Psychosocial intervention in pediatric epilepsy: A critique of the literature

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Abstract

It is well documented that youth with epilepsy are at increased risk for psychopathology. The current literature supports a biopsychosocial model of adjustment to pediatric epilepsy, and implies that interventions focused on changing youths' cognitions and illness appraisals, as well as enhancing their coping skills, may be an effective treatment for psychosocial maladjustment associated with pediatric epilepsy. The purpose of this article is to review and critique the extant literature covering psychological interventions that target psychosocial adjustment in youth with seizures followed by those aimed at reducing seizure frequency. For health care professionals treating epilepsy, establishing evidence-based interventions that target psychiatric difficulties in youth with epilepsy should be paramount in the promotion of optimal epilepsy outcomes. Thus, future recommendations for clinical endeavors and research proposals are also presented.

Keywords: Pediatric epilepsy; Evidence-based psychological interventions; Psychopathology

1. Introduction

It is well documented that youth with epilepsy are at increased risk for psychiatric symptoms. With a prevalence rate of 21–60% for psychopathology in children with seizures, the risk is three to six times that of the general population and significantly higher than that of children with other pediatric chronic illnesses [1–3]. More specifically, prevalence rates have been reported to range between 10 and 30% for clinically significant depressive symptoms and DSM-IV diagnoses of depression in children with epilepsy [4–6]. Unfortunately, these symptoms often go undetected, and a majority of those with significant comorbid psychiatric symptoms do not receive adequate mental health services [7–9]. Experts have indeed highlighted the gap between the above-mentioned prevalence rates and access to mental health, underscoring the salience of a mental health presence in pediatric epilepsy clinics. In fact, the development of evidence-based standards of mental health care for children with epilepsy has become a priority recommendation [10].

The relationship among pediatric epilepsy and psychiatric symptoms appears to be quite complex, illustrating contemporary conceptualizations of adjustment to pediatric chronic illness, which take into account a host of biopsychosocial variables, including illness parameters, family adjustment, coping methods, and individual cognitive appraisal factors (e.g., self-efficacy, locus of control). For example, the extensively documented transactional stress and coping model theorizes pediatric chronic illness as a stressor to which the child and family must adapt in the midst of a complex interplay of these biopsychosocial variables, which impact both parent and child adjustment [11]. For example, families are faced with the fluid crises of epilepsy that may wax and wane with the course of the illness, affecting typical development and illness coping in both youth and family members.
Indeed, support for neurological etiologies of psychopathology related to epilepsy and/or underlying CNS deficits is accumulating [12,13]. However, researchers have also demonstrated the significant contribution of seizure-related stressors to children’s psychosocial adjustment [14,15]. For example, children and adolescents must cope with stigma, limited independence from their caregivers, side effects of medications, academic difficulties, and fears of future seizures [16,17]. One of the most difficult challenges posed to children with recurrent seizures and their families may be the noncontingency associated with epilepsy. Thus, perceived control, self-esteem, and behavior management have been suggested as salient targets of intervention, for which psychopharmacological and medical interventions are not indicated [14]. Similarly, a growing body of adult literature provides support for the importance of self-efficacy in seizure management [18,19], and a handful of pediatric epilepsy studies have shown that children’s perceptions of control, self-efficacy, and coping skills are related to depressive symptoms [20–22]. Thus, the current literature would support a biopsychosocial model of adjustment to pediatric epilepsy and implies that interventions focused on changing youths’ general perceptions and specific illness appraisals as well as enhancing coping skills may be an effective treatment for pediatric psychosocial maladjustment.

The above-mentioned studies support the role of psychological mechanisms in depressive symptoms and highlight the importance of a combined medical and psychosocial approach to the treatment of pediatric epilepsy. Unfortunately, the development of evidence-based psychosocial interventions for youth with epilepsy is quite sparse in extant literature, and only two review papers could be located. First, Fenwick reviews behavioral methods of treatment for epilepsy, including a few pediatric studies with small sample sizes suggesting that children can identify preseizure cues and use relaxation techniques to reduce seizure frequency [23]. No studies designed to target psychiatric symptoms in children with epilepsy were included in this review. In a more recent article, Krishnamoorthy [24] briefly reviews the literature on psychosocial interventions for individuals with epilepsy, including relaxation, cognitive-behavioral therapies (CBTs), EEG biofeedback, and educational interventions. Krishnamoorthy concludes that the studies reviewed have numerous methodological limitations and very small sample sizes. Information regarding inclusion of pediatric patients in the articles that were reviewed was also limited. Thus, the purpose of the present article is to provide a comprehensive review of the literature on psychosocial interventions for youth with epilepsy.

2. Overview of studies

Psychological interventions in pediatric epilepsy, though underutilized, have historically served two purposes: to reduce seizure frequency and to target psychological adjustment, including seizure management, coping skills, stress management, problem behaviors, etc. First, psychological interventions aimed at reducing distress and improving psychosocial adjustment are summarized (see Table 1 for outline). A critique of these 10 studies follows. Next, psychological interventions that target a reduction in seizure frequency (see Table 2 for outline) are summarized and subsequently critiqued.

The 16 studies in this review were used because they included pediatric patients (under the age of 18) with epilepsy, were published between 1979 and 2005, and made reference to a psychological intervention.

2.1. Psychological interventions targeting psychosocial adjustment

Austin and colleagues [25] developed a program entitled Be Seize Smart to target family members’ fears about epilepsy as well as seizure knowledge, management, information, and support needs. The program was delivered by a nurse via telephone to 10 families with children aged 7–13 who had been diagnosed with epilepsy for at least 2 but no more than 12 months. The study design consists of (1) initial contact and pre-intervention assessment; (2) phone contact 2 to 4 weeks later to provide information, answer questions, and address seizure management concerns; (3) group telephone conferences with other families 2 to 4 weeks later; (4) nurse telephone contact to address any remaining concerns; and (5) postassessment. Outcome measures for parent and child concerns/fears, seizure management, and knowledge were developed for study. Psychosocial care needs, children’s attitudes toward epilepsy, and family functioning were measured by previously validated tools. Results revealed that at postassessment, children had significantly lower scores for epilepsy concerns and need for information as well as higher general knowledge about seizures and better family functioning, compared with their pretest scores. At postassessment, parents also evidenced significantly greater knowledge about seizures and a reduced need for information and for supports compared with the initial assessment.

In another study, Hufford and colleagues [26] examined the effectiveness of an interactive video conferencing intervention protocol with three adolescents and their mothers. Information was obtained on the severity, frequency, and priority of specific problems (e.g., depression, substance use, risky behaviors) from parents and teens during an initial intake. Five subsequent sessions led by doctoral-level clinical psychology students covered discussion of previous events, progress toward goals, and associated barriers. After completion of the six sessions, families were given the option of up to four additional counseling sessions. Outcomes were measured using self-report instruments developed by the researchers. Mothers reported a 40% reduction in problem severity and a 73% reduction in frequency of family problems from pre- to postintervention. Similarly, from pre- to postintervention teens reported 63
Table 1  
Characteristics of studies using psychological interventions to target psychosocial adjustment in pediatric epilepsy

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Target of intervention</th>
<th>Study design</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austin et al. (2002) [25]</td>
<td>10 families</td>
<td>Reduce concerns and fears, seizure management</td>
<td>Pre–post treatment group</td>
<td>Group family telephone conference, education by nurse, seizure management</td>
<td>Both parent and child knowledge about seizures improved, and informational needs were met</td>
</tr>
<tr>
<td>Glueckauf et al. (2002) [27]</td>
<td>22 teens at risk and their parents</td>
<td>Reduce problem behaviors</td>
<td>Random assignment to video conference counseling (VC), office-based counseling (OB), or waiting list (WL)</td>
<td>Identification of problem, goal setting, barriers to goals</td>
<td>Parent and teen reported reductions in problem severity and frequency across VC and OB, discrepancy in parent and teacher report of prosocial behavior</td>
</tr>
<tr>
<td>Hoare and Kerley (1992) [29]</td>
<td>14 parents</td>
<td>Reduce psychological distress</td>
<td>Descriptive</td>
<td>Nonspecific</td>
<td>Attraction was high; participants more likely to have more family problems than nonparticipants.</td>
</tr>
<tr>
<td>Hufford et al. (1999) [26]</td>
<td>3 adolescents and their mothers</td>
<td>Reduce problem behaviors</td>
<td>Pre–post treatment group</td>
<td>Emphasis on identifying problem, setting goals, and barriers to goal delivered via interactive video conferencing</td>
<td>Mother and teen reported reductions in problem severity and family problems</td>
</tr>
<tr>
<td>Lewis et al. (1990) [30]</td>
<td>252 families</td>
<td>Increase epilepsy knowledge and decision-making skills</td>
<td>Random assignment to treatment (TG) or control (CG) group</td>
<td>CG: didactic education TG: body cues, seizure management, coping skills, telling others</td>
<td>Children in TG showed greater knowledge compared with those in CG; children in TG viewed themselves as more competent than those in CG; TG parents reported significant reduction in anxiety</td>
</tr>
<tr>
<td>Lewis et al. (1991) [31]</td>
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<tr>
<td>Lewis et al. (1990) [30]</td>
<td>20 children aged 8–16</td>
<td>Improve attitude toward epilepsy</td>
<td>Pre–post treatment group</td>
<td>Summer epilepsy camp; no formal epilepsy education; interactions with other children with epilepsy</td>
<td>No pre–post camp differences in attitudes toward epilepsy</td>
</tr>
<tr>
<td>Snead et al. (2004) [33]</td>
<td>7 adolescents aged 13–18 and their parents (Pilot study of 4 families)</td>
<td>Improve epilepsy management, coping skills, communication</td>
<td>Pre–post treatment group</td>
<td>Cognitive-behavioral intervention focused on healthy behaviors, stress management, social concerns, communication</td>
<td>No significant pre–post changes in quality of life (QOL), depression, or anxiety; significant effect toward positive change in QOL</td>
</tr>
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(continued on next page)
and 84% reductions in problem severity and family problems, respectively.

Glueckauf and colleagues [27] expanded on their previous study [26] and examined the effectiveness of video conferencing-based family counseling on problem behaviors in 22 teens aged 12 to 19 with epilepsy and their families. Eligible teens had, or were at risk for, problem behaviors (e.g., depressed affect for at least four weeks, suicidal ideation or behaviors, poor school performance/attendance, social isolation, aggressive behavior, nonadherence to medical regimen, sexual promiscuity, and substance abuse) as reported by family or community referral sources. Teens and their families were randomly assigned to one of three conditions: interactive video conferencing-based family counseling (VFC), office-based family counseling (OFC), or waiting list (WL). Families assigned to the VFC group who did not have access to digital services received speaker-phone counseling (SPC). Individuals in the waiting list group were randomized to OFC or VFC after the initial phase of the study was complete. The intervention for VFC, SFC, and OFC groups consisted of a 2-hour assessment and 90-minute videotaped family interview followed by four biweekly 90-minute to 2-hour sessions. More specifically, after the second session, the counselor conducted a behavior-systems analysis of the more salient problems and proposed strategies for interventions. Families were then taught how to set and track progress of goals. In sessions 3 through 6, discussion of weekly events, identification of and suggestions for removing barriers to goal accomplishment, praise for efforts, and review of assignments were conducted. Study outcome measures included those developed by the authors, as well as previously validated measures of social skills and therapist–client relationship. Nonparametric statistical analyses revealed significant pre- to 1-week postintervention reductions in parent- and child-reported problem severity and frequency across all three treatment groups. In addition, teens and parents reported maintenance of treatment gains regarding problem behaviors across the VFC, OFC, and SFC groups at 6-month postintervention follow-up. Interestingly, teens’ ratings of the severity of their problems were lower and therapist–client alliance was poorer than their parents’ ratings across treatment modalities and assessments. Results also revealed significant increases in parent-reported prosocial behavior across treatment groups from pre- to 1-week postintervention, whereas teachers reported no significant changes. Finally, teachers reported an increase in behavior problems at follow-up.

With the results of their cross-sectional study on pediatric adjustment to epilepsy [28], Hoare and Kerley [29] designed a parent group counseling program to reduce the psychological distress of children with epilepsy and their families and to identify the factors associated with psychosocial outcome. However, attendance for the program was abysmal, as only 12% of the 108 families who were initially approached attended a meeting. And, of those 14 parents who attended the first meeting, attrition

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Target of intervention</th>
<th>Study design</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tieffenberg et al. (2000) [34]</td>
<td>99 children and their parents</td>
<td>Improve independence and self-management of epilepsy</td>
<td>Random assignment to treatment (TG) or control (CG) group</td>
<td>Identify cues, recognize seizure triggers, handle risk, develop good decision making</td>
<td>Children showed significant increase in internal health locus of control; parent’s knowledge/anxieties decreased; School attendance improved and visits to physician decreased for TG compared with CG</td>
</tr>
<tr>
<td>Williams et al. (1995) [38]</td>
<td>101 children referred out of 535</td>
<td>Various targets</td>
<td>Descriptive information on referral patterns</td>
<td>Ranged from adjustment to education, adherence</td>
<td></td>
</tr>
</tbody>
</table>

Table 1 (continued)
was high for subsequent sessions. Thus, the effectiveness of the intervention could not be examined. Descriptive statistics revealed that participants were statistically more likely than nonparticipants to have marital problems, family stress, a child with more severe epilepsy, and greater concern over the effect of epilepsy on their child’s development. Participating parents felt that individual sessions with a trained counselor would be more beneficial and indicated their preference for this counselor to be part of the clinic neurology team. In comparison, 26 families who did not respond to the initial invitation returned a questionnaire citing no problems, child’s epilepsy well-controlled, inconvenience of counseling sessions, and sessions unlikely to help with their problems as the most common reasons for not attending.

In a large international study, Lewis and colleagues [30] examined the efficacy of The Children’s Epilepsy Program, an intervention designed to provide knowledge about epilepsy as well as teach decision-making and communication skills to youth aged 7 to 14 with epilepsy and their parents. A pilot study to explore the intervention with 40 families preceded the larger randomized clinical trial. For the clinical trial, children and their parents were randomly assigned to the control (CO, \( N = 126 \)) or the treatment (TX, \( N = 126 \)) condition. The CO group received three 2-hour educational sessions conducted by a physician, and the TX group received four consecutive 90-minute sessions. For the CO group, parents and children attended the sessions together, which were didactic in format with a subsequent question/answer session. The TX sessions for youth were led by an elementary school teacher and covered understanding body messages, controlling seizures with medication, telling others about seizures, and coping skills/adaptation (parent data are detailed in study below). More specifically, the coping session included how to handle bullying, teasing, and frustration; rehearsal and role-playing strategies to combat negative attitudes; and anger management exercises, among others. Outcome data on behavior problems and social history were collected. School records were also available for a majority of participants and contributed information regarding classroom behavior and academic performance. Results revealed no significant differences across groups prior to the CO and TX interventions; however, at the 5-month follow up, the TX group showed significantly greater knowledge of epilepsy and associated treatments compared with the CO group, though both groups demonstrated a significant improvement in knowledge about seizures. After adjustment for covariates, results revealed that the TX group viewed themselves as being more competent than the CO group in social interactions and skills at the 5-month follow up. Youth in the TX group were also more likely to mention their gains in social skills in response to an open-ended question.

In a separate article, Lewis and colleagues discuss the efficacy of The Children’s Epilepsy Program for parents [31]. The TX program for parents was led by a social worker and designed to help parents acknowledge their grief, anger, and fears regarding their child’s seizures as well as to better understand the disorder. Four TX sessions for

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Table 2
Characteristics of studies using psychological interventions to reduce seizures in pediatric epilepsy

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample size</th>
<th>Target of intervention</th>
<th>Study design</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrews et al. (2000)</td>
<td>44 children and adults</td>
<td>Reduction of seizures</td>
<td>Pre–post treatment group</td>
<td>Relaxation, biofeedback, counseling</td>
<td>Significant reduction in seizure frequency</td>
</tr>
<tr>
<td>Dahl et al. (1985) [41]</td>
<td>18 children aged 7–17 and their parents</td>
<td>Reduction of seizures</td>
<td>Randomization to behavior modification (BM), attention control (AC), or control (CG) group</td>
<td>BM: identify seizure cues, functional behavior analysis, relaxation AC: epilepsy information</td>
<td>Significant improvement in seizure index for BM only</td>
</tr>
<tr>
<td>McCusker and Hicks (1999) [42]</td>
<td>14-year-old male</td>
<td>Reduction of seizures</td>
<td>Case study</td>
<td>Relaxation, sensory imagery, habituation to seizure cues</td>
<td>Reduction in seizure frequency</td>
</tr>
<tr>
<td>Reiters and Andrews (2000) [40]</td>
<td>2 children, 1 teen, 8 adults</td>
<td>Reduction of seizures</td>
<td>Pre–post treatment group</td>
<td>Relaxation, biofeedback, counseling</td>
<td>Reduction in seizure frequency, improvement in quality of life</td>
</tr>
<tr>
<td>Schmid-Schönbein (1979) [43]</td>
<td>7 adults, 9 adolescents</td>
<td>Reduction of seizures</td>
<td>Pre–post treatment group</td>
<td>Individual and group sessions focused on seizure triggers and behavioral intervention</td>
<td>50% of participants achieved 80–100% reduction in seizures</td>
</tr>
<tr>
<td>Williams et al. (1979) [44]</td>
<td>14 children, 17 adolescents, 6 adults</td>
<td>Reduction of seizures</td>
<td>Pre–post treatment group</td>
<td>Individual and family assessment, psychiatric treatment</td>
<td>4 showed “moderate”, and 12 showed “marked” improvement, 9 were seizure free</td>
</tr>
</tbody>
</table>
parents included education, decision making, working as a family system, and coping/adapting. Pre- and postdata were collected on parents’ perceptions of the problems, knowledge regarding seizures, parental anxiety, and impact of the TX (e.g., most important things learned, changes in family functioning) via interview and paper-and-pencil questionnaires. Results revealed that parents’ knowledge improved significantly across both the TX and CO groups; however, parental anxiety was significantly more reduced in the TX group versus the CO group. In contrast to the initial hypotheses, data did not support the premise that following intervention, parents in the TX group would be more supportive of their child’s participation in activities.

To examine the impact of epilepsy camp, Sawin and colleagues [32] investigated attitudes toward epilepsy in 20 campers aged 8 to 16. The purpose of epilepsy camp was to provide recreational experience for children with epilepsy who might not be able to participate in other camps, as well as the opportunity for children to build relationships with other children sharing a similar diagnosis. Notably, no formal epilepsy education was included in camp programming. Prior to camp, families were invited to participate in the study. Twenty-three consenting campers completed the initial assessment before arriving for camp. On the last day of camp, each of these campers was given the second questionnaire to return in 1 month. Complete data were available for 20 campers. Results revealed no pre–post (4 weeks following camp) differences in attitudes toward epilepsy. However, youth with more frequent seizures (at least weekly) reported significantly more negative attitudes toward epilepsy both before and after the camp experience. Finally, there was a trend for children with infrequent seizures (fewer than six seizures per year) to show improvement in attitudes over time; however, the sample size of 13 likely limited power in this analysis.

Snedak and colleagues [33] examined the effectiveness of a cognitive-behavioral/psychoeducational group intervention for adolescents diagnosed with epilepsy and their parents. Taking Charge of Epilepsy was based in part on the work of DiIorio and colleagues [18] and focuses on medical aspects of epilepsy (adherence, education), healthy behaviors and attitudes (health habits, diet, exercise, sleep), stress management (anxiety, depression, emotions, cognitive-behavioral coping skills), social concerns (self-image and self-esteem, driving, dating), and interacting with family and peers (behavioral rehearsal of communication skills and negotiation with caregivers). Initially, a pilot group of four families participated in six weekly intervention sessions led by licensed clinical psychologists and psychology trainees. Teens attended a structured group intervention session, and parents simultaneously attended a more informal parent group. Based on parental feedback from the pilot study, the parent sessions were redesigned to be more structured. In the clinical trial follow-up study, the group intervention was presented to four families at once and three more families within 9 months. Participants were teens between the ages of 13 and 18 who had at least one seizure in the last 2 years and were currently prescribed AEDs. Parents and teens completed six group intervention sessions and separately kept a daily log of thoughts. Teens additionally recorded seizure frequency throughout the intervention. Outcome measures included well-validated measures of child-reported epilepsy-specific quality of life (QOLIE-AD-48 [34]) and depressive (CDI [35]) and anxiety (RCMAS [36]) symptoms. t tests revealed no significant pre–post intervention changes in quality of life; however, nonparametric statistical analyses revealed a significant effect toward a positive change in quality of life. No significant effects or trends were observed for depressive or anxious symptoms. Finally, open-ended questions revealed family satisfaction with and perceived relevancy of the intervention.

In another study, Tieffenberg and colleagues [37] designed and implemented a program to teach independence and illness self-management to children with epilepsy and asthma. Participants were randomized to intervention (TX, 64 asthma and 54 epilepsy completers) or control (CO, 43 asthma and 45 epilepsy) groups. Children in the TX group were also divided according to age (6–8, 9–12, and 13–15). For both TX and CO groups, home interviews, which comprised health locus of control scales and a sociocultural survey (knowledge of epilepsy and treatments, family dynamics, patient–physician relationship, and child independence and self-management) were completed before randomization and at 6- and 12-month follow-ups. This intervention content focuses on an age-appropriate, child-focused responsibility for illness management that is facilitated by parents and guided by physicians. Five 2-hour meetings led by group coordinators who received specialized training were used to disseminate the program. More specifically, children and parents in the TX group received education on epilepsy and learned how to do the following: identify bodily cues and personal triggers, recognize balance in life, understand treatment, handle risk situations, and develop healthy decision-making strategies. Games, drawings, stories, videos, and role playing were used to illustrate key concepts of the program. A booster session occurred 2 to 6 months after completion of the initial program. Results revealed that children in both the asthma and epilepsy treatment groups showed a significant increase in internal health locus of control, which was maintained at 1-year follow-up. In both illness groups, parents’ knowledge improved, and fears and anxieties decreased. Further, children with seizures in the TX group had significantly fewer seizures and visits to the physician office as well as improved school attendance, compared with children with seizures in the CO group.

Finally, Williams and colleagues’ article [38] is salient to this review; although, the purpose was not to examine the effectiveness of psychological intervention on adjustment in youth with epilepsy but to validate a patient satisfaction with services questionnaire. Psychology referral patterns in a medical university based epilepsy clinic for 533 children aged 2 months to 27 years followed over a 2-year period.
were also presented. Of the 533 children seen, 101 were referred for psychological services. Specifically, 19% of all children were seen for brief psychological interventions, which focused on acceptance of the diagnosis and medical status, behavior management, clarification of myths about epilepsy, and concerns regarding medication side effects and adherence. Additionally, a significant number of children were referred for psychoeducational, neuropsychological, speech, or behavioral evaluations. Outpatient psychotherapy for family, individual, or both was recommended for 14% of families, parent training for 4%, and state-funded programs for severely disturbed children for 2%.

2.1.1. Critique

The above-summarized studies make an important contribution to the literature by investigating the impact of psychological interventions on psychosocial adjustment in pediatric epilepsy. They are characterized by several strengths, including multipartisan designs. To illustrate, several studies used parallel or combined parent and child interventions [25,27,30,31,37] and/or teacher report outcomes [27,30]. Study designs were also strengthened by the use of randomization in 4 of the 10 studies [27,30,31,37] and a comparison group of youth with asthma [37]. Additionally, three studies used pilot data for streamlining their subsequent, more formalized intervention studies [27,30,31,33]. Snead and colleagues [33] employed empirically supported information in the development of their intervention in addition to well-validated outcome measures. Select studies also attended to issues surrounding feasibility in dissemination of the intervention. For example, to minimize transportation difficulties, Glueckauf et al. [27] used advanced technology in the form of video conferencing; the Snead [33] and Lewis [30,31] interventions were designed for a brief group format; and Williams et al. [38] provided intervention at a medical center epilepsy clinic. Similarly, the Sawin study [32] was conducted in a naturalistic setting, though it was not intended to be a “true” psychological intervention.

The above-reviewed studies share familiar weaknesses, including lack of detailed information, poorly defined or validated outcome measures, small sample sizes, and design limitations. For example, details are absent regarding the intervention content [29] and sample characteristics such as pretreatment symptom severity [27,38]. As a result, consumers of the literature are left unaware of how many participants were clinically depressed prior to the intervention. Exclusion of these data could significantly impact outcomes (e.g., regression to the mean if pretreatment scores are clinically elevated) and for whom the intervention is appropriate (e.g., those at risk, those with clinical symptoms, youth with epilepsy in general). Similarly, researchers have used outcome measures that are often ill-defined or nonstandardized [25,30]. Traditionally, these measures have also not been readily accessible to clinicians for use or further validation.

With the exception of Lewis et al. [30,31] and Tieffenberg [37], most studies are plagued by small sample sizes, potentially limiting the generalizability of findings and adequate power to detect significant findings. Also, many of the studies have less than ideal study designs. For example, in the Lewis studies [30,31], the control and treatment groups received different numbers of sessions with differing lengths. Other studies lack a control group to allow for stronger evidence that improvements were indeed due to the intervention and not extraneous factors [25,33]. It is also sometimes unclear what the level of training in evidence-based psychosocial intervention is for those who are providing the intervention [25,30,37]. Conversely, attention to standardized training of those providing the intervention and/or routine assessment of adherence to the standardized intervention protocol can greatly enhance treatment fidelity. Additionally, although the therapeutic relationship has a significant impact on treatment outcomes, it was assessed in only one study [27]. Finally, studies [29,30,32,37] frequently failed to control for potential psychological mediators [19,22,22] that likely play a salient role in study findings. Notably, small sample sizes do limit the feasibility of advanced analyses required to examine these indirect relationships.

2.2. Psychological interventions targeting seizure control

Next, the other venue in which psychological interventions are employed for youth with epilepsy, those that target seizure control, is reviewed. First, Andrews and colleagues [39] examined the effectiveness of a neurobehavioral program for reducing seizure frequency in 44 patients aged 9 and older with complex partial epilepsy. Daily seizure logs were used to chart seizures and “life problem issues” for a 2-month baseline period, during treatment, and posttreatment. Treatment was provided by an “epilepsy counselor” and included 5 consecutive days of intense instruction in daily relaxation, guided relaxation training, biofeedback, and counseling. Participants were provided relaxation tapes and therapy workbooks and were encouraged to practice at home for 30 minutes daily. Following treatment, participants received a 10-minute follow-up weekly phone contact for 6 months. Results revealed that participants experienced a significant reduction in seizure frequency following treatment. In addition, total seizure control, defined as seizure freedom for 6 months, was achieved by 35 of 44 patients.

Another article by these same authors [40] describes the outcomes of 11 participants, including two 9-year-olds and a 17-year-old, who participated in the intervention described in the previous article [39]. Results revealed improvements in quality of life and reduction in seizure frequency from pre- to postintervention.

Dahl and colleagues [41] evaluated the effectiveness of a behavioral modification treatment in reducing seizure frequency. Eighteen children of average intelligence between the ages of 7 and 17 diagnosed with seizures for at least 2
years and experiencing at least one seizure per month were randomly assigned to one of three conditions: behavior modification (BM), attention control (AC), and control (CG) groups. Following a 10-week baseline, children in the BM and AC participated in six 1-hour weekly sessions led by a clinical psychologist. The BM intervention consisted of a functional analysis of seizure behavior and teaching both the child and parent to identify preseizure events and engage in or reinforce relaxation techniques. Parents and teachers were also instructed how to neutrally handle seizures to refrain from overprotective parenting. Behavioral rehearsal, role playing, and homework were included to promote mastery of skills. In contrast, the AC group received epilepsy and seizure information in an unstructured conversation format. Following completion of the 6-week intervention for BM and AC, all three groups were followed for 10 subsequent weeks and at a 1-year follow-up. The outcome measure was a pocket calendar of seizure frequency and severity logs, and nonparametric statistical analyses revealed that at the 10-week and 1-year follow-up, only BM demonstrated significant improvements in the seizure index (frequency × severity). In addition, the BM evidenced a significantly greater reduction in seizure severity compared with both AC and CG.

With a single-subject design, McCusker and Hicks [41,42] evaluated a psychological intervention aimed at seizure management for a 14-year-old boy with a learning disability and intractable complex partial epilepsy. Baseline seizure frequency was recorded for 10 days, followed by the introduction of behavioral interventions, which included relaxation exercises involving sensory imagery and repeated habituation to stressful seizure triggers. A reduction in seizure frequency was observed, and a 2-month follow-up assessment revealed that treatment gains had been maintained.

In another study, Schmid-Schonbein [43] examined the effectiveness of self-control therapy (SC) in addition to pharmacological treatment in reducing seizure frequency for 16 patients, 9 of whom were adolescents aged 12–17, with intractable epilepsy. SC focuses on the warning cues as well as external and emotional triggers of a seizure, and unique behavioral plans are developed to counteract the seizures. Initially, there were four to six individual sessions at 1- to 2-week intervals, with individual and group sessions alternating at 2- to 4-week intervals following the initial sessions. Sessions varied from 5 to 40 with an average of 20 sessions. Booster sessions occurred 6 and 12 months following treatment, and a telephone follow-up occurred at 24 months. Descriptive statistics revealed that 8 of the 16 patients achieved 80–100% reduction in seizures, and 3 other patients improved by 50–60%. Treatment effects were reportedly observed for 6 months and, in some cases, 12 months.

Finally, Williams and colleagues’ [44] reported significant improvements in seizure control following psychiatric intervention in a sample of 14 children (aged 3–12), 17 adolescents (aged 13–18), and 6 adults (aged 19–32). The intervention, ranging from 2 to 70 sessions, was provided by a child psychiatrist and consisted of individual and family assessment followed by psychiatric treatment focused on alleviating psychological contributors to seizures. Participants kept a daily record of their seizures, which was used as the outcome measure in this study. At the end of treatment, more than half of the patients showed marked improvement (n = 12) or were seizure free (n = 9). At follow-up, 14 participants were seizure free, and 8 showed marked improvement.

2.2.1. Critique

The above-reviewed studies examining the effectiveness of psychological interventions in reducing seizure severity have several strengths, one of which involves the use of evidenced-based behavioral interventions such as relaxation and habituation [39,41,42]. In addition, the Dahl et al. [41] study used random assignment and provided concomitant parent and child intervention, noting that parental encouragement of behavioral techniques is crucial to the success of the program. These studies also tailored the interventions to individuals with epilepsy and provided a nonpharmacological approach for individuals who are already likely prescribed polytherapy. By activating patients’ personal resources to increase seizure control [43], these interventions become individualized and likely indirectly enhanced participants’ psychosocial adjustment to seizures; however, data were not available to support this conclusion.

The findings of these studies must be qualified by the following limitations, many of which are similar to the limitations outlined in the previous critique (e.g., lack of detailed information, small sample size, study design concerns, and neglect of psychological mediators that likely impact outcomes). The first limitation involves a frequent lack of detailed information regarding sample characteristics, outcome measures, and the behavioral intervention itself. For example, in the Joy et al. [39] study, neither the age range nor percentage of participants who were children was provided. Reiter and Andrews [40] reported measurement of quality of life; however, they did not provide a description of how quality of life was assessed. Similarly, outcome measures in the Schmid-Schoenbin study were not well defined, and limited information was provided for the statistical analyses used [43]. Further, Williams et al. [44] did not provide specifications of the intervention. If the field of pediatric epilepsy strives to promote evidence-based practice, clinicians cannot use indicated interventions if they are not comprehensively described in the literature and/ or readily available.

Small sample sizes represent another weakness of behavioral intervention studies targeting seizure control, particularly of those including pediatric participants [40,42]. Similarly, wide age ranges pose challenges regarding at which ages the intervention is most appropriate or, on the other hand, ineffective [39,40,44]. Although the Dahl et al. study [41] has the strength of randomization, the
entire sample size was 18, limiting power and, subsequently, group comparisons. Other concerns related to study design, including absence of control groups [39,40,43], a variable number of intervention sessions within a single study [43,44,44], and lack of clarity on the level of training in evidence-based behavioral intervention for intervention providers [25,30,37,39,40,43], also pose serious limitations. Finally, none of these studies assess psychological mediators that may have played a significant role in seizure reduction through the enhancement of coping skills and/or perceived control over seizures [22].

3. Conclusions

In summary, the conclusions of this pediatric review are similar to those of Krishnamoorthy [24], who posited that comprehensive randomized clinical trials are necessary before implications of the effectiveness of psychosocial interventions for youth with epilepsy can be surmised. Indeed, the literature reviewed in this article provides support for the use of psychological interventions in youth with epilepsy; however, extant studies are fraught with limitations. The most common weaknesses of these studies include small sample designs, absence of pertinent information regarding outcome measures and interventions, use of nonvalidated outcome measures, lack of randomization or a control group, variable treatment sessions and other design concerns, and neglect of psychological mediator assessment. These weaknesses limit generalization of findings, treatment fidelity, and power to detect true differences between groups, etc.

Lest the grim state of the current literature deter the pursuit of evidence-based psychological interventions as an adjunctive treatment for youth with epilepsy, several relevant points are highlighted. First, the nature of cognitive-behavioral interventions renders them amenable to epilepsy-specific psychosocial adjustment and should thus be promoted [24]. Second, common pathogenic mechanisms for epilepsy and depression have been proposed, inferring that if depression is not treated, epilepsy may not be managed as effectively as possible [45]. Similarly, behavioral interventions have been shown to reduce seizure severity and frequency as well as improve psychological adjustment [30,46]. Thus, evidence-based psychological interventions for youth with epilepsy seem indeed relevant, and further steps should be taken to develop, research, and disseminate such interventions.

4. Future directions and recommendations

Historically, epilepsy research has focused on issues related to the basic science of seizures, medications, evaluation methods, vagal nerve stimulation, the ketogenic diet, and epilepsy surgery. The etiologies of seizures and effective management must continue to be examined; however, parallel endeavors to explore psychological interventions for youth with epilepsy must receive adequate attention, given the high comorbidity of psychosocial difficulties in these children. This critique has highlighted the importance of recognizing and treating the psychosocial effects of epilepsy on the pediatric patient and family, and thus the following recommendations for clinical activities and research endeavors are offered.

According to Devinsky [47], physicians often underestimate the impact of patients’ stressors, environment, family, and fears, and subsequently behavioral approaches to epilepsy are neglected. Further, Gilliam and colleagues [48] reported that 79% of neurologists who see epilepsy patients do not screen for depression in their clinic but that they would if an evidence-based treatment improved compliance and quality of life. Subthreshold depressive symptoms may also be elevated in individuals with epilepsy, resembling an “epilepsy like dysthymia,” and creating additional challenges for health care professionals [49]. Thus, the presence of a psychologist or psychiatrist in epilepsy clinics who could provide a variety of on-site psychological services similar to those described Williams et al. [38] would greatly benefit both epilepsy health care providers and families. Notably, with the strong endorsement of evidence-based medicine and the priority recommendations from experts in the field [10], these clinical recommendations beg the question of which interventions to use. Until epilepsy-specific psychological assessment and intervention tools are available, those supported by research in the fields of psychology and psychiatry should be used. For example, mental health clinicians should use standardized protocols, including psychosocial assessment measures at baseline and post-medical and -psychological interventions (i.e., cognitive-behavioral therapy, behavior management, epilepsy surgery, ketogenic diet, vagal nerve stimulation, and medication therapy). These assessments will assist not only in quantifying effects of treatments but also in defining what components may be included for psychosocial interventions and the enhancement of routine medical treatment efficacy. At the same time, research to develop standardized psychosocial evaluation tools and treatment protocols in the pediatric epilepsy clinic should be paramount and a high priority of researchers in the field.

Finally, specific recommendations for the establishment of evidenced-based interventions for psychosocial adjustment in pediatric epilepsy are offered. First, an efficient and standardized tool, which assesses epilepsy-specific psychological adjustment, must be validated in youth with epilepsy and sensitive to the measurement of clinical change. Second, multisite randomized clinical trials should be designed to examine content and methods of delivery of cognitive-behavioral interventions adapted for children and adolescents with epilepsy and their families. Such studies would directly inform the practice of evidence-based medicine. For example, given the salience of learned helplessness and perceived control to epilepsy management, adaptation of an evidence-based cognitive-behavioral intervention focused on control enhancement [50] would seem relevant. Similarly, self-efficacy related to manage-
ment of epilepsy has a demonstrated association with depressive symptoms, and has been highlighted as clinically salient to the development of manualized interventions designed to enhance psychosocial adjustment to epilepsy [22,51]. In addition, given the robust support for the impact of family adjustment on adherence, seizure control, and quality of life [52], a caregiver component should be included in the intervention. Specifically, caregiver guilt and struggles specific to parenting a child or teen with epilepsy (e.g., relaxed discipline, overprotectiveness) should be included because they may cause barriers to parenting and the enhancement of developmentally appropriate independence [53]. Interventions should also be age specific and sensitive to challenges that may be specific to a particular age, such as adolescence. Within the design of the study, training for individuals who will be disseminating the treatment and measures to ensure the fidelity of these interventions and adherence to treatment protocol should be included. Reports of study findings should contain statistics such as effect size and clinical significance. And lastly, dissemination of the manualized treatments and training workshops for clinicians to promote the practical use of evidence-based medicine for youth with epilepsy should be a priority of researchers.

References


