



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

Janelle L. Wagner^{a,b,c,*}, Gigi Smith^{a,b}, Pamela Ferguson^{b,d}, Karen van Bakergem^c, Stephanie Hrisko^e

^a Medical University of South Carolina, College of Nursing, Charleston, SC, United States

^b Medical University of South Carolina, Comprehensive Epilepsy Program, Charleston, SC, United States

^c Medical University of South Carolina, Department of Pediatrics, Charleston, SC, United States

^d Medical University of South Carolina, Division of Biostatistics and Epidemiology, Charleston, SC, United States

^e University of South Carolina School of Medicine, Columbia, SC, United States

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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

* Corresponding author at: Medical University of South Carolina, 99 Jonathan Lucas St., Charleston, SC 29425, United States. Tel.: +1 843 425 0772; fax: +1 843 792 9258.

E-mail addresses: wagnerjl@musc.edu (J.L. Wagner), smithgi@musc.edu (G. Smith), ferguspl@musc.edu (P. Ferguson), vanbake@musc.edu (K. van Bakergem), stephanie.hrisko@gmail.com (S. Hrisko).

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

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