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### HEALTH PSYCHOLOGY | RESEARCH ARTICLE

# The impact of therapeutic camp on children with congenital hand differences

Amy Lake<sup>1</sup>\*, Shelby Parker Cerza<sup>2</sup>, Lesley Butler<sup>2</sup>, Scott Oishi<sup>3</sup> and Andrea Brown<sup>4</sup>

**Abstract:** The goal of this study was to evaluate the efficacy of hand camp by investigating camp participation and outcomes on self-esteem, physical function, activity participation, and peer relationships. Forty patients with a congenital hand difference seen in hand clinic between the ages of 10 and 13 were eligible to attend hand camp. Participation involved completion of questionnaires at 3-time points: before camp (Pre-Camp Questionnaires), immediately following camp (Immediate Follow-Up Questionnaires) and 6-months after camp (Final Follow-Up Questionnaires). The questionnaires administered included: Demographic Form, Patient Reported Outcomes Measurement Information System (PROMIS), Rosenberg Self-Esteem Scale (RSES), and Camp Expectation Questionnaire. Thirty-six patients were included (22 females, 14 males), average age of 11.17 years. Diagnoses included: central deficiency, transverse deficiency, radial longitudinal deficiency, ulnar longitudinal deficiency, and overgrowth conditions. PROMIS Upper Extremity Function significantly improved from pre-camp to immediate follow-up (46.24 to 48.95; p = 0.016), as well as at pre-camp and final follow-up (46.24 to 49.44; p = 0.008). PROMIS Peer Relation scores significantly improved from pre-camp to immediate follow-up (52.26 to 57.91; p = 0.002). RSES results indicated significant improvements in self-esteem between pre-camp and immediate follow-up (23.92 to 26.81; p < 0.001), and between pre-camp and final follow-up (23.92 to 25.72;

#### ABOUT THE AUTHOR

Amy Lake is an Occupational Therapist and Certified Hand Therapist with over 20 years of experience working with children born with hand differences. Not only has she treated these children therapeutically in the outpatient setting but she has also been instrumental in expanding the hand camp model within her institute as well around the US and world. She has seen the impact of therapeutic camps in this population and willingly shared this model with others attempting to replicate hand camp within their institutes. There are now several Hand Camp models around the US and world based off of this current model. This paper reflects Amy Lake and Scottish Rite's ongoing interest on the impact of therapeutic camp on pediatric participants. It is hoped that this paper benefits other researchers and pediatric patients who desire to implement or who are already providing a therapeutic experience through camp or other activities.

#### PUBLIC INTEREST STATEMENT

My name is Amy Lake and I am an Occupational Therapist and Certified Hand Therapist. For the past 20 years, I have worked closely with children with Hand Differences and directed camps for these children between the ages of 6-17. I have witnessed, firsthand, how camp impacts the lives of these children, especially in the areas of selfesteem, self-confidence, peer relations and physical functioning. Camp is difficult to study due to its unique qualities, subjective nature, and unpredictable group sample. However, since I have been co-directing camps, each child has left camp impacted in some way and I knew, if we tried hard enough, we could demonstrate these positive outcomes. I believe there is a need for this model to be shared and replicated by others, not only for children born with hand differences but for all children with any difference visible or otherwise.





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p < 0.001). Peer relationships, upper extremity function, and self-esteem improved immediately following hand camp. Upper extremity function and self-esteem scores continued to improve significantly throughout the 6-month follow-up period. The study authors believe that research related to therapeutic camping experiences is integral when identifying best-practice interventions to increase quality of life outcomes for children with congenital hand differences.

#### Subjects: Health Psychology; Emotion; Child Development; Mental Health Research

#### Keywords: hand difference; self-esteem; camp; psychosocial function; peer relations

Congenital upper limb differences affect approximately 1 in 100,000 children in the United States and the gold standard of treatment continues to be maximizing overall function (Bae, Canizares, Miller, Waters & Goldfarb, 2017; Ekblom et al., 2010; Giele et al., 2001; Koskimies et al., 2011). In 2001 however, after the World Health Organization (2001) proposed a standard language to describe *states and disability* (the International Classification of Function, Disability, and Health, or ICF), there has been a shift to assess pediatric patients in a more holistic manner and begin looking more closely not only at physical but also psychological and social well-being (Bae et al., 2017).

When attempting to understand the specific psychosocial factors that impact individuals with a hand difference, the literature is sparse. Varni et al. (1989) found that social support (including parent, teacher, classmate, etc.) significantly predicted self-esteem in children with a congenital/ acquired hand difference. Thus, those children with increased social support had higher self-esteem, which is considered an integral aspect of psychological functioning (King et al., 1993). In other pediatric medical populations that are characterized by a deformity, such as cleft lip, burns, and traumatic amputations, it has been found that therapeutic interventions such as formal therapy, peer support, and other forms of intervention, can impact the level of distress caused by the physical deformity in a positive manner while decreasing anxiety (Madden et al., 2006).

There are few, well-established assessments used to address psychosocial needs or outcomes for children with congenital hand differences. In a 2020 meta-analysis, 17 studies were analyzed and found to use a wide variety of tools in order to best assess the physical, psychological, and social functioning of children born with a hand difference (Miller et al., 2020). These three areas of functioning remain consistent within the hand differences literature. This meta-analysis highlights the need for routine psychosocial evaluations throughout the treatment course of this unique patient population (Miller et al., 2020).

Congenital differences of the hand and upper extremity range from mild to severe and can affect function, social interactions, and self-confidence (Lake, 2010). Most often, the goal of children born with a hand difference is to reach maximal functional independence and gain acceptance of their difference. Many types of care are available: therapy, use of prosthetics or aids, surgical intervention, and support groups.

Although reconstructive surgery, if needed, is typically managed at an early age, many children born with upper limb differences experience lasting aesthetic and functional differences. These differences may hinder psychosocial functioning throughout life, causing social anxiety and depression (Ardon et al., 2012; Franzblau et al., 2015; Joachim & Acorn, 2000).

Hands are one of the most noticed parts of the body second only to the face and are essential for daily tasks and interactions with other people and the environment, making them difficult to conceal

(Andersson et al., 2011; Franzblau et al., 2015; Jakubietz et al., 2005). Although many studies have focused on functional outcomes following reconstruction, much less is known regarding the social and emotional outcomes of congenital hand differences (Andersson et al., 2011; Franzblau et al., 2015., Joachim & Acorn, 2000; Rumsey & Harcourt, 2007).

In Eileen Bradbury's book *Counseling People with Disfigurement* (Bradbury, 1996), she found that having a hand difference or disfigurement can create social avoidance for the individual as well as others surrounding him/her. She also states that adolescence is a time of considerable change, not only in school but also in body image. The environment is more competitive and less protected. The changes an adolescent's body goes through can evoke increased self-consciousness which can be intensified in those with a visible difference (Bradbury, 1996).

Addressing these psychological differences associated with congenital upper limb differences has been a goal for clinicians for many years. However, identifying and attending to these differences has been problematic and difficult due to time constraints, hospital regulations, and maintaining HIPPA compliance with patients. Many hospital-based parent-run support groups have been organized through the years though their success is contingent on parents having the time and energy year after year to keep them viable. One support group, The Lucky Fin Project, has withstood the test of time and only flourished over the years and has become a worldwide support group for children with upper limb differences (The Lucky Fin Project, 2021).

In light of the psychosocial impact on children with a hand difference and their families, in the mid-1990s our specialty pediatric orthopedic hospital began using groups to provide full encompassing support. These support groups soon converged into weekend getaways for families so they could spend more time together discussing challenges and successes they face raising a child with a congenital hand difference. This in turn led to the idea of camps, both weekend camps for families and week-long camps for kids.

The idea of summer camps for kids first started in the late 1800s and has evolved over the years to incorporate many sports, religious, and diagnosis-specific camping opportunities (Scribnick & Johnsen, 2013). It has been written that "camp, if it is worthy, is one of the greatest socializing, humanizing, civilizing factors which can enter the life of a boy or girl" (Barr et al., 2010). As estimated by the American Camp Association (2018), 10–12 million individuals go to camp every year. Most of these campers are comprised of children and youth, yet also included in this count are family and adult camp programs (Henderson et al., 2007). Children with chronic conditions are typically excluded from traditional summer camps due to their increased need for medical care or physical limitations which could prevent them from participating in regular camp activities (Barr et al., 2010).

Research by Austin (1989) and Breslau (1985) indicates that children with chronic illnesses are at a greater risk of experiencing psychological difficulties such as behavior problems, poor selfconcept, and social withdrawal. Pless (1984) estimated a 1.3 to 3 times greater risk of psychological or social issues during childhood in a chronically ill child when compared to a healthy child. In addition, a child's perception of, or attitude about, his or her condition may play a role in the development of problems, including social adjustments with peers, coping mechanisms, and how they adapt to his/her chronic condition (Briery, 1999).

Therapeutic camping for children with chronic conditions was a concept proposed in the 1970s. It provided a typical camp experience for children with a chronic illness while also providing a psychosocial intervention to help decrease the burden of disease and provide support, respite, and skill building through recreational activities (Barr et al., 2010; Moola et al., 2013). There have been multiple diagnosis-specific camp models established and studied for conditions such as spina bifida,

epilepsy, pediatric cardiac conditions, and cancer (Bultas et al., 2013; Holbein et al., 2013; Martiniuk et al., 2014; Sawin et al., 2001). Across these diagnosis-specific camps, there were several common findings and outcomes, such as increased independence with activities of daily living, decreased parent/child anxiety, increased self-esteem and increased social, emotional and physical functioning (Bultas et al., 2013; Holbein et al., 2013; Martiniuk et al., 2014; Sawin et al., 2001).

As an attempt to address these concerns of self-image, self-esteem, and confidence, this pediatric orthopedic specialty hospital established hand camps for patients with congenital hand differences and their families starting in 1995. Based on age, patients may be eligible for one of three hand camp programs: Family Camp is designed for patients between 6 and 9 years of age and their immediate family; Tween Camp is aimed for patients between 10 and 13 years of age; and Teen Camp is for patients between 14 and 17 years of age. These camps allow patients and families the opportunity to interact, share concerns, and provide support for one another. In addition, camps strive to provide an opportunity to build self-esteem and confidence through participation in camp activities and programs.

To date, no research has been conducted on the effects of camp participation in the pediatric congenital hand difference (anomaly) population. The goal of this study was to evaluate the efficacy of a therapeutic hand camp for children with a congenital hand difference. Attendees of the 2015 Tween Camp (ages 10–13 years) completed self-report assessments of self-esteem, function, participation in activities, and relationships with peers. Attendees also completed an assessment to determine if they believed camp objectives were met. This specific camp was chosen for the initial study due to the camp attendees' ability to complete assessments independently. Future goals include completing similar research with the other camper groups.

#### 1. Method

#### 1.1. Patient sample

Approval from the Institutional Review Board was obtained. All hand patients at a tertiary treatment center were eligible to attend the tween camp if they were between the ages of 10 and 13 and diagnosed with a congenital hand difference. To appropriately identify these patients a computer database was used to track patient age and diagnosis. The database then created a report of all eligible patients, and subsequently the camp directors sent applications to qualifying candidates. Two months prior to the tween camp, 200 applications were disseminated via standard mail. The first 40 applicants to return a completed application were enrolled in the camp, on a first come, first serve basis. The accepted applicants were notified within two-weeks of processed applications. Of the 40 camp participants, 36 were consented, enrolled, and completed the study protocol—2 declined to participate, 1 did not complete camp, and 1 did not complete the follow-up protocol.

#### 1.2. Assessments

Study participants completed a set of questionnaires at the following time points: 1 to 2 weeks prior to attending camp (Pre-Camp Questionnaires); 1 to 2 weeks following camp participation (Immediate Follow-Up Questionnaires); and 6 months after camp (Final Follow-Up Questionnaires). The questionnaires administered included: A Camp Demographic Form, Patient Reported Outcomes Measurement Information System (PROMIS), Rosenberg Self-Esteem Scale (RSES), and a Camp Expectation Questionnaire based on the established camp objectives and goals (Pilkonis et al., 2014; Rosenberg, 1965; Waljee et al., 2015). The 6-month time point was selected to assess if skills achieved post-camp can be maintained. Based on these patient reported outcomes and knowledge of previous literature, the researchers hypothesized that there would be noted improvements in the camper's self-reported patient reported outcome (PRO) scores pre- and post-camp.

Table 1. Questionnaires				
Questionnaire	Description	Valid	Reliable	
Camp Demographic Form	Self-report questionnaire which included demographic information, family history and status, previous camps attended, type of health care coverage, and goals of camp.	N/A	N/A	
Patient Reported Outcomes Measurement Information System (PROMIS)	A set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. Subscales include Peer Relations, and Physical Function Upper Extremity (Pilkonis et al., 2014).	Yes (Devine et al., 2018; Waljee et al., 2015)	Yes (Dewalt et al., 2013; Hung et al., 2011)	
Rosenberg Self-Esteem Scale (RSES)	10-item scale that measures global self- worth by measuring both positive and negative feelings about self.	Yes (Park & Park, 2019; Rosenberg, 1965)	Yes (Rosenberg, 1965; Shorkey & Whiteman, 1978)	
Camp Expectation Questionnaire	A measure to determine if defined camp objectives and goals are met according to the camper. Administered pre-camp to determine the importance of defined camp objectives and goals, and post camp at the immediate and 6-month time points to determine if said objectives and goals were met.	N/A	N/A	

The primary assessments were selected based on their reliable, valid, and strong psychometric properties (see Table 1).

**Camp Demographic Form**. This form collected general demographic information about participants and their families. This included a multitude of variables from age at time of camp, gender, ethnicity, medical diagnosis, and family history.

PROMIS. The PROMIS instruments are used to assess various patient-reported health states and functioning, both physical and psychological. They were created, refined, and psychometrically assessed by the National Institute of Health with hopes of being able to understand and assess a variety of factors that impact and contribute to quality of life (Cella et al., 2007; Dewalt et al., 2013; Hung et al., 2011; Jensen et al., 2015; Waljee et al., 2015). The PROMIS instruments have specific pediatric versions, for ages 5–18, that can be completed by the pediatric patient themselves or a parent proxy. In this study, only patient self-report was collected. PROMIS measures are given a raw score that was converted to a standardized T-score to account for standard error and to ensure confidence. The PROMIS Upper Extremity measure assesses upper extremity functioning, for example: "I could tie my shoelaces by myself," and "I could put on my clothes by myself." The PROMIS Upper Extremity measure has been found to have good construct validity and test-retest reliability among children with congenital hand differences and orthopaedic conditions (Hung et al., 2011; Waljee et al., 2015). The PROMIS Peer Relationships is a self-report measure for pediatric respondents that assesses the presence and level of relationships, for example: "I felt accepted by other kids my age," and "I was able to talk about everything with my friends." Additionally, the PROMIS Peer Relationships scale has been found to have construct validity and high internal consistency reliability (Devine et al., 2018; Dewalt et al., 2013)

**Rosenberg Self-Esteem Scale**. The RSES was created to assess an individual's "global selfworth" by measuring positive and negative feelings about oneself. This brief, reliable and valid measure was created to assess a pattern of functioning and relation to oneself (Rosenberg, 1965; Gray-Little et al., 1997; Myers & Winters, 2002). The impact of self-esteem has been found to impact the individual by enhancing initiative, pleasant feelings, and resilience (Baumeister et al., 2003; Ciarrochi et al., 2007). This measure has been found to have high content validity, rating internal consistency and test-retest reliability, as well as, content validity (Park & Park, 2019; Rosenberg, 1965; Shorkey & Whiteman, 1978). The following are sample questions of the RSES: "I wish I could have more respect for myself," and "I am able to do things as well as most other people."

**Camp Expectations Questionnaire**. This self-report questionnaire assessed participant expectations. Participants answered a series of pre- and post-questions on a Likert scale of 0 to 10, with 0 being less important/low functioning and 10 being most important/high functioning. This measure was created specifically for this population and camp participants; it has not previously been researched. Therefore, there is no reliability or validity information. Examples of questions on this measure are: "How often do you need help with daily activities? (i.e. putting on clothes, washing hair, tying shoes, etc.," and "How easy is it for you to make friends?")

#### 1.3. Hand camp mission and objectives

The Hand Camp Mission Statement and Objectives were developed by the hand camp directors to give structure and goal-oriented direction. These objectives were informed by medical expertise, previous research findings, and observation of camp over a 25-year period to define the purpose of camp as well as expected outcomes following the campers' experience.

#### 1.3.1. Hand camp mission statement

Hand Camp is an opportunity for children with upper limb differences to meet others facing similar challenges. The weekend retreat for children ages 10–13 provides a safe environment to share experiences, challenges, fears and successes. In addition, camp gives children an opportunity to focus on enhancing confidence and self-esteem through team building, exposure to new experiences, developing leadership skills, as well as to help and encourage each other during goal directed organized activities.

Hand Camp Objectives. To assess the hand camp experience there were several objectives that were identified as goals for the camper's experience. Many of the objectives were not assessed in a measurable way. The following two objectives were able to be assessed through the PROs administered to camp attendees:

- (1) Enhance self-esteem and self-confidence
- (2) Increase relationships with peers

Activities offered at hand camp consist of high and low ropes elements, archery, arts and crafts, team building activities, time for same sex peer to peer discussion/activity time, as well as directed and non-directed time to work on activities of daily living.

#### 1.4. Statistical methods

Descriptive statistics were conducted to summarize the data set. Paired t-tests were used to compare the mean patient scores at pre-camp, immediate follow-up, and final follow-up time points. Correlation analyses were also conducted. All statistical analyses were conducted with a significance level of 0.05.

#### Figure 1. Race.



#### 2. Results

#### 2.1. Demographics

Thirty-six patients were included in the final cohort (22 females; 14 males). The patient group included 28 Whites, 5 Hispanics, 1 African American, 1 Asian, and 1 unknown race (see Figure 1). Average age of the campers was 11.17 years (range, 10–14 years; one camper turned 14 during camp). As the camp was not specific to one congenital hand diagnosis, the diagnoses varied amongst the patients. Patient diagnoses were categorized as: central deficiency (cleft hand and polysyndactyly), transverse deficiency (symbra-chydactyly with or without Poland's syndrome), radial longitudinal deficiency, ulnar longitudinal deficiency, and overgrowths (macrodactyly) (see Figure 2).

All patients, except for one, had previously attended a hospital-sponsored hand camp. Average number of previous camps attended was 3.15 (range, 1–7 times). Two patients had a family history of congenital hand differences.

#### 2.2. Self-report measures

The PROMIS subscales included Physical Function Upper Extremity and Peer Relations (Pilkonis et al., 2014; Waljee et al., 2015). Upper extremity function significantly improved from pre-camp to immediate follow-up (46.24 to 48.95; p = 0.016), as well as between pre-camp and final follow-up (46.24 to 49.44; p = 0.008) (see Table 2). Average peer relationship scores significantly improved from pre-camp to immediate follow-up (52.26 to 57.91; p = 0.002). However, there was a significant decrease in peer relationships between immediate follow-up and final follow-up (57.91 to 52.92; p = 0.008). It should be noted that the peer relationship scores at final follow-up had almost returned to pre-camp scores (52.92; p = 0.41) (see Table 3).



#### Table 2. PROMIS Physical Function Upper Extremity

#### PROMIS Physical Function Upper Extremitiy



+Higher scores indicate higher functioning

\* Significant difference between Pre-Camp and Immediate Follow-Up; p=0.016

\*\* Significant difference between Pre-Camp and Final Follow-Up; p=0.008



+Higher scores indicate better peer relations

\* Significant difference between Pre-Camp and Immediate Follow-Up; p=0.002

\*\* Significant difference between Immediate and Final Follow-Up; p=0.008

The RSES was administered at each time point: pre-camp, immediate follow-up and final follow-up (Waljee et al., 2015). Results of the RSES found a statistically significant improvement of patient's self-esteem between both pre-camp and immediate follow-up (23.92 to 26.81; p < 0.000), as well as between pre-camp and final follow-up (23.92 to 25.72; p < 0.000) (see Table 4).

The Camp Expectation Questionnaire was also used to determine if the defined camp objectives and goals were met according to the camper. This questionnaire was administered at: pre-camp, immediate and final follow-up. Pre-camp compared to immediate follow up was found to be significant (39.92 to 44.25; p < 0.001) (see Table 5).

A correlation analysis was conducted to assess the relationship between self-esteem (RSES) and camp expectations. Pre-camp self-esteem and expectations were strongly correlated (-.619; p = 0.01), indicating that prior to camp, self-esteem (15.72) and camp expectations (39.92) were

#### Table 4. Rosenberg Self-Esteem Scale





+Higher scores indicate higher self-esteem

\* Significant difference between Pre-Camp and Immediate Follow-Up; p<0.001

\*\* Significant difference between Pre-Camp and Final Follow-Up; p<0.001

#### **Table 5. Camp Expectation Questionnaire**



+Higher scores indicate camp expectations being met

\* Significant difference between Pre-Camp and Immediate Follow-Up; p<0.001

low. Immediately following camp, self-esteem scores and camp expectations were significantly correlated (-.343; p = 0.05), indicating improvement in both variables.

#### 3. Discussion

Though there is limited research assessing the efficacy of therapeutic camps, previous research has shown camp can be one of the greatest opportunities for a child to cultivate skills of socialization and increase character (Barr et al., 2010). It is also well known that most children with chronic illnesses often times do not fit into the traditional camp mold and are excluded from participating in established camps (Barr et al., 2010). Previous research has reported that children with chronic physical disorders can have a higher risk of psychosocial issues when compared to children without physical differences (Austin, 1989; Breslau, 1985; Pless, 1984). Camps for children with chronic conditions have become more established and can serve as a method for addressing psychosocial needs. These camps help children achieve a more positive outlook on their condition, assist them in adapting to their environment, as well as increase their peer relationships in the community (Briery, 1999; Bultas et al., 2013; Holbein et al., 2013; Martiniuk et al., 2014; Sawin et al., 2001). How children feel about their difference plays an important role in their social interactions and relationships with others (Briery, 1999).

Seeing a need within the congenital hand difference community, this specialty hospital developed Hand Camp with the hope to assist this very unique pediatric population. Since 1995, Hand Camp has been offered for children with a congenital hand differences and their families to address physical needs as well as psychological needs by incorporating both aspects in the mission and objectives of the camp. Since its inception, Tween Camp has grown 400%, with an increase from 10 to 40 campers. Through the years, campers and parents have verbalized the impact felt by attending Hand Camp, however no objective data had been collected. The researchers in this study attempted to prove that the outcomes of camp are both positive and purposeful and can, in fact, help increase self-esteem, self-confidence, and physical functioning.

The RSES demonstrated that self-esteem increased immediately after camp (1 to 2 weeks after camp) and continued to increase for at least 6 months following camp. This paper found that on the RSES, participants reported much lower self-esteem scores when compared to the scores for healthy norms. With mean scores of 23.92 pre-camp and 25.72 post-camp, respectively, compared to the norms for pediatric females (m = 28.32, SD = 5.49) and pediatric males (m = 31.36, SD = 5.13) (Bagley et al., 1997). While the scores are lower than the norms, it is important to note the sustained improvement from pre- to post-camp.

In addition, upper extremity function results were significantly improved immediately following camp as well as at the final follow-up, suggesting skills learned during camp relating to activities of daily living were sustained for 6 months following camp. The participants in this study showed to have higher upper extremity functioning (pre-camp, m = 46.24; post-camp, m = 49.44) compared to another study assessing pediatric patients with congenital hand differences (m = 42.8; SD = 12.3; Waljee et al., 2015). Normalized scores for upper extremity function were created based on item response theory, with the mean normative score being 50 (SD = 10; PROMIS Pediatric Profile Instruments, 2019b). It should be highlighted that the post-camp upper extremity scores of participants in the current study were 0.66 lower than the normative mean, indicating these children gained valuable skills that improved upper extremity functioning.

Peer relations improved significantly immediately post-camp, however, returned to baseline after 6-months. This suggests that camp has a positive effect on the interactions with peer's immediately post-camp. However, there exists a need for continued contact or communication between children with congenital hand differences to maintain confidence in their ability to foster positive peer relationships in their home town setting long term. When comparing the peer relations of campers to the normative scores, participant scores were higher (precamp, m = 52.26, post-camp, m = 52.92) than the normative score of 50 (SD = 10; Dewalt et al., 2013; PROMIS Pediatric Profile Instruments, 2019a). The authors feel it is important to note that these findings are contradictory to the hypothesized outcomes, as they are not consistent with anecdotal observations of camper experience over a 20-year span. This highlights the need for continued research with this study population and further investigation into peer relations with comparative analysis to healthy norms.

Following camp, participants indicated improved skills in peer interaction, daily physical activities, willingness to try new things, and confidence in explaining their hand difference. Meeting these camp objectives combined with increased self-esteem (RSES), upper extremity functioning (PROMIS), and peer relations (PROMIS), provided useful skills for campers to translate into their everyday life. This suggests that following camp, a child is: more apt to participate in extracurricular activities; have higher self-esteem with regard to their hand difference; be more independent in activities of daily living; and manage negative reactions from others regarding the appearance of their hand.

Resilience is defined as the capacity to recover quickly from difficulties; toughness (Simpson et al., 1989). Children that are born with or acquire a difference from trauma/disease undergo many challenges throughout their life span. It has been shown that those who have physical differences may be more likely to have lower self-esteem and difficulties with peer relationships (Briery, 1999; King et al., 1993; Madden et al., 2006). Through years of working with campers with hand differences, the authors, anecdotally, have seen the impact of a hand difference on pediatric patients. These children are keenly aware of their difference compared to their peers. In hopes of providing specialized support, camp was created to provide campers with tools to enhance their self-esteem, peer relationships and upper extremity functioning. Through the camp experience the authors aim to help children accept their differences, and provide an opportunity for these children and the world to learn resilience and accept themselves and others despite their differences.

A strength of this study is the ability to track a group of patients over a 6-month period to assess the impact camp has on their physical and psychosocial functioning. In addition, the outcome measures used yielded similar results which supported the hypothesis of the study, that camp can indeed make a positive impact on children with congenital hand differences.

#### 3.1. Limitations and future directions

A limitation of this study is the relatively small number of participants included as well as a diverse group of upper limb diagnoses. Another limitation of this study is the inability to tease out other life events happening simultaneously during this 6-month time frame such as: school-related difficulties, parent/family issues, social changes, environmental changes, or other impactful experiences. The limitation of selection bias must also be addressed, even though this camp operated on first-come-first-serve basis, this was not a randomized study and may have been impacted by the ability of parents to check and respond to mail correspondence. The researchers feel that in the future this should be studied in a longitudinal manner to see if those who attend Hand Camp multiple times, can increase/maintain good self-esteem, self-confidence, peer relationships, and upper extremity functioning. Another future direction of research is to include the other hand camps for older and younger children with congenital hand differences. Conducting longitudinal research may pose difficulties with possibly altering the camp experience, taking time away from camp planning, and being intrusive to children and families, which has also been noted by another camp research study (Henderson et al., 2007). Finally, a limitation of the current study and future direction for continued research is to include a control group for comparison, considering use of eligible participants who did not attend camp. The current study used a convenience sampling method, as those enrolled were exclusively eligible participants who attended camp. The use of a control group would enhance this study by ensuring that the camp intervention is producing the primary outcomes of increased self-esteem, upper extremity function, and improved peer relations. However, it should be noted that between the pre-camp and immediate post-camp surveys all campers were at camp; therefore, there are fewer confounding variables impacting the camp intervention.

Ultimately, the authors of this study believe that research related to therapeutic camping experiences is an integral aspect when identifying best-practice interventions to increase positive quality of life outcomes for children with congenital hand differences.

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#### Disclosure of potential conflicts of interest

We have no conflicts of interest to disclose.

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#### References

- American Camp Association. (2018). ACA facts and trends. Retrieved from http://www.acacamps.org/pressroom/aca-facts-trends
- Andersson, G. B., Gillberg, C., Fernell, E., Johansson, M., & Nachemson, A. (2011). Children with surgically corrected hand deformities and upper limb deficiencies: Self-concept and psychological well-being. *The Journal of Hand Surgery, European Volume*, 36(9), 795–801. https://doi.org/10.1177/ 1753193411412869
- Ardon, M. S., Janssen, W. G., Hovius, S. E., Stam, H. J., & Selles, R. W. (2012). Low impact of congenital hand differences on health-related quality of life. Archives of Physical Medicine and Rehabilitation, 93(2), 351–357. https://doi.org/10.1016/j.apmr.2011.09.004
- Austin, J. K. (1989). Comparison of child adaptation to epilepsy and asthma. *Journal of Child and Adolescent Psychiatric Nursing*, 2(4), 139–144. https://doi.org/10. 1111/j.1744-6171.1989.tb00379.x
- Bae, D. S., Canizares, M. F., Miller, P. E., Waters, P. M., & Goldfarb, C. A. (2017). Functional impact of congenital hand differences: Early results from the congenital upper limb differences (CoULD) registry. The Journal of Hand Surgery, 43(4), 321–330. https://doi. org/10.1016/j.jhsa.2017.10.006
- Bagley, C., Boitho, F., & Bertrand, L. (1997). Norms and construct validity of the rosenberg self-esteem scale in Canadian high school populations: Implications for counselling. *Canadian Journal of Counseling*, 31(1), 82-92. https://files.eric.ed.gov/fulltext/EJ553572.pdf
- Barr, R. D., Silva, A., Wong, M., Frid, W., Posgate, S., & Browne, G. (2010). A comparative assessment of attendance and nonattendance at Camp Trillium by children with cancer and their families: Including their utilization of health and social services. *Journal* of *Pediatric Hematology/Oncology*, 32(5), 358–365. https://doi.org/10.1097/mph.0b013e3181dccc1f
- Baumeister, R. F., Campbell, J. E., Krueger, J. I., & Vohs, K. D. (2003). Does high self- esteem cause better performance, interpersonal success, happiness, or healthier lifestyles? *Psychological Science in the Public Interest*, 4(1), 1–44. https://doi.org/10. 1111/1529-1006.01431
- Bradbury, E. (1996). Counselling people with disfigurement. British Psychological Society.
- Breslau, N. (1985). Psychiatric disorder in children with physical disabilities. Journal of the American Academy of Child Psychiatry, 24(1), 87–94. https://doi. org/10.1016/s0002-7138(09)60415-5

- Briery, B. (1999). Psychosocial changes associated with participation in a pediatric summer camp. Journal of Pediatric Psychology, 24(2), 183–190. https://doi.org/ 10.1093/jpepsy/24.2.183
- Bultas, M. W., Budhathoki, C., & Balakas, K. (2013). Evaluation of child and parent outcomes after a pediatric cardiac camp experience. *Journal for Specialists in Pediatric Nursing*, *18*(4), 320–328. https://doi.org/10.1111/jspn.12040
- Cella, D., Yount, S., Rothrock, N., Gershon, R., Cook, K., Reeve, B., Ader, D., Fries, J. F., Bruce, B., & Rose, M., & PROMIS Cooperative Group. (2007). The patientreported outcomes measurement information system (PROMIS): Progress of an NIH roadmap cooperative group during its first two years. *Medical Care*, 45(Suppl 5), S3–S11. doi: 10.1097/01. mlr.0000258615.42478.55
- Ciarrochi, J., Heavan, P. C. L., & Fiona, D. (2007). The impact of hope, self-esteem, and attributional style on adolescents' school grades and emotional well-being: A longitudinal study. *Journal of Research in Personality*, 41(6), 1161–1178. https://doi.org/10.1016/j.jrp.2007.02.001
- Devine, K. A., Willard, V. W., Hocking, M. C., Stapleton, J. L., Rotter, D., Bukowski, W. M., & Noll, R. B. (2018). PROMIS peer relationships short form: How well does self-report correlate with data from peers? Journal of Pediatric Psychology, 43(9), 1059–1067. https://doi. org/10.1093/jpepsy/jsy038
- Dewalt, D. A., Thissen, D., Stucky, B. D., Langer, M. M., Dewitt, E. M., Irwin, D. E., Lai, J.-S., Yeatts, K. B., Gross, H. E., Taylor, O., & Varni, J. W. (2013). PROMIS pediatric peer relationships scale: Development of a peer relationships item bank as part of social health measurement. *Health Psychology*, 32(10), 1093–1103. https://doi.org/10.1037/a0032670
- Ekblom, A. G., Laurell, T., & Amer, M. (2010). Epidemiology of congenital upper limb anomalies in 562 children born in 1997 to 2009: A total population study from Stockholm, Sweden. *The Journal of Hand Surgery*, 35(11), 1742–1754. https://doi.org/10.1016/j.jhsa.2010.07.007
- Franzblau, L. E., Chung, K. C., Carlozzi, N., Chin, A. Y., Nellans, K. W., & Waljee, J. F. (2015). Coping with congenital hand differences. *Plastic and Reconstructive Surgery*, 135(4), 1067–1075. https:// doi.org/10.1097/PRS.00000000001047
- Giele, H., Giele, C., Bower, C., & Allison, M. (2001). The incidence and epidemiology of congenital upper limb anomalies: A total population study. *The Journal of Hand Surgery*, 26(4), 628–634. https://doi.org/10. 1053/jhsu.2001.26121
- Gray-Little, B., Williams, V. S. L., & Hancock, T. D. (1997). An item response theory analysis of the Rosenberg Self-Esteem Scale. *Personality & Social Psychology Bulletin*, 23(5), 443–451. https://doi.org/10.1177/ 0146167297235001
- Henderson, K. A., Bialeschki, M. D., & James, P. A. (2007). Overview of camp research. *Child and Adolescent Psychiatric Clinics of North America*, 16(4), 755–767. https://doi.org/10.1016/j.chc.2007.05.010
- Holbein, C. E., Murray, C. B., Psihogios, A. M., Wasserman, R. M., Essner, B. S., Ohara, 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. https://doi. org/10.1093/jpepsy/jst003

- Hung, M., Clegg, D. O., Greene, T., & Saltzman, C. L. (2011). Evaluation of the PROMIS physical function item bank in orthopaedic patients. *Journal of Orthopaedic Research*, 29(6), 947–953. https://doi.org/10.1002/jor.21308
- Jakubietz, R. G., Jakubietz, M. G., Kloss, D., & Gruenert, J. G. (2005). Defining the basic aesthetics of the hand. *Aesthetic Plastic Surgery*, 29(6), 546–551. https://doi. org/10.1007/s00266-005-0100-6
- Jensen, R. E., Potosky, A. L., Reeve, B. B., Hahn, E., Cella, D., Fries, J., Smith, A. W., Keegan, T. H. M., Wu, X.-C., Paddock, L., & Moinpour, C. M. (2015). Validation of the PROMIS physical function measures in a diverse US population-based cohort of cancer patients. *Quality of Life Research*, 24(10), 2333–2344. https:// doi.org/10.1007/s11136-015-0992-9
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248. https://doi.org/10.1046/j. 1365-2648.2000.01466.x
- King, G. A., Shultz, I. Z., Steel, K., Gilpin, M., & Cathers, T. (1993). Self-evaluation and self-concept of adolescents with physical disabilities. *American Journal Occupational Therapy*, 47(2), 132–140. https://doi. org/10.5014/ajot.47.2.132
- Koskimies, E., Lindfors, N., Gissler, M., Peltonen, J., & Nietosvaara, Y. (2011). Congenital upper limb deficiencies and associated malformations in Finland: A population-based study. *The Journal of Hand Surgery*, 36 (6), 1058–1065. https://doi.org/10.1016/j.jhsa.2011.03.015
- Lake, A. (2010). Hand therapy for children with congenital hand differences. *Techniques in Hand & Upper Extremity Surgery*, 14(2), 78–84. https://doi.org/10. 1097/bth.0b013e3181d79f2e
- Madden, L. H., Cadogan, J., & Emerson, M. P. (2006). 'Outlook': A psychological service for children with a different appearance. *Clinical Child Psychology and Psychiatry*, 11(3), 431–434. https://doi.org/10.1177/ 1359104506064987
- Martiniuk, A., Silva, M., Amylon, M., & Barr, R. (2014). Camp programs for children with cancer and their families: Review of research progress over the past decade. *Pediatric Blood & Cancer*, 61(5), 778–787. https://doi. org/10.1002/pbc.24912
- Miller, R., Samarendra, H., & Hotton, M. (2020). A systematic review of the use of psychological assessment tools in congenital upper limb anomaly management. *Journal* of Hand Therapy: Official Journal of the American Society of Hand Therapists, 33(1), 2–12.e1. https://doi. org/10.1016/j.jht.2018.11.001
- Moola, F. J., Faulkner, G. E. J., White, L., & Kirsh, J. A. (2013). The psychological and social impact of camp for children with chronic illnesses: A systematic review update. *Child: Care, Health and Development*, 40(5), 615–631. https://doi.org/10.1111/cch.12114
- Myers, K., & Winters, N. C. (2002). Ten-year review of rating scales. II: Scales for internalizing disorders. Journal of the American Academy of Child and Adolescent Psychiatry, 41(6), 634–659. https://doi. org/10.1097/00004583-200206000-00004

Park, J., & Park, E. (2019). The rasch analysis of Rosenberg self-esteem scale in individuals with intellectual

disabilities. Frontiers in Psychology, 10. https://doi. org/10.3389/fpsyg.2019.01992

- Pilkonis, P. A., Yu, L., Dodds, N. E., Johnston, K. L., Maihoefer, C. C., & Lawrence, S. M. (2014). Validation of the depression item bank from the patient-reported outcomes measurement information system (PROMIS(R)) in a three-month observational study. *Journal of Psychiatric Research*, 56, 112–119. https://doi.org/10.1016/j.jpsychires.2014. 05.010
- Pless, I. B. (1984). Clinical assessment: Physical and psychological functioning. *Pediatric Clinics of North America*, 31(1), 33-45. https://doi.org/10.1016/ s0031-3955(16)34534-5
- PROMIS Pediatric Profile Instruments. (2019a). PROMIS pediatric short form v2.0 – Peer relationships: Measure specific scoring quide. Northwestern University.
- PROMIS Pediatric Profile Instruments. (2019b). PROMIS pediatric short form v2.0 - Upper extremity: Measure specific scoring guide. Northwestern University.
- Ramkumar, R. (2021). About. Retrieved September 1, 2020, from https://luckyfinproject.org/
- Rosenberg, M. (1965). Society and the adolescent selfimage. Princeton University Press
- Rumsey, N., & Harcourt, D. (2007). Visible difference amongst children and adolescents: Issues and interventions. Developmental Neurorehabilitation, 10(2), 113–123. https://doi.org/10.1080/ 13638490701217396
- Sawin, K. J., Lannon, S. L., & Austin, J. K. (2001). Camp experiences and attitudes toward Epilepsy: A pilot study. Journal of Neuroscience Nursing, 33(1), 57–64. https://doi.org/10.1097/01376517-200102000-00008
- Scribnick, E. G., & Johnsen, S. (2013). Fresh air for city kids: The early years of summer camp. *The Historical Perspective*, 4(2), 19–22.
- Shorkey, C. T., & Whiteman, V. L. (1978). Correlations between standard English and dialectical Spanish versions of five personality scales. *Psychological Reports*, 43(3), 910. https://doi.org/10.2466/pr0.1978. 43.3.910
- Simpson, J. A., & Weiner, E. S. C., Oxford University Press. (1989). The Oxford english dictionary. Clarendon Press.
- Varni, J. W., Rubenfeld, L. A., Talbot, D., & Setoguchi, Y. (1989). Determinants of self-esteem in children with congenital/acquired limb deficiencies. *Journal of Developmental and Behavioral Pediatrics*, 10(1), 13–16. https://doi.org/10.1097/00004703-198902000-00003
- Waljee, J. F., Carlozzi, N., Franzblau, L. E., Zhong, L., & Chung, K. C. (2015). Applying the patient-reported outcomes measurement information system to assess upper extremity function among children with congenital hand differences. *Plastic and Reconstructive Surgery*, 136(2), 200e–207e. https:// doi.org/10.1097/prs.00000000001444
- World Health Organization. (2001). World Health Organizations international classification of functioning, disability and health (ICF). WHO.

#### Developmental Rational for Participant Selection

Sample population: Pediatric patients with diagnosed congenital hand difference

Number of participants: 36 patients

Average age (range) of participants: 11.7 years (11-14)

Gender of participants: 22 females; 14 males

Ethnicity of participants: 28 White; 5 Hispanic; 1 African American; 1 Asian; 1 Unknown

Location of sample: Texas, USA; mix of rural and urban communities

**Sample identification/selection:** A computer database was used to track patient age and diagnosis. The database then created a report of all eligible patients, and subsequently the camp directors sent applications to qualifying candidates. 200 applications were disseminated via standard mail. The first 40 applicants to return a completed application were enrolled in the camp, on a first come, first served basis

**Contact with patients:** Patient and parents were approached to participate in research at after they were invited and selected to attend camp. Patients were then consented via mail and phone, as approved by the governing IRB. Subsequent contact following obtaining consent/assent for research participation was made in person, as well as via mail and phone.

*Incentives/rewards:* There were no direct incentives or rewards associated with participating in research.

**Parent consent/child assent procedures:** All potential participants were invited by a research team member in person to participate in research. The research team member thoroughly reviewed the consent form in accordance with HIPAA and governing IRB requirements. Consent and assent were obtained from all participants.

**Rate of participant acceptance to participate in research:** 95% acceptance rate; 2 out of 40 patients/parents declined

#### **Inclusion criteria**

- (1) English-speaking male and female patients of all ethnicities
- (2) Between 10 and 14 years of age
- (3) Diagnosed with a congenital hand difference
- (4) Patients who were selected by the computer program and invited to participate in the weekend camp
- (5) Following submission and subsequent approval of camp attendance application, the first 40 patients to complete said process will be approached for research participation.

#### **Exclusion criteria**

- (1) Patients without a congenital hand difference
- (2) Below age of 10 years or above age of 14 years

- (3) Non-English speaking
- (4) Patients who applied for camp participation but were not granted one of the 40 available spots

**Attrition rate:** 5.3% attrition rate; 2 out of 38 participants decided to cease their research participation prior to the completion of study-related data collection



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