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Camp for Youth With Type 1 Diabetes

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Abstract

Camps for youth with type 1 diabetes (T1D) have grown in size and scope since they first emerged in the 1920s. Anecdotal evidence suggests that attending camp with other youth with T1D is beneficial, largely attributed to sharing fun, active experiences and removing the isolation of living with diabetes. However, few studies have evaluated the psychosocial and medical impacts of T1D camp attendance during and after camp sessions. In addition, T1D camps have been a setting for numerous studies on a variety of T1D-related research questions not related to camp itself, such as testing novel diabetes management technologies in an active, nonlaboratory setting. This paper reviews the evidence of psychosocial and medical outcomes associated with T1D camp attendance across the globe, provides an overview of other research conducted at camp, and offers recommendations for future research conducted at T1D camp.

Keywords

Pediatrics; Type 1 diabetes; Camping; Research; Psychosocial outcomes; Education; Glycemic control

Introduction

The discovery of insulin was a pivotal moment in the history of type 1 diabetes (T1D) because it made living into adulthood possible for children diagnosed with T1D. Soon after

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Compliance with Ethical Standards

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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insulin therapy became widely available in the 1920s, several camps for children with T1D were created, presumably as a resource to support the medical and social needs of young people who were now living longer with this chronic condition. As T1D was relatively rare, there was a need for a setting in which children and adolescents were able to meet others with T1D and to form friendships and connections. With time, the scope and size of T1D camps has grown, with the American Diabetes Association (ADA) reporting in 2011 that over 30,000 children attended T1D camps in North America and an additional 16,000 youth attended camps throughout the world [1]. This is congruent with a rapid growth in camps serving children with numerous special health care needs across the USA [2].

As the number of campers continues to increase and anecdotal discussions of the benefits of camp abound, there is a need to more rigorously study the effects of T1D camps. The last review of the literature about T1D camps was published in 2009 by Maslow and colleagues and focused on the history and safety of T1D camps [3], but provided little discussion on the potential impact of T1D camps on psychosocial outcomes. Given the recent growth in camps and how much remains to be understood about the potential medical, educational, social, and behavioral impacts of camp attendance among children and adolescents with T1D, an updated review of the literature surrounding diabetes camps is warranted. The aims of this paper are to (1) describe the range of T1D camp experiences, (2) summarize the current research literature regarding psychosocial outcomes of youth who attend T1D camps, (3) describe other forms of research conducted at T1D camps, and (4) offer recommendations for conducting research in the context of the challenges and opportunities of T1D camps.

T1D Camp Experiences

The ADA reports that the major goal of diabetes camps is to “facilitate a traditional camping experience in a medically safe environment” [1] for children and adolescents with T1D. There are no formal guidelines for the format, activities, or structure of camps for youth with T1D, and a variety of experiences, locations, and settings exist. This is likely a reflection of the many different organizations that support T1D camps with financial support, programming information, or by hosting camps. These groups are diverse and include the ADA, the Leona M. and Harry B. Helmsley Charitable Trust, the American Camp Association, the Diabetes Education and Camping Association, and many other local organizations and diabetes centers. Most commonly, T1D camps are overnight camps in a setting where children and adolescents are away from their parents for several days at a time. Most provide typical types of camping activities such as archery, swimming, horseback riding, and arts and crafts. There are also day camps (especially for younger children), sports camps (e.g., basketball, skiing, hockey), and weekend retreats for youth with diabetes and their families. For many youth, this may be the first time they are away from their primary caregivers for an extended period, giving them the opportunity to experience some independence and offering caregivers a chance for respite from the demands of caring for a child with T1D.

Within the T1D camp setting, diabetes management activities such as blood glucose checks and insulin administration are typically completed in a group setting to promote the shared experience of diabetes care and normalize diabetes management behaviors. The ADA has

published guidelines in a position statement regarding the provision of diabetes care and necessary medical staff in the camp setting [1]. In general, youth follow the same diabetes management plan at camp as at home. Staff members typically represent a variety of medical disciplines (i.e., physicians, nurses, diabetes educators, dietitians, psychologists) and are equipped to manage and oversee diabetes care in the camp setting using various insulin delivery methods, insulin types, and technologies (e.g., continuous glucose monitors, insulin pumps). There is also a focus on hypoglycemia prevention at T1D camp, as the high level of activity can raise the risk for hypoglycemic events. Therefore, close monitoring of blood glucose, especially overnight, and possible insulin dose adjustments are standard in most T1D camp settings. With the increased use and accuracy of continuous glucose monitors (CGMs), there is the potential that overnight hypoglycemia events could be prevented and awakening campers for blood glucose checks could be reduced, but at this time, there are no specific guidelines for optimal use of this technology in the camp setting. The combination of expert staff and specific diabetes management plans at T1D camps helps to maximize the ability of each participant to enjoy the camp experience as much as possible in a safe manner.

Psychosocial Outcomes of T1D Camps

Anecdotal and qualitative evidence communicate the perceived psychosocial benefits experienced by children and adolescents attending diabetes camps, emphasizing the positive aspects of socializing with other youth with diabetes, including feeling less isolated, and learning how to manage diabetes in a safe and supportive environment [4, 5]. In a qualitative study of adolescents with T1D using open-ended interviews, Scholes and colleagues reported adolescents with higher A1C spontaneously mentioned camp more frequently as a place to interact with others with similar experiences, compared to those with lower A1C, who rarely mentioned camp [4]. While a single finding from this qualitative research is not conclusive, it suggests that the social aspects of the T1D camp experience may be particularly salient for some youth, especially those with suboptimal diabetes outcomes.

Quantitative research evaluating the psychosocial outcomes of participating in camps for youth with diabetes has been conducted intermittently over the years since camps were initiated, with results generally reflecting modest benefits in terms of feelings about oneself and one's diabetes. Satisfaction among campers, counselors, and parents is often reported to be high [6]. Using pre-post designs to compare participant ratings prior to and after camp is completed, researchers have shown improvements in attitudes toward diabetes, quality of life, self-efficacy related to diabetes management, self-worth/ self-esteem, and perceived coping ability [6, 7•, 8–10]. Similar findings have been reported among participants in camps for children with juvenile idiopathic arthritis [11] and heart disease [12], and for siblings of children with cancer [13], which provide further support for the potential benefits of similar camps. A recent meta-analysis of 31 studies conducted at camps for youth with various chronic conditions (including six studies focused on T1D) reflects these trends, reporting a small but statistically significant improvement in camp attendees' self-perception [14•]. However, these reported improvements in subjective well-being represent individual studies which used primarily self-report, subjective measures. Moreover, the findings are not consistent and follow-up measures were collected at most 6 months after camp, making

long-term changes difficult to assess. In fact, some data suggest no benefits in quality of life comparing youth who had previously attended diabetes camp to those who had not [15]. As the number of youth attending T1D camps grows, so does the need for research that better describes what outcomes and to what degree T1D camps can potentially impact campers, in order to further refine the camp experience and maximize any potential psychosocial benefits.

Medical and Educational Outcomes of T1D Camp

During T1D camps, formal and informal educational opportunities designed to strengthen campers' knowledge of diabetes management and skills related to diabetes care are often available. Frequently addressed educational topics include the importance of frequent blood glucose monitoring, signs/ symptoms of hyperglycemia and hypoglycemia, and carbohydrate counting. Younger children may spend time focused on learning specific diabetes-related skills such as checking their own blood glucose or giving their own insulin injections, while adolescents may receive information on topics related to self-efficacy and achieving more independence in their diabetes care.

Formal trials comparing specific educational interventions at camps have shown mixed results in relation to knowledge attainment, feelings of self-efficacy, goal-setting, and glycemic control. Garcia-Perez and colleagues reported on the results of a series of seminars covering a variety of diabetes-specific educational and psychosocial topics (provided by CDEs, psychologists, and physicians), including carbohydrate counting, recognition of hypoglycemia/hyperglycemia, relaxation strategies, and games promoting healthy behaviors. Among campers age 11–18 compared to youth who did not attend camp, the authors reported an increase in youth's enjoyment of the school environment but no change in diabetes knowledge or anxiety levels [16]. Nabors and colleagues reported on a 2-year study in which parents and children (ages 8–16) engaged in goal-setting for specific learning objectives at camp, such as diabetes knowledge and management skills. In the first year, parents and children independently set goals for learning on diabetes topics while at camp. Among the participating campers, 63 % reported that camp was good or great at teaching them about their diabetes. In the second year, parents and children were guided in their goal-setting by a psychologist and 69 % of children reported that camp was good or great at teaching them about their diabetes. These promising findings suggest that guided goal-setting may support educational aims of T1D camps. However, the authors did not assess long-term knowledge retention, as post-camp surveys were collected on the last day of camp. These results may also be biased by the use of self-report while still at camp [17]. Santiphrahbhab and colleagues described a specific education intervention at T1D camp, which used games, lectures, and small group discussions to emphasize components of diabetes self-management on a variety of topics. Pre- and posttests demonstrated a significant increase in knowledge immediately following camp, and this effect remained at 3- and 6- month follow-up assessments [8].

There is less evidence available regarding lasting improvements in glycemic control in the months and years after attending T1D camps. Despite the education interventions in place at the camp setting studied by Garcia-Perez and colleagues, the authors showed no changes in

glycemic control when following participants up to 1 year following camp attendance [16]. Santiphrahbhab and colleagues showed improved glycemic control 3 months following camp; however, this change was not sustained at the 6-month post-camp follow-up [8]. Using a retrospective chart review of diabetes clinic visit data 3–7 months after a camp session, Wang and colleagues reported that adolescents (ages 12–18) attending a T1D camp had significantly improved glycemic control compared to their peers that did not attend camp. This indication of better glycemic control was more prominent in females; however, camp attendance was not randomized, and pre-camp glycemic control was not reported for either group [18], limiting the ability to draw conclusions about change or improvement in glycemic control over time.

Taken together, the effects of T1D camps on diabetes knowledge, diabetes skill attainment, and glycemic control are generally positive but difficult to interpret due to the relatively small body of relevant studies and mixed findings. Further research with more rigorous methods (e.g., longer follow-up periods, measures other than self-report) is needed to determine the optimal educational and behavioral interventions and their degree of impact on knowledge, self-management skills, and glycemic control.

Other Types of Research in T1D Camp Settings

In addition to research about psychosocial, medical, and educational aspects of T1D camp attendance, numerous studies of other topics not specifically related to the camp experience are completed at T1D camps every year. Given the access to large cohorts of youth with T1D in a highly monitored environment at camp, researchers have been able to conduct studies on many different questions related to T1D, including children's ability to estimate their own glucose [19], frequency of whole grain intake [20], and diabetic retinopathy in adolescents [21]. In addition, diabetes camps have provided a safe environment to conduct clinical trials to evaluate novel diabetes treatment and technologies. In the first study evaluating a real-time CGM system in diabetes camp over a decade ago, 45 campers used the now defunct Cygnus Gluco Watch biographer for overnight glucose monitoring over 154 nights [22]. More recently, the first pilot study of CGM systems with remote monitoring capability took place at diabetes camp. In a study using the University of Virginia Diabetes Assistant (DIAS) Platform, remote monitoring of CGM data at diabetes camp was demonstrated to be feasible and effective in reducing the risk of prolonged nocturnal hypoglycemic events [23]. This provided the proof of concept, safety, and efficacy data for eventual development of remote monitoring CGM systems that have recently become commercially available.

Clinical trials evaluating closed-loop, automated insulin delivery systems have also been conducted at T1D camps. Closed-loop systems use complex control algorithms that interpret CGM trends to adjust insulin delivery via an insulin pump, offering the potential to decrease the burden of diabetes management while improving glycemic control. Clinical trials of these systems conducted at diabetes camps have included the MD-Logic Artificial Pancreas system [24], DIAs unified safety system [25], bi-hormonal “bionic” pancreas system [26], and Medtronic hybrid closed-loop system [27]. The setting at T1D camps is unique in that it has characteristics of both a laboratory and the home setting: campers are highly monitored, yet also have the freedom to engage in everyday activities. As such, diabetes camp is a

highly desirable environment for closed-loop studies trying to monitor safety and efficacy during activities; this provides evidence for functionality in the home setting that is more compelling than data from highly controlled laboratories. Campers may not directly benefit in the short term from participating in these types of research studies because experimental technologies are usually not available for public use for some time after they are first tested. Participation in research also has the potential to change or interfere with the typical camp experience. Yet, the contributions of this research to translate these new technologies to real-life settings potentially benefit everyone living with T1D.

Recommendations for Future Research at T1D Camp

The existing body of research evaluating psychosocial, medical, and clinical research outcomes associated with T1D camp is important and promising, but conclusions are difficult to draw due to conflicting results across studies. It is important to consider and improve the common methodological limitations of studies evaluating camps for youth with chronic illnesses (including T1D) as this field of research progresses. This must happen in the context of one of the major goals of T1D camps: to provide a “typical” camp experience; thus, there should be an impetus to minimize disruptions to camp with any type of research.

First, there are a wide variety of camp experiences available in many different locations, which can limit the generalizability of results to campers in other settings or to larger populations. Even though most research on T1D camp has been focused mainly on the typical overnight sleep-away camps to date, it would be important to consider other types of T1D camp experiences such as day camps, family camps, or weekend retreats in future research to better study the impact of these experiences on youth with T1D. Further, the highly variable research methods used in camp research complicate interpretation of results. Most notably, sample sizes tend to be small and highly selective, often over-representing people who choose and can afford to attend camps [14••]. To counter this problem, outcomes from camps serving a variety of conditions are often evaluated together [9, 10]; this may be appropriate to better understand the common experiences related to camp for youth with complex chronic medical conditions, but limits the ability to study diabetes-specific experiences. Moreover, pre-post designs or brief (e.g., 3-month) follow-up periods limit the conclusions that can be drawn regarding maintenance of changes seen in any psychosocial, medical, or clinical research outcomes over time or outside of the camp setting.

As described in this paper, no confirmatory conclusions about consistent impact on psychosocial or behavioral outcomes can be drawn; this may be due to a true lack of impact or may reflect limitations in the types of interventions delivered at camps. Because most camps are not designed to offer psychological treatment to individuals in need of intervention, participants often report high psychosocial functioning at the start and change cannot be detected over time [14••]. In contrast to psychoeducational or behavioral interventions targeting adherence, quality of life, or glycemic control in medical/clinic settings, camp programming tends to be based on typical camp activities and is not typically designed to target such outcomes using principles of behavioral health theories [14••]. While sustained health behavior change leading to improved health outcomes is ideal, the short-term improvements in subjective feelings related to diabetes that appear immediately during

and after camp are perceived by campers and parents to be valuable and should not be dismissed. It is possible that effects of brief camp experiences are not strong enough to impact psychosocial well-being or health behaviors long-term or that we do not have the measures to capture these improvements [6]. On the other hand, in research among returning campers with pediatric burns, the evidence suggests that the effects of attending camp for consecutive summers may be cumulative and by maintaining long-lasting relationships with other campers, counselors, and the community, there may be a stronger and longer lasting positive influence over time [28]. It is not yet known if results would be similar among youth attending T1D camps over consecutive years. Our recommendations for future studies of T1D camps are as follows:

1. Evaluate a wide variety of camp types, locations, and age groups in order to increase sample size and better determine if effects can be generalized to larger populations.
2. Consider evaluating camp experiences in relation to developmentally appropriate outcomes to better tailor future interventions to youth at different developmental stages. For example, outcomes related to diabetes-related skill attainment (such as giving insulin injections) are more relevant for younger children with T1D, while more complex self-management skills may be more appropriate for adolescents.
3. Collect outcome data not only pre- and immediately post-camp but also over several months to years after camp ends to determine the length of potential impact.
4. Explore longer-term trajectories of key diabetes outcomes among campers to determine the short-term (e.g., glycemic control), medium-term (e.g., diabetes knowledge or skill attainment), and long-term (e.g., quality of life, self-efficacy, family functioning) effects across domains of living with T1D. Exploring trajectories among one-time and repeat campers may help determine the dose effects of camp over time.
5. Researchers should be aware that clinical trials may interfere with typical camping experiences, and this should be emphasized to youth and parents during the informed consent process to ensure youth and their parents are aware of any possible disruptions. Those conducting research in the camp setting should make every effort to minimize the interference with camp activities when conducting clinical trials in order to preserve as much of the camp experience for the participants as possible.

Conclusions

Overall, the wide variety of camp experiences and locations makes it a unique setting to bring together large groups of youth with T1D to foster relationships, share common experiences, and enjoy typical childhood experiences in a medically safe environment. Although there are many hypothesized benefits of T1D camp—such as the ability to form relationships with peers, learn more about diabetes, and potentially have improvement in

psychosocial and medical outcomes—more research is required to determine the veracity and retention of these potential impacts. Thus far, T1D camp has proven to be a setting that is amenable to clinical research, and the data gathered from campers have helped advance diabetes technologies and care, which may prove with time to benefit the T1D community at large. Furthermore, T1D camps have traditionally been a place where those with an interest in advocacy and service can volunteer and have the possibility of impacting youth with T1D in a positive manner. T1D camp continues to expand in size and locations across the globe, and as its popularity increases, so too does the importance of rigorous research to evaluate its impact on the lives and health of campers.

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