

Family Diabetes Camp: Fostering Resiliency Among Campers and Parents

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■ ABSTRACT

Youth with diabetes frequently have limited access to traditional camps because of the need for accessible medical staff. With organized camping becoming more specialized with regard to meeting the needs of youth, there is an increased interest in developing and examining the efficacy of programs that serve individuals in specific illness groups, such as youth with type 1 diabetes. In a collaborative effort between a local university, a diabetes center of a local hospital, and the Lions Club, a diabetes camp was created to assist youth in the management of their diabetes. Data were collected over the 3-day family diabetes camp through three approaches: a pre- and post-program resiliency-based questionnaire, the 14-item Camper Learning Scale, and open-ended questions for parents of children with diabetes who were involved in camp. Wilcoxon *t* tests were used to analyze any differences between pre- and post-program scores on resiliency. The results indicated a positive increase of parents' perceptions of their child's resiliency ($Z = -1.833$, $P = 0.67$). Findings from the Camper Learner Scale indicated that 77.14% of campers felt they "learned a little" or "learned a lot" about crucial youth development outcomes (e.g., independence). Finally, direct content analysis of the qualitative measures indicated several themes among parent respondents, which were generalized into three categories: motivation, community, and challenges. Diabetes camps and family diabetes camps have a great opportunity to address some of the challenges young people face while living with the second most common chronic illness facing youth.

Worldwide, ~78,000 youth are diagnosed with type 1 diabetes each year (1), of which 40,000 are in the United States (2). For the past two decades, the prevalence of type 1 diabetes has been increasing in the United States regardless of sex, age, or race/ethnicity. During 2008–2009, an estimated 18,436 people <20 years of age in the United States were newly diagnosed with type 1 diabetes (3). The forecast for future diagnosis rates is bleak, with numbers worldwide expected to increase by 77% in the next 25 years (2).

One of the major challenges of living with diabetes is carrying out

effective self-care. Youth have demonstrated an inability to self-manage their diabetes (4,5). Lack of self-care can lead to emotional issues such as aggression, antisocial behavior, anxiety, and depression. Poor diabetes management can lead to medical complications, including blindness, kidney failure, stroke, nonemergent amputation, and even death (6,7). The consequences of poor diabetes self-care are underscored by findings from a recent meta-analysis of 569 studies that youth with chronic disease demonstrate significantly more mental, social, and academic problems than their healthy peers (8).

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There is no doubt that, “with intensive management of their diabetes, patients can achieve lower glycemia and reduce the risk of developing complications, including severe disease” (9). Fortunately, there has been an increase in diabetes camps focusing on helping youth manage their diabetes (10). Some camps have even added a familial component, with the understanding that camp creates relational bonds. Family diabetes camps can be highly effective at helping with diabetes management and assisting parents in gaining the skills they need to help their child effectively manage the disease (4).

Diabetes Camps

One of the trends in organized camping is the creation of specialized programs that serve user groups who may not traditionally have had their needs met. There are >500 camps worldwide that serve children with a specific disease, and ~30,000 youth with type 1 diabetes attend such camps (11). With an increasingly larger number of youth with diabetes being served annually, there has been a corresponding need to create programs for youth with type 1 diabetes in camp settings (10).

Diabetes camps are an effective medium for peer support, whereby campers are encouraged to share experiences; develop self-management skills; and participate in the realistic practice of exercise, glucose monitoring, diet, and insulin injection in an authentic setting with or without parental influences (11–16). According to the American Diabetes Association (ADA), “camps for children and youth focused on diabetes are invaluable” (11). Furthermore, professional camp organizations such as the Diabetes Education Camping Association reinforce diabetes camps as venues where youth are among their peers while supported by health care professionals in an atmosphere that promotes excitement and adventure (17).

Diabetes camps usually include a multitude of health care professionals,

including physicians, nurses, dietitians, and trained therapists, as well as recreation staff who help to create a supportive and safe environment in which youth and their families can learn best practices for diabetes self-management (17). For example, carbohydrate counting is an essential skill for self-management and a crucial part of training offered in camps serving youth with diabetes. High levels of physical activity in a camp setting (e.g., canoeing) can also affect campers’ blood glucose levels, providing opportunities for youth to learn to manage their own blood glucose and improve their self-care.

The link between high-quality diabetes self-management now and improved quality of life in later adulthood is often unclear for youth living with this disease. A variety of supports are needed for youth with type 1 diabetes to acquire effective self-management skills. If parents allow children with diabetes to independently manage their own care (with supervision as needed), the children will develop the skills necessary for a lifetime of effective self-management.

One promising intervention to enhance diabetes self-care among youth is through outcome-focused camps that are theoretically grounded. Such programs have been shown to be more effective than programs that are not theory based (14). Several studies have shown that theory-based camps enhance self-esteem, self-image, and motivation among youth affected by chronic diseases such as diabetes (5,16). However, there is limited research about the socio-emotional implications and outcomes of youth participation in diabetes camps that are grounded in resiliency theory.

Resiliency

Resiliency is seen as the ability to make positive adaptations to life’s circumstances despite exposure to severe adversity and a multitude of risks (18). Resiliency characteristics that are

fostered in youth are often carried into adulthood (19). Youth diagnosed with diabetes face a new normal that will invariably affect everything they do. Treatment is complex and demanding and necessitates regular blood glucose testing, determining appropriate insulin doses, and monitoring diet and exercise. According to Borus and Laffel, “The spontaneity and sense of immortality and exceptionalism that are hallmarks of the teen years are counter to effective diabetes management” (4). Using resiliency as a framework for education that positions youth to address their own needs could be helpful (20).

Wolin and Wolin (21) identified seven traits or assets that make up resilient individuals’ strength: positive relationships, insight, independence, initiative, creativity, humor, and values orientation. With theory-based camp programming (or outcome-focused programming), these seven traits are embedded in the recreation activities to demonstrate evidence-based practice. Building the traits associated with resiliency gives a person the power to overcome adversity throughout life (21–23).

Diabetes camps focus specifically on overcoming the adversity of living with type 1 diabetes. Previous research has examined the effect of focusing on resiliency in after-school programs (24), resiliency in summer camp settings (20), and self-determination in a diabetes camp (14,16), but little research exists on resiliency training in youth at family-centered diabetes camps. Moreover, camps have been shown to be a positive force and a “unique educational institution” for youth, and diabetes camps specifically have been shown to be effective in providing the supports necessary for self-management and skill development (11,25). Therefore, the purpose of this study was to examine the impact of a theory-based, family diabetes camp on participants’ resiliency, parents’ views of

their child's resiliency, and traditional camp outcomes (e.g., friendship).

Design and Methods

This mixed-methods study explored the role resiliency played in the development of campers and parents engaged in a family diabetes camp in 2015. The research project was a collaborative effort between a local university, a diabetes center, and the Lions Club District 24.

Participants

The camp catered to families of children diagnosed with type 1 diabetes. Families encompassed single parents, married couples, partners, and siblings. Permission to participate, through the use of assents and consents, was obtained from parents and campers. Campers ranged in age from 6 to 17 years. Thirty-five campers and 34 parents completed surveys.

Setting

The 3-day family diabetes camp was held in southeastern Virginia. All youth were required to have at least one adult family member present at camp. The camp had many components of a traditional camp (e.g., archery), as well as workshops on diabetes and parent breakout sessions focused on the development of resilient youth and proper diabetes self-management.

As an example of incorporated diabetes-related activities, before each meal, the amount of carbohydrate in the meal was shared verbally to allow campers to adjust their insulin doses as needed (targeting the resiliency trait of initiative). The camp was designed to keep campers highly physically active throughout the day, which required them to continuously monitor their blood glucose levels and adjust insulin as needed (targeting traits such as insight and independence). The camp also had sessions for younger campers who wanted to practice giving their own insulin injections (targeting independence). Additionally, the traditional camp setting helped form friend-

ships among the campers (targeting relationship-building) and allowed campers to participate in recreational activities and discuss daily challenges with campers who also have type 1 diabetes (targeting creativity).

Two 60-minute parent sessions were held at camp with the medical and university team. These sessions, grounded in resiliency theory, included guided discussions, but allowed parents to ask questions and talk with other parents about shared challenges. The sessions covered the seven traits of resiliency and ways to promote them in youth.

Parents then took turns sharing ways in which their child demonstrated resiliency, whether it related to diabetes management or not. For example, the session facilitator prompted, "Please provide some examples of your child demonstrating creativity." Reflecting on the response would lead to identifying new creative ways their child could manage diabetes (e.g., engaging in different types of physical activity to help manage blood glucose). The facilitator then furthered the discussion to help parents find new ways of fostering resiliency in their children.

Camp Staff

The camp is run entirely by volunteers. Health care professionals (e.g., diabetes educators) associated with the local diabetes center volunteer their time at camp. Many members of the Lions Club also prepared and staffed the camp. Additionally, the family diabetes camp's partnership with a local university provided a service-learning opportunity for college students, who served as camp counselors. Recreation majors volunteered at the camp for the opportunity to put their skills into practice, work among youth and families with medical needs, and gain exposure to a treatment team in a community recreation setting. Faculty members assisted the college students in planning and implementing a variety of theory-based, outcome-focused activities. The student counselors led

the campers in reflective learning discussions related to participation in the camp activities (e.g., horseback riding), as well as their thoughts and feelings during the activities.

Data Collection

Data were collected through three approaches: a pre- and post-program questionnaire called the Resiliency and Attitude Skills Profile-Modified (RASP-M), the American Camp Association's (ACA's) retrospective Camper Learning Scale, and a set of three open-ended questions given to parents (only) after camp. Campers and parents completed the self-report RASP-M questionnaires immediately before camp and immediately upon its completion. This instrument consisted of 24 "I" statements, such as "I am good at making friends" measured on a 6-point Likert scale, with multiple inquiries about each of the seven resiliency traits. The questionnaire has demonstrated evidence of reliability (Cronbach's alpha = 0.84) and construct validity (20).

The 14-item Camper Learning Scale is effective at measuring the ACA's seven outcomes for positive youth development (26,27), targeting friendship, family citizenship, teamwork, perceived competence, independence, interest in exploration, and responsibility. The survey uses a 4-point Likert scale from 1, indicating "I didn't learn about this" to 4, indicating "I learned a lot about this." Robust samples tested led to criterion-related evidence of validity (28). Once data were entered, the ACA's Youth Outcome Battery Excel spreadsheet automatically summed the total and calculated the percentage of campers who "learned a little" or "learned a lot" about each of the seven outcomes.

Three qualitative open-ended questions were included at the end of the camp evaluation, including:

- What led you and your child/family to register for this year's diabetes camp?
- What did you find to be the most

valuable/beneficial activity (if any) at camp and why?

- What challenges, if any, do you and your child/family face with regard to diabetes management?

Researchers used a traditional qualitative approach with directed content analysis to study the written responses campers submitted at the end of the camp session (29). Directed content analysis was chosen because it can offer supporting and non-supporting evidence for the theory used. All respondents were given pseudonyms to protect confidentiality.

Results

Data were collected at the diabetes camp during the summer of 2015. The camper demographics were:

- Sex: 55% male
- Mean age: 10 years
- Race/ethnicity: 71% Caucasian, 20% African American, 9% no response
- Mean A1C: 7.84% (ADA recommendation: 7.5–8.5%, depending on age)
- Diabetes duration: 5% <1 year, 30% 1–2 years, 47% 4–5 years, and 18% ≥5 years

RASP-M Questionnaire

Thirty-two matched sets of pre- and post-program RASP-M questionnaires were collected (69% response rate), including 14 from parents and 18 from youth. Wilcoxon *t* tests were used to analyze any differences between pre- and post-program responses from campers, and any differences between pre- and post-program responses from parents. The results from parents indicated an increase in difference between respondents' RASP-M scores ($Z = -1.833$, $P = 0.67$) before and after the program, but was not significant. The results from the campers did not indicate a significant increase in difference between RASP-M scores ($Z = -1.481$, $P = 0.139$) pre- and post-program.

Camper Learning Scale

To assess the more traditional outcomes from campers, the data were

TABLE 1. Direct Content Analysis

Categories	Subcategories	Occurrences
Motivation (for child's participation)	New experience	12
	Previous experience	7
	Building new relationships	6
	Referred	5
	Gain knowledge	4
	Total	34
Community	Camaraderie	11
	Relationships with children	9
	Relationships with parents	6
	Meeting new people	5
	Total	31
Challenges	Psychological	5
	Meal planning	3
	Monitoring	3
	Not significant	1
	Total	12

analyzed using the ACA's Youth Outcome Battery Excel spreadsheet, which allows practitioners to efficiently evaluate youth-serving programs. Camp counselors administered the Camper Learning Scale to all campers at the end of camp, and then used only campers whose parents consented for data entry. A total of 31 campers completed the retrospective survey and had parental consent (69% response rate). After matching all data, 77.14% of campers felt that they "learned a little" or "learned a lot" about the seven outcomes (e.g., friendship).

Qualitative Analysis

Direct content analysis was conducted on responses of the 14 parents who consented and completed the open-ended questions, which resulted in three unique categories among parent respondents: motivation, community, and challenges (Table 1).

The motivation category was further divided into the subcategories of new experience, previous experience, building new relationships, referred, and gain knowledge, with the highest frequency being the desire for youth to gain a new experience. For exam-

ple, Susan described her motivation of arranging for a new experience for her child when she stated she wanted "to let my daughter have an experience to be around other children going through the same thing she is." Although parents' motivations differed, all respondents had a strong interest in creating a new and different experience for their child.

Another major category was the community that developed among both parents and children. Camaraderie was stated as an important aspect of the sense of community and was described by Lisa when she stated that "camaraderie with other children who have diabetes is the most valuable aspect of camp for my daughter." The building of a unique community was prevalent in all of the respondents' answers, making it evident that this was a valuable part of camp experience.

The third category that emerged among respondents was the challenges they faced with diabetes. Many respondents described physiological challenges related to living with diabetes. For example, Mike stated he needed to "be more supportive—not judging my child based on his blood

sugar.” Although many of the parent respondents indicated multiple challenges with diabetes management, many also indicated that camp aided in dealing with these challenges.

Discussion

Camps are a driving force for positive youth development (30,31). Previous research has explored the impact among youth of attending diabetes camps grounded in self-determination theory (5,14,16,32), but very little evidence exists on the impact of such an experience on a child’s resiliency. Findings from this study could assist in determining what will help a youth with diabetes become more resilient.

This is especially important for children with a chronic illness such as type 1 diabetes, for whom life changes after diagnosis are significant. Unfortunately, youth with diabetes have limited access to traditional camps due to the need for accessible medical staff (32). Therefore, diabetes camps, and the even more uncommon family-centered diabetes camps, need to be further evaluated for program efficacy. Diabetes camps and family diabetes camps have great potential to address some of the challenges of youth living with this illness (10).

Based on the Camper Learning Scale results, 77.14% of the campers learned either a little or a lot about the components of the ACA’s youth outcomes framework (e.g., friendship). This further supports the importance of providing a diabetes camp experience, since children with type 1 diabetes are not often permitted to attend traditional camps. Other research supports the use of the Camper Learning Scale, as well as the RASP-M instrument to determine program efficacy in youth-service agencies (20). Using both measures in conjunction with qualitative data adds to the literature on evaluation of programs for youth, and specifically

organizations providing medical specialty camps.

Results from the RASP-M used at this family diabetes camp show promise. Although neither campers nor parents had statistically significant gains on scores of resiliency, a positive shift in parent scores over a 3-day camp has programming significance. It is likely that administering a follow-up survey to parents 2 weeks or even 1 month after camp would be more effective in obtaining an accurate measurement. It is likely that parents did not have the time to see significant changes while still at camp; yet, once back home, behavior change might have become more apparent. Additionally, a 3-month follow-up would have been helpful to compare scores of resiliency to campers’ 3-month A1C values. Very little research exists on the use of the parent version of the RASP-M (33). Thus, this study adds to the limited body of literature on this topic. This also gives practitioners a new measure to consider using in youth-serving settings in which investigating parents’ perspective of program impact is warranted.

The categories discerned through the qualitative results indicate the challenges faced by parents who raise and support children living with type 1 diabetes. These findings are supported by previous research (14). Within the Community category, the theme of camaraderie (i.e., resiliency relationships trait) has been identified as a key component in self-determination theory and diabetes camp research (5). Parents also indicated the need to be more supportive of their children as they begin to independently manage their illness. This need to assume autonomy-supportive roles by allowing youth be more independent has been identified as the foundation for more self-determined and resilient behaviors (20,34,35).

Practitioner Implications

Through partnerships formed and maintained between the local uni-

versity, the diabetes center of a local hospital, and the Lions Club, the implementation of the family diabetes camp has continued for 10 years. Each partner has played a vital role in keeping the camp affordable, accessible, and entertaining for enrolled constituents. University recreation majors volunteered their time to gain additional professional experience as camp counselors, giving campers the opportunity to meet and learn from students in higher education. The partnership with the diabetes education center of a local hospital allowed the campers and their parents around-the-clock access to medical care and professionals while at the camp. The members of the Lions Club teamed up with the medical staff to develop appropriate meals for the youth, along with unique programming for both campers and parents that was supported by the university students and staff.

Our family diabetes camp applies evidence-based practices through the use of medical staff expertise and camp counselors, who are able to apply their classroom education to the camp setting. Together, the knowledge of these two groups ensures the high-quality care of the campers, as well as appropriate guidance through the weekend activities for both parents and campers. The partnership allows college students to help the medical team have fun with their patients and the patients’ parents, an occurrence that is not usually possible in the clinical environment. Health care professionals in turn provide the tools and knowledge needed for youth with diabetes to take the next steps toward self-management. The supports provided by both sources encourage children with the disease to self-manage their care, promoting the resiliency trait of independence. The medical camp gives parents the opportunity to discuss the challenges of giving their child the independence needed to make the transition to self-care with other parents facing the same issues. Campers are able to

watch their peers as they learn to successfully self-manage the disease.

The parents of children with type 1 diabetes need support as well. The camp offered two parent sessions during the 3-day weekend. The sessions taught parents how to assist in increasing their child's resiliency and gave them the opportunity to ask questions and interact with each other about their individual experiences. The findings in this study begin to show support that diabetes camps allow parents to develop a sense of camaraderie, which is invaluable as their children age and face new challenges.

Limitations and Future Directions

Although the sample size was a slight limitation to this study affecting the generalizability of the findings, medical specialty camps are often small in scale and run less frequently than traditional nonspecialty day and resident camps (32). For this study, some of the campers arrived late, resulting in missing the pre-program questionnaire, and others failed to include their camper ID number for matching of pre- and post-program questionnaires. This can be partly addressed by following up with campers who arrive late to administer the surveys to them and their parents. Future recommendations would be to assess longer camps serving youth with diabetes, in addition to comparing camps with and without a family component.

Conclusion

Youth with diabetes have limited access to traditional camps due to the need for accessible medical staff (10). The emergence of medical specialty camps, and specifically diabetes camps and family diabetes camps, calls for further evaluation for program efficacy. This is especially important as current trends indicate an unfortunate growth in the number of individuals diagnosed with type 1 diabetes each year.

Family diabetes camps provide a safe and innovative environment focusing on youth's ability to effec-

tively manage their disease. The lack of interactive opportunities and settings that focus on effective diabetes management indicates a need for more specialty medical camps supporting the management of incurable diseases that can lead to complications when poorly managed. Given the adversity that youth with such diseases face, programs based on resiliency theory are appropriate. Using theory- and outcome-based programming will also assist camps and programs in seeking funding by confirming their evidence-based approach to recreation services.

Specialty medical camps not only need to incorporate more opportunities to foster resiliency, relationships, family support, and autonomy, but also collaborate with professionals who are certified, trained, and passionate about assisting youth on their journey to a well-managed disease. Providing this type of opportunity can better assist youth as they address various aspects of diabetes self-management that develop as they age, which is essential to effective overall diabetes care and quality of life.

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Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

E.L.H. co-programmed the diabetes camp, collected data, and wrote the manuscript. K.R. co-programmed the camp, served as a counselor, led the parent workshops, and collected data. R.R. wrote and edited the manuscript. M.T. and J.G. served as counselors and wrote parts of the manuscript. E.L.H. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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