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Research Article

Functional and Psychosocial Outcomes of a Medically Supported Summer Camp for Children and Adolescents with Spina Bifida

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Abstract

Aim: Children with spina bifida face chronic health concerns that require lifelong care, which may contribute to observed social difficulties. Summer camps offer a unique space for the development of relationships, interpersonal skills, and social confidence. This study aimed to observe the impact of a medically supported summer camp for children with spina bifida. **Methods**: A cohort of 20 children with spina bifida (7 males; age M=14.1 ± 3.5) attended Camp Patrick 2023 and completed the Pediatric Camp Outcome Measure (PCOM), a validated self-report questionnaire evaluating overall functioning and perceptions of camp experience. **Results**: Participants were found to have positive PCOM scores (total score M=118.6 ± 13.9) comparable to scores for children with other chronic conditions attending their respective summer camps. The individual items with the most positive scores demonstrated high reported levels of self-esteem and social and emotional functioning while at camp. All respondents said they would return to camp next year. **Conclusion:** Attending Camp Patrick had a positive impact on the emotional and social function, self-esteem, and physical activity of children with spina bifida. Understanding the positive experiences of camp provides insight into potential recommendations for improving functionality and quality of life in this population as well as targeted functional areas for intervention.

Keywords: Spina Bifida; Summer Camp; Social Functioning; Physical Functioning; Quality-Of -Life

Introduction

Spina bifida is a birth defect affecting the spine that occurs in 1 in every 2,758 births in the United States each year [1]. Failure of the neural tube to close during the fourth week of gestation results in a spinal cord malformation that often leads to complications affecting several organ systems and may result in considerable disability [2]. Individuals with spina bifida experience a variety of physical and health concerns such as hydrocephalus, Chiari II malformation, bladder and bowel dysfunction, sensory loss, seizures, lower limb weakness or paralysis, as well as other orthopedic abnormalities [3,4]. Management of spina bifida is complex, and care is best provided through routine assessments by a multidisciplinary team. This team also provides emotional support and addresses neurodevelopmental and psychosocial concerns, mobility and means of locomotion, weight maintenance, and skin care [4]. Given their diverse needs, individuals with spina bifida require lifelong care and strict adherence to complex medical routines [3].

In addition to physical health concerns, children with spina bifida often experience psychosocial difficulties. As seen with many chronic medical conditions, individuals with spina bifida have been found to have more depressive symptoms, reduced self-esteem, and a decreased ability to develop meaningful relationships, new friendships, or excel in social situations compared to typical peers [4-7]. Repeated doctor's visits and extended hospital stays limit social exposure throughout childhood and impact social development, leading to feelings of isolation and a lower sense of social self-efficacy. Children with spina bifida are also at risk for developing attention problems, internalizing symptoms, educational difficulties and social maladjustment, and exhibit social difficulties such as social immaturity, lower feelings of social acceptance, and decreased influence in family discussions [4,7-8]. Additionally, children and adolescents with spina bifida have been found to have reduced health-related quality of life compared to typically developing individuals and children with other chronic health conditions [4]. These difficulties often persist into adulthood, and individuals with spina bifida demonstrate delays in acquiring autonomy skills and independent functioning compared to typically developing peers [7-9].

It is therefore important to provide opportunities for children with spina bifida that bolster psychosocial development. Summer camps offer an additional opportunity for social engagement outside of school or the home and have been established as an important setting for learning and developing social and emotional skills [10,11]. Richmond, Sibthorp, and Wilson (2019) examined long-term camp outcomes and found that typical adults who had attended camp as children attributed the development of skills such as an appreciation for differences, independence, perseverance, and responsibility to their camp experiences. However, while recent studies highlight the potential use of interventions in the camp setting and the perceived impact of camp on participant independence, most rely on parent reports and fail to evaluate the perspectives of the campers themselves as well as the efficacy of camp to affect participants' emotional, social, and physical activity and function.

This study aimed to explore the experiences of individuals with spina bifida after participation in Camp Patrick, a medically supported summer camp designed for children and adolescents with spina bifida. The primary objective of this study was to evaluate the impact of camp participation on self-esteem, emotional, social, and physical function using a validated camper-report questionnaire. We hypothesized that campers would report positive experiences with regard to emotional, social, and physical functioning. Findings from this study will provide comprehensive insight for families and healthcare teams into functional domains that are impacted by camp and may highlight avenues for future intervention.

Methods

This study was conducted in June 2023 at Camp Patrick, a week-long medically supported summer camp for children with spina bifida, located at the Whispering Hope Ranch in Payson, Arizona. This study was approved by the Institutional Review Board at Phoenix Children's Hospital (#IRB-23-100). Informed consent was obtained from the participant's parent or guardian or the adult camper in person during the first day of camp. Assent was also obtained from children at this time. The study aims and procedures were explained during the consenting process and before the completion of the outcome measure. The outcome measure was collected via electronic survey following completion of the entire week of camp.

Participants

Children and young adults were eligible for inclusion in this study if they had a diagnosis of spina bifida, attended the entire week of Camp Patrick, and were 8 years of age or older at the time of camp. 53 campers were initially consented for participation. Twenty eligible campers completed the outcome measure after completion of camp.

Outcome Measure

The Pediatric Camp Outcome Measure (PCOM) [12] was used to examine functional levels during camp. The PCOM is a 29-item,

self-report questionnaire designed to assess perceptions of camp experiences. This measure was initially developed in 2008 at Stanford University and validated in children 8 years and older with cardiac abnormalities attending a specialty summer camp. The scale demonstrated strong reliability (subscale Cronbach's alphas ranged from 0.80 to 0.89; total score Cronbach's alpha=0.93). The PCOM was validated in additional groups in camps for children with cancer and sickle cell disease14 showing high internal consistency and construct validity [13].

Twenty-seven items contribute to a total score and are further divided into four subscales reflecting perceptions of self-esteem, emotional functioning, social functioning, and physical functioning. Participants are asked to answer each question on a 5-point Likert-type scale ranging from 1 to 5, in which higher scores represent more positive experiences (1=almost never or very bad/sad/hard; 5=almost always or very good/happy/easy). For this study, the language of three questions in the physical functioning subscale was modified to accurately reflect the abilities of those with spina bifida, many of whom are wheelchair ambulators. Item 23 was modified to inquire about participation in "physical activity" rather than "sports activity." In item 24, the term "exercise" was changed to "on the go," and in item 25, "sit down" was changed to "take a break."

Two additional questions are not included in the PCOM rating scores and reflect overall satisfaction with the camp. The first of these uses a 5-point Likert-type scale to rate how likely a participant is to tell other children about camp (1=it was very bad; 5=it was very good). The final question inquires whether the participant would want to return to camp next year (yes/no). The complete list of items can be found in (Table 1)

	Number of Responses					
Item (Subscale**)**	**1**	**2**	**3**	**4**	**5**	**Mean Score**
1. How often did you feel like yourself at camp? (SE)	0	0	0	3	17	4.8
2. How did you feel about yourself at camp? (SE)	0	0	2	5	12	4.5
3. How often were you proud of yourself at camp ? (SE)	0	0	5	6	8	4.2
4. How often did you like yourself at camp? (SE)	0	0	2	7	10	4.4
5. How often did you feel like you could do the activities the other kids at camp were doing? (SE)	0	0	2	3	14	4.6
6. How happy or sad were you at camp? (EF)	0	0	1	5	14	4.6
7. How often were you nervous at camp ?[a] (EF)	0	0	5	4	11	4.3
8. How often did you worry at camp ?[a] (EF)	0	1	2	6	11	4.3
9. How often did you worry about your health condition at camp ?[a] (EF)	0	0	5	2	13	4.4
10. How often were you lonely at camp ?[a] (SF)	0	1	0	5	14	4.6
11. How often did you worry about what the other kids at camp thought about you ?[a] (EF)	0	1	3	2	14	4.4
12. How often did you feel sad or blue at camp ?[a] (EF)	1	1	0	3	15	4.5

13. How often did you spend time with your friends at camp? (SF)	0	1	0	5	14	4.6
14. How often did you have someone to talk to at camp? (SF)	0	2	1	4	13	4.4
15. What was it like to make friends at camp? (SF)	0	1	3	9	7	4.1
16. What was it like to play with kids you did not know very well? (SF)	0	1	9	6	4	3.6
17. How often did you play with the other kids at camp? (SF)	0	1	3	9	7	4.1
18. How often did you feel like you were part of the group at camp? (SF)	0	1	0	5	14	4.6
19. How often did you feel left out at camp?[a] (SF)	0	1	0	2	17	4.7
20. How often did you get along with the other kids at camp? (SF)	0	0	2	9	9	4.3
21. How often were you active at camp? (PF)	0	0	3	2	15	4.6
22. How often did you feel like you had energy at camp? (PF)	0	0	6	6	8	4.1
23. How often did you participate in a physical activity at camp? (PF)	0	1	4	5	10	4.2
24. How often are you on the go at camp? (PF)	0	1	1	3	15	4.6
25. How often did you get tired and have to take a break from an activity at camp?[a] (PF)	0	3	7	4	6	3.6
26. How often did you feel homesick at camp?[a] (EF)	0	0	6	4	10	4.2
27. How much did you like or dislike camp? (EF)	0	0	0	1	19	4.9
Additional Questions						
What would you tell other kids about Camp?	0	0	0	2	18	4.9
Would you want to come back to Camp next year?	Yes = 20			No = 0		N/A

Table 1: Pediatric Camp Outcome Measure (PCOM) Item Responses; **SE:** Self-Esteem Subscale; **EF**: Emotional Functioning Subscale; **SF**: Social Functioning Subscale; **PF**: Physical Functioning Subscale. [a]Negatively phrased items were reverse coded for score calculations

If a response for a single item was missing, the score for the missing item was estimated as the average score of the completed items within the corresponding subscale. Total scores and subscale scores were calculated with this estimated score. If more than one item was missing from a subscale, the item was left blank, and the corresponding subscale score and total score were excluded.

Statistical Analysis

Demographic data and past summer camp history were analyzed using descriptive statistics. Responses to each item on the PCOM were combined and presented as means with appropriate ranges for the total score and each subscale score. The likelihood of each camper returning or recommending participation in Camp Patrick was reported as a percentage of total responses. Mean PCOM scores from campers with spina bifida were qualitatively compared to mean PCOM scores from previous studies conducted at camps for children with congenital heart disease, cancer, and sickle cell disease. Secondary statistical analyses included paired t-tests to examine the relationship between sex and PCOM scores and linear regression analyses to examine age and PCOM scores. Statistical analysis was conducted using R version 4.3.1 and statistical significance was set a $p<0.05$.

Results

Participants

Twenty participants consented and enrolled in the study met eligibility criteria and completed the PCOM questionnaire following participation in Camp Patrick. Three participants were missing one item. The score for these items was estimated as the average score of the completed items within the corresponding subscale and total and subscale scores were calculated with this estimated score. One participant was missing four items within the self-esteem subscale and the corresponding subscale, and total scores were excluded.

Participants ranged in age from 8 to 20 years, and all carried a diagnosis of spina bifida and participated in the full week of camp. Demographic data is presented in (Table 2). The mean age of participants was 14.1 years, and the majority were female (n=13, 65%). Eighteen (90%) participants had attended Camp Patrick in the past and 6 (30%) participants had a history of attendance at an alternative summer camp.

Characteristics	N	Mean (SD)
Gender		
Female	13	
Male	7	
Age, years		14.1 (3.5)
8-12	7	
13-17	9	
18+	4	
Prior Camp Patrick Attendance		
Yes	18	
No	2	
Prior Attendance at Other Camps		
Yes	6	
No	14	

Table 2: Demographics (n=20).

PCOM

The mean total PCOM score was 118.6 (range 74-132). The mean PCOM subscale scores were 22.6 (range 17-25) for self-esteem, 35.8 (range 29-40) for emotional functioning, 39.2 (range 20-44) for social functioning, and 21.2 (range 13-25) for physical activity. PCOM scores of campers with spina bifida are comparable to PCOM scores for children with sickle cell disease, congenital heart disease, and cancer as reported in (Table 3). Full questionnaire results for this study are displayed in Table 1. There were no significant differences in total score or subscale scores between genders and there was no association between age and total or subscale PCOM scores ($p>0.05$). All campers reported they would tell other children that camp was “very good” (90%) or “good” (10%). All campers said they would return to camp next year.

Subscale and Total	Spina Bifida (n=20)	Sickle Cell Disease[16] (n=9)	Congenital Heart Disease[25] (n=51)	Cancer[26] (n=1,230)	Possible Range
Self-Esteem	22.6[a]	22.1	20.4	22.5	5-25
Emotional	35.8	32.1	32.9	35.0	8-40
Social	39.2	38.9	36.4	39.9	9-45
Physical	21.2	20.6	18.0	20.5	5-25
Total	118.6[a]	113.7	107.7	117.9	27-135

Table 3: Comparison of Mean PCOM Scores; [a]One participant was excluded due to missing data, n=19.

The three highest-rated items were item 1 from the self-esteem subscale ("how often did you feel like yourself at camp;" mean=4.85, range 1-5), item 19 from the social functioning subscale ("how often did you feel left out at camp;" mean=4.75, range 1-5), and item 27 from the emotional functioning subscale ("how much did you like or dislike camp;" mean=4.95, range 1-5). Seventeen campers said they almost always (highest rating) feel like themselves at camp and 3 said they often feel that way. Seventeen reported they seldom (highest rating) feel left out at camp, 2 stated not often, and only 1 camper stated they often felt left out. Nineteen campers said they really liked camp (highest rating), and 1 camper said they liked it.

The two lowest rated items were questions 16 from the social functioning subscale ("what was it like to play with kids you did not know very well;" mean=3.65, range 1-5) and 25 from the physical functioning ("how often did you get tired and have to take a break from an activity at camp;" mean=3.65, range 1-5). Four campers reported it was very easy (highest rating) to play with kids they did not know, 4 said it was easy, 9 reported it was just okay, and 1 camper said it was hard to play with kids they did not know. Six campers said they rarely (highest rating) got tired and had to take a break, 4 said they did not have to take a break often, 7 said they sometimes had to take a break, and 3 reported they often had to take a break.

Discussion

Medical specialty camps are growing in popularity, however, research on this topic remains focused on camps for children with chronic illness or disability as a generalized category. Medical specialty summer camps have been shown to have a positive effect on attitudes towards illness, self-esteem, self-efficacy, the quality of peer relationships, and promote high levels of emotional, physical, and social functioning for children with chronic medical conditions such as type I diabetes, heart disease, sickle cell disease, cancer [14-18]. These camps designed specifically for individuals with chronic illnesses provide an opportunity to engage with other campers with a similar condition and increase participants' sense of self-worth and self-esteem [19]. Camp provides children with chronic conditions the opportunity to develop independence and practice managing their condition, as well as meet and learn techniques and practices from peers who share their diagnosis. Reports from children with serious medical conditions attending medically supported summer camps revealed common perceptions such as a sense of belonging, enjoyment, "being myself," positive affect, and personal growth [20]. Feedback from physicians and nurses volunteering at medical specialty summer camps also emphasized a perceived positive influence of camp on children's perception of their condition and healthcare ownership [21].

While there is a recognized need for specialty camps and the summer camp industry in the United States continues to grow, [22] opportunities for individuals with spina bifida to attend camps are limited. Given the complex daily medical needs and mobility constraints faced by those with spina bifida, very few camps are equipped to provide a safe, accessible, and medically supported environment, and even fewer are specifically tailored for children with spina bifida. Medically supported summer camps created specifically for individuals with spina bifida include Camp Spifida in Pennsylvania, Camp Krazy Legs in Georgia, Camp Friendship in Louisiana, Camp V.I.P. in Alabama, Camp MITIOG in Missouri, Camp Independence in Illinois, Camp for

All in Texas, and Camp Patrick in Arizona. These 1-week summer camps are fully accessible with full medical support staff on-site during camp, including multiple physicians and nurses as well as medical and allied health students serving as counselors. Except for Camp Friendship, all are overnight camps, and the majority are of minimal to no cost to campers and families. They are primarily run by volunteers and funding for these camps is derived from grants, sponsorships, donations, and fundraisers. These camps create an inclusive psychologically safe space where campers can try new things, strengthen their character, make lifelong friends, and build a strong network of support.

Limited research has been published on the impact of camps for children with spina bifida. Four studies focused on evaluating the effectiveness of camp-administered interventions targeting independence and coping skills in children with spina bifida during participation in Camp Independence. Following both camper and parent participation in collaborative goal identification, daily educational workshops, and goal-monitoring while at camp, parents perceived improved camper management of activities of daily living and independence [23,24]. Parents' perceptions of their child's future were also found to be positively associated with camper responsibility and task mastery and perceptions of child vulnerability were negatively associated with condition-related responsibility [25]. Repeated participation in summer camp and this camp-based intervention across multiple summers was associated with higher parent-reports of improvement in their child's medical responsibility, mastery of medical tasks, and social skills [3]. One other study by Zimmerman et al. (2019) described the structural benefits of Camp V.I.P. where parents, siblings, and children with spina bifida attend camp together. Caregiver ratings of their child's camp experience were also collected and showed reports of increased confidence and independence in the majority of campers.

To our knowledge, this is the first study to use a standardized, validated measure to evaluate the impact of a medically supported summer camp for children and young adults with spina bifida. Participants with spina bifida were found to have a mean total PCOM score of 118.6, which is comparable to PCOM scores for children with other chronic medical conditions attending their respective summer camps [16,25]. PCOM scores for self-esteem, emotional, social, and physical functioning were also similar across disease groups. These scores suggest that a summer camp designed specifically for individuals with spina bifida has a positive impact on their functioning and is as beneficial as camps designed for children with other chronic medical conditions.

The most positive scores from campers highlight high levels of self-esteem, social, and emotional functioning while at camp. 85% of participants reported they almost always feel like themselves at camp and seldom feel left out and 95% gave the highest possible rating with regards to liking camp. These findings are consistent with previously reported perceptions of summer camp from children with a serious illness emphasizing feelings of belonging, enjoyment, being myself, positive affect, personal growth, and escape [18]. Additionally, 90% of campers reported they would tell others that camp was "very good" and all respondents stated they would return to camp next year.

Through participation in outdoor and social activities, Camp Patrick provides an opportunity for children with spina bifida to engage with their peers and fosters a strong sense of inclusiveness and identity. At camp, participants are developing new relationships, interpersonal skills, confidence, and social self-efficacy while creating a strong support system within the community. Building and strengthening these skills and networks is especially critical for children with chronic illness or disability. Higher levels of social self-efficacy have been associated with increased life satisfaction, decreased number of hospital visits, and increased overall functioning [17]. Participation in a medically supported summer camp therefore serves as an excellent opportunity for improvement in functionality and quality of life.

The positive experiences of campers support the efficacy of a summer camp for children and young adults with spina bifida. Further research should focus on objectively evaluating which specific aspects of camp are most beneficial for campers with spina bifida to optimize camp experience and identify targets for intervention. One of the lowest-rated questions about camp was regarding the need to take frequent breaks during activities at camp. Given limitations in physical functioning, mobility, and strength, as well as other orthopedic issues faced by children with spina bifida, future exploration into the camp activities themselves may highlight ways to enhance positive outcomes in function and quality of life. Additionally, for many campers their lowest-rated item was talking to people they did not know. Children with disabilities often struggle to make friends or meet new people and summer camp provides the opportunity to build social skills and encourage confidence when interacting with similar peers, as well as reduce feelings of isolation.

The primary limitation of this study was the small sample size with only 20 children and young adults completing the outcome measure. We attempted to minimize the dropout rate through the use of an electronic survey; however, many families were lost to follow-up. In the future, we would like to conduct a more robust study with a larger and more diverse group of campers and examine additional health-related measures to explore how camp experiences can be translated into life-long skills and used to

maximize function and quality of life for children with spina bifida and their families.

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