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Program Evaluation of Camp V.I.P: Promoting Self-confidence and Independence for Patients with Spina Bifida☆

Kathrin Zimmerman, BA [a], McKenna Williams, BA [a], Anastasia Arynchyna, MPH [a], Brandon G. Rocque, MD, MS [a], Jeffrey P. Blount, MD [a], Anna Graham, BS [a], Betsy Hopson, MSHA [a,b,*]

[a] *University of Alabama at Birmingham, Department of Neurosurgery, Section of Pediatric Neurosurgery, United States of America*
[b] *Children's of Alabama, United States of America*

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ABSTRACT

Purpose: Camp V.I·P (Victory, Independence, Possibilities) was established by the Spina Bifida Association of Alabama in 2012. The goal is to provide children with spina bifida (SB) and their families a traditional-style summer camp focusing on self-empowerment and fostering independence in medical self-management.
Design and methods: Part 1 of this study describes Camp V.I·P. structure. Part 2 describes an online survey to caregivers of campers gauging camp effectiveness and value and evaluating perceptions of confidence/independence and family connections. Camper characteristics were compared to the overall SB clinic population.
Results: 63 children with SB, 81 siblings, and over 100 caregivers have attended camp. Campers are similar to the overall clinic population in race, gender, and ambulation status. At camp, there are significantly more children with myelomeningocele (versus other spinal dysraphism) and lumbar functional level (versus thoracic).
Survey results show that confidence grew in 93% of campers, and 86% gained greater independence. Parents stated that they created lifelong friendships. The majority of caregivers (91%) indicated “certainty” that they would attend camp again.
Conclusion: Camp V.I·P is a family-centered environment that emphasizes respite, nurture, and the continuum between family and clinic. Our research shows that camp can be a useful tool to aid in independence, confidence, and social adaption.
Practice implications: Camp has become an integral part of our comprehensive care of children with SB and has been shown to reinforce what is taught through the clinic by creating trust between the care team and campers.

Introduction

Spina bifida is the most common complex neurologic birth defect consistent with life in the United States. Clinical manifestations may include hydrocephalus, bladder and bowel incontinence, gastrointestinal disorders, swallowing abnormalities, sensorimotor impairments, pressure ulcers, obesity, and learning disabilities (Bowman, Boshnjaku, & McLone, 2009; Mathews, Honein, & Erickson, 2002; McClugage et al., 2012). Since 1993, the pediatric spina bifida team at UAB/Children's of Alabama has provided longitudinal, interdisciplinary, comprehensive care to children with spina bifida (SB). Our experience has demonstrated that integration and collaboration with the SB community outside of the clinic is a key to improving access and quality of care. Patients and families have significant needs that extend beyond acute medical issues and that are an important part of the overall disease burden of SB. Examples include low self-esteem, personal identity challenges, isolation, anxiety, depression, and economic hardship (Davis et al., 2017; Rocque et al., 2015; Sims-Williams, Sims-Williams, Mbabazi Kabachelor, & Warf, 2017). To address some of these difficulties, the Children's of Alabama (COA) Comprehensive Spina Bifida Program has developed a working partnership with the Spina Bifida Association of Alabama (SBA of AL). These groups have coordinated a series of community and social events serving both the adult and pediatric population. Each event serves to provide an opportunity for social interaction, social support and fun as well as an opportunity to learn more about the many protean issues associated with SB. In this paper, we describe one of these events, Camp V.I·P.

Previous studies have examined various facets of the camp experience for children with chronic disease. The most common condition discussed in the literature is pediatric cancer, but there are also reports of camps for children with renal disease, diabetes, burns, epilepsy, and inflammatory bowel disease, among others (Armstrong-James,

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* Corresponding author at: University of Alabama at Birmingham, Department of Neurosurgery, 1600 7th Avenue S. Lowder 400, Birmingham, AL 35233, United States of America.

E-mail address: Betsy.hopson@childrensal.org (B. Hopson).

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Cadogan, Williamson, Rumsey, & Harcourt, 2018; Bandino, Garfinkle, Zickefoose, & Hsieh, 2014; Békési, Török, Kökönyei, Bokrétás, Szentes, Telepóczki, & European KIDSCREEN Group, 2011; Blas, 2007; Kennedy & Richards, 2016; Laing & Moules, 2014; Martiniuk, Silva, Amylon, & Barr, 2014; Salazar & Heyman, 2014; Shepanski et al., 2005; Weissberg-Benchell & Rychlik, 2017; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006; Wu, McPhail, Mooney, Martiniuk, & Amylon, 2016). The present study is the first to describe a disease-specific camp focused on children with spina bifdia.

Camp V.I·P (Victory, Independence, Possibilities) was founded in 2012 to provide a free summer camp experience for children with SB and their families. Funding is derived from grants, corporate sponsorships, donations, and earnings from other SBA of AL events. Camp V.I·P is a family camp that embraces the goal of providing a traditional camp experience for individuals with SB, with a focus on self-empowerment and fostering independence in medical self-management.

The purposes of this manuscript are twofold: 1) to outline the development and evolution of Camp V.I·P. and provide a description of participants; and 2) to report quantitative and qualitative feedback from camp participants about the impact of Camp V.I·P.

Methods

In part 1, we describe the structure of Camp V.I·P, including details of how it has evolved over time and how we have actively sought feedback from the community on ways to improve the camp experience. We report numbers of camp participants and describe specific steps taken to improve camp participation. In addition, we performed a review of the electronic medical record to determine gender, race, diagnosis, and ambulation status of the campers with SB and compared these values to the overall population of our SB clinic. Results are summarized with descriptive statistics, and comparisons assessed using Chi-square.

In part 2, IRB approval was obtained and a survey was administered to evaluate participant growth in two domains: confidence and independence. Multiple-choice surveys were delivered to the caregivers of pediatric camp participants via online development software (Survey Monkey Inc., San Mateo, California) after camp conclusion in July 2017. Caregivers were eligible for survey participation if they had attended camp at least once. IRB approval and patient consent was obtained prior to conducting program evaluation for research purposes.

The survey was developed by the camp director using specific questions related to camp programming. Likert-type rating scale was used as well as free text responses. The survey was composed of questions to assess the camp experience; satisfaction with activities and facilities; and caregiver's perception of the impact that participation in camp had on their child's self-confidence, independence, and future outlook. Additional qualitative data were obtained from free-response sections of the survey.

This survey instrument has not been previously used, nor is it validated. Results are presented here as an evaluation of family satisfaction with the camp experience and an assessment of the impact of camp on the child and family.

Results

Part I

Since its establishment in 2012, CAMP V.I·P has hosted 63 patients with SB, 81 siblings, and over 100 caregivers, many of whom have attended camp multiple times. We have worked to grow and improve the camp experience each year based upon structured and informal feedback and evaluations. In 2017, there were a total of 32 children with SB, who participated in CAMP V.I·P. Nine campers had never attended camp before. The camp is 3 days in duration over a weekend in the summer. All costs for the camp are covered by the SBA of AL so that there are no costs to families other than transportation to the camp.

Camp VIP has been built around activities that would ensure each member of the family unit has a unique experience filled with respite and substance. The weekend begins with a faux-Hollywood-celebrity entrance, complete with a cheering line of “paparazzi”, red carpet, and welcome gifts. Next, campers are given keys to their fully accessible, individual family cabins. When they enter their rooms, they find gifts, including camp T-shirt, hanging name tags with their printed schedule, beach towels, snacks, drinks, a cooler, beach balls, and playing cards. The goal of the initial experience is to embrace and somewhat overwhelm them with events that validate them and reinforce that they are important, have value, and are cared for by persons across the spectrum of care. During the first evening, get-acquainted games are played before dinner, and the evening ends with a dance party. The remainder of the weekend consists of activities such as adaptive water skiing, canoeing, water tubing, boating, fishing, putt-putt golf, an accessible swimming pool and tree house, and arts and crafts organized by over 60 volunteers. These activities are carefully structured to enable campers to approach challenging thresholds and overcome them in a safe and supervised setting. The activities are staffed by experts to maximize participant success. The goal of the overall experience is one of triumphing over adversity and fear. There are also educational activities offered by COA medical staff, such as wound-care education, orthotics fittings, adaptive exercise, shunt and hydrocephalus review and questions, and private self-catheterization education sessions.

A unique aspect of Camp V.I·P is that it utilizes a family-centered model. Children with SB attend camp with their families, including parents and siblings. One of the goals of camp has been to integrate siblings into all of the camp activities. Since inception, a total of 81 siblings have attended camp, more than individuals with SB. Seventy-one percent of families who have attended camp brought one or more siblings in addition to the family member with SB. We believe this family-inclusive model allows for bonding between children with SB and their siblings in an environment where both can participate equally. Siblings participate alongside campers with SB in all camp activities. Meanwhile, parents/caregivers have an opportunity to establish support networks.

Patients and families sign up voluntarily for camp. Initially it was popularized by word of mouth and social media by the SBA of AL. Popularity and demand grew quickly such that there was an almost immediate increase in applicants. Each year attendance priority is given to individuals who have not attended camp previously. Therefore, during the first week of camp registration, only new campers can submit a camp application. In the next week, priority is given to campers who have only attended 1 prior camp, and then the final week of registration is open for all campers.

A total of 63 campers have attended camp, from 59 families. Age of camp participants ranged from 6 to 17 years of age, with a median age of 11 years. Among the children with SB, 37 (59%) were female. Fifty (79%) were white/non-Hispanic; 7 (11%) were Asian, 4 (6%) were black, and 2 (3%) Hispanic. Fifty-seven children (90%) had a diagnosis of myelomeningocele, while 5 had a diagnosis of lipomyelomeningocele, and one camp attendee had split cord malformation. Thirty-two (51%) were non-ambulators, and 28 (44%) were community ambulators. Two campers (3.4%) had neurological function at the thoracic level (thoracic lesion level as defined in the CDC National Spina Bifida patient registry, no leg movement). Thirty-two campers (55%) had lumbar functional level, and 24 (41%) had sacral functional level. Clinical and demographic data of the participant population is summarized in Table 1. Similarly, the makeup of the entire institutional spina bifida clinic is summarized in Table 1. Comparison between the camp population and the overall clinic population are shown. The group of children with SB who have attended camp does not differ significantly from the population of our multi-disciplinary SB clinic in race, gender, or ambulation status. However, there are significant differences in diagnosis and functional level. A larger proportion of children at camp

Table 1
Characteristics of children with spina bifida who participated in the camp survey (data abstracted from medical record).

Demographics and clinical characteristics	Camp population (n = 63)		Clinic population (n = 619)	*p*-value (Chi sq)
Current age	Median	11 y		
	Range	6–17 y		
Gender	Male	26(41%)	291 (47%)	P = 0.38
	Female	37(59%)	328 (53%)	
Race/ethnicity	American Indian or Alaska Native	0 (0%)	3 (0.5%)	P = 0.15
	Asian/Pacific Islander	7(11%)	49 (8%)	
	Black or African American	4 (6%)	102 (17%)	
	Hispanic:	2 (3%)	47 (8%)	
	White/Caucasian	50(79%)	447 (72%)	
	Multiple ethnicity/other	0 (0%)	12 (2%)	
Type of spina bifida	Myelomeningocele	57(90%)	448 (75%)	P = 0.021
	Lipomyelomeningocele	5 (8%)	94 (16%)	
	Other	1 (2%)	53 (9%)	
Lesion level (n = 58)	Thoracic	2 (3.4%)	94 (18%)	P = 0.011
Data missing for 5 patients	Lumbar	32(55%)	216 (42%)	
	Sacral	24(41%)	208 (40%)	
Type of ambulation status	Community ambulatory	15(63%)	266 (52%)	P = 0.15
	Household ambulator	3(13%)	27 (5%)	
	Non-ambulator	6 (25%)	206 (40%)	
In a typical month, how often do you have bowel accidents when not ill?[a]	Daily	2 (8%)	120 (28%)	P < 0.001
	Weekly	3 (12%)	60 (14%)	
	Monthly	5 (20%)	30 (7%)	
	Less than monthly	10(40%)	20 (5%)	
	Never	5 (20%)	188 (44%)	

[a] For bowel continence, data were not abstracted from the medical record for the camp population. Rather, these results come from the parent responses to the survey. Data from the clinic population are taken from the medical record.

have diagnosis of myelomeningocele (90% campers vs. 75% in clinic). In addition, at camp there are more children with lumbar functional level and fewer with thoracic functional level than in the clinic as a whole (lumbar 55% v. 42%, thoracic 3.4% vs. 18%) (Table 1).

An observation from the earliest camp experience was that campers were often fearful of participating in some activities, particularly water skiing and tubing. To encourage participation, a point system was created. During subsequent camps, campers were divided into teams, and each family was given points for activities they participated in over the weekend. After implementing this competitive aspect, the number of participants in activities increased. For example, water skiing increased from 70% to 93% participation, and tubing increased from 56% to 100%. Volunteers and parents/caregivers reported that by trying new things, campers' confidence began to grow immensely.

Since camp began in 2012, effort has been made annually to continually improve the camp experience and to add new elements. Each year, based on both volunteer and family feedback, modifications are made to camp activities, family gifts, meals, and overall camp flow. Because most of these changes were based on anecdotal observation, there was a desire to establish a more systematic method for understanding and improving the camp experience. With this in mind, a camp survey was developed prior to the camp in 2017.

Part II

In total, 59 caregivers were eligible for survey enrollment and 32 caregivers (54%) completed post-camp surveys.

Ninety-three% (n = 27) of caregivers reported that their child's confidence increased after attending camp. When asked what contributed most to their child's increase in self-esteem, caregivers indicated the following: volunteer connection (29%), camp activities (25%), gaining new skills (14%), making new friends (18%), seeing old friends (4%). In response to the question “Because of Camp V.I.P my child is more confident”, 33% of caregivers strongly agreed, 57% of caregivers agreed, and 3% of caregivers disagreed (Table 2).

Eighty-six% (n = 25) of caregivers reported that their child's independence increased after attending camp. When asked what contributed most to their child's increase in independence, caregivers indicated the following: camp activities (44%) volunteer connection (20%), and gaining new skills (20%). In response to the question “Because of Camp V.I.P my child is more independent”, 30% of caregivers strongly agreed and 57% of caregivers agreed (Table 2).

Families who completed the survey reported making strong connections at camp (Table 2). The majority of families reported that they continued to talk to people they met at camp after camp was over. Most reported that their child had friends at camp, that they made new friends at camp, and that they continued to communicate with camp friends after camp via social media, text messaging, and contact in clinic.

The vast majority of caregivers (91%) indicated that they were “certain” that their child would want to return to Camp V.I.P in the future. The camp activities with the highest percentage of “excellent” rating included pool party (97%), VIP welcome (93%), water-tubing (67%), arts and crafts (63%), and s'mores (60%). In terms of accessibility, 78% (n = 18) rated the facilities as “excellent”, and 22% rated the facilities as “good” (Table 3).

When given the opportunity to provide free-text comments on how Camp V.I.P has impacted their child's life, responses included the following themes: connection, belonging, increasing self-confidence, and sibling inclusion (Table 4).

Because of our group's previous work showing the importance of bowel continence in maintaining social and employment activities outside the home for adults with spina bifida, we included a single question about bowel continence in the camp survey (5). Overall, 60% of campers reported bowel accidents less than monthly. When compared to the clinic population, this is a significantly higher level of continence (Table 1).

Discussion

The findings of this study suggest that a diagnosis-specific, family camp can be effective in improving the confidence and independence for individuals affected by SB. Of the camp participants who completed surveys, 100% wish to return to camp and rated the overall camp experience as excellent. We feel that the success of the camp is based on three critical factors.

Table 2
Survey responses.

Survey section	Responses	
Confidence and independence	Did you see your child's confidence grow at Camp VIP? (n = 29)	
	Yes	27 (93%)
	No	2 (7%)
	If yes, what do you think contributed most your child's confidence/self-esteem? (n = 28)	
	Camp activities	7 (25%)
	Volunteer connection	8 (29%)
	Making new friends	5 (18%)
	Seeing old friends	1 (4%)
	Gaining new skills	4 (14%)
	Other (please specify)	3 (11%)
	"All of the above!"	
	"They simply make the kids feel like the special God-formed treasures that they are"	
	Did you see your child's independence grow at Camp VIP? (n = 29)	
	Yes	25 (86%)
	No	4 (14%)
	If yes, what do you think contributed most to your child's independence? (n = 25)	
	Camp activities	11 (44%)
	Volunteer connection	5 (20%)
	Making new friends	1 (4%)
	Seeing old friends	1 (4%)
	Gaining new skills	5 (20%)
	Other (please specify)	2 (8%)
	"Not being different and the connections with campers, staff, facility"	
	"The fact that he could maneuver most of the camp independently whether using his cane or wheelchair"	
	To what extent do you agree with the following statements:	
	Because of Camp VIP I feel my child is more independent (n = 30)	
	Strongly agree	9 (30%)
	Agree	17 (57%)
	Disagree	2 (7%)
	Strongly disagree	0
	N/A	2 (7%)
	Because of Camp VIP I feel my child is more confident (n = 30)	
	Strongly agree	10 (33%)
	Agree	17 (57%)
	Disagree	1 (3%)
	Strongly disagree	0
	N/A	2 (7%)
	I felt that my child felt good about themselves while at Camp VIP (n = 30)	
	Strongly agree	22 (73%)
	Agree	8 (27%)
	Disagree	0
	Strongly agree	0
	N/A	0
	I felt that my child was happy while at Camp VIP (n = 30)	
	Strongly agree	22 (73%)
	Agree	8 (27%)
	Disagree	0
	Strongly disagree	0
	N/A	0
Family connections	I continued to talk to people I met at Camp VIP when it was over. (n = 30)	
	Strongly agree	12 (40%)
	Agree	16 (53%)
	Disagree	0
	Strongly disagree	0
	N/A	2 (7%)
	In what way did you keep in contact with friends made at Camp VIP? (n = 30)	
	Facebook/other social media	19 (63%)
	Phone calls/texting	4 (13%)
	Emails	1 (3%)
	Clinic	2 (7%)
	N/A	1 (3%)
	Other	3 (10%)
	My child had friends while at Camp VIP. (n = 32)	
	Strongly agree	12 (38%)
	Agree	19 (59%)
	Disagree	1 (3%)
	Strongly disagree	0
	My child made new friends while at Camp VIP. (n = 30)	
	Strongly agree	11 (37%)
	Agree	17 (57%)
	Disagree	1 (3%)
	Strongly disagree	0
	N/A	1 (3%)
	My child continued to talk to people he or she met at Camp VIP when it was over. (n = 27)	
	Strongly agree	7 (26%)
	Agree	12 (44%)
	Disagree	5 (19%)
	Strongly disagree	1 (4%)
	N/A	2 (7%)
	My child kept in contact with friends he or she made at Camp VIP by: (n = 30)	
	Facebook/other social media	7 (23%)
	Phone calls/texting	4 (13%)
	Email	1 (3%)
	Clinic	5 (19%)
	N/A	13 (43%)

First, the camp was designed by people familiar with spina bifida from both the clinic and the family, each bringing their own expertise to the process. Goals were set to address the needs observed in the clinic setting and the typical strains felt by families with medically complex members. This unique approach to camp development created an atmosphere where families could obtain much-needed respite, make new connections, and learn new skills that would impact their daily lives. Simultaneously, children with SB could face and overcome new challenges and have fun in a socially rich environment.

Secondly, the camp design is focused on the entire family unit. Often siblings of medically complex individuals report feeling isolated, jealous, and left out because of time constraints and the needs of their sibling (7–10). Therefore, Camp V.I.P. makes no distinction between any children who attends. Camp V.I.P provides the opportunity for siblings and patients to participate in activities side-by-side, receiving the same attention and recognition. This approach has created the opportunity for healing and bonding between the siblings. Similar benefits to siblings have been shown in camps focusing on children with cancer. (Wu et al., 2016 and Wellisch et al., 2006). We also attribute the camp success to organized and planned opportunities for parent connections throughout the weekend. Many parents commented throughout the weekend that camp is the first and only place where they have felt like they are surrounded by individuals who can "complete their sentences." Our survey found that 93% of the families who attend camp continue to stay in touch after camp. Previous studies of disease-specific camps have shown similar benefits in building relationships with other children and families to whom the camper can easily relate. (Kennedy & Richards, 2016and Armstrong-James et al., 2018).

Finally, most of the volunteers who work during the camp weekend are physicians, nurses, and staff from the SB clinic. Anecdotally, we have observed that this allows the campers' medical team to experience life with their patients in a fun setting and allows a bond to form between the care team and camp families. Furthermore, we have observed that for camp participants, this has led to reduced anxiety when care is provided in the hospital/clinic setting. Half of parents surveyed reported that the volunteer connections contributed to the increased confidence their child gained at camp. An additional and unexpected benefit of camp came from the staff and volunteers who participated. From

Table 3
Survey rating of camp activities.

Session	Ratings (n = 32)					
	Excellent	Good	Adequate	Poor	Unacceptable	Not applicable
Pool party (n = 30)	97%	3%	0%	0%	0%	0%
VIP Welcome (n = 30)	93%	0%	3%	0%	0%	3%
Water-Tubing (n = 30)	67%	24%	0%	0%	0%	8%
Arts & Crafts (n = 30)	63%	21%	4%	0%	0%	13%
Campfire and S'mores (n = 30)	60%	23%	0%	0%	0%	17%
Wound Care Session (n = 30)	33%	7%	3%	0%	0%	57%
Self-Catheterization Session (n = 30)	33%	7%	3%	0%	0%	57%
AFO Session (n = 30)	33%	0%	7%	0%	0%	60%
Trampoline (n = 30)	33%	33%	3%	0%	0%	30%
Morning exercise (n = 30)	23%	3%	3%	0%	0%	70%

anecdotal observation, volunteers felt that they had gained better insight into the daily lives of their patients and families with SB. This greater breadth of knowledge improved their overall capacity to deliver high quality, compassionate care in the clinic. We have not quantified these observations but will move toward doing so with further experience in camp.

Table 4
Themes abstracted from free-response section of survey.

Theme	Quotes
Connection	"We are not from the Birmingham area, we used to go to SB clinic and not know anyone, now we see faces we can connect with staff and SB families, making coming to clinic more welcoming and exciting about who we might be able to see, instead of such a stressful sterile environment. Thankful beyond explanation for camp and those who make it happen" "We want to cry every time we leave [camp] because we will miss everyone and it's such an amazing experience. She is more willing to try new things. Realizes other kids have same problems as well as different problems. It gives other members of the family a chance to relate to other moms and dads as well as siblings without SB" "It is helpful to see other families with the same situation"
Belonging	"She looks forward to it [camp]. She doesn't feel any different at camp" "[Camper] loves going to camp. He talks about it all the time and can't wait till next year to go back" "She loves camp and keeps asking when she can go back. She was able to do everything she wanted without any problems or being told she couldn't access it" "She begs to go back every year and she has made new friends that we are still in contact with. She sees other kids just like her and she doesn't feel alone or different"
Self-confidence	"It boosted her self-confidence" "It made him feel more confident to see that there are kids just like him who have the same struggles and use the same equipment" "I have seen my son's confidence grow since he began attending [camp]. He was able to try new things like tubing and water skiing that he would never be able to do without the camp. This in turn built up confidence to try new things…. leading him to just coming back from a trip with Boy Scouts coral reef sailing in Key West for 7 days on a sail boat" "She learned to cath by herself while at camp!! She feels like there is nothing that she can not do while at camp. She never feels left behind like she sometimes does when she is at activities that are all children without spina bifida" "Camp VIP helped to giver her joy and confidence. She'll learn the skill of self cathing on the toilet. She became completely independent in this skill at age 6."

The majority of campers had a diagnosis of myelomeningocele (versus a closed spinal dysraphism like lipomyelomeningocele or split cord malformation). This is similar to the makeup of the spina bifida clinic. However, there were no campers with thoracic functional level. These individuals, who have no meaningful neurological function in their legs, comprise 18% of the clinic, yet make up only 3.4% of camp participants. Post hoc analysis showed that this difference in functional level between the clinic and camp populations was statistically significant ($p = 0.021$). It is possible that these patients and families perceive that they would not be capable of participating in camp. Future efforts to engage these families in the camp process would be warranted.

Finally, camp participants had significantly higher rates of bowel continence than the clinic population. Bowel continence is particularly important, as in our previous work, we have shown that among adults seen in a multi-disciplinary adult spina bifida clinic, only level of education and bowel continence are significant predictors of self-identification as "disabled" (Davis et al., 2017). It would be reasonable to assume that children with more frequent bowel incontinence are less likely to feel comfortable engaging in a social activity such as camp. This further highlights the importance of bowel management as a crucial component of comprehensive care for individuals with spina bifida.

Limitations

This study has several limitations. The focus of part 1 is to describe the development of camp and its evolution to its current form. This is necessarily retrospective and relies largely on the recollection of the camp organizers. When comparing clinical and demographic variables between campers and the overall SB clinic population, we have used data extracted from the medical record wherever possible. However, some campers come from outside our medical center, and thus their data are not available. Furthermore, the bowel continence camper data is based on survey report, rather than on medical record data.

This self-report survey questionnaire used in this study was designed and written by the investigators to gather data from parents about their perceptions of the impact and benefits of camp. Questions regarding self-confidence, independence, and connectedness of the child are answered by the parents, rather than by the child him or herself. While parent-proxy is likely an accurate assessment for many of the campers, we have not directly asked the campers themselves.

Conclusion

Herein, we have presented the concept of a diagnosis-specific, family-centered three-day camp and our initial experiences. Key elements are 1) an immersive experience that validates each patient and family member within the family unit and 2) carefully constructed challenges, such as adaptive water skiing, that ensure the capacity to overcome the challenge. The environment emphasizes respite, nurture, the value of the family, and the continuum between the clinic and the family in the provision of multi-dimensional care. The impact of the camp exceeded our greatest hopes, and it has become an integral part of our process for comprehensive care and transition.

CRediT authorship contribution statement

Kathrin Zimmerman: Writing - original draft. **McKenna Williams:** Methodology, Data curation, Software. **Anastasia Arynchyna:** Formal analysis. **Brandon G. Rocque:** Conceptualization, Formal analysis, Writing - review & editing. **Jeffrey P. Blount:** Conceptualization, Formal analysis. **Anna Graham:** Data curation. **Betsy Hopson:** Conceptualization, Methodology, Formal analysis, Writing - review & editing.

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