Coping Openly with Epilepsy (COPE): A Pediatric Self-Management Intervention

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Medical University of South Carolina

American Epilepsy Society | Annual Meeting
# Disclosure

<table>
<thead>
<tr>
<th>Name of Commercial Interest</th>
<th>Type of Financial Relationship</th>
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<td>None</td>
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American Epilepsy Society | Annual Meeting
Learning Objectives

• Explore the development of and preliminary findings for the COPE intervention
Coping Openly with Epilepsy (COPE)
Working Definitions

• Self-Management
  – The steps or skills needed to manage epilepsy in the context of everyday life
    • Can include cognitive and behavioral *coping skills*

• Coping Skills
  • Ways that individuals **think** and **behave** to handle problems that arise
    – Primary and secondary
      » Weisz’ Primary and Secondary Control Enhancement Training (PASCET)

Primary Coping Skills

• Changing *behaviors* in situations in which one has control over the outcome
  – taking prescribed medications as directed
  – healthy sleep habits
  – nutritional eating
  – setting goals
  – problem solving specific to epilepsy treatment regimen adherence
  – engaging in pleasurable activities
  – stress reduction/relaxation

Secondary Coping Skills

- Changing one’s *thinking patterns* regarding the situation when the situation itself cannot be changed
- Restructuring perceptions of what it means to have epilepsy
- Looking for any benefits or positive impacts of epilepsy

Self-Efficacy

• The personal conviction of one’s capabilities to initiate and successfully complete tasks associated with daily epilepsy management
  – Beliefs or “self-confidence” in one’s abilities
• Higher SE is related to
  – more positive attitudes about epilepsy
  – fewer depressive symptoms
  – less seizure worry
  – lower stigma

<table>
<thead>
<tr>
<th>Module</th>
<th>Title</th>
<th>Content</th>
<th>Techniques Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y1, Y2 CG3, CG4</td>
<td>My Epilepsy</td>
<td>Definition &amp; prevalence; diagnosis &amp; causes; treatments; resources&lt;sub&gt;PC&lt;/sub&gt;</td>
<td>Didactic, rehearsal</td>
</tr>
<tr>
<td>CG1</td>
<td>Child Development</td>
<td>Development; health; self-efficacy&lt;sub&gt;PC&lt;/sub&gt;</td>
<td>Didactic</td>
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<tr>
<td>Y3, Y4 CG2</td>
<td>My Behavior Plan</td>
<td>Activities; lifestyle relaxation&lt;sub&gt;PC&lt;/sub&gt;</td>
<td>Didactic, behavioral rehearsal</td>
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<tr>
<td>Y5 CG5</td>
<td>Thinking Outside of “My Box”</td>
<td>Changing thoughts, perceptions&lt;sub&gt;SC&lt;/sub&gt;</td>
<td>Didactic, role play, behavioral rehearsal, vignettes</td>
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<tr>
<td>Y6 CG4</td>
<td>Positive Me</td>
<td>Epilepsy self-efficacy, goal setting&lt;sub&gt;PC, SC&lt;/sub&gt;</td>
<td>Didactic, behavioral rehearsal, vignettes</td>
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<tr>
<td>CG6</td>
<td>Managing My Child’s Behavior</td>
<td>Basic behavior management skills&lt;sub&gt;PC&lt;/sub&gt;</td>
<td>Didactic, role play</td>
</tr>
<tr>
<td>Y7 CG7</td>
<td>Solving My Puzzle &amp; My Voice</td>
<td>Problem solving &amp; communication skills training&lt;sub&gt;PC, SC&lt;/sub&gt;</td>
<td>Didactic, role play, behavioral rehearsal, vignettes</td>
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<tr>
<td>Y8 CG8</td>
<td>Living Well with Epilepsy</td>
<td>Review of skills&lt;sub&gt;PC, SC&lt;/sub&gt;</td>
<td>All</td>
</tr>
</tbody>
</table>

Note: (Y=Youth; CG= Caregiver; PC=Primary Coping; SC=Secondary Coping)
COPE Design

• Participants
  – Youth
    • ages 10-15 diagnosed with epilepsy (345 codes) for at least one year
    • At least low average IQ (>85)
    • No serious mental health diagnoses
  – A caregiver willing to participate

• Intervention
  – Combines evidence-based traditional cognitive-behavioral skills with theory driven models of self-management in epilepsy
  – Delivered by pediatric psychologist, social worker, & epilepsy nurse practitioner
  – 8 weekly, 1.5 hour group sessions
**COPE Design**

- Baseline Assessment
- Randomization
- COPE
- WLC
- Modules 1-8
- Post Assessment
- Booster Session
- COPE Skill Use Assessment
## COPE Assessment

<table>
<thead>
<tr>
<th>Measure</th>
<th>Construct Measure</th>
<th>Report</th>
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<tbody>
<tr>
<td>Seizure Self-Efficacy Scale for Children (SSES-C)</td>
<td>Self-efficacy for seizure management</td>
<td>Y</td>
</tr>
<tr>
<td>Epilepsy Self-Efficacy Scale (ESES)</td>
<td>Caregiver self-efficacy for managing child’s seizures</td>
<td>CG</td>
</tr>
<tr>
<td>Epilepsy Knowledge Quiz</td>
<td>Epilepsy knowledge</td>
<td>Y; CG</td>
</tr>
<tr>
<td>KIDCOPE</td>
<td>Behavioral and cognitive coping skills</td>
<td>Y</td>
</tr>
<tr>
<td>Children’s Health Inventory for Coping (CHIC)</td>
<td>Youth behavioral and cognitive coping skills</td>
<td>CG</td>
</tr>
<tr>
<td>Child Attitude Toward Illness (CATIS)</td>
<td>Attitude toward epilepsy</td>
<td>Y</td>
</tr>
<tr>
<td>Pediatric Inventory for Parents (PIP)</td>
<td>Stress related to pediatric chronic illness</td>
<td>CG</td>
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<tr>
<td>Seizure Social Severity Scale (SSSS)</td>
<td>Seizure severity, impact of seizures</td>
<td>CG</td>
</tr>
<tr>
<td>COPE Skills</td>
<td>Cognitive and behavioral self-management skills</td>
<td>Y; CG</td>
</tr>
<tr>
<td>Children’s Depression Inventory (CDI)</td>
<td>Depressive symptoms</td>
<td>Y</td>
</tr>
<tr>
<td>COPE Rating Form</td>
<td>Satisfaction with intervention</td>
<td>Y; CG</td>
</tr>
<tr>
<td>COPE AFA Form</td>
<td>Accessibility, feasibility, &amp; accuracy</td>
<td>Y; CG</td>
</tr>
</tbody>
</table>
8 of 9 reported that COPE “very much”
- addressed their needs
- covered things they wanted to know
- included helpful handouts
- information was easy to follow

7 reported that COPE was “very much”
- easy to attend sessions
- apply skills to my life

8 reported that youth skills assignments were “very much” relevant to the youth’s needs.

Most helpful component
- Group format (N=5).

COPE Youth Feasibility Results

- All 9 reported that
  - They learned from COPE
  - COPE helped them “a lot” learn to use skills on their own.
- Handouts & assignments helped
  - 6 reported “a lot,”
  - 3 reported “a little.”
- Most helpful skills
  - Education modules (n=4)
  - Coping skills (n=4)
- At the start of COPE, 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.
### COPE YOUTH OUTCOMES (N=9)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (pre-post)</th>
<th>SD</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td>Coping Skills</td>
<td>2.50; 2.90</td>
<td>0.57; 0.57</td>
<td>&lt;0.01</td>
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<tr>
<td>Seizure Self Efficacy</td>
<td>59.3; 65.0</td>
<td>9.8; 10.6</td>
<td>&lt;0.01</td>
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<tr>
<td>Seizure Knowledge</td>
<td>9.67; 11.0</td>
<td>2.12; 2.00</td>
<td>0.02</td>
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</table>

Wagner et al. (2010). Epilepsy & Behavior, 18, 3, 280-285
COPE Lessons Learned

- Improvements in youth coping skills, self-efficacy, and seizure knowledge
  - Trends for caregiver variables
- Participants did not often use cognitive skills following intervention
- Recruitment was difficult but retention was strong
- Consider ways to reduce time commitment for families without diluting content
Randomized clinical trials are indicated
  – Multi-site strongly recommended given recruitment difficulties
Must assess self-efficacy and self-management as primary outcomes
Restructure recruitment strategies
Reduce time burden on families
Consider internet-based delivery for some components
COPE Acknowledgements

• Parents Against Childhood Epilepsy (PACE)
• Gigi Smith, MSN, CPNP
• Karen van Bakergem, LMSW
• Pam Ferguson, PhD
• Stephanie Hrisko, BA
• MUSC Comprehensive Epilepsy Program
• Participating Families
One final acknowledgement

- My brother Aaron