



## The benefits of a camp designed for children with epilepsy: Evaluating adaptive behaviors over 3 years <sup>☆</sup>

Sandra Cushner-Weinstein <sup>\*</sup>, Madison Berl, Jay A. Salpekar, Jami L. Johnson,  
Phillip L. Pearl, Joan A. Conry, Marian Kolodgie, Audrey Scully,  
William D. Gaillard, Steven L. Weinstein

*Center for Neuroscience and Behavioral Medicine, Children's National Medical Center, Division of Neurosciences and Behavioral Medicine, Department of Neurology, George Washington University School of Medicine and Health Sciences, 111 Michigan Avenue, Washington, DC 20010-2970, USA*

Received 29 August 2006; revised 11 October 2006; accepted 14 October 2006

---

### Abstract

**Objective.** Children with epilepsy attending a condition-specific overnight camp were evaluated for behavioral changes over 3 consecutive years, using a modification of the Vineland Adaptive Behavioral Scale.

**Methods.** Trained counselors completed pre- and postcamp assessments for each camper. Repeated-measures MANOVA was used to analyze effects of the camp experience for each year, with respect to gender and age. Repeated-measures ANOVA was conducted to evaluate long-term effects from year-to-year comparisons for return campers, following three successive camp experiences.

**Results.** A significant change in social interaction was observed over 3 years. Despite some decline at the start of camp in consecutive years, the overall trend for return campers suggests a positive cumulative impact of continued camp participation, with improvements in the domains of social interaction, responsibility, and communication.

**Conclusion.** A condition-specific camp designed for children with epilepsy can improve adaptive behaviors and social interactions. Overall net gains appear to increase over time, suggesting additional benefits for return campers.

© 2006 Elsevier Inc. All rights reserved.

**Keywords:** Epilepsy camp; Chronic illness camp; Adaptive behavior and epilepsy; Self-esteem and epilepsy; Psychosocial; Condition specific camps; Peer relationships; Socialization

---

### 1. Introduction

The number of disease-specific camps for children with chronic health conditions has increased significantly during the past 15 years, despite a dearth of research supporting their therapeutic value. As early as the 1970s, camps were created for children with cancer and cerebral palsy. Presently, disease- or condition-specific camps nationwide include approximately 138 asthma camps, 91 muscular dystrophy camps, 65 diabetes camps, 60 cancer camps, 47 hemophilia

camps, 40 sickle cell anemia camps, 26 renal disease camps, 17 obesity or weight management camps, 13 Crohn's disease camps, 7 burn camps, 3 neurofibromatosis camps, 3 Tourette's syndrome camps, and 25 camps for children with epilepsy. Although some of the children attending these camps can and do attend regular summer camps, many choose to attend a camp for their specific condition.

Disease-specific camps seem to preferentially attract children with chronic health conditions, often enticing them to return year after year, even when their condition is well controlled. Benefits perceived by campers may include involvement in formal or informal support groups, the common bond of condition-related experience, feedback from peers and leaders, and the instillation of hope from meeting successful survivors. Staff expect the campers to try new activities without unnecessary restrictions, which

---

<sup>☆</sup> Supported by Grant M01-RR13297 from the General Clinical Research Center Program of the National Center for Research Resources, National Institutes of Health, Department of Health and Human Services.

<sup>\*</sup> Corresponding author. Fax: +1 202 884 2676.

E-mail address: [scushwei@cnmc.org](mailto:scushwei@cnmc.org) (S. Cushner-Weinstein).

may be a unique experience for a child with a chronic condition. Additionally, children are acknowledged for their contribution as helpers versus the ones in need of help. One important function of condition-specific camps is to improve social functioning by transforming the condition into the community norm, thus reducing the social isolation often associated with childhood illness.

Disease-specific camps may vary in length (from 3 to 14 days, with a more common length of 7 days), hours per day (residential versus day), age of camper (range, 6–18), staff-to-camper ratio for supervision (from 1:2 to 1:6), percentage of volunteers versus paid staff (all paid to 100% volunteer), utilization of staff with the condition (0–80%), overall goal or purpose, use of formal versus informal education, frequency of educational sessions, support groups (professionally facilitated with topics to peer-run informal groups), composition of camper groups (chronological versus developmental age, and sometimes inclusion of unaffected siblings), fees and use of scholarships, and activities (condition-based, goal-directed activities versus a general recreational camp). Because camps vary greatly, it is difficult to compare condition-specific camps with each other and with recreational camps. It is also difficult to evaluate the long-term benefits from attendance at camps, as children grow as a function of maturation over time regardless of the camp experience and many campers attend multiple camps. The variety of camp designs reduces the ability to generalize findings and results across different populations. Despite these limitations, the popularity of condition-specific camps supports the need for further research into the therapeutic value of the camp experience.

Camp Great Rock is an overnight summer camp in the Washington, DC metropolitan area designed to promote socialization and foster independence in children aged 7 through 17 with epilepsy. The aim of this study was to assess the impact of the camp experience on these goals using pre- and posttests of adaptive behaviors. It was hypothesized that children who attended the camp would improve their skills in the areas of social interaction, cooperation, communication, and responsibility.

### 1.1. Review of epilepsy

Children with epilepsy are known to have more behavioral issues and social isolation than children without epilepsy. Psychosocial and adjustment problems are common [1–3], producing behavioral disturbances [4–7], anxiety [8–11], depression [12,13], low self-esteem [5,14,15], and increased prevalence of attempted suicide [16,17]. In addition, children with epilepsy are more socially isolated and withdrawn than their peers [18–20]. Other difficulties include a greater likelihood of cognitive impairment in the form of learning disabilities and academic underachievement [3,13,21,22]. Several factors increase a child's vulnerability to psychosocial problems, including the severity and type of seizures, the age at seizure onset, and adverse effects of antiepileptic medications

[23,24]. Even in cases when the seizures are controlled with medication, long-term psychological and social impairment often persists [17,25–28].

Epilepsy in childhood can also have extended adverse effects on the child and family. Maladaptive dependencies may occur [29,30], and parents tend to be overprotective and emotionally overinvolved with their child [3,29,31]. Education and support groups that help parents foster positive attitudes directly improve how children cope with epilepsy [32]. Also, teaching coping strategies and providing education during the first 6 months following the diagnosis often help children and their parents adapt more positively to the condition [33–35]. These interventions have a positive impact by reducing anxiety and depression and expanding knowledge about the disorder [36–38]. In turn, the child's attitude about their illness could impact psychosocial adjustment, as observed in children with other chronic disorders [39].

### 1.2. Review of camp research

The majority of research related to condition-specific camps examines four primary benefits: an increase in knowledge about the condition with better self-management [40–44]; an increase in self-esteem, self-concept, and/or self-perception [45–47]; a change in attitude toward the illness [48,49]; and improvement in adaptive coping skills and quality of life [50]. Anecdotal reports suggest that children benefit from attending condition-specific camps by establishing friendships, having fun, feeling less alone, and improving their self-image [51–54].

Increasing knowledge and self-management from camp participation have been attributed to both formal and informal education, as well as specialized activities relative to disease management. Spontaneous informal discussion about cancer was observed between a majority of campers as reported by Bluebond-Lagner et al. [40]. Discussions about the condition were an accepted norm at camp, and campers demonstrated statistically significant gains in knowledge about the condition. Intensive formal condition management training sessions decreased episodes of hypoglycemia and daily insulin levels while increasing knowledge in a camp designed for children with diabetes [41]. Education about asthma triggers and the appropriate use of inhalers in a camp for asthmatic youth was associated with a reduction in emergency room visits and hospitalizations [43]. In two other camps with formal educational sessions with targeted activities for juvenile arthritis and phenylketonuria (PKU) management, the short-term functional improvements achieved during camp were not maintained over time [42,44]. However, campers with PKU continued to demonstrate increased knowledge about their condition after the camp experience [44].

Time-intensive experiences in the form of summer camps appear to be useful interventions in promoting self-esteem and self-perception [45–47,50], while considering the influence of age on a child's perception of living with a chronic

health condition. Eng evaluated 69 children between the ages of 6 and 16 attending a cancer-specific camp. Most of the children were diagnosed within a year of the camp. The Piers Harris Self-Concept Scale and human figure drawings were used to evaluate pre and postcamp changes. No change was observed with the Piers Harris Scale postcamp, but a significant change in emotional indicators was observed in the human drawings, suggesting an improvement in self-perception [45]. In a group of campers aged 9–18 undergoing dialysis or kidney transplants, a significant reduction in reported depression was observed postcamp, with a trend toward reduced hopelessness persisting 1 month following camp [46]. Self-esteem improvement was also observed in 50% of females and 32% of males attending a camp for burn survivors [47]. Younger children (aged 7–12) with cancer demonstrated benefits in self-esteem as measured by an altered Harter Self-Perception Profile at a cancer-specific camp, whereas teenagers showed mixed effects on self-esteem, varying by nationality [50].

Participation in a pediatric illness-related summer camp can also improve children's attitude toward their condition and lower their level of anxiety [48,49]. Following week-long condition-specific camps for children with asthma, diabetes, and spina bifida, Briery and Rabian identified a positive impact on camper attitudes toward their condition [48]. Reduced anxiety was demonstrated in postcamp tests among children with asthma and diabetes [48]. However, Sawain et al. did not observe a change in attitude among 20 campers attending an epilepsy camp (aged 8–16), but found a significant relationship between attitude score and seizure frequency [49].

Positive social behavior change and enhanced quality of life have been reported in association with condition-specific camps, although systematic evaluation of this change is limited. Quality of life was measured using the Perceived Illness Experience Scale (Quality of Life) in children with cancer and their siblings attending a camp [50]. Improved quality of life in siblings of children with cancer was observed in both the short and long term, whereas children with cancer demonstrated no change. These results contrast with the authors' belief that camping programs play an important role in encouraging adjustment to chronic illness. Mixed reviews and problems with impact assessment are noted in the article on the effect of camps on quality of life by Epstein et al. [55]. The lack of randomized or controlled clinical trials of camps for intervention is highlighted, thus emphasizing the logistical challenges associated with this study design in camp evaluation.

### 1.3. Camp Great Rock

Camp Great Rock includes traditional camp experiences (rope course, swimming, arts, crafts, etc.) combined with activities that have condition-specific goals and relevance. Objectives of Camp Great Rock are to encourage a sense of inclusion, build social relationships, increase feelings of self-worth and independence, promote an understanding

of epilepsy and its effective management, and desensitize children from the fear of seizures. Professionally facilitated support groups are held three times during the week for similar-age groups and cover topics such as labeling and communicating feelings, understanding and living well with epilepsy, setting goals and becoming assertive, managing anger, and disclosing and relating to others. These support group experiences are designed to encourage reflective and supportive peer responses while allowing campers to realize that they are not the only ones challenged by the condition. Campers engage in activities as a group as often as possible, even when taking medicine.

At Camp Great Rock, 8 to 10 children are placed in bunks according to their chronological age or their developmental age, when they are not socially functioning at their chronological age. Direct interaction with each other, rather than adult-facilitated social interaction, is fostered. Children receive positive feedback when they participate, communicate openly, and demonstrate responsible and helpful behavior. Campers experience acceptance by others, and are encouraged to join in the camp community. During the weeklong stay, these experiences aim to destigmatize seizures and epilepsy. The camp staff includes medical professionals and counseling staff and counselors in a 2:1 ratio to campers, to ensure a safe environment and allay parental concerns. More than half of the counselors and counselors-in-training have epilepsy and serve as models and mentors for the campers. Many of the camp counselors-in-training advance from campers into positions of increased responsibility, so the hope of upward mobility is encouraged, and anticipated.

At Camp Great Rock, benefits gained from camp were gathered from anecdotal reports and evaluations completed by parents and campers. The three benefits commonly listed by children were meeting others with epilepsy, making friends, and having fun. Parents chose greater independence, learning about epilepsy, and having their children feel better about themselves as the major benefits. In this 3-year study, we chose to assess the primary benefits of increased social relationships and independence. These benefits were evaluated using a modification of the Vineland Adaptive Behavior Scale. Social relationships and inclusion were observed and evaluated with three subscales—social interaction, communication, and cooperation—pre- and postcamp. Independence was evaluated using the subscale responsibility also pre- and postcamp. Campers had to remain for the full 7 days of our residential camp to be included in the study.

## 2. Methods

### 2.1. Subjects

Observations were made over 3 years from summer 1998 to 2000 as approved by the institutional review board of Children's National Medical Center. Camp attendance increased over the 3 years, with 35 campers in 1998 (Year 1), 43 in 1999 (Year 2), and 57 in 2000 (Year 3). Twelve campers attended all 3 years of camp. One return camper attended in

Years 1 and 2 only, and 28 campers attended in Years 2 and 3 only. Each year, several campers were excluded from the analysis (3, 3, and 1, respectively) because pre- or postcamp measures were not obtained as a result of late arrival or early dismissal from camp. Six campers in Year 1, 9 campers in Year 2, and 5 campers in Year 3 returned as counselors-in-training, and although they were evaluated, they were not included in this analysis due to their new role as aides to primary counselors.

Although specific numbers changed from year to year, approximately half (range, 41–48%) of the campers were female. The mean age of campers was 10 in Year 1 (range, 7–17), 11 in Year 2 (range, 6–16); and 11 in Year 3 (range, 7–16). Age was categorized as younger (7–11) or older ( $\geq 12$ ) in the analysis. Approximately half of the children had comorbid disorders including learning disabilities, attention-deficit hyperactivity disorder (ADHD), borderline intelligence, pervasive developmental disorder (PDD), mild mental retardation, anxiety disorders, and depression identified by clinical diagnosis as reported by parent registration forms and/or the referring clinician. (Table 1).

## 2.2. Assessment of adaptive functioning

The Camp Vineland Adaptive Behavior Scale (C-VABS) was developed to evaluate each camper's progress across four functional domains. Based on the Vineland Adaptive Behavior Scales (VABS): Classroom Edition [56], questions were modified to be relevant to camp experiences. For example, "shows desire to please a *teacher*" was changed to "shows desire to please a *camp counselor*." The VABS is a standardized measure of functional abilities including a child's performance in the daily activities necessary for taking care of oneself and getting along with others. Particular survey domains were selected based on their relevance to the overall experience of camp and ability to be reliably observed during the week, and questions were modified to fit the environment. Mean scores were obtained for each question to assess the standard deviations and compare them with the standard deviations of responses used as the norm for the VABS. There was no significant difference. For each of the four domains, counselors scored specific items on a scale of 0 to 4, with 0 signifying never, 1 meaning almost never, 2 meaning sometimes, 3 meaning usually, and 4 meaning always (see Appendix). In addition, a summary score reflecting the average of all items within a domain was calculated for each domain. The four domains surveyed were Social Interaction, Cooperation and Active Participation, Responsibility/Initiation of Daily Living Tasks, and Communication.

Table 1  
Demographics of campers

	1998	1999	2000
Total number of campers	35	43	57
Age			
7–11	19	26	26
12–17	16	17	31
Sex			
Male	18	22	31
Female	17	21	26
Ethnicity			
African-American	7	13	19
Asian	1	1	1
Mexican-American	1	1	2
Indian	0	2	0
Caucasian	26	26	35
Comorbid disability			
Learning disability/attention-deficit hyperactivity	18	21	28
Mental retardation	4	5	7
Anxiety	*	4	6
Depression	*	3	5

\* Measurements of anxiety and depression were not obtained in 1998.

## 2.3. Procedure

Consent from parents and assent from children were obtained at registration on the first day of camp. Children were observed over the course of the 7-day overnight program at Camp Great Rock by two of the counselors assigned to a cabin. Raters were not blinded observers. Counselors were formally trained prior to the start of camp on how to accurately complete the C-VABS. The two lead counselors in each bunk completed ratings for each child in the cabin, for an average of eight campers per counselor. Together, they determined the appropriate ratings for each camper. The counselors completed identical surveys for each camper after the first full day of camp and again at the end of camp. Initial assessments were completed after the first full day to allow counselors to familiarize themselves with the behavioral aspects of their campers. For campers who returned for subsequent camps, the same counselor did not necessarily rate the same camper in consecutive years.

Univariate analysis of variance (ANOVA) was conducted to assess which of the four domains were significantly different from pre- to post-camp. Repeated-measures multivariate analysis of variance (MANOVA) was used to assess the effects of the camp experience for each year of camp with gender and age as between-subject factors. Repeated-measures ANOVA was used to analyze the long-term effects or adaptive changes from year to year and following successive camp experiences.

## 3. Results

### 3.1. Individual year results

#### 3.1.1. Year 1

Significant improvement is demonstrated, using ANOVA, in the two domains Social Interaction ( $P < 0.01$ ) and Communication ( $P = 0.01$ ) (Table 2). Repeated MANOVA reveals effects of time ( $P = 0.01$ ), age ( $P < 0.01$ ), and gender ( $P < 0.01$ ) for Year 1. Younger children are rated higher in Communication ( $P = 0.05$ ). Girls are rated higher than boys across the three domains Cooperation ( $P = 0.01$ ), Responsibility ( $P < 0.01$ ), and Communication ( $P < 0.01$ ). A trend toward a time  $\times$  gender interaction is observed ( $P = 0.06$ ) such that boys show greater improvements over time across all domains, particularly with Communication skills.

#### 3.1.2. Year 2

Univariate tests reveal significant improvement in Social Interaction ( $P < 0.05$ ) and a trend toward improvement in Cooperation ( $P = 0.08$ ) (Table 2). Repeated MANOVA reveals main effects of age ( $P = 0.02$ ) and gender ( $P < 0.01$ ) for Year 2 (Table 3). In contrast to Year 1, younger children are rated lower in Cooperation ( $P < 0.05$ ) and Communication ( $P < 0.01$ ). Girls continue to be rated higher than boys in Communication ( $P = 0.06$ ). A trend toward a time  $\times$  age interaction effect is demonstrated ( $P = 0.09$ ) such that older campers improve significantly with Communication skills, whereas younger campers decline slightly with Communication skills.

#### 3.1.3. Year 3

Significant improvement is demonstrated across all four domains (Fig. 1): Social Interaction,  $P < 0.01$ ; Coopera-

Table 2  
Mean change in domain summary scores on the C-VABS from precamp to postcamp within the same year

	Year 1 (1998) (n = 34)		Year 2 (1999) (n = 39)		Year 3 (2000) (n = 56)	
	Change	P value	Change	P value	Change	P value
Social interaction	0.31	0.01 <sup>a</sup>	0.27	0.04 <sup>b</sup>	0.548	<0.01 <sup>a</sup>
Cooperation/active participation	0.15	0.16	0.26	0.08	0.513	<0.01 <sup>a</sup>
Responsibility/initiative	0.04	0.91	0.11	0.31	0.437	<0.01 <sup>a</sup>
Communication	0.35	0.01 <sup>a</sup>	0.11	0.26	0.411	<0.01 <sup>a</sup>

<sup>a</sup>  $P < 0.01$ .

<sup>b</sup>  $P < 0.05$ .

Table 3  
Mean domain summary scores on C-VABS pre- and postcamp with respect to age and gender<sup>a</sup>

	Year 1			Year 2			Year 3	
	Pre	Post		Pre	Post		Pre	Post
Social interaction								
Younger	2.59	2.79	Younger	2.25	2.48	<i>Younger</i> <sup>a</sup>	2.07	2.70
Older	2.35	2.81	Older	2.60	2.82	Older	2.56	2.95
Girls	2.79	2.93	Girls	2.30	2.70	Girls	2.39	3.03
Boys	2.18	<b>2.66</b> <sup>c</sup>	Boys	2.50	2.59	Boys	2.25	2.65
Cooperation/active participation								
Younger	2.65	2.76	Younger	2.36	2.53	<i>Younger</i> <sup>b</sup>	1.79	<b>2.50</b> <sup>b</sup>
Older	2.28	2.48	<i>Older</i> <sup>b</sup>	2.94	3.19	Older	2.60	2.88
<i>Girls</i> <sup>b</sup>	2.91	3.00	Girls	2.87	3.12	<i>Girls</i> <sup>b</sup>	2.26	<b>3.08</b> <sup>d</sup>
Boys	2.06	<b>2.28</b> <sup>c</sup>	Boys	2.44	2.62	Boys	2.12	2.38
Responsibility/initiative								
Younger	2.67	2.87	Younger	2.77	2.89	<i>Younger</i> <sup>b</sup>	2.00	<b>2.79</b> <sup>d</sup>
Older	2.92	2.74	Older	3.07	3.17	Older	3.04	3.17
<i>Girls</i> <sup>b</sup>	3.34	3.15	Girls	3.08	3.15	<i>Girls</i> <sup>b</sup>	2.76	3.17
Boys	2.22	<b>2.47</b> <sup>c</sup>	Boys	2.77	2.93	Boys	2.31	2.83
Communication								
<i>Younger</i> <sup>b</sup>	2.64	2.92	Younger	2.36	<b>2.20</b> <sup>c</sup>	<i>Younger</i> <sup>b</sup>	2.00	2.49
Older	2.02	2.88	<i>Older</i> <sup>d</sup>	2.82	<b>3.22</b> <sup>c</sup>	Older	2.53	2.86
<i>Girls</i> <sup>b</sup>	3.10	3.12	<i>Girls</i> <sup>c</sup>	2.82	3.00	<i>Girls</i> <sup>d</sup>	2.37	<b>3.15</b> <sup>b</sup>
Boys	1.63	<b>2.31</b> <sup>b</sup>	Boys	2.37	2.43	Boys	2.17	2.31

<sup>a</sup> Italics indicate gender and age effects, boldface indicates interaction effects.

<sup>b</sup>  $P < 0.05$ .

<sup>c</sup>  $0.10 > P > 0.05$ .

<sup>d</sup>  $P < 0.01$ .

tion,  $P < 0.01$ ; Responsibility,  $P < 0.01$ ; Communication,  $P < 0.01$ . Repeated MANOVA (Table 3) reveals main effects of time ( $P < 0.01$ ) and age ( $P = 0.01$ ) and a trend toward a gender effect ( $P = 0.06$ ). Similar to Year 2, younger children are rated significantly lower across all four domains ( $P < 0.05$ ). Girls continue to be rated higher than boys in Cooperation ( $P < 0.05$ ), Responsibility ( $P < 0.05$ ), and Communication ( $P < 0.01$ ). Significant time  $\times$  age interaction effects indicate that younger children improve more in Cooperation ( $P < 0.05$ ) and Responsibility ( $P < 0.01$ ) skills. Significant time  $\times$  gender interaction effects reveal that girls improve more in Cooperation ( $P < 0.01$ ) and Communication ( $P < 0.01$ ) skills.

### 3.2. Year-to-year comparisons

Year-to-year comparisons were made for the 28 children who attended camp in Years 2 and 3 and the 12 children who attended camp for 3 consecutive years.

#### 3.2.1. Two years of camp (Year 2 and Year 3)

Repeated-measures MANOVAs reveal significant effects of time on Social Interaction ( $P < 0.01$ ), Cooperation ( $P < 0.05$ ), and Communication ( $P < 0.05$ ) and a trend toward an effect on Responsibility ( $P = 0.07$ ) (Table 4). No significant improvement is seen in any domain for this cohort following Year 2 camp, but significant declines in functioning are noted between the end of Year 2 and the beginning of Year 3, followed by significant improvements in functioning following Year 3 camp (Fig. 2). With respect to Social Interaction, there is a trend toward a significant decline between Year 2 postcamp and Year 3 precamp ( $P = 0.07$ ), which is followed by significant gains after Year 3 camp ( $P < 0.01$ ). Cooperation lacks significance from pre- to postcamp in Year 2, but a significant decline in skills between Year 2 and 3 camps is noted ( $P < 0.05$ ), followed by significant gains after Year 3 camp ( $P < 0.01$ ). Also, no significant differences are captured for Responsibility after Year 2 camp, but skills are rated significantly

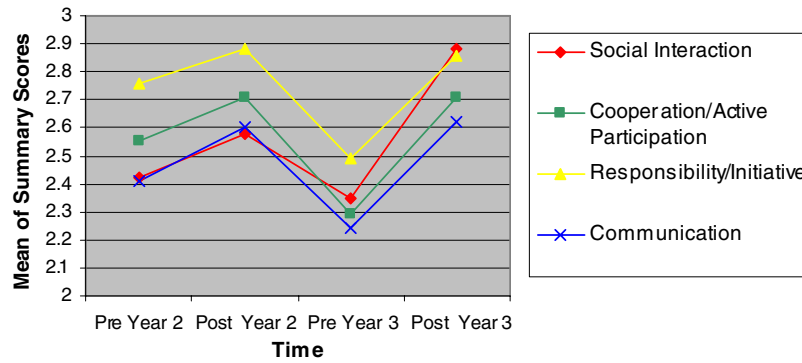


Fig. 1. Mean summary scores on C-VABS domains across time for campers attending Years 2 and 3 ( $n = 28$ ).

Table 4  
Mean summary scores on C-VABS domains across time for campers attending Years 2 and 3 ( $n = 28$ )

	Year 2		Year 3	
	Pre	Post	Pre	Post
Social interaction	2.42	2.58	2.35	2.88 <sup>a</sup>
Cooperation/active participation	2.55	2.71	2.29 <sup>b</sup>	2.71 <sup>b</sup>
Responsibility/initiative	2.76	2.88	2.49 <sup>b</sup>	2.86 <sup>a</sup>
Communication	2.41	2.60	2.24 <sup>a</sup>	2.62 <sup>a</sup>

<sup>a</sup>  $P < 0.01$ , significant change from previous score.  
<sup>b</sup>  $P < 0.05$ , significant change from previous score.

lower at the start of Year 3 ( $P < 0.05$ ), followed by significant gains after Year 3 camp ( $P = 0.01$ ). Lastly, for Communication, no significant gains are evident after Year 2 camp, but skills are lower at the start of Year 3 camp ( $P < 0.01$ ) and then increase significantly after Year 3 camp ( $P < 0.01$ ).

### 3.2.2. Three years of camp

Significant long-term effects of camp were computed by comparing the mean scores. Repeated-measures MANOVAs reveal a significant main effect of time on Social Interaction ( $P < 0.05$ ), Responsibility ( $P < 0.05$ ), and Communication ( $P = 0.05$ ) (Table 5, Fig. 2). With respect to Socialization, significant improvement is made following Year 1 camp. Those gains are generally maintained and remain at the same level after Year 2 camp. Another advance in skill development is measured after Year 3

camp. With respect to Responsibility, no improvement immediately follows Year 1 camp; however, between the end of Year 1 camp and the beginning of Year 2 camp, skills increase markedly ( $P < 0.05$ ). Responsibility skills improve again after Year 3 camp ( $P = 0.01$ ). For Communication, a trend toward improvement follows Year 1 camp ( $P = 0.08$ ). Those gains are maintained and improve further following a second year of camp ( $P < 0.05$ ). Gains continue to be maintained but Communication scores generally remain the same at the beginning and end of camp for Year 3.

## 4. Discussion

A weeklong camp experience improved Social Interaction consistently for each year of camp, which is strongly in line with the primary objectives of the camp. In addition, improvement in Communication and Cooperation for 2 of the 3 years, as well as Responsibility for Year 3, further supports the aims of the camp in increasing adaptive functioning and independence.

Camp success is best illustrated by the results for Year 3, when every domain shows significant improvement. It is plausible that the increased number of campers in Year 3 allowed for greater power to detect differences compared with previous years. However, these results could also reflect differences in the effectiveness of each year of camp or raters. Year 3 has the benefit of other dynamics, as 30% of the campers were return campers.

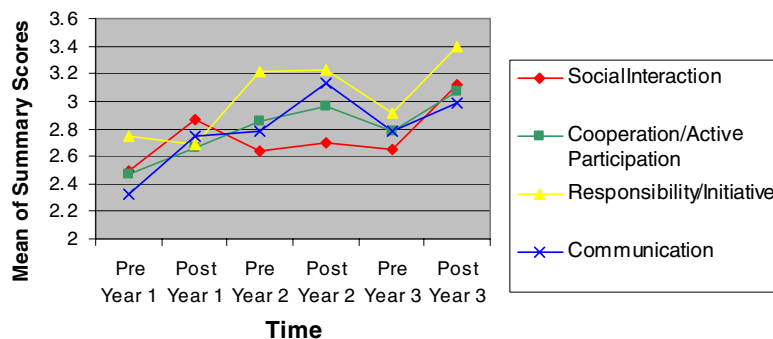


Fig. 2. Mean summary scores on C-VABS domains across time for campers attending Years 1, 2, and 3 ( $n = 12$ ).

Table 5  
Mean summary scores on C-VABS domains across time for campers attending Years 1, 2, and 3 ( $n = 12$ )

	Year 1		Year 2		Year 3	
	Pre	Post	Pre	Post	Pre	Post
Social interaction	2.49	2.87 <sup>a</sup>	2.64	2.70	2.65	3.12 <sup>a</sup>
Cooperation/active participation	2.47	2.66	2.86	2.96	2.78	3.07
Responsibility/initiative	2.75	2.68	3.21 <sup>a</sup>	3.23	2.92	3.40 <sup>a</sup>
Communication	2.33	2.74	2.78	3.13 <sup>a</sup>	2.78	2.99

<sup>a</sup>  $P < 0.05$ , significant change from previous score.

Changes in Responsibility may have been propelled by social pressure from return campers, who impart more responsible behavior by quickly indoctrinating new campers in the daily routine of camp. In addition, refinements in camp programming may have been more effective than in previous years in addressing issues across all domains.

Such findings support the concept that providing children with opportunities to learn social skills from peers, teens, and adults with the same medical condition helps to create an uncommon experience of empowerment and inclusion. Campers broaden their perception of their potential by observing others with seizures participating in a variety of activities. Because seizures are common to everyone at camp, they are no longer an acceptable reason to refrain from participation. As an “insider” or member of the group of individuals with seizures, the fear of rejection is no longer an issue for the campers and relationships are encouraged. Personal confidence is increased and ultimately encourages participation as well as social and emotional growth. An emotional catharsis often occurs, as campers express their worries and fears in group sessions while discussing seizures either witnessed or experienced while at camp.

Gender and age effects are associated with different factors. Girls are consistently rated higher than boys in Cooperation, Responsibility, and Communication, yet changes in functioning are mixed for girls and boys across different years. Likewise, a consistent age effect from year to year is not observed regarding changes in functioning. Rater bias may confound age and gender effects because each counselor assessed only the campers in his or her cabin, who are organized by both age and gender.

The results indicate a positive, cumulative impact of attending camp for consecutive years. Improvements in Social Interaction, Responsibility, and Communication were observed for return campers regardless if they returned for 1 or 2 additional years. Cooperation is also significantly improved in the group of children that attended camp in Years 2 and 3. Although there is a tendency toward a decline at the beginning of camp in the post- to precamp domain mean summary scores found in consecutive years for return campers (Table 4), the gains made during camp are replicated and, in some cases (Social Interaction), exceed levels from the previous year. This is particularly true for the subset of campers who attended camp for 3 years, as the overall trend from Year 1 precamp

to Year 3 postcamp demonstrates an overall significant improvement in all areas (Fig. 2).

Limitations of the study include issues of measurement, confounding factors, and the small number of subjects who attended 3 years of camp. The same rater did not evaluate each camper across years, and thus, differences from year to year may reflect differences in rater bias. Precamp measures are constrained by the limited amount of time a counselor has to witness all facets of each camper’s behavior. The new setting may influence some campers’ behaviors, and only over time would they act as they do in more familiar settings. Attempts to avoid subjectivity include having two primary counselors for each child provide the ratings, allowing an adjustment period prior to the initial assessment, and using consistent time points to conduct assessments. However, counselors were not unbiased observers. For example, they may be invested in seeing improvement in the children who were their campers. It may be useful in future studies to have blinded raters make observations for the first and last days of camp. Although the camp program was similar from year to year, the social milieu may have changed, which could affect aspects of group dynamics or specific peer interactions. These yearly differences may contribute to the differences observed each year. It is also difficult to evaluate the long-term benefits from attendance at any camp, as children grow as a function of maturation over time regardless of the camp experience. In addition, it would be helpful to use a regular camp as a control when evaluating changes in these behavioral domains.

## 5. Conclusion

The results strongly suggest that participation in Camp Great Rock, a condition-specific camp for children with epilepsy, can improve adaptive functional behaviors. Reduced socialization with peers and communication skills are common problems for children with epilepsy. Most encouraging is the significant and consistent improvement in social interactions associated with camp attendance during all 3 years. Furthermore, overall net gains at the end of each camp season appear to be maintained or increased, suggesting continued camp participation leads to additional benefit for return campers. The decline in skills at the start of each camp may even support the benefit of a mid-year intervention, like a retreat or minicamp, to promote

the continued advancement of skills and encourage generalization of adaptive skills to noncamp settings.

Long-term implications for specialty overnight camps like Camp Great Rock are potentially far-reaching for the child and family. Commonly, the child returns to the family with more knowledge about his or her condition, enhanced self-confidence, and greater willingness to accept responsibility at home. This change may, in turn, impact and alter parent protectiveness and child dependency. For some campers, a social network is established outside of camp and children maintain contact throughout the year. Ultimately, interventions that focus on adaptive behaviors, including psychosocial development, may be key to determining a child's overall outcome and quality of life.

### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.yebeh.2006.10.007](https://doi.org/10.1016/j.yebeh.2006.10.007).

### References

- [1] Vining E. Educational, social, and life-long effects of epilepsy. *Pediatr Clin North Am* 1989;36:59–61.
- [2] Hoare P, Kelly S. Psychosocial adjustment of children with chronic epilepsy and their families. *Dev Med Child Neurol* 1991;33:201–15.
- [3] Ostrom KJ, Smeets-Schouten A, Kruitwagen CL, Peters AC, Jennekens-Schinkel A. for the Dutch Study Group of Epilepsy in Childhood. Not only a matter of epilepsy: early problems of cognition and behavior in children with “epilepsy only”—a prospective, longitudinal, controlled study starting at diagnosis. *Pediatrics* 2003;112:1338–44.
- [4] Hoare P. The development of psychiatric disorders among children with epilepsy. *Dev Med Child Neurol* 1984;26:3–13.
- [5] Austin JK, McDermott N. Parental attitude and coping behaviors in families of children with epilepsy. *J Neurosci Nurs* 1988;20:174–9.
- [6] Devinsky O, Vasquez B. Behavioral changes associated with epilepsy. *Neurol Clin* 1993;11:127–49.
- [7] Dunn DW, Austin JK. Behavioral issues in pediatric epilepsy. *Neurology* 1999;53(Suppl 2):S96–S100.
- [8] Graae F. High anxiety in children. *J Clin Psychiatry* 1990;51(Suppl.):S50–3.
- [9] Alqwash RH, Hussein MJ, Matloub FF. Symptoms of anxiety and depression among adolescents with seizures in Irbid, northern Jordan. *Seizure* 2000;9:412–6.
- [10] Torta R, Keller R. Behavioral, psychotic, and anxiety disorders in epilepsy: etiology, clinical features, and therapeutic implications. *Epilepsia* 1999;40(Suppl. 10):S6–S20.
- [11] Goldstein MA, Harden CL. Epilepsy and anxiety. *Epilepsy Behav* 2000;4:228–34.
- [12] Kanner AM. Depressive disorders in epilepsy. *Neurology* 1999;53(Suppl. 2):S26–32.
- [13] Dunn DW, Austin JK, Huster GA. Symptoms of depression in adolescents with epilepsy. *J Am Acad Child Adolesc Psychiatry* 1999;38:1132–8.
- [14] Austin JK. A model of family adaptation to new-onset childhood epilepsy. *J Neurosci Nurs* 1996;28:82–92.
- [15] Viberg M, Blennow G, Polski B. Epilepsy in adolescence: implications for the development of personality. *Epilepsia* 1987;28:542–6.
- [16] Hauser WA, Hesdorffer DC. Epilepsy, frequency, causes and consequences. New York: Demos; 1990.
- [17] Levin R, Banks S, Berg B. Psychosocial dimensions of epilepsy: a review of the literature. *Epilepsia* 1988;29:805–16.
- [18] Stores G, Piran N. Dependency of different types in schoolchildren with epilepsy. *Psychol Med* 1978;8:441–5.
- [19] Hoare P, Kerley S. Helping parents and children with epilepsy cope successfully: the outcome of a group programme for parents. *Psychosom Med* 1992;36:759–67.
- [20] Dunn DW, Harezlak J, Ambrosius WT, Austin JK, Hale B. Teacher assessment of behaviour in children with new-onset seizures. *Seizure* 2002;11:169–75.
- [21] Austin JK, Harezlak J, Dunn DW, Huster GA, Rose DF, Ambrosius WT. Behavior problems in children before first recognized seizures. *Pediatrics* 2001;107:115–22.
- [22] Perrine K, Kiolbasa T. Cognitive deficits in epilepsy and contribution to psychopathology. *Neurology* 1999;53(Suppl. 2):S39–48.
- [23] Bourgeois BFD. Antiepileptic drugs, learning, and behavior in childhood epilepsy. *Epilepsia* 1998;39:913–21.
- [24] Meador KJ, Gillian FG, Kanner AM, Pellock JM. Cognitive and behavioral effects of antiepileptic drugs. *Epilepsy Behav* 2001;2:SS1–SS17.
- [25] Dodrill CB, Batzel LW, Queisser HR, Temkin NR. An objective method for the assessment of psychological and social problems among epileptics. *Epilepsia* 1980;21:123–35.
- [26] Seidenberg M, Berent S. Childhood epilepsy and the role of psychology. *Am J Psychol* 1992;47:1130–3.
- [27] Wildrick D, Parker-Fisher S, Morales S. Quality of life in children well-controlled epilepsy. *J Neurosci* 1996;28:192–8.
- [28] Galletti F, Rinna A, Acquafondata C. An insight into childrens' and adolescents' experience of seizures and epilepsy. *Seizure* 1998;7:309–16.
- [29] Williams J, Lange B, Sharp G, et al. Altered sleeping arrangements in pediatric patients. *Clin Pediatr* 2000;39:635–42.
- [30] Chavez JM, Buriel R. Mother–child interactions involving a child with epilepsy: a comparison of immigrant and native-born Mexican Americans. *J Pediatr Psychol* 1988;13:349–61.
- [31] Hodes M, Garralda ME, Rose G, Schwartz R. Maternal expressed emotion and adjustment in children with epilepsy. *J Child Psychol Psychiatry* 1999;40:1083–93.
- [32] Austin JK, McBride AB, Davis HW. Parental attitude and adjustment to childhood epilepsy. *Nurs Res* 1984;33:92–6.
- [33] Shore C, Austin J, Musick B, Dunn D, McBride A, Creasy K. Psychosocial care needs of parents of children with new-onset seizures. *J Neurosci Nurs* 1998;30:169–74.
- [34] Ridsdale L, Kwan I, Cryer C. for the Epilepsy Care Evaluation Group. Newly diagnosed epilepsy: can nurse specialists help? A randomized trial. *Epilepsia* 2000;41:1014–9.
- [35] Cushner Weinstein S, Weinstein S, Bethke L, Salpekar J, Elling N, Gaillard W. What parents and children worry about with a new diagnosis of epilepsy: the benefit of educational groups. *Epilepsia* 2003;44(Suppl. 9):S117.
- [36] Tan SY, Bruni J. Cognitive behavior therapy with adults and patients with epilepsy: a controlled outcome study. *Epilepsia* 1986;27:225–33.
- [37] Lewis MA, Hatton CL, Salas I, Leake B, Chiofalo N. Impact of the children's epilepsy program on parents. *Epilepsia* 1991;32:354–74.
- [38] Becu M, Becu N, Manzur G, Kochen S. Self-help epilepsy groups: an evaluation of effect on depression and schizophrenia. *Epilepsia* 1993;34:841–5.
- [39] McCubbin HI, Patterson JM. Family transitions: adaptation to stress. In: McCubbin HI, Figley CR, editors. *Stress and the family: coping with normative transitions*, Vol. 2. New York: Brunner/Mazel; 1983.
- [40] Bluebond-Lagner M, Perkel D, Goertzel T, Nelson K, McGeary J. Children's knowledge of cancer and its treatment: impact of an oncology camp experience. *J Pediatr* 1990;116:207–13.
- [41] Misuraca A, Di Gennaro M, Lioniello M, Duval M, Aloï G. Summer camps for diabetic children: an experience in Campania, Italy. *Diabetes Res Clin Pract* 1996;32:91–6.

- [42] Milliet J, Carman D, Browne R. Summer camp: effects on function of children with autoimmune diseases. *Arthritis Care Res* 1996;9:309–14.
- [43] Kelly CS, Shield SW, Gowen MA, Jaganjac N, Andersen CL, Strobe GL. Outcomes analysis of a summer asthma camp. *J Asthma* 1998;35:165–71.
- [44] Singh RH, Kable JA, Guerrero NV, Sullivan KM, Elsas LJ. Impact of camp experience on phenylalanine levels, knowledge, attitudes, and health beliefs relevant to nutrition management of phenylketonuria in adolescent girls. *J Am Diet Assoc* 2000;100:797–803.
- [45] Eng B, Davies B. Effects of a summer camp experience on self-concept of children with cancer. *J Pediatr Oncol Nurs* 1991;8:89–90.
- [46] Warady BA, Carr B, Hellerstein S, Uri A. Residential summer camp for children with end-stage renal disease. *Child Nephrol Urol* 1992;12:212–5.
- [47] Biggs KS, Heinrich J, Jekel JF, Cuono CB. The burn camp experience: variables that influence the enhancement of self-esteem. *J Burn Care Rehabil* 1997;18:93–8.
- [48] Briery BG, Rabian BJ. Psychosocial changes associated with participation in a pediatric summer camp. *Pediatr Psychol* 1999;24:183–90.
- [49] Sawain KJ, Lannon SL, Austin JK. Camp experience and attitudes toward epilepsy: a pilot study. *J Neurosci Nurs* 2001;33:57–64.
- [50] Kiernan G, Gormaley M, MacLachlan M. Outcomes associated with participation in a therapeutic recreation camping programme for children from 15 European countries: data from the “Barretstown Studies.” *Soc Sci Med* 2004;59:903–13.
- [51] Dahl MV, Roering MJ, Pride HB, Rabinowitz LK. Camp Knutson: the first three years. *J Am Acad Dermatol* 1996;35:96–100.
- [52] Jerzierski M. Camp Barnabas: enlarging the spirit, encouraging the heart—where children with special challenges can just be kids. *J Emerg Nurs* 1997;23:501–4.
- [53] Page CJ, Pearson J. Creating therapeutic camp and recreation programs for children with chronic illness and disabilities. *Pediatrician* 1990;17:297–307.
- [54] Thomas D, Gaslin TC. “Camping up” self-esteem in children with hemophilia. *Issues Compr Pediatr Nurs* 2001;24:253–63.
- [55] Epstein I, Stinson J, Stevens B. The effects of camp on health-related quality of life in children with chronic illnesses: a review of the literature. *J Pediatric Oncol Nurs* 2005;22:89–103.
- [56] Stevens FI. Vineland Adaptive Behavior Scales: classroom edition. *J Couns Dev* 1986;65:112–3.