EVALUATION OF THE IMPACT OF CAMP MIDICHA ATTENDANCE ON CAMPERS' DIABETES KNOWLEDGE, DIABETES DISTRESS, AND QUALITY OF LIFE

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ABSTRACT

EVALUATION OF THE IMPACT OF CAMP MIDICHA ATTENDANCE ON CAMPERS' DIABETES KNOWLEDGE, DIABETES DISTRESS, AND QUALITY OF LIFE

by Meghan R. Caswell-Pohl

Children and adolescents who are living with diabetes and the accompanying treatment regimen experience many challenges as they cope with and treat their illness. An effective diabetes care regimen requires proper diet/nutrition, carbohydrate counting, insulin shots/pumps, blood glucose monitoring, endocrinologist office visits, multisystemic and cognitive-behavioral therapy, and physical activity. One area to consider as a part of diabetes management/treatment is attendance at a summer camp for youth with diabetes. Camps for youth with diabetes provide an environment where having diabetes is the norm. Camps provide campers with formal and informal opportunities for learning about diabetes, settings that promote and foster social support, as well as opportunities to share and discuss successes, fears, concerns, and surprises about diabetes (McAuliffe-Fogarty, Ramsing, & Hill, 2007).

While summer camps are recognized as a valuable means of delivering services to youth, there is minimal research that examines outcomes for campers with diabetes. The present study conducted a program evaluation of Camp Midicha, a diabetes camp serving children throughout Michigan. The impact of Camp Midicha attendance on campers' diabetes knowledge, diabetes distress, and quality of life were examined. Camper, parent/guardian and staff acceptability of Camp Midicha and its programs/outcomes were evaluated and reported.

Contrary to expectation, a significant decrease in diabetes knowledge on pre-camp to post-camp assessments was found. However, diabetes knowledge significantly increased for pre-camp to follow-up and post-camp to follow-up. In addition, a positive correlation was found for number of camp sessions and diabetes knowledge. The predicted effect of Camp Midicha

attendance on diabetes distress was not found. In contrast, it was found that campers who had attended four or five sessions experienced an increase in diabetes distress. No significant effects were found for campers' quality of life.

Results found that the feedback forms completed by campers, parents/guardians, and medical staff revealed more positive results than the knowledge, diabetes distress, and quality of life instruments that campers completed. The majority of participants agreed that campers experienced increased diabetes knowledge and quality of life and decreased diabetes distress as a result of attending Camp Midicha. Campers, parents/guardians, and staff indicated that Camp Midicha is beneficial and an acceptable program/intervention for children and adolescents with diabetes. Further investigation of the benefits of attending/working at a camp for diabetes is needed.

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CHAPTER I

INTRODUCTION

Diabetes is one of the most common chronic diseases in school-aged children. In the United States, approximately 215,000 people under 20 years of age and about 1 in every 400 children and adolescents has diabetes (Centers for Disease Control and Prevention, 2011). Living with diabetes and the accompanying treatment regimen can be challenging throughout the lifespan. Lifestyle changes for the person diagnosed and their family often are needed in order to track consumed carbohydrates, monitor blood glucose levels, administer and adjust insulin levels, and engage in physical activity (Hauser, DiPlacido, Jacobson, Willett, & Cole, 1993; Hollidge, 2001; Landolt et al., 2002; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). These components of the diabetes care regimen require extensive education, practice, and monitoring. Similar to other diseases/illnesses (e.g., asthma, cancer, attention deficit hyperactivity disorder), if treatment is not followed there can be both immediate (e.g., hypo- or hyperglycemia) and future complications (e.g., vision loss, nerve damage, failing organs, amputation).

While all children face significant challenges throughout their development, children with disabilities and illnesses face additional challenges that are specific to their condition(s). Research indicates children with diabetes are at greater risk for developing psychological difficulties such as poor self-concept, behavior problems, mental illness (e.g., depression, anxiety, disordered eating), and social withdrawal (Battaglia, Alemzadeh, Katte, Hall, & Perlmuter, 2006; Colton, Olmstead, Daneman, Rydall, & Rodin, 2004; Kovacs et al., 1985). Thompson, Zeman, Fanurik, and Sirotkin-Roses (1992) estimated the risk of significant psychological or social problems during childhood for children with chronic illness is 1.3 to 3

times greater than for healthy children. Approximately three times more adolescents with diabetes have psychiatric disorders than their same-age peers. Major depressive, conduct, generalized anxiety, and eating disorders are the most prevalent psychiatric disorders (Kovacs, Goldston, Obrosky, & Bonar, 1997). Grey, Whittemore, and Tamborlane (2002) reported the prevalence of depression in children with diabetes to be two times greater and three times greater in adolescents than youth without diabetes. Jones, Lawson, Daneman, Olmstead, and Rodin (2000) found that eating disorders were significantly more common in females with diabetes (10%) than in the control group (4%). The most common DSM-IV eating disorder diagnosis was ED-NOS (9%) followed by bulimia nervosa (1%). Research indicates children and adolescents with diabetes may experience an increased psychological burden and have psychosocial needs. There are several evidence-based treatment options for effective diabetes care including proper diet/nutrition, insulin shots/pumps, blood glucose monitoring, endocrinologist office visits, multisystemic and cognitive-behavioral therapy, and physical activity. One area that has received minimal research attention as a part of diabetes management/treatment is the impact/effectiveness of diabetes camps on children and adolescents who attend (e.g., impact on diabetes knowledge, physical and mental health outcomes, diabetes management).

CHAPTER II

SUPPORT FOR DIABETES CAMP PROGRAM EVALUATION

American Diabetes Association Diabetes Camp Position Statement

In 1925, Dr. Leonard F.C. Wendt established the first Michigan diabetes camp. Since then, the concept of specialized residential and day camps for children and adolescents with diabetes has become widespread throughout the United States and many other parts of the world. It is estimated that 15,000 to 20,000 campers with diabetes are served each summer by more than 200 diabetes camps in North America, with more than 350 camps worldwide (American Diabetes Association, 1990). In 2007, the American Diabetes Association (ADA) released a position statement, "Diabetes Care at Diabetes Camp" that stated the mission of camps for children and adolescents with diabetes is to "facilitate a traditional camping experience in a medically-safe environment." An additional goal is to enable children with diabetes to meet and share their experiences with one another while they learn to be more responsible for their condition.

In the position statement, ADA (2007) discussed diabetes education and psychological issues of those attending camp. Camp provides an informal atmosphere for age-appropriate diabetes education and equips campers with knowledge and skills to manage their diabetes. Campers are often eager to learn and participate in camp activities, which may suggest an optimal learning environment to teach diabetes management skills. Examples of appropriate educational topics for camp promoted by the ADA include:

- Blood glucose monitoring
- Recognition and management of hypo-/hyperglycemia and ketosis

- Insulin injection techniques
- Carbohydrate counting
- Insulin dosage adjustment based on nutrition and activity schedules
- Pump issues
- Importance of diabetes control
- Healthy lifestyle issues
- Problem-solving for caring for diabetes at home versus camp
- Life skills for independent living
- Stress management and coping skills
- Sexual health and preconception issues
- Diabetes complications
- New therapies including technologies

At the 2006 Diabetes Education and Camping Association conference, representatives from diabetes camps throughout the United States addressed their mission statements. All camps included diabetes education in addition to regular camping goals of recreation and socialization.

ADA (2007) indicated that medical personnel and psychologists/social workers should aim at improving the psychological well-being of campers. Staff members should be willing to address general and specific psychosocial issues and be able to offer suggestions for follow-up. One of the most important psychosocial issues that affect adolescents with chronic illness is self-esteem (Vitulano, 2003). Adolescents who have low self-esteem are at risk for poor compliance as indicated by less frequent checking of blood sugar (Murphy, Thompson, & Morris, 1997). Yi, Vitaliano, Smith, Yi, and Weinger (2008) found patients with diabetes who had low or moderate resilience levels showed a strong association between rising distress and worsening HbA_{1c} across

time. Resilience was defined by a factor score of self-esteem, self-efficacy, self-mastery and optimism. Low resilience was also associated with fewer self-care behaviors when faced with increasing distress. The current study aims to evaluate the impact of camp attendance on campers' diabetes knowledge and quality of life (a related but different concept than self-esteem).

The ADA position statement also addressed research at camp and stated that research is often performed and encouraged at diabetes camps. The research must not interfere with the integrity of the camping experience and should be minimally invasive. The study should be approved by an institutional review board as well as the camp medical and program director before camp. In addition, parents and campers must sign a consent form, along with the summary/synopsis of the research protocol, and ability to contact the principal investigator prior to consent.

Need for Diabetes Summer Camp Evaluation

Summer camps are recognized as a valuable means of delivering services to children and adolescents with chronic illnesses such as diabetes. Plante, Lobato, and Engel (2001) identified camps as a form of group intervention for pediatric chronic conditions. From her research, Bennett-Johnson (1995) suggested that "diabetes knowledge and skills should be reintroduced in an expanded format on a regular basis, as the child grows and matures." Camps for youth with diabetes provide campers with formal and informal opportunities for learning about diabetes, settings that promote and foster social support as well as opportunities to share and discuss successes, fears, concerns, and surprises about diabetes. Camps also provide an environment where having diabetes is the norm rather than the exception, and opportunities to be exposed to new settings with people who are similar (McAuliffe-Fogarty, Ramsing, & Hill, 2007).

While there are a number of camping programs that exist, there seems to be a lack of evidence-based research to support such camps for both camper and staff outcomes. Hunter, Rosnov, Koontz, and Roberts (2006) stated, "there is a staggering discrepancy between the number of camps in existence and the number of published articles pertaining to systematic evaluation of these camps." Results of their PsychINFO literature review indicated that fewer than 35 pertained to camps for chronically ill children (Hunter et al., 2006). For the current study, the term "diabetes camp" was used in a PsychINFO literature review and resulted in 11 peer-reviewed journal articles. Further investigation through ERIC and Medline resulted in several more articles. Hunter et al. (2006) suggest there is a lack of adequate information on the impact of diabetes camp goals and additional investigation needs to evaluate the outcomes and effects on youth who participate in such camps. The researchers also state that diabetes summer camps should be empirically evaluated as interventions to achieve better medical and psychological outcomes.

McAuliffe-Fogarty and colleagues (2007) stated that the current research on diabetes and other medical specialty camps is limited but does indicate promise for benefits-based programming. Program evaluations of diabetes camp are important for several reasons. Program evaluations can provide valuable information to program decision makers and stakeholders including the degree to which the camp produces intended outcomes (e.g., increased diabetes knowledge, better metabolic control), staff accountability, whether consumers and staff are satisfied with programs, and what aspects of the program need modification (Roberts & Steele, 2005). The current study conducted a program evaluation of Camp Midicha that will focus on impact on campers who attend (i.e., diabetes knowledge, diabetes distress, and quality of life) and parent and staff perceptions and acceptability (i.e., social validity questionnaire).

CHAPTER III

LITERATURE REVIEW

History of the Organized Camp Experience

"Camps" that are discussed in this literature review are defined as day and resident (i.e., overnight or sleepover) camps that are conducted with specific social and developmental goals in mind. In addition, these camps are organized experiences in group living and outdoor activities in which leaders are trained to accomplish outcomes. The earliest camps were not-for-profit experiments directed by educators who saw opportunities to teach children in ways schools did not (Eells, 1986). The Gunnery Camp is considered the first organized American camp. In 1861, Frederick W. and Abigail Gunn operated a home school for boys and took them on a two-week trip. The students spent time boating, fishing, and trapping (American Camp Association, 2011). From the 1860s to the 1920s, individuals in education (e.g., headmasters, university students) created camps focused on bringing children out of deprived urban settings and into the New England countryside. At camp, children experienced community living and being away from home in an outdoor, recreational setting. The experience included physical exercise (e.g., hiking), mental challenges (e.g., cooperative problem-solving), social skill development (e.g., making friends), and spiritual events (e.g., outdoor worship) (Eells, 1986). These camp experiences have continued over the last 150 years.

As the youth camping experience movement progressed, it was propelled by many factors such as the concern for the physical, mental, and spiritual health of children, dissatisfaction with traditional schooling, interest in American Indian traditions, conservationism, philanthropic interests of social service organizations, and progressive educational theories. In 1910, the Camp Directors Association of America (CDAA) was founded

which developed a model for the organized camp experience for youth. In 1935, the name was changed to the American Camping Association (ACA) and in 2004 changed to the American Camp Association (ACA, 2011).

During the 1960s and 1970s, camps aligned with humanistic psychology trends to popularize summer camps as therapeutic environments for youth. In more recent years, a renewed enthusiasm for summer camp has occurred due to trends toward outdoor education, teaching values, and providing day care for working families. In addition, camps have been placed into the research spotlight for several reasons including the effect of physical play on development (e.g., Bjorklund & Brown, 1998), interest in positive youth development (e.g., Roth and Brooks-Gunn, 2003), factors that promote development (e.g., Leffert et al., 1998), and accountability for program outcomes (e.g., National Collaboration for Youth, 1997).

History and Vision of American Camp Association

The ACA is a community of camp professionals who, for over 100 years, have shared their knowledge and experience and have strived to ensure the quality of camp programs. The mission of the ACA is to enrich the lives of children, youth and adults through the camp experience. The ACA states that it values the world, the people who live in it, and the contribution each individual can make, and strives to instill these values in the children who attend its camps. ACA believes that the camp experience is essential to every child's growth and education by encouraging children to value their uniqueness and to understand and appreciate their part in the larger community. A quality camp experience is intended to help children grow into committed, responsible citizens by teaching them to appreciate, respect, and care for the world in which they live (ACA, 2011).

Importance of Camp Experience Research

Camp research has been ongoing for many years. Henderson, Bialeschki, and James (2007) reviewed the history of camp research as well as the challenges and implications of camp research. Henderson et al. (2007) suggested that camp research could be classified into two major areas of research: operations and outcome research.

Operations

Research in camp operations focuses primarily on the physical and emotional health and safety of campers and often aligns with the ACA Camp Accreditation Program. This research provides the basis for best practices in camps and has examined staffing, camp evaluation, and business analyses (Henderson et al., 2007). One important aspect of camp is having effective, competent, and caring staff. Camp staff play a large role in camp safety and effective camp operation. Past research with camp staff has suggested that staff have developed skills, particularly in relation to leadership and responsibility (Bileschki, Henderson, & Dahowski, 1998; Chenery, 1994; DeGraaf & Glover, 2003; Dworken, 2004; Garst & Johnson, 2003; Jacobs, McAvoy, & Bobilya, 2005). Several of these studies are described below.

Chenery (1994) interviewed 318 campers, staff, directors, and alumni in order to identify the benefits of the organized camping experience. This information was used primarily to justify and explain the camp experience to decision makers. The interviewed individuals reported the following outcomes as a result of the camp experience: learning about oneself, learning specific activity skills, learning about group living and interpersonal skills, having fun, and gaining an appreciation for nature.

Bileschki et al. (1998) conducted focus groups to examine counselors' perceptions both positive and negative about the camp staff experience. Bileschki et al. (1998) suggested that this

type of information can improve planning and design of new programs, evaluate existing programs, and provide marketing ideas. Fifty-two individuals who had worked at various camps for at least one season participated in the study. The group interviews were analyzed and positive outcomes of being a camp staff member were determined. Staff reported personal and professional positive outcomes such as opportunities for relationships and teamwork with staff and campers, diversity appreciation, development of interpersonal skills, practicing leadership and responsibility, role modeling and mentoring, technical and administrative skill development, and personal growth. Staff also identified negative influences from working at a camp which included dealing with diversity, low wages, lack of time for self, negative perceptions of influential others, frustration with campers, cliques, and lack of director support. Bileschki et al. (1998) offer recommendations to camp directors in order to improve the camp experience for staff and campers.

Garst and Johnson (2003) conducted a study to examine how participation in a residential camp impacted the development of leadership and other life skills in adolescent counselors. In addition, the researchers identified how camp teen counselors positively impacted the youth with whom they interacted and supervised. Sixty eight adolescents aged 14-18 years participated in focus groups where they were given the opportunity to discuss, explore, and describe their camping experiences. Focus group questions were open-ended and asked about how adolescents became involved with camp, memorable experiences, skill development, how adolescents might or might not be important for camp, and how the leadership experience might be improved. Data analysis revealed that participating in camp helped adolescents to: (a) become more responsible for themselves and the youth under their supervision, (b) overcome shyness and become more confident talking in front of large groups, (c) communicate effectively to campers and to adults

in camp, and (d) manage and problem-solve stressful situations. Participants identified a number of specific ways that they helped youth at camp including talking, listening, sharing, and empathizing, as well as teaching campers specific skills during camp classes. This allowed the adolescent counselors to develop a mentoring relationship with youth campers.

DeGraff and Glover (2003) studied how the camp experience impacted staff years after the camp experience. In addition, male and female perceptions of the camp experience were examined for differences. Participants were divided into five groups: 1) staff who worked 5-10 years ago; 2) 11-15 years ago; 3) 16-25 years ago; 4) 26 to 41 years ago; 5) 41 or more years ago. The 29 participants completed a semi-structured interview where questions focused on the before, during, and after camp experience. The responses were divided into four themes/content areas including motivators for working at camp, personal impacts of the camp experience, professional impacts of the camp experience, and reflections on camp. Overall results indicated that a majority viewed the camp experience in positive terms and all respondents recognized the long-term positive impact that the camp experience had on their lives. The motivator mentioned the most by respondents was that they had been campers at the camp they worked at. Men were twice as likely to identify working with kids as a motivator than women. Personal impacts of the camp experience were varied and included improved self-confidence, increased appreciation of nature, spiritual growth, and the development of specific life and interpersonal skills. Participants (n=13) discussed the long-term friendships that were developed at camp. In addition, participants (n=17) talked about how camp impacted how they approached other relationships and family life. When professional impacts were examined, 24 of the 29 participants commented that their camp experience had a positive impact on their professional lives. DeGraff and Glover (2003) found that half of the respondents entered the teaching profession and four of the 14 changed

their career goal to education as a result of their camp experience. Respondents (n=10) indicated the camp experience as a confidence builder and a way to develop marketable skills (e.g., teamwork, leadership, responsibility, technical skill development). Although the results of this study are qualitative, making it difficult to generalize to other programs or individuals, this study provides support for continuing evaluation of the camp experience impact on staff and not just campers.

Jacobs et al. (2005) examined how the summer camp experience impacted staff members and if emotional intelligence is developed through summer camp employment. Jacobs et al. (2005) proposed that summer camp employment helps to equip staff members with critical competencies that contribute to career and leadership advancement. Six residential summer camps with summer seasons of at least six weeks and staff who worked directly with campers participated in the study. Participants completed the Bar-On Emotional Quotient Inventory (EQ-I; Bar-On, 1997) pre- and post-camp. Staff members linked specific programs, responsibilities, and attributes of their summer camp experience with the changes they experienced. The EQ-i data revealed significant increases in emotional intelligence for summer camp staff members. Respondents reported they experienced minor or significant increases along the majority of the fifteen subscales. The programs, responsibilities, and attributes of the summer camp experience that were reported most often as leading to these changes include: residential work environment, meaningful and rewarding employment, a fun atmosphere, multiple leadership opportunities, diverse and challenging responsibilities, difficult campers and demanding situations, limited distractions, and being outdoors.

Dworken (2004) examined the unique contributions and impacts that camps have made on individuals who have worked as camp staff. A total of 188 camp staff representing 117

different resident camps participated in the study. The participants were asked to rate (1 = no-, 2 = moderate-, 3 = much impact) how their camp experience made an impact on the development of their skills or attitudes in 17 different life-skills areas. Questions about the impact of the camp staff experience on their relationships, career and educational choices, community involvement and volunteerism, and motivation to work at camp were also included. Open-ended questions relating to the uniqueness of camp, the benefits they received, and general comments were completed.

The top five ranking life skills that were impacted as a result of the camp experience were leadership skills, sense of responsibility, ability to relate to children, self-confidence, and conflict resolution skills. The skills ranked six through ten included group or team skills, decision-making skills, role models or mentors, people of different backgrounds, and sense of life purpose.

Participants were asked about their motivation to work at camp and the reasons with the highest percentages (92 percent to 86 percent) included that it was fun, they wanted to work with children, and they enjoyed being outdoors. Fifty-one percent reported they were a camper and always wanted to be a counselor and wanted to gain skills for future employment. Current (73.8%) and former (51.7%) staff reported camp made an impact on their career choice. For about half of the participants, camp had made an impact on their educational choices. Forty-six percent of current staff had taken on leadership in professional organizations while 57% of former staff had done the same. Results also indicated 41.4% of the current staff and 63.8% of the former staff were currently involved in community volunteer work. Camp had also made a huge impact on the friendships staff made and kept for many years.

Research on staff outcomes has numerous applications for camp directors, individual staff members, stakeholders, and the ACA. Data from camp staff research could be used to enhance marketing efforts for staff recruitment and stakeholders. Research suggests that camp is a safe and nurturing environment, a caring community, and an important educational experience. In addition, camp may provide many opportunities for personal and professional growth. Research participants have reported learning new skills, working with children or people from different backgrounds, building leadership and interpersonal skills, taking on new/different responsibilities, or being part of a team. In addition, camp staff reported that they gained independence, self-confidence, morals and ethics, responsibility, decision-making skills, role models, compassion, and commitment. Many of these skills are important factors of success in the workplace. In addition to the skills mentioned earlier, camp staff also recognized that they gained skills in problem solving, communications, organization, supervision, and management. Summer camp employment not only provides outdoor fun and meaningful work, but it also helps equip staff members with skills and attributes that contribute to future career and leadership opportunities. The previously described studies describe not only the benefits and outcomes of summer camp employment but also offer insight regarding the components, aspects, attributes, and programs of the summer camp that lead to those specific benefits and outcomes. This information can help guide camp professionals as they plan for summer camp staff training. The current study includes staff perceptions of Camp Midicha but focuses on camper outcomes and program evaluation of Camp Midicha.

Another area of operations research is evaluation which is important for providing quality camp experiences. Henderson et al. (2007) stated that all ACA-accredited camps reported that they conducted evaluations (Henderson & Bialeschski, 1994). A majority of the evaluation

research has focused on satisfaction studies with campers and parents. Unfortunately, these evaluations are used for decision making within the camp but are not published or shared with external sources (Henderson et al., 2007). While these evaluations may be internal only, it may be important to share these results externally or begin to move toward standardized evaluation instruments in order to better compare and communicate results. The current study will use Witt and Elliot's (1985; unpublished manuscript) Intervention Rating Profile to examine camper, parent, and staff perceptions of Camp Midicha. Items were modified to better evaluate the camp's programs, activities, and goals.

Outcomes

In addition to studying camp operations, researchers have also examined youth outcomes related attending summer residential camps. The outcomes studied are diverse due to the nature of summer camps available to youth and areas of research interest. For example, one researcher may examine the impact of camp on campers' self-esteem and social skills while another may examine the HbA1c levels of children who attended a camp for children with diabetes. Regardless of the area of research and method of measurement, researchers appear to be examining the ways in which youth may benefit as a result of camp attendance. The following literature review will briefly summarize youth outcome research and will lead into the focus of the current study – examination of the impact of camp attendance on youth with diabetes.

In 1929, Dimock and Henry conducted what is considered the first systematic research on the outcomes of camp attendance. The study examined behavioral changes in 216 boys who attended a seven-week session at Camp Ahmek in Canada between 1925 and 1928. Case studies and longitudinal group observations with standardized, pre-/post- behavior ratings were used to examine outcomes. Overall, results suggested positive behavioral changes along many

dimensions such as social skills, independence, and the willingness to try new things. Some boys experienced decreases in positive behaviors including manners and sportsmanship while some showed little change in some areas. Parents reported that most boys grew in multiple, positive ways while at camp. Dimock and Hendry (1929) concluded the following: (1) Camp had a net positive but idiosyncratic effect on boys' behavior; (2) Change most likely depended on type of program, peer pressures, quality of leadership, and prevailing attitudes; (3) Younger boys benefited more than older boys; (4) Degree of behavior change was unrelated to length of camp session; (5) Parents' ratings tended to be more favorable than camp staff's ratings; and (6) Several weeks after camp, positive behavior changes continued at home. While this study was one of the first evaluations of camp outcomes, it had its limitations such as being an all-boys camp.

Since Dimock and Hendry's (1929) study, researchers have continued to examine the beneficial effects/outcomes of the camp experience including camper, parent, and staff outcomes/perceptions. During the 1950s, camp research was often published as bibliographies such as the Annotated Bibliography on Camping (Joy, 1955). Henderson et al. (2007) stated that these bibliographies were updated through the 1980s with the last publication being the Bibliography of Research (van der Smissen & Brookhiser, 1982). Camp research continued throughout the 1980s and 1990s and in recent years, camp research has experienced resurgence and the focus on youth development outcomes has emerged. Researchers have examined the general youth population with results suggesting that camp participation impacts youth in a variety of ways by enhancing affective (self-esteem and self-concept), behavioral (self-reported behaviors and behavioral intentions), cognitive (knowledge, skills, abilities, and attitudes), physical, social, and spiritual growth (American Camp Association, 2005; Arnold, Bourdeau, &

Nagele, 2005; Garst & Bruce, 2003; Gillett, Thomas, Skok, & McLaughlin, 1991; Henderson, 2001; Marsh, 1999; Shepard & Speelman, 1986; Thurber, Scanlin, Scheuler, & Henderson, 2007).

Researchers have also focused on children with identified problems including learning disabilities and psychosocial problems (Michalski, Mishna, Worthington, & Cummings, 2003), family dysfunction (Lewicki, Goyett, & Marr, 1996), chronic medical conditions (Hamburg & Inoff, 1982; Thomas & Gaslin, 2001; Wu, Prout, Roberts, Parikshak, & Amylon, 2011), emotional and delinquency problems (Castellano & Soderstrom, 1992; Goodwin & Staples, 2005), and gang involvement (Harris, Fried, & Arana, 1995). Generally, the results of these studies support improvement in camper outcomes including in health, development, and behavior.

According to the ACA, approximately 10 to 12 million individuals attend camp each year (ACA, 2011). While this number consists primarily of children and adolescents, parents and staff are a part of the camp experience. Approximately 500,000 jobs are filled each summer by college students, teachers, health care professionals, water front professionals, sport specialists, and directors (ACA, 1998). In addition, volunteers participate in camp programs in a variety of ways (e.g., health care professionals, educators, parents, church laypeople). Over the past 150 years, camping has influenced the lives of many people. For the majority of individuals, camp has been an enjoyable experience where they have fun participating in activities outdoors and enhancing their overall development. For example, campers learn new skills, make new friends, and become more independent and responsible (ACA, 2005; Arnold, Bourdeau, & Nagele, 2005; Garst & Bruce, 2003; Marsh, 1999). For many years, the research has been anecdotal or examined in a single camp setting and in many cases results are used internally. In addition,

individuals who are involved in the organized camp experience know that camp contributes to the physical, behavioral, emotional, and social development of children who attend and can be a rewarding and beneficial experience for camp staff. Presently, programs for youth are being held more accountable and documentation of best practices and goal attainment are essential. Therefore, further research is needed to document and communicate the efficacy of camp attendance for campers and staff. This study will focus on examining the impact of attending a camp for youth with diabetes.

Review of Diabetes Camp Evaluations

The diabetes camp evaluations that exist in the literature have examined a variety of outcomes including the impact of camp attendance on attitudes toward illness (Briery & Rabian, 1999), illness adjustment (Holden et al, 1991), diabetes knowledge (Harkavy et al., 1983; Johnson et al., 1982; Santiprabhob et al., 2008), use of coping strategies (Smith, Schreiner, Brouhard, & Travis, 1991) and self-esteem (McCraw & Travis, 1973). Summer diabetes camps have also been shown to decrease manifest anxiety among campers (McCraw & Travis, 1973), increase metabolic control and adherence behaviors (Santiprabhob et al., 2008; Spevak, Johnson, Riley, & Silverstein, 1991), and decrease blood glucose levels (Strickland, McFarland, Murtiashaw, Thorpe, & Baynes, 1984; Marrone et al., 2009). In terms of impact on staff at diabetes camp, Johnson (2007) found that pharmaceutical students who assisted medical staff at a diabetes camp reported increased confidence in their diabetes knowledge and patient care skills as a result of participating in the camp. Several studies will be discussed in further detail.

Hamburg and Inoff (1982) studied the relationships between degree of diabetic control and health status and behavioral factors in 211 children and adolescents with type 1 diabetes, aged 5–19 yrs, who attended a diabetes camp. Three variables were measured: demographic,

behavioral, and health variables. The behavioral variables consisted of a Knowledge of Diabetes test (Hamburg & Inoff, 1982) and the Nowicki-Strickland Children's Test of Locus of Control (Nowicki & Strickland, 1973). The health status variables consisted of level of diabetic control, medical history data, hypoglycemia symptoms, behavioral problems, and for girls, menarcheal status. Diabetic control was measured by counselor-monitored urine tests across a two-week period and improved with age except for the 15-19 year old girls, whose control worsened. Duration of camp attendance was negatively related to diabetic control in females only.

Diabetic control was negatively related to knowledge of diabetes. Hamburg and Inoff (1982) suggested that the acquisition of a high level of knowledge may be a coping strategy in response to the stress of poor diabetic control. Males in poor diabetic control tended to have more internal locus of control (i.e., ready to take action to confront their difficulties), and females in poor diabetic control tended to be more external (i.e., feeling powerless and acting compliant). Sixteen percent of children were described by parents as having some degree of emotional or behavior problem with nine to 11 year olds having the highest reported prevalence. This study, while contributing to diabetes research, did not specifically examine the impact of the camp on those who attended. Instead, Hamburg and Inoff (1982) facilitated research at a camp because campers' diabetic regimens are closely monitored. Therefore, the diabetic control variable was studied with minimal confounding effects. While the camp served the researchers' purpose, they may have missed an important research opportunity.

In a 1991 study, Smith and colleagues conducted a preliminary evaluation on the impact of a stress management camp curriculum on adolescent's choices of coping strategies used to deal with personally identified stressful situations. At the beginning of camp, 108, 13-17 year old campers with type 1 diabetes completed The Ways of Coping Checklist – Revised (Lazarus &

Folkman, 1988) and stress ratings. The Ways of Coping Checklist - Revised identifies strategies used to cope with a specific stressful event and provides eight strategy subscales. Stress ratings included ratings of the degree of stress perceived by the camper for the situation identified using a visual analog measure. Ratings ranged from "not stressful at all" to "as stressful as could possibly be." At the end of camp, campers were provided a copy of the stressful situation identified at the beginning of camp and rated what coping strategies they would use in the future if the situation were to happen again. Following the intervention (e.g., life skills curriculum), campers reported an intent to use more problem-focused and fewer detachment strategies to deal with a stressful situation. This study provides a preliminary investigation into program evaluation of diabetes camp curriculum and suggests future research. Diabetes camps have other goals besides the impact of a specific curriculum such as diabetes education, psychosocial well-being, and glycemic control. Smith et al. (1991) could have examined other benefits of camp attendance. Another area of future research is follow-up assessments to determine if the results would persist.

Spevack et al. (1991) conducted a study that assessed the effect of a diabetes summer camp on children's diabetes management behaviors, diabetes control, and relationship between adherence behaviors and diabetic control. Post-camp changes were also examined. Sixty four children, aged seven to 12 years old, participated in the study. Two weeks before camp, each child and parent participated in three separate 24-hour recall interviews. From this data, 13 adherence measures were quantified. At the beginning of camp, glycosylated hemoglobin (HbAlc) and glycosylated serum protein (GSP) levels were obtained from each child. GSP was also obtained at the end of camp. HbA1c is an index of diabetic control and represents average blood glucose levels over the past two to three months. GSP provides similar information but

over 10 to 14 days. During camp, each child was interviewed regarding diabetes management behaviors on three separate occasions. Follow-up occurred at six and 12 weeks post-camp in which the child and parent completed the 24-hour recall interview. HbAlc was obtained at 12 weeks post-camp. Spevack and colleagues (1991) found that nine of 13 adherence behaviors (e.g., injection regularity, exercise duration, glucose testing frequency) improved while attending the diabetes camp. GSP levels indicated that children were in poorer diabetic control at the end of camp compared to the beginning. Calories consumed increased significantly during camp but may be a result of increased exercise while attending camp. A relationship between any of the adherence behaviors and glycemic control was not found. Metabolic and behavioral changes associated with the camp experience were not maintained after camp. This study suggests that while campers engaged in more adherence behaviors while at camp, these behaviors did not generalize to the home environment. While improvements in metabolic control and adherence behaviors are important outcomes of camp, outcomes may not have been maintained due to the duration of the intervention (i.e., camp). Other areas to consider as outcomes of camp are improvements in diabetes management through education and psychosocial issues (ADA, 2007).

Briery and Rabian (1999) examined the relationship between a one-week pediatric summer camping program and children's attitude toward their condition (i.e., asthma, diabetes, spina bifida) and levels of trait anxiety. Prior to this study there had been no empirical investigation into the effects of pediatric summer camps on the construct of attitudes toward illness and its correlates, such as trait anxiety. Children ages six to 16 years completed the Child Attitude Toward Illness Scale (Austin & Huberty, 1993) and the trait scale of the State-Trait Anxiety Inventory for Children (Spielberger, 1973) both pre- and post-camp. Overall, children had better attitudes toward their illnesses and lower levels of trait anxiety at the end of camp. The

changes were evident across diagnostic groups and gender suggesting that specialized camps may provide a benefit for children with special needs (e.g., chronic illness). Briery and Rabian (1999) concluded that participation in a pediatric summer camp was related to changes in psychosocial functioning. The authors speculate that the child's experience of developing a true peer group is what brought about the observed results. Further investigation revealed previous camp experience influenced trait anxiety and attitude toward illness. Returning campers, those who had attended the previous camp sessions, exhibited greater levels of trait anxiety and worse attitudes toward illness than new campers, those experiencing camp for the first time. Briery and Rabian (1999) provide explanations for this result including children with poorer attitudes toward their illness may be more likely to be referred back to camp. In addition, returning campers' attitudes may be more positive than those they had in previous years of camp experience, however, these data are not available. One limitation to this study was the absence of follow-up data. Regardless of limitations, this study was a first attempt to empirically examine psychosocial functioning benefits from a structured pediatric summer camp.

Cheung, Cureton, and Canham (2006) compared the quality of life of adolescents (13-17 years old) with diabetes who attended diabetes camp with adolescents who never attended diabetes camp. Researchers mailed two copies of the consent letter, demographic form, quality of life questionnaire, gift certificate incentive, and self-addressed stamped return envelope to the first 100 participants from the Diabetes Society of Santa Clara Valley's (DSSCV) directory. The Diabetes Quality of Life for Youths (Ingersoll & Marrero, 1991) was used to assess participants' quality of life. The measure is divided into three categories: Satisfaction with Life, Impact of Diabetes, and Worries About Diabetes. Twenty-nine campers and 10 noncampers returned the questionnaires. Results indicated no significant difference in quality of life among adolescents

who attended diabetes camp and those who did not, but provided evidence of the value of social support.

Cheung, Cureton, and Canham (2006) state as the adolescent's dependence on parents decrease, they often rely on peers for support (Greco, Pendley, McDonell, & Reeves, 2001). Adolescents need support from peer groups, family members, classmates, and health care professionals to cope with diabetes. Attendance at a diabetes camp may provide the positive social environment and support adolescents with diabetes need. Diabetes camps are a source of recreation and education that can assist adolescents with diabetes to cope with the stresses related to diabetes management and improve psychosocial functioning (Chueng et al., 2006). Camp also provides the opportunity to form peer relationships and contribute to quality of life (Van der Ven, 2003). Camp allows adolescents with diabetes the opportunity to share knowledge of and experiences with their disease and form friendships with other adolescents with diabetes.

Hunter et al. (2006) conducted a program evaluation of a one-week diabetes summer camp based on the mission statement and goals of the summer camp curriculum. Campers ages seven to 17 years and one of their parents completed pre-, post-, and follow-up (3-month) measures. Measures included a demographic and medical information form, Camp Discovery Self-Management Skills Checklist (Hunter et al., 2006), Diabetes Family Responsibility Questionnaire (Anderson, Auslander, Jung, Miller, & Santiago, 1990), Activity Survey (Hunter et al., 2006), Self-Perception Profile for Children (SPP; Harter, 1985) Self-Perception Profile for Adolescents (Harter, 1988), modified Kansas Coping Inventory for Children (KanCope; Danovsky, 1994), Blood-Glucose Logs, modified Child Evaluation Inventory (CEI; Kazdin, Esvelt-Dawson, French, & Unis, 1987), and a post-camp questionnaire for parents, campers, and staff. Results indicated that a number of the camp's goals were partially or not being met. The

camp's goal to increase campers' self-management skills was only partially met because skills increased for the youngest group of campers but not for the older campers. Results for the camp's goal to enhance campers' self-esteem were mixed. Older campers' global self-worth decreased over time while younger campers' global self-worth increased over time. The camp's goal of increasing time spent with one other person was successful for adolescents but not for the younger campers. Although the camp did not achieve all of its specific goals, campers, parents, and staff were generally very satisfied with their camp experience. Hunter et al. (2006) indicate not all program evaluations need to be as comprehensive as their evaluation but reflect on its importance. Hunter et al. (2006) state that camp developers expend many resources, including time, money, and energy, to ensure that camps are implemented successfully and "if something is considered worth doing with expenditures of effort, time, and money, it is worth evaluating whether the outcomes justify the expenditures" (Roberts & Steele, 2005, p. 351).

Santiprabhob and colleagues (2008) evaluated the effectiveness of a diabetes camp in Thailand on glycemic control (HbA1c level), knowledge (40-item multiple choice test), and psychosocial benefits among patients with type 1 diabetes. In order to assess psychosocial benefits of camp, patients were asked to write down their expectations from attending camp on the first day and their impressions towards the camp on the last day. Glycemic control among patients with infrequent and frequent self-monitoring of blood glucose (SMBG) was also compared. During a five day camp, 60 patients (10-46 years old) were taught diabetes self-management education (DSME). After camp, patients were divided into two groups based on frequency of SMBG (<3 versus 3-4 times/day) and were followed up until 6-month post-camp. Patients' HbA1c levels and knowledge were assessed at baseline, 3- and 6-month post-camp.

Results indicated HbA1c levels decreased significantly at 3-month post-camp but did not sustain at 6-month monitoring for both SMBG groups. The patients with frequent SMBG had a lower mean HbA1c level. A significant improvement in knowledge was noted and sustained up to 6-months post-camp. The patients found diabetes camp of benefit and felt they could better cope with diabetes. Santiprabhob et al. (2008) state that the psychosocial benefits and knowledge gained by patients attending diabetes camp suggests the importance of including a camp in a diabetes management plan. Camp may provide individuals an opportunity to bond and share with others who share a similar experience. The experience and bonding that individuals gain during camp may help them accept and cope with their diabetes (Santiprabhob et al., 2008).

Wang and colleagues (2008) performed a retrospective study of medical records to examine whether attending a 20-day diabetes camp improved metabolic control (e.g., HbAlc), adherence to the medical regimen, psychological well-being, and quality of life. Data was obtained for adolescents with type 1 diabetes, aged 12-18 years. Patients who did (n = 77) and did not (n = 106) attend Camp Sweeny were compared. Demographic information was attained from patients' medical records. In addition, 82 patients and a parent had completed psychological screens. Twenty four of these patients had attended Camp Sweeney. Patients completed the Beck Depression Inventory, Second Edition (BDI-II; Beck, Steer, & Brown, 1996), self-reported adherence (Littlefield et al., 1992), self-efficacy (Littlefield et al., 1992), and quality of life (Diabetes Control and Complications Trial Research Group, 1988) questionnaires. Parents completed the Personal Adjustment and Role Skills Scale III (PARS-III; Walker, Stein, Perrin, & Jessop, 1990), adherence (Littlefield et al., 1992), and quality of life (DCCT Research Group, 1988) questionnaires. Results indicated that metabolic control increased (i.e., lower HbAlc) over time in adolescents who attended the diabetes camp at baseline and follow-up,

while it increased in those adolescents who did not attend. Seven months after camp these significant differences in metabolic control remained for girls but not for boys. Parental report indicated that adherence and adjustment improved for adolescents who attended camp while parents of patients who did not attend camp did not report the change. Wang et al. (2008) suggested that additional studies are needed to determine if these findings can be generalized to other diabetes camps.

Diabetes-related knowledge is a crucial element of diabetes self-management, which is a component of diabetes camp. In order to assess the impact of camp attendance on campers' diabetes knowledge, a valid, reliable, and developmentally appropriate assessment is required. Most diabetes knowledge questionnaires have been developed and evaluated primarily for adult populations, or have become outdated with advances in type 1 diabetes treatments (Davis, 1995; Ellis et al., 2004; Fitzgerald et al., 1998; van den Arend, Stolk, Rutten, & Schrijvers, 2000). In order to address the aforementioned issues, Heidgerken and colleagues (2007) developed and conducted an initial evaluation of the Diabetes Awareness and Reasoning Test child and parent report versions (DART/DART-P). The DART included questions that resulted in a Total Scale Score and seven subscales: General Knowledge (13 items), Insulin (23 items), Nutrition (11 items), School (4 items), Hyper/Hypoglycemia (13 items), Problem-Solving (7 items), and Pump (12 items). The DART-P had five subscales: General Knowledge, Insulin, Hypo/Hyperglycemia, Problem-Solving, and Pump. Participants were 139 children (eight to 18 years old) with type 1 diabetes and 64 parents from an outpatient pediatric diabetes clinic and an overnight camp for youth with diabetes. Item analyses were conducted to develop the DART and DART-P and resulted in an 84-item multiple-choice DART and a 60-item DART-P. Reliability analyses for the DART and DART-P indicated adequate internal consistencies for the Total Score and all of

the subscales except the child School Factors subscale. Preliminary validity support was provided through examination of demographic moderators (e.g., age, education) and correlations with HbAlc. Test-retest reliability and construct validity were not examined. The results suggest initial psychometric support for the DART and DART-P. Heidgerken and colleagues (2007) suggested that the DART and DART-P appeared to be suitable for routine clinical use or research protocols. The current study is interested in campers' diabetes-related knowledge and the DART appears a reliable and valid measure that is both current and developmentally appropriate.

Even with the limited research examining diabetes camps, it appears there are benefits for youth who attend. This is evident from studies that have used pre-, post-, and follow-up assessments, parent and physician reports, and qualitative data. However, it appears there is lack of systematic investigation which may be due to one or many potential reasons. One example of this is method confounds including number of participants, lack of a control group, measures administered, and lack of follow-up assessments. Researchers who want to conduct a program evaluation of diabetes camps have minimal previous research to guide their program evaluation. Program evaluation may be a low priority for camp developers/staff given the tremendous effort needed to organize these camps each year. Others may feel it is too difficult to develop reliable and valid program evaluations. Another issue may be that program evaluation is seen as impeding on the camping experience or that it is unnecessary paperwork. Regardless, research on the benefits and impact of diabetes camp on children and adolescents seems promising and should continue to be developed. This study attempts to contribute to diabetes camp research by examining the impact of camp attendance on campers' diabetes knowledge, diabetes distress, and

quality of life. Campers, parents, and camp medical staff will complete a social validity questionnaire about Camp Midicha's activities, outcomes, and impact on campers.

Information about Camp Midicha

The American Diabetes Association's (ADA) Camp Midicha is located at the YMCA's Camp Copneconic in Fenton, Michigan. YMCA's Camp Copneconic is accredited by the American Camp Association. Camp Copneconic partners with Camp Midicha to provide campsite, dining accommodations, programs and counselor staff. Camp Midicha's first priority is the physical and medical safety of children and adolescents while they enjoy a traditional camp experience; the priority is not perfecting blood sugar management. Camp Midicha staff includes:

- Physicians, nurses, and other health care providers who provide round-the-clock medical supervision.
- Registered dietitians who plan meals and snacks, and manage all special dietary needs.
- Program staff trained to deliver fun, safe, and supervised recreational activities and sports.
- Counselors trained to recognize specific diabetes care needs.

The staff receives training in diabetes management, emergency procedures, and cabin supervision. Every counselor receives extensive training which addresses team building, homesickness, and behavior management (ADA, Camp Midicha 2009-10 brochure).

Camp Midicha offers several camp experiences for children and adolescents with diabetes from ages eight to 17 years old. Children and adolescents are given opportunities to explore the great outdoors and enjoy traditional camp activities, discover new things about themselves and how to manage their diabetes, connect with other kids and adults living with diabetes. Activities

at Camp Midicha include but are not limited to swimming, kayaking, canoeing, hiking, archery, ropes course, sing-a-longs, campfires, diabetes education, and arts and crafts. Even though the diabetes camp schedule seems like an ordinary camp schedule, diabetes management is incorporated into the schedule. For example, before breakfast, lunch, dinner, and bedtime, blood glucose is monitored and insulin is administered. Camp provides an excellent example for campers to fit diabetes into their life instead of their life around diabetes. In 2010, Camp Midicha took place over two; one-week sessions (June 20-25 and June 27-July 2).

Purpose

The review of the literature suggests that diabetes camps are an important area to consider in the management/treatment of children and adolescents with type 1 diabetes. Although several researchers have conducted studies to examine the impact and/or effectiveness of diabetes camps, additional work is needed. The current study aims to further past research by conducting a program evaluation of Camp Midicha. More specifically, the study will examine the impact of Camp Midicha attendance on campers' diabetes knowledge, diabetes distress, and quality of life. Diabetes knowledge and psychosocial issues were two areas identified by the ADA (2007) as areas that camps can improve for campers and are being examined in the current study. Few studies have investigated parent/guardian and staff acceptability and evaluation of diabetes camps. This study includes a social validity rating scale. Results of this program evaluation may provide information to program decision makers and stakeholders including the degree to which the camp produced intended outcomes (e.g., impact on campers), whether parents and staff are satisfied with Camp Midicha, and what aspects of the camp may need modification.

Research Questions

This study aims to conduct a program evaluation of Camp Midicha. The evaluation will examine the impact of Camp Midicha attendance on campers' diabetes knowledge, diabetes distress, and quality of life. Additionally, parent and medical staff perceptions of Camp Midicha will be collected and analyzed. This will include the parent and medical staff perceptions of the camp's programs and goals as well as its effects on the children and adolescents who attend. Camp Midicha provides both formal (American Association of Diabetes Educators, 1994) and informal (e.g., discussions with medical staff, peers, and counselor) education in addition to the traditional camping experience. The results may be used by Camp Midicha personnel to inform camp practices and procedures. In addition, the results may be shared with stakeholders to provide evidence that Camp Midicha is a beneficial component of child and adolescent diabetes care.

1. What is the impact of Camp Midicha attendance on campers' diabetes knowledge?
    a. It is hypothesized that campers' diabetes knowledge will increase on post- and follow-up assessments.
2. What is the impact of Camp Midicha attendance on campers' diabetes distress?
    a. It is hypothesized that campers' will report a decrease in diabetes distress at post- and follow-up assessments.
3. What is the impact of Camp Midicha attendance on campers' quality of life?
    a. It is hypothesized that campers' will report an increase in quality of life at post- and follow-up assessments.
4. What is the parent perception of Camp Midicha and its impact on campers?

a. It is hypothesized that parents will report that Camp Midicha is an effective and beneficial program for children and adolescents with diabetes.

5. What is the staff perception of Camp Midicha and its impact on campers?
    a. It is hypothesized that staff will report that Camp Midicha is an effective and beneficial program for children and adolescents with diabetes.

Depending on the final sample, additional questions regarding differences among campers' will be examined. For example:

1. Are there differences in camper outcomes in relation to number of sessions attended?
    a. As the number of sessions attended increases, the campers' diabetes knowledge will increase.
    b. As the number of sessions attended increases, the campers' diabetes distress will decrease.
    c. As the number of sessions attended increases, the campers' quality of life will increase.

CHAPTER IV

METHODOLOGY

Procedure

The methods used in this study were approved by the IRB of Central Michigan University. Prior to the start of camp, Camp Midicha sent a letter describing the camp evaluation methods (Appendix A and B) to campers and their families. Data collection is a part of the normal camp procedures, and so assessment forms were incorporated into already existing camp activities and routines. It was expected that all campers would complete the forms as a part of Camp Midicha's procedures. Campers, parents/guardians, and staff gave their consent to analyze the data. Participants completed rating scales/questionnaires prior to camp, the first and last day of camp, and at follow-up. Participants also included parents/guardians of the children with diabetes as well as Camp Midicha medical staff. Data were coded and stored at the American Diabetes Association (ADA) office in Bingham Farms, MI. Only the primary researcher, her advisor, and Camp Midicha program personnel had access to the data. All participants were assigned a code and the key was kept in a locked, secure location.

The General Information Form (GIF**;** Greco et al., 2001) was completed for each camper from existing Camp Midicha data (e.g. camp application) by an ADA employee. During camp registration and associated day one activities, campers received and completed three pre-test measures, taking 30-40 minutes. Pre-test measures included: Diabetes Knowledge Questionnaire (DKQ – Revision of DART; Heidgerken et al., 2007), Diabetes Distress Scale-17 (DDS-17; Polonsky et al., 2005), and Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL; Varni, 1998). Children and adolescents attended their selected session of camp and on the last day of camp completed the three pre-test measures: DKQ, DDS-17, PedsQL, and the Camp

Midicha Camper Feedback form. Follow-up occurred four to five months after Camp Midicha in which parent/guardians and campers were emailed and mailed the same four measures: DKQ, DDS-17, PedsQL, and Camp Midicha Parent/Guardian Feedback form. Both post-camp and follow-up measures took 30-45 minutes to complete. The Camp Midicha Staff Feedback form was emailed to medical staff as a surveymonkey link at follow-up. These procedures are summarized in Table 1.

Table 1. *Adminstration of Tests for Camp Midicha Program Evaluation*.

Time	**Tests Administered**
Pre-Test – 1st day of camp	DKQ - Revision of DART (Heidgerken et al., 2007) DDS-17 (Polonsky et al., 2005) PedsQL (Varni, 1998)
Post-Test – Last day of camp	DKQ - Revision of DART (Heidgerken et al., 2007) DDS-17 (Polonsky et al., 2005) PedsQL (Varni, 1998) Camp Midicha Camper Feedback Form
Follow-up – 4-5 months after camp	GIF (Greco et al., 2001) DKQ - Revision of DART (Heidgerken et al., 2007) DDS-17 (Polonsky et al., 2005) PedsQL (Varni, 1998) Camp Midicha Parent/Guardian Feedback Form Camp Midicha Staff Feedback Form

Measures

Demographic Information

A revised version of the General Information Form (GIF; Greco et al., 2001) was used to collect demographic information about the individuals who attended Camp Midicha. The GIF included demographic information such as date of birth, sex, ethnic group, and place of residence. The GIF was modified for this study in order to gain additional diabetes-related

information about each camper. For example, type of diabetes, time of diabetes diagnosis, type of insulin therapy, and number of times attending Camp Midicha. The information on the GIF was collected from Camp Midicha archival data by an ADA employee (i.e., camp application form). See Appendix I for information that was retrieved about campers.

Diabetes Knowledge Questionnaire

The Diabetes Knowledge Questionnaire (DKQ) is a shortened version of the Diabetes Awareness and Reasoning Test (DART; Heidgerken et al., 2007). The reason for the shortened version is explained below. The DART is an 84-item multiple-choice diabetes knowledge questionnaire for pediatric patients with type 1 diabetes (8-18 years old) (Heidgerken et al., 2007). According to Heidgerken et al., (2007) items were developed by a team of clinical psychologists, clinical psychology doctoral students, and pediatric endocrinologists who specialize in working with children with diabetes. All questions were reviewed by a team of endocrinologists and nurse practitioners and based on their recommendations the DART was revised. The DART, which consists of parallel child and parent versions, was designed to include questions that focus on the variety of type 1 diabetes treatment regimens currently used in pediatric populations, and particularly the more intensive diabetes regimens. The DART measures general diabetes knowledge as well as specific dimensions of diabetes care such as blood glucose monitoring, hyper/hypoglycemia, sick day management, insulin administration, and carbohydrate counting. The DART also includes applied questions assessing the respondent's ability to problem solve the most effective way to manage diabetes, given a particular problematic situation (e.g., elevated blood glucose level) and a particular regimen (e.g., specific correction factor).

In order to be minimally invasive to the camping experience and as requested per Camp Midicha personnel, the DART was shortened to 26 items (ADA, 2007) and renamed the Diabetes Knowledge Questionnaire (DKQ). The following subscales were removed: Insulin (23 items), Nutrition (11 items), Problem-Solving (7 items), and Pump (12 items). The General Knowledge and Hyper/Hypoglycemia subscales remain and each contains 13 items. Items remaining on the DKQ are intended to assess basic diabetes knowledge and care. Each item is written as a true or false statement and provides two possible answers (A. or B.) and the DKQ takes about 10-15 minutes to complete. The DART (84-items) has promising preliminary psychometrics. Adequate internal consistency was found for the Total Score and all subscales except School Factors, which has been removed from the DKQ. Examination of demographic moderators and correlations with HbAlc provided preliminary validity support (Heidgerden et al., 2007; Appendix J).

Diabetes Distress Scale-17

The Diabetes Distress Scale (DDS-17; Polonsky et al., 2005) is a 17-item rating scale designed to assess diabetes-related emotional distress and assist clinicians and patients to identify areas where intervention might be helpful (Polonsky et al., 2005). The scale includes four subscales: emotional burden (e.g., feeling overwhelmed by diabetes), physician-related distress (worries about access, trust, and care), regimen-related distress (concerns about diet, physical activity, medications), and diabetes-related interpersonal distress (not receiving understanding and appropriate support from others). Each item is rated on a 6-point Likert scale measuring the degree to which it is currently problematic, from 1 (no problem) to 6 (serious problem). The DDS-17 takes 5-10 minutes to complete. The DDS-17 has been found to have a consistent,

generalizable factor structure as well as good internal reliability and validity (Mullan, Fisher, Skaff, and Polonsky, 2006; Polonsky et al., 2005). See Appendix K.

Pediatric Quality of Life Inventory Version 4.0

The Pediatric Quality of Life Inventory Generic Core Scale *(PedsQL; Varni, 1998)* is a 23-item self-report measure to assess the core dimensions of health (e.g., health-related quality of life) as defined by the World Health Organization as well as school functioning. The Child Self-Report Form (Child: 8-12 and Teen: 13-18) were used in this study. Items on the inventory are rated on a five-point Likert type scale ranging from never (0) to almost always (4) and is then reversed scored to calculate the summary scores (0 = 100 and 4 = 0). The PedsQL contains three summary scores (Total Scale, Physical Health, and Psychosocial Health) and a high summary score suggests a high quality of life. This inventory has been used with children and adolescents in pediatrician's offices, hospital specialty clinics, and community settings. The reliability and validity of this scale has been widely evaluated and deemed appropriate for research and screening purposes. See Appendices L and M.

Camp Midicha Feedback Forms

Campers, staff, and parents/guardians all evaluated the effectiveness of the camping experience. Three different forms were developed adapted from the Witt and Elliott (1985, unpublished manuscript) Intervention Rating Profile.

Camper Feedback Form. The campers completed a rating scale regarding their perceptions of the camp. This scale measured the camper's willingness to implement and recommend the intervention as well as their perception of camp effectiveness. The feedback form included 14 items and the camper indicated their level of agreement with each item. Each

item is rated on a 5-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree). Diabetes knowledge, diabetes distress, and quality of life were addressed on the form (e.g., After attending camp, my distress about my diabetes decreased). Campers were also asked to indicate their most and least favorite thing(s) about camp. See Appendix N.

Parent/Guardian Feedback Form. The parents/guardians of Camp Midicha campers were asked to complete a rating scale regarding their perceptions of the camp. This scale measured the parent's willingness to recommend the intervention as well as their perception of camp effectiveness. The feedback form included 13 items and the parent/guardian indicated their level of agreement with each item. Each item is rated on a 5-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree). Diabetes knowledge, diabetes distress, and quality of life were addressed on the form (e.g., After attending camp, campers' distress about diabetes decreases). Parents/guardians were able to indicate additional comments/suggestions. See Appendix O.

Staff Feedback Form. The camp medical staff completed a rating scale regarding their perceptions of the camp. This scale measured the staff's willingness to implement and recommend the intervention as well as their perception of camp effectiveness. The feedback form included 16 items and the medical staff indicated their level of agreement with each item. Each item is rated on a 5-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree). Diabetes knowledge, diabetes distress, and quality of life were addressed on the form (e.g., After attending camp, campers' distress about diabetes decreases). The feedback form also addressed staff skills/abilities as a result of volunteering at Camp Midicha (i.e., My diabetes-related knowledge improved/increased as a result of working at Camp Midicha; My abilities and skills improved as a result of volunteering at Camp Midicha.). Staff were able to indicate additional comments/suggestions. See Appendix P.

CHAPTER V

RESULTS

Participants

A total of 354 campers participated in at least one of the study assessment batteries (e.g., DKQ, DDS-17, PedsQL, Feedback Form) at pre-, post, or follow-up. Participants consisted of individuals 7-17 years old. The mean age was 11.9 years with a standard deviation of 2.4 years. Nineteen campers did not report their age. Demographics of the participants are shown in Table 2. There were 337 (95.2%) with type 1 diabetes, and two (0.6%) with type 2; 15 (4.2%) did not report their type of diabetes. The race/ethnicity of residential participants was as follows: 91.5% Caucasian, 2.3% African American, 0.3% Asian/Pacific Islander, 0.6% Native American, 0.3% Multi-racial, 0.8% Other, and 4.2% did not report their race/ethnicity. There were 216 (61%) of residential participants using pumps and 121 (34.2%) using injections for insulin delivery. Two hundred and twenty six campers reported the date of their diabetes diagnosis (88 did not report). On average, these campers had been living with diabetes for 5.1 years with a standard deviation of 3.4 years (Range = 0.2-16 years). Campers had attended 2.6 sessions (*SD* = 2.6, range = 1-6, N = 339) including the current session. At follow-up, 40 parents/guardians completed the Camp Midicha Parent/Guardian Feedback Form. Two parents/guardians left one item blank which resulted in 38 parents/guardians who completed the form in full. Thirteen medical staff completed the Camp Midicha Staff Feedback Form.

Table 2. *Camp Midicha Participant Demographic Information.*

354 campers completed at least one test administration.

	N	Missing	Mean	SD	Range
Age	335	19	11.9	2.4	7 to 17
Sex	339	15			
	N (%)				
Female	192 (56.6)				
Male	147 (43.4)				
Ethnicity	339	15			
	N (%)				
Caucasian	324 (91.5)				
African American	8 (2.3)				
Asian/Pacific Islander	1 (0.3)				
Native American	2 (0.6)				
Multiracial	1 (0.3)				
Other	3 (0.8)				
Type of Diabetes	339	15			
	N (%)				
Type 1	337 (95.2)				
Type 2	2 (0.6)				
Years of Diabetes	226	88	5.1	3.4	0.2 to 16
Insulin Therapy	339	15			
	N (%)				
Pump	216 (61)				
Injections	121 (34.2)				
Oral Medication	1 (0.3)				
Other	1 (0.3)				
Camp Attendance	339	15	2.6	2.6	1 to 6
	N (%)				
One	117 (33.1)				
Two	75 (21.2)				
Three	42 (11.9)				
Four	65 (18.4)				
Five	18 (5.1)				
Six	20 (5.6)				
Seven	2 (0.6)				

Data were analyzed using SPSS statistical package for Windows and an alpha level of .05 was used for all statistical tests.

Research Question 1: What is the impact of Camp Midicha attendance on campers' diabetes knowledge?

The first hypothesis was that the campers' diabetes knowledge (DKQ) would increase on post- and follow-up assessments. It was also hypothesized that as the number of camp sessions attended increased, the campers' diabetes knowledge would increase. A small number of participants completed the DKQ pre- (N = 158) and follow-up camp assessments (N = 38). When the DKQ was analyzed, only 21 participants completed the DKQ all three times. This hypothesis was analyzed four ways.

First, a one-way within subjects ANOVA was conducted to compare the effect of camp attendance on diabetes knowledge (pre-, post-camp, and follow-up). A significant effect for camp attendance on diabetes knowledge was found, Wilks' Lambda = 0.697, F (2, 19) = 4.123, p = .033. Post hoc comparisons were conducted between conditions by using three paired samples t-tests. The first paired samples t-test included 138 participants and indicated a significant difference in diabetes knowledge on the pre-camp (M = 21.65, SD = 2.67) and post-camp (M = 20.3, SD = 3.59) assessments; t(137) = 4.33, p = .000, indicating that diabetes knowledge actually decreased from pre-camp to post-camp. A significant difference in diabetes knowledge on the pre-camp (M = 21.36, SD = 2.68) and follow-up (M = 22.82, SD = 2.32) assessments was found; t(21) = -2.51, p = .020 (N = 22), indicating in this case an increase in diabetes knowledge. The third paired samples t-test indicated a significant difference in diabetes knowledge score on the post-camp (M = 20.81, SD = 3.3) and follow-up (M = 22.89, SD = 2.01) assessments; t(36) = -4.19, p = .000 (N = 37), again indicating an increase in diabetes knowledge. See Table 3.

Table 3. *Diabetes Knowledge Questionnaire (DKQ) Pre-, Post-, and Follow-up T-tests*

	N	Pre-	Post-	Follow-up	*t*	*df*
DKQ pre-/post-	138	21.65 (2.67)	20.3 (3.59)		4.33***	137
DKQ pre-/follow-up	22	21.36 (2.68)		22.82 (2.32)	-2.51*	21
DKQ post-/follow-up	37		20.81 (3.3)	22.89 (2.01)	-4.19***	36

* = $p < .05$, ** = $p < .01$, *** = $p < .001$. Standard Deviations appear in parentheses below means.

Second, a 2 (pre-camp, post-camp) x 7 (camp sessions) repeated measures ANOVA determined that the mean score on the DKQ differed significantly between the administrations, $F(1, 131) = 7.469$, $p < .05$ (N = 138) and indicated that campers' diabetes knowledge decreased from pre- to post- test assessments. A paired samples t-test indicated a significant difference in diabetes knowledge pre-camp (M = 21.65, SD = 2.67) and post-camp (M = 20.30, SD = 3.59) assessments, t(137) = 4.331, p = .000 (N = 138), resulting in a decrease in diabetes knowledge. The interaction effect between time of administration and camp sessions attended was not significant, F (6, 131) = 0.358, p = .904, indicating that time of administration and the number of camp sessions attended did not have an effect on campers' diabetes knowledge.

Third, a Pearson's product-moment correlation coefficient was computed to assess the relationship between the number of camp sessions attended and the DKQ post-camp assessment scores. There was a positive correlation between the two variables, r = 0.123, n = 310, p = .030. This result suggests that increases in the number of camp sessions attended is correlated with increases in diabetes knowledge.

Finally, on the Feedback form, 61.3% of campers agreed (40.7%) or strongly agreed (20.6%) with the statement, "My diabetes knowledge improved as a result of camp attendance." The mean score on this item was 3.82, SD = 0.92, N = 319. The camper feedback form had a

high number of participants because the post-test assessments were administered after breakfast on the last day of camp. Campers were served meals at the same time during camp; therefore, almost all campers were in one area supervised by adults to complete the post-test assessments before they could move to their morning activity.

Research Question 2: What is the impact of Camp Midicha attendance on campers' diabetes distress?

The second hypothesis stated that campers would report a decrease in diabetes distress (DDS) at post- and follow-up assessments. It was also hypothesized that as the number of sessions attended increased, the campers' diabetes distress would decrease.
This was analyzed three ways.

A one-way within subjects ANOVA was conducted to compare the effect of camp attendance on diabetes distress (DDS pre-, post-camp, and follow-up). The effect for camp attendance on diabetes distress was nonsignificant, Wilks' Lambda = 0.920, F (2, 34) = 1.484, p = .241) indicating that overall camp attendance did not have an effect on overall diabetes distress. The DDS-17 consists of four subscales: emotional burden and physician-, regimen-, and diabetes-related interpersonal distress. When examining ANOVA results for the subscales, no significant effects were found. See Table 4.

Table 4. *ANOVA for Diabetes Distress Scale (DDS-17; N = 36)*

	df	*F*	*p*
Overall Diabetes Distress	2	1.484	.241
Emotional Burden	2	.082	.922
Physician-related Distress	2	2.759	.078
Regimen-related Distress	2	2.316	.114
Interpersonal Distress	2	2.154	.132

* = $p < .05$, ** = $p < .01$, *** = $p < .001$.

A 2 (pre-camp, post-camp) x 7 (camp sessions) repeated measures ANOVA determined that the mean score on the DDS-17 did not differ significantly between the administrations, F (1, 198) = 0.273, p =.602 which indicated that campers' diabetes distress did not change from pre- to post- test assessments. The interaction effect between time of administration and camp sessions attended was significant, F (6, 198) = 2.535, p = .022. This suggests that campers' diabetes distress was affected by the interaction of the time of administration and the number of camp sessions attended. Post hoc comparisons were conducted between conditions by using paired samples t-tests. Number of camp sessions attended was individually selected to determine significant interaction effects. There were no significant differences in diabetes distress for participants who attended one, two, three, six, or seven camp sessions. A significant difference in diabetes distress was found for the 34 participants attending four camp sessions on the pre-camp (M = 1.60, SD = 0.66) and post-camp (M = 1.80, SD = 0.89) assessments; t(33) = -2.06, p = .047, indicating that diabetes distress actually increased from pre-camp to post-camp. For participants (N = 14) who attended five camp sessions a significant difference in diabetes distress on the pre-camp (M = 1.52, SD = 0.80) and post-camp (M = 2.11, SD = 1.13) assessments was found; t(13) = -2.96, p = .011, indicating an increase in diabetes distress. See Table 5.

Table 5. *DDS-17 Interaction Effect between Time of Administration and Camp Sessions Attended*

Sessions Attended	N	Pre-	Post-	*t*	*df*
One	73	1.72	1.62	1.28	72
		(0.75)	(0.77)		
Two	48	1.87	1.90	-0.28	47
		(0.79)	(0.93)		
Three	22	1.73	1.65	0.48	21
		(1.04)	(0.98)		
Four	34	1.60	1.80	-2.06*	33
		(0.66)	(0.89)		
Five	14	1.52	2.11	-2.96*	13
		(0.80)	(1.13)		
Six	13	1.30	1.29	0.15	12
		(0.27)	(0.42)		
Seven	2	1.94	1.83	1.00	1
		(2.74)	(2.58)		

* = $p < .05$, ** = $p < .01$, *** = $p < .001$. Standard Deviations appear in parentheses below means.

A Pearson's product-moment correlation coefficient was computed to assess the relationship between the number of camp sessions attended and the DDS-17 post-camp assessment scores. The correlation between the two variables was not significant, $r = 0.022$, $n = 309$, $p = .701$. This result suggests that the number of camp sessions attended is not correlated with diabetes distress as measured by the DDS-17.

Finally, on the Feedback form, 58.5% of campers agreed (34.2%) or strongly agreed (24.3%) with the statement, "After attending camp, my distress about my diabetes decreased." The mean score on this item was 3.85, SD = 0.93, N = 315.

Research Question 3: What is the impact of Camp Midicha attendance on campers' quality of life?

The third hypothesis stated that campers would report an increase in quality of life at post- and follow-up assessments. In addition, it was hypothesized that as the number of sessions attended increased, the campers' quality of life would increase. Again, a one-way within subjects

ANOVA was conducted to compare the effect of camp attendance on campers' quality of life (pre-, post-camp, and follow-up). The effect for camp attendance on quality of life was nonsignificant, Wilks' Lambda = 0.976, F (2, 32) = 0.388, p = .682) indicating that camp attendance did not have an effect on overall quality of life. When examining ANOVA results for the subscales, no significant effects were found.

A 2 (pre-camp, post-camp) x 7 (camp sessions) repeated measures ANOVA determined that the mean score on the PedsQL did not differ significantly between the administrations, F (1, 178) = 2.111, p =.148 which indicated that campers' quality of life did not change from pre- to post- test assessments. The interaction effect between time of administration and camp sessions attended was not significant, F (6, 178) = 1.484, p = .186. This suggests that campers' quality of life was not significantly affected by the interaction of the time of administration and number of camp sessions.

A Pearson's product-moment correlation coefficient was computed to assess the relationship between the number of camp sessions attended and the PedsQL post-camp assessment scores. The correlation between the two variables was not significant, r = -0.076, n = 292, p = .197. This result suggests that the number of camp sessions attended is not correlated with quality of life.

Finally, on the Feedback form, 63.5% of campers agreed (35%) or strongly agreed (28.5%) with the statement, "Camp Midicha improved my quality of life." The mean score on this item was 3.97, SD = 0.89, N = 317. See Table 6 for complete Camper Feedback Form results.

Research Question 4: What is the parent perception of Camp Midicha and its impact on campers?

The fourth hypothesis addressed parent/guardian perception of Camp Midicha and hypothesized parents/guardians would report that Camp Midicha was an effective and beneficial program for children and adolescents with diabetes. As part of the follow-up measures, parents/guardians were asked to complete the Camp Midicha Parent/Guardian Feedback form. Forty out of 354 (11.4%) parents/guardians returned a Feedback Form. There were two forms where the participant had skipped one item. Overall, the results on the feedback form were positive, the Total Mean Score was 4.61, SD = 0.64, N = 38. Ninety seven percent of parents/guardians agreed (15.4%) or strongly agreed (82.1%) with the statement, "Camp Midicha is beneficial to children and adolescents with diabetes." The mean score on this item was 4.74, SD = 0.72, N = 39.

Items two, eight, and twelve addressed the focus of this study and had parents/guardians indicate their level of agreement regarding campers' diabetes knowledge, diabetes distress, and quality of life. Item two stated, "Campers' diabetes knowledge improves as a result of camp attendance." and 82.5% of parents/guardians agreed (40%) or strongly agreed (42.5%). The mean score was 4.13, SD = 1.04, N = 40. For diabetes distress, 72.5% of parents/guardians agreed (40%) or strongly agreed (32.5%) with the statement, "After attending camp, campers' diabetes-related distress decreases." The mean score for this item was 4.02, SD = 0.83, N = 40. Finally, 95% of parents/guardians agreed (45%) or strongly agreed (50%) that "Camp Midicha improves campers' quality of life." The mean score for item 12 was 4.4, SD = 0.78, N = 40.

On the parent/guardian feedback form, the highest mean score items were as follows (Items listed had a mean score of 4.8 or higher):

- Item seven: “I would send my child to Camp Midicha in future years.”
- Item six: “Camp Midicha’s activities and programs are appropriate in meeting campers’ needs.”
- Item five: “I would suggest Camp Midicha to a parent/guardian of a child who has been diagnosed diabetes.”
- Item one: “Camp Midicha is an acceptable program/intervention for a child with diabetes.”

In addition, all the items on the parent/guardian/guardian had a mean score of four or higher. The results of the parent/guardian feedback form suggest that parents/guardians agree that Camp Midicha is a valuable component of their child’s diabetes treatment regimen. See Table 7.

Research Question 5: What is the staff perception of Camp Midicha and its impact on campers?

The final hypothesis stated that Camp Midicha staff would report that Camp Midicha was an effective and beneficial program for children and adolescents with diabetes. Thirteen out of 51 medical staff (25.5%) completed the staff feedback form that was sent via surveymonkey.com. Overall, the results on the feedback form were positive, the Total Mean Score was 4.63, SD = 0.31, N = 13. One hundred percent of medical staff agreed (7.7%) or strongly agreed (92.3%) with the statement, “Camp Midicha is beneficial to children and adolescents with diabetes.” The mean score on this item was 4.92, SD = 0.28, N = 13.

Items two, nine, and thirteen addressed the focus of this study and had medical indicate their level of agreement regarding campers’ diabetes knowledge, diabetes distress, and quality of life. Item two stated, “Campers’ diabetes knowledge improves as a result of camp attendance.”

and 100% of staff agreed (15.4%) or strongly agreed (84.6%). The mean score was 4.85, SD = 0.38, N = 13. For diabetes distress, 92.3% of staff agreed (53.8%) or strongly agreed (38.5%) with the statement, "After attending camp, campers' diabetes-related distress decreases." The mean score for this item was 4.31, SD = 0.63, N = 13. Finally, 100% of staff agreed (38.5%) or strongly agreed (61.5%) that "Camp Midicha improves campers' quality of life." The mean score for item 12 was 4.62, SD = 0.51, N = 12.

In addition to camper outcomes, the staff feedback form addressed staff outcomes as a result of volunteering at Camp Midicha. For item eight, "My diabetes-related knowledge improved/increased as a result of working at Camp Midicha," 92.3% of staff agreed (23.1%) or strongly agreed (69.2%) with a mean score of 4.54, SD = 0.88, N = 13. Finally, 84.7% of staff agreed (38.5%) or strongly agreed (46.2%) with the statement, "My abilities and skills improved as a result of volunteering at Camp Midicha." The mean score on this item was 4.31, SD = 0.75, N = 13.

Interestingly, the staff feedback form had the highest Total Mean Score but was only slightly higher than the parent/guardian feedback form followed by the camper feedback form. On the staff feedback form, the highest mean score items were as follows (Items listed had a mean score of 4.8 or higher):

- Item five: "I would suggest Camp Midicha to a parent/guardian of a child who has been diagnosed diabetes."
- Item one: "Camp Midicha is an acceptable program/intervention for a child with diabetes."
- Item two: "Campers' diabetes knowledge improves as a result of camp attendance."
- Item four: "CM is effective in meeting its goals and purpose."

When comparing the highest mean score items, items one and five fell in the top four on the staff and parent/guardian feedback forms. Additionally, the staff feedback form had the highest mean scores for the items that addressed campers' diabetes knowledge, diabetes distress, and quality of life. However, on the parent/guardian and camper feedback forms, the diabetes knowledge, diabetes distress, and quality of life items had the lowest mean scores of all the items. See Table 8.

Table 6. *Camp Midicha (CM) Camper Feedback Form Results*

354 Campers completed at least one camp assessment.

Feedback Statement	N	Mean	SD	Strongly Agree	Agree	Neither Agree/ Disagree	Disagree	Strongly Disagree
1. CM is an acceptable program/intervention for a child with diabetes.	320	4.67	0.53	222 (62.7%)	91 (25.7%)	6 (1.7%)	1 (0.3%)	0
2. My diabetes knowledge improves as a result of camp attendance.	319	3.82	0.92	73 (20.6%)	144 (40.7%)	78 (22%)	18 (5.1%)	6 (1.7%)
3. I would suggest CM to other kids with diabetes.	319	4.7	0.53	234 (66.1%)	76 (21.5%)	8 (2.3%)	1 (0.3%)	0
4. CM's activities and programs met my needs.	317	4.29	0.74	138 (39%)	138 (39%)	36 (10.2%)	4 (1.1%)	1 (0.3%)
5. I would like to attend CM again.	316	4.61	0.78	235 (66.4%)	48 (13.6%)	27 (7.65)	2 (0.6%)	4 (1.1%)
6. After attending camp, my distress about my diabetes decreased.	315	3.85	0.93	86 (24.3%)	121 (34.2%)	85 (24%)	20 (5.6%)	3 (0.8%)
7. CM helped me to feel normal about having diabetes.	317	4.34	0.87	173 (48.9%)	97 (27.4%)	34 (9.6%)	9 (2.5%)	4 (1.1%)
8. I had a negative experience while at camp.	319	1.55	1.02	13 (3.7%)	10 (2.8%)	19 (5.4%)	56 (15.8%)	221 (62.4%)
9. CM programs and activities are appropriate for a variety of children and adolescents with diabetes.	315	4.49	0.65	174 (49.2%)	125 (35.3%)	14 (4%)	0	2 (0.6%)
10. I like the procedures used at CM.	318	4.08	0.85	106 (29.9%)	148 (41.8%)	49 (13.8%)	12 (3.4%)	3 (0.8%)
11. CM improved my quality of life.	317	3.97	0.89	101 (28.5%)	124 (35%)	79 (22.3%)	9 (2.5%)	4 (1.1%)
12. CM helped me to cope better with my diabetes.	317	4.14	0.93	135 (38.1%)	113 (31.9%)	54 (15.3%)	9 (2.5%)	6 (1.7%)
13. I made new friends at camp that I would like to stay in contact with.	319	4.72	0.57	242 (68.4%)	70 (19.8%)	2 (0.6%)	4 (1.1%)	1 (0.3%)

Table 6. *Camp Midicha (CM) Camper Feedback Form Results (continued)*

14. Overall, CM is beneficial to children and adolescents with diabetes.	318	4.65	0.6	225 (63.6%)	76 (21.5%)	15 (4.2%)	2 (0.6%)	0
Total Mean Score	292	4.35	0.44					

Table 7. *Camp Midicha (CM) Parent/Guardian Feedback Form Results*

40 out of 354 (11.3%) parents/guardians completed form.

Feedback Statement	N	Mean	SD	Strongly Agree	Agree	Neither Agree/ Disagree	Disagree	Strongly Disagree
1. CM is an acceptable program/intervention for a child with diabetes.	40	4.83	0.68	36 (90%)	3 (7.5%)	0	0	1 (2.5%)
2. Campers' diabetes knowledge improves as a result of camp attendance.	40	4.13	1.04	17 (42.5%)	16 (40%)	4 (10%)	1 (2.5%)	2 (5%)
3. Most parents would find CM initiatives appropriate.	39	4.69	0.73	30 (76.9%)	8 (20.5%)	0	0	1 (2.6%)
4. CM is effective in meeting its goals and purpose.	40	4.55	0.75	25 (62.5%)	14 (35%)	0	0	1 (2.5%)
5. I would suggest CM to a parent/guardian of a child who has been diagnosed diabetes.	40	4.85	0.66	37 (92.5%)	2 (5%)	0	0	1 (2.5%)
6. CM's activities and programs are appropriate in meeting campers' needs.	40	4.88	0.65	38 (95%)	1 (2.5%)	0	0	1 (2.5%)
7. I would send my child to CM in future years.	40	4.9	0.63	39 (97.5%)	0	0	0	1 (2.5%)
8. After attending camp, campers' diabetes-related distress decreases.	40	4.02	0.83	13 (32.5%)	16 (40%)	10 (25%)	1 (2.5%)	0
9. CM does not result in negative side-effects for campers.	40	4.68	0.76	31 (77.5%)	7 (17.5%)	1 (2.5%)	0	1 (2.5%)
10. CM programs and activities are appropriate for a variety of children and adolescents with diabetes	40	4.73	0.72	32 (80%)	7 (17.5%)	0	0	1 (2.5%)
11. I like the procedures used at CM.	40	4.5	0.78	24 (60%)	14 (35%)	1 (2.5%)	0	1 (2.5%)
12. CM improves campers' quality of life.	40	4.4	0.78	20 (50%)	18 (45%)	1 (2.5%)	0	1 (2.5%)
13. Overall, CM is beneficial to children and adolescents with diabetes.	39	4.74	0.72	32 (82.1%)	6 (15.4%)	0	0	1 (2.6%)

Table 7. *Camp Midicha (CM) Parent/Guardian Feedback Form Results (continued)*

Total Mean Score	38	4.61	0.64

Table 8. *Camp Midicha (CM) Staff Feedback Form Results*

13 out of 51 Medical Staff (25.5%) completed form.

Feedback Statement	N	Mean	SD	Strongly Agree	Agree	Neither Agree/ Disagree	Disagree	Strongly Disagree
1. CM is an acceptable program/intervention for a child with diabetes.	13	4.92	0.28	12 (92.3%)	1 (7.7%)	0	0	0
2. Campers' diabetes knowledge improves as a result of camp attendance.	13	4.85	0.38	11 (84.6%)	2 (15.4%)	0	0	0
3. Most camp personnel would find CM initiatives appropriate.	13	4.69	0.48	9 (69.2%)	4 (30.8%)	0	0	0
4. CM is effective in meeting its goals and purpose.	13	4.85	0.38	11 (84.6%)	2 (15.4%)	0	0	0
5. I would suggest CM to a parent/guardian of a child who has been diagnosed diabetes.	13	5.00	0.00	13 (100%)	0	0	0	0
6. CM's activities and programs are appropriate in meeting campers' needs.	13	4.85	0.38	11 (84.6%)	2 (15.4%)	0	0	0
7. I would be willing to volunteer at CM in future years.	13	4.77	0.44	10 (76.9%)	3 (23.1%)	0	0	0
8. My diabetes-related knowledge improved/increased as a result of working at Camp Midicha.	13	4.54	0.88	9 (69.2%)	3 (23.1%)	0	1 (7.7%)	0
9. After attending camp, campers' diabetes-related distress decreases.	13	4.31	0.63	5 (38.5%)	7 (53.8%)	1 (7.7%)	0	0
10. My abilities and skills improved as a result of volunteering at Camp Midicha.	13	4.31	0.75	6 (46.2%)	5 (38.5%)	2 (15.4%)	0	0
11. CM does not result in negative side-effects for campers.	13	4.15	0.99	6 (46.2%)	4 (30.8%)	2 (15.4%)	1 (7.7%)	0

Table 8. *Camp Midicha (CM) Staff Feedback Form Results (continued)*

12. CM programs and activities are appropriate for a variety of children and adolescents with diabetes.	13	4.69	0.48	9 (69.2%)	4 (30.8%)	0	0	0
13. I like the procedures used at CM.	13	4.62	0.51	8 (61.5%)	5 (38.5%)	0	0	0
14. CM improves campers' quality of life.	13	4.62	0.51	8 (61.5%)	5 (38.5%)	0	0	0
15. The staff training on June 19 adequately prepared me for Camp Midicha.	13	4.08	0.49	2 (15.4%)	10 (76.9%)	1 (7.7%)	0	0
16. Overall, CM is beneficial to children and adolescents with diabetes.	13	4.92	0.28	12 (92.3%)	1 (7.7%)	0	0	0
Total Mean Score	13	4.63	0.31					

CHAPTER VI

DISCUSSION

The purpose of this study was to conduct a program evaluation of Camp Midicha's effectiveness in addressing the needs of children and adolescents with diabetes. The ADA (2007) identified diabetes knowledge and psychological issues as areas that diabetes camps can improve for campers. Living with diabetes and the accompanying treatment regimen can be challenging and research has documented adherence and coping difficulties in children and adolescents with diabetes (Hauser et al., 1993; Hollidge, 2001; Landolt et al., 2002; Meijer et al., 2000). Camp Midicha may be an ideal setting for campers to learn and maintain management of their diabetes. Camp staff (medical and counselors) are trained in diabetes management and work with campers to improve their knowledge and coping skills. Campers are able to meet and share their experiences with one another which may positively affect psychological well-being. Therefore, the evaluation examined the impact of Camp Midicha attendance on campers' diabetes knowledge, diabetes distress, and quality of life. In addition, campers, parents/guardians, and medical staff completed a feedback form that evaluated the effectiveness of the camping experience. It was expected that camper's diabetes knowledge and quality of life would increase while diabetes distress would decrease on post- and follow-up assessments. In addition, because campers attend a varying number of sessions, the number of camp sessions attended was expected to affect assessment outcomes. It was hypothesized that as the number of sessions attended increased, the campers' diabetes knowledge and quality of life would increase while diabetes distress would decrease. Lastly, it was anticipated that campers, parents/guardians, and medical staff would report that Camp Midicha is a highly effective program/intervention for children and adolescents with diabetes. The findings of this study provide only partial support for

the hypotheses which will be discussed below. Overall, while those completing the feedback forms were highly positive regarding the effectiveness of Camp Midicha, scores on the specific instruments reflected varying results.

Interestingly, this study found that diabetes knowledge decreased at the post-camp assessment but increased at follow-up. There may be several reasons for this. First, there may be an instrument affect due to taking the measure so many times. Second, the information may have provided a foundation for seeking out or receiving more information from the internet or medical service providers. It is further possible that campers were excited to be going home when they took the measure post-camp and so they did not attend to it properly, but were able to answer accurately at follow-up. Supporting the effectiveness of the camp experience was the positive correlation between number of sessions attended and knowledge. The camper feedback form (post-assessment) indicated that a majority of campers agreed or strongly agreed that their diabetes knowledge increased as a result of attending camp. This perception data is important to consider because perceptions often affect behavior. For example, if campers perceive they are gaining diabetes knowledge they may continue to attend Camp Midicha. In addition, they may seek further knowledge to improve their condition and adherence.

While Camp Midicha is very structured in terms of schedule, activities, and diabetes management, formal diabetes education was not a major focus at camp. This factor may also contribute to the diabetes knowledge results. Camp Midicha appeared to focus on providing a typical camp experience while keeping campers medically safe. Diabetes education was scheduled for 30 minutes after lunch and was conducted by the cabin's medical staff personnel. The medical staff determined the diabetes education for their cabin and therefore the education varied. Diabetes education seemed to happen more informally (e.g., learning to give insulin shot,

treat low/high blood sugars responsibly, insert infusion site, set insulin pen). Throughout camp, medical staff and counselors encouraged campers to become more independent in their diabetes treatment. For example, medical staff handed insulin pens to campers to give themselves their injection. Campers also learned to change their infusion sites independently. In addition, campers were recognized at meal times for positive diabetes-related behaviors including learning to conduct a new diabetes regimen task. Regardless of this limitation, results suggest that these camp attendees experience an increase in diabetes knowledge. It is difficult to determine what part of camp may have contributed to this increase. At Camp Midicha there are many situations in which diabetes education may have occurred but may not have been measured by the DKQ. Therefore, the feedback form may have captured the learning opportunities that occurred informally.

Similar to the diabetes knowledge results, the findings for diabetes distress indicated varying results. Surprisingly, campers who attended four or five Camp Midicha sessions reported an increase in diabetes distress at post-assessment. In contrast to this result, support for decreased diabetes distress was found on the camper feedback form. Briery and Rabian (1999) found returning campers exhibited examined trait anxiety and worse attitudes toward illness than new campers. Briery and Rabian (1999) speculated that campers with poorer attitudes toward their diabetes may be more likely to be referred back to camp. Perhaps, this is the case for campers at Camp Midicha. One reason for the increase in diabetes distress may be related differences in diabetes treatment at camp and at home. Camp Midicha provides campers with a structured, medically-safe environment. At the end of camp, campers may return to an environment where the treatment level may not be as intensive and well-monitored as Camp Midicha. Therefore, the camper experiences increased diabetes-related distress as they cope with returning to their

previous environment. Another possibility for the increased distress may be the focus of diabetes at Camp Midicha. Camp Midicha is solely a camp for individuals with diabetes. While camp personnel attempt to provide a typical camp experience, they must also ensure a medically safe environment for its campers. As a result, diabetes and its treatment is a major focus of camp which makes it difficult to ignore and may cause more distress for campers. Lastly, it may be important to consider the age of the campers who attended four and five sessions as other factors may influence distress such as stage of development (e.g., adolescence). Of the 48 campers who attended four or five sessions, over two-thirds were 12-16 years old. This is important to consider as research has indicated varying degrees of psychosocial issues and regimen adherence related to diabetes especially during adolescence (Band, 1990; Battaglia et al., 2006; Colton et al., 2004; Kovacs et al., 1997; Pendley et al., 2002; Stewart, Emslie, Klein, Haus, & White, 2005; Thomas et al., 1997; Thompson et al., 1992). While camps for children/adolescents with diabetes focus on providing a typical camp experience in a medically safe environment it may also be important to examine camp practices and supports for adolescents with diabetes in order to improve the their levels of distress, adherence, and psychosocial issues.

Finally, the low mean scores on the pre- DDS-17 may have impacted the analysis. The pre-DDS-17 Total and Subscale scores were low for a majority of the individuals who attended Camp Midicha. Due to the fact that pre-test scores were low there was not much room for diabetes distress levels to decrease at post-camp and follow-up assessments.

As indicated previously, the camper feedback form provided support for decreased diabetes distress for campers. A majority of campers agreed or strongly agreed that their diabetes distress decreased as a result of attending Camp Midicha. Interestingly, of the 14 items on the feedback form, the diabetes distress item had the lowest percentage of agreement and second

lowest mean score. While campers indicated on the feedback form that their diabetes distress decreased, on item 14 the lowest percentage of campers agreed or strongly agreed with the statement. In addition, close to a quarter of campers indicated they neither agreed nor disagreed with the statement, which was the highest percentage for all items.

Results were mixed when examining the effects of attendance at Camp Midicha on campers' quality of life. Camp Midicha was not found to increase campers' quality of life as measured by the PEDsQL or when looking at number of sessions attended. Importantly, similar to the DDS-17 pre-test scores, the PedsQL pre- Total and Subscale summary scores were high. These campers tended to report a high quality of life. Therefore, when the campers completed the post- and follow-up assessments there was minimal room for improved quality of life. Support for the camp impacting quality of life was found with the camper feedback form results. The camper feedback form indicated a majority of campers agreed or strongly agreed that Camp Midicha improved their quality of life.

As predicted, the parent/guardian and staff feedback form results strongly supported that Camp Midicha is an effective and beneficial program for children and adolescents with diabetes. The total mean scores on the parent/guardian and staff feedback form were both high with staff ratings being the highest. One possible explanation for the higher medical staff perceptions of Camp Midicha may be related to the amount of work and time devoted in order for camp to run smoothly and successfully. Medical staff are assigned to one cabin of campers. This may have allowed for direct observation of changes in the campers they care for throughout the week. Medical staff also made at least one goal for each of their campers and at the end of the week reported on the campers' progress toward his/her goal. Medical staff may be looking for changes and growth in their campers which was reflected in the feedback form. In addition, staff may

have inflated perceptions of Camp Midicha and the outcomes for campers due to the commitment that Camp Midicha requires.

While this study focused on camper outcomes, the staff feedback form contained four items that addressed staff perceptions as a result of volunteering at Camp Midicha. Staff agreed that they would be willing to volunteer at Camp Midicha in future years and their abilities, skills, and diabetes related-knowledge improved/increased. This result is similar to Johnson (2007) who found that pharmaceutical students' reported increased confidence in their diabetes knowledge and patient care skills as a result of assisting medical staff at a diabetes camp. Another interesting finding on the staff feedback form was that item 15 had the lowest mean score of the 16 items. Item 15 stated, "The staff training on June 19 adequately prepared me for Camp Midicha." While staff agreed that the staff training adequately prepared them for Camp Midicha, it may be important to further investigate the one-day training in order to find areas that may need improvement.

Support for the hypotheses of this study varied and a discrepancy was found between scores on the feedback forms and those on the specific instruments (e.g., DKQ, DDS-17, & PEDsQL). Specifically, the feedback forms were highly positive regarding the effectiveness of Camp Midicha while scores on the specific instruments were varied and indicated less support for the hypotheses. Reasons for these result differences are discussed. First, participants may have felt pressure to give positive ratings or "fake good" on the various assessments. As a result, the feedback form results were positive but limited significant results were found on the direct measures. For example, campers completed the pre-test assessments during registration and in many instances his/her parent/guardian accompanied the camper. The camper may have filled out the pre-test assessments more positively due to parent/guardian presence. Therefore, when

the camper completed the post-test and follow-up assessments the expected outcomes were not found.

Second, the feedback form was an "indirect" assessment while the DKQ, DDS-17, and PEDsQL were "direct" assessments. While there are pros and cons to both types of assessments, one con of an indirect assessment (i.e., survey) may have played a role in the highly positive feedback form results (Allen, 2008). More specifically, it is feasible that the campers' perceptions of their gains/abilities may not align with their actual gains/abilities as assessed on the direct measures. For example, a majority of campers agreed or strongly agreed that they experienced an increase in diabetes knowledge and quality of life and a decrease in diabetes distress. However, the results of the direct assessments did not align as closely as was hypothesized.

Lastly, it is important to consider the individuals who chose to participate in the study especially for the parent/guardian and staff feedback forms. While completion of the assessments was part of the normal camp experience for campers, the parent/guardian and staff feedback forms were sent as part of the follow-up assessment. Therefore, the parents/guardians and medical staff had a choice to participate which may have resulted in selection bias and ultimately the highly positive feedback. Those who participated may have been parents and medical staff who were particularly pleased with Camp Midicha and were motivated to express their high satisfaction with Camp Midicha.

McAuliffe et al. (2007) stated that diabetes camps provide an environment where having diabetes is the norm rather than an exception. Campers in the current study reported that Camp Midicha helped them to feel normal about having diabetes, and a large majority reported they made a new friend who they would like to stay in contact with. This item had the highest mean

score out of the 14 items on the camper feedback form. Briery and Rabian (1999) found that participation in a pediatric summer camp was related to changes in psychosocial functioning and that the child's experience of developing a true peer group is what brought about the observed results. In addition, camp may provide adolescents who attend diabetes camp with a positive social environment and support where they are able to form peer relationships and share diabetes knowledge and experiences (Cheung et al., 2006; Van der Van, 2003). Santiprabhob et al. (2008) reported that campers found diabetes camp of benefit and felt they could better cope with diabetes. A similar result in this study, a majority of campers indicated Camp Midicha helped them to better cope with their diabetes. The researchers stated that the psychosocial benefits and knowledge gained from attending diabetes camp suggests the importance of camp in a diabetes management plan. The results on the camper feedback form seem to suggest support for Briery and Rabian's (1999), Cheung's et al. (2006), Santiprabhob (2008) and Van der Van's (2003) speculations. Attendees at Camp Midicha are provided an opportunity to cope with and feel normal about having diabetes and develop a peer group that understands and supports their condition.

Limitations

There were several limitations to the study. First, the duration of the intervention (i.e., camp) may have played a role in limited support on knowledge, distress, and quality of life assessments. Camp Midicha is one week long and changes in diabetes knowledge, diabetes distress, and quality of life may be difficult to detect in a short amount of time. Intensity and duration of camp may need to be increased to observe changes in behavior and/or cognitions.

Next, the DKQ may not have been the most appropriate measure to examine campers' diabetes knowledge. The DART (Heidgerken et al., 2007) was shortened for this study because it

was an 84-item multiple choice assessment. The ADA camp director asked for the DART to be shortened in order to save time and not affect the flow of camp registration (pre-assessment) and the last day of camp activities (post-assessment). This aligns with ADA's (2007) position statement which states camp research must not interfere with the integrity of the camping experience and should be minimally invasive. It is possible that the two subtests (General Information and Hyper/Hypoglycemia) of the original seven were not all-inclusive of the diabetes knowledge gained at camp.

While this study did not account for the socioeconomic status (SES) of the families who attended Camp Midicha, it may be important factor to consider. The one-week overnight camp costs $600 which may be more affordable for families with a higher SES. Camp Midicha offers scholarships and financial aid to families; however, it is possible that Camp Midicha serves children and adolescents with a higher SES. When examining varying levels of SES, research indicates differences related to access and distribution of resources and services for individuals. Overall, individuals with a low SES have more negative physical, psychological, and educational outcomes than high SES individuals. For example, lower SES has negative psychological health outcomes, while more positive psychological outcomes such as optimism, self-esteem, and perceived control have been linked to higher levels of SES for youth (APA, 2012).

Camp Midicha campers may come from higher SES families whose current and projected outcomes are positive. Therefore, campers may be well-educated in their condition and treatment, have low diabetes distress, and a high quality of life prior to attending camp. This seems likely as pre-test instruments were either high (diabetes knowledge and quality of life) or low (diabetes distress). Future research may need to examine the SES of campers and compare

outcomes of such groups. It may also be beneficial for camps to target children with a low SES in order to improve diabetes-related outcomes.

An unexpected challenge and limitation of this study was gathering data in a camp setting. The researchers had limited consultation with camp director and camp committee to determine the most appropriate times of administration in order to maximize participants. Campers received their pre-test assessments at the beginning of registration and were asked to complete the packet as they made their way through registration. Unfortunately, many campers did not complete and turn-in their pre-test materials prior to leaving registration. The post-test assessments ran much smoother because all campers completed their packet after breakfast on the last day of camp. Medical and cabin staff were present to assist with completion of the packets and cabins could not leave the dining commons until packets were completed. It may have been beneficial to conduct the pre-test assessment similarly to the post-test assessment in order to increase the number of campers completing the pre- and post-test assessments. Lastly, it may have been beneficial for medical staff to complete the feedback form on the last day of camp. On the last day of camp, medical staff were asked to complete ADA forms and the feedback could have been included. Unfortunately, the researchers were unaware of this procedure in order to have the feedback form prepared.

Finally, while 354 campers completed at least one of the study assessment batteries, a very small sample completed all three administrations (pre-, post-, and follow-up). One reason for this may be due to the small number of campers who completed the follow-up packet. The follow-up occurred four to five months after camp and campers may have thought too much time had passed since camp. Another reason may be that the camper had filled the forms out two previous times and did not want to complete the same forms a third time. In addition, the

parent/guardian and staff samples were small. The feedback forms were emailed or mailed four to five months after camp and parents/guardians and staff may have thought too much time had passed since camp. In addition, the ADA office that supports Camp Midicha had feedback forms for staff, parents/guardians, and campers that had already been sent prior to this study's follow-up. Participants may have filled out those forms and did not want to fill out another round of forms.

Future Directions

Future areas of research include examination of the instrument used to assess diabetes knowledge. While this study did find support for the increase in diabetes knowledge, the reliability and validity of the DKQ may be important to consider before future use. The DKQ included only two subtests from the original DART and was also changed from multiple choice to true/false answers. These changes may not have captured the main areas of diabetes knowledge gain during the camp experience. As stated previously, formal diabetes education was varied by cabin and did not appear to be the main focus of Camp Midicha. While camp is more of an informal atmosphere for diabetes education it might be beneficial to implement a diabetes curriculum for camp to ensure campers are receiving similar education and improving their diabetes knowledge.

This study provided preliminary evidence that medical staff found Camp Midicha to be an effective and beneficial camp for children and adolescents with diabetes. Additionally, medical staff agreed that their own abilities, skills, and diabetes knowledge improved as a result of working at Camp Midicha. In addition to medical staff, there are cabin counselors (one employed by YMCA & one with diabetes), counselors-in-training, and various support staff (e.g., camp director, dieticians). It may be important to include all Camp Midicha staff and assess

how different camp personnel perceive camp. Additionally, while this study focused on camper outcomes and only minimally on staff outcomes, previous research has found numerous benefits for camp staff (Bileschki et al. 1998; Chenery, 1994; DeGraaf et al.,2003; Dworken, 2004; James, 2003; Purcell, 1996). Further examination at Camp Midicha could include more specific identification of staff outcomes that result from the camp experience. Lastly, information on how to improve Camp Midicha procedures or the camp experience from a staff perspective may also be important to examine.

Unfortunately, this study revealed increases in diabetes distress as well as higher levels of distress in campers who attended four or five camp sessions. The majority of those campers were adolescents, which is an important developmental age as it relates to diabetes treatment. Several researchers have investigated adolescents with diabetes had have found increased psychosocial issues and decreased regimen adherence (Band, 1990; Battaglia et al., 2006; Colton et al., 2004; Kovacs et al., 1997; Pendley et al., 2002; Stewart et al, 2005; Thomas et al., 1997 Thompson et al., 1992). Camp may focus on providing a typical camp experience in a medically safe environment but may also be a venue for providing additional support for adolescents with diabetes. Future research may find that camps could help address the challenges that diabetes bring to adolescents and vice versa.

Finally, it may be beneficial to examine a comparison group. For example, future research could collect data on children and adolescents who do not attend Camp Midicha. This information could then be compared to Camp Midicha attendees in order to determine the benefits and outcomes associated with attendance and nonattendance at Camp Midicha.

In conclusion, although not all camper outcomes were achieved on the DKQ, DDS-17, and PEDsQL, campers, parents/guardians, and staff were very satisfied with their camp

experience as shown by the feedback form results. All participants agreed that Camp Midicha is beneficial and an acceptable program/intervention for children and adolescents with diabetes. This study supports previous research which has indicated that diabetes camps are an important area to consider in the management/treatment of children and adolescents with type 1 diabetes. The results of this study may provide information to program decision makers including the impact Camp Midicha had on campers, whether parents and staff are satisfied with Camp Midicha, and what aspects of the camp may need modification. Finally, this study warrants future research to examine campers' SES, formal diabetes education during camp, specific staff outcomes, and the campers' stage of development.

APPENDICES

APPENDIX A

LETTER TO DIRECTOR OF PROGRAMS - COMMUNITY INITIATIVES WITH EXPLANATION OF STUDY

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support
Name of Investigator: Meghan Caswell, B.A. **Phone:** 989-330-4342

Name of Advisor: Sandra Morgan, Ph.D. **Phone:** 989-774-6484

Invitation to Conduct and Analyze Camp Midicha's Program Evaluation:

As a graduate student at Central Michigan University, I am asking your permission to analyze Camp Midicha's program evaluation data. I am asking your permission to analyze the questionnaires/rating scales that your residential campers completed before, during, and after camp attendance. I am also asking your permission to analyze parent and staff perceptions of and satisfaction with Camp Midicha's programs and initiatives.

As a type 1 diabetic, who was diagnosed at 12 years old, I am interested in working with children and adolescents with diabetes and how diabetes care can be improved. This project is designed to gain a better understanding of the impact of Camp Midicha on the individuals with diabetes who attend in hopes of making the camp the best possible experience for all campers. If you agree to allow me to analyze your program evaluation data, I hope to provide you with the following:

- Impact of Camp Midicha attendance on campers' diabetes knowledge, diabetes distress, and quality of life
- Information regarding the development of social support in youth with diabetes
- Information regarding camper, parent, and staff acceptability and effectiveness of diabetes camps

In addition, I hope the results of this program evaluation may provide information to program decision makers and stakeholders including the degree to which the camp produced intended outcomes (e.g., impact on campers), whether campers, parents, and staff are satisfied with Camp Midicha, and what aspects of the camp may need modification.

Confidentiality

Any information that is gathered about the campers, parents, and staff will be completely confidential and anonymous. No identifying marks or names will be attached to any information about your campers, parents, and staff. Only group results of this project will be reported and/or published; no identifying characteristics will be mentioned in any published reports. You, as the program director, will not have access to your patients' responses, unless the parent or patient indicates otherwise. However, you will have access to the data and results.

Risks/Benefits

Your decision to participate in this project will contribute to diabetes research. It will provide more information regarding the impact that diabetes camps may have on individuals with diabetes research. It may also help to inform diabetes camp of how to better meet the needs of its campers. Similar questionnaires/scales to those your campers, parents, and staff will complete have been used in several research studies and there are no known risks associated with them.

If you have any questions please contact Meghan Caswell-Pohl or Sandra Morgan. I hope you will consider allowing us to analyze Camp Midicha's program evaluation data.

If you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48895.

Meghan Caswell-Pohl

7-27-10

Date

Meghan Caswell-Pohl, B. A.
Doctoral School Psychology Student
Central Michigan University

Letter of Study Approval and Permission to Analyze Program Evaluation
Date: November 10, 2010
Meghan Caswell-Pohl
4245 Cooper Ave
Royal Oak, MI 48073

Dear Meghan,

I have reviewed the request to analyze Camp Midicha's program evaluation. I feel that this project will be beneficial and informative to Camp Midicha's programs and initiatives as well as for diabetes research. You have my permission to analyze Camp Midicha's program evaluation for this project.
If you have any questions regarding this letter of approval, please give me a call.

Sincerely,

Stephanie Camalo
American Diabetes Association
Associate Director – Corporate Development and Youth Initiatives
248-433-3830 Extension 6695
30200 Telegraph Rd., Suite 105
Bingham Farms, MI 48025

APPENDIX B

COVER LETTER – WEEK ONE

Dear Parent(s)/Guardian(s),

This year at Camp Midicha, we will be collecting information on how the camp experience impacts your son/daughter with diabetes. Specifically, we would like to see if the camp experience affects campers' diabetes knowledge, adjustment, quality of life, and perceived social support from peers. We would also like to examine your perceptions and satisfaction of Camp Midicha. Louis Vader has been working with Meghan Caswell-Pohl and Sandra Morgan from Central Michigan University to figure out a way to capture the impact of Camp Midicha on its campers. Data will be collected as a part of your son's/daughter's normal camping experience.

Meghan has been a type 1 diabetic for 14 years and is interested in working with children and adolescents with diabetes and their families to improve diabetes care. Meghan will be assisting Camp Midicha with data collection during and after camp.

Enclosed you will find the following information:

- Camp Midicha Parent Consent and Camper Assent Form – Explains the data collection to occur during and after your son's/daughter's attendance at Camp Midicha. **You only need to return the enclosed consent forms if you do NOT want to your ratings or your child's ratings to be analyzed.**

We hope you will allow us to analyze your child's rating scales so that we can help make the camp experience as useful as possible. We also hope that you, the parent, will complete the camp acceptability/perception questionnaire after Camp Midicha. We look forward to working with you and your child/adolescent to inform diabetes research and care.

Sincerely,

Louis Vader, BSW, MPA
American Diabetes Association
Director of Programs-Community Initiatives
248-433-3830 Extension 6695
30200 Telegraph Rd., Suite 105
Bingham Farms, MI 48025

Meghan Caswell-Pohl, B.A.
School Psychology Doctoral Student
Central Michigan University
989-330-4342
Email: mrcaswell@gmail.com

APPENDIX C

PARENT CONSENT FORM – WEEK ONE

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support.

Name of Investigator: Meghan Caswell-Pohl, B.A. **Phone:** 989-330-4342

Name of Advisor: Sandra Morgan, Ph.D. **Phone:** 989-774-6484

Invitation to Participate:

I am a graduate student at Central Michigan University and I am interested in working with children and families of children with diabetes. I have been working with Louis Vader and the Camp Midicha camp committee to figure out a way to assess your child's upcoming camp experience. We are interested in how the camp experience affects campers' diabetes knowledge, adjustment, quality of life, and perceived social support from peers as well as your perception of the camp experience.

This topic is particularly important to me as I have lived with type 1 diabetes for 14 years and am interested in working with children and adolescents with diabetes and how diabetes care can be improved. This project is designed to gain a better understanding of the impact of Camp Midicha on the individuals with diabetes who attend in hopes of making the camp the best possible experience for all campers.

I will be assisting at the camp in many ways. As part of the camping experience, your child will be completing several rating scales. The first administration will be incorporated into the first day of camp activities (June 20). The total time on day one will be approximately 25 to 45 minutes. On the last day of camp (June 25), your son/daughter will complete four questionnaires that will take about 20-40 minutes. Approximately one month after Camp Midicha, a random sample of participants will be mailed three questionnaires to complete. These questionnaires will take approximately 15-30 minutes to complete. We would also appreciate your input regarding Camp Midicha. Approximately one month after Camp Midicha, you will be sent a satisfaction questionnaire that will take approximately 5-10 minutes to complete.

If you give us permission to analyze your child's rating scales, we will ask his/her permission prior to completing the scales. You and your child may stop participation at any time. In addition, you and your son/daughter will not be penalized or lose any benefits to which you are entitled and your future relations with Central Michigan University or the American Diabetes Association will not be affected.

<u>Questionnaire Examples</u>

The following form will only be administered on the first day of camp:

- A peer support rating scale in several areas of diabetes-related treatment that will take 10-15 minutes to complete. He/she will rate how often his/her friends support them and their diabetes and how important it is that his/her friends support them and their diabetes.

The following questionnaires will be given three times (first and last day of camp and one month after camp):

- A true and false diabetes knowledge questionnaire for children/adolescents with type 1 diabetes. This questionnaire will take 5-10 minutes to complete.
- A rating scale about the problems and hassles he/she may experience as an individual with diabetes. This rating scale will take 5-10 minutes to complete.
- A rating scale that assesses quality of life in children and adolescents, which takes 5-10 minutes to complete.

A satisfaction questionnaire for you and your child will also be given. Your child will complete the questionnaire on the last day of camp and you will complete the questionnaire approximately one month after camp. This questionnaire will examine your and your child's satisfaction with Camp Midicha and will take 5-10 minutes to complete.

In addition, demographic (i.e., age, sex) and diabetes-related information will be collected from your son's/daughter's Camp Midicha application. You and your child's names will not be listed on any forms.

Confidentiality

Your and your son's/daughter's participation is voluntary. All campers will be assigned a code. The key to this code will be kept in a secure location and destroyed upon data collection. Any information that is gathered about you and your son/daughter will be kept confidential unless we have become concerned about your son's/daughter's well being during our review of the rating scales. For example, if we suspect or believe that your son/daughter is hurting himself/herself or someone else we will have to break confidentiality. This includes but is not limited to diabetes-related care and health. We will also have to break confidentiality if child abuse is suspected. People who we may have to tell include, but are not limited to, you as parents, Camp Midicha personnel, doctors, and/or law enforcement. Once we have notified the appropriate people, we will provide you with contact information for resources to appropriate care.

Your and your son's/daughter's responses will be kept confidential and only the researchers and Camp Midicha program personnel (e.g, Lou Vader) will have access. Only group results of this project will be reported and/or published; no identifying characteristics will be mentioned in any published reports.

Risks/Benefits

Your decision to participate in this project will contribute to diabetes research. It will provide more information regarding the impact that diabetes camps may have on individuals with diabetes research. It may also help to inform diabetes camp of how to better meet the needs of its campers. Similar questionnaires/scales to those your son/daughter will complete have been used in research studies. Other than the risks stated above, there are no other known risks associated with the questionnaires/scales. If you have any questions please contact Meghan Caswell-Pohl or Sandra Morgan. I hope you will allow your son/daughter to participate in this project.

If you have questions about your and your son's/daughter's rights as a participant in this project or if you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by

calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48859.

Meghan Caswell-Pohl, B.A.	Sandra Morgan, Ph.D.
School Psychology Doctoral Student	Associate Professor
Central Michigan University	Central Michigan University
Phone: (989) 330-4342	Phone: (989) 774-6484
Email: mrcaswell@gmail.com	Email: morga1sk@cmich.edu

Because the data will be collected as part of the typical camp experience, we are asking permission to include your and your child's ratings in the analysis of the camp. If you and your child would like to participate, you do not need to respond. ***If you do NOT want us to evaluate your and your child's responses as a part of this project, please complete and return this form.***

I, _____ **do NOT give permission** for my ratings and information to be analyzed in this project.

I, _____ **do NOT give permission** for _____ (child's name) for whom I am the parent or guardian of, to participate in this project.

_____	_____	Meghan Caswell-Pohl
Parent's/Guardian's Signature	Date	Investigator's Signature

Please return this form in the addressed, stamped envelope as soon as possible. Thank you.

APPENDIX D

COVER LETTER – WEEK TWO

Dear Parent(s)/Guardian(s),

This year at Camp Midicha, we will be collecting information on how the camp experience impacts your son/daughter with diabetes. Specifically, we would like to see if the camp experience affects campers' diabetes knowledge, adjustment, quality of life, and perceived social support from peers. We would also like to examine your perceptions and opinions of Camp Midicha. Louis Vader has been working with Meghan Caswell-Pohl and Sandra Morgan from Central Michigan University to figure out a way to capture the impact of Camp Midicha on its campers. Data will be collected as a part of your son's/daughter's normal camping experience.

Meghan has been a type 1 diabetic for 14 years and is interested in working with children and adolescents with diabetes and their families to improve diabetes care. Meghan will be assisting Camp Midicha with data collection before, during, and after camp.

Enclosed you will find the following information:

- Camp Midicha Parent Consent and Camper Assent Form – Explains the data collection to occur before, during, and after your son's/daughter's attendance at Camp Midicha. **You only need to return the enclosed consent forms if you do NOT want to your ratings or your child's ratings to be analyzed.**

We hope you will allow us to analyze your child's rating scales so that we can help make the camp experience as useful as possible. We also hope that you, the parent, will complete the camp acceptability/perception questionnaire. We look forward to working with you and your child/adolescent to inform diabetes research and care.

Sincerely,

Louis Vader, BSW, MPA
American Diabetes Association
Director of Programs-Community Initiatives
248-433-3830 Extension 6695
30200 Telegraph Rd., Suite 105
Bingham Farms, MI 48025

Meghan Caswell-Pohl, B.A.
School Psychology Doctoral Student
Central Michigan University
989-330-4342
Email: mrcaswell@gmail.com

APPENDIX E

PARENT CONSENT FORM – WEEK TWO

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support.

Name of Investigator: Meghan Caswell-Pohl, B.A. **Phone:** 989-330-4342

Name of Advisor: Sandra Morgan, Ph.D. **Phone:** 989-774-6484

Invitation to Participate:

I am a graduate student at Central Michigan University and I am interested in working with children and families of children with diabetes. I have been working with Louis Vader and the Camp Midicha camp committee to figure out a way to assess your child's upcoming camp experience. We are interested in how the camp experience affects campers' diabetes knowledge, adjustment, quality of life, and perceived social support from peers.

This topic is particularly important to me as I have lived with type 1 diabetes for 14 years and am interested in working with children and adolescents with diabetes and how diabetes care can be improved. This project is designed to gain a better understanding of the impact of Camp Midicha on the individuals with diabetes who attend in hopes of making the camp the best possible experience for all campers.

I will be assisting at the camp in many ways. As part of the camping experience, your child will be completing several rating scales. **Prior to camp**, please have your child complete the enclosed **Diabetes Knowledge Questionnaire** and **return** it in the self-addressed stamped envelope. The questionnaire will take 5-10 minutes to complete.

The completion of ratings scales will be incorporated into the first day of camp activities (June 27). The total time on day one will be approximately 25 to 45 minutes. On the last day of camp (July 2), your son/daughter will complete four questionnaires that will take about 20-40 minutes. Approximately one month after Camp Midicha, a random sample of participants will be mailed three questionnaires to complete. These questionnaires will take approximately 15-30 minutes to complete. We would also appreciate your input regarding Camp Midicha. Approximately one month after Camp Midicha, you will be sent a satisfaction questionnaire that will take approximately 5-10 minutes to complete.

If you give us permission to analyze your child's rating scales, we will ask his/her permission prior to completing the scales. You and your child may stop participation at any time. In addition, you and your son/daughter will not be penalized or lose any benefits to which you are entitled and your future relations with Central Michigan University or the American Diabetes Association will not be affected.

<u>Questionnaire Examples</u>

The following form will only be administered on the first day of camp:

- A peer support rating scale in several areas of diabetes-related treatment that will take 10-15 minutes to complete. He/she will rate how often his/her friends support them and their diabetes and how important it is that his/her friends support them and their diabetes.

The following questionnaires will be given three times (first and last day of camp and one month after camp):

- A true and false diabetes knowledge questionnaire for children/adolescents with type 1 diabetes. This questionnaire will take 5-10 minutes to complete (Also completed by your child prior to camp – Diabetes Knowledge Questionnaire).
- A rating scale about the problems and hassles he/she may experience as an individual with diabetes. This rating scale will take 5-10 minutes to complete.
- A rating scale that assesses quality of life in children and adolescents, which takes 5-10 minutes to complete.

A satisfaction questionnaire for you and your child will also be given. Your child will complete the questionnaire on the last day of camp and you will complete the questionnaire approximately one month after camp. This questionnaire will examine your and your child's perceptions of/satisfaction with Camp Midicha and will take 5-10 minutes to complete.

In addition, demographic (i.e., age, sex) and diabetes-related information will be collected from your son's/daughter's Camp Midicha application. You and your child's names will not be listed on any forms.

Confidentiality

You and your son's/daughter's participation is voluntary. All campers will be assigned a code. The key to this code will be kept in a secure location and destroyed upon data collection. Any information that is gathered about you and your son/daughter will be kept confidential unless we have become concerned about your son's/daughter's well being during our review of the rating scales. For example, if we suspect or believe that your son/daughter is hurting himself/herself or someone else we will have to break confidentiality. This includes but is not limited to diabetes-related care and health. We will also have to break confidentiality if child abuse is suspected. People who we may have to tell include, but are not limited to, you as parents, Camp Midicha personnel, doctors, and/or law enforcement. Once we have notified the appropriate people, we will provide you with contact information for resources to appropriate care.

Your and your son's/daughter's responses will be kept confidential and only the researchers and Camp Midicha program personnel (e.g, Lou Vader) will have access. Only group results of this project will be reported and/or published; no identifying characteristics will be mentioned in any published reports.

Risks/Benefits

Your decision to participate in this project will contribute to diabetes research. It will provide more information regarding the impact that diabetes camps may have on individuals with diabetes research. It may also help to inform diabetes camp of how to better meet the needs of its campers. Similar questionnaires/scales to those your son/daughter will complete have been used in research studies. Other than the risks stated above, there are no other known risks

associated with the questionnaires/scales. If you have any questions please contact Meghan Caswell-Pohl or Sandra Morgan. I hope you will allow your son/daughter to participate in this project.

If you have questions about your and your son's/daughter's rights as a participant in this project or if you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48859.

Meghan Caswell-Pohl, B.A.
School Psychology Doctoral Student
Central Michigan University
Phone: (989) 330-4342
Email: mrcaswell@gmail.com

Sandra Morgan, Ph.D.
Associate Professor
Central Michigan University
Phone: (989) 774-6484
Email: morga1sk@cmich.edu

Because the data will be collected as part of the typical camp experience, we are asking permission to include your and your child's ratings in the analysis of the camp. If you and your child would like to participate, you do not need to respond. ***If you do NOT want us to evaluate your and your child's responses as a part of this project, please complete and return this form.***

I, _____ **do NOT give permission** for my ratings and information to be analyzed in this project.

I, _____ **do NOT give permission** for _____ (son's/daughter's name) for whom I am the parent or guardian of, to participate in this project.

Meghan Caswell-Pohl

_____ _____ _____

Parent's/Guardian's Signature Date Investigator's Signature

Please return this form in the addressed, stamped envelope as soon as possible. Thank you.

APPENDIX F

CHILD/ADOLESCENT WITH DIABETES ASSENT FORM – WEEK ONE

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support.

What is this research about?

My name is Meghan Caswell-Pohl, and I am a student at Central Michigan University. I have had type 1 diabetes for 14 years and am interested in learning how to help children and adolescents with diabetes. My project is trying to measure the impact of Camp Midicha. We want to examine what you learn and experience from camp. Your parents have been informed of your participation in this project but we would like your permission to study the forms you complete for Camp Midicha.

What will happen to me in this research?

You will complete two sets of questionnaires/rating scales while you are at camp. On the first day of camp you will complete four questionnaires/rating scales, which will take about 25-45 minutes. The four questionnaires/rating scales include the following:

- A rating scale asking about the peer support you receive for your diabetes management.
- A rating scale asking about the problems and hassles you may experience as an adolescent with diabetes.
- A true/false questionnaire asking about your diabetes knowledge.
- A rating scale asking about your quality of life.

On the last day of camp, you will complete four questionnaires that will take about 20-40 minutes to answer. You will complete the rating scale about the problems and hassles you may experience as an individual with diabetes, the true/false questionnaire, and the rating scale about your quality of life. You will also complete a questionnaire about your opinions about camp.

Approximately one month after camp, you may be selected to complete three questionnaires you completed on the last day of camp (problems and hassles rating scale, true/false questionnaire, and the rating scale about your quality of life). The forms will take about 15-30 minutes to complete.

What are the risks and benefits if I participate in this project?

The questionnaires/rating scales you will fill out are similar to some that have been used in many other projects. If at any time you feel uncomfortable with a question, you do not have to answer it. Your participation is completely voluntary, you do not need to answer any question you do not want to, and we plan to keep all of your answers confidential. The word confidential means your specific answers will not be shared with anyone else (your parents, friends, doctors, etc.). You will be given an identification (ID) number so your name will only appear on this assent signature form and the key that has your name and ID number. These forms will be kept in a locked storage unit which will be separate from your other completed forms. Only my teacher and I will have access to the locked storage unit. The key will be destroyed once data collection is completed.

If your responses indicate that you are having a very difficult time and/or that your health and safety are at risk, we may need to contact your parents or other professionals in your area. For example, if we suspect or believe that you are hurting yourself or someone else we have to contact people to ensure you are safe. We will also have to contact authorities if child abuse is suspected. Once we have notified the appropriate people, we will provide your parents with contact information for resources in your area.

By taking part in this project you may help me and others learn about the importance of camp in helping children and adolescents with diabetes. This information may help to develop effective ideas for helping children and adolescents better manage their diabetes and how we can make your camp experience better.

What if I do not want to be in the project?

Your participation is completely voluntary. If you give us permission to examine your rating scales, you can stop participating in the study at any time and we will not be upset with you. If you decide not to participate or stop your participation in this project, you will not be penalized or lose any benefits to which you are entitled and your future relations with Central Michigan University or the American Diabetes Association will not be affected.

What if I have questions about this project?

If you have any questions, please ask them. You can call my research advisor or me; our phone numbers and emails are listed below. If you have questions about your rights as a participant in this project or do not like how this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48859.

I hope that you will participate in this project.

Meghan Caswell-Pohl, B.A.
School Psychology Doctoral Student
Central Michigan University
Phone: (989) 330-4342
Email: mrcaswell@gmail.com

Sandra Morgan, Ph.D.
Associate Professor
Central Michigan University
Phone: (989) 774-6484
Email: morga1sk@cmich.edu

Because the data will be collected as part of the typical camp experience, we are simply asking your permission to include your ratings in the analysis of the camp. If you would like to participate, you do not need to respond. ***If you do not want to participate, please complete and return this form***.

I, _____ **do NOT give permission** for my ratings and information to be analyzed in this project.

_____	_____	Meghan Caswell-Pohl
Camper's Signature	Date	Investigator's Signature

_____	Meghan Caswell-Pohl
Camper's Printed Name	Investigator's Printed Name

APPENDIX G

CHILD/ADOLESCENT WITH DIABETES ASSENT FORM – WEEK TWO

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support.

What is this research about?

My name is Meghan Caswell-Pohl, and I am a student at Central Michigan University. I have had type 1 diabetes for 14 years and am interested in learning how to help children and adolescents with diabetes. My project is trying to measure the impact of Camp Midicha. We want to examine what you learn and experience from camp. Your parents have been informed of your participation in this project but we would like your permission to study the forms you complete for Camp Midicha.

What will happen to me in this research?

Before you come to **camp**, please **complete** the **Diabetes Knowledge Questionnaire** and **return** it in the self-addressed, stamped envelope.

You will complete two sets of questionnaires/rating scales while you are at camp. On the first day of camp you will complete four questionnaires/rating scales, which will take about 25-45 minutes. The four questionnaires/rating scales include the following:

- A rating scale asking about the peer support you receive for your diabetes management.
- A rating scale asking about the problems and hassles you may experience as an adolescent with diabetes.
- A true/false questionnaire asking about your diabetes knowledge.
- A rating scale asking about your quality of life.

On the last day of camp, you will complete four questionnaires that will take about 20-40 minutes to answer. You will complete the rating scale about the problems and hassles you may experience as an individual with diabetes, the true/false questionnaire, and the rating scale about your quality of life. You will also complete a questionnaire about your satisfaction with camp.

Approximately one month after camp, you may be selected to complete three questionnaires you completed on the last day of camp (problems and hassles rating scale, true/false questionnaire, and quality of life rating scale). The forms will take about 15-30 minutes to complete.

What are the risks and benefits if I participate in this project?

The questionnaires/rating scales you will fill out are similar to some that have been used in many other projects. If at any time you feel uncomfortable with a question, you do not have to answer it. Your participation is completely voluntary, you do not need to answer any question you do not want to, and we plan to keep all of your answers confidential. The word confidential means your specific answers will not be shared with anyone else (your parents, friends, doctors, etc.). You will be given an identification (ID) number so your name will only appear on this assent signature form and the key that has your name and ID number. These forms will be kept in a locked storage unit which will be separate from your other completed forms. Only my

teacher and I will have access to the locked storage unit. The key will be destroyed once data collection is completed.

If your responses indicate that you are having a very difficult time and/or that your health and safety are at risk, we may need to contact your parents or other professionals in your area. For example, if we suspect or believe that you are hurting yourself or someone else we have to contact people to ensure you are safe. We will also have to contact authorities if child abuse is suspected. Once we have notified the appropriate people, we will provide your parents with contact information for resources in your area.

By taking part in this project you may help me and others learn about the importance of camp in helping children and adolescents with diabetes. This information may help to develop effective ideas for helping children and adolescents better manage their diabetes and how we can make your camp experience better.

What if I do not want to be in the project?

Your participation is completely voluntary. If you give us permission to examine your rating scales, you can stop participating in the study at any time and we will not be upset with you. If you decide not to participate or stop your participation in this project, you will not be penalized or lose any benefits to which you are entitled and your future relations with Central Michigan University or the American Diabetes Association will not be affected.

What if I have questions about this project?

If you have any questions, please ask them. You can call my research advisor or me; our phone numbers and emails are listed below. If you have questions about your rights as a participant in this project or do not like how this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48859.

I hope that you will participate in this project.

Meghan Caswell-Pohl, B.A.
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Phone: (989) 330-4342
Email: mrcaswell@gmail.com

Sandra Morgan, Ph.D.
Associate Professor
Central Michigan University
Phone: (989) 774-6484
Email: morga1sk@cmich.edu

Because the data will be collected as part of the typical camp experience, we are simply asking your permission to include your ratings in the analysis of the camp. If you would like to participate, you do not need to respond. If you do not want to participate, please complete and return this form.

I, _____ **do NOT give permission** for my ratings and information to be analyzed in this project.

_____	_____	Meghan Caswell-Pohl
Camper's Signature	Date	Investigator's Signature

_____	Meghan Caswell-Pohl
Camper's Printed Name	Investigator's Printed Name

APPENDIX H

CAMP MIDICHA STAFF CONSENT FORM

Title of Project: Evaluation of the Impact of Camp Midicha Attendance on Campers' Diabetes Knowledge, Diabetes Distress, Quality of Life, and Social Support.

Name of Investigator: Meghan Caswell-Pohl, B.A. **Phone:** 989-330-4342

Name of Advisor: Sandra Morgan, Ph.D. **Phone:** 989-774-6484

Invitation to Participate:

I am a graduate student at Central Michigan University and I am interested in working with children and families of children with diabetes. I have been working with Louis Vader and the Camp Midicha camp committee to figure out a way to assess Camp Midicha's impact on the campers who attend. We are also interested in your perceptions of Camp Midicha and your experience as a staff member.

This topic is particularly important to me as I have lived with type 1 diabetes for 14 years and am interested in working with children and adolescents with diabetes and how diabetes care can be improved. This project is designed to gain a better understanding of the impact of Camp Midicha on the individuals with diabetes who attend in hopes of making the camp the best possible experience for all campers.

I will be assisting at the camp in many ways. As part of the camping experience, we ask that you complete a feedback form. Approximately one month after Camp Midicha, you will be sent a feedback form that will take approximately 5-10 minutes to complete. We can send it you via email or mail.

You may stop participation at any time. In addition, you will not be penalized or lose any benefits to which you are entitled and your future relations with Central Michigan University or the American Diabetes Association will not be affected.

Confidentiality

Your participation is voluntary. You will be assigned a code. The key to this code will be kept in a secure location and destroyed upon data collection. Your responses will be kept confidential and only the researchers and Camp Midicha program personnel (e.g, Lou Vader) will have access. Only group results of this project will be reported and/or published; no identifying characteristics will be mentioned in any published reports.

Risks/Benefits

Your decision to participate in this project will contribute to diabetes research. It will provide more information regarding the impact that diabetes camps may have on individuals with diabetes research. It may also help to inform diabetes camp of how to better meet the needs of its campers. Similar questionnaires/scales to those you will complete have been used in research studies. There are no other known risks associated with the questionnaires/scales. If you

have any questions please contact Meghan Caswell-Pohl or Sandra Morgan. I hope you will allow you will participate in this project.

If you have questions about your rights as a participant in this project or if you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall, Central Michigan University, Mt. Pleasant, MI 48859.

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Because the data will be collected as part of the typical camp experience, we are simply asking your permission to include your ratings in the analysis of the camp. If you would like to participate, please indicate if you prefer the questionnaire by email or mail. If you do not want to participate, please complete and return this form.

How would you like to receive the feedback form? ____ Email ____ Mail (Check one)

I, _____ **do NOT give permission** for my ratings and information to be analyzed in this project.

_____	_____	Meghan Caswell-Pohl
Staff Member's Signature	Date	Investigator's Signature
_____		Meghan Caswell-Pohl
Staff Member's Printed Name		Investigator's Printed Name

APPENDIX I

GENERAL INFORMATION FORM

Individual with Diabetes Information

1. Date of Birth: _____
(MM) (DD) (YYYY)
2. Sex (Check One): ____ Female ____ Male

3. Ethnic Group (Check One):
____ White/Caucasian ____ Black/African American ____ Asian/Pacific Islander
____ Native American ____ Hispanic/Latin American ____ Multiracial
____ Other (Please Describe): _____

4. Place of Residence: (Please indicate City/Town and State) _____

5. Type of Diabetes (Check One):
____ Type 1 diabetes ____ Type 2 diabetes
____ MODY ____ Other (Please Describe): _____

6. Month and year diabetes was diagnosed: _____

7. Type of insulin therapy (Check One):
____ Insulin injections (syringe) ____ Insulin pump
____ Oral Medication ____ Other (Please Describe): _____

8. Most recent HbA1c level: _____ (also known as A1c or glycated hemoglobin and provides a glimpse of blood glucose control over the last 2-3 months)

9. How many times have you attended Camp Midicha (Check One)?
____ 0 times (This is my first time) ____ 1 time ____ 2 times
____ 3 times ____ 4 times ____ 5 times
____ 6 times ____ 7 times ____ 8 or more times

APPENDIX J

DIABETES KNOWLEDGE QUESTIONNAIRE

Directions: Please complete the following 26 True/False statements. Read each item carefully before selecting your answer. If the statement is True, circle A. If the statement is False, circle B.

1. Shaking, sleepiness, sweating, hunger, and dizziness are signs of hypoglycemia.
   A. True
   B. False

2. The most important treatment for most people with Type 2 Diabetes drinking lots of water.
   A. True
   B. False

3. In Type I diabetes, white blood cells attack the pancreas.
   A. True
   B. False

4. When sugar overflows in the blood to the kidneys, a person would get very thirsty, urinate frequently, and get sleepy.
   A. True
   B. False

5. Hemoglobin A1C levels represent sugar levels on the average over the past 2-3 months.
   A. True
   B. False

6. Without insulin, sugar will build up in the bloodstream.
   A. True
   B. False

7. Blood glucose monitoring tells you sugar levels for the past 24 hours.
   A. True
   B. False

8. Frequent urination, thirst, and nausea are signs of hyperglycemia.
   A. True
   B. False

9. Glucagon is mixed with NPH and given 30 minutes before eating a meal or snack.
   A. True
   B. False

10. All of the following are associated with Type 2 diabetes: average weight, having a family member with diabetes, and low intake of fat.
    A. True
    B. False

11. If moderate or large ketones are present, the individual should NOT take 3 glucose tablets and recheck in fifteen minutes.
    A. True
    B. False

12. Diabetic Ketoacidosis (DKA) is a condition when the blood sugar gets too low.
    A. True
    B. False

13. It is important to check blood glucose levels when I feel bad, when I drive, and as often as the doctor instructs.
    A. True
    B. False

14. Without insulin in the body, normal blood sugars can be maintained with diet, exercise, and drinking lots of water.
    A. True
    B. False

15. A person with diabetes "pushes fluids" when they are sick in order to prevent dehydration and push ketones out of the body.
    A. True
    B. False

16. In people with Type I diabetes, the pancreas no longer makes insulin.
    A. True
    B. False

17. When ketones are negative/trace, give no extra insulin.
    A. True
    B. False

18. Damage to the kidneys as a result of poor diabetes control can be repaired by increasing the insulin dose.
    A. True
    B. False

19. People with diabetes who smoke are at increased risk for heart and nerve damage.
    A. True
    B. False

20. If a child or a teen has moderate/large ketones, they should eat 30 grams of carbohydrates.
    A. True
    B. False

21. Smoking, high blood pressure, and poor diabetes control as a teenager all increase the likelihood of damage to the eyes.
    A. True
    B. False

22. When a child or teen with diabetes is sick, they should check for ketones if their blood sugar is greater than 240mg/dl.
    A. True
    B. False

23. A student may need to leave school if moderate to large ketones and vomiting are present.
    A. True
    B. False

24. For individuals with diabetes, exercise should be avoided due to its impact on blood glucose levels.
    A. True
    B. False

25. A student with diabetes is experiencing inability to concentrate, hunger, and shakiness in the class right before lunch. This student is probably having low blood sugar (hypoglycemia).
    A. True
    B. False

26. Symptoms of a blood glucose level less than 40mg/dl can include hunger, extreme thirst, and seizures.
    A. True
    B. False

APPENDIX K

DIABETES DISTRESS SCALE (DDS-17)

Directions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problems that people with diabetes may experience. Consider the degree to which each of the items may have distressed or bothered you **DURING THE PAST MONTH** and circle the appropriate number.
Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1." If it is very bothersome to you, you might circle "6."

Problems	**Not a Problem**		**Moderate Problem**		**Serious Problem**		Office Use Only
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6	A
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6	B
3. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6	A
4. Feeling that my doctor doesn't give me clear enough directions on how to man- age my diabetes.	1	2	3	4	5	6	B
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6	C
6. Feeling that I am often failing with my diabetes regimen.	1	2	3	4	5	6	C
7. Feeling that friends or family are not supportive enough of my self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6	D
8. Feeling that diabetes controls my life.	1	2	3	4	5	6	A
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6	B
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6	C

11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6	A
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6	C
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6	D
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6	A
15. Feeling that I don't have a doctor who I can see regularly about my diabetes.	1	2	3	4	5	6	B
16. Not feeling motivated to keep up my diabetes self-management.	1	2	3	4	5	6	C
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6	D

APPENDIX L

ID # _____

PEDIATRIC QUALITY OF LIFE INVENTORY VERSION 4.0 CHILD REPORT

PedsQL ™ - Pediatric Quality of Life Inventory Version 4.0 - CHILD REPORT (ages 8-12)

DIRECTIONS: On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

	Never	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4
About My Feelings *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4
How I Get Along with Others *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

About School *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

APPENDIX M

ID # _____

PEDIATRIC QUALITY OF LIFE INVENTORY VERSION 4.0 TEEN REPORT

PedsQL ™ - Pediatric Quality of Life Inventory Version 4.0 - TEEN REPORT (ages 13-18)

DIRECTIONS: On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

	Never	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4
About My Feelings *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4
How I Get Along with Others *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

About School *(PROBLEMS WITH…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

APPENDIX N

CAMP MIDICHA CAMPER FEEDBACK FORM

(Adapted from the Witt and Elliott [1985] Intervention Rating Profile)

	Strongly Disagree	**Disagree**	**Neither Disagree nor Agree**	**Agree**	**Strongly Agree**
Camp Midicha is an acceptable program/intervention for children with diabetes.	1	2	3	4	5
My diabetes knowledge improved as a result of camp attendance.	1	2	3	4	5
I would suggest Camp Midicha to other kids with diabetes.	1	2	3	4	5
Camp Midicha's activities and programs met my needs.	1	2	3	4	5
I would like to attend Camp Midicha again.	1	2	3	4	5
After attending camp, my distress about my diabetes decreased.	1	2	3	4	5
Camp Midicha helped me to feel normal about having diabetes.	1	2	3	4	5
I had a negative experience while at camp.	1	2	3	4	5
Camp Midicha programs and activities are appropriate for a variety of children and adolescents with diabetes.	1	2	3	4	5
I like the procedures used at Camp Midicha.	1	2	3	4	5
Camp Midicha improved my quality of life.	1	2	3	4	5
Camp Midicha helped me to cope better with my diabetes.	1	2	3	4	5
I made new friends at camp that I would like to stay in contact with.	1	2	3	4	5
Overall, Camp Midicha is beneficial to children and adolescents with diabetes.	1	2	3	4	5

1. What was/were your most favorite thing(s) about camp?

2. What was/were your least favorite thing(s) about camp?

APPENDIX O

CAMP MIDICHA PARENT/GUARDIAN FEEDBACK FORM

(Adapted from the Witt and Elliott [1985] Intervention Rating Profile)

	Strongly Disagree	**Disagree**	**Neither Disagree nor Agree**	**Agree**	**Strongly Agree**
Camp Midicha is an acceptable program/intervention for a child with diabetes.	1	2	3	4	5
Campers' diabetes knowledge improves as a result of camp attendance.	1	2	3	4	5
Most parents would find Camp Midicha initiatives appropriate.	1	2	3	4	5
Camp Midicha is effective in meeting its goals and purpose.	1	2	3	4	5
I would suggest Camp Midicha to a parent/guardian of a child who has been diagnosed diabetes.	1	2	3	4	5
Camp Midicha's activities and programs are appropriate in meeting campers' needs.	1	2	3	4	5
I would send my child to Camp Midicha in future years.	1	2	3	4	5
After attending camp, campers' diabetes-related distress decreases.	1	2	3	4	5
Camp Midicha does not result in negative side-effects for campers.	1	2	3	4	5
Camp Midicha programs and activities are appropriate for a variety of children and adolescents with diabetes.	1	2	3	4	5
I like the procedures used at Camp Midicha.	1	2	3	4	5
Camp Midicha improves campers' quality of life.	1	2	3	4	5
Overall, Camp Midicha is beneficial to children and adolescents with diabetes.	1	2	3	4	5

Additional Comments/Suggestions:

APPENDIX P

CAMP MIDICHA STAFF FEEDBACK FORM

(Adapted from the Witt and Elliott [1985] Intervention Rating Profile)

	Strongly Disagree	**Disagree**	**Neither Disagree nor Agree**	**Agree**	**Strongly Agree**
Camp Midicha is an acceptable program/intervention for children and adolescents with diabetes.	1	2	3	4	5
Campers' diabetes knowledge improves as a result of camp attendance.	1	2	3	4	5
Most camp personnel would find Camp Midicha initiatives appropriate.	1	2	3	4	5
Camp Midicha is effective in meeting its goals and purpose.	1	2	3	4	5
I would suggest Camp Midicha to a parent/guardian of a child who has been diagnosed diabetes.	1	2	3	4	5
Camp Midicha's activities and programs are appropriate in meeting campers' needs.	1	2	3	4	5
I would be willing to volunteer at Camp Midicha in future years.	1	2	3	4	5
My diabetes-related knowledge improved/increased as a result of working at Camp Midicha.	1	2	3	4	5
After attending camp, campers' diabetes-related distress decreases.	1	2	3	4	5
My abilities and skills improved as a result of volunteering at Camp Midicha.	1	2	3	4	5
Camp Midicha does not result in negative side-effects for campers.	1	2	3	4	5
Camp Midicha programs and activities are appropriate for a variety of children and adolescents with diabetes.	1	2	3	4	5

	Strongly Disagree	**Disagree**	**Neither Disagree nor Agree**	**Agree**	**Strongly Agree**
I like the procedures used at Camp Midicha.	1	2	3	4	5
Camp Midicha improves campers' quality of life.	1	2	3	4	5
The staff training on June 19 adequately prepared me for Camp Midicha.	1	2	3	4	5
Overall, Camp Midicha is beneficial to children and adolescents with diabetes.	1	2	3	4	5

Additional Comments/Suggestions:

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