Research in Outdoor Education

Volume 12 Article 4

2014

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Recommended Citation
Griswold, Michael; Hegarty, C. Boyd; Harrist, Chris; Trauntvein, Nate; and Griswold, David (2014) "Exploring the Social Impacts of a Summer Camp for Youth With Tourette Syndrome," *Research in Outdoor Education*: Vol. 12 , Article 4.
DOI: 10.1353/roe.2014.0002
Available at: https://digitalcommons.cortland.edu/reseoutded/vol12/iss1/4

Research in Outdoor Education 2014, Vol. 12, pp. 15–35

Exploring the Social Impacts of a Summer Camp for Youth With Tourette Syndrome

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Abstract

Although a wealth of research exists documenting the positive social outcomes promoted by summer camps, research specifically examining youths with Tourette Syndrome (TS) within the camp context is lacking. This study utilized a phenomenological approach to explore the social impacts of a weeklong camp specifically for youths with TS, involving focus groups with 18 campers aged 10–16, interviews with 10 staff members, and participant observations compiled by the researcher. Multiple themes and sub-themes concerning the social impacts of the camp experience were identified, including (a) relatedness (not alone and self-assurance); (b) social development (friendships, optimism, educational experience, and bullying); (c) programmatic outcomes (unique program opportunities and cabin bonding); and (d) various implications for professional practice and future research are discussed.

Keywords: *Tourette Syndrome, summer camp, youths, tics, phenomenological*

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Introduction

Youths with Tourette Syndrome (TS) experience a number of unique social challenges, including isolation, discrimination, and bullying, all of which have interrelated and residual impacts on the quality of life for these youths. Of equal imminence and importance as the United States ramps up its effort to combat bullying in schools, is the need to better understand the unique problems faced by specific segments of the youth population, such as individuals with TS, in addition to developing solutions for their well-being and safety. Although there is no one answer for addressing these issues, a combination of approaches, including the identification and development of support communities for youths with TS, can provide at least a partial step forward.

TS is a genetically inherited neurological disorder whose most notable symptoms are involuntary verbal and motor tics. The severity of these tics varies from person to person, resulting in a complex diagnostic process. Verbal tics are often seen as involuntary sounds, such as sniffing, throat clearing, squeaks, and grunts, while motor tics commonly involve physical movements, such as rapid eye blinking, twitches of the mouth, shrugs, and the repetitive twitching of muscles and limbs (Lambert, 1998; Poutney, 2009). According to Dedmon (1990), in order for TS to be officially diagnosed, "multiple motor tics and one or more vocalizations occur every day or intermittently for more than one year" (p. 1).

Adding to the challenge of having TS is the scarcity of others with whom a diagnosed child might have consistent social contact. According to a report by the Centers for Disease Control and Prevention (2009), three out of every 1,000 children age six through 17 are diagnosed with TS in the United States. Thus, it is not uncommon that a youth with TS is the only person with the disorder in their school, making it potentially difficult for these children to engage with others affected by the disorder.

Despite the acknowledgment of this social isolation and its incumbent difficulties, there is currently a dearth of recommendations for how these conditions can be adequately addressed. A study by Kenney, Kuo, and Jimenez-Shahed (2008) indicated that "Education of family, teachers, classmates, and other school personnel helps create an accepting environment for a child with Tourette syndrome who may otherwise be teased, ridiculed, disciplined, or simply told to 'stop it'" (p. 655), but educational programs specifically about TS remain few and far between. Christner and Dieker (2008) suggest that open communication can lead to improved quality of life for youths with TS in schools, but formal support for initiating greater dialogue and communication around TS is currently lacking on a wide scale.

Further, there are limited resources telling youths with TS where they can go for help and how they can personally work through their social challenges. The Tourette Syndrome Association, a national nonprofit with more than 30 support chapters across America, has been providing community programmatic efforts since 1972. However, as the primary organization providing advocacy in the face of a growing TS population, the creation of additional social groups are needed.

Camp Research

This study was born out of the desire to learn whether communities composed of, and created specifically for youths with TS, particularly summer camps, might hold at least part of the answer to filling these gaps and addressing the social challenges youths with TS face. For over 160 years, summer camps have carried the reputation of positively shaping and developing the lives of youths coming from a range of backgrounds, and recent research has confirmed these assertions (e.g., Dworken, 2001; Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007). Recent studies report that summer camp programs produced a number of positive social outcomes for youths through intentional recreation and social based activities, including the development of friendships (Dworken, 2001), improved positive identity (Henderson et al., 2007) increased self-esteem (American Camp Association, 2005), and more effective communication skills (Garst & Bruce, 2003). In evaluating the impact and value of camp relationships, summer camp presents a unique opportunity for youths to interact with older camp leaders and role models in a manner that contrasts with authority figures, like teachers at school. Affirming the benefits of these relationships with camp staff, researchers Spencer, Jordan, and Sazama (2005) utilized tenets of the Relational Culture Theory (RCT) to assess the "well-established link between strong relationships with adults and better psychological health in young people" (p. 355). They found that youths most often connected to adult leaders who exhibited "authentic engagement" (p. 358), seen as intentional listening skills and behaviors that represented similarities to the youths' personalities (Spencer et al., 2005).

Additional research focused on segregated camp environments (those that offer programs exclusively for particular populations, such as people with disabilities and/or chronic illnesses) has yielded outcomes similar to those measured at camps for more general segments of the population, including: increases in sociability (Gillard & Watts, 2013), social acceptance (Goodwin & Staples, 2005), and perceived self-competence (Meltzer & Rourke, 2005). Notably, participants in Goodwin and Staples' 2005 exploratory study highlighted the lack of activities and support groups in their local communities specifically for people with disabilities. This finding parallels the challenge youths with TS face in identifying support groups and social outlets accessible in their area.

Taken in aggregate, these and other similar studies suggest that youths with TS may benefit from experiences in a segregated summer camp setting. Unlike most social settings within which these youths are accustomed, summer camp has the potential to provide a safe and fun social experience that aids in the development of greater feelings of relatedness and social competence. Since youths with TS are faced with limited opportunities to meet and connect with others affected by the same disorder, a summer camp program catering specifically to youths with TS would present numerous opportunities to intentionally evoke positive social outcomes and changes. Currently, however, there are very few identifiable TS camp programs in the United States, meaning there is the lack of access for youths with TS to a tailored summer camp experience. Further, no known documented research exists assessing the social impacts of camp for youths with TS.

Purpose of this Study

This study explores and describes the social experience for youths participating as campers in a one-week residential camping program designed exclusively for boys and girls aged 8 to 16 sharing a diagnosis of TS. The specific aim of this study was to answer the following two questions: (a) “What are the social outcomes for youths with TS at camp?” and (b) “What are the social factors at camp that influenced these social outcomes?” These questions are intended to describe youths’ social experiences at camp, and may provide important implications concerning how their social development is affected by their camp experience. The findings in this study have the potential to fill an important gap in research addressing camp programs designed specifically for the TS population, and holds the potential for promoting new forms of support and social outlets for youths with TS as part of the larger effort to improve their quality of life.

Methods

Research Design

For this study, a phenomenological research design was used to describe the social impacts on youths with TS participating in a weeklong residential summer camp program. Phenomenological research is a qualitative process in which a researcher seeks to fully understand and describe the lived experiences by a group of people pertaining to a particular phenomenon (Creswell, 2009). In order to obtain these understandings and provide substantial descriptions, the researcher develops questions that answer *what* happened within a particular lived experience and *how*. As part of this process, the researcher purposely brackets any past experiences or biases that they may share in order to fully understand the meanings of the phenomenon (Creswell, 2009).

Participants

A purposive sampling method was employed in pinpointing the participants for this study (Fraenkel & Wallen, 2003). The populations studied were youths diagnosed with TS and adult camp staff members working at a TS camp.

A total of 18 campers assented to the study comprising of both new and returning campers aged 10–16. The data provided by these campers were gathered primarily through a series of semi-structured, focus group interviews.

Additional data were gathered through 10 one-on-one interviews with adult staff members of the camp. A total of seven out of the 10 participating staff members in this study had TS, and these staff members comprised of some of the camp's administrators, senior cabin counselors, and members of the medical staff.

Research Setting

This research study took place at a one-week residential camp in the Midwest United States, serving approximately 40 boys and girls with TS, ranging in age from 8 to 16. According to the camp's mission statement, "The goal of the camp is to allow children with TS an opportunity to meet other children, share similar experiences and coping mechanisms in a safe and positive environment." The camp is one of few across the United States that offer a weeklong overnight program specifically for youths with TS. Another unique feature of the camp is that their staff consists primarily of volunteers over two-thirds of whom have TS.

The daily activities of the camp include swimming, boating, horseback riding, and a ropes course with a zip line. Additional structured activities include skill periods, cabin time activities, meals, and twilight activities. Within structured activities, campers have the freedom to choose their own skill periods and cabin activities each day.

Instrumentation and Procedures

Data for this study was collected using five focus group interviews with campers, 10 individual interviews with adult staff members, and participant observations. Prior to the beginning of the data collection period, permission for this research was received by the University of New Hampshire's Institutional Review Board.

Interview guides and questions for both focus groups and individual interviews were adopted and modified from Gillard and Watt's (2013) study examining developmental experiences at a camp for youths with cancer. These questions were designed to address the campers' and staff members' perceptions as part of their social experience at camp. All interviews were semi-structured where each camper and staff member was asked the same listing of questions with the intention of the researcher probing and asking follow-up questions to clarify details and meanings from specific responses. Examples of focus group questions that were asked included "Complete this sentence: Camp is a place I…What do you mean by that?"; "Has camp changed the way in which you feel about socially interacting with others? How so or why not?"; "Has camp changed the way you feel about having Tourette's? How so or why not?" Each camper that participated in these focus groups was also asked to complete a short demographic survey that allowed the researcher to organize them into age-specific groups. All focus groups took place outside of the camp's infirmary during free-time activities and cabin rest hours throughout the week. These time frames were chosen with the purpose of not taking away campers from the organized programs that were part of the camp's curriculum. Each focus group took approximately 35 minutes to complete and was audio recorded and transcribed verbatim to ensure accuracy in reporting all responses.

Similarly to the camper focus groups, each individual staff interview took place during free-time activities, cabin rest hours (when it did not conflict with focus groups), and during assigned time off for specific staff members. The researcher used a similar interview guide that was consistent with the questions asked in the focus groups. Examples of individual interview questions that were asked included "Complete this sentence: Camp is a place where campers…What do you mean by that?"; "Does camp change the way campers feel about socially interacting with others? How so or why not?"; "Does camp change the way campers feel about having Tourette's? How so or why not?" As with the focus groups, each individual interview took approximately 30 minutes to complete and was audio recorded and transcribed verbatim to ensure accuracy in reporting all responses.

As part of a third method of data collection, the lead researcher recorded 10 observations in a reflexive journal. These observations focused on components of the lived camp experience, including reflections on informal conversations with campers and staff members, as well as general observations during both structured and unstructured activities throughout the week. These activities included cabin conversations and relationships (which arose out of the cabin that the researcher resided in), skill periods, camp-wide activities such as themed activities and dances, and common area experiences such as meals. Since the researcher was an active participant in the camp, the researcher did not fully record experiences as they happened, but rather, compiled field notes by carrying his journal to all camp related activities, later expounding on these observations during assigned time off and at night after all campers went to bed.

The primary goals for conducting participant observations was to document and transcribe meaningful socializations, any apparent changes in the moods of campers, and program experiences that contributed to the social experience of camp. This required factual and accurate documentation reflecting on the context such as the setting, activity, and social interactions that took place (Henderson, 2006). Additionally, the observations allowed the researcher to compare and identify social themes in conjunction with the notes and audio recordings from all focus groups and individual interviews.

Role of the Researcher

As a means for collecting data during the camp program, the researcher served as a senior cabin counselor for boy campers aged 12–14. The researcher and lead author, who is an experienced camp professional, served in this counselor role as a person living with TS. Through the coordination and participation as a senior cabin counselor, the researcher was able to develop connections and rapport with the campers. The building of rapport was seen to establish greater levels of comfort and trust in sharing with the researcher during focus groups.

Data Analysis

The strategy for analyzing the data involved Creswell's (2007) version of phenomenological methods. According to Creswell's method, which was adopted and modified from Moustakas' (1994) phenomenological description, an exhaustive review of all transcripts from the focus groups, individual interviews, and participant observations were performed. As outlined by Creswell, this extensive review process involves five primary steps of analysis. These five steps involved (a) transcribing all focus group and individual interview audio recordings as well all field notes and reflexive journal entries; (b) compiling data and listing all significant statements from each focus group, individual interview, and series of observations that described the campers' lived social experience at camp; (c) open coding: taking the list of significant statements and categorizing them into specific themes; (d) analysis where written descriptions were made describing *what* and *how* these particular experiences took place; and (e) analysis involving a series of final descriptions that synthesized the experience(s).

Trustworthiness

The researcher utilized two primary methods to ensure the study's trustworthiness. The first process involved the triangulation of data through (a) focus groups with campers, (b) individual interviews with adult staff members, and (c) participant observations. Secondly, a *member checking* process was performed at the end of each focus group and individual interview where key comments and accounts were reiterated back to the respondents to clarify the accuracy of the researcher's understandings. Additional notes and observations were recorded to describe the participants' clarifying responses.

Threats to the Study

There were threats to this study that should be acknowledged. One potential threat is that the researcher served as a counselor as part of the camp program. Because of this, it is possible that the researcher shared influence on the camp experience for both campers and staff members. Therefore, this could have affected the participants' responses within focus groups and individual interviews.

A second threat to this study was that participation inevitably took away valuable time for participants to experience certain elements of the camp, specifically, the cabin rest hours and free-time cabin periods which took place concurrently with the study's group interview times. Although these cabin periods are important to the social experience at camp, the researcher chose these time frames so as to not interfere with structured camp programs. Also, due to the voluntary nature of the campers participating in this study, the campers maintained the choice to participate in focus groups in place of these cabin periods.

Results

A number of significant themes and sub-themes were identified based on the data gathered from focus groups with campers, individual interviews with adult staff members, and participant observations. These were *Relatedness*, *Social Development*, and *Programmatic Outcomes*. Subthemes are indicated under each theme heading. The various quotations from the participants presented here are meant to provide a greater context for understanding these social impacts and their causes.

1. Relatedness Themes

The first overarching theme that arose during analysis of the study data was an emergent sense of relatedness reported by campers. A number of positive experiences connected to feelings of relatedness were reported, and it was found that these experiences could be further broken down into two subthemes of (a) not feeling alone, and (b) an increased feeling of self-assurance.

Theme 1a: Not alone

> I thought I was isolated to only having Tourette's so I always use to think 'Oh my goodness, I'm the only one…What am I going to do? No one will accept me.' And then I came here [camp] …its really nice to know that I'm not alone. —16-year-old camper

One of the themes that emerged most frequently in conversations with campers was their realization that they were *not alone* in having TS. Many campers commented that camp was the first place they had ever met someone else with the disorder, and that meeting others with TS in a camp setting helped to lessen feelings of isolation. More specifically, campers frequently maintained the attitude and perception within their responses that they were the only one in their school and hometown having TS. Therefore, the opportunity of meeting and developing relationships with other campers at camp helped them to establish a stronger sense of relatedness and social connection upon returning back home. In addition to this, other campers described that meeting new people with TS helped them to feel better about themselves. Along with this, it was a common experience that the camp provided youths with TS the opportunity to learn and share about their own experiences living with the disorder. As one 16-year-old camper commented,

> My opinion is there is no better way to feel better about yourself than to talk to kids who have the same problems than you and it makes you feel again like you're not alone…I feel like anybody can benefit from that kind of thing no matter what.

Staff members shared similar sentiments. After being asked if camp changes how campers feel about having Tourette's, one staff member stated, "Oh definitely… a lot of kids come to camp thinking that they're the only ones. And then they come here and realize that they're not. It's a huge life changing experience in my opinion."

Additional observational data gathered by the researcher were consistent with these responses. It was evident that meeting other kids with similar symptoms and tics evoked feelings of comfort among campers. One 14-year-old camper commented in an informal conversation, "I've never met someone who has the same tic as me… It's awesome being able to ask how they deal with it and what other tics they have." These social exchanges, which commonly took place during cabin periods, revealed themselves as important factors in the social experience of campers. It was also seen to positively affect the development of relationships between campers and counselors.

As an extension to this theme, feelings of empathy were prevalent in campers' accounts of their experiences at camp. Campers frequently commented on the positive impact of being around others who knew exactly what they were going through. In contrast, campers also indicated that, though family members and peers back home were accepting of their Tourette's, they didn't truly understand what it was like living with the disorder: "It's different here [camp] because there's like, I know my parents and my sister try hard to understand what I'm going through, but they don't have it so they don't exactly understand it. Here there's lots of kids here that understand exactly what you're going through."

Such responses indicated that a primary difference between their normal social contexts and the camp environment was simply the lack of people with TS outside of camp. The ability to meet others with TS presented campers with the unique opportunity to share an experience with people similar to them, leading to increased feelings of social inclusiveness and support. This was in contrast to described feelings of isolation in other social environments, such as school and back at home. Through researcher observations, it was seen that these feelings of inclusiveness and support often arose in connection with the recreational nature of the camp environment. More specifically, it was seen that the opportunity to share a mutually exclusive space and take part in fun recreational activities together contributed to the campers' level of social connectivity and feelings of belonging.

Another aspect of the social experience at camp that appeared to have a positive social impact on campers was the level of engagement amongst the camp's staff. Through various observations, it was evident that staff members were very intentional about engaging in conversations with campers about their home lives and how their parents and friends responded to their disorder. This informal engagement, which commonly took place during cabin-related activities, appeared to build rapport and help campers to openly discuss their TS. In speaking with staff members about these conversations, they indicated that many campers do not have the opportunity to talk about their Tourette's back at home, and that being around others with TS positively impacted their ability to talk more openly and grow more comfortable with their disorder.

Theme 1b: Self-Assurance

"I can be myself here." —16-year-old camper

A second prominent theme emerging from the data was the campers' shared feelings of self-assurance at camp. The camp's staff put a great deal of emphasis on explaining to the campers that camp was a place that they could tic openly and freely without judgment. Although this was seen to be an important element of the social fabric at camp, it also came as a culture shock for many campers, who indicated that they commonly felt the need to hide and suppress their tics back at home. A number of campers expressed that the social environment of camp helped them to grow more comfortable with, and less self-conscious of, their tics. As one 14-year-old camper commented toward the end of the week:

> Camp has changed the way I feel about having Tourette's because it makes me feel better about myself just knowing that people actually care that I have it and people won't bully me… makes me feel good that I can just let it everything [tics] loose and without having to worry about "Oh why'd you do that?"; "What's that?", like "When did you start doing that?"… just all this stuff.

Staff members added to this perception by describing the camp environment as a "safe haven" that helped kids with TS to feel "normal." Further, staff members expressed ownership over the fact that a large part of their responsibility at camp was to ensure that campers felt they could tic openly and feel free from judgment. This responsibility was due to the perception that the majority of individuals with TS, especially youths, do not feel comfortable ticcing in front of others within their regular social environments. Observational data obtained as a fellow senior cabin counselor were consistent with these findings. However, it was observed that campers, especially ones that were new to the camp, took more time before ticcing openly in front of others, and a number of campers appeared to suppress and hold in their tics until the midway point of the week. In informal conversations with some of these campers, they indicated that it took time for them to adapt to the new social norm of tics being accepted and encouraged. Many expressed further that the camp environment was unlike home and school where they were commonly told to "stop it." The varying levels of comfort campers felt as part of the camp's social environment was seen to be a critical factor in their self-confidence and the degree to which they eventually opened up about their TS.

2. Social Development Themes

Data gathered from the study also revealed several themes related to campers' social development at camp, spanning a range of positive and negative perceptions and experiences. Within the overarching theme of social development, sub-themes identified included the development of (a) friendships, b) optimism (as result of meeting older counselors with TS), as well as exposure to (c) educational experiences, and (d) coping with bullying.

Theme 2a: Friendships

> If you were in school and you tried to make friends with somebody it might be more difficult because they see you as slightly different and therefore we have to take more time to adjust…And camp like where everybody is having these issues, having tics, having outbursts, it's a lot easier. It makes you feel like this is the school and how it should be, feel, and it's more natural. —16-year-old camper

Campers and staff members frequently spoke about the impact of making friends at camp. Campers in particular commented that they felt it was easier to make friends at camp than back at home. These comments reflected not only the commonalities between the campers, but a diminished feeling of self-consciousness about their disorder. Another contributing factor that was seen to affect the development of friendships at camp was the ability for the campers to quickly move beyond talking about their disorder. Campers indicated that they commonly needed to spend a lot of time clarifying what their disorder was to their friends back home, which they described as a stressful and uncomfortable experience. In contrast, being surrounded by others at camp with TS drastically limited the need for these explanations, making it easier to develop friendships.

Informal conversations also revealed a great deal about the development of friendships between campers. By the end of camp, many campers made intentional efforts to exchange e-mail addresses, phone numbers, and social media contacts. Supporting this observation, campers commented that they highly valued staying in touch with camp friends throughout the year. Maintaining these connections appeared to correlate with a strengthened realization that campers were not alone in their disorder.

Theme 2b: Optimism

> It's so nice because their [counselors'] tics aren't as bad. It gives me hope that my Tourette's won't be as bad when I'm older. And it gives me hope that they are so poised and so mature in their Tourette's and they're successful and that gives me hope definitely. —16-year-old camper

Another major theme revealed by the data was the development of a more optimistic outlook about living with TS. It was very apparent that the senior cabin counselors at camp had a profound impact on this particular element of the campers' social experience. Within focus groups, campers consistently used words such as "hope" and "motivation" to describe their relationships with their counselors.

On the other side of the equation, staff members indicated that being a positive role model for campers was one of the most rewarding benefits of their jobs. As adults living with TS, they were driven to demonstrate levels of understanding and appreciation for what the campers were experiencing. Many staff members shared statements such as, "I can understand someone who can't control their tics," and "We know exactly what they are going through." One specific staff member, who was once a camper at the camp, said the following about the impact of his role as a counselor:

> When I was a camper, my counselor was a big role model for me…I didn't know anyone with Tourette's, and she kind of helped me out to understand what it was and you know she gave me that other perspective. So I'm just kind of like paying it forward by being that person just letting them know like answering the questions that they have and letting them know that like it will be fine even though you have it… Like you can do whatever you want to do. You can be who you want to be no matter what.

In this way, cabin counselors contributed greatly not only in the delivery of the camp program, but also in positively shaping the campers' outlook on their disorder. This attitudinal shift among the campers was seen to be a benefit to the social experience at camp.

Theme 2c: Educational Experience

Before coming here, I thought I had it bad with my tics. —16-year-old camper

While the majority of campers exhibited knowledge of the verbal and motor tics that come with TS, many were surprised to learn about the co-existing symptoms of the disorder such as *attention deficit hyperactivity disorder* (ADHD), *obsessive compulsive disorder* (OCD), and *anxiety*. Many had also never been exposed to more severe forms of TS prior to coming to camp.

Through informal conversations with staff members, it was apparent that the campers expressed excitement and intrigue in learning about these different characteristics of TS, especially during organized cabin periods.

In observing a rest hour period with the youngest boys cabin (aged 10–12), one camper excitedly approached the camp director and shouted, "I didn't know about COD, what is COD?! I didn't know that came with it." The camp director corrected the camper with a chuckle, indicating that they meant "OCD" before proceeding to explain what OCD was. This moment, along with others, highlighted how discussions between campers helped to broaden their scope of what it means to have TS. Moreover, it appeared that camp offered a unique opportunity and setting for campers to engage and socialize around their TS. The uniqueness of these socializations was consistent in focus groups, where many campers suggested that they have little to no opportunity back home to meet and talk with others with the disorder.

As mentioned previously, the camp experience also exposed the campers to different levels of tic severities. It was commonly explained in interviews that the exposure allowed the campers to realize how "good" or "bad" they had it, as it concerned specific tics and co-existing disorders. One of the leading causes for these reactions was witnessing the intensity of tics among the campers with severe forms of TS. The tics exhibited by these campers were much more prominent, manifesting as consistent uncontrollable vocalizations and harsh movements. While in some cases this exposure to more severe cases of TS served as an educational experience, it was also observed that when these campers exhibited a tic, it frequently drew laughter and unwanted staring by others. This leads into the fourth sub-theme of social development drawn from analysis of camper and staff data: bullying.

Theme 2d: Bullying

> I know it sounds vice versa, but some kids in my cabin treat me badly for my tics while no [sic] one of friends treat me bad at home and they don't have Tourette's, which I find kind of ironic, but that's just my experience. —14-year-old camper with a severe TS symptoms

The severity of tics among the campers occurred along a rather broad spectrum, ranging from campers who exhibited little to no signs of tics, to others who vocalized and twitched uncontrollably. Due in large part to this range of symptoms, reports of bullying were not uncommon in interviews with staff members, who observed older campers picking on other campers' tics throughout the week. In speaking about the cause of this bullying, the camp director shared,

> I do have issues of bullying between Tourette's kids because, um, they're bullied all through the year and then they see that other people have,

> you know, all these other kids have Tourette's… their tics are made fun of throughout the year so now they have the opportunity to make fun of somebody else's tics.

Through additional observational data, the researcher found that a contributing cause to this bullying was the level of receptiveness and toleration that the camp exhibited toward such behaviors. As suggested by many of the interviews and focus groups, campers were commonly the only case of TS back home. Upon arriving at camp, there appeared a period of transition, where certain campers struggled to rid themselves of their identity as a victim. As part of this transition, some older campers appeared to take advantage of their new social status by picking on others. These instances of bullying were common during times when the entire camp community was convened, such as before meal times and during twilight activities.

One camper with a severe form of TS expressed in a focus group interview that attending camp made them feel as though they were "the worst-case scenario." It was clear from observing campers with more severe cases of TS that their unique circumstances affected their social experience at camp, and yet despite these unfortunate social dynamics, it was observed that they, too, still established friendships with others and that they enjoyed their week at camp. Upon further investigation, it appeared as though the camp's staff did not have specific plans or strategies in place for addressing these campers, other than simply promoting acceptance and mitigating inappropriate reactions by others.

3. Programmatic Outcomes Themes

The overall goals of the camp's program were to provide opportunities for the campers to "learn new skills, develop character, and make friends." The camp offered a variety of programs, including structured skill periods (i.e., archery, horseback riding, arts and crafts, etc.), outdoor recreational activities (i.e., boating and swimming) and specialized programs (i.e., themed twilight activities, cabin periods, and challenge course activities). These programmatic efforts elicited a number of positive and negative viewpoints from campers, and sub-themes relating to this category of camp experience included (a) unique programming opportunities, and (b) cabin bonding.

Theme 3a: Unique Programming Opportunities

> At camp you have a lot of activities like the *Hunger Games* that we never really do anything like that back at home and Gaga, which is the same thing, but there's games like it, but not exactly like it and I think that's a good thing about camp. You get to do unique activities that only that camp does. —13-year-old camper

Many campers commented in focus group interviews that they thoroughly enjoyed the programs that were offered, and that many of the camp activities offered were typically unavailable back home, such as water blobbing (an activity involving an air-inflated trampoline device for jumping into the lake), Gaga (an enclosed variation of dodge ball), arts and crafts, themed twilight activities, high ropes courses with zip lining, and the singing of camp songs. Many campers also cited and outwardly expressed their enjoyment of twilight activities such as *The Hunger Games,* Gold Rush, camp-wide capture the flag, campfires, and the week ending dance.

Through observational data, it appeared that these sorts of camp programs positively affected the ability of campers to engage and socialize with each other. The opportunity to participate in the ropes course and ride the zip lines seemed to be a particular catalyst for camper bonding. The ropes course was composed exclusively of high-rope elements such as the Catwalk, Multivine Traversing, and an Inclined Log that led to the zip-lining platform. Many campers had to overcome not only the challenge of the course's elements, but also their personal apprehensions and fears (i.e., a fear of heights or a fear of failure).

Although it was observed that some campers embraced the challenge of these elements and completed them without hesitation, there were a number of campers who struggled to complete these tasks. Regardless of their performance, though, it was observed that campers were consistently supportive of and encouraging to one another. Campers were commonly seen shouting out words of encouragement such as "You can do this!", "If I can do it, you can too!" and "It was so much fun, you have to try it!" These activities appeared to have a positive impact, as campers in many cases were seen talking about their experiences throughout the rest of the week, especially during meal times and cabin periods.

Theme 3b: Cabin Bonding

> They [campers] can't just walk away from a situation as easily. They can't just say, 'Oh, I don't, I don't like this kid'… we'll [counselors] kind of bring them together and they kind of have to be there for the week and so they have to learn how to adapt to more and work with other people. And they might not get off the right foot at first, we can show them how they can change either one or the other can change their ways and help them to work together more. So I think from a social standpoint, I guess it helps them with resolving conflict and especially it helps, I guess it helps them with their overall social skills. —Senior cabin counselor

One of the most influential parts of the camp's program observed was the live-in experience in cabins. The camp was composed of five different cabins that were assigned according to gender and age. As part of cabin life, the campers were pushed to develop and practice habits necessary for successful cooperative living, such as the sharing of living space, cabin-cleaning responsibilities, and participation in cabin-related activities (i.e., cabin free time and sitting together at all meals). Among these, the most critical part of the cabin experience observed was the bonds that arose between cabin mates throughout the week. As a live-in senior counselor for a group of nine boys aged 12–14, the researcher observed that the cabin's participation in camp-wide activities assisted in the development of relationships between campers. For instance, during the twilight activity, *The Hunger Games*, each cabin was assigned as a competing "district" against other cabins. Within their cabin assignments, campers participated in a number of team-building activities, ranging from the making of district flags, to developing strategies for displaying cabin spirit, to the selection of cabin participants for both individual and group skills competitions. This intentional programming appeared to provide a positive means for campers to engage socially in a way that was also fun and meaningful.

Numerous staff members reported additional perspectives on the impact of the live-in cabin experience. One staff member commented that the cabin experience encouraged campers to "rely on others" to get through the week: learning how to cope with being away from home, how to establish relationships with fellow cabin mates and counselors, and learning responsibilities for maintaining the cleanliness of the cabin, while supporting the general performance of the cabin in camp-wide activities. These intentional programmatic aspects of the live-in cabin experience were seen to produce increased levels of rapport between campers and staff, as well as the learning of various social skills.

Staff members also suggested that the live-in experience helped teach campers how to resolve conflicts. Many staff members shared the opinion that campers with the disorder were often catered to by their parents at home. In contrast, camp provided a space for campers to take responsibility for their own actions and to resolve their own conflicts. Although it was observed that campers experienced various conflicts throughout the week (i.e., arguments over tics and general tension in making decisions as a cabin), it was seen that cabin-related programs, in conjunction with the intentional efforts of camp staff, served as important factors in providing a positive social experience.

Discussion and Implications for Practice

There are numerous recommendations based on the findings of this study that the camp might consider to improve the outcomes of their program. As seen throughout the study, the social impacts of the camp program revolved greatly around the campers meeting others with TS for the first time. With this, the exposure of different levels of tic severities and co-existing disorders often resulted in campers coming to a new understanding of their own condition in context with that of others. Though this reconceptualization was generally positive, there were also negative evaluations that emerged, particularly for campers with more severe TS symptoms. To improve this educational component of the camp experience, camper and staff interviews suggested that incorporating organized TS group discussions may offer a great deal of value to the social experience at camp. Such discussions might give campers the opportunity to share experiences and feelings related to their disorder, and allow them a more intentional space to ask questions and build greater levels of rapport with one another. It is suggested that these group discussions could be incorporated during the free-time periods that are already built in as part of the camp's curriculum.

A second recommendation relates specifically to campers with severe TS at camp. As seen in this study, these campers struggled socially due to the severity of their tics, so much so that one of the campers indicated that being at camp made them feel as though they were the "worst-case scenario." Observations revealed that these campers were frequently embarrassed throughout the week due to the nature of their tics, resulting in a different level of social integration and impact in comparison to other campers. Based on these anecdotes and observations, it is recommended that camp administrators take intentional efforts in developing staff trainings for strategically addressing the needs of future campers with severe forms of TS. This may involve bringing in outside specialists who work primarily with extreme cases of TS, or providing explicit trainings and strategies for staff members to utilize in their work at camp. Organized TS discussions may also help to provide a productive forum for these campers to openly talk about their condition and their specific social needs.

A third recommendation is for the camp to assess overall length and content of its staff trainings. The training attended by the researcher was a one-day training that provided basic information about the disorder, medical procedures of the camp, and brief period of time in which to review camper profiles. Although the staff members for this particular TS camp travel from across the country in order to attend, based on the researcher's past experience working as a camp administrator and facilitating staff trainings, it is recommended that that the training period last at least a full weekend. With this, additional specific trainings should include, but should not be limited to, intentional team-building activities, practicing conflict resolution scenarios, discussing clear descriptions of staff protocols, and programmatic planning. Covering these specific topics will undoubtedly help to develop more cohesion amongst the staff and also prepare them with tools and confidence to more fully execute their responsibilities. Lastly, the camp should consider soliciting feedback from all staff members either after the conclusion of the training period or at the end of camp to assess how adequately the training met their needs. Based from these evaluations, changes or modifications can be made.

A fourth recommendation is that the camp should consider developing additional programs and social retreats for campers throughout the year, to better support and maintain the positive outcomes emerging from the camp's weeklong summer program. As seen in the course of this study, numerous campers spoke very highly of their social experience at camp and the impacts that it had in shaping their outlooks on living with TS. Knowing these outcomes, the camp has a unique opportunity to provide specialized programs to address the current lack of TS support groups. The implementation of these additional programs would provide opportunities to strengthen the camp's mission, while also serving as a way to maintain the personal connections between campers and the camp as a whole.

Further to this recommendation, the camp should also consider supplementing existing camp programs and developing opportunities to engage with families affected by TS. This may include weekend retreats or weeklong programs for youths with TS to experience along with their families. As demonstrated by Lambert (1998) parents of youths with TS place a great deal of value on interacting with other parents who are going through similar experiences and challenges. Creating additional weekend retreats and family gatherings may provide additional avenues of social support for the families affected by the disorder, while also creating a means for introducing more people to the camp environment.

In the course of this study, the researcher witnessed that a number of campers exhibited less tics while participating on the camp's ropes course and zip line. Based on these observations and past experiences of the researcher, who himself lives with TS, it is common that activities requiring a great deal of focus can limit the compulsion to tic. Based on this information, the camp may also wish to consider providing a greater number of programmatic opportunities that help campers achieve similar "flow" experiences. Although it is difficult to provide specific suggestions for such programs, the camp may consider soliciting feedback from camper evaluations to discover if specific camp activities are seen to cause more or less tics. This may also serve as an important area of future research in assessing youths with TS in recreational settings such as summer camp.

A final recommendation is for the camp to include evaluations administered to the parents and families of the campers. Although it is seen that the camper is typically the beneficiary of the camp experience, it can be equally important and informative to assess what parents observe from their children after the conclusion of camps. In so doing, the camp would have the opportunity to evaluate parental perceptions as a means of assessing the impacts of current programs being offered.

Future Research

This foundational study provided important knowledge and background in exploring the social impact of a weeklong summer camp program for youths diagnosed with TS. It should be understood that the findings in this study reflect experiences specific to the camp setting in which the study took place. Until more data is gathered from other camps, the data gathered in this study is not generalizable to the greater population of youths with TS who attend summer camp.

The examination of the social impacts of camp for youths with TS is an evolving phenomenon that to date has seen very limited research. Therefore, it is recommended that future researchers conduct comparative studies between multiple camps offered exclusively for youths with TS. As seen within the literature review of this study, there are very few existing TS camps across the country. Examining multiple camps within the context of one study will help to assess whether similar or different outcomes occur, and whether generalizations across camps can be made. With this, the use of different data collection procedures may be used to focus on different aspects of the camp experience for this population. This may include researching areas such as the emotional implications of the camp experience, tic frequencies, or various other qualities of life affected by camp.

A second area of future research should evaluate the social impact of camp by conducting a posttest with campers after the conclusion of the camping program. Performing a postcamp analysis (e.g., 1-month, 6-month follow-up telephone interviews or surveys) may help to develop a more robust understanding of how campers perceive their camp experience, and the potential impacts it has in their lives outside of camp.

A third area of future research should involve the assessment of other recreational venues in which youths with TS participate. As seen in this study, campers spoke very highly on their experiences participating in fun recreational programs at camp. Because of this, it would be important to assess if, and how, social experiences within different recreational constructs may generate similar or different outcomes. Specific programs that may be important to research are community based programs and organized after school programs. Information from such studies may not only help to compare other recreational experiences to camp, but it may also generate tangible working knowledge for practitioners to use in accommodating the needs of this population.

The current study assessed the impacts of youths being around others with TS within the same camp environment. However, it would be important for future researchers to assess how these experiences may differ within different environments involving traditional participants. For example, this may involve assessing youths with TS who participate in traditional camp programs or recreational opportunities outside of the camp environment. Assessing different socially inclusive experiences may help to bring about a greater understanding of the differences between inclusive and segregated experiences for the TS population.

In conclusion, this phenomenological approach in studying the social impacts of camp for youths with TS found a series of themes revolving around relatedness, social development, and programmatic outcomes. As a foundational study, it contributes to the growing knowledge of camp research in understanding the social impacts of camp among different populations of people. While this study is not generalizable to the greater camping context, it presents important implications and cause for current and future camp professionals seeking to serve this population.

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