THE IMPACT OF A RESIDENTIAL SUMMER CAMP ON ATTITUDES AND BEHAVIORS ASSOCIATED WITH DIABETES SELF-MANAGEMENT IN CHILDREN AND ADOLESCENTS

Sarah Drewes

Thesis

Approved: 

Advisor
Dr. Deborah D. Marino

Faculty Reader
Dr. Lonnie Lowery

Faculty Reader
Dr. Sandra Hudak

Accepted: 

Interim School Director
Mrs. Sue Rasor-Greehalgh

Interim Dean of the College
Dr. James M. Lynn

Dean of the Graduate School
Dr. George R. Newkome

Date
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CHAPTER I
INTRODUCTION

Diabetes mellitus is one of the leading chronic diseases found in youth that continues to increase in prevalence around the world (1). Successful management of Type 1 diabetes requires responsibility of both educational and managerial aspects of the disease on a continuous basis. For children and adolescents, the complexity of the disease is a challenge when attempting to appropriately manage it in their busy lives. Research has suggested that many different environments such as schools and the workplace provide opportunities to increase the knowledge and attitude associated with diabetes (2). A frequently overlooked environment that provides optimal opportunities for diabetes education is summer residential camp (2). Camps give the adolescent an opportunity to obtain knowledge and confidence to independently manage their diabetes away from the home environment.

One camp that targets children and adolescents with diabetes mellitus is Camp Ho Mita Koda, founded in 1929 (3). This camp is designed to provide a normal camping experience for children with type 1 and type 2 diabetes, while also enhancing knowledge and skills associated with the management of these chronic diseases. Dr. Henry John, a physician from the Cleveland Clinic, along with his wife, Betty, founded the camp. Camp Ho Mita Koda, which means, “welcome my friend” in the Sioux Indian language,
began with 6 children with diabetes who joined Dr. and Mrs. John at their summer home in Newbury, Ohio (3). After that successful summer in providing normal activities and receiving positive feedback from the children’s families, the camp grew to eventually 300 campers each summer on 75 acres of land outside of Newbury, Ohio (3).

In 1958, Dr. John retired and the Board of Trustees as well as volunteers began directing the camp (3). The camp eventually was led by an executive director, Jacquie Dickinson, in 1991, and became a year-round occupation, which included fundraising, planning, and employee training (3). Camp Ho Mita Koda has now merged with the Diabetes Association of Greater Cleveland in 2006 and is now housed in business offices in Beachwood, Ohio, year-round (3).

This camp is designed to not only provide a normalized camp experience for children with diabetes, but is also a unique opportunity to improve self-management of diabetes for each child. Education is a main priority of Camp Ho Mita Koda staff and educational goals exist for each activity planned such as consistent blood glucose monitoring daily and throughout activities, carbohydrate counting that is incorporated into each meal served at camp, as well as enhancing self confidence, interpersonal skills, and conflict resolution through the camp experience (4). Nutrition education is also incorporated into daily activity led by dietetics staff and an educational session is planned as an elective activity at least once a day (4). All staff members review these goals during the staff orientation process in order to express their importance throughout the camp experience.
Goals and Hypotheses

This study aims to provide evidence of the importance of the camp experience for children with type 1 diabetes in terms of self-confidence, attitude towards their disease, as well as perceived confidence in managing their disease. It is hypothesized that:

1) Adolescents participating in an eleven-day residential camp targeting diabetes management will demonstrate increased perceived confidence in diabetes self-management at the end of the camp experience.

2) Adolescents with hemoglobin A1c values of less than 7.5%, as recommended by the American Diabetes Association for this age group, will have higher perceived confidence to manage diabetes as compared to adolescents with higher than normal hemoglobin A1c values.

Significance of Study

The purpose of this study is to obtain data regarding changes in attitudes and behaviors associated with diabetes self-management and perceived confidence of management in adolescents who attend Camp Ho Mita Koda for an 11-day session. Data from this study will also examine correlations between hemoglobin A1c values and perceived confidence about self-management techniques.

Results from this study will not only provide data for Camp Ho Mita Koda, but will provide insight to the impact of specialty and therapeutic camps on diabetes self-management. Parents, physicians, nurses, dietitians, as well as children will be able to utilize this data and support research that found that the camp experience is not only for a
chance to get away from everyday life, but to make short and long-term changes that may have an impact on their present and future health.

Definition of Terms

Type 1 diabetes—Type 1 diabetes is one of two types of diabetes mellitus. There are two forms of type 1 diabetes: immune-mediated and idiopathic. Immune mediated diabetes is the autoimmune destruction of beta-cells of the pancreas. Idiopathic diabetes is a type in which the origin is unknown. Individuals with type 1 diabetes are dependent on exogenous insulin to prevent ketoacidosis and death (5).

Hemoglobin A1c—Hemoglobin A1c, also known as glycated hemoglobin, is the patient’s mean plasma glucose level from the past two to three months. This measurement is used to monitor glycemic control in the individual and reflects the amount of glucose bound to hemoglobin over the life of a red blood cell. Normal values for adults range from 4.0 to 6.0% and a 1% increase is associated with a 35 mg/dl increase in mean plasma glucose (6). For school aged children between 6 and 12 years, hemoglobin A1c values are recommended to be below 8% and for adolescents and young adults between 13 and 19 years of age are recommended below 7.5% (7).

Self-management—Self-management refers to the individual’s ability to manage his or her diabetes rather than depend on a physician, diabetes educator, nurse, or family members to provide constant attention to disease management (2).
Carbohydrate Counting—Carbohydrate counting is one nutritional method used to control blood glucose levels for individuals with diabetes. Individuals determine the amount of carbohydrate in a particular food, determine the serving size, and then compare this to the number of carbohydrate servings recommended per day by the individual’s dietitian (8).

Blood Glucose Monitoring—Blood glucose monitoring is a method used to monitor diabetes on a daily basis that can be measured up to eight times a day. For example, blood glucose may be measured once before and after breakfast, lunch, and dinner as well as at bedtime and once throughout the night. Values are recorded and these records are used to look for patterns of high and low blood sugar levels in order to achieve ultimate control (5).

Residential Summer Camps—A camp that requires campers to live and dine at the camp for at least one night up to possibly eight weeks in length. It is estimated that 10 to 12 million children participate in camp each year. These camps usually offer a variety of activities and are secluded from city life (9).

Specialty Camps—These are camps designed specifically to meet the needs of a certain population for example, horseback riding or camps for mentally handicapped. They offer activities that cater to their population and tend to have educational sessions to promote learning about the camp specialty (9).
American Camp Association—This Association, also known as ACA, is a collaboration of camp professionals who work to ensure high quality of camps across the country by monitoring education as well as safety of each camp who wants to be accredited. The ACA is also a forerunner in youth outcomes research (9).

Assumptions

The following assumptions are made in regard to this study:

1) Campers will complete the questionnaire in an honest manner and without parental guidance.

2) All questionnaire information will be collected in a manner that will ensure confidentiality of each participant.

3) The questions within the questionnaire will examine both the behaviors and attitudes associated with diabetes self-management of each camper.

Limitations to the Study

There are expected limitations to this study. It is expected that there will be campers who may have attended a camp other than Camp Ho Mita Koda. Responses from these campers will not directly ensure that any gains were the responsibility of this camp. Because this study examines the short-term effect of one summer at camp, there will not be any data collection on the long-term effects as a result of camp on adolescent campers. Another limitation is that there is no comparison group to campers at a different camp. Lastly, use of the Patient Activation Measure with adolescents has not
been reported and the self-reporting of the child or the adolescent may be inaccurate due to misunderstanding the question or a lack of effort in responding to the questionnaire.
CHAPTER II

REVIEW OF LITERATURE

Introduction

Disease management education for children and adolescents with type 1 diabetes has been recommended for a variety of settings because there is a need to specifically examine the child’s ability to function outside his or her own home environment (2). In a different environment, a new level of responsibility occurs and the child must take control of his or her own actions. It may be difficult for parents to enable their child to accept responsibility, and it requires additional self-confidence and independence of the child. While many environments such as schools, friend’s houses, and the workplace provide this opportunity for independence, they typically only exist over a short length of time. Specialty recreational camps, however, provide a unique opportunity to educate children over at least 24 hours in a safe and secure environment, while giving parents a chance to allow children to take responsibility of their disease. While the American Diabetes Association has developed standards of care for children and adolescents with diabetes, literature is lacking on the ability of recreational camps to have an impact on disease management. Support for these camps is increasing and it is important to measure the camp’s success at being able to promote much needed mentoring in an enjoyable setting.
Type 1 Diabetes and Children

Diabetes mellitus is one of the leading chronic diseases found in youth (1). The prevalence and incidence of type 1 diabetes has been increasing worldwide. It is estimated that 1.82 cases per 1000 youth are diagnosed with either type 1 or type 2 diabetes in the United States (1). The prevalence of diabetes for children between the ages 5 and 9 years and 10 and 14 years are 1.25 cases per 1000 youth and 2.29 cases per 1000 youth, respectively (1). The peak incidence age is at 10 to 12 years for girls and 12 to 14 years for boys (10). These values are only expected to rise as the trend has been consistently increasing.

The American Diabetes Association has developed standards of care for children and adolescents with type 1 diabetes. These guidelines discuss age groups and disease management responsibilities that are appropriate for various age categories. Diabetes is a serious disease with several long-term complications such as nephropathy, hypertension, dyslipidemia, retinopathy, celiac disease, and hypothyroidism (7). It is important to educate children and their families on proper disease management techniques focusing on glycemic control, insulin management, nutrition education, medical nutrition therapy, and exercise (7).

Current research has suggested a link between glycemic control and diabetic complications, which has caused the American Diabetes Association to develop specific recommendations relating to this topic. Three age specific groups have recommended values for both blood glucose and hemoglobin A1c within these standards with standard values becoming more similar to adult standards as the child ages (7). For children 6 to
12 years, it is recommended that preprandial blood glucose levels be between 90 and 180 mg/dl, bedtime blood glucose between 100 and 180 mg/dl, and hemoglobin A1c values between 7.5% and 8.5% (7). Adolescents are recommended to have preprandial blood glucose values between 90 and 130 mg/dl, bedtime blood glucose between 100 and 180 mg/dl, and hemoglobin A1c less than 7.5% (7). While these are recommendations made by the American Diabetes Association, the values expressed in the Standards of Care are mostly based on research with adults due to the lack of research on children and adolescents with diabetes (7).

Because of the many challenges and complications associated with diabetes, management requires much time and continuous education. It involves insulin doses, regular blood glucose monitoring, regular exercise, and a “healthy diet” (11). It is necessary that the patient as well as the family continue to educate themselves in each of these areas.

Children and Adolescents and Self-management of Type 1 Diabetes

The care of diabetes and the level of responsibility given to the child are dependent on the family. Recommendations are made by the American Diabetes Association for four age groups between birth and adolescence with the amount of responsibility increasing as age increases. Of these four age groups, two of the most critical are perhaps the pre-adolescent and adolescent years (7).

Children between the ages 8 and 11 years are able to accept a large amount of responsibility such as doing insulin injections, blood glucose testing, and appropriate dosing following meals (7). This age is also associated with greater anxiety and mild depression due to the fact that they realize that diabetes will always be present and a
difference between themselves and their peers will exist (7). Fear may also be connected to this age group because children are more active, causing a lack of metabolic control and the presence of diabetic complications (7).

Adolescents are one of the most difficult age groups because children at this age do not want to allow diabetes management to interfere in relationships with their peers (7). This is associated with increasing physical, cognitive, and emotional maturity. Adolescents are capable of total disease management, but like any teenager, may not perform the necessary tasks. When asked, teenagers describe diabetes as one of the following terms, “habit, a little devil, a nightmare, stress, a prison, death, or hell (11).” Non-compliance to self-management has been linked to lower self-esteem, cause additional conflict with parents, and increase feelings of being different (11).

Conflicts with parents also affect the adolescent’s ability to care for diabetes (7). Research has shown that adolescents, who fail to adhere to a regimen, have less motivation, less support, and believe that nonadherence will provide a sense of freedom from diabetes (7). Coping skills, training, and peer support have demonstrated to improve the quality of life as well as improved adjustment for adolescents battling diabetes on a daily basis (7).

Patient Activation Measurement Tool

Chronic disease management has become critical due to the increased prevalence of these conditions. Many researchers are in the process of developing measurement tools that help researchers determine an individual’s confidence in managing his or her condition. One tool, which has been validated, is the Patient Activation Measure (PAM) (12). This tool was developed as part of the disease self-management trend in healthcare,
where patients help make decisions regarding their disease management plan rather than receiving full instructions from medical staff (12). Prior to the development of PAM, there were no existing measurement tools that focused on patient-oriented care, patient activation, and patient behaviors (12). The original PAM tool was 22 questions and has now been reduced to 13 questions which examine a range of disease management aspects such as the level of responsibility the individual has in managing the disease, how confident the individual is about managing the disease, the changes in lifestyle, and the ability to prevent future problems associated with the disease (12). Results from this measurement tool can supply researchers with information about the individual’s ability and confidence in managing their chronic disease and improving their overall quality of life.

Adolescents with Type 1 Diabetes and Quality of Life Measures

The connection between quality of life and the management of diabetes has become a studied aspect of disease management. Research has suggested that the tighter the glycemic control, the better the quality of life of the individual (13). This conclusion suggests that better glycemic control also demands consistent and accurate disease management, which is uncommon in the lives of adolescents (13). To measure quality of life, questionnaires divided into different domains that represent different aspects of the individual’s life are utilized. These measurement tools are unique in that they provide data regarding life satisfaction, the impact of the disease, as well as the effect the disease has on the well being of the individual (10). Some aspects used to measure quality of life include health, family, school, friends, and of course the disease itself (13). By obtaining
data via questions, researchers are able to combine all aspects to create an overall sense of the individual’s view of his or her own quality of life.

Adolescence is a beneficial time period to obtain data on quality of life due to the fact that it is a time when teenagers are influenced by parents, peers, teachers, and their disease. When asked, campers with type 1 diabetes between the ages of 8 and 15 years stated that the most frequently thought-of aspect of their lives were their families (13). The second most frequent domain was friends, which was followed by diabetes (13). This demonstrates the child’s reliance on family and friends in their lives. A shift in thinking was also observed in this study from more concrete responses to more abstract. For example, the older the child, the more likely he or she would choose the more abstract domain of health rather than the more concrete diabetes response or choose living well rather than self-care behaviors. This may reflect an adolescent’s maturity in that the realization of proper disease management in terms of overall health would also provide an adolescent with feelings that he or she fits in with peers and normalizes his or her disease (13).

Quality of life measurements are beneficial research tools in that they allow researchers to observe which areas of an individual’s life have the greatest impact on disease management, the individual’s confidence in maintaining the disease, as well as a look into the life of an individual with the disease.

Effect of Residential Summer Camps

According to the American Camping Association, who is responsible for the accreditation process of camps, residential camps have been in existence since 1861. It is estimated that 10 to 12 million children participate in camp each year and over 500
million children have participated throughout history (14). While camp has most likely affected a large population of children and adolescents, only a few formal and reputable studies have been completed (15). The first systematic research of the camp experience was conducted in 1929 and examined positive outcomes from the camp experience (15). This study utilized pre-post behavior surveys, case studies, and longitudinal group observations. As the first scientific study conducted at a camp, a positive outcome was found for social skills, independence, and willingness to try new things (15).

Studies between 1929 and the present have examined a variety of topics including beneficial effects of single programs, children experiencing a positive self-concept, healthy beliefs about effort and mastery, and self-actualization (15). A specific camp experience that has been studied are 4-H camps through a pre-post questionnaire. These studies have concluded that these camps have a positive impact on life skills such as decision-making, acceptance of differences, and respect for others (15).

More recently, the American Camping Association, in collaboration with Philliber Research Associates, has completed research evaluating the effects of camps and more specifically, the developmental outcomes of the camp experience (16). This study examined two hundred camps that were randomly chosen and were either day, residential, co-ed, and/or single gender. Of the 80 camps who chose to participate, 57% with one week sessions, 31% were two and four week sessions, 12% were six, seven, or eight week sessions with campers between the ages of 8 and 14 with no developmental disabilities (16). For this study, campers completed pre- and post-surveys and parents along with a follow up survey conducted six months after participating in camp.
Four developmental domains, separated in ten subgroups, were evaluated (16). These four domains include positive identity, social skills, physical and thinking skills, and positive values and spirituality (16). These four domains encompassed many areas such as self-esteem, independence, leadership, friendship skills, peer relationships, adventure and exploration, and environmental awareness (16). All of these domains, with the exception of positive values and spirituality showed increases throughout the camp experience.

The domain of social skills is one of importance because it measures feelings of self worth. This domain includes leadership, friendship skills, social comfort, and peer relationships (16). Campers throughout camp as well as after six months reported increases in leadership qualities (16). This suggests that because camp requires children to take on more responsibilities, it enhances the feeling of importance in campers. Social comfort, which was measured by asking questions about social discomfort and then was reversed, showed a continual increase through camp and after participation (16). Friendship skills showed an increase between pre- and post-surveys, but a decrease six months after participation, even though survey scores six months after participation were still higher than the pre-camp surveys (16). Peer relationships, which examined the children’s ability to maintain friendships and get along with each other, actually decreased throughout camp and then increased after camp (16).

The purpose of this study was to evaluate the purpose of camps and the effect of the camps on the lives on American youth. This study suggests that throughout camp an increase in positive identity, the ability to make friends, and feelings of adventure and exploration was evaluated by campers. In comparison to parent evaluations, the largest
difference between pre- and post-surveys were found in independence, making friends, and adventure and exploration, which in turn have been linked to a positive influence on academic performance.

Specialty Camps

Residential camps have existed for over a century. In an effort to normalize life for children suffering from diseases, camps specializing in the specific disease have developed. Many times, these camps are called therapeutic camps rather than specialized camps and work to not only provide a normal camp experience, but also increase children’s knowledge, self-management, and perception of themselves and their disease (17). As reported in an article by Cushner-Weinstein et al, there are currently 138 asthma camps, 91 muscular dystrophy camps, 60 cancer camps, 47 hemophilia camps, 40 sickle cell anemia camps, 26 renal disease camps, 17 obesity and weight management camps, 13 Crohn’s disease camps, 7 burn camps, 3 neurofibromatosis camps, 3 Tourette’s syndrome camps, 25 epilepsy camps, and 65 diabetes camps (18). While much time, organization, and money are used in the planning stages, little research examining the influence of camp experience in terms of self-management, self-esteem, self-concept, self-perceptions, and attitude and knowledge towards themselves and their disease has been completed (18).

In comparison to regular residential camps, camps for children and adolescents with chronic conditions are designed to not only be fun, but also to build self-care skills, improve health outcomes, and enhance attitudes and motivation for self-care (19). While this classification of camps encompasses a wide variety of diseases, they do have many
similarities in terms of overall camp objectives and standards. With these objectives in mind, many specialty camps have originated to provide these opportunities.

Camps for Children with Epilepsy

Epilepsy is one chronic condition that has resulted in the creation of camps aimed to provide a normal camp experience. There are many challenges in living with epilepsy including many behavioral and social issues (18). Research has suggested that the camp experience improved social interaction, communication, cooperation, responsibility, and overall adaptive functioning and independence (18). A follow-up with campers suggests that they return home with increased knowledge about epilepsy, enhanced self-confidence, and greater willingness to accept responsibility at home (18). This study also followed the children over a three-year period, which also supported that camp, over time, had a positive influence on social and behavioral issues relating to the disease.

Camp for Children with Phenylketonuria

Camps have been designed for children with phenylketonuria to improve compliance to diet, teach harmful effects of noncompliance, and overcoming barriers (20). This study revolved around the Health Belief Model and measured perception of efficacy, peer rejection, barriers, isolation, support, and benefits for adolescents. Of all of these measures, only perceived benefits of compliance showed improvement after the one-week camp session. Researchers suggested that decreased measures reflect the attitude and type of choices that adolescents make on a day-to-day basis (20).

Camp for Children with Burns

Burn victims are a group of individuals that have also benefited from camps. Research has examined the impact of camp on the self-esteem of pediatric burn patients
The campers evaluated were between the ages of 6 and 18 years and had 1% to 90% Total Burn Surface Area. With a pre-post survey, 29% of the campers had increased self-esteem scores while 58% had no change after camp (21).

In general, specialty camps for epilepsy, phenylketonuria, and burns have shown to be effective in terms of disease management and personal confidence. While the American Camping Association stresses the importance of evaluating the camp experience, it is also important to evaluate the camp experience for those individuals who may benefit the most from camp, those with chronic diseases, illnesses, or conditions.

Purpose and Guidelines for Diabetes Camps for Children

The American Diabetes Association has examined diabetes camps, their purpose, and disease management. It is estimated that 15,000 to 20,000 campers attend diabetes camps around the world each year (22). In a mission statement by the American Diabetes Association, it is stated that the camps “facilitate a traditional camping experience in a medically safe environment (22).” Recommendations for diabetes camps are similar to standards of care for individuals with type 1 diabetes and for children with diabetes in schools or day care environments. One difference between these environments are that diabetes camps have a greater emphasis on balancing physical activity with insulin dosage to maintain blood glucose levels because exercise has an impact on blood glucose levels even 12 to 18 hours after completion (22). It is because of this that it is also recommended that documentation and observation be completed on a consistent basis (22).

Guidelines for diabetes camps have been recommended by the American Diabetes Association and include the following (22):
- Each camper should have a standardized comprehensive health history form and health evaluation form.
- The family should provide documentation of previous hospitalizations or illnesses, severe hypoglycemia, previous hemoglobin A1c levels, medications, significant medical conditions, and psychological issues.
- Food intake and activities should be documented for each camper throughout camp.
- Multiple blood glucose determinations should be made and recorded throughout each 24-hour period.
- Any camper with a bedtime blood glucose level of less than 100 mg/dl and campers on an insulin pump with blood glucose of greater than 240 mg/dl should have their blood glucose rechecked overnight.
- Three meals and two snacks should be given at set times each day accommodating special dietary needs when needed.
- The carbohydrate component of food, exchange value, and/or calorie count should be taught to campers, according to their developmental level, to enable them to learn how to balance food and activity.
- Each camp should have a medical director who is a physician with experience with type 1 and type 2 diabetes, one on-site physician at all times, nursing staff, and registered dietitians.
- Each camp should have written camp policies and medical management procedures available at camp.
• Each diabetes camp should provide diabetes education for campers to teach self-management skills.

Research regarding type 1 diabetes camps and their impact on the quality of life in Italy has been completed. As previously mentioned, research has suggested that good metabolic control is associated with a better quality of life and camps have shown to do this over a short-term period by allowing children the opportunity to demonstrate individuality and responsibility for their disease. Because camp is not year-round, however, it is difficult to obtain long-term results in attempting to change the child’s attitude towards the disease as well as increase knowledge about the disease and disease management. A need for additional research is apparent due to the fact that literature is insufficient in this area.

Camp Ho Mita Koda

The mission of Camp Ho Mita Koda, as stated in camp literature, is “to enable children to live well with diabetes through an enjoyable camp experience (23).” Children who attend the camp range between the ages of 7 to 19 years. Different lengths of sessions ranging from 1 night to 11 days exist with the shorter sessions for younger campers and longer sessions for pre-adolescents and adolescents between 11 and 15 years (23).

In the effort to provide normal camping activities, many of the programs and activities offered at Camp Ho Mita Koda are similar to those offered at other recreational summer camps (23). Activities such as swimming, canoeing, sailing, fishing, soccer, volleyball, basketball, archery, fencing, rope courses, hiking, horseback riding, drama,
and arts and crafts are only a few of several (23). The camp also has programs such as team building activities, talent shows, and awards banquets. Cooking classes are also offered in order to educate campers how to prepare simple and healthy meal items and snacks (23).

Camp Ho Mita Koda currently completes a post-camp survey that evaluates the campers’ likes and dislikes associated with the camp experience such as activities, food, counselors, nutrition education sessions, and asks for additional input to make the experience better (24). This survey was not validated and is not utilized for research purposes, but is used to improve the overall camp atmosphere.

Summary

While the camp industry is growing as well as the prevalence of diabetes in children and adolescents, there is a greater need for specialty camp environments that provide educational and social opportunities for these individuals. Furthermore, literature is lacking that discusses the impact that diabetes camps have on the campers’ attitudes and behaviors associated with diabetes self-management.

Camp Ho Mita Koda and the Diabetes Association of Greater Cleveland also find the purposes of this study to be beneficial in promoting and improving the camp in future years. Development of this research included two hypotheses. The first relates to the impact that Camp Ho Mita Koda has on perceived confidence in diabetes self-management after the eleven-day camp session. The second hypothesis builds on the first and suggests that adolescents with higher perceived confidence in diabetes management will also have better hemoglobin A1c values that suggest better glycemic control. The design of this study examines these two hypotheses.
CHAPTER III
METHODOLOGY

This study was reviewed and approved by the University of Akron Institutional Review Board prior to the start of any research (APPENDIX A). All methods were also discussed and approved by the Diabetes Association of Greater Cleveland and Camp Ho Mita Koda staff.

Participants

Camp Ho Mita Koda in Newbury, Ohio, is the location for this study. Campers were between the ages 11 and 15, with one 10-year old and one 16-year old camper. All participants attended one of the following camp sessions:


Prior to the opening day of camp, a cover letter from the researcher (APPENDIX B), a cover letter from the Diabetes Association of Greater Cleveland (APPENDIX C), a parental permission form (APPENDIX D), and child assent form for participation (APPENDIX E) were mailed to each family. Extra copies of all forms were also available for participants who forget the forms and were still willing to participate.

For confidentiality purposes, a finalized camp roster for each session was coded on the opening day of the session by a Camp Ho Mita Koda staff member and Camp
intern for the researcher to ensure that each camper remains confidential. Code numbers for session 4 ranged from 1 to 53 and 75 to 132 for session 5.

Prior to the first day of each camp session, July 6 and July 20, an individual involved in the Diabetes Association of Greater Cleveland as well as Camp Ho Mita Koda informed all camp staff and counselors involved on these days about the procedure and purpose of this study. As each camper arrived for the check-in procedure, staff collected the consent forms and gave the camper an index card with their pre-assigned code number. Three stations were arranged in the dining room with one being the nutrition staff, another the nursing staff, and the third for this project. When the camper and parent reached the table for this project, the researcher or a team member ensured that consent forms were complete and then gave the camper a survey with their number written on it for completion. Campers were asked to complete the survey while waiting in line for the next station and without help from parents.

On the last day of each camp session, July 17 and July 31, the researcher was present at Camp Ho Mita Koda to administer the post-survey to each camper. Nutrition interns aided the researcher by dividing the numbered surveys by individual cabins. The interns went to each cabin to have campers complete the surveys in order to maintain confidentiality from the researcher. The surveys were returned to the principle researcher.

Survey

The survey utilized in this study is a modification of the Patient Activation Measure (PAM) Survey as well as various questions relating to the Camp Ho Mita Koda experience specifically. Judith Hibbard of University of Oregon developed the Patient
Activation Measure. For purposes of the study, the developers of the measurement tool gave permission to modify original questions to use the word “diabetes” rather than “health condition (APPENDIX F).” All of these questions are based on a Likert-type scale ranging from disagrees strongly to agree strongly. The term, non-applicable, is also an option. Thirteen questions are modified questions of the PAM tool.

There is also a section of the first survey that includes five demographic questions about age, gender, specific camp session, number of years he/she has attended Camp Ho Mita Koda, and the length of time the individual has been diagnosed with diabetes (APPENDIX G). This was completed on the first day of each camp session.

Questions relating to the camp experience will only be on the post-survey, which is given at the end of the camp session and are specific to the Camp Ho Mita Koda experience (APPENDIX H). These questions evaluate the ability to discuss diabetes with peers, try new things, and gain new knowledge about diabetes. These questions are also based on a Likert-scale and responses range from disagree strongly to agree strongly, with non-applicable as another choice.

Hemoglobin A1c Values

When campers arrive at Camp Ho Mita Koda, camp staff drew blood to test each camper’s hemoglobin A1c. These blood samples were coded by camp staff and sent to a lab for interpretation. Hemoglobin A1c values are then returned to camp staff within 24 hours. For this session, camp staff coded the blood samples with the same code numbers used for each camper’s survey before the list was given to the researcher. For session 5, camp staff coded blood samples as the same codes used for this study prior to sending them to the lab to decrease the ability for experimental error.
Data Collection and Management

The surveys were compiled into an Excel format and correlated with the assigned number. Demographic data was entered, which includes age, gender, number of years in attendance at Camp Ho Mita Koda, and number of years with type 1 diabetes diagnosis. Responses from pre- and post-Patient Activation Measure survey were also entered into Excel. Overall mean scores for both surveys and for both camp sessions were calculated and compared statistically to determine whether any significant differences were found. Responses for each individual question were also scored and averages were calculated in order to determine differences between pre- and post-survey results.

Pre- and post- PAM scores were analyzed using two different methods thoroughly explained by Gerber at Cornell University (25). First scores from both surveys were categorized into four stages that are associated with different levels of knowledge and confidence. Individual scores on both surveys were also observed in order to determine whether campers were categorized in a different stage on the post-survey from the pre-survey.

Responses to individual questions were also examined using procedures discussed by Gerber at Cornell University (25). Each question had been categorized in one of four categories such as the individual’s belief that an active role in disease management is important, the individual’s level of confidence and knowledge to take action, the individual’s ability to take action, and the individual’s ability to maintain confident and consistent, even in times of stress. Mean scores to each question were analyzed in order to determine the areas in which the camp may need to focus general camp objectives for future years.
In order to test the second hypothesis for the study, which discusses differences between PAM scores for campers with low hemoglobin A1c values and those with high hemoglobin A1c values. An overall mean hemoglobin A1c value was calculated for the entire sample and two groups were formed. Group A are those campers with hemoglobin A1c values below the mean value and Group B are campers with A1c values greater than the mean. Average Patient Activation Measure survey scores, for both the pre- and post-surveys, were calculated and compared statistically using factorial ANOVA. Both tables and graphs are used to demonstrate this data.

Data obtained from the specific camp questions on the post-survey were also compiled in Excel. Overall scores as well as scores for each individual question were compiled and means calculated.
CHAPTER IV
RESULTS

This study was designed to explore the impact of a residential diabetes summer camp on each camper’s confidence in disease management. Purposes of this study include examining changes in camper’s attitudes and behaviors in managing diabetes after attending Camp Ho Mita Koda for 11 days as well as examining any connections between the camper’s hemoglobin A1c values and changes in confidence. A total of 99 campers participated in entirety or in portions of the study with 88 campers completing both surveys and obtained a hemoglobin A1c value. Fifty-one and 48 campers completed the demographic portion of the survey during session 4 and session 5, respectively and a total of 95 campers completed the questions designed specifically for Camp Ho Mita Koda campers.

Demographic Information Regarding Participants

Information regarding the demographic profile of the participants such as gender, age, number of years at camp, and number of years diagnosed with diabetes can be found in Table 1. A mean for each category was calculated along with the number of participants who responded with each subcategory is also provided in this table. A majority (54.35%) of participants during both sessions were female with session 4 having a larger majority than session 5. The average age for both sessions was 13.19 years, with the average age for session 4 at 14.02 years and 12.35 years for session 5. Participants
reported an average 6.68 years of being diagnosed with diabetes and 3.72 years of attendance at Camp Ho Mita Koda.

Table 1: Survey Participant Demographics

<table>
<thead>
<tr>
<th></th>
<th>Session 4 (N=51)</th>
<th>Session 5 (N=48)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>31 (60.7%)</td>
<td>23 (47.9%)</td>
</tr>
<tr>
<td>Males</td>
<td>20 (39.2)</td>
<td>25 (52.1)</td>
</tr>
<tr>
<td><strong>Average Age:</strong></td>
<td>14.02</td>
<td>12.35</td>
</tr>
<tr>
<td>10 Years</td>
<td>0</td>
<td>1 (2.1)</td>
</tr>
<tr>
<td>11 Years</td>
<td>0</td>
<td>12 (25.0)</td>
</tr>
<tr>
<td>12 Years</td>
<td>2 (3.9)</td>
<td>16 (33.3)</td>
</tr>
<tr>
<td>13 Years</td>
<td>16 (31.4)</td>
<td>9 (18.8)</td>
</tr>
<tr>
<td>14 Years</td>
<td>13 (25.5)</td>
<td>8 (16.7)</td>
</tr>
<tr>
<td>15 Years</td>
<td>19 (37.3)</td>
<td>2 (4.2)</td>
</tr>
<tr>
<td>16 Years</td>
<td>1 (1.9)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Average Years Attending Camp:</strong></td>
<td>4.02</td>
<td>3.42</td>
</tr>
<tr>
<td>First Year</td>
<td>5 (9.8)</td>
<td>5 (10.4)</td>
</tr>
<tr>
<td>1 Year</td>
<td>0</td>
<td>5 (10.4)</td>
</tr>
<tr>
<td>2 Years</td>
<td>1 (1.9)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>3 Years</td>
<td>6 (11.8)</td>
<td>10 (20.8)</td>
</tr>
<tr>
<td>4 Years</td>
<td>10 (19.6)</td>
<td>11 (22.9)</td>
</tr>
<tr>
<td>5+ Years</td>
<td>29 (56.9)</td>
<td>16 (33.3)</td>
</tr>
<tr>
<td><strong>Average Years with Diabetes:</strong></td>
<td>6.73</td>
<td>6.63</td>
</tr>
<tr>
<td>1 Year</td>
<td>3 (5.9)</td>
<td>1 (2.1)</td>
</tr>
<tr>
<td>2 Years</td>
<td>1 (1.9)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>3 Years</td>
<td>4 (7.8)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>4 Years</td>
<td>6 (11.8)</td>
<td>5 (10.4)</td>
</tr>
<tr>
<td>5 Years</td>
<td>8 (15.7)</td>
<td>6 (12.5)</td>
</tr>
<tr>
<td>6 Years</td>
<td>3 (5.9)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>7 Years</td>
<td>3 (5.9)</td>
<td>5 (10.4)</td>
</tr>
<tr>
<td>8 Years</td>
<td>5 (9.8)</td>
<td>3 (6.3)</td>
</tr>
<tr>
<td>9 Years</td>
<td>4 (7.8)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>10 Years</td>
<td>7 (13.7)</td>
<td>4 (8.3)</td>
</tr>
<tr>
<td>11+ Years</td>
<td>7 (13.7)</td>
<td>8 (16.7)</td>
</tr>
</tbody>
</table>

Hemoglobin A1c Values

Hemoglobin A1c values were obtained by camp staff for each camper on the opening day of their specific session. Blood samples were sent to a laboratory and hemoglobin A1c values were returned to the camp within the first week of the session. The average hemoglobin A1c value for both sessions was 9.25% with values of 8.81%
and 9.69% for session 4 and 5 respectively. Of all campers, 67.4% had hemoglobin A1c values between 7.1 and 10.0%, with the majority of these campers with values between 8.1 and 9.0%. Hemoglobin A1c values for both sessions are presented in Table 2.

<table>
<thead>
<tr>
<th>Hemoglobin A1c Values</th>
<th>Session 4 (N=50)</th>
<th>Session 5 (N=45)</th>
<th>Total for Both Sessions (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6.0%</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6.1-7.0%</td>
<td>4</td>
<td>1</td>
<td>5 (5.3)</td>
</tr>
<tr>
<td>7.1-8.0%</td>
<td>11</td>
<td>8</td>
<td>19 (20)</td>
</tr>
<tr>
<td>8.1-9.0%</td>
<td>16</td>
<td>9</td>
<td>25 (26.3)</td>
</tr>
<tr>
<td>9.1-10.0%</td>
<td>11</td>
<td>9</td>
<td>20 (21.1)</td>
</tr>
<tr>
<td>10.1-11.0%</td>
<td>3</td>
<td>9</td>
<td>12 (12.6)</td>
</tr>
<tr>
<td>11.1-12.0%</td>
<td>4</td>
<td>6</td>
<td>10 (10.5)</td>
</tr>
<tr>
<td>12.1-13.0%</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>13.1-14.0%</td>
<td>1</td>
<td>3</td>
<td>4 (4.21)</td>
</tr>
</tbody>
</table>

Patient Activation Measure Survey

In order to examine any changes in camper confidence in managing diabetes, the Patient Activation Measure survey was given on both the first and last day of the camp session to those campers who chose to participate. Ninety-six campers completed the survey on the first day of the camp session, with 50 and 46 campers completing it at the beginning of session 4 and session 5, respectively (Table 3). Ninety-two campers completed the second survey at the end of camp, with 46 campers completing the survey each session (Table 3). A decrease in number is most likely due to campers leaving camp prior to the completion of the session.

This survey utilizes a Likert scale and scores were determined by following instructions provided by the Patient Activation Measure procedures, which then are converted to a score between 0 and 100. Table 3 displays the mean Patient Activation Measure score for each individual session. Significant differences between pre- and post-scores were found as mean scores for both sessions increased from the pre-survey to the
post-survey (p<0.0000) (Table 3). Session 4 mean scores increased from 67.29 to 72.10 with an increase in 4.81 points. Session 5 increased similarly by 4.96, from 65.43 to 70.39, between the two surveys.

Table 3: Patient Activation Measure Survey Averages for Both Sessions

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Pre-Survey</th>
<th>N</th>
<th>Post-Survey</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 4</td>
<td>50</td>
<td>67.29±16.64</td>
<td>46</td>
<td>72.10±17.37</td>
<td>+4.81</td>
</tr>
<tr>
<td>Session 5</td>
<td>46</td>
<td>65.43±13.12</td>
<td>46</td>
<td>70.39±14.58</td>
<td>+4.96</td>
</tr>
</tbody>
</table>

Cumulative Patient Activation Measure scores are associated with four stages in personal chronic disease management and the individual’s willingness to change as explained by Gerber at Cornell University (25). Stage 1 is the lowest stage of activation and includes scores between 0 and 47. Stage 2, with a PAM score between 48 and 55, is the second lowest stage. PAM scores between 56 and 67 are included in stage 3 and stage 4, the highest level of activation, includes PAM scores between 68 and 100. Each stage correlates with a noted amount of confidence in disease management as well as areas that may need improvement and reinforcement.

Figure 1 represents all camper’s pre- and post-survey scores in relation to the four stages of activation measures, which are described by the range of scores associated with each stage. Of the four stages, the majority of campers scored in the fourth stage, which indicates a score between 68 and 100 points, for both the pre- and post-PAM. In stage 2, between 47 and 55 points, were 10 campers on the pre-PAM and 6 on the post-PAM. Twenty campers in session 4 and 18 campers in session 5 had scores between 56 and 67 and were found in stage 3. Only 9 and 8 campers, for session 4 and 5, respectively scored 47 points, which is the lowest stage.
Figure 1: Division of camper pre- and post-PAM scores into four stages designed by Gerber at Cornell University (25).

Campers also changed between stages when examining pre- and post-PAM scores. Figure 2 demonstrates the number of campers who remained in the same stage as well as those who moved up or lower in stages. It is observed that 43 campers remained in the highest stage, Stage 4 suggesting that many campers have confidence in managing his or her disease, but may need some reinforcement at certain times. Fourteen campers increased in scores to place them in Stage 4 on the post-PAM. Six campers remained in Stage 3, while 6 campers moved down from stage 4 and 6 campers moved up into this category. Of the 7 campers that were in stage 2, 4 moved down from either stage 3 or stage 4 when scoring the post-PAM. Only 1 camper remained in this stage and 2 moved from stage 1. Six campers stayed in stage 1 between the pre- and post-surveys and 3 campers moved down from higher stages.
Figure 2: Changes between the pre- and post-PAM scores in relation to the four stages as explained by Gerber at Cornell University.

Responses to each individual question were also examined for both surveys. These responses, extracted from pre-Patient Activation Measure, are listed in Tables 4 and 5. All questions have a mean score between 3.0 and 3.5 out of 4 possible points suggesting that in general campers responded that they agree or agree strongly with the statement. Questions with the lowest mean scores, with 3.04±0.86, 3.14±0.81, 3.16±0.77, and 3.16±0.75 of 4, respectively, were “I am confident I can figure out solutions when new situations or problems arise with my diabetes,” “I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress,” “I know the different medical treatment options available for my diabetes,” and “I am confident I can tell a doctor concerns I have even when he or she does not ask.” Questions that had the highest response score of 3.4±0.78 and 3.39±0.72 of 4, respectively, were “I am confident that I can tell when I need to go get medical care and
when I can handle a health problem myself,” and “I understand the nature and causes of my diabetes.”

Table 4: Patient Activation Measure Pre-Survey Responses

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>DS</th>
<th>D</th>
<th>A</th>
<th>AS</th>
<th>NA</th>
<th>Mean±SD*</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for managing my diabetes.</td>
<td>96</td>
<td>0</td>
<td>5</td>
<td>59</td>
<td>31</td>
<td>1</td>
<td>3.29±0.71</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td>97</td>
<td>0</td>
<td>1</td>
<td>53</td>
<td>42</td>
<td>1</td>
<td>3.32±0.68</td>
</tr>
<tr>
<td>I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes.</td>
<td>97</td>
<td>0</td>
<td>3</td>
<td>51</td>
<td>42</td>
<td>1</td>
<td>3.34±0.72</td>
</tr>
<tr>
<td>I know what each of my prescribed medications does.</td>
<td>96</td>
<td>0</td>
<td>8</td>
<td>40</td>
<td>45</td>
<td>3</td>
<td>3.38±0.90</td>
</tr>
<tr>
<td>I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.</td>
<td>97</td>
<td>1</td>
<td>4</td>
<td>46</td>
<td>44</td>
<td>2</td>
<td>3.4±0.78</td>
</tr>
<tr>
<td>I am confident I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>96</td>
<td>2</td>
<td>4</td>
<td>53</td>
<td>35</td>
<td>2</td>
<td>3.16±0.75</td>
</tr>
<tr>
<td>I am confident that I can follow through on medical treatments I need to do at home.</td>
<td>96</td>
<td>1</td>
<td>3</td>
<td>48</td>
<td>42</td>
<td>2</td>
<td>3.36±0.80</td>
</tr>
<tr>
<td>I understand the nature and causes of my diabetes.</td>
<td>96</td>
<td>1</td>
<td>6</td>
<td>42</td>
<td>47</td>
<td>0</td>
<td>3.39±0.72</td>
</tr>
<tr>
<td>I know the different medical treatment options available for my diabetes.</td>
<td>97</td>
<td>0</td>
<td>7</td>
<td>63</td>
<td>26</td>
<td>1</td>
<td>3.16±0.75</td>
</tr>
<tr>
<td>I have been able to maintain the lifestyle changes for my diabetes that I have made.</td>
<td>97</td>
<td>0</td>
<td>8</td>
<td>55</td>
<td>32</td>
<td>2</td>
<td>3.3±0.71</td>
</tr>
<tr>
<td>I know how to prevent further problems with my diabetes.</td>
<td>95</td>
<td>0</td>
<td>4</td>
<td>60</td>
<td>30</td>
<td>1</td>
<td>3.25±0.70</td>
</tr>
<tr>
<td>I am confident I can figure out solutions when new situations or problems arise with my diabetes.</td>
<td>97</td>
<td>0</td>
<td>9</td>
<td>60</td>
<td>26</td>
<td>2</td>
<td>3.04±0.86</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</td>
<td>97</td>
<td>1</td>
<td>8</td>
<td>54</td>
<td>32</td>
<td>2</td>
<td>3.14±0.81</td>
</tr>
<tr>
<td>Scoring Key: N=Sample size, DS=Disagree Strongly (1 point), D=Disagree (2 points), A=Agree (3 points), AS=Agree Strongly (4 points), NA=Not Applicable (0 points) *SD=Standard Deviation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Responses differed on second Patient Activation Measure, which was completed on the last day of the camp session. Responses to each question on the post-survey are provided in Table 5. The lowest scoring question, which scored 3.24±0.83 of 4 points,
was “I know what each of my prescribed medications does.” Questions with the highest
mean scores, 3.63±0.7, 3.48±0.62, and 3.46±0.68 of 4 points, respectively, were “I am
confident that I can follow through on medical treatments I need to do at home,” “Taking
an active role in my own health care is the most important factor in determining my
health and ability to function,” and “When all is said and done, I am the person who is
responsible for managing my diabetes.”

Table 5: Patient Activation Measure Post-Survey Responses

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>DS</th>
<th>D</th>
<th>A</th>
<th>AS</th>
<th>NA</th>
<th>Mean±SD*</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for managing my diabetes.</td>
<td>94</td>
<td>1</td>
<td>5</td>
<td>48</td>
<td>48</td>
<td>0</td>
<td>3.46±0.68</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td>95</td>
<td>1</td>
<td>1</td>
<td>41</td>
<td>52</td>
<td>0</td>
<td>3.48±0.62</td>
</tr>
<tr>
<td>I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes.</td>
<td>95</td>
<td>0</td>
<td>6</td>
<td>50</td>
<td>39</td>
<td>0</td>
<td>3.35±0.56</td>
</tr>
<tr>
<td>I know what each of my prescribed medications does.</td>
<td>94</td>
<td>1</td>
<td>6</td>
<td>47</td>
<td>37</td>
<td>3</td>
<td>3.24±0.83</td>
</tr>
<tr>
<td>I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.</td>
<td>95</td>
<td>0</td>
<td>4</td>
<td>40</td>
<td>51</td>
<td>0</td>
<td>3.54±0.58</td>
</tr>
<tr>
<td>I am confident I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>94</td>
<td>0</td>
<td>8</td>
<td>40</td>
<td>46</td>
<td>0</td>
<td>3.38±0.67</td>
</tr>
<tr>
<td>I am confident that I can follow through on medical treatments I need to do at home.</td>
<td>95</td>
<td>0</td>
<td>1</td>
<td>36</td>
<td>56</td>
<td>2</td>
<td>3.63±0.70</td>
</tr>
<tr>
<td>I understand the nature and causes of my diabetes.</td>
<td>95</td>
<td>1</td>
<td>7</td>
<td>42</td>
<td>44</td>
<td>1</td>
<td>3.33±0.72</td>
</tr>
<tr>
<td>I know the different medical treatment options available for my diabetes.</td>
<td>95</td>
<td>1</td>
<td>7</td>
<td>45</td>
<td>42</td>
<td>0</td>
<td>3.42±0.61</td>
</tr>
<tr>
<td>I have been able to maintain the lifestyle changes for my diabetes that I have made.</td>
<td>95</td>
<td>2</td>
<td>4</td>
<td>44</td>
<td>44</td>
<td>1</td>
<td>3.42±0.61</td>
</tr>
<tr>
<td>I know how to prevent further problems with my diabetes.</td>
<td>94</td>
<td>1</td>
<td>2</td>
<td>50</td>
<td>41</td>
<td>0</td>
<td>3.44±0.52</td>
</tr>
<tr>
<td>I am confident I can figure out solutions when new situations or problems arise with my diabetes.</td>
<td>95</td>
<td>0</td>
<td>8</td>
<td>51</td>
<td>36</td>
<td>0</td>
<td>3.31±0.62</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</td>
<td>95</td>
<td>3</td>
<td>5</td>
<td>40</td>
<td>45</td>
<td>2</td>
<td>3.27±0.87</td>
</tr>
</tbody>
</table>

Scoring Key: N=Sample size, DS=Disagree Strongly (1 point), D=Disagree (2 points),
A=Agree (3 points), AS=Agree Strongly (4 points),
NA=Not Applicable (0 points)
*SD=Standard Deviation
A comparison of mean PAM scores can be found in Table 6. When comparing mean scores for each question for both the pre- and post-survey, the majority of mean scores increased between the two surveys with only two questions decreasing in mean scores. These two questions decreased in mean scores. The question, “I know what each of my prescribed medications does” decreased by 0.14 points and the question, “I understand the nature and causes of my diabetes,” decreased by 0.6 points indicating that campers generally have less confidence in the knowledge regarding diabetes.

Of all 13 questions, the mean response for 11 of the questions increased between the pre- and post-surveys (Table 6). The statements, “I am confident that I can follow through on medical treatments I need to do at home,” and “I am confident I can figure out solutions when new situations or problems arise with my diabetes,” both increased by 0.27 points between the two surveys as well as also having one of the highest mean scores on the post-PAM survey. Another statement that received high scores, with a difference of 0.22 points, was the statement that “I am confident that I can tell a doctor concerns I have even when he or she does not ask.”

Paired t-tests were completed to determine the level of significance between pre- and post-PAM. These values are demonstrated in Table 7 and utilize data from 88 participants that completed all questions on the pre- and post-surveys as well as hemoglobin A1c values. Only four statements showed no significance. These questions are, “I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes,” “I know what each of my prescribed medications does,” “I understand the nature and causes of my diabetes,” and
“I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.”

Table 6: Comparison of Patient Activation Measure Pre- and Post-Survey Responses for Individual Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>N for Pre-Survey</th>
<th>N for Post-Survey</th>
<th>Difference Between pre- and post-means</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for managing my diabetes.</td>
<td>96</td>
<td>94</td>
<td>+0.17</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td>97</td>
<td>95</td>
<td>+0.16</td>
</tr>
<tr>
<td>I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes.</td>
<td>97</td>
<td>95</td>
<td>+0.01</td>
</tr>
<tr>
<td>I know what each of my prescribed medications does.</td>
<td>96</td>
<td>94</td>
<td>-0.14</td>
</tr>
<tr>
<td>I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.</td>
<td>97</td>
<td>95</td>
<td>+0.14</td>
</tr>
<tr>
<td>I am confident I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>96</td>
<td>94</td>
<td>+0.22</td>
</tr>
<tr>
<td>I am confident that I can follow through on medical treatments I need to do at home.</td>
<td>96</td>
<td>95</td>
<td>+0.27</td>
</tr>
<tr>
<td>I understand the nature and causes of my diabetes.</td>
<td>96</td>
<td>95</td>
<td>-0.06</td>
</tr>
<tr>
<td>I know the different medical treatment options available for my diabetes.</td>
<td>97</td>
<td>95</td>
<td>+0.26</td>
</tr>
<tr>
<td>I have been able to maintain the lifestyle changes for my diabetes that I have made.</td>
<td>97</td>
<td>95</td>
<td>+0.12</td>
</tr>
<tr>
<td>I know how to prevent further problems with my diabetes.</td>
<td>95</td>
<td>94</td>
<td>+0.19</td>
</tr>
<tr>
<td>I am confident I can figure out solutions when new situations or problems arise with my diabetes.</td>
<td>97</td>
<td>95</td>
<td>+0.27</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</td>
<td>97</td>
<td>95</td>
<td>+0.13</td>
</tr>
</tbody>
</table>

Scoring Key: N=Sample size, DS=Disagree Strongly (1 point), D=Disagree (2 points), A=Agree (3 points), AS=Agree Strongly (4 points), NA=Not Applicable (0 points) *SD=Standard Deviation
Table 7: Comparison of pre- and post-scores for each individual question (N=88)

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre-Survey Means</th>
<th>Post-Survey Means</th>
<th>T-value</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for managing my diabetes.</td>
<td>3.21±0.65</td>
<td>3.43±0.65</td>
<td>-3.40</td>
<td>0.001*</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td>3.4±0.63</td>
<td>3.49±0.59</td>
<td>-2.18</td>
<td>0.032*</td>
</tr>
<tr>
<td>I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes.</td>
<td>3.36±0.66</td>
<td>3.35±0.59</td>
<td>0.179</td>
<td>0.859</td>
</tr>
<tr>
<td>I know what each of my prescribed medications does.</td>
<td>3.27±0.89</td>
<td>3.23±0.81</td>
<td>0.502</td>
<td>0.617</td>
</tr>
<tr>
<td>I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.</td>
<td>3.34±0.73</td>
<td>3.51±0.59</td>
<td>-1.985</td>
<td>0.05*</td>
</tr>
<tr>
<td>I am confident I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>3.17±0.81</td>
<td>3.40±0.63</td>
<td>-2.44</td>
<td>0.016*</td>
</tr>
<tr>
<td>I am confident I can follow through on medical treatments I need to do at home.</td>
<td>3.31±0.79</td>
<td>3.55±0.73</td>
<td>-2.84</td>
<td>0.006*</td>
</tr>
<tr>
<td>I understand the nature and causes of my diabetes.</td>
<td>3.39±0.67</td>
<td>3.35±0.68</td>
<td>0.564</td>
<td>0.574</td>
</tr>
<tr>
<td>I know the different medical treatment options available for my diabetes.</td>
<td>3.16±0.64</td>
<td>3.36±0.63</td>
<td>-3.06</td>
<td>0.003*</td>
</tr>
<tr>
<td>I have been able to maintain the lifestyle changes for my diabetes that I have made.</td>
<td>3.20±0.70</td>
<td>3.35±0.77</td>
<td>-1.75</td>
<td>0.083*</td>
</tr>
<tr>
<td>I know how to prevent further problems with my diabetes.</td>
<td>3.19±0.63</td>
<td>3.40±0.55</td>
<td>-2.89</td>
<td>0.005*</td>
</tr>
<tr>
<td>I am confident I can figure out solutions when new situations or problems arise with my diabetes.</td>
<td>3.09±0.74</td>
<td>3.30±0.61</td>
<td>-2.57</td>
<td>0.011*</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</td>
<td>3.19±0.74</td>
<td>3.31±0.82</td>
<td>-1.27</td>
<td>0.206</td>
</tr>
</tbody>
</table>

*Significant

Comparison of Hemoglobin A1c Values and Patient Activation Measure Responses

The mean hemoglobin A1c value was 9.25% for both sessions. Two groups representing those with A1c values less than the mean (Group A) and those with values greater than the mean (Group B) were formed between all campers. The mean hemoglobin A1c value for Group A was 7.95% and for Group B was 10.65%. Once
established, Patient Activation Measure responses for each group were also examined. For Group A, those with hemoglobin A1c values less than 9.25%, had a mean score of 66.48 for the pre-PAM and 71.11 for the post-PAM. Group B, those with hemoglobin A1c values greater than 9.25%, had a mean score of 68.95 for the pre-PAM and 74.95 for the post-PAM. Upon completing statistical analysis of both the pre- and post-PAM, no significant differences between group A and group B and their associated PAM scores were found (Figure 3).

![Comparison of Hemoglobin A1c Values Above and Below the Mean and the Patient Activation Measure Scores](image)

Figure 3: Comparison of Hemoglobin A1c values and Patient Activation Scores.

Camp Ho Mita Koda Questions

Five questions were included on the second survey given to campers that related specifically to the Camp Ho Mita Koda experience in relation the camp’s ability to improve confidence in managing their diabetes. Ninety-five participants completed this section of the survey with an average score for these five questions of 16.31±2.76 out of 20 possible points. One participant circled between “agree” and “agree strongly” for the second question, between “disagree” and “agree” for the third question, and between
“disagree” and “agree” for the last question. These responses were included in the overall average by scoring them as halfway between the two responses. For example, the score would be 3.5 for the response for circling between “agree” and “agree strongly.”

Table 8 displays responses given for these specific questions as well as the mean score for each question.

Table 8: Survey Responses for Camp Ho Mita Koda Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>DS</th>
<th>D</th>
<th>A</th>
<th>AS</th>
<th>NA</th>
<th>Mean±SD*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since coming to camp, I feel that I can make good decisions about my diabetes, even without my family around.</td>
<td>95</td>
<td>0</td>
<td>0</td>
<td>33</td>
<td>62</td>
<td>0</td>
<td>3.65±0.48</td>
</tr>
<tr>
<td>Since coming to camp, I feel more comfortable with talking about diabetes with my friends.</td>
<td>94</td>
<td>2</td>
<td>4</td>
<td>39</td>
<td>46</td>
<td>3</td>
<td>3.31±0.90</td>
</tr>
<tr>
<td>Since coming to camp, I feel that I am willing to try something new for taking care of my diabetes.</td>
<td>94</td>
<td>0</td>
<td>7</td>
<td>40</td>
<td>46</td>
<td>1</td>
<td>3.37±0.72</td>
</tr>
<tr>
<td>Since coming to camp, I have learned more about diabetes.</td>
<td>95</td>
<td>1</td>
<td>20</td>
<td>37</td>
<td>35</td>
<td>2</td>
<td>2.83±0.90</td>
</tr>
<tr>
<td>Since coming to camp, I have gained new skills to manage my diabetes.</td>
<td>94</td>
<td>0</td>
<td>15</td>
<td>41</td>
<td>36</td>
<td>2</td>
<td>3.15±0.84</td>
</tr>
</tbody>
</table>

Scoring Key: N=Sample size, DS=Disagree Strongly (1 point), D=Disagree (2 points), A=Agree (3 points), AS=Agree Strongly (4 points), NA=Not Applicable (0 points) *SD=Standard Deviation

The majority of campers who completed this section of the survey, 62 of 95 or 65.3%, agreed strongly that he or she could make decisions about how to care for their diabetes, even without their family present which indicates an increase in confidence in making good decisions regarding diabetes management with the help of the caregiver. Most campers, 89.5%, also agreed or agreed strongly that they could talk about diabetes with their friends and 91.5% of campers were also willing to try new diabetes management techniques. The question obtaining the lowest mean score of 2.83 and more disagreeable responses than any other question, 20 out of 95 campers or 21.1%, related to
learning more about diabetes while at camp. The majority of campers, 75.8%, however, responded “agree” or “agree strongly” to this question. Eighty one percent of campers believed that they gained new skills in terms of diabetes management while at camp.
CHAPTER V
DISCUSSION

Introduction

Disease management, which typically focuses on lifestyle changes in diet, exercise, as well as consistent blood glucose management, is a challenge to teach to any individual impacted with a chronic disease (26). Glasgow and Anderson suggested in 1995 that increased attention be given to the adolescent population with diabetes not only because of the biological changes occurring during this time period, but also due to the cognitive and social factors that have an impact on lifelong disease management (27).

While it is recommended by the American Diabetes Association that as a child ages, he or she should have increased participation and control in disease management, research has not always supported this ideology (7, 28). Health professionals and guardians are challenged when attempting to teach disease management techniques to adolescents, due to the fact that this age group tends to rebel and desire independence (7). Research has examined the adolescent’s ability to manage his or her diabetes when outside of the home and away from guardian guidance, however little research has examined the child’s ability to function independently in a supportive learning environment when they are away from parents for more than 24 hours (2). Residential summer camps provide a unique and comfortable environment where children function independently for a period of time while also learning social, mental, and physical skills.
(2). Because of this independence, the camp environment is an ideal place to thoroughly examine a child’s self-management skills and their confidence in these skills.

The impact of the camp experience has become an area of research within the last decade, mostly in part to efforts by the American Camp Association (14,15). Research that has been completed at residential camps without a specific disease focus has demonstrated a positive impact on developmental skill building in the areas of decision-making, communication, and leadership (16). Little research on these developmental outcomes, however, has examined the impact of specialty residential camps that focus much of the camp curriculum around a specific disease or condition, while also providing a normalized camp experience.

The American Diabetes Association has provided support for specialty camps aimed at children with either type 1 or type 2 diabetes. However, research on the effectiveness, efficiency, value, and success of camp and camper goal achievement through the residential camp experience is lacking (29). The purpose of the current study was to examine the impact that Camp Ho Mita Koda, a diabetes residential summer camp, had on the attitudes and behaviors associated with the confidence to self-manage type 1 diabetes after an 11-day camp session.

Patient Activation Measure Scores and Stages

The tool utilized in this study to examine the impact on confidence in disease management for adolescents resulting from their experience at Camp Ho Mita Koda was the Patient Activation Measure (PAM). Two different evaluation methods were utilized to determine changes in the camper’s confidence. The first evaluates total Patient Activation Measure scores to determine the stage of confidence of each individual at the
beginning and end of the study. Responses from each individual question can also be evaluated to determine what areas of disease management need reinforcement and improvement, whether it is for individuals or for the entire population of Camp Ho Mita Koda campers.

Research discussed by Gerber has examined four stages that correlate with Patient Activation Scores (25). These stages relate to the individual’s confidence and ability in chronic disease management. Stage 1 relates to individuals who score between 0 and 47 points and typically do not understand their role in disease management and do not have basic knowledge about their disease, treatments, or management. A total of 9 campers and 8 campers on the pre- and post-PAM survey, respectively, had a PAM score in this stage. While this is a small percentage of the total number of adolescents attending camp, it is important to focus on these individuals and educate each regarding their role in diabetes self-management (25).

Individuals who are included in stage 2, either from pre- or post-PAM scores, tend to have more confidence in their ability to manage their chronic condition, but lack basic knowledge about their disease, treatment options, and self-management while also feeling less in charge of their own health. These individuals may be less experienced or may have had less success with behavior change in the past (25). Ten campers on the pre-PAM and 6 campers on the post-PAM had scores within the stage 2 range. These campers may benefit from general diabetes education as well as establishing obtainable goals to ensure feelings of success that could lead to sound and confident choices in their disease management (25).
Patient Activation Measure scores between 55 and 67 are associated with stage 3, in which individuals take action to maintain and improve their health. These individuals differ from those in stage 1 and 2 because they tend to have the basic knowledge of their disease and treatments while also have experience and success in decision-making. They also have increased confidence in disease management. Of all campers who completed the survey, 20 and 18 campers scored in stage 3 on the pre- and post-PAM surveys, respectively. Six campers moved up from either stage 1 or 2 after completing the post-survey indicating that the camp experience may have had a positive impact on their level of confidence. This data is also encouraging in that many campers have confidence in managing their diabetes, but also may also benefit from the camp experience in that they have the ability to increase knowledge and confidence.

Stage 4, which is reflective of those who score between 67 and 100 points, tends to represent individuals who are confident and consistent in managing chronic illnesses, but may need reinforcement in times of stress. An increase in confidence and skills is encouraged. There were 49 Camp Ho Mita Koda campers who scored in this category on the pre-PAM and this number increased to 57 campers on the post-survey. Because diabetes self-management education is a lifelong process and the camping experience has been associated with increased levels of independence and leadership, the camp experience will only continue to increase the individual’s level of confidence and adherence to their particular treatment (16, 26).

Utilization of the Patient Activation Measure is an advantage for health care providers. For the camp population, camp staff is able to use survey scores to determine which campers may need more focus in terms of disease management. In general,
campsers within stage 1 and stage 2 may need more baseline education while those campers with scores in stage 3 or 4 may need reinforcement and motivation to consistently manage their diabetes.

The variety of scores and the presence of campers in each stage, however, provide challenges for camp staff when planning camp programming and mentoring. Camp staff aims to create programs that will be beneficial to each camper, no matter the stage, through individual and group education (4). Research has suggested that as a whole, camper’s knowledge and skills improve after camp (30). While some may increase greater than others, an overall increase was observed, which may indicate that improvements are seen no matter the camper’s readiness to change behaviors. With this knowledge, perhaps programs should be designed to allow those who have more knowledge and skills to participate and mentor those who have less knowledge and skills. This in turn would allow those who are more confident to reinforce skills and gain more confidence while also allowing those with less knowledge, learn and also gain confidence in self-management skills as suggested by Gerber at Cornell University (25).

Analysis of Individual Questions on Both the Pre- and Post-Patient Activation Measure

The purpose of the utilization of the Patient Activation Measure was to examine the level of confidence demonstrated by adolescents attending a diabetes summer camp for 11 days. After examining the overall PAM score, researchers and healthcare providers are able to describe the level of confidence an individual has in managing chronic illnesses. Because managing diabetes is a multi-faceted process, it is also important to examine the individual’s willingness to change his or her lifestyle in order to promote good health. Following procedures explained by Gerber, each question included
on the Patient Activation Measure is part of a particular category that examines the level of confidence an individual possess when caring for their chronic illness (25). Of the 13 questions, the first 2 questions examine the individual’s belief of having an active role in his or her care as important, the next 6 questions examine the individual’s level of confidence and knowledge to take action in managing the chronic illness, the following 3 questions examine the individual’s ability to take action, and the last 2 questions examine the individual’s ability to maintain management through times of stress (25).

Of the two questions regarding the individual’s belief of having an active role in disease management as important, both statements had a significant increase between pre- and post-PAM surveys, possibly indicating an increase in the camper’s ability and confidence in managing his or her diabetes without the presence of guardians. While it is encouraging that both statements regarding the individual’s role in self-management increased after the camp experience, it is important to note that adolescence is marked as a period in life when noncompliance and decreased adherence in management are noted, therefore leading to decreased motivation to effectively manage their diabetes (11). These are considerations that should be made when designing educational objectives in the hope to continue to motivate these adolescents, especially when targeting an audience such as the camp environment.

Six questions provide insight into the individual’s confidence and knowledge to take needed action to manage diabetes. The statement, “I am confident I can follow through on medical treatments I need to do at home,” had one of the largest increases of 0.27 points between mean pre- and post-surveys as well as the highest mean score on the post-PAM. Two statements in this category were the only two to decrease between the
pre- and post-surveys. While the statement, “I understand the nature and causes of my diabetes,” received a high score on the pre-PAM survey, it also decreased in mean score on the post-PAM survey by 0.06 points. Reasons for the decrease may be due to obtaining a high baseline score on the pre-PAM survey. The other statement that decreased was, “I know what each of my prescribed medication does,” which decreased by 0.14 points. Camp Ho Mita Koda focuses most educational objectives on lifestyle and behavior modifications rather than education on the purpose of medications may explain this decrease.

While the only two statements that decreased between the two surveys were found in this category, four of the questions showed an increase. This suggests that the majority of campers at Camp Ho Mita Koda are aware and knowledgeable of diabetes in general, when to receive medical attention, and have a large amount of confidence in managing their diabetes. It is the hope that because campers attending both sessions had been diagnosed with type 1 diabetes for 6.68 years, on average, that they would possess at least minimal knowledge of the disease and feel comfortable with his or her medical team to obtain the care and medical advice when needed. Research has suggested that even though adolescents are more educated in terms of diabetes management, social pressure and social conformity have a large impact, therefore causing them to have poorer control (28, 31). The end result may be complications related to diabetes in the future.

For the 3 questions related to the individual’s ability to take action in managing chronic conditions, all had a significant increase between the two surveys. It is important to note that this is a challenging area of focus when educating individuals of any age due to the fact that the individual must understand that actions taken every day in the effort to
control his or her diabetes may have an effect on their health in the future. This is even more of a challenge for adolescents who tend to not worry about the future and are typically less compliant (11). Continuous diabetic education is needed and the data obtained from Camp Ho Mita Koda suggests that the education and support provided at camp did have an impact on the camper’s attitudes and behaviors associated with diabetes self-management.

Two questions related to the individual’s ability to maintain disease management even through times of stress. Between the pre- and post-PAM surveys, both mean scores for these questions increased. The question, “I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress,” did not show a significant difference between pre- and post-PAM scores. The significant difference observed between pre- and post-PAM surveys for the question, “I am confident I can figure out solutions when new situations or problems arise with my diabetes,” may indicate that camper have confidence in the ability to maintain lifestyle changes even during times of stress. This may suggest that the campers had strong fundamental knowledge and possibly support from home and health care providers to be confident and maintain diabetic control. This is also evidenced by the fact that 43 campers who completed both the pre- and post-surveys obtained scores on both surveys that placed them in the highest confidence stage as developed by Gerber.

Patient Activation Measure and Glycemic Control

In order to examine hypothesis 2, which asks whether campers with better glycemic control had higher perceived confidence in managing their diabetes, statistical analyses were completed to compare Patient Activation Measure scores between those
campers with high hemoglobin A1c values to those with lower hemoglobin A1c. No significant differences were found between campers with better glycemic control and campers with less control.

Hemoglobin A1c values are valuable indicators of glycemic control used by many health professionals. It is recommended that individuals with diabetes maintain glucose control as close to normal as possible, however some flexibility is typically given to adolescents (7). Recommendations for normal ranges of hemoglobin A1c values for adolescents and children are based on data from adult studies and are therefore similar to these values (7). In the Diabetes Control and Complications Trial, a group of adolescents with type 1 diabetes were analyzed and hemoglobin A1c values were over 1% higher than current adult recommendations (7). Values similar to adults can be recommended to adolescents, but risk of hypoglycemia and feelings of failure may be noted. With this research, the American Diabetes Association recommends hemoglobin A1c values for children between 6 and 12 years below 8% and below 7.5% for adolescents and young adults between 13 and 19 years of age (7).

Hemoglobin A1c values for adolescents may be associated with puberty (30). In a study that followed 118 adolescents to observe changes in diabetic control throughout adolescence, found that hemoglobin A1c values for both males and females increased between pre-puberty and post-puberty (32). Females increased an estimated 0.92% and males increased 0.29% (32). Because Camp Ho Mita Koda campers who participated in this study ranged in age between 10 and 16 years, it is possible that puberty may have had an impact in glycemic control of this population.
Research has suggested that the adolescent years are typically a time period in which poor glycemic control is observed (28). While the American Diabetes Association suggests that adolescents become more independent when discussing self-management, researchers have found that high levels of responsibility at this age are associated with poorer metabolic control (7, 28). It is interesting to note that the mean hemoglobin A1c for session 5 was 2.7% higher than session 4, while the average age for session 5 was 1.67 years younger than session 4. This contradicts current research, which suggests that preadolescents typically have better hemoglobin A1c values than adolescents and may indicate that age may not have as large of a role in self-management than originally thought (28). In this study, little correlation between the camper’s age and their associated hemoglobin A1c value was found (r=0.0495). This may indicate that this camper sample has similar management practices outside of camp resulting in similar hemoglobin A1c scores, no matter the age.

In a study that examined glycemic control in adolescents with type 1 diabetes after 20 days at diabetes camp, hemoglobin A1c values did improve, even seven months following the camp experience, in comparison to adolescents of the same age who did not attend camp (30). Both males and females improved in terms of hemoglobin A1c values, with females showing a significant difference. Parents and campers also had reports of adherence to diabetes management after camp. Factors that contribute to glycemic control are frequent exercise, preplanned meals, diabetes education, and structured environment for management, which are all part of the camp experience (7). It is the hope that adolescents attending Camp Ho Mita Koda will continue the skills and
behaviors enforced and obtained at camp in the following months and a difference in hemoglobin A1c values would be observed.

Camp Ho Mita Koda Questions

As suggested by the American Diabetes Association in a mission statement supporting the camp experience, camps for diabetic children should create a normal camp experience where activities and daily schedules are similar to other summer residential camps, while also providing a safe and educational environment (22). Camp Ho Mita Koda staff as well as the American Diabetes Association have specific camp objectives that encompass not only nutrition education or glycemic control measures, but also the social aspects of disease management that are needed to ensure continuous disease control (4, 22). Research has shown that children who attend residential camps become more confident, develop social skills, grow more independent, show more leadership qualities, experience self-esteem, and are willing to try new things (14). In an effort to examine Camp Ho Mita Koda’s effect on these qualities, five questions were asked on the post-survey, given on the final day of the camp session.

While no baseline measures were taken in regards to these five questions, they do provide some insight into which of the Camp objectives the campers have either identified with or felt they had obtained while at camp. Each question asked on the post-survey began with the phrase, “Since coming to camp,” and then asked questions about confidence in talking with friends about diabetes, confidence in decision-making in regards to diabetes management, confidence in trying something new for taking care of their diabetes, as well as any increased knowledge about the disease and management skills.
The highest scoring question, which scored between agree and agrees strongly, asked whether since coming to camp the campers felt that they could make decisions about their diabetes, even when family members are not present. The high score for this question is also reflected by the significant increase observed on the two questions on the PAM survey that related to the individuals belief of having an active role in disease management which were, “When all is said and done, I am the person who is responsible for managing my diabetes,” and “Taking an active role in my own health care is the most important factor in determining in my health and ability to function.” This may suggest that the camp experience did increase the independence of the campers in terms of disease management. Research supports these findings. In a study completed by the American Camp Association, results after examining outcomes of several campers with disabilities suggested a positive and predominant outcome for both self-reliance and independence after a 1-week residential camp experience (17).

The statement, “Since coming to camp, I have learned more about diabetes,” received the lowest mean score of 2.83 of 4 possible points or in other words, the majority of campers may disagree or agree with this statement. This may be reflective of lower mean scores found on questions related to diabetes knowledge on the Patient Activation Measure that also scored low when compared to other questions. These questions included on PAM are, “I know what each of my prescribed medication does,” and, “I understand the nature and causes of my diabetes,” which both decreased in mean scores between the pre- and post-Patient Activation Measure. This is not due to a lack in diabetes education while at Camp Ho Mita Koda, but rather related to the fact that objectives related to diabetes education are more associated with self-management.
techniques such as glucose monitoring skills, nutrition education, and improved confidence in these skills (4). It may be beneficial for Camp Ho Mita Koda staff to ensure that all campers learn the basic knowledge of the etiology of diabetes in order to understand the nature and causes of diabetes. Because adolescents tend to rebel from carrying out daily regimens and have more independence, having the underlying knowledge may reinforce the importance to adhere to diabetes management in the present and the future (11).

The other three questions asked on the survey that relate to feeling comfortable in talking about diabetes with friends, willing to try something new for taking care of diabetes, and gaining new skills in disease management all had mean scores over 3, suggesting that the overall, the campers agree with each statement. While little research has been completed on these aspects in relation to diabetes camps, research has supported positive outcomes in these areas in the general camp population (14). Supportive relationships were one examined aspect of camp completed by the American Camp Association. This research suggested that the development of supportive relationships were one of camp’s strengths not only between campers, but also between campers and staff (14). Other research completed by the American Camp Association, however, found that camper’s ability and desire to create new friendships after six months had decreased (16). This may indicate that while at camp and surrounded by children with similar lives and interests, the willingness to create supportive friendships exists, but in an environment with a much larger variety of children, this desire may decrease.

Similar to what was reported by Camp Ho Mita Koda campers, in terms of willingness to try new things, research has found that children are typically willing to try
new activities and skills by the end of the camp period. An observed decrease back to the baseline value in this willingness after six months has been found in general camp research. This also relates to the other question on the Camp Ho Mita Koda survey of gaining new skills while at camp, which the mean score suggests that campers agree with this statement. Camp Ho Mita Koda objectives focus on gaining and improving many skills that are associated with diabetes management, which most likely account for this score.

When observing camper demographics, it is important to note that of all participants who attended Camp Ho Mita Koda, 56.9% and 33.3% of campers during session 4 and 5 respectively, attended Camp Ho Mita Koda for five or more years. This high rate of returning campers may be due to friendships, the comfortable environment, or reinforcement of skills. Research that examines the impact of the camp experience on returning campers is lacking. One study, which examined a summer camp, found that new campers made more gains in terms of personal development than returning campers (17). This study suggests that camps need to not only focus on making new campers comfortable, but also reinforce and welcome returning campers. Camp Ho Mita Koda has a large return rate, which may suggest that Camp does make an impact on campers, whether it is related to reinforcement of diabetes management skills or the friendships and support systems made year after year.

As previously mentioned, residential summer camps provide a unique and structured environment that allow children and adolescents to be independent and grow socially, physically, and mentally. Research that examines the long-term effects of these camps, specifically specialty summer camps, is lacking. Diabetes management is an
educational experience that must continue throughout life. When diagnosed with diabetes at a young age, it is important to remember the characteristics of this age in terms of educational capacity and social abilities. Adolescents do not want to be different from their peers. Diabetes camps, however, provide these adolescents an opportunity to be surrounded with other adolescents, both younger and older, with longer or shorter diagnoses, in a community designed to be comfortable and supportive. It is the hope that researchers will examine the long-term aspects of diabetes camps in the future.

Implications and Suggestions for Future Research

Data obtained from this study can be utilized in several different ways in that different approaches may be considered. Different correlations such as the correlation between their level of confidence in diabetes self-management and gender, number of years with diabetes, number of years attending camp, and age may provide beneficial information for both researchers as well as for Camp Ho Mita Koda administration.

While short-term changes in confidence in disease management were noted in this population, it would also be suggested that a follow-up data collection be completed in future studies. This would not only determine whether campers continue with disease management and the confidence associated with it, but also provide some insight to camp administrators of areas that need special attention while at camp in the effort to create lifelong habits.

Returning campers provide another unique aspect to long-term studies. Because the majority of campers in this study had attended Camp Ho Mita Koda previously, it would be interesting to examine the impact on these children versus children who are
attending camp for the first time. A longitudinal study may also be beneficial to examine the impact of the camp experience on these children over several years.

While nutrition education and increases in knowledge were not a main focus of this study, self-management skills are equally important for dietitians to acknowledge. It is necessary for dietitians to work and motivate clients, especially the adolescent population, to combine nutrition education and self-management skills and techniques to ensure adherence. Targeting this population, while they are gaining more independence not only in disease management, but also in life in general, is crucial in that the time to build confidence in management skills will promote good health in the future.
REFERENCES


APPENDIX A.

INSTITUTIONAL REVIEW BOARD APPROVAL.

NOTICE OF APPROVAL

Date: May 22, 2008

To: Sarah Drewes
   40 Gloucester Ct., Apt. 4A
   Akron, Ohio 44313

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 20080504
   "The Impact of a Residential Summer Camp on Attitudes and Behaviors Associated with Diabetes Self-Management in Adolescents"

Thank you for submitting an IRB Application for Review of Research Involving Human Subjects for the referenced project. Your protocol represents minimal risk to subjects and has been approved under Expedited Category #7.

Approval Date: May 22, 2008
Expiration Date: May 22, 2009
Continuation Application Due: May 8, 2009

In addition, the following is/are approved:

☐ Waiver of documentation of consent
☐ Waiver or alteration of consent
☐ Research Involving children
☐ Research involving prisoners

Please adhere to the following IRB policies:

- IRB approval is given for not more than 12 months. If your project will be active for longer than one year, it is your responsibility to submit a continuation application prior to the expiration date. We request submission two weeks prior to expiration to insure sufficient time for review.
- A copy of the approved consent form must be submitted with any continuation application.
- If you plan to make any changes to the approved protocol you must submit a continuation application for change and it must be approved by the IRB before being implemented.
- Any adverse reactions/incidents must be reported immediately to the IRB.
- If this research is being conducted for a master’s thesis or doctoral dissertation, you must file a copy of this letter with the thesis or dissertation.
- When your project terminates you must submit a Final Report Form in order to close your IRB file.

Additional information and all IRB forms can be accessed on the IRB web site at:
http://www.uakron.edu/research/orsp/compliance/IRBHome.php

☐ Approved consent form/s enclosed

Cc: Deborah Marro- Advisor
Cc: Rosalie Hall - IRB Chair

Office of Research Services and Sponsored Programs
Avon, OH 44325-2102
330-972-7668 • 330-972-6281 Fax

The University of Akron is an Equal Education and Employment Institution.
Dear Parent or Guardian,

My name is Sarah Drewes and I am a graduate student in the Nutrition and Dietetics Program at the University of Akron. I have been involved with a summer camp in Northern Wisconsin both as a camper for 7 years and a counselor for 10 years. Because of the importance of the camp experience for my development, I wanted to find a Masters thesis topic that would combine my love for camp and nutrition.

This summer I am planning on visiting Camp Ho Mita Koda to evaluate the impact of the camp experience on your child’s confidence in managing their diabetes. Two surveys will be given to campers, one on the first day of camp and the second on the last day. It will be a short and simple survey that will be part of the check-in and check-out camp procedure.

Included with this letter is a parent consent form. I am hoping that you will allow your child to participate in this study that will benefit your child and Camp Ho Mita Koda. The information from this survey will assist Camp Ho Mita Koda in providing the best possible camp experience for children with diabetes.

If you choose to allow your child to participate, please complete the parental consent form and bring it to camp on the first day. It will be collected with the other camp paperwork. Your child is not required to participate and can decide not to participate at any time.

I look forward to seeing all of the campers on opening day to kick off a great camp experience!

Thank you in advance for your cooperation and help in completing my education!

Sincerely,

Sarah Drewes
Graduate Student
University of Akron
June 22, 2008

Dear Campers and their families:

Camp Ho Mita Koda is pleased to support the research project of Ms. Sarah Drewes, a graduate student at The University of Akron. Diabetes Association of Greater Cleveland and Camp Ho Mita Koda can assure you that personal and medical information will be kept confidential during this project.

Participation is encouraged, but optional. We support this research project because it allows us the opportunity to learn more about the benefits of the camp experience for our adolescents with type 1 diabetes.

The Diabetes Association of Greater Cleveland also gives Ms. Drewes permission to analyze the data, and to report the findings in professional literature, while giving appropriate recognition to Camp Ho Mita Koda and the Diabetes Association of Greater Cleveland (DAGC).

Sincerely,

Douglas Rogers, MD
Medical Director
APPENDIX D.

PARENTAL CONSENT FORM.

IMPACT OF CAMP HO MITA KODA ON SELF-MANAGEMENT OF DIABETES

Two surveys will be given to campers at Camp Ho Mita Koda to evaluate the impact of the camp experience on your child’s confidence in managing their diabetes. The first survey will be given on the first day of your child’s camp session during check-in and the second survey will be given on the last day of your child’s camp experience. This short survey includes simple questions about managing diabetes.

Measures will be taken to protect the confidentiality of your son or daughter. Hemoglobin A1c values will also be obtained from camp administrators after they have been coded, preventing the researcher from having access to the campers names.

Your child's participation in this project is voluntary. By giving your permission, your child may still decide not to participate and can change their mind at any time.

All information will be kept confidential and secure. Only the researcher will have access to the information. If you have any questions about this study, you may contact Sarah Drewes or Dr. Deborah Marino through the University of Akron at (330) 972-7721. This project has been reviewed and approved by The University of Akron Institutional Review Board. If you have questions about your rights or your child’s rights as a research participant, you may call the IRB at (330) 972-7666.

Signing your name indicates your permission for your child to participate in this study. You will be given a copy of this form to keep.

______________________________  ______________________________
Parent/Legal Guardian Signature  Parent/Legal Guardian Signature

Name of child:______________________________

Date:______________________
APPENDIX E.

CHILD ASSENT FORM.

IMPACT OF CAMP HO MITA KODA ON SELF-MANAGEMENT OF DIABETES

My name is Sarah Drewes and I am a student in the Nutrition and Dietetics Program at the University of Akron.

I am asking you to take part in this research study at Camp Ho Mita Koda because I am trying to learn more about the impact of the camp experience on your confidence in managing your diabetes.

If you agree to participate in this study, you will be given two surveys, one of the first day of camp and the second on the last day of camp. It will be a short and simple survey that includes questions about managing diabetes and will be part of the check-in and check-out camp procedure.

Your name will remain confidential by camp staff and the researcher will not have access to your names. Hemoglobin A1c values will also be obtained from camp administrators and your name will not be associated with these values.

By participating in this study, it will provide information that will assist Camp Ho Mita Koda in providing the best possible camp experience for other children with diabetes in future years.

Your participation in this project is voluntary. Please talk this over with your parents before you decide whether or not to participate. I will also ask your parents to give their permission for you to take part in this study. But even if your parents say “yes” you can still decide not to do this.

If you don’t want to be in this study, you don’t have to participate. Remember, being in this study is up to you and no one will be upset if you don’t want to participate or even if you change your mind later and want to stop.

If you have any questions about this study, either now or later, you may contact Sarah Drewes or Dr. Deborah Marino through the University of Akron at (330) 972-7721.

Signing your name means you agree to participate in this study. You will be given a copy of this form to keep.

____________________________________  __________
Name of Subject               Age

____________________________________
Signature                 Date
APPENDIX F.

PATIENT ACTIVATION MEASURE.

Appendix A: Patient Activation Measure Item, Chronic
Patient Activation Measure, 13-Item

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think the doctor wants you to say. If the statement does not apply to you, circle N/A.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree Strongly</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for managing my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I know what each of my prescribed medications does.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident that I can follow through on medical treatments I need to do at home.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I understand the nature and causes of my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I know the different medical treatment options available for my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I have been able to maintain the lifestyle changes for my diabetes that I have made.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I know how to prevent further problems with my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident I can figure out solutions when new situations or problems arise with my diabetes.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</td>
<td>Disagree Strongly</td>
<td>Agree</td>
<td>Agree Strongly</td>
<td>N/A</td>
</tr>
</tbody>
</table>
APPENDIX G.

DEMOGRAPHIC SURVEY.

Please answer the following questions.

I am:
___ a girl   ___ a boy

How old are you?
___ 11 years
___ 12 years
___ 13 years
___ 14 years
___ 15 years
___ 16 years

I am at camp for:
___ Session 4
___ Session 5

How many years have you come to Camp Ho Mita Koda?
___ this is my first time
___ 1 time
___ 2 times
___ 3 times
___ 4 times
___ more than 4 times

How long have you had diabetes?
___ 1 year
___ 2 years
___ 3 years
___ 4 years
___ 5 years
___ 6 years
___ 7 years
___ 8 years
___ 9 years
___ 10 years
___ more than 10 years
APPENDIX H.

CAMP HO MITA KODA SURVEY.

Please circle the best response for each the following statements about your experience at Camp Ho Mita Koda.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree Strongly</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree Strongly</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since coming to camp, I feel that I can make good decisions about my diabetes, even without my family around.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since coming to camp, I feel more comfortable with talking about diabetes with my friends.</td>
<td>Disagree Strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since coming to camp, I feel that I am willing to try something new for taking care of my diabetes.</td>
<td>Disagree Strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since coming to camp, I have learned more about diabetes.</td>
<td>Disagree Strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since coming to camp, I have gained new skills to manage my diabetes.</td>
<td>Disagree Strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>