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Family Diabetes Camp Amidst COVID-19: A Community of Practice Model

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Abstract

Studies have found that youth are experiencing higher anxiety levels than prior to COVID-19, and youth with type 1 diabetes are at higher risk. Medical specialty camps are a type of camp that provide opportunities for youth with chronic illnesses to share common goals, increase socialization, improve camper well-being, and increase knowledge of diabetes management. The program evaluation sought to determine the impact of a campers' outcomes of independence and perceived competence and familial impact during COVID-19. Over half the participants were at their first diabetes camp and 71% of the campers felt their perceived competence "increased a little bit" because of camp. Over 95% of parents felt that their participation in camp had increased their diabetes knowledge. Qualitative data from parents revealed 2 themes, camp as a meeting place and learning from others. The findings from this study demonstrate that medical specialty camps influence campers' perceptions of independence and competence and that families play an important role in creating a community of practice.

Key words: type 1 diabetes, camp, COVID, community of practice

Introduction

Type 1 diabetes (T1D) is a chronic condition affecting approximately 1 in 400 youth in the United States (Hutchison et al., 2021). Youth living with type 1 diabetes are at risk of experiencing adverse medical and psychological outcomes as they age (Hynes et al., 2016). In



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addition, studies have found that youth are experiencing higher anxiety levels prior to COVID-19, with those diagnosed with preexisting health conditions at higher risk for the development of future complications (Hutchison et al., 2021; Waselewski et al., 2020). Further thwarting matters, other challenges experienced by youth in general will also affect those with T1D. For example, disruption to daily routines, activities, and loss of access to school-based health care providers can contribute to the progression of negative health outcomes (Pavlovic et al., 2021). While engagement in sedentary behavior is acceptable in moderation, stay-at-home mandates provide access to sedentary behavior in excess (Margaritis et al., 2020). To mitigate potential long-term adverse impacts of the current ongoing global health crisis, it is important that support and resources (e.g., camp) reach youth (Waselewski et al., 2020), including those with T1D. These supports must also be created with the youth in mind and other members of their support circle such as parents (Pals et al., 2019).

T1D and Youth

The management of T1D is an ongoing process experienced throughout the lifespan, requiring the integration of self-care into their everyday experiences (Pavlovic et al., 2021). For youth and adolescents with T1D, lifestyle adaptations can be difficult, requiring youth to develop new skills including glucose monitoring and insulin administration (Johnson et al., 2019). Failure to manage T1D for youth can lead to additional health complications throughout their life including higher rates in emergency hospitalizations, episodes of diabetic ketoacidosis, and self-management difficulties, all of which provide additional risk to youths' overall wellbeing (Cengiz et al., 2017). For example, diabetes distress, defined as "negative feelings that are specifically related to having and treating diabetes" (Pyle & Kelsey, 2021, p. 1713), is recognized as a comorbidity that can impact the management of diabetes long-term. Additionally, stressors of managing a chronic condition during times of self-identity and self-esteem building can impact a youth's self-image, shaping their attitudes towards diabetes management behaviors (Douma et al., 2018).

Engaging youth in age-appropriate T1D management interventions can aid in a comprehensive approach to identifying specific sources of distress and needed additional supports. Self-management processes can be conceptualized as components of three distinct categories: focusing on the needs of T1D management, resource access, and managing day-to-day operations (Schulman-Green et al., 2012). Behaviors such as controlling diet, injecting insulin, and monitoring blood glucose are fundamental for overall glycemic control (Luo et al. 2019, p. 4483). The development of coping skills for youth with T1D can improve knowledge,

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confidence, and performance in related self-management (Johnson et al., 2019). Structured programming components that focus on diabetes education can be helpful for the development of self-management skills and build self-efficacy (Johnson et al., 2019).

Positive Youth Development

Positive youth development (PYD) is an approach used and supported by recreational professionals to engineer and structure programs, like camps, that foster positive outcomes (Allen et al., 2021; Hill et al., 2015). By shifting views of youth development from prior identified deficit perspectives, the intent of PYD is to foster overall well-being for youth by focusing on strengths that lead to satisfying adulthood. For over a century, the American Camp Association served as the governing body for the organized camping industry, identifying and documenting outcomes associated with PYD within the context of camp (ACA, 2011).

Participation in organized camp experiences can provide beneficial opportunities for youth, supported through autonomous environments unique to the camping experience. Within the camp environment, recreation professionals directly assess programming and identified outcomes. Outcome-focused programming (OFP) is an approach utilized by recreation professionals to design and execute recreational experiences grounded in specific goals (Hill et al., 2020). During the experience, recreation professionals can assess the progress of participants through observation and debriefing techniques. For youth with T1D, camp can provide a supportive environment for youth to practice self-management skills and receive immediate feedback, which could influence their perception of competence.

Medical Specialty Camps

Medical specialty camps are a type of camp that provide opportunities for youth with chronic illnesses to share common goals, increase socialization, increase independence, improve camper well-being, and increase knowledge of diabetes management (Collins et al., 2021).

Furthermore, participation in medical camps may foster positive relationships between youth and healthcare providers, ultimately supporting positive health behaviors and self-management skills (DiDomizio & Gillard, 2018; Schulman-Green et al., 2012). Among medical specialty camps, those that involved families provided a unique opportunity for further benefits, such as opportunities to build relationships using a shared experience (Collins et al., 2021; Hill et al., 2019). Participation can also have the propensity to improve communication and family bonding because of the altered power structure where parents are taken out of a position of authority (Duerden et al., 2013). That is, despite some challenges that may deter family participation, medical specialty camps designed for engagement for the entire family can provide a safe space

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for enrichment that supports youth as they continue to learn and practice diabetes management (Douma et al., 2018; Griffith & Larson, 2014; Hill et al., 2019). Research suggests family diabetes camp can positively impact camper resilience, learning, and desired camper outcomes when engineering intentional experiences (Collins et al., 2021). Multiple studies demonstrate relationship parental acknowledgment in their direct role to support autonomous behavior (Collins et al., 2021; Hill et al., 2019; Hill et al., 2015), but little research exists about the impact of a family diabetes camp experience during COVID-19.

One overarching aim of this project is to identify a community of practice (CoP) to improve the evidence-based practice for diabetes camps. There are three characteristics of a CoP: a common domain of interest, community, and practitioners. Through the collection and reporting of empirical data to measure diabetes camp's impact on participants, parents, and counselors, we aim to contribute to a CoP serving diabetes camps. Therefore, the purpose of this research study was to determine the impact of campers' outcomes of independence and perceived competence and familial impact during COVID-19.

Methods

Program Description

Programming for the family diabetes camp was held at a local camp during May of 2021, from 9 am to 5 pm, with lunch and dinner provided. Historically, this camp was held as a 3-day overnight weekend camp. However, since our population of campers are at higher risk of COVID-19 complications, it was safest to host one for the day. Camp programming included five primary activities for campers: horseback riding, archery, tie dye, fishing, and rock climbing. Nine cohorts of campers rotated through the five activities throughout the day, in addition to volunteer led activities and games. Programming for parents consisted of five expert-led educational workshops covering recreation, parenting, nutrition, exercise, and medical information from a youth-diabetes perspective. During mealtimes and snacks, sheets consisting of nutritional information were provided for all camp participants, including families and staff. This specific family diabetes camp, established through community partnerships involving researchers, medical professionals, and community leaders, has been held for over 25 years. The program providers consist of a partnership between a mid-Atlantic university, medical diabetes professionals from the surrounding community, the Lions Club, and university researchers. A total of 40 volunteers and staff partnered to provide positive and meaningful programs tailored to youth with T1D. The engagement of all partners accounts for effective programming for youth from both a physiological and developmental perspective of positive

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youth development. Due to the expensive medical costs associated with T1D and the financial struggles of many of the parents due to the pandemic, support from the Lions Club International Foundation made it free to all participants. The collaboration of all three entities (i.e., hospital, Lions Club, and local university) has played a fundamental role in providing innovative, evidence-based practices while making the program accessible for participants.

COVID-19 Protocol

Per recommendation from state mandates and organizational recommendations from the American Camp Association at the time of camp, multiple COVID-19 mitigation strategies were implemented to support the well-being of campers, families, and volunteers. Before COVID-19, family diabetes camp was offered as a 3-day overnight weekend camp held at an alternative facility outside the scope of the established partnership that accommodated the large camping group. Given the limited space allotted for safe social distancing and health practices associated with COVID-19, camper registration was limited to 60. In addition to social distancing protocols, an enforced face mask mandate, and symptom monitoring prior to arrival, traditional programming formatting was altered to accommodate for additional safety measures.

Parent Sessions

Parents were encouraged to participate in five expert-facilitated educational sessions, which took place at the same time as youth programming. Youth development, exercise, and medical professionals provided research-supported information relevant to youth T1D self-management in parent-oriented programming sessions. Sessions included two parent focus groups (recreating with T1D, parenting a child with T1D) and three open-discussion sessions with field-experts (diabetes educator, registered dietician, and physiologist). In past years, parent sessions were limited to only the two focus groups.

Participant Description

Participants in this study were from a mid-Atlantic region community in the United States. Participants were recruited from this program due to the study's aims to investigate the experiences of both youth and parents in medical specialty camps. Additionally, the programming used is theory-based, situating camper outcomes within PYD. The group included 37 campers with a mean age of 11 years old and 22 parents.

Measurement and Data Collection

The American Camp Association Youth Outcome Battery (ACA-YOB) Basic Version was the primary data source for this study. From the ACA-YOB, two outcomes, independence and perceived confidence, were selected from the seven original outcomes (friendship, family citizenship, teamwork, perceived competence, independence, interest in exploration, and responsibility) to use for the youth questionnaire. These two outcomes were selected as they both align with our family diabetes camp mission, helping youth to become more independent in their diabetes management and to increase knowledge. Collectively, the 14-item questionnaire used a 5-point Likert scale ranging from 1 indicating no change to 5 indicating maximum change. Robust testing of this instrument contributes to the reliability and validity of this scale (Sibthorp et al., 2013). For example, outcome-focused questions included "How much, if any, has your experience as a camper in this camp changed you in each of the following ways?" Prior to data collection, all methodologies and approaches were approved by the researchers' university institutional review board. Data were collected after the camp experience in paper format and electronically. Before arrival at camp, families were informed of the study electronically and again once they arrived at the facility. Both parents and youth were informed of their rights as participants and explained the purpose and procedures for the research study.

In addition to the ACA-YOB for youth, an additional parent questionnaire (created by the camp) that included closed and open-ended questions, provided supplemental data. Parent feedback questionnaires were sent to families via email after the camp experience. These questionnaires targeted their overall experience at camp and included feedback on policy change and program satisfaction. Questions included "How helpful is camp at increasing diabetes education for you?" and "What do you think is your and your child's biggest takeaway from camp?" Quantitative measures were analyzed using descriptive statistics, and open-ended questions were analyzed using direct content analysis. Themes were cross-referenced with contributing researchers.

Results

Participant Demographics

A total of 37 youth (of 39) and 22 (of 23) parents provided insight into their experience at camp. Family Diabetes Camp included 43% female campers and 60% campers who reported as Caucasian. The average age of campers was 10.7 years. The majority of campers (60%) identified as Caucasian, 16% African American, 16% Latino and 18% did not answer. Campers

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had an average self-reported HbA1c Level of 8.0 and the average years with diabetes was 3.7. When asked about their enjoyment of camp, they averaged 9.0 (on a 1–10 scale), and 73% planned to attend camp again next year. This year, 52% of campers were new to Family Diabetes Camp. Horseback riding, rock climbing and fishing were campers' favorite activities. Parents who attended were 80% female.

Data from the Youth Outcomes Battery were entered into the preformulated Excel sheet. It produced the percentage of campers who affirmed they learned something about the identified outcomes. Campers who marked a 3 or higher for each item (positive response) were averaged. Most of the campers (71%) felt their perceived competence "increased a little bit" and 32% felt their independence "increased a little bit."

Parent Quantitative Data

Parents (99%) expressed overall satisfaction with the programming despite the COVID-19 protocol and 76% of families strongly agreed the camp was well organized. Fifty-two percent of parents were first-time attendees of diabetes camp. Most of the families were local; the average travel time to camp was 37 minutes. Approximately 81% of families expressed overall satisfaction with the camp itself. This included their perceptions of their family's enjoyment of camp in addition to the programs and activities offered. With diabetes education playing a major programming and outcome implementation component, over 95% of respondents felt that their participation in camp had increased their diabetes knowledge. Out of the five educational sessions offered to parents during camp, "Ask a diabetes educator" was the top preference (indicated by 41% of parents). Despite a newer diabetes education workshop being a preferred session by the parents, 60% of respondents favored returning to a format with just two educational workshops (like in previous years) within the camp.

Parent Qualitative Data

Open-ended questions were analyzed using a constant comparative method (Boeije, 2010). Using this method, each potentially meaningful piece of data was bracketed, and meaningful phrases were categorized into meaning units. Meaning units were reviewed by each research team member, and were organized into thematic categories (Boeije, 2010; Sato & Haegele, 2019). Based on this analysis, three themes were constructed from the meaning units that illustrated key experiences within the program. Table 1 provides examples of direct quotes from participant responses that support each of the constructed themes. The first constructed theme focused on parents' perceptions of how the camp's function as a meeting space for people

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connected by commonalities in their life experiences. According to the parents, a sense of community that was developed through the camp lessened feelings of loneliness for families who found value in being within close proximity to others with similar experiences. For example, one parent expressed “sharing experiences with kids going through the same things as him, helping him feel even more ‘normal’” as a significant role in their experience.

Table 1. Example Quotes Supporting Qualitative Themes

Theme 1: Camp as a meeting place	Theme 2: Learning from others
I loved meeting other parents with different amounts of experience.	We are very new to this, so I just soaked up all the info other parents were throwing out and it was also reassuring to hear from others who had the same thoughts and feelings we did at diagnosis.
It was nice to discuss various situations related to school	Learning some tactics to navigate my newly diagnosed child
I just enjoyed the interaction with other parents.	Learning about the importance of exercise
Sharing with like parents	Learning he is not alone
Confirmation of all the things we go through as a family are not unique.	Learning how to feel comfortable being diabetic.
I liked hearing other parents’ experiences with their kids: challenges, successes, experiences.	Learning how to feel even more “normal”
Ability to ask personalized questions- and hear/share stories with other parents going through the same thing	

The second theme focused on participants’ experiences with learning through interacting with other families and how this learning served an important role for the families and youth. Educational sessions were seen as a space to gain new knowledge from professionals and share their experience with others who may be going through or experiencing something similar. The small, private group setting of camp provided a safe space for both parents and professionals to exchange dialogues and interact. Exemplifying this, a parent explained, “We are newly diagnosed—so him meeting and seeing other ‘real’ kids who have T1D and seeing that he isn’t different or the only one” was meaningful to the family.

Discussion

The purpose of this study was to determine the impact of a campers' outcomes of independence and perceived competence and familial insight during COVID-19. Additionally, we hope to help create a CoP to foster the network of practitioners and the community. These campers and families have no other camp experience available within 150 miles of our camp location. In 2020, due to the pandemic, we had to cancel the camp season (like many camps). The lack of providing this annual experience for our campers hindered many of the benefits both campers and their families gain from the opportunity (Collins et al., 2021). During the pandemic, many youth were denied out-of-school time experiences, and those who are autoimmune compromised, had even fewer options. This program evaluation not only explored the impact of diabetes camp during the pandemic, but provided youth and their families with a beneficial, safe, and educational camp experience. Other studies have similar findings showing diabetes camp to be effective during the pandemic (Williams et al., 2022). In this current study, 71% of campers felt their perceived competence increase. These increases broadly support the work of other studies linking medical camps, PYD, and positive psychosocial health outcomes (Johnson et al., 2019; Kirk & Hinton, 2019; Waselewski et al., 2020). While the focus of diabetes camp is fun in a safe environment, it is also focused on learning about diabetes.

Many teachable moments, under health care supervision (e.g., CoP), can take place at camp. Campers might learn about using a pump, counting carbs, or how physical activity at camp impacts their blood sugar. Camp provides a safe space to test new strategies and ask questions that might not be possible outside of this setting. For example, a study by Collins et al. (2021) demonstrated that 50% of campers learned about the impact of exercise on management of diabetes. Learning new skills at camp can be effective at increasing one's competence. The increase in competence of the current study was of particular significance due to 52% of campers being new to camp.

The current study also found that despite parent proximity, some youth expressed feelings of independence within their camp experience. That is, 32% of campers felt their independence increased, which further supports the role of diabetes camp as a meaningful component in diabetes self-management practices, particularly during a time of high stress for youth (Waselewski et al., 2020). The increase was minimal, likely due to the short 1-day camp model, and the fact that parents were present. Having parents present might minimize campers' independent behaviors. In addition, the role of parents at camp provides additional support for youth living with T1D. These findings corroborate the unique role of family support in chronic

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condition management in medical specialty camps discussed in prior studies (Collins et al., 2021; Hill et al., 2019).

The open-ended responses from parents guided two themes, camp as a meeting place and learning from others. The camp as a meeting place aligns with one component of a CoP. Camp as a meeting place is essential for youth with T1D since they are always the minority when compared to their non-diabetic peers. Studies have explored friendship as an outcome for out-of-school time programs for youth with diabetes (e.g., Allen et al., 2021). Diabetes camp is a space where youth and families can connect to learn from others; explore new medical technology; and for one time a year, be with kids who all (medically) have the same chronic illness. These data also support the need for parents to connect with others who also have youth with diabetes. This study supports similar findings on parental benefits at family diabetes camp (Collins et al., 2021).

This possibly presents an attractive avenue for future research about the perception of parent involvement by youth within a medical specialty camp. During a time filled with additional stressors, bidirectional support for both youth and parents may provide a common space that encourages growth and healing for both parent and child (Duerden et al., 2013). Themes identified through qualitative data analysis highlighted the experience of the family at diabetes camp. The findings are supported by research, particularly highlighting the need for diabetes youth-centered programming (Douma et al., 2018; Hill et al., 2019). Identifying community, learning, and growth has been associated with self-determined behavior, necessary for building overall resilience and consistent self-management habits (Hill et al., 2019).

This study has implications for both practitioner and researcher practices, helping to support a CoP such as the Diabetes Education & Camping Association (DECA), the American Camp Association (ACA) and Friends for Life. While the inclusion of parents produces additional considerations, an administrative team may not traditionally consider findings from this study and other studies suggest parent involvement in out-of-school programming can be beneficial (Duerden et al., 2013; Hill et al., 2019). Although autonomy is needed to encourage self-determined behavior necessary for managing chronic illness, positive support systems play an important role in overall diabetes management. Family diabetes camp can provide both medical and relational supports needed within the adjustment period following diagnosis and continued through life (Kirk & Hinton, 2019). Intentional programming including both the youth and parent while also providing separate parental educational workshops to encourage youth

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independence is recommended for future camp programs. For example, one parent mentioned her conflicted feelings over missing an educational workshop to participate as a spectator in her child's activity. Although campers' independence is encouraged, intentional programming between both camper and parent can be implemented by practitioners to create neutral spaces for interaction and recreation.

Researchers should consider investigating and evaluating the impact of medical specialty camps and their role in facilitating the growth of communities for different populations. Diabetes camps need a CoP to streamline the resources, training materials, measures, outcomes, and theoretical models. Additionally, the investigation of medical specialty camps as affinity groups and spaces for individuals living with a chronic condition and disability should be considered. Continued evaluation of theory-based medical specialty programming is needed to assess the overall impact of our field's theoretical frameworks and other interventive measures.

Limitations

Although our findings were meaningful and can positively impact practice, we had a few limitations. We used the ACA-YOB basic version, which exists as a retrospective design, this does limit getting base-line resulting in possible response bias. We also had a small sample size, but this is more common in medical specialty camps due to medical staff to camper ratio that is required. The duration was short, especially for a residential camp. Historically, this camp is 3 days long, but due to COVID, the overnight stay was not an option. Family camps, especially medical family camps are rare, but future studies should explore the possibility of extended family diabetes camps even beyond the 3 days or consider a maintenance program (e.g., monthly sessions). Finally, our sample was predominately Caucasian, yet diabetes is more common among African Americans (Spanakis & Golden, 2013). Increasing the diversity of our campers should be a focus to better serve all families.

Conclusion

The incidence rate and prevalence of T1D is increasing (Mobasseri et al., 2020) and self-management is vitally important to limit long-term complications and to ensure quality of life for youth. A diabetes diagnosis is significant and not only affects the individual but also can strain relations with family members, friends, and classmates and may present real or perceived barriers to involvement in activities that are typical rites of passages for youth (e.g., sleepovers, summer camps and athletics). Self-care knowledge and coping mechanisms can aid youth with the skills necessary to manage diabetes thus opening doors and opportunities. Medical specialty

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camps that utilize a positive youth development framework are uniquely positioned to provide children the skills and perspectives necessary to successfully live with their diabetes. The 2021 camp experience used evidence-based practice to serve our campers during a time in which youth with T1D had nearly no options for organized recreation. These camps not only give youth the tools to be successful, such as enhancing perceptions of independence and competence, they also create opportunities for parents and family members to adjust perceptions of what youth can accomplish.

The findings from this study demonstrate that medical specialty camps influence campers' perceptions of independence and competence and that families play an important role— although there is still much to learn about what that role is. Future research that builds on integrating the family into a camp in conjunction with youth is important to determine how to enhance support networks for youth living with diabetes. Creating a community of practice for diabetes camps is a societal need to improve the lives of our youth with diabetes and their families.

Author Note

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Dr. Eddie Hill is now an Associate Professor at Weber State University in Ogden, Utah.

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