THE SOCIAL IMPACT OF A SUMMER CAMP FOR YOUTH WITH TOURETTE SYNDROME

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Like many young people, youth with Tourette Syndrome (TS) experience a number of social challenges that impact their quality of life. As a genetically inherited neurological disorder, youth with TS experience common symptoms such as involuntary verbal and motor tics. Research studies examining the impact of these tics have consistently reported that these youth are commonly misjudged, bullied and teased, and are likely to experience depression and anxiety as result of their symptoms (Cutler et. al., 2009; Zinner et. al, 2012; Center for Disease Control and Prevention, 2007). To date, there are limited resources available suggesting where youth with TS can go for help and how they can potentially work through and overcome their social challenges.

Within the past decade, a number of well-publicized research studies have reported that summer camps serve as a setting for producing positive social outcomes. These outcomes include, but are not limited to, developing friendship skills, improved positive identity, increased self-esteem, and the ability to connect with others (ACA, 2005; Henderson et. al., 2007; Garst & Bruce, 2003; Dworken, 2001). In addition to these studies, research reports focusing on segregated summer camps, which offer programs exclusively for specific populations (i.e., people with disabilities and/or chronic illnesses), yielded similar outcomes such as developing positive social identity, social acceptance, and establishing meaningful friendships (Goodwin and Staples, 2005; Conrad & Altmaier, 2009; Gillard & Watts, 2013). The purpose of this study is to explore and understand the social outcomes experienced at a camp specifically designed for youth with TS. With this study being the first of its kind, the researcher’s objectives were to report what the youth felt as part of their experience at camp and how their experience could present valuable implications for future research.

Methods

Forty-four campers attended a TS camp this past summer. Of this total, eighteen youth ages ten to seventeen took part in this study. Seventeen of these participants shared a confirmed diagnosis of TS and one shared a diagnosis of Obsessive Compulsive Disorder (OCD), a common co-existing condition of TS. A phenomenological research design was employed to discover the social outcomes for these youths attending camp. Data collection methods involved ten one on one interviews with adult staff members (seven had TS), five focus groups with campers, and participant observations. Data analysis for this study consisted of multiple rounds of open coding (Creswell, 2007) and the horizontalization of significant statements shared by the participants (Moustakas, 1994). Three methods for data collection allowed the researcher to triangulate the data and draw stronger connections between emerging themes.

Results

One of the most evidential themes that emerged from this study was the youths realizing that they were “not alone”. The majority of the campers participating in this study commented,
“I thought I was the only one with Tourette’s”. For many campers attending camp, this was the first time that they had ever met someone else with the disorder. As Alicia stated, “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…its really nice to know that I’m not alone.” Chris, one of the oldest campers, commented on the broader impact of his experience by stating, “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.”

A second prominent theme that emerged throughout the study was the feeling of self-assurance at camp. Many campers commented “I can be myself here”. As an extension to this theme, numerous campers indicated that they commonly felt that they needed to hide and suppress their tics outside of camp. Nicole commented on her experience by stating, “I feel free to be myself. This is like home [camp] and when I have to go back to Washington, it’s probably one of the worst feelings ever because then I know that I keep like holding in my tics and that’s one of the worst feelings. I can actually be free here”. Benjamin adds, “It makes me feel like I’m wanted like I won’t have to worry about my tics or people staring at me. It makes me feel like I’m just normal”.

A last major theme that emerged was the feeling of hope as result of the youths meeting older camp counselors with TS. Like many of the campers, David felt strongly that meeting older counselors with TS helped him to realize that things get easier living with the disorder. He states, “It feels like there’s a bit hope like I can get through this. I can just push myself, pull myself together and just get through this.” Christy added, “It’s so nice because they’re 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.”

**Discussion and Applications to Camp**

As seen in this study, this specific TS camp allowed the campers to develop meaningful relationships with fellow campers and adults living with TS. As explained by the campers, the opportunity for this type of social interaction is very limited outside of their camp experience. As a foundational study examining TS and camp, the positive social outcomes that were discovered suggest the need for producing greater awareness and public support for how camp can be a valuable resource for individuals and families affected by TS. In building support from this study and continued research, it will help to develop more opportunities for making camp programs more accessible for this population.

Although this study maintained an intentionally atheoretical approach, the findings relate to existing youth development theories that are applicable to the camp environment. One particular theory that relates to this study is Alfred Bandura’s Social Cognitive Theory. As part of this theory, it explains how people acquire new or differing attitudes through the observations of others within a particular environment. This concept was seen to apply to the youths in this study as they developed new attitudes and behaviors as result of meeting and observing others with TS at camp. This observational and relational exchange within the camp environment

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helped the youths to develop greater levels of confidence and optimism for how they perceive their disorder.

A second theory that applied to this study is the Relational Culture Theory (RCT) as seen in a previous camp study by Spencer, Jordan, Sazama (2005). In conceptualizing the importance of meaningful relationships in camp, the researcher’s offer that the RCT contributes to the “well-established link between strong relationships with adults and better psychological health in young people” (p. 355). This concept shares a distinct connection in demonstrating the positive social outcomes that existed between the youths with TS and their older camp counselors. This connection indicates that current and future camp professionals working with youths with TS should be mindful of the importance that older counselors have in shaping not only the camp experience, but also the youth’s outlook on living with their disorder.

References
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