HHS Public Access

Author manuscript

Dev Med Child Neurol. Author manuscript; available in PMC 2020 October 27.

Published in final edited form as:

Dev Med Child Neurol. 2019 December ; 61(12): 1392–1399. doi:10.1111/dmcn.14250.

Camp-based psychosocial intervention dosage and changes in independence in young people with spina bifida

COLLEEN F BECHTEL DRISCOLL[1], **CAITLIN B MURRAY**[2], **CHRISTINA E HOLBEIN**[3], **COLLEEN STILES-SHIELDS**[1], **GINA CUEVAS**[1], **GRAYSON N HOLMBECK**[1]

[1]Psychology Department, Loyola University Chicago, Chicago, IL

[2]Center for Child Health, Behavior and Development, Seattle Children's Research Institute, Seattle, WA

[3]Children's Hospital of Philadelphia, Philadelphia, PA, USA.

Abstract

AIM—To examine associations between camp-based intervention dosage and changes in independence-related skills for young people with spina bifida.

METHOD—Participants were 110 individuals (mean age [SD] 14y 7mo [6y 1mo], range 6–32y; 66 females, 54 males) who attended a summer camp for individuals with spina bifida between 2 to 6 times (mean 2.40; operationalized as 'dosage'). Parents of young campers (e.g. those <18y) also participated in data collection. Campers and/or parents completed preintervention measures assessing campers' level of medical responsibility, mastery over medical tasks, and social skills. Outcomes included change in preintervention scores from dose 1 to final dose.

RESULTS—Hierarchical regression analyses with and without covariates (age, IQ, and lesion level at dose 1) revealed that increased dosage was significantly associated with greater parent-reported improvements in campers' medical responsibility and mastery over medical tasks. Increased dosage was also significantly associated with camper-report of increased medical responsibility, but this relationship was no longer significant when including covariates. Intervention dosage was not associated with changes in campers' social skills.

INTERPRETATION—Repeated participation in a camp-based intervention was associated with improvements in condition-related independence. Future work may focus on the development of interventions to promote improvements in social skills for young people with spina bifida.

Spina bifida, a neural tube defect resulting in spinal cord and nerve damage, occurs in approximately 3 out of every 10 000 live births in the United States.[1] Individuals with spina bifida experience a variety of physical and health concerns affecting body structure (e.g. hydrocephalus, pressure sores), body function (e.g. bladder/bowel dysfunction, sensory loss, seizures), and activity/participation (e.g. limited mobility).[2,3] These chronic health concerns

Correspondence to Grayson N Holmbeck, Psychology Department, Loyola University Chicago, 1032 W Sheridan Road, Chicago, IL, USA. gholmbe@luc.edu.

SUPPORTING INFORMATION

The following additional material may be found online:

require lifelong care from multiple providers and strict adherence to complex medical routines.[4] Attainment of independence is a critical component of development, yet young people with chronic health conditions, including spina bifida, face additional challenges in attaining behavioral and medical independence.[4] In addition to the described medical concerns, young people with spina bifida have been found to experience social difficulties, demonstrating less socially competent behaviors[5] and poorer social adjustment[6] than typically developing peers.

With advances in medical care and resulting increases in life expectancy, a growing number of multi-component treatment programs have been developed to foster the attainment of life skills in young people with chronic health conditions.[7] The core feature of these programs, commonly delivered in rehabilitation and residential (i.e. live-in) settings, is the provision of experiential opportunities for practicing and mastering independence and social skills within a supportive learning environment.[8,9] Similarly, summer camp programs have become an increasingly popular context for providing independence programming to young people with chronic medical conditions. Medical camps are unique in their ability to tailor programming to the distinct medical and psychosocial needs of each pediatric condition. Indeed, there are many summer camp programs specific to a variety of chronic health conditions, such as kidney disease, cancer, sickle cell disease, HIV/AIDS, diabetes, obesity, and asthma.[10–12] Campers are provided with ample opportunities to practice condition-specific self-management behaviors among knowledgeable medical staff and without assistance from their caregivers.[10,11] Furthermore, given these young people commonly experience social isolation and low peer acceptance in school and other settings, the accepting, engaging atmosphere of camp may provide important and needed exposure for campers to practice social skills, build friendships, and strengthen social development. Indeed, meta-analytic research has found that young people who attend medical camp programs show improvements in important social outcomes, including self-perception and self-esteem.[12]

Still, the research on camp-based programs specifically for individuals with spina bifida is sparse. Two studies on camp-based independence interventions for spina bifida have been conducted by our research group to date. This research has found that participants in a camp-based intervention, consisting of collaborative (i.e. parent and camper) goal identification, goal-monitoring by camp counselors, and 1-hour daily group workshops that included psychoeducation and teaching of cognitive tools improved on medically related and social goals.[13] This intervention was also associated with improved camper management of spina bifida responsibilities and independence in completion of spina bifida-related tasks, which was maintained 1-month postintervention.[13] These results were later replicated with a larger sample and modified intervention.[14]

Most summer camps in the United States report that over half of their campers return over multiple years.[15] In line with this trend, we have observed that many individuals with spina bifida return to camp and participate in the independence intervention year after year. While our previous efforts have yielded promising results regarding the short-term impacts of camp-based interventions for young people with spina bifida, the cumulative impact of the camp intervention (e.g. for those participating over multiple summers) remains unknown. Further, young people with spina bifida are at risk for executive dysfunction and intellectual

difficulties that may interfere with intervention efficacy because of difficulties retaining and applying intervention strategies.[16,17] Thus, repetition and continued encouragement to use previously learned information may enhance treatment efficacy and lead to long-term improvements in young people's ability to gain independence and mastery over medical tasks.

Therefore, the current study sought to expand the results of previous papers by examining associations between dosage (defined for the purposes of this study as the number of years an individual participated in a camp-based intervention) and the original study's secondary outcomes – medical self-management and social skills. (The original study[12,13] included achievement of specific self-management and social goals as the primary outcomes. However, as these specific goals change for each camper from year to year, these were not included in the current study's longitudinal analyses). It was hypothesized that increased dosage would predict greater improvements in camper- and parent-reported medical self-management and social skills. Given the potential impact of sociodemographic and condition severity factors on the outcome variables, all analyses were run with and without the following covariates: camper age, IQ, and lesion level (a proxy for condition severity) at dose 1. Lastly, an effort was made to disentangle the contribution of expected developmental changes from camp-facilitated improvements in self-management and social skills over time, as repeated camp visits represent not only increased exposure to camp interventions but also increasing normative maturation over time. It was predicted that participation in the intervention would be associated with improvements in skills beyond those effects because of typical development.

METHOD

Participants

Participants included individuals with spina bifida attending an overnight summer camp in a small Midwestern town for at least two summers between 2009 and 2014. This summer camp exclusively serves individuals with spina bifida and is conducted in week-long consecutive sessions by age group (children [age 7–12y], adolescents [age 13–17y], and young adults [age ≥18y]). Individuals with severe allergies or unpredictable health conditions (e.g. uncontrolled seizures) are not permitted to attend camp.

Every camper was approached to participate in the study. For campers under 18 years of age, one parent/caregiver was also invited to complete study questionnaires. Figure S1 (online supporting information) illustrates the progression of participants in the study. The inclusion criterion for the present study required completion of study measures during at least two summers within the 2009 to 2014 timeframe. Campers/families who completed study measures only once within the timeframe (n=79) were not included in the analyses. The final sample consisted of 110 individuals with spina bifida (mean age [SD] 14y 7mo [6y 1mo], range 6–32y; 66 females, 54 males). Additional participant demographics and condition-specific characteristics are provided in Table I. It should be noted that for the young adult subsample (campers ≥18y; n=34), parents were not included in data collection.

Procedure

This study was approved by the Institutional Review Board at Loyola University Chicago. Families received information about the camp through contact with their health care professionals and various print and online information from a local spina bifida organization. Financial assistance was available for families who could not afford to pay. Camper consent/assent, parent permission (for campers aged <18y), parent consent, and questionnaires were sent to registered campers via mail approximately 1 month (4–6wks) before the start of camp. Campers/families completed questionnaires before the start of camp, and questionnaires were collected by study staff on the first day of camp. At baseline, campers and their parents (for campers <18y) completed measures assessing camper medical self-management and social skills, condition-related information, and demographic information (details provided below). Brief neurocognitive tests were administered by trained research assistants during camp. Additional questionnaires were administered on the last day of camp and approximately 1-month after camp; however, the present study utilized data from baseline (pretreatment) only. Parents and campers received monetary compensation for completion of materials. No study-related adverse events occurred.

Intervention

The camp intervention has been described previously.[13,14] The intervention, which was embedded within a typical summer camp program, was designed to target self-management skills and social skills known to be problematic for individuals with spina bifida using evidence-based strategies.[13] The intervention had three components: (1) goal-setting; (2) counselor-camper discussions about these goals; and (3) 1-hour daily workshops. Before the start of camp, campers (and parents, if applicable) identified one medical self-management goal and one social goal to address throughout the camp session. Repeat participants were encouraged to choose goals most relevant to them each summer. Camp counselors, who were each assigned to one camper for the duration of the session, monitored camper goals daily, reviewed goals with campers, and engaged in problem-solving to help the campers achieve their goals. Camp counselors had all earned a high school diploma (or equivalent) and were screened and hired by the larger camp organization. They were supervised by trained interventionists.

In addition to goal-setting and monitoring, campers participated in daily 1-hour, manualized group workshops for 4 days during the camp week. Interventionists were postbaccalaureate research assistants in a health-related field and were trained and supervised by doctoral-level graduate students. Each week, workshops were led by a single interventionist; workshop groups consisted of approximately 16 campers (eight females). Workshops included psychoeducation and strategies (e.g. problem-solving, communication skills) to target behavioral change in self-management and social skills. Skills were taught and practiced using multiple interactive activities, such as group and partner discussions, art projects, games, workbook exercises, and role plays. Campers were provided with workbooks to use throughout the week and take home at the conclusion of camp. Each day, a different topic was addressed: (1) building friendships and communication skills; (2) self-esteem and emotional wellness; (3) living with spina bifida (e.g. personal and outside reactions to spina bifida, community involvement); and (4) health-related self-care. Three versions of the

intervention manual were used to ensure developmentally appropriate content and activities for each age group. In an effort to maintain the engagement of repeat participants, the manual was updated yearly to include new games and warm-up activities.

Measures

As mentioned previously, for young adults (age ≥18y), only the participating camper completed questionnaires. Questionnaires that were completed by parents (i.e. when campers were <18y only) are designated below.

Medical self-management

Two aspects of medical self-management were assessed in this study and are detailed below.

Independence in completing spina bifida-related tasks—The Sharing of Spina Bifida Management Responsibilities questionnaire was adapted from the Diabetes Family Responsibility Questionnaire, a measure that has shown adequate internal consistency and concurrent validity.[18] The Sharing of Spina Bifida Management Responsibilities questionnaire was used to assess changes in responsibility for spina bifida tasks across several domains (e.g. health appointments, communication about spina bifida, medications). Both campers and parents completed this measure, indicating who was responsible for 34 tasks (1=parent, 2=shared, 3=camper, 4=not applicable). Mean total scores were computed, with higher scores indicating greater camper responsibility. Items deemed ‘not applicable’ by respondents were considered missing data; therefore, alphas for this scale could not be computed because reliability programs only include participants who respond to all items.

Mastery of self-management skills (<18y only)—The 48-item Spina Bifida Independence Survey was adapted from a validated diabetes questionnaire (i.e. Diabetes Independence Survey).[19] Only parents reported on this measure, responding ‘yes’, ‘no’, ‘not sure’, or ‘not applicable’ regarding their child’s mastery of condition-related skills (e.g. medication management, catheterization). Ratio scores of ‘yes’ responses to the total number of item responses were calculated to determine the degree to which a camper had mastered condition-related tasks, with higher scores indicating greater mastery of tasks. Again, items deemed ‘not applicable’ by respondents on this scale were considered missing data, precluding internal consistency analyses.

Social skills (<18y)

Parents completed the 26-item Social Skills Measure, which was developed for this study to measure campers’ social skills specifically targeted by the intervention.[20,21] Parents rated how often their children demonstrated important verbal and nonverbal interpersonal skills (e.g. ‘Stays on topic during conversations’, ‘Maintains appropriate eye contact’) using a 5-point Likert scale (1=never to 5=always). A total score was computed by averaging across all items. In the current sample, internal consistency was excellent (α=0.91–0.97). See Table SI (online supporting information) for information on this questionnaire, including frequencies of responses for each item.

Demographics and covariates

Medical and demographic covariates—Parents and young adult campers completed a demographics form assessing camper's age, sex, ethnic group, and medical characteristics (i.e. lesion level, spina bifida type, number of shunt surgeries, and ambulation status). Total household income was reported on a 21-point scale, from under $10 000 per year to over $200 000 per year, with increments of $10 000.

Intellectual functioning—Trained research assistants administered the Wechsler Abbreviated Scale of Intelligence.[22] Scores on the Vocabulary and Matrix Reasoning subtests were converted to norm-referenced scores, yielding an estimated Full-scale IQ score. If already administered within the past 2 years, the Full-scale IQ score was extracted from previous camp evaluations or from an ongoing longitudinal study that used the same measures (e.g. Devine et al.[6])

Statistical analysis

Data were analyzed using SPSS for Windows (version 22; IBM Corp., Armonk, NY, USA). Missing data (at the questionnaire level) were handled using listwise deletion. Total change scores were created for each dependent variable by subtracting the preintervention total score at dose 1 from the last collected preintervention total score at dose *n* (where *n* ranged from 2–6) for each participant. For example, a camper attending three times in 2008, 2009, and 2010 would have a medical self-management change score calculated as precamp self-management in 2010 minus precamp self-management in 2008. Preintervention scores at each dose were used in calculating change scores in an effort to maximize the sample size for analyses (because of attrition at the 1-month postintervention assessments). Importantly, this use of preintervention scores produced a very conservative test of our hypotheses.

Dosage (total number of years participating in the intervention) was entered as the independent variable in a series of hierarchical multiple regression analyses to examine the associations between participating in the intervention for multiple years (increased dosage) and changes in health-related and social skills outcomes. Regressions were performed with and without the following covariates: age at dose 1, IQ, and lesion level (a proxy for condition severity). When analyses included covariates, the covariate and independent variables were entered simultaneously (e.g. in a single block). Separate regressions were performed for each outcome variable as well as for parent- and camper-report (when data from both reporters were available). Additional analyses were performed to determine if a curvilinear relationship existed between dosage and the medical self-management and social skills outcomes. However, the results of these analyses were non-significant and, therefore, are not reported here.

To better understand the contribution of typical developmental change (vs the cumulative contribution of camp participation) on the potential gains associated with frequent camp attendance, we conducted univariate analyses of covariance. These analyses included participants with a final dosage of two or three (n=67) and compared campers who attended camp consecutively (n=51) versus those who attended with a gap of at least 1 year (n=16), as repeat camp experiences were a few years after the initial experience for some campers. If

maturation completely accounted for the changes, then the group of non-consecutive attenders would make larger gains than the consecutive attenders in independence in performing spina bifida-related self-management tasks and mastery of these tasks. All analyses included the covariate of camper age at dose 1. These analyses were only run for those outcomes that yielded significance in the original analyses.

RESULTS

Preliminary analyses

All variables were examined for outliers using stem-and-leaf plots, but none were identified. Additionally, all independent and dependent variables were tested for skewness. All variables were found to have acceptable skewness values (e.g. less than 1.0).[23]

Table II presents the demographic characteristics for campers who attended single versus multiple camp sessions. Final dosage for all campers (dosage range 1–6 times) and those included in this study's analyses (dosage range 2–6 times) was not significantly correlated with camper age, Full-scale IQ score, lesion level, type of spina bifida, or family income (r=0.03–0.09, p=0.26–0.68). Additionally, final dosage was not significantly correlated with baseline camper-reported self-management skills or parent-reported condition-related independence or social skills (p=0.08–0.50). On the other hand, baseline parent-report of camper's independence in completing self-management tasks was associated with more frequent camp attendance (r=–0.21, p=0.02); attending camp more frequently was related to lower levels of baseline parent-reported responsibility.

Medical self-management skills

Increased dosage was significantly associated with parent-report of increased camper independence in performing spina bifida related self-management tasks and increased camper mastery of these tasks as well as camper-report of increased independence in performance of spina bifida-related self-management tasks (Table III).

When including the covariates of camper age, IQ, and lesion level, increased dosage was found to be significantly associated with parent-report of increased camper independence in performing spina bifida-related self-management tasks and increased camper mastery of these tasks (Table III). However, when including these covariates, increased dosage was no longer significantly associated with camper-report of increased independence in spina bifida self-management tasks (Table III).

Effect size values (R^2; Table III) suggest moderate practical significance for the effect of dosage on parent-report of camper independence in performing spina bifida-related self-management tasks. However, R^2 values indicate small effects for all other analyses (Table III).

Social skills

Increased dosage was not significantly associated with changes in parent-reported social skills (Table III). When including the covariates of camper age, IQ, and lesion level, dosage

remained non-significant for parent-reported social skills (Table III). Further, effect size values (R^2; Table III) suggest low practice significance (e.g. small effect sizes).

Maturation as an alternative explanation for findings

Changes in parent-report of camper independence in completing medical tasks were found to be significantly different for campers who attended continuously versus those who attended non-continuously (F[1,45]=4.39, p=0.04), such that those campers who had a gap in participation had larger positive changes (M_{change}=0.28) than those who attended continuously (M_{change}=0.10). However, the groups did not differ on camper-reported changes in independence in completing spina bifida-related self-management tasks (F[1,62]=3.89, p=0.053) or parent-reported changes in camper mastery over condition-related tasks (F[1,44]=0.66, p=0.42).

DISCUSSION

Summer camps provide a unique context in which to deliver psychosocial interventions to young people with chronic health conditions, as camps provide access to groups of children with similar conditions and a safe, inclusive, and appealing environment to engage young people in skill building and the development of independence. Indeed, the therapeutic camp literature has nearly doubled in the past decade,[10] adding to the growing evidence-base of the short-term psychosocial benefits of participating in medical illness camps. However, few studies have examined the benefits of repeated exposure to camp-based interventions on health and well-being in any pediatric population. The purpose of our study was to bridge this critical gap in knowledge through the evaluation of the potential benefits of repeated participation in a camp-based intervention targeting medical self-management and social skills in young people with spina bifida.

Individuals with spina bifida tend to achieve lower levels of autonomy compared to their peers and have been shown to be non-adherent (up to 50%) to specific aspects of their medical regimen.[24] Our findings that repeated participation in a camp-based psychosocial intervention is associated with greater gains in both responsibility and competency for medical tasks are encouraging. Indeed, simultaneous growth in medical responsibility and mastery are necessary for optimal disease management.[25] Medical adherence rates can rapidly decrease if the child assumes responsibility for a medical task without first demonstrating competency in this skill.[23–25] Therefore, repeated participation in the intervention may not only be associated with increases in mastery and autonomy, but decreases in deleterious secondary health complications as well. Further, camp participants who first participated at younger ages reported greater gains in health-related independence, which is consistent with recommendations to incorporate life skills training for children with disabilities in treatment plans to support health and functional outcomes through adolescence and adulthood.[26]

Contrary to our hypothesis, repeated participation in the intervention was unrelated to changes in social skills. These findings are similar to our previous work that has shown small to non-significant effects of the intervention on social-related outcomes.[13] It is possible that a more intensive intervention is required to improve the interpersonal skills

deficits in this population. Overall, young people with chronic conditions often benefit socially from attending a condition-specific camp because they achieve an overall sense of belonging and 'normalcy' with peers who have the same condition.[27] However, specific social skills strategies, such as those delivered in our intervention, may not be easily applied or generalized when delivered in a camp setting because it is very different from young people's day-to-day social experiences with their typically developing peers (e.g. in a school setting). Therefore, it is possible that they may also have difficulty building upon their basic skill set, have fewer socially skilled peers who can model prosocial behaviors, or that it may be difficult to demonstrate growth in social skills because of underlying neurocognitive deficits related to social behaviors,[5] accounting for the lack of association between dosage and campers' social skills. Incorporating young people without spina bifida into the group or including a parent training component may help them to translate social skills more easily into their daily lives.[6] Lastly, using different assessment methods of social skills (e.g. direct observation) might have yielded different results. The response styles of parents on the Social Skills Measure used in this study may have been slightly negatively skewed (Table SI); parents of young people with spina bifida may be biased reporters of their child's social skills, friendships, and social status.[5]

The camp setting is inherently distinct from other settings (e.g. day programs, residential facilities, orthopedic rehabilitation programs, support groups) in which groups of young people with spina bifida may participate. Namely, the camp environment's recreational atmosphere, which emphasizes fun activities, friendships, and personal growth,[27] may predispose some young people to be more receptive to interactive, group-based independence-related programming and more motivated to work toward independence goals.[12] Further, campers are removed from more familiar environments (e.g. medical settings, home, school) and care providers (e.g. parents, physicians, physical and occupational therapists);[5,14] the novelty of the camp surroundings and camp caregivers (i.e. counselors) may push young people out of their 'comfort zones' to make strides in health-related independence skills. However, despite these unique features, similar independence interventions likely have utility when adapted to other settings. A pilot study (n=14) of a family-based independence intervention for young people with spina bifida at a children's hospital demonstrated promising findings, although multiple barriers (e.g. busy family schedules, travel time and distance) to participation were noted.[28] Intervention components, including goal-setting and problem-solving, can also be reinforced year-round at routine clinic visits or other health care encounters.[5,10] Still, more research is needed to determine the effectiveness of independence interventions aimed at young people with spina bifida in other settings.

This study is highly novel as it is the first to generate an empirical evidence base for the potential benefits of repeated participation in a camp-based psychosocial intervention. Several other study strengths are notable, including the use of a longitudinal data set, inclusion of multiple reporters, broad age range of participants (across multiple developmental stages), and inclusion of specific outcomes known to be problematic for this population. On the other hand, it is important to interpret these findings in the context of several methodological limitations. First, given the lack of a control group in this study, and in research evaluating camp programs more generally, we cannot rule out the possibility that

the overall camp experience may be responsible for significant effects. Further, it is possible that the sample of individuals with spina bifida who attend camp are different in some way from individuals with spina bifida who do not choose to attend camp. The significant correlation between baseline parent-report of camper medical responsibility and final dosage (such that campers with lower baseline levels of responsibility attended more frequently) indicates that the sample may have been biased towards those campers who had the most to gain from the camp experience. However, this may also be indicative of the perceived effectiveness of the intervention, as parents reporting lower baseline levels of camper independence may enroll their child in camp more frequently because they see that their child continues to benefit from the intervention year after year. Further, the use of listwise deletion may have introduced additional bias in the analyzed sample.

It is also possible that developmental changes over time may be conflated with improvements in campers' medical responsibility and competency. In fact, this study's analyses partially supported the alternate hypothesis that natural development accounted for the increase of camper responsibility for self-management tasks. On the other hand, development alone did not account for findings related to camper self-report of responsibility or parent-report of camper mastery and most of the effects remained significant after controlling for age. Therefore, while it is important to consider the impact of expected developmental change, it is likely that maturation does not solely account for this study's significant findings.

While randomized controlled trials are needed to make robust claims about intervention effects, there are several inherent challenges when attempting to use this type of design within a camp setting, including ethical challenges related to randomizing children with chronic illnesses.[10] Still, consideration of whether the results of this study are due to the intervention versus the overall camp experience, developmental factors, and/or other external factors (as many factors can influence young people during the summer and school year) may be important for the design of future intervention studies. Indeed, investigators have begun to implement creative approaches to conducting randomized controlled trials in a camp setting, such as a recent study that compared children with asthma receiving a problem-solving intervention with those receiving a 'standard cabin chat'.[29]

Moreover, the design of the present study precluded our ability to evaluate the specific components and processes that account for change in campers' self-management. Our camp intervention included several treatment techniques such as goal setting and monitoring, psychoeducation, and specific strategies (e.g. problem solving, communication) to help campers make gains in independent self-management of their condition; it is possible that one or more of these components are necessary or critical ingredients for treatment to improve campers' medical independence and competency. A dismantling approach in which one group receives all components of the treatment, while one or more groups receive variations without all of the components, may help to tease apart which components of our intervention are the most important for campers to make continued gains in medical responsibility and competency.[30] Future work may also examine non-specific intervention factors to optimize intervention efficacy. For instance, it will be important to examine mediators of treatment efficacy (e.g. improvements in self-efficacy, disease knowledge, the

presence of social support and peer role-modeling, time spent away from caregivers) to determine whether these variables may account for the gains in medical self-management.[10] Identifying whether one or all of these processes trigger changes in self-management outcomes will be critical to improving our understanding of camp-based intervention programs for young people with spina bifida.

It is also difficult to disentangle whether our results reflect inherent sample or reporter biases. With respect to sample biases, the results that showed continued improvements in self-management may be driven by ongoing participation of families who are better adapted or who have high levels of motivation and resources to attend camp each summer. But while this study's participants encompassed a range of sociodemographic backgrounds, this is not a population-based sample and should not be considered representative of all individuals with spina bifida. Regarding reporter biases, we found that dose was related to continued improvements in camper self-management according to parent-report, but this effect was non-significant per camper-report after accounting for the covariates. Additionally, we found that analyses using parent-report of camper responsibility indicated greater intervention effects than analyses using corresponding camper-report. Previous research has found similar discrepancies, such that young people generally report more responsibility and competency compared to their parents.[14,31] Thus, it is possible that these results may be explained by a 'ceiling effect', such that campers maintained a high level of self-perceived independence with little response variation across summers. Finally, it will be important to determine whether the statistically significant effects found here also produce clinically significant change that is detectable in campers' everyday medically related behavior, as this study's analyses suggested small-to-moderate effect sizes. Future work may include measures of adherence to provide a more complete picture of the intervention's effects on spina bifida medical management.

The current study represents an important step forward in understanding the potential positive impact of repeated participation in a camp-based psychosocial intervention program on medical self-management for individuals with spina bifida. Camp may be an ideal context in which to teach and practice medical self-management strategies through providing a supportive atmosphere where young people are encouraged by peers, counselors, and medical staff to independently and competently manage their medical regimen without the involvement of daily caregivers. Patient-centered research designs incorporating child/parent focus groups and mixed methods data collection (i.e. qualitative and quantitative measures) could be useful in identifying barriers and facilitators to acquiring self-management and social skills via camp-based interventions, particularly for those who have repeatedly participated in the program. Overall, innovative interventions, including experimental or multi-arm designs, should be piloted within the camp setting to enhance our understanding of the efficacy and mechanisms of camp-based psychosocial treatments for this population and other pediatric medical illnesses. This work may represent an optimal path forward to inform and tailor camp-based psychosocial treatments designed to maximize health and well-being in young people with chronic pediatric conditions, including individuals with spina bifida.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGEMENTS

This work was supported in part by a research grant from the Kiwanis Neuroscience Research Foundation: Illinois-Eastern Iowa District of Kiwanis International.

The authors would like to thank Kiwanis Neuroscience Research Foundation: Illinois-Eastern Iowa District of Kiwanis International, Camp Independence, YMCA Camp Duncan, the Illinois Spina Bifida Association, and the undergraduate and graduate research assistants who assisted with camp procedures and data management. The authors would also like to extend their appreciation to the campers and parents who contributed their time and effort to this study. The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

REFERENCES

1. National Birth Defects Prevention Network. Prevalence of spina bifida and anencephaly before and after folic acid fortification, NBDPN Neural Tube Defect Ascertainment Project; 1995–2006 [Internet]. Available at: http://www.nbdpn.org/current/2010pdf/NTD%20fact%20sheet%2001-10%20for%20website.pdf (accessed 1 January 2017).
2. Cascio DP, Ries JK. Spina bifida In: Castillo CL, editor. Children with Complex Medical Issues in Schools: Neuropsychological Descriptions and Interventions. New York: Springer, 2008: 435–56.
3. Copp AJ, Adzick NS, Chitty LS, Fletcher JM, Holmbeck GN, Shaw GM. Spina bifida. Nat Rev Dis Primers 2015; 1: 15007.
4. Dicianno BE, Kurowski BG, Yang JM, et al. Rehabilitation and medical management of the adult with spina bifida. Am J Phys Med Rehabil 2008; 87: 1027–50. [PubMed: 18923330]
5. Holbein CE, Lennon JM, Kolbuck VD, Zebracki K,Roache CR, Holmbeck GN. Observed differences in social behaviors exhibited in peer interactions between youth with spina bifida and their peers: neuropsychological correlates. J Pediatr Psychol 2015; 40: 320–35. [PubMed: 25427551]
6. Devine KA, Holmbeck GN, Gayes L, Purnell JQ. Friendships of children and adolescents with spina bifida: social adjustment, social performance, and social skills. J Pediatr Psychol 2012; 37: 220–31. [PubMed: 21930663]
7. Kingsnorth S, Healy H, Macarthur C. Preparing foradulthood: a systematic review of life skill programs for youth with physical disabilities. J Adolesc Health 2007; 41: 323–32. [PubMed: 17875457]
8. King G, McPherson A, Kingsnorth S, et al. Residentialimmersive life skills programs for youth with disabilities: service providers' perceptions of experiential benefits and keyprogramfeatures. Disabil Rehabil 2015; 37: 971–80. [PubMed: 25136941]
9. McPherson AC, King G, Rudzik A, et al. Optimizinglife success through residential immersive life skills programs for youth with disabilities: study protocol of a mixed-methods, prospective, comparative cohort study. BMC Pediatr 2016; 16: 153. [PubMed: 27600167]
10. Moola FJ, Faulkner GEJ, White L, Kirsh JA. The psychological and social impact of camp for children with chronic illnesses: a systematic review update. Child Care Health Dev 2013; 40: 615–31.
11. Odar C, Canter KS, Roberts MC. Relationship betweencamp attendance and self-perceptions in children with chronic health conditions: a meta-analysis. J Pediatr Psychol 2013; 38: 398–411. [PubMed: 23381729]
12. Woods K, Mayes S, Bartley E, Fedele D, Ryan J. An evaluation of psychosocial outcomes for children and adolescents attending a summer camp for youth with chronic illness. Child Health Care 2013; 42: 85–98.
13. O'Mahar K, Holmbeck GN, Jandasek B, Zukerman J. Acamp-based intervention targeting independence among individuals with spina bifida. J Pediatr Psychol 2009; 35: 848–56. [PubMed: 20026569]

14. Holbein CE, Murray CB, Psihogios AM, et al. A camp-based psychosocial intervention to promote independence and social function in individuals with spina bifida: moderators of treatment effectiveness. J Pediatr Psychol 2013; 38: 412–24. [PubMed: 23435204]
15. American Camp Association. Camper enrollment report2017. Available at: https://www.acacamps.org/sites/default/files/resource_library/2017_CamperEnrollmentReport.pdf (accessed 2 February 2018).
16. Rose BM, Holmbeck GN. Attention and executive functions in adolescents with spina bifida. J Pediatr Psychol 2007; 32: 983–94. [PubMed: 17556398]
17. Zabel TA, Jacobson LA, Zachik C, Levey E, Kinsman S, Mahone EM Parent- and self-ratings of executive functions in adolescents and young adults with spina bifida. Clin Neuropsychol 2011; 25: 926–41. [PubMed: 21955110]
18. Anderson BJ, Auslander WF, Jung KC, Miller JP, Santiago JV. Assessing family sharing of diabetes responsibilities. J Pediatr Psychol 1990; 15: 477–92. [PubMed: 2258796]
19. Wysocki T, Meinhold PM, Taylor A, et al. Psychometric properties and normative data for the parent version of the Diabetes Independence Survey. Diabetes Educ 1996; 22: 587–91. [PubMed: 8970288]
20. McLone DG, Ito J. An Introduction to Spina Bifida. Chicago, IL: Children's Memorial Spina Bifida Team, 1998.
21. Wills KE. Neurocognitive functioning in children withs pina bifida and/or hydrocephalus. J Clin Child Adolesc Psychol 1993; 22: 247–65.
22. Wechsler D Wechsler Abbreviated Scales of Intelligence (WASI). San Antonio: Psychological Corporation, 1999.
23. Tabachnick BG, Fidell LS. Using Multivariate Statistics. 6th edn Boston: Pearson, 2013.
24. Psihogios AM, Kolbuck V, Holmbeck GN. Condition self-management in pediatric spina bifida: a longitudinal investigation of medical adherence, responsibility-sharing, and independence skills. J Pediatr Psychol 2015; 40: 790–803. [PubMed: 26002195]
25. Wiebe DJ, Chow CM, Palmer DL, et al. Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence. J Pediatr Psychol 2014; 39: 532–41. [PubMed: 24602891]
26. Committee on Improving Health Outcomes for Children with Disabilities. Opportunities for Improving Programs and Services for Children with Disabilities. Washington, DC: The National Academies Press, 2018.
27. Gillard A, Allsop J. Camp experiences in the lives of adolescents with serious illnesses. Child Youth Serv Rev 2016; 65: 112–9.
28. Greenley RN. A family intervention to enhance involvement in condition management of youth with spina bifida: a pilot study. First World Congress on Spina Bifida; 2009; Orlando, FL.
29. Pulgaron ER, Salamon KS, Patterson CA, Barakat LP. A problem-solving intervention for children with persistent asthma: a pilot of a randomized trial at a pediatric summer camp. J Asthma 2010; 47: 1031–9. [PubMed: 20858029]
30. Kazdin AE. Mediators and mechanisms of change in psychotherapy research. Ann Rev Clin Psych 2007; 3: 1–27.
31. Psihogios AM, Holmbeck GN. Discrepancies in mother and child perceptions of spina bifida medical responsibilities during the transition to adolescence: associations with family conflict and medical adherence. J Pediatr Psychol 2013; 38: 859–70. [PubMed: 23843631]

What this paper adds

- Participating in an intervention over multiple summers is associated with increases in campers' responsibility for spina bifida-related tasks.
- Repeated summer camp intervention participation is associated with improved mastery over condition-related tasks for campers with spina bifida.
- Repeated camp intervention participation is not associated with changes in social skills for campers with spina bifida.

Table I:

Sample demographics and condition-specific characteristics (*n*=110)

	%	*n*
Sex (female)	60	66
Ethnic group		
African American	14	15
Asian American	6	7
White	56	61
Latino	20	22
Other/multiethnicity	5	5
Type of spina bifida		
Myelomeningocele	87	96
Lipomeningocele/meningocele	6	6
Occulta	1	1
Unknown or uncertain	6	7
Lesion level		
Sacral	18	20
Lumbar	58	64
Thoracic	13	14
Unknown	11	12
Shunt status (present)	89	95
	Mean (SD)	*n*
Age, y:mo (range: 6–32y)	14:7 (6:1)	110
Yearly family income	7.51 (5.21)	88[a]
Full-scale IQ score	82.51 (18.39)	101[a]

Yearly family income was reported on a 21-point scale, from <$10 000 per year to >$200 000 per year, with each point on the scale representing increments of $10 000. For this sample, family income ranged from <$10 000 to >$200 000+ per year with a mean of ~$65 000 and a standard deviation of ~$50 200.

[a]Sample size is reduced for these characteristics because of missing data/assessments.

Table II:

Demographic and condition-specific characteristics for participants who attended single (*n*=79) versus multiple (*n*=110) camp sessions

	Final dosage=1	Final dosage >1
Sex (Female)	65%	60%
Ethnic group (non-white)	32%	45%
Type of spina bifida (myelomeningocele)	71%	87%
Lesion level		
Sacral	13%	18%
Lumbar	56%	58%
Thoracic	5%	13%
Unknown	26%	11%
	Mean (range)	Mean (range)
Age (y:mo)	16:5 (7–41y)	14:6 (6–32y)
Yearly family income	7.87 (2–21)	7.50 (1–21)
Full-scale IQ score	83.1 (55–121)	82.5 (55–121)

Yearly family income was reported on a 21-point scale, from <$10 000 per year to >$200 000 per year, with each point on the scale representing increments of $10 000. For this sample, family income ranged from <$10 000 to >$200 000 per year with a mean of ~$65 000 and a standard deviation of ~$50 200.

Table III:

Summary of hierarchical multiple regression analyses for associations between dosage and changes in camper- and parent-report of medical self-management and social skills outcomes with and without covariates

	Camper-report						Parent-report					
Outcome	***n***	***b***	**95% CI**	***β***	R^2	***p***	***n***	***b***	**95% CI**	***β***	R^2	***p***
Without covariates												
SOSBMR	104	0.06	0.01, 0.11	0.20	0.04	0.04	77	0.14	0.07, 0.16	0.50	0.25	0.00
SBIS	–	–	–	–	–	–	75	1.86	0.61, 3.11	0.33	0.11	0.00
Social skills	–	–	–	–	–	–	77	0.05	–0.04, 0.14	0.13	0.02	0.26
With covariates												
SOSBMR	84	0.05	–0.01, 0.11	0.18	0.14	0.09	63	0.12	0.07, 0.17	0.51	0.34	0.00
SBIS	–	–	–	–	–	–	61	1.76	0.44, 3.08	0.33	0.18	0.01
Social skills	–	–	–	–	–	–	63	0.03	–0.07, 0.13	0.09	0.05	0.52

For campers >18y, parent-report was not collected. CI, confidence interval for *b*; SOSBMR, Sharing of Spina Bifida Management Responsibilities questionnaire; SBIS, Spina Bifida Independence Survey.