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Feasibility of a pediatric cognitive-behavioral self-management intervention: Coping Openly and Personally with Epilepsy (COPE)

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ARTICLE INFO

Article history:

Received 12 October 2010

Received in revised form 16 February 2011

Accepted 21 February 2011

Keywords:

Cognitive behavioral intervention

Self-management

Psychosocial

ABSTRACT

A pilot study was conducted to examine the feasibility and satisfaction of an integrated cognitive-behavioral and self-management intervention for youth with epilepsy (YWE) and caregivers. The Coping Openly and Personally with Epilepsy (COPE) intervention was based on empirically supported cognitive-behavioral techniques and theory driven self-management content. Content of the intervention consists of epilepsy education, primary and secondary coping skills. Children and adolescents ages 10–15, who had been diagnosed with epilepsy for at least six months (ICD-9345 codes), had at least average intelligence, no history of a serious mental illness, were not currently being treated for major depression, and lived within an 80 mile radius were considered eligible. Nine youth and their caregivers completed the COPE program and provided self-report data on feasibility, accuracy, and satisfaction of the COPE program. Caregivers and youth reported a high level of satisfaction with the COPE program, and findings support the feasibility and accuracy of the intervention content and delivery. Results provide a foundation for future randomized, controlled, clinical trials to examine the effectiveness of the COPE program for youth with epilepsy and their caregivers.

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1. Introduction

Despite the documented psychiatric comorbidities and psychosocial adjustment difficulties in youth with epilepsy (YWE¹), there is a paucity of research examining the effectiveness of psychological interventions for this population.² A significant number of YWE do meet criteria for a clinical diagnosis of depression or anxiety and require significant mental health intervention.^{3,4} At the same time, many youth who do not have these comorbid diagnoses still report poor quality of life and psychosocial distress,^{5,6} suggesting they could benefit from psychosocial interventions to bolster epilepsy self-management skills.

Self-management skills encompass personal resources, including cognitive and behavioral coping skills, needed to manage a chronic condition in the context of everyday life.⁷ Specifically, epilepsy self-management can involve adhering to prescribed

treatment regimen, interacting with health care providers, mastery of behavioral techniques, lifestyle changes to promote healthy, safe living, and emotion and problem focused coping.^{8–10} Contemporary theories of self-management encompass family participation,¹¹ which is particularly important given the evidence that caregivers of YWE experience significant stress, difficulties coping with epilepsy, are overprotective, and report spending less time in recreational activities.^{1,12,13}

Self-efficacy for seizure management is one cognitive aspect of self-management and has been defined as the belief in one's abilities to initiate, maintain, and complete tasks related to daily epilepsy self-management.⁸ Indeed, self-efficacy for seizure management is related to attitudes towards epilepsy, seizure worry, and depressive symptoms in YWE.^{5,6,14} Further, adult studies have documented that self-efficacy contributes significantly to later self-management outcomes, even when considered with social support,¹⁵ and adults report high self-efficacy for specific tasks such as taking medication and obtaining social support but not for sleep behaviors, exercising, and stress reduction behaviors.¹⁶ Thus, individuals with epilepsy may have less self-confidence (self-efficacy) in their ability to engage in health enhancing behaviors and would likely benefit from interventions that teach and promote these self-management behaviors. However, psychological interventions tailored towards

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YWE are sparse, and only a few have included aspects of self-management.² None have targeted self-efficacy.

We must turn to the general child psychology literature and other pediatric illness populations for development of and evidence regarding the effectiveness of psychosocial interventions targeting cognitive (e.g., self-efficacy, attitudes towards illness) and behavioral (e.g., relaxation, behavior management) coping skills as aspects of illness self-management. For example, an intervention focusing on diabetes related coping aspects of diabetes self-management has shown benefit for youth and caregivers.¹⁷ In addition, primary and secondary control enhancement training (PASCET^{18–20}) was developed to focus on the delineation between primary control, or efforts to change external conditions to be desirable, and secondary control, or efforts to cope by adjusting one's beliefs or expectations. The PASCET model appears particularly relevant to YWE given the unfortunate reality that some challenges related to epilepsy are not under one's primary control (e.g., complete seizure control, epilepsy diagnosis) but that there are daily activities that youth can do to promote management of epilepsy (e.g., sleep hygiene, dietary practice, stress reduction). Further, the PASCET model directly targets self-efficacy, a particularly salient aspect for YWE.

An intervention which introduces traditional cognitive and behavioral coping skills within the framework of self-management for pediatric epilepsy would likely be beneficial and would follow priority recommendations of Living Well with Epilepsy II to improve the development, testing, and access to psychosocial interventions for YWE.²¹ Thus, the Coping Openly and Personally with Epilepsy (COPE) intervention was based on empirically supported cognitive-behavioral techniques¹⁸ and theory driven self-management content.²² COPE focuses on enhancing coping skills, particularly self-efficacy, to promote resilience and epilepsy self-management in YWE and their caregivers. Content of the intervention was targeted towards older youth and early adolescents because there appear to be developmental differences in attitudes, with older adolescents reporting more negative attitudes towards having epilepsy compared to younger adolescents,²³ and research has pointed out the importance of intervening before children develop stable, negative thinking patterns.²⁴ In addition, by expanding knowledge, enhancing coping skills, and identifying supportive resources, the COPE intervention promotes resilience and positive adjustment²⁵ instead of focusing on diagnostic indicated intervention.

A pilot study was conducted to examine the feasibility and satisfaction of COPE, an integrated cognitive-behavioral and self-management intervention for YWE and caregivers. Because the content of COPE is novel to YWE and evidence-based intervention development is often not well described in the pediatric epilepsy literature, the overall purpose of this paper is to twofold: (1) to

detail the development of the COPE intervention and (2) to provide data on feasibility and satisfaction with the COPE program.

2. Materials and methods

2.1. Intervention development

Development of the COPE intervention content began with a review of the literature, recommendations from Living Well with Epilepsy II,²¹ and findings from our recent focus group study.⁶ Two individuals with expertise in child psychosocial adjustment to epilepsy created the COPE modules. One of these individuals also had expertise in evidence-based cognitive-behavioral interventions for youth with pediatric chronic illnesses, and the other had additional expertise in the medical aspects of pediatric epilepsy. Two external experts provided constructive feedback, and revisions were made following consultation. An individual with expertise in social work with families in a hospital setting performed a final review of the modules.

Content of the intervention was transformed to media modules for dissemination in a group setting. Presentation of the intervention was designed to be interactive, engaging, stimulating, and it also included review throughout the sessions to encourage mastery of skills. Manuals were developed for the study therapists in order to promote treatment fidelity and adherence to the intervention material. Workbooks were designed for participants and included colorful review pages, homework assignments, and additional resources. All materials underwent a final review by the social work expert and a graduate assistant.

2.1.1. Module content

Eight youth modules covered epilepsy education, primary coping skills, and secondary coping skills. The modules for the youth intervention are outlined in Table 1. Eight caregiver modules covered epilepsy education (including child development), primary coping skills (including behavior management), and secondary coping skills. The modules for the caregiver intervention are outlined in Table 2.

2.2. Participants

Eligible children were identified with the assistance of the pediatric epilepsy team at the Medical University of South Carolina (MUSC). According to eligibility criteria 46 youth were identified as eligible. Children and adolescents ages 10–15 who had been diagnosed with epilepsy (ICD-9345 codes) for at least six months, had at least average intelligence (cognitive ability was confirmed via chart review), had not been diagnosed with a serious mental illness (e.g., schizophrenia, bipolar disorder), were not currently

Table 1
Youth COPE modules.

	Title	Content
1	Epilepsy education I	Definition of epilepsy; prevalence rates; diagnosis and causes of epilepsy
2	Epilepsy education II	Epilepsy treatments; lifestyle factors that affect seizures; resources
3	Primary coping:	Introduction to coping skills; behavior change: pleasant events scheduling, helping others, engaging in healthy life behaviors; introduction to relaxation: deep breathing
4	Primary coping skills II	Relaxation: sensory imagery
5	Secondary coping	Changing thoughts and perceptions when one cannot realistically change the situation (e.g., self-talk, recognition and reshaping of negative thinking, distraction, and generation of alternative ways to cope)
6	Integration of primary and secondary control	“Positive me” – focus on strengths, self-efficacy; goal setting
7	Problem solving and communication	Problem solving and communication skills training; seizure disclosure
8	Living well with epilepsy	Review of skills learned

Table 2
Caregiver COPE modules.

	Title	Content
1	Child development and psychosocial issues in pediatric epilepsy	Basic child development; prevalence of psychological symptoms; mental health services
2	Primary and secondary coping skills	Overview of coping skills the youth are learning
3	Epilepsy education I	Definition of epilepsy; prevalence rates; diagnosis and causes of epilepsy
4	Epilepsy education II	Epilepsy treatments; lifestyle factors that affect seizures; resources
5	Self-efficacy	Integration of primary and secondary coping skills in context of seizure management and caregiver distress
6	Behavior management	Introduction to basic behavior management principles
7	Problem solving and communication	Problem solving and communication skills training
8	Living well with epilepsy	Review of skills learned

being treated for major depression, and lived within an 80 mile radius were considered for the study.

Of the 46 youth who were eligible, the following reasons, in order of frequency, were cited for not participating: unavailable (e.g., did not return our phone calls, disconnected phone number, 19), interested but could not commit due to scheduling conflicts (8), not interested (2), and scheduled but did not show for the pre-assessment appointment (3). Therefore, 14 youth (8 females, 6 males) and their parents were enrolled in the study; however, only nine youth completed the COPE study. The reasons for study non-completion were as follows: pre-assessment decision that child would not benefit from intervention (1), voluntary withdrawal after pre-assessment due to a family emergency situation (1), completed pre-assessment but did not return for the intervention despite our attempts to contact them (2) attended the first intervention session and then voluntarily withdrew due to a serious illness in another family member (1). Assent and consent were obtained in accordance with the established methods of the Institutional Review Board at MUSC.

2.3. Instruments

As part of a larger assessment protocol, youth were given a 13-item quiz on seizure knowledge before and after the COPE program. Immediately following the COPE intervention children and parents anonymously completed the COPE rating form and the COPE accuracy, feasibility, and acceptability (AFA) form, which were two tools adapted from previous measures by the authors for the purposes of this study. Adapted from the parent and child satisfaction scales (PCSS), which assesses satisfaction with psychological treatment and has demonstrated validity and reliability,²⁶ the COPE rating form was designed to assess satisfaction with the COPE intervention. The COPE rating form consists of 6 items, including several Likert scale questions assessing how much the participant liked (child)/was satisfied with (caregiver) the intervention and whether the participant would recommend the program to others. Two items were open ended questions about what was most helpful to the participant and anything the participant would change about the program.

The COPE AFA form is an adaptation of Bakas et al.²⁷ tool to assess accuracy, feasibility, and acceptability of an intervention. Both the caregiver and youth AFA forms assessed accuracy (COPE program addressed relevant problems), feasibility (COPE program materials were easy to use, understand), and acceptability (format of COPE program, relationship with therapists was desirable). Following developmental considerations, the parent Likert scales had greater degrees of choices for answers. The caregiver AFA form included 24 questions on a 5 point Likert scale, and the youth AFA form included 12 questions in a yes/no or 3 point Likert scale format.

An additional follow up questionnaire created for this project by the investigators (COPE skills) was mailed to parents and youth one

month following the booster session to assess parent and youth use of the skills learned during the COPE intervention. Responses were kept anonymous. The child follow up questionnaire contained 7 items regarding use of specific skills taught during COPE (circled from a response list) and frequency of use of the skill indicated (3 item Likert scale). The parent follow up questionnaire contained 10 items regarding parent and child use of specific skills (circled from a response list) and frequency of use of skill indicated (5 item Likert scale).

2.4. Procedure

Group 1 was run for eight weeks in the Summer of 2007 and included weekly evening 1-h simultaneous youth and caregiver group intervention sessions, with the final session combining youth and caregivers into one group and lasting 1.5 h. Group 2 was held in the Winter of 2008 and consisted of two 4-h group intervention sessions on two Saturdays separated by three weeks. Groups 1 and 2 were formed to accommodate family availability and to explore the satisfaction, accuracy, and feasibility of an 8 week versus a two session format.

A pediatric psychologist conducted the child group and a licensed social worker conducted the parent group. A pediatric epilepsy nurse practitioner disseminated the two education modules to both parents and children in their respective groups and floated between groups when assistance was needed. A psychology graduate student and a nursing graduate student also assisted with the group intervention. Prior to delivery of the intervention, the pediatric psychologist trained the other two therapists and two student therapists in the cognitive-behavioral skill techniques, and she met with the therapists before and after each session to review skills, provide support, and problem solve any concerns raised during the groups. All therapists utilized the treatment manuals developed for this intervention.

During the intervention sessions, activities such as vignettes, role-plays, and behavioral rehearsal were included to promote group interaction and mastery of material. Homework assignments for both caregivers and children were also distributed to promote treatment adherence. Each caregiver and child was given a COPE notebook, which included colorful, developmentally appropriate delivery of content and skills covered during sessions and the homework assignments. The children received \$5 gift cards for each session they attended, and small trinkets or coupons were provided to children for completion of homework assignments to encourage participation. In addition, parents received a \$25 gas card at the end of the program.

Immediately following completion of and at the same visit as the 8th module, parents and children filled out satisfaction, feasibility, and knowledge measures as part of a larger post-assessment protocol and were each compensated \$30 for their time. At the caregivers' request, an IRB amendment was approved to add a 1 h booster session. This session was offered two months

following completion of the intervention modules. The purpose of the booster session was to reinforce skills learned and to assist parents and children with problem solving for barriers to use of and success with skills. This session also included time for parents to discuss needs and access to epilepsy resources. No assessment was conducted at this session. However, participants were mailed questionnaires (one for caregiver, one for youth) to complete regarding use of skills taught during COPE. These COPE Skills questionnaires were mailed four to six weeks after completion of the COPE program and returned via self-addressed, postage paid, anonymous envelopes.

2.5. Analysis

Data analysis for this portion of the study was descriptive, with the exception of the quiz on seizure knowledge. Each correct item on the quiz was assigned one point, and items were summed for total score. Pre- and post-program results were compared by Wilcoxon Signed Rank Test.

3. Results

Nine youth [5 male, 4 female; average age = 12.89 years (SD = 1.69)], eight mothers, and one father completed the COPE program. Diagnoses included frontal lobe epilepsy ($N = 5$), temporal lobe epilepsy ($N = 3$), and unspecified focal epilepsy ($N = 1$). In terms of seizure frequency within the previous 12 months, one participant had 1–3 seizures; five youth had 4–11 seizures; two youth had at least 1 seizure per week; and one youth had at least 1 seizure per day. Full demographics are presented elsewhere.²⁸

3.1. Intervention dose

One family missed one group session, and the interventionists covered the missed module before the regularly scheduled session the following week. All other families attended all sessions. We observed a 100% participation rate among caregivers and youth during group sessions. In addition, youth completed 100% of the skills assignments. Youth skill assignment progress from the previous week (measured by completion and return of hard copy skill assignments) was reviewed at the beginning of each new session, and youth received \$5 gift card for completion.

3.2. Feasibility and accuracy

3.2.1. Caregiver

Eight of the nine caregivers reported that the information in the COPE program was “very much” easy to follow and that the COPE program “very much” addressed their needs, covered things they wanted to know, and included helpful handouts. Seven of nine reported that the COPE program was “very much” easy to attend and apply skills to my life. Eight of nine also reported that homework assignments given to the youth were “very much” relevant to the youth’s needs. Parents ($N = 5$) reported that the most helpful part of the program was the group format. One hundred percent of the caregivers gave the highest endorsement to the staff helping them apply information to their own situations. In response to the statement ‘I am using the COPE skills to help myself’, four chose ‘very much;’ five chose “a little.” To the statement ‘I am using the COPE skills to help my child’, six and three, respectively, responded “very much” and “a little.” Two statements were rated by the parents: (1) ‘I am using the COPE skills to help myself’ and (2) ‘I am using the COPE skills to help my child. Four caregivers chose “very much,” and five caregivers chose “a little” for statement 1 – using COPE skills to help myself. Six

caregivers chose “very much,” and three caregivers chose “a little” for statement 2 – using COPE skills to help child.

3.2.2. Youth

All nine youth reported that they learned from the COPE program and that the COPE program helped them ‘learn to use skills on their own’ “a lot.” Six of nine reported that the COPE handouts and assignments helped them “a lot,” and three reported they helped “a little.” When asked what helped them the most from the COPE program, 4 youth reported that the education modules were most helpful. Four others reported that various coping skills were most helpful. In response to ‘I am using the COPE skills to help myself’, five responded “a lot” and four responded “a little.”

The mean score for the seizure knowledge quiz before the COPE program was 9.7, and the mean score afterwards was 11.0. Most participants’ quiz scores increased by two points. The mean post-program score was significantly higher than the mean pre-program score ($p = 0.02$).

3.3. Acceptability and satisfaction

One hundred percent of caregivers endorsed the highest ratings for the following items: they liked the program; they liked the handouts; and the group format was desirable. Eight youth gave their highest endorsement to the items ‘I felt like I “fit in” during COPE sessions’ and ‘I liked the COPE program.’

3.4. Use of skills

Six of nine caregiver and youth follow up questionnaires (4 questionnaires from the 8 week intervention group and 2 from the 2, half day intervention group) were returned four to six weeks after completion of the COPE program. Six youth (2, “a little”; 4, “often”) endorsed that they had used the COPE skills in the past month. All six youth reported using deep breathing, and five reported scheduling pleasant events. Five reported using problem solving and/or setting goals. Only 1 child reported using cognitive restructuring skills.

Similarly, three parents reported using deep breathing, sensory imagery, changing life habits, and behavior management skills; five reported scheduling pleasant events. Only one caregiver reported using problem solving and setting goals. No one reported using cognitive restructuring strategies.

Aggregately, three families appeared to benefit from the program, generally reporting use across skills, and three families appeared to benefit less from the program (endorsed few skills used). Though statistical methods were not possible, in visual comparison of parental and youth responses, there was agreement. In other words, if a youth reported low benefit, the caregiver of that youth reported low benefit. Conversely, if a youth reported using more skills, the caregiver of that youth reported using more skills.

3.5. Informally obtained qualitative statements

Parents requested the booster session be added for additional review and consultation with each other and COPE therapists. Statements that caregivers made when they were given the opportunity to provide verbal feedback during the booster session indicated a realization that epilepsy is more than seizures. Caregivers reported that they were not always attending to parenting issues with their children with epilepsy, because they were attributing all problems to epilepsy. Caregivers were interested in local resources and volunteered to help plan epilepsy support events in our local area.

Youth verbalized that they appreciated meeting other YWE. In fact, when asked informally at the start of the program, no child identified that he/she knew a peer with epilepsy. During the program, youth were observed to exchange phone numbers and talked about getting together.

4. Discussion

Results of this feasibility and satisfaction pilot study revealed several important findings. Recruitment was extremely difficult, and this was partially a result of limited support to fund a full time research assistant who could approach families in the epilepsy clinic. Instead, telephone contact was the most common method of recruitment. Nineteen families were unable to be reached via telephone, suggesting that personal, face-to-face interaction in the pediatric neurological clinic might enhance recruitment. Time constraints and scheduling were cited as the most common barriers by those actively refusing participating; however, all six families who had scheduling conflicts were interested in participating at another time, suggesting that it was the scheduling times for the group and not the total time commitment that was a barrier. In addition, once a family committed to attending COPE, retention was not a problem. In further support of feasibility of the intervention, a majority of caregivers reported ease of attendance to the program. Likewise, participants reported strong satisfaction with the COPE program, including that they liked the COPE program and that it was beneficial for them. Caregivers even asked for an additional booster session due to their positive experience with COPE.

In terms of accuracy of delivery of educational program content, youth knowledge of epilepsy improved following the COPE intervention, and both youth and caregivers reported that the content of the COPE program was relevant to their needs. Finally, follow up data revealed that behavioral coping skills were used more often than cognitive coping skills, though use of neither was optimal, indicating that COPE program material would be improved by including more time to practice and reinforce these skills or simplification of goals for these skills.

Together these initial results support the feasibility, accuracy, and satisfaction of the COPE program for YWE and their caregivers. However, results also indicate that continued development of COPE is necessary. For example, minor revisions to the intervention content, particularly the cognitive restructuring module, are necessary to improve use and mastery of these skills during and post intervention. Barriers (e.g., time constraints, inability to reach individuals via telephone) identified the need for potential changes in recruitment and intervention dissemination to allow easier access to the COPE intervention.

4.1. Limitations

This project was designed as a pilot study; however, the sample size was small and may not represent the general pediatric epilepsy population. There is no control group against which to compare changes over time. Only one father participated; therefore, results pertain to mothers, and more information is needed on father involvement in the COPE intervention. In addition, longer term follow-up would provide information on whether the program has lasting effects.

4.2. Lessons learned and future directions

Pilot testing of the COPE program follows Stage One of the Stage Model of Therapy Research^{29,30} in which pilot testing and manual development occur. Certainly, several important lessons were learned at this stage. In general, though a group format enhances

scheduling difficulties and perhaps recruitment woes, the group interactions appeared particularly beneficial for families, and it seems important to maintain this format.

Recruitment was extremely difficult, and it is likely that face-to-face recruitment in the epilepsy clinic would have yielded higher participation rates. However, notably, once participants began the intervention, retention was strong, suggesting that, perhaps larger incentives for participation and reduced time demands may improve enrollment and participation in the COPE intervention.

Indeed, published rates of refusal for enrollment in behavioral interventions for youth with medical diagnoses are 37%, on average. Recommendations based on previous lessons learned in the field and subsequent expert recommendations³¹ include appropriate monetary incentives, repeated contact with participants between visits (computer modules, phone calls, birthday and holiday cards), emphasizing benefits of research, minimizing participant burden (reducing number of visits and supplementing group visits with interactive computer skill assignments).³¹ These recommendations should be utilized to inform the design of future studies, including continued development of the COPE intervention.

Many well designed pediatric psychology intervention studies have shown initial improvements in behavior and functioning post-treatment but have failed to maintain these benefits;³² therefore, future interventions should also include structured booster sessions to review skills, to provide problem solving for barriers to skill use, and to promote continued use of skills learned. In the COPE intervention specifically, to address the lower than expected skill use and mastery, multimodal and interactive computer modules that provide a review of skills and assignment completion between group sessions may be beneficial. Treatment fidelity data (time spent, number of entries, etc.) regarding skill exposure would also then be available. Indeed, technological considerations for pediatric self-management intervention have been effective and may eliminate barriers such as time, distance, availability, and cost.³³

Future development of the COPE intervention should involve a pilot randomized, controlled clinical trial (RCT) to evaluate the effect size of a slightly modified COPE intervention based on the findings of this study, and then, if indicated, a multisite RCT to examine the effectiveness of the COPE intervention as has been done with an adult epilepsy self-management intervention.^{22,34} Indeed, our research team is continuing to develop the COPE intervention to address the previously identified research gaps and potentially provide an evidence-based, standardized program.

5. Conclusion

In conclusion, this pilot feasibility and satisfaction study has provided valuable information for researchers to continue the development of self-management programs for YWE and their caregivers. Common challenges to psychosocial intervention RCTs include recruitment and accessibility barriers; however, we must develop practical solutions to these barriers and revise intervention content and design based on pilot findings. Future studies may have a significant impact on the comprehensive care of YWE and their caregivers by addressing previous limitations and providing empirical support for self-management interventions.

Acknowledgements

The results presented are partial findings from a study funded by Parents Against Childhood Epilepsy (PACE).

The authors would like to thank Kelly Cavins for her assistance with recruitment of participants for this study.

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