for the state scale, and 0.73–0.86 for the trait scale (Spielberger, 1983).

Behavior Assessment System for Children-Parent Report Scale (BASC2-PRS)

Reynolds and Kamphaus (1992) originally developed BASC2-PRS to help parents identify behavior problems in their children. The instrument has been revised and the current 2nd edition (BASC-2) consists of 134–160 items depending on the age of the child. Parents of children between the ages of 2 years and 5 years will complete 134 items, which are comprised of both adaptive and clinical scales. Adaptive scales include items related to activities of daily living, adaptability, functional communication, and social skills. Clinical

scales include items related to aggression, anxiety, attention, atypicality, depression, hyperactivity, somatization, and withdrawal. For children between the ages of 6 years and 11 years, there are an additional 26 items. These additional items include conduct problems (clinical scale) and leadership (adaptive scale). Cronbach's alphas range from 0.74 to 0.80 based on a normative sample drawn from classrooms, community mental health centers, residential schools, and juvenile detention centers (Flanagan, 1995).

Study Outcomes

Sample Size

The study sample included 24 parents in the usual care group and 22 parents in the intervention group.

Results

Parent Confidence—The analysis of variance (ANOVA) revealed that the main effects of time ($p = .094$), group ($p = .669$), and interaction ($p = .077$) on parent confidence were not significant for pre-test versus one week post intervention, pre-test versus eight weeks post intervention, or one week versus eight weeks post intervention. Although there was no statistical significance, there was an overall trend toward significance among participants in the Intervention Group. When comparing parental belief scores from one week to eight weeks after transition to home, mean scores for parental belief in the Intervention Group increased from 71.82 to a score of 79.09 and decreased in the Usual Care Group from 78.64 to 69.64.

Depression—The ANOVA revealed that the main effects of time ($p = .077$) and group ($p = .615$) on parent depressive symptoms were not significant for pre-test versus one week post intervention, pre-test versus eight weeks post intervention, or one week versus eight weeks post intervention.

Participants in both the Intervention Group and the Usual Care Group reported a range of depressive symptoms that were classified as mild to moderate, and in one case severe. Mean scores on the BDI-II ranged from 5.29 to 11.29 over the course of the study. A score between the ranges of zero to nine indicates minimal depression, but a score between the range of 10 and 18 indicates mild depression (Beck et al., 1996).

Anxiety—The multiple analysis of variance (MANOVA) revealed that the main effect of time was significant for differences in state anxiety for both the Usual Care Group and the Intervention Group ($p = .005$). Mean scores of state anxiety for both groups combined was more pronounced at pre-intervention ($M = 42.32$) versus one week posttest ($M = 36.91$) and pre-intervention ($M = 42.32$) versus eight week posttest ($M = 34.50$).

The MANOVA also revealed the main effects of time, group, and interaction were not significant ($p = .418$) when comparing one week posttest versus eight week posttest.

Child Behavior—The MANOVA revealed the main effect of time was not significant ($p = .187$), and the main effect of group was not significant ($p = .431$) when comparing pretest

versus one week posttest indicating that simultaneous differences did not exist by time or group. However, the effect of the interaction was significant for internalized behavior assessment system score only ($p = .037$) as the Usual Care Group reported a significant decrease in internalizing behavior scores in their children over time. The MANOVA revealed the main effect of time was not significant ($p = .551$), and the main effect of group was not significant ($p = .329$) when comparing pretest versus eight week posttest indicating that simultaneous differences did not exist by time or group. The effect of the interaction was also not significant ($p = .058$). The MANOVA also revealed that the main effects were not significant for time ($p = .437$), group ($p = .080$), or interaction ($p = .405$) when comparing one week posttest versus eight week posttest.

Discussion

Study Findings

Parent Confidence—When comparing parental belief scores from one week to eight weeks after transition to home, mean scores for parental belief in the Intervention Group increased from 71.82 to a score of 79.09 and decreased in the Usual Care Group from 78.64 to 69.64. These findings support the idea that the COPE intervention did have an impact on parent's confidence as scores on the Parental Beliefs Scale increased for parents in the Intervention Group only.

The goal of the COPE intervention was to increase parent confidence in their parenting skills by providing education designed to teach parents how to help their child cope with hospitalization. Unfortunately, the education provided did not significantly increase the belief parents had in their ability to manage their child's responses to the management of their condition.

The COPE intervention may not be successful with parents of children with chronic neurological conditions because parent confidence is dependent on a variety of factors and education alone is often not enough to significantly impact their parenting role (McNelis, Buelow, Myers, & Johnson, 2007; Rodenburg et al., 2007). The relationship between education and change has always been tenuous. For parents of children with neurological conditions, they are going to leave the hospital with a child who will continue to have ongoing medical complications and the information provided in the COPE intervention applies to general hospital information and does not address many of the needs of this vulnerable population. Additionally, the COPE intervention lacks a mechanism for providing support and access to additional resources that may have been an important factor why parents in this study continued to have difficulty maintaining belief in their parenting role and may have impeded them from obtaining greater benefit from this study.

It is important to note that parents in both the Intervention Group and the Usual Care Group had moderate scores ($M = 73.95$) on the Parental Beliefs Scale at pretest indicating that overall, participants were unsure how to parent their children during medical procedures and reported low levels of confidence in their parenting abilities. This finding is consistent with findings in the literature that parents of chronically ill children often struggle with how to continue their normal parenting role (Rodenburg, et al., 2011; Mu & Chang, 2010).

Depression—Participants in both the Intervention Group and the Usual Care Group reported a range of depressive symptoms that were classified as mild to moderate, and in one case severe. Although the COPE intervention did not influence the degree of depressive symptoms reported by parents, it is important to note that many parents experienced some degree of depressive symptoms as noted by the scores on the BDI-II. These findings are consistent with studies in the literature that demonstrate that parents of children with neurological conditions often experience feelings of sadness or depression (Ferro et al., 2011; Mu, 2005; Tzoufi et al., 2005; Ferrari, 1989; Rutter et al., 1970).

The education provided by the COPE intervention was designed to indirectly decrease depression by increasing parent knowledge and positive coping strategies. However, before an educational intervention can be successful, parents need to successfully manage feelings of depression in order to be able to effectively interpret the situation. It is possible that factors contributing to depression among this group of parents were multifactorial and not fully addressed by the COPE intervention as the COPE intervention did not offer a full range of supportive resources to these parents.

Anxiety—The findings from this study indicate that parental anxiety is highest at the time of acute hospitalization. These findings were not unexpected as the literature supports that the time of diagnosis and hospitalization is the time of greatest stress for parents (Aytch et al., 2001; Oostrom et al., 2001). Parenting a child acutely hospitalized with a neurological diagnosis produces anxiety related to management of the child's condition. This anxiety is often attributable to the uncertainty of a child's prognosis when they are admitted to the hospital to manage neurological symptoms (Lv et al., 2009).

These findings have important implications for designing and implementing future research studies with this population of vulnerable parents as most education is provided to parents during the hospitalization when their anxiety level is at its highest. This can interfere with their ability to learn and retain important information. Intervention studies need to acknowledge this and tailor the delivery of information to ensure parents are able to understand the information and feel they have the ability and confidence to utilize their knowledge to care for their child.

Behavior—Children in the Usual Care Group experienced higher levels of internalizing behaviors (i.e. – anxiety) during the hospitalization. These findings indicate that hospitalization is stressful for children and it is not clear from the findings why child internalizing behaviors in the Usual Care Group changed without any intervention. The Usual Care Group, however, was comprised of a higher percentage of children with seizures (91.7%) as compared to the Intervention Group (59.1%). Seizures are a frightening experience, even when it is a chronic issue. The increased internalizing behaviors in the children in the Usual Care Group during the acute hospitalization may have been secondary to the seizure diagnosis as children with epilepsy are noted to have higher incidences of behavior problems (Rodenburg et al., 2011; Berg et al., 2005; Oostrom et al., 2001; Austin & Dunn, 2000). Children who are hospitalized experience stress that may manifest as internalizing behaviors and this may naturally improve once their seizure activity is controlled and they are discharged home.

Limitations

This study was limited by sample size. Based on a medium effect size, it is possible that statistical significance for many of the proposed research questions may have been reached if the original proposed sample size had been attained. Attrition was a significant limiting factor to procuring a full sample across the length of the study. Participants were asked to complete three phases of the COPE intervention over a twelve week period. Although 46 participants enrolled, only 21 completed all three phases, thus limiting the ability to study the effect of the COPE intervention over time. Parents may have decided not to continue their participation in the COPE intervention because they found the information provided to be limited and not relevant to their family. A second possibility is that they may have discontinued their participation because the COPE intervention lacks the emotional and social support they needed to be able to help their child cope with the hospitalization. The contributions of these reasons to the high attrition rate, however, remain speculative and warrant further investigation.

Parents expressed an interest in the study, but some articulated that the demands of work-life balance prevented them from ongoing participation. Ancillary comments from parents indicated that they felt the information provided as part of the COPE intervention was not applicable to their child. They did not understand or recognize the fact that even though their child may be acting normally, the hospitalization was stressful for their child. They did not attribute certain behavioral changes in their child, like acting out, to stress from being in the hospital. Young children express stress in different ways and parents may not be aware of this and often think their pre-school aged child may be too young to be affected by these experiences. This lack of knowledge regarding the effects of hospitalization on young children may have influenced their decision to not complete the study.

The content and mode of delivery in the COPE intervention was also a limitation of this study. The COPE intervention does not address many areas of concern for parents of children with chronic conditions. Although parents of children with neurological conditions do need information pertaining to helping their children cope with medical procedures, their need for information regarding the medical management of their child's condition may be the priority. Phase I of the COPE intervention was administered during the hospitalization, which is a time of great stress since the child is often experiencing seizure exacerbation. Phases II and III were administered at home. This was a limiting factor as a research team member was not present to answer questions and explain the information in more detail if needed.

Lastly, the fact that the measurement instruments were provided to participants on paper only and needed to be mailed back to the investigator was a limiting factor. This placed an additional burden on parents; they may have been more likely to complete online versions of the questionnaires (Hunter, 2012). Because the materials were only available in English and non-English speaking families were excluded, this restricted the pool from which to recruit participants. This study did not use an objective measure to assess child behavior problems, but rather relied upon self-report data. This method of data collection has its own limitations as based on social desirability; thus, parents may have underreported child behavior problems.

Summary

Findings from this study highlight several important factors when considering research with families of chronically ill children. Parents of children with neurological conditions face many challenges on a daily basis. In addition to everyday child rearing practices, they also have to manage often complicated medical conditions. How parents respond to their child's needs and experiences may additionally help the child cope with the experience of living with a chronic condition. This, in turn, has implications for improving the functioning of the entire family. Intervention research needs to be developed to facilitate the transition of care from hospital to home.

The findings from this study lay the groundwork for future research involving parents of children with chronic conditions. Parents experience an increased level of anxiety during a child's hospitalization. However, this acute period is when they are provided with education on how to care for their child at home. Children with neurological conditions are unique in the sense that they often experience exacerbations of their condition, which results in repeat hospitalizations. This is challenging for parents who now also need to know how to help their young child cope with hospital stays and medical procedures. The family is burdened with the responsibility of minimizing behavioral regression while helping to promote the cognitive and emotional development of their child during these acute events. Parents often are not even aware of the effects a hospitalization may have on a young child. Future research needs to focus on the effects of repeated hospitalizations and determine how parents can help prepare their child for these repeated experiences. Currently, there are no published intervention studies that successfully provide this information for parents of children with neurological conditions. This is a population that presents unique challenges and future research should focus on how to best meet the needs of these families.

Findings from this study indicate that parents are interested in helping their children, but often have difficulty finding the time to participate in research related activities. Intervention studies need to be designed with this in mind as the information discovered through future studies may be invaluable.

Finally, the results from this study are useful to nursing practice. Nurses who care for these families need to be able to recognize that these families require additional education and support beyond medical management of the child's condition. Nurses can support these families and help teach them strategies to facilitate coping in their child. More and more children are living with chronic neurological conditions and continued research is necessary to help to improve the quality of their lives.

Acknowledgments

Source Funding

The study was supported through a pre-doctoral NRSA awarded by the NIH/NINR.

References

1. Austin JK, Dunn DW. Children with epilepsy: quality of life and psychosocial needs. Annual review of nursing research. 2000; 18(1):26–47.
2. Austin JK, McNelis AM, Shore CP, Dunn DW, Musick B. A feasibility study of a family seizure management program: “Be Seizure Smart. Journal of Neuroscience Nursing. 2002; 34(1):30–37.
3. Austin JK, Dunn DW, Johnson CS, Perkins SM. Behavioral issues involving children and adolescents with epilepsy and the impact of their families; recent research data. Epilepsy & Behavior. 2004; 5:S33–S41.10.1016/j.yebeh.2004.06.014 [PubMed: 15351344]
4. Aytch LS, Hammond R, White C. Seizures in infants and young children: An exploratory study of family experiences and the needs for information and support. Journal of Neuroscience Nursing. 2001; 33(5):278–290. [PubMed: 11668886]
5. Beck, AT.; Steer, RA.; Brown, GK. Manual for the Beck Depression Inventory. 2. San Antonio: The Psychological Corporation; 1996.
6. Berg AT, Smith SN, Frobish D, Levy SR, Testa FM, Beckerman B, Shinnar S. Special education needs of children with newly diagnosed epilepsy. Developmental Medicine & Child Neurology. 2005; 47:749–753. [PubMed: 16225738]
7. Buelow JM, McNelis A, Shore CP, Austin JK. Stressors of parents of children with epilepsy and intellectual disability. Journal of Neuroscience Nursing. 2006; 38(3):147–154. [PubMed: 16817666]
8. Duffy LV. Parental coping and childhood epilepsy: the need for future research. Journal of Neuroscience Nursing. 2011; 43(1):29–35. [PubMed: 21338042]
9. Ferrari, M. Epilepsy and its effects on the family. In: Hermann, BP.; Seidenberg, M., editors. Childhood Epilepsies: Neurological, Psychological, and Intervention Aspects. New York: Wiley; 1989. p. 159-72.
10. Ferro MA, Avison WR, Campbell K, Speechley KN. Prevalence of trajectories of depressive symptoms in mothers of children with newly diagnosed epilepsy. Epilepsia. 2011; 52(2):326–336. [PubMed: 21204823]
11. Ferro MA, Boyle MH. The Impact of Chronic Physical Illness, Maternal Depressive Symptoms, Family Functioning, and Self-esteem on Symptoms of Anxiety and Depression in Children. Journal of abnormal child psychology. 2014:1–11. [PubMed: 24272365]
12. Flanagan R. A review of the behavior assessment system for children (BASC): Assessment consistent with the requirements of the individuals with disabilities education act (I DEA). Journal of School Psychology. 1995; 33(2):177–186.
13. Hunter L. Challenging the reported disadvantages of e-questionnaires and addressing methodological issues of online data collection. Nurse researcher. 2012; 20(1):11–20. [PubMed: 23061269]
14. Jantzen S, Muller-Godeffroy E, Hallfahrt-Krisl T, Aksu F, Pust B, Khol B, Redlich A, Sperner J, Thyen U. FLIP & FLAP - A training programme for children and adolescents with epilepsy, and their parents. Seizure. 2009; 18:478–486. [PubMed: 19477662]
15. Lv R, Wu L, Jin L, Lu Q, Wang M, Qu Y, et al. Depression, anxiety and quality of life in parents of children with epilepsy. Acta Neurologica Scandinavica. 2009; 120(5):335–341. [PubMed: 19456304]
16. McNelis AM, Buelow J, Myers J, Johnson EA. Concerns and needs of children with epilepsy and their parents. Clinical Nurse Specialist: The Journal of Advanced Nursing Practice. 2007; 21(4): 195–202.
17. Melnyk BM. Coping with unplanned childhood hospitalization: effects of informational interventions on mothers and children. Nursing Research. 1994; 43(1):50–55.10.1097/00006199-199401000-00011 [PubMed: 8295841]
18. Melnyk BM, Alpert-Gillis LJ, Hensel PB, Cable-Beiling RC, Rubenstein JS. Helping mothers cope with a critically ill child: A pilot test of the COPE intervention. Research in Nursing & Health. 1997; 20:3–14. [PubMed: 9024473]
19. Melnyk BM, Alpert-Gillis LJ. The COPE Program: A strategy to improve outcomes of critically ill young children and their parents. Pediatric Nursing. 1998; 24(6):521–539. [PubMed: 10085993]

20. Melnyk BM, Feinstein NF, Moldenhouer Z, Small L. Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*. 2001; 27(6):548–558. [PubMed: 12024526]
21. Melnyk BM, Alpert-Gillis L, Feinstein N, Crean H, Johnson J, Fairbanks E, Small L, Rubenstein J, Slota M, Corbo-Richert B. Creating opportunities for parent empowerment: Program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*. 2004; 113(6):e597–e607.10.1542/peds.113.6.e597 [PubMed: 15173543]
22. Mu P. Paternal reactions to a child with epilepsy: uncertainty, coping strategies, and depression. *Journal of Advanced Nursing*. 2005; 49(4):367–376.10.1111/j.1365-2648.2004.03300.x [PubMed: 15701151]
23. Mu PF, Chang KP. The effectiveness of a programme of enhancing resiliency by reducing family boundary ambiguity among children with epilepsy. *Journal of Clinical Nursing*. 2010; 19:1443–1453.10.1111/j.1365-2702.2009.03075.x [PubMed: 20500354]
24. Ostrom KJ, Schouten A, Kruitwagen CL, Peters AC, Jennekens-Schinkel A. Parents' perceptions of adversity introduced by upheaval and uncertainty at the onset of childhood epilepsy. *Epilepsia*. 2001; 42(11):1452–1460.10.1046/j.1528-1157.2001.14201.x [PubMed: 11879349]
25. Reynolds, CR.; Kamphaus, RW. Behavior assessment system for children (BASC). Circles Pines: AGS; 1992.
26. Rodenburg R, Meijer AM, Dekovic M, Aldenkamp AP. Parents of children with enduring epilepsy: predictors of parenting stress and parenting. *Epilepsy & Behavior*. 2007; 11(2):197–207.10.1016/j.yebeh.2007.05.001 [PubMed: 17604228]
27. Rodenburg R, Wagner JL, Austin JK, Kerr M, Dunn DW. Psychosocial issues for children with epilepsy. *Epilepsy & Behavior*. 2011; 22:47–54.10.1016/j.yebeh.2011.04.063 [PubMed: 21705279]
28. Rutter, M.; Graham, PJ.; Yule, W. A Neuropsychiatric Study in Childhood. Heinemann Medical; Philadelphia: 1970.
29. Shatla R, Sayyah H, Azzam H, Elsayed RM. Correlates of parental stress and psychopathology in pediatric epilepsy. *Annals of Indian Academy of Neurology*. 2011; 14(4):252–256. [PubMed: 22346012]
30. Snead K, Ackerson J, Bailey K, Schmitt MM, Madan-Swain A, Martin RC. Taking charge of epilepsy: the development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy & Behavior*. 2004; 5:547–556.10.1016/j.yebeh.2004.04.012 [PubMed: 15256193]
31. Spielberger, CD. State-Trait Anxiety Inventory. Redwood City: Mind Garden; 1983.
32. Tieffenberg JA, Wood EI, Alonso A, Tossutti MS, Vicente MF. A randomized field trial of ACINDES: A child-centered training model for children with chronic illnesses (asthma and epilepsy). *Journal of Urban Health*. 2000; 77(2):280–297.10.1007/BF02390539 [PubMed: 10856009]
33. Tzoufi M, Mantas C, Pappa S, Kateri M, Hyphantis T, Pavlou M, Mavreas V, Siamopoulou-Mavridou A. The impact of childhood chronic neurological disease on Greek families. *Child: Care, Health, & Development*. 2005; 31(1):109–115.10.1111/j.1365-2214.2005.00492.x
34. Wirrell EC, Wood L, Hamiwka LD, Sherman EM. Parenting stress in mothers of children with intractable epilepsy. *Epilepsy & Behavior*. 2008; 13:169–173.10.1016/j.yebeh.2008.02.011 [PubMed: 18337182]

Table 1

Parent Demographic Characteristics by Group (Usual Care and Intervention)

Parent Characteristic	Usual Care Group		Intervention Group	
	<i>n</i>	%	<i>n</i>	%
Gender				
Female	19	79.2	18	81.8
Male	5	20.8	4	18.2
Age				
18 to 29	5	20.8	5	22.7
30 to 39	9	37.5	10	45.5
40 to 49	10	41.7	7	31.8
Ethnicity				
White/Caucasian	20	83.3	18	81.8
Black/African American	1	4.2	1	4.5
Latino/Hispanic	3	12.5	3	13.6
Marital Status				
Single	2	8.3	4	18.2
Divorced	2	8.3	1	4.5
Living with partner	2	8.3	2	9.1
Married	18	75.0	15	68.2
Highest Degree Completed				
Less than high school	0	0.0	1	4.5
High School	10	41.7	7	31.8
Two-year college	2	8.3	5	22.7
Bachelor's degree	8	33.3	4	18.2
Master's degree	4	16.7	3	13.6
PhD or higher	0	0.0	2	9.1
Yearly Household Income				
Less than 25,000	4	16.7	7	33.3
25,000 to 50,000	3	12.5	2	9.5
50,000 to 75,000	2	8.3	3	14.3
75,000 to 100,000	5	20.8	4	19.0
More than 100,000	10	41.7	5	23.8

Table 2**Intervention Timeline**

	Intervention Group	Usual Care Group
During admission to the unit	<ul style="list-style-type: none"> Signed informed consent Completed questionnaires (including demographic information) Received information about the hospital unit and information in phase I of COPE 	<ul style="list-style-type: none"> Signed informed consent Completed questionnaires (including demographic information) Received information about the hospital unit
Three days after discharge from hospital	<ul style="list-style-type: none"> Received telephone call to review information given in the hospital during phase I of the COPE 	<ul style="list-style-type: none"> Received telephone call to review satisfaction with hospital admission and discharge
One week after discharge from hospital	<ul style="list-style-type: none"> Completed questionnaires at home 	<ul style="list-style-type: none"> Completed questionnaires at home
Four to six weeks after discharge	<ul style="list-style-type: none"> Received phase III information at home 	<ul style="list-style-type: none"> Received coloring book at home
Four to six weeks after phase III of the intervention	<ul style="list-style-type: none"> Completed questionnaires at home 	<ul style="list-style-type: none"> Completed questionnaires at home