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Sense of mastery and attitude towards illness: Examining longitudinal benefits of a medical specialty camp for youth with sickle cell disease

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Abstract

Medical specialty camps can play an important role in the positive development of psychosocial outcomes for children and youth with sickle cell disease (SCD). This study examined how sense of mastery and attitude towards illness outcomes changed over 6 months for 100 campers aged 8–16 years with SCD. The outcomes were measured twice before and twice after camp. Latent growth curve modeling was used to analyze data. Results showed no changes in the outcomes for this study population. Implications for future research designs, populations, and outcomes are discussed, as are implications for communications about camp, and policy and practice.

Keywords

summer camp, sickle cell disease, resilience, multisite, longitudinal

Introduction

Sickle cell disease (SCD) is a hereditary life-long illness affecting red blood cells that "sickle" or deform from the usual biconcave disc to a crescent shape. This change impairs the cells' ability to

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pass through blood vessels and leads to severe anemia. The resultant effects are episodes of severe pain and other serious problems such as infections and damage to many organs including the lungs, heart, liver, brain, and others. SCD affects around 100,000 people in the United States and millions of people throughout the world and is particularly common among people whose ancestors came from sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere, Saudi Arabia, India, and Mediterranean countries (https://www.cdc.gov/ncbddd/sicklecell/data.html).

Children and youth with SCD face medical challenges such as managing chronic and acute pain, cerebrovascular events, and neurocognitive difficulties (Helps et al., 2003). Sickle cell disease is characterized by recurrent, acute, and chronic pain, often requiring emergency management and hospitalization (Benton et al., 2007). Psychosocial problems include poor self-concept, social adjustment problems, behavior problems, and symptoms of depression, anxiety, and pica (Benton et al., 2007).

Limited evidence has examined non-medical programs to provide help and support as children and their families manage this complex illness. Programs to support an optimistic or hopeful outlook and improve adherence to recommendations for medical management of SCD pain may result in improved resilience and adaptive behavior (Ziadni et al., 2011). However, few studies exist regarding the efficacy of recreational programs for children with SCD.

Literature review

Resilience, sense of mastery, and attitude toward illness

Resilience can be defined as the ability to bounce back after encountering difficulty. Resilience factors include facing fear, optimism, and the presence of social support (Southwick & Charney, 2012). Living with a serious and lifelong illness such as SCD requires resilience. For children and youth living with SCD, resilience could be enhanced by their having a sense of mastery and a positive attitude toward the illness.

Prince-Embury's conceptualization of sense of mastery in resilience includes sub-components of optimism, self-efficacy, and adaptability (Prince-Embury, 2007, 2008). A sense of mastery is relevant for children and youth living with SCD because feeling in control is important when living with an illness that requires constant vigilance to stay healthy.

Another component of resilience for youth living with illnesses is their attitude towards the illness. This reflects how favorably or unfavorably children feel about having a chronic physical condition (Austin & Huberty, 1993). A systematic review of the literature on children's attitude towards illness found attitudes toward illness to be reliably associated with internalizing and externalizing symptoms and with self-efficacy for disease management (Ramsey et al., 2016). Attitude towards illness is relevant for children and youth living with SCD because having a positive attitude about life with SCD could contribute to resilience.

Sense of mastery and attitude toward illness are two of many psychosocial outcomes that can possibly be influenced by participation in recreational programs. Resilience is also associated with coping strategies and hope, and programs promoting hopeful outlooks can result in increased adaptive behaviors for youth with SCD (Ziadni et al., 2011). Such programs for children and youth with SCD could be designed to provide opportunities to build resilience. However, less is known about programs aiming to promote resilience, but rely on unstructured approaches rather than formal educational sessions.

Camp

Professionals serving youth with chronic and serious illnesses have long advocated that because of their life situations, these youth can benefit from supported camp experiences (Goodwin & Staples, 2005; Klee et al., 1997). Many descriptive, exploratory, and quasi-experimental studies have found positive outcomes associated with camp such as improved self-perceptions for children with a variety of illnesses (Odar et al., 2013), improved social connections for youth with HIV/AIDS (Gillard et al., 2011), and improved attitude toward illness for children with epilepsy and asthma (Austin & Huberty, 1993). Such changes are encouraging, given that children typically attend camp for only a few or several days, suggesting that camp can be a peak experience of intensity and profound significance (Maslow, 1962).

Still, limited research exists on camps for youth with SCD. In a qualitative study involving children with various kinds of illnesses including SCD, researchers found that campers with SCD specifically perceived camp as a place for enjoyment, positive interactions with adult staff, "being myself," personal growth, and escape (Gillard & Allsop, 2016). In another study of campers with various kinds of serious illnesses including SCD, hope and goal-directed behaviors contributed to psychosocial functioning following a camp experience for all campers (Woods et al., 2013). However, in a different study of campers with various illnesses including SCD, no significant changes were found in attitude toward illness or perceptions of illness benefit or burden (Faith et al., 2019). One case description of medical support and programming for youth with SCD at a remote and physically challenging camp site reported SCD-related medical problems occurred in 10% of the children and episodes of SCD-related illness increased during the year when the camp was held at a site at a higher elevation (Powars & Brown, 1990). However, to our knowledge no research exists specifically on camp for children with SCD.

Study purpose and contribution

Despite evidence of MSCs as catalysts for psychosocial growth and improved attitudes towards illness, very little longitudinal research is present within the extant literature establishing if these changes are sustained beyond the camp experience. Given this gap in the literature, the present study examined how sense of mastery and attitudes towards illness changed over a 6-month period for a sample of children and youth with SCD.

Understanding potential changes in children's attitudes towards illness and sense of mastery after participating in a MSC is important in considering the overall resilience and quality of life of children and youth with SCD and how programs such as camp can play a role. The following study examined how sense of mastery and attitude toward illness changed over time in 100 children and youth with SCD who attended a medical specialty camp.

Methods

Setting and background

The setting for this study was The Hole in the Wall Gang Camp (Hole in the Wall), located in northeast Connecticut. During the time of this study, Hole in the Wall served around 1000 children aged 7–15 years living with serious illnesses in its free-of-charge summer camp program. The summer program was a medically-supported recreational and residential 7-day camp experience; no formal educational or informational sessions about illness were held. Children engaged in

traditional camp activities such as arts and crafts, swimming, talent shows, and more, all while being carefully medically supervised by physicians, nurse practitioners, and registered nurses skilled in the care of children with SCD. Special considerations for campers with SCD involved close adult supervision to ensure hydration and temperature control because extremes of temperature can trigger pain and other complications in children with SCD. For example, many campers with SCD used the outdoor pool, and could dry off in a warming hut to avoid becoming chilled after swimming. Medical care involved monitoring and treating pain and fatigue.

Children were predominantly referred to the camp by healthcare providers such as nurses, pediatric hematologists, child life specialists, and social workers at the regional pediatric sickle cell programs where they received their care. Healthcare providers told children and their families about camp, coordinated with camp staff to submit applications (including extensive medical information), helped children and their families prepare for camp, and helped arrange transportation to camp via bus departing from their local hospital program or (less commonly) via family transportation. Many healthcare providers also volunteered at Hole in the Wall.

In the Northeast region of the United States, healthcare providers involved with the care of children with SCD meet regularly through the New England Pediatric Sickle Cell Consortium to collaborate on clinical care, advocacy, and other initiatives. Through these meetings, a gap in the understanding about the potential impacts of camp on patients living with SCD was discussed. A longitudinal study examining campers' resilience (sense of mastery) and attitude toward illness was designed. The outcomes of "sense of mastery" and "attitude toward illness" were selected because these were two areas that the camp-experienced health care providers identified as possibly changing after children with SCD spend time at Hole in the Wall. Through discussions at meetings of the New England Pediatric Sickle Cell Consortium and after determining which regional hospitals referred a large number of patients to Hole in the Wall, we selected as participating institutions Yale-New Haven Hospital, Boston Children's Hospital, Boston Medical Center, Connecticut Children's Medical Center, and Hasbro Children's Hospital. Yale-New Haven Hospital served as the multi-site coordinating center for the study and the Institutional Review Boards (IRBs) of all five hospitals approved the study.

Participants

Characteristics. The study sample consisted of children with SCD aged 8–15, who could read and communicate in English. Study participants were selected by healthcare providers at participating hospitals to attend the camp. Although not a focus of the present study, approximately one-third of campers had never before attended camp. Anecdotally, staff within the five hospitals and clinics had different approaches to inviting patients to attend camp, with some using camp as a "reward" for meeting goals and others using camp as encouragement to improve health behaviors or social connections.

SCD severity was assessed through chart review by a team of medical professionals including a pediatrician and two nurses. Severe designation criteria included any genotype, "frequent" VOC (>2 hospitalizations/year), CVA, multiple acute chest syndrome (ACS) episodes, and more than 2 significant complications. Moderate designation criteria included severe genotype (SS or S-Beta 0 thal) and minimal complications (1 ACS, <2 VOC hospitalizations/year), and mild genotype (SC, S-Beta + thal) with 1–2 complications. Mild designation criteria included any genotype with no complications.

Procedure. Healthcare providers at each of the five hospitals in this study introduced the study to children and their parents/caregivers during late winter and spring of 2019, as part of routine visits or treatments for their SCD. During the process of introducing the camp to patients and their caregivers, providers also invited children to participate in this study through child assent forms and parent/caregiver consent forms. After assent and consent were obtained, campers completed the first survey as a paper questionnaire at their hospital or clinic visit acting as a pre-camp assessment of the study variables (described in the proceeding measures section). Campers completed the second survey instrument on their first day at camp. Finally, children completed the final survey instrument after competition of their camp experience. Approximately 6 months after the end of camp, campers were invited to a social event at their respective hospitals and asked at that time to complete the fourth survey. Campers who could not attend the event were mailed surveys with a self-addressed, stamped, return envelope. However, many campers were unreachable by camp several months after their attendance. To incentivize participation in the study, campers received a $5 gift card for each survey they completed.

Measures

Sense of mastery. One of three scales in the Resiliency Scales for Youth and Adolescents, the Sense of Mastery Scale (SOM) consists of 20 items and is a self-report designed for children and youth aged 9–18 (Prince-Embury, 2007). The SOM scale measures optimism, self-efficacy, and adaptability. Response options are ordered on a 5-point Likert-type scale from never to almost always. According to Prince-Embury (2007), in samples of children aged 9–18 in three age-bands, alpha coefficients for SOM ranged from .85–.95 (.77–.89 for self-efficacy, .69–.91 for optimism, and .56–.82 for adaptability). Associations were found between SOM and negative psychological symptoms (Prince-Embury, 2008).

Child attitude toward illness. The Child Attitude Toward Illness Scale (CATIS) assesses how favorably or unfavorably children feel about having a chronic physical condition (Austin & Huberty, 1993). The CATIS consists of 13 items and has been identified as a reliable and valid self-report assessment tool across chronic illnesses (Ramsey et al., 2016). Response options are provided on a 5-point scale using opposing adjectives (e.g., very good to very bad, very sad to very happy). The survey administrator must alter each item so that children can respond with respect to their specific illness. In this study, the items were altered to include the term "sickle cell disease." Although originally developed for children aged 8–12, the CATIS has demonstrated reliability and validity in youth aged 8–22. According to Ramsey et al. (2016), the CATIS has demonstrated adequate to excellent internal consistency (.77–.90) and adequate test–retest reliability over a two- or 4-week period (r = .77 and .80). Further, the CATIS has demonstrated construct validity through strong associations with behavior problems, depression, self-esteem, and self-efficacy for managing illness.

Data analyses

Prior to analyses, the data were screened for missingness across the four measured waves. As illustrated in Table 1, there were no missing questionnaires for Time 1, but there was a marked decline in the ratio of complete to incomplete measures at Time 4, where 44% of respondents did not complete the final questionnaire. To avoid the requisite consequences of the relatively high level(s) of missing data (i.e., listwise deletion and biased standard errors) an expectation maximization (EM)

Table 1. Number of completed/versus incomplete questionnaire per measurement.

	Time 1	Time 2	Time 3	Time 4
Completed	100	98	96	66
Incomplete	0	2	4	44

imputation technique was utilized to impute missing data across the four measured waves. Specifically, the data were imputed dependent on wave level characteristics utilizing EQS 6.3 software (Byrne, 2006). The EM approach to manage the missing data was selected as it reduces the potential for Type 1 or 2 error associated with deletion-based family of missing data techniques.

After screening and managing missingness, the data were screened for participant level nonnormality utilizing a combination of Mahalanobis distance and the chi-square distribution ($p < .001$) function in SPSS 27 software, which suggested there were no highly unusual cases in the data set (i.e., outliers). Next the data were screened for multivariate nonnormality utilizing the MVN package (version 5.8; Korkmaz et al., 2014). This analysis indicated the data were not multivariate normal (Mardia kurtosis = 5.21, $p < .001$). As such, techniques robust to this nonnormality were selected to analyze the data (e.g., Bootstrapped Standard Errors, Robust Maximum Likelihood).

The primacy of study hypotheses was concerned with change over time, relative to potential covariates. Additionally, given the four measurement occasions several families of analyses were available. Given the latent nature of the data, a latent growth curve model (LGCM) was employed as the potential analysis as it would allow for all variables to be included in one model, versus other techniques which might require several tests, thus inflating potential rates of Type 1 error.

Both the CATIS and SOM scales were composited following the scale guidelines (i.e., Prince-Embury, 2007; Ramsey et al., 2016) for this longitudinal analysis. Specifically, the CATIS scale was transformed into a single factor by summing and dividing the 13 items (i.e., item 1 + item 2…+ item 13/13). Similarly, the SOM scale is reflective of three summed subscales (1. Optimism, 2. Self-Efficacy, and 3. Adaptability) which were also summed to create age dependent scores of SOM (see also Prince-Embury, 2007). After items were transformed into composite scores, hypothesis testing utilized LGCM.

Results

Study participants

Data regarding attitudes towards illness and sense of mastery were collected from 129 potential campers at Time 1 of the study in the months before the start of camp. Of the 129 campers enrolled in the study, 100 actually attended camp. The reasons for the 29 campers not attending camp were variable (e.g., changed mind about going to camp, summer school requirements, health-related factors) and beyond the scope of the present study. As such these 29 were removed from the analyses. Participants were an average of 13.05 years old (SD = 1.94 years, Range = 8.54–16.38 years). Regarding the SCD severity of the 100 study participants, 21 were classified as mild (21%), 38 were classified as moderate (38%), and 41 were classified as severe (41%). SCD severity averaged 2.20 (SD = .765).

Table 2. Latent growth curve model of model parameters.

	Model 1	Model 2	Model 3	Model 4	Model 5
CATIS model parameters					
Intercept mean	3.347 (*SE* = .030)	3.347 (*SE* = .049)	3.365 (*SE* = .046)	3.297 (*SE* = .064)	3.295 (*SE* = .066)
Intercept variance	X	.202	.200	.305	.313
Residual variance	.36	.158	.179	.154	.241, .091, .120, .271
Slope mean	X	X	X	.033 (*p* = .065)	.038 (*p* = .021)
Slope variance	X	X	−.010 (*SE* = .003)	.002 (*SE* = .006; *p* = .751)	−.018 (*SE* = .006; *p* = .006)
Covariance	X	X		−.035 (*SE* = .015; *p* = .018)	−.011 (*SE* = .015, *p* = .480)
SOM model parameters					
Intercept mean	2.814 (SE = .023)	2.814 (SE = .036)	2.813 (SE = .036)	2.845 (SE = .044)	2.853 (se = .044)
Intercept variance	X	.097	.098	.110	.111
Residual variance	.216	.119	.120	.116	.138, .089, .142, .098
Slope mean	X	X	X	−.021 (SE = .016, *p* = .181)	−.025 (SE = .016, *p* = .111)
Slope variance	X	X	−.000 (SE = .003)	.001 (SE = .004)	.001 (SE = .005)
Covariance	X	X	0	−.005 (SE = .009, *p* = .554)	−.007 (SE = .010, *p* = .782

Note: Model 1 is most restrictive; Model 5 is least restrictive.

Latent growth curve model construction

As part of the LGCM process, five separate models were conducted from the most restrictive condition to the least restrictive condition. Additionally, the analyses were conducted with change in CATIS and change in SOM separately to reduce potential error in interpretation (i.e., collinearity).

As illustrated in Table 2, from model 1 to model 2 we see a significant reduction in the residual variance in both CATIS and SOM (.360–.158 in CATIS; .216 to .119 in SOM). This is because we can partly explain the error (i.e., residual variance) with the addition of intercept variance (which was not available in model 1). From model 1 to model 2 we also see a significant change (.202 for CATIS; .097 for SOM) in intercept variance, indicating respondents increased the respective value from the mean value (3.347 for CATIS; 2.814 for SOM). Next from model 2 to model 3, we see a slight increase in the mean and residual values for CATIS score (slope variance = −.010, *SE* = .003). Indicating that the slope was primarily flat; conversely, we see no meaningful change in slope variance for SOM score (slope variance = .000; *SE* = .003).

From model 3 to model 4 we see a decline in the mean and residual variance for CATIS score, but a moderate increase in the intercept variance (.200–.305). The low slope mean (.033) and low slope variance (.002), suggest the slopes did not change in an atypical manner. Our relatively low slope mean and negative covariance between the intercept and slope ($\beta = -.035$, $p = .018$) suggest that the higher someone is on CATIS, the flatter their slope is over time. Put differently, campers who started high on the CATIS grew slower than campers who started lower on CATIS. The slope mean for model 5 was .038 ($p = .021$) indicating that on average, scores in CATIS increased by .038 units

Table 3. Latent growth curve model of CATIS and SOM model fit.

	Model 1	Model 2	Model 3	Model 4	Model 5
CATIS model Fit(s)					
χ^2 (*DF*)	207.864 (12)	60.005 (11)	53.917 (10)	41.858 (8)	27.640 (5)
RMSEA	.404	.211	.210	.206	.213
SRMR	.401	.201	.150	.127	.240
CFI	.000	.745	.771	.824	.882
Change in CFI	n/a	.745***	.026**	.053**	.058**
SOM model Fit(s)					
χ^2 (*DF*)	137.781 (12)	43.864 (11)	43.845 (10)	41.592 (8)	36.004 (5)
RMSEA	.324	.173	.184	.205	.249
SRMR	.343	.196	.194	.185	.159
CFI	.000	.719	.711	.713	.735
Change in CFI	n/a	.719***	−.008	.002	.022**

Note: χ^2 = Chi Square; DF = Degrees of Freedom; RMSEA = Root Mean Squared Error of Approximation; SRMR = Standardized Root Mean Square Residual; CFI = Comparative Fit Index; *indicates $p < .05$; **indicates $p < .01$; ***indicates $p < .001$.

between each of the four time periods. In effect, the shift from model 1 to model 5 suggests there were small positive significant changes in CATIS score over time.

LGCM results

While the LGCM results for CATIS score suggest some positive change for respondents with a lower starting score (i.e., lower intercept), the same result was not evidenced in the analyses of the SOM data. More specifically, from model 3 to model 4 we see a nonsignificant increase in the mean and a slight decrease in residual variance, but a moderate increase in the intercept variance (.098–.110). The low slope mean (−.021) and low slope variance (.001), suggest the slopes were not changing in an uncharacteristic manner. Our relatively low slope mean (−.021) and negative covariance between the intercept and slope (−.005, $p = .554$) suggests there was no relation between where someone started on their SOM score (i.e., pre-camp level) and their slope (i.e., change in SOM over time). Moreover, the slope mean for model 5 was non-significant, indicating no change across the 4 waves of data collection in SOM scores.

Despite evidence of significant growth in CATIS, it must be contextualized within the relatively poor model fits demonstrated in Table 3, where model fits should markedly improve from model 1 to model 4, but not significantly improve from model 4 to model 5. Yet, as demonstrated in Table 3 only the first threshold was met, where model fits significantly ($p < .05$) improved from model 1 to model 4. However, the transition between model 4 and model 5 suggests even more room for model improvement (e.g., *CFI* = .824 to .882). The only difference between model 4 and 5 relates to the residuals (i.e., model error) being restricted (model 4) to unrestricted (model 5). The improvement in model fit demonstrated in model 5 suggests the residuals were significantly uneven across the four measurement occasions, and this bears out in the LGCM analyses (variances of Time 1 = .241, Time 2 = .091, Time 3 = .120, Time 4 = .271). These uneven residuals suggest potential differences across time points were not due to time, but rather due to

measurement error. Indeed, this error was easily contextualized within the setting where data were collected, (camp at Time 2 and Time 3) and the less consistent environments at Time 1 and Time 4.

As indicated in Table 3, similar issues with the residuals emerged in the analyses of the SOM data. Indeed, the model fit indices were substantially worse in SOM analyses; moreover, the data did not suggest any significant change overtime within the overall SOM score. Given the lack of demonstrated growth across CATIS and SOM in combination with the poor model fits illustrated in Table 3, the additional exploration of the data (e.g., the addition of covariates) in the poor model fit would only compound potential type 1 error associated with the inclusion of additional variables (i.e., finding effects when there are none).

Discussion

This study examined children's sense of mastery and attitudes towards illness over a 6-month period for a sample of children and youth with SCD who attended an overnight medical specialty summer camp. Results showed no change in study participants' sense of mastery or attitude toward illness.

Multiple complementary explanations exist for the lack of change over time. Given the relatively high "starting scores" (i.e., intercept means, see Table 2), improvement over time might not be possible due to ceiling effects. Scores might have been high at Time 1 due to children wanting to be "good patients" in the presence of their healthcare providers, as they typically completed the surveys in their hospitals or clinics. Alternatively, it could be the case that camp, as a program for the sample in this study, was not quantitatively influential in the measured dimensions.

A critical limitation of this study is low sample size. Indeed, within the present study a longitudinal approach was employed to counteract the potentially low sample size. However, the relatively high attrition over the four measured waves in the study could indicate the study sampling strategy must be more robust and consistent in future investigations. The sample size did not allow for deeper exploration of subsample differences (i.e., SCD severity, previous camp experience). Rather than attempting to collect data from more campers with SCD, future research could involve collecting data from campers with other serious illnesses to determine if or how the rate of change differs across these illness specific subgroups. With the addition of comparison data, it would be possible to examine both inter-individual levels of change and factors which promote change across and within groups, in addition to collecting data about other potential variables such as health behaviors. Doing so could inform recruitment of participants in programs such as camp and allow for more robust analyses of non-respondents.

Qualitative and mixed methods research could illustrate other potential changes or benefits realized by campers with SCD, such as changes in feelings of belonging or social connections (Devine et al., 2015; Gillard et al., 2011; Knapp et al., 2015). Open-ended questions to elicit campers' perspectives of how they changed after camp could offer more insights. Inclusion of qualitative data and analysis in a mixed methods study could further understanding of the potential nuance and disconnections that might emerge in quantitative data and analysis (Pluye & Hong, 2014). Future research could also include reports on campers made by their parents/caregivers or healthcare providers because these stakeholders might observe changes that children and youth do not observe in themselves.

Although "sense of mastery" and "attitude toward illness" were identified by the investigators as important outcomes for campers with SCD, these two outcomes were not commonly referred to in the program logic model, communications with potential campers or their families, or intentionally programmed for or educated about in the camp setting studied for this project. Still, these outcomes were perceived by the investigators as likely to occur through informal communications and

interactions between campers and between campers and medical staff as they reflected on their peak experience at camp. Adult perceptions may not fit those of the campers, and such perceptions may change as campers grow up. Further, due to SCD being a lifelong, chronic condition, a week at camp might not be long enough to affect the two specific outcomes of sense of mastery and attitude toward illness. Practitioners should consider if improving campers' sense of mastery and attitude toward illness are desired outcomes of the camp experience or if there are other more intentional goals.

An alternative explanation for the lack of change over time could be that improvements in attitude toward illness and sense of mastery were not the primary outcomes of attending camp. Indeed, campers were asked to rate how fun camp was and overwhelmingly rated their experience as "a lot of fun." It could be that considering the relatively intensive nature of their illness, fun can be more important to children than building resilience to cope with SCD. However, being able to have fun could be an indicator of resilience and mastery. Given Hole in the Wall's focus on providing medically supported recreational activities (i.e., "fun"), the outcomes of "escape" or "respite from illness" could be more relevant outcomes for the lived experiences of this population of children with SCD, as found in other research at this camp (Gillard & Allsop, 2016). This study could be replicated at other medical specialty camps that have structured educational programming about illness.

Implications

The sense of mastery and attitude toward illness aspects of resilience were deemed important by stakeholders in this study. This study suggests some adjustments in stakeholders' understanding and communications about the potential outcomes of camp. For example, communications about camp with potential campers and their families should avoid mention of improvements in sense of mastery and attitude toward illness for children with SCD, at least until future studies can examine these outcomes as discussed above. Camp professionals and healthcare practitioners should reflect on intended outcomes of camp, and how these outcomes come to be, such as through development and refinement of logic models or theories of change.

Conclusion

Reporting null results is a challenge for research teams. Practitioners and researchers want to see evidence of their hard work reflected in positive outcomes for children and youth. This study did not show evidence of increases in sense of mastery and attitude toward illness for a sample of campers with sickle cell disease. Rather than dwelling on null results, these data serve as an opportunity to reflect on the research questions driving this study and to use the results to grow and improve both in research and practice around recreational programs for children with SCD. Doing so can avoid the "file drawer problem" that leads to publication bias. In a review of high-quality social science studies, strong results were 40% points more likely to be published than null results and 60% points more likely to be written up (Franco et al., 2014). The results from this study are shared in the spirit of combating this bias.

This study contributes to knowledge of the role of camps for children and youth with serious illnesses. Further, lessons from this study can support camp professionals, healthcare providers, and youth researchers in their efforts to learn more about recreation-based programs for children and youth with serious illnesses such as SCD.

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