

RESEARCH ROUNDUP

December 2013

Issue 1



Howdy! Welcome to the first issue of Research Roundup for the Hole in the Wall Gang Camp!

The purpose of this newsletter is to share with you recent research about camps, children, youth, and families living with serious and life-threatening illnesses, and similar research to increase your knowledge and skills in your work.

Twice a year, we will recap research topics along themes such as diagnosis groups, staff training, etc. The good part? The research is summarized, so your brain doesn't hurt! The best part? You can use this information to help children and their families!

The theme of this issue is **research reported in 2013 on camps for youth with chronic illness**. Five studies are summarized, and a list of additional studies is provided at the end.

Happy reading! Let's lasso some knowledge!



Assessing the social effect of therapeutic recreation summer camp for adolescents with chronic illness

Authors: Jared Allsop, Sandra Negley, and Jim Sibthorp
Journal: Therapeutic Recreation Journal, 47(1), 35-46.

Introduction: This study examined the effects of a therapeutic recreation-based summer camp on social self-efficacy levels and social performance with peers among 79 adolescents with neurofibromatosis. This study is important because for adolescents with chronic illness, a lack of social self-efficacy is a serious problem.

Methods: One group of campers (the control group) attended a traditional summer camp session, and the other group (the treatment group) attended a therapeutic recreation (TR) camp session. Trained therapeutic recreation professionals worked with the second group of campers to develop social goals, and did structured observations of social performance of campers throughout the second camp session. Campers in both sessions completed self-reports about their social self-efficacy at the beginning and end of camp.

Results: There was no evidence that the TR program increased social self-efficacy more than the traditional summer camp program. However, campers in both types of programs did increase social self-efficacy.

For more information, or to read more of this research, please contact Ann Gillard at 860.429.3444, ext. 116 or Ann.Gillard@holeinthewallgang.org

Campers in the TR program had a greater increase over the length of the camp session in social performance with peers than campers in the traditional camp program.

Recommendations for Practice:

1. Programs based on social self-efficacy and social cognitive theories can provide significantly meaningful results for campers.
2. Peer models and vicarious experiences were powerful in increasing social performance.
3. The therapeutic recreation-based processes of assessments, and program planning, implementation, and evaluation was useful in achieving higher levels of social interaction. Trained, devoted, and educated TR professionals were important in this process.
4. Self-reports might not be useful in measuring some changes. Structured observations might be a better method.



Relationship between camp attendance and self-perceptions in children with chronic health conditions: A meta-analysis

Authors: Cathleen Odar, Kimberly S. Canter, and Michael C. Roberts

Journal: Journal of Pediatric Psychology, 38(4), 398-411.

Introduction: This study examined the association between camp attendance and changes in self-perceptions in children with chronic health conditions, using meta-analysis. Meta-analysis compiles many studies about the same topic. This topic is important because self-perception improvements following camp attendance relate to quality of life and psychosocial functioning, which are commonly believed to change through the support provided by camp experiences.

Methods: The authors examined 31 studies that included post-camp and follow-up measures of campers' global self-perceptions (i.e., self-esteem, concept,

competence, or worth), children's chronic health conditions, and camp components. Campers had chronic conditions such as asthma, diabetes, obesity, kidney disease, craniofacial difference, congenital heart disease, epilepsy, juvenile rheumatoid arthritis, and cancer.

Results: Children experienced small, but statistically significant, improvements in self-perceptions at post-camp and, to a lesser degree, at follow-up. Children with the conditions of obesity, congenital heart disease, epilepsy, and juvenile rheumatoid arthritis had greater improvements in self-perceptions than children with other conditions. It did not matter if the camp provided an educational component aiming to affect campers' self-perceptions.

Recommendations for Practice:

1. Children with many chronic conditions (e.g., diabetes, asthma, and cancer) might not display benefits in self-perceptions over the course of camp participation, so the benefits of camp should be more accurately portrayed to families considering camp.
2. Camp participation should be especially encouraged for children with obesity, congenital heart disease, epilepsy, or juvenile rheumatoid arthritis.
3. In program planning, staff should be aware that having a camp component addressing self-perceptions might not be necessary, because this does not lead to greater self-perception improvements. Instead, camps might want to consider activities that are simply for entertainment or education value or that have been demonstrated empirically to contribute to beneficial outcomes.



An evaluation of psychosocial outcomes for children and adolescents attending a summer camp for youth with chronic illness

Authors: Kristine Woods, Sunnye Mayes, Emily Bartley, David Fedele, and Jamie Ryan

Journal: Children's Health Care, 42(1), 85-98.

Introduction: This study evaluated health-related quality of life and hope in 102 youth with a variety of chronic illnesses (average age, 13.2; cancer, 36.9%, kidney disease, 21.4%) after participation in a summer camping program. This study is important because for youth with chronic illness, lower levels of hope are associated with increased levels of depression and anxiety, and higher levels of hope relate to an increase in positive coping strategies, among other positive outcomes.

Methods: Campers completed pre-camp and post-camp self-reports using the Pediatric Quality of Life Inventory and Children's Hope Scale.

Results: Hope and goal-directed behaviors increased from pre- to post-camp. Campers became more confident in their ability to identify strategies to accomplish goals. Campers' identification and development of personal goals was associated with enhancement of perceived health-related quality of life at the post-camp assessment. However, no significant differences emerged in health-related quality of life from pre- to post-camp.

Recommendations for Practice:

1. There are psychosocial benefits associated with hopeful thinking, so camps should assist campers with determining their goals, visualizing ways to meet them, and increasing their beliefs in successfully moving toward their goals.
2. At camp, youth with chronic illness can engage in therapeutic recreation, make social connections, set future goals, and gain understanding about their illness in a medically safe setting. Camps should consider their design. At the camp in this study, a set of daily challenges were presented with the ultimate goal of teaching youth to

overcome disease-related difficulties through the concepts of "character," "coping," and "connection," which seemed to have bearing on campers' increases in hope.



Initial examination of a new questionnaire assessing perceived social support in summer camp and home environments for children with cancer and their siblings

Authors: Yelena P. Wu, G. John Geldhof, Michael C. Roberts, Sangeeta Parikshak, and Michael D. Amylon

Journal: Children's Health Care, 42(1), 67-84.

Introduction: This study developed a scale (Children's Assessment of Perceived Social Support) to use with children with cancer and their siblings. The purpose of the scale was to assess perceived support from individuals in the home and summer camp settings and about cancer and non-cancer-related issues. This study is important because no measures exist of perceived support across settings and about illness-specific issues.

Methods: Parents completed family demographic questionnaires. Sixty-five children with cancer and 85 siblings completed sentences describing sources of social support about non-cancer-related issues (e.g., "My parents want to hear about my problems") and cancer-related issues (e.g., "My parents want to hear about problems I have because of cancer"), and rated how true each sentence was for them.

Results: Children’s perceptions of cancer-related versus non–cancer-related support came from different sources. With parents and people at camp, both sets of campers did not perceive any differences between support on cancer-related and non–cancer-related issues. Classmate and teacher support was different for cancer-related versus non–cancer-related issues for both sets of campers. Close friends of oncology campers (but not siblings) were perceived as offering different support for cancer-related versus non–cancer-related issues.

Recommendations for Practice:

1. Consider using the Children’s Assessment of Perceived Social Support to document outcomes of camp.
2. Camps can use this scale to measure potential increases in perceived social support pre- to post-camp and to see whether changes in social support relate to beneficial outcomes (e.g., improved psychological well-being or social functioning). This information can be shared with stakeholders such as funders, parents/caregivers, etc.



Evaluation of child and parent outcomes after a pediatric cardiac camp experience

Authors: Margaret W. Bultas, Chakra Budhathoki, and Karen Balakas

Journal: Journal for Specialists in Pediatric Nursing, 18(4), 320-328.

Introduction: This study evaluated the effects of a cardiac camp experience on children with heart disease and their parents, specifically (a) child anxiety levels, (b) parent anxiety levels, (c) child’s attitude toward illness, and (d) child’s psychosocial functioning, including self-esteem, social functioning, physical functioning, and emotional functioning. This study is important because specialty camps for children with heart disease are often unavailable because of children’s medical history, ongoing medical needs, medications, physical limitations, and reduced stamina.

Methods: Forth-nine parent-child dyads completed questionnaires about the four areas listed above on the first, third, and fifth (last) days of a residential camp.

Results: There were decreases in parent anxiety (especially for parents of first-time campers) and child trait anxiety, and positive psychosocial outcomes in the areas of self-esteem, social, physical, and emotional functioning.

Recommendations for Practice:

1. Parents of children with heart disease should consider sending their children to camp because it can be beneficial psychosocially for parents and could reduce some caregiver burden.
2. Pediatric nurses and cardiologists should be available on site to campers during the entire camp experience.
3. Camps aiming to serve youth with heart disease should provide a safe environment where campers learn that they are not alone in living with heart disease, feel accepted, make lifelong friends, build self-confidence, and feel it is normal to not always feel well, have scars, and take medicine.



Here are some more articles that came out in 2013:

1. Gillard, A., & Watts, C. E. (2013). Program features and developmental experiences at a camp for youth with cancer. *Children and Youth Services Review*, 35(2013), 890-898. doi: 10.1016/j.chilyouth.2013.02.017
2. Holbein, C. E., Murray, C. B., Psihogios, A. M., Wasserman, R. M., Essner, B. S., O'Hara, L. K., & Holmbeck, G. N. (2013). A camp-based psychosocial intervention to promote independence and social function in individuals with spina bifida: Moderators of treatment effectiveness. *Journal of Pediatric Psychology*, 38(4), 412-424. doi: 10.1093/jpepsy/jst003
3. Lense, M., & Dykens, E. (2013). Musical learning in children and adults with Williams Syndrome. *Journal of Intellectual Disability Research*, 57(9), 850-860. doi: 10.1111/j.1365-
4. Mouton, L., & Bruce, J. (2013). Current practices for training staff to accommodate youth with special health care needs in the 4-H camp setting. *Journal of Extension*, 51(1), 34-34.
5. Papaioannou, C., Evaggelinou, C., Barkoukis, V., & Block, M. (2013). Disability awareness program in a summer camp. *European Journal of Adapted Physical Activity*, 6(2), 19-28.
6. Provident, I. M., & Colmer, M. A. (2013). Muscular dystrophy summer camp: A case study of a non-traditional level I fieldwork using a collaborative supervision model. *Work*, 44(3), 337-345. doi: 10.3233/WOR-121510
7. Swank, J. M. (2013). Obstacles of grief: The experiences of children processing grief on the ropes course. *Journal of Creativity in Mental Health*, 8(3), 235-248. doi: 10.1080/15401383.2013.821922

