



Impact of Condition Specific Camps on Resiliency and Adaptive Behavior in Children with Heart Conditions

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BACKGROUND

Heart conditions can have a profound effect on the development of children physically and mentally. Camp Heartbeat is a five-day residential camp established in 2011, to reduce the social isolation that is often associated with heart disorders, and increase the knowledge and understanding the campers have about their condition. The camp provides opportunities for the kids to work with professional staff and become better self advocates and self managers of their condition. They learn from peers and adult volunteers who live effectively with the condition, serving as role models and offering hope for a successful future to our campers.

AIMS OF STUDY

A study by Children's National Medical Center demonstrated that a condition-specific camp designed for kids with epilepsy can increase social interactions, cooperation/active participation, responsibility/initiative, and communication in its campers over a three-year period [1]. A second study for children with NF1 suggested that resiliency could serve as a moderator for the quality of life, regardless of severity of condition [2]. Our aim was to determine the impact of condition-specific camps on children with heart conditions. The Price-Emory Resiliency Scales, Herth Hope Index, and Loneliness Scale were used to identify possible shifts in resiliency, hope and loneliness of campers with heart conditions from pre-camp to post-camp and long term, for campers who attended consecutive years between 2012-2014.



MATERIALS AND METHODS

Approximately fifty percent of the campers with congenital heart disorders or pacemakers who attended Brainy Camps from 2012-2014, or 39 campers, participated in this research project. 39 campers participated for one year, 13/39 participated for 2 consecutive years, and 3/39 participated for 3 consecutive years. Of the 39 that participated, 15 were females and 24 were males with ages ranging from 8-17 years old. The camp was held in High View, West Virginia and the campers came from the Washington Metropolitan area. The research was conducted using online surveys taken before camp and through I-pads at the end of camp. Surveys were administered via the online survey tool Qualtrics to include the Price-Emory Resiliency Scales, the Loneliness Scale, the Social Skills Inventory, the PROMIS scales, and the Herth Hope Index. Parents completed a demographic questionnaire, the Vanderbilt and the BASC questionnaire. Data from the Price-Emory Resiliency Scales, Herth Hope Index and Loneliness Scale were analyzed for this study.

This study looked at the Resiliency Scales by Price-Emory for children and adolescents. Resiliency reflects how an individual is able to overcome both internal and external stresses. The survey questions were written at a third-grade reading level and consist of 20 questions that form the Sense of Mastery scale, 24 questions forming the Sense of Relatedness scale, and 20 questions forming the Emotional Reactivity scale, which all combine as a measurement of resiliency.

For the **three scales**, mastery, relatedness and emotional reactivity, used to determine resilience, T score ranges were developed based on the distribution of scores from normative samples relative to age for scales and subscales. Statistics were established on what was an average, below average and above average range. **Together these combine to provide a way to evaluate a child's resources or strengths and vulnerability relative to resiliency.**

The Herth Hope Index measured child's sense of hope and the Loneliness Scale measured the child's sense of isolation.

Averages of group scores were taken for single year, 2 consecutive year and 3 consecutive year participants and compared to average scores in normative data as charted in Table 1, Table 2 and Table 3.

RESULTS

Table 1. 39 Campers for 1 Year

Test	Pre	Post	T score range
Mastery	57.4	53.4	53.7 +/- 10.1
Relatedness	51.6	45.9	53 +/- 10.2
Emotional Reactivity	46.5	48.5	46.2 +/- 9.9
Loneliness	34.3	37.1	
Hope	28.3	30.6	

Table 2. 13/39 Campers for 2 Consecutive Years

	Hope	Loneliness	Mastery	Relatedness	Emotional Reactivity
Year 1	31.4	32.3	55.9	56.0	43.4
Year 2	31.7	31.2	55.0	54.5	43.3

Table 3. 3/39 Campers for 3 Consecutive Years

	Hope	Loneliness	Mastery	Relatedness	Emotional Reactivity
Year 1	33.7	32.3	53.3	60	40.3
Year 2	33.0	25.7	43.3	57.3	33.7
Year 3	35.0	26.5	43.0	61.7	37.0



DISCUSSION

Resiliency Scales question topics:

Sense of Mastery scale: optimism, self-efficacy, adaptability

Sense of Relatedness scale: trust, support, comfort, tolerance

Emotional Reactivity scale: sensitivity, recovery, impairment [2]

For the Resiliency Scales, the results across 2012-2014 were in average range amongst all values, demonstrating that children with heart conditions are equally resilient to their normative peers. Mastery and Relatedness decreased between pre- and post-camp, while Emotional Reactivity increased. In contrast for those who attended camp 2 years consecutively, the Mastery, Relatedness and Emotional Reactivity scores decreased. For the 3 year consecutive attendees, there was only a slight increase in Relatedness between years 1 and 3.

A child's sense of mastery and self-efficacy is a core characteristic of resiliency that provides children the opportunity to interact with their environment. The Sense of Mastery Scale encompasses optimism, self-efficacy, and adaptability. A sense of relatedness is linked to the ability to be resilient against adversity, as relationships strongly relate to psychological well-being. It incorporates a sense of trust, perceived access to support, tolerance to differences, and comfort with others. The last scale, Emotional Reactivity, can be described as the threshold of tolerance prior to the occurrence of an adverse event. It measures sensitivity, recovery skills, and impairment of functioning due to emotional arousal. Reactivity is the speed and intensity of a child's negative emotional response keeping in mind the importance of the child's regulation of said reactivity. A strong emotional reactivity with difficulty self-regulating is associated with vulnerability. Resiliency can be used to coping strategies and overall quality of life in children managing chronic heart conditions.

Loneliness scores increased between pre- and post-camp surveys for single year participants. For those who attended 2 years consecutively and 3 years consecutively a decreasing trend was seen, indicating that the decreased sense of isolation the more years they attended camp. This may have been due to the community they built at camp and their increased knowledge about others with their conditions.

Hope scores increased across all three groups. This could be caused by the time spent in a community of children with illnesses like their own. This may lead to increased self esteem and improvement in successfully managing their health demands while living with the uncertainty of their heart condition.

Limitations of these results include the small numbers of campers in Camp Heartbeat, variability in data collection sites where pre camp was taken in the child's home versus post camp at the campsite, and the small number of return campers who continued their participation in the study.

Future plans: To combine data from all the camps and evaluate the impact of condition specific camps on a large cohort of participating youth. Examine individual subscales including self-efficacy, trust, support, and optimism to determine strengths and vulnerabilities and compare differences between conditions. Evaluate the influence of co-morbidities of learning, anxiety, and depression on resiliency, loneliness, and adaptive behavior. Identify potential targets for future interventions.

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