The Wilderness Experience for Adolescents with Type 2 Diabetes (WE-AD) Program

Ву

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TABLE of CONTENTS

Introduction	3
Systematic Review. Introduction. Methods. Summary of Programs. Analysis. Conclusion.	7 7 8 10 22 25
Program Plan Program Overview and Rationale. Program Context. Relevant Program Theories. Goals and Objectives. Implementation Plan. Logic Model. Detailed Budget Program Sustainability.	28 29 34 38 39 46 47 48
Evaluation Plan. Introduction and Rationale for the Evaluation. Approach to the Evaluation. Evaluation Study Design. Evaluation Study Methods. Logic Model. Evaluation Planning Table. Dissemination Plan.	51 52 54 56 60 60 66
Discussion	69
Acknowledgements	73
References	74
Appendix Table 1 – Summary of Similar Programs and Studies Figure 1 – WE-AD Program Logic Model	80 80 83

INTRODUCTION

The Epidemic of Type 2 Diabetes

The growing epidemic of type 2 diabetes mellitus (DM) is one of the major threats to the health of the public facing the nation. Narayan et al estimated that those born in the year 2000 have a lifetime risk of developing diabetes of 32.8% for males and 38.5% for females. Minority groups face even more dire predictions, with an estimated incidence among Hispanics of 45.4% for males and 52.5% for females. The effect on mortality underscores the seriousness of this disease. Men diagnosed with diabetes at age 40 will die an average of 11.6 years earlier than men without diabetes. Women fare even worse, with those diagnosed with diabetes at age 40 dying an average of 14.3 years earlier than women without diabetes.

Type 2 Diabetes in Children and Adolescents

Perhaps more disturbing is that a disease originally referred to as "adult-onset" diabetes has crept into the pediatric population fueled by the growing problem of overweight and obesity. The SEARCH study looked for new cases of type 2 diabetes in youth age 10-19. Researchers identified 3,600 new cases in the study population each year, which corresponds to an annual incidence rate of 8.5/100,000 from 2002-2005.²

In North Carolina the prevalence of type 2 diabetes among children is estimated by the NC Department of Health and Human Services from the Child Health Assessment and Monitoring Program (CHAMP) and the Annual Health School Services Report. CHAMP is a telephone survey of parents conducted on a sample drawn from the North Carolina Behavioral Risk Factor Surveillance System (NC BRFSS) database. The 2006 prevalence of diabetes in children in NC

was 4/1,000, of which an estimated 25% were type 2. The Annual Health School Services report, based on data from NC school nurses, found 4,437 students with diabetes during the 2005-2006 academic year, of which an estimated 31% were type 2.³

Risk-taking behavior in adolescence

Adolescence is often a time of great personal and social exploration. It is a time when people seek to push boundaries and partake in risk-taking behaviors fueled by a desire to try new things and experience new sensations without the maturity to self-regulate behavior.⁴

Adolescents today are faced with a barrage of challenges to healthy living including the appeal of unhealthy diets, a propensity for sedentary lifestyles and peer pressure to experiment with tobacco, binge drinking, and illicit drugs. While risk-taking behaviors present threats to the health of all adolescents, those with type 2 diabetes are at exceptional risk. Unhealthy diets, sedentary lifestyle, tobacco use, binge drinking and illicit drug use can impair blood sugar control.⁵⁻⁹ Non-adherence to recommended diabetes medical treatment compounds the effects of these health-related behaviors. Poor blood sugar control, in turn, increases the risk for developing acute and chronic diabetic complications, resulting in increased morbidity and mortality.¹⁰

Program Plan and Evaluation – The WE-AD program

In the following, I describe a detailed program plan and evaluation strategy for a new program: The Wilderness Experience for Adolescents with Type 2 Diabetes (WE-AD) program. The WE-AD program seeks to utilize wilderness experiences to help adolescents with type 2 diabetes to improve their decision-making skills and increase their self-confidence/sense of self-efficacy in an environment of peer support.

In their description of the *wilderness challenge model*, Kimball and Bacon describe wilderness experiences as adventure therapy that is a "frontal assault on learned helplessness, dependency, and feelings of low self-worth." The wilderness challenges people to push their boundaries, learn new skills and adapt to new and changing situations. In doing so, these experiences have the power to build self-confidence and foster a strong sense of self-efficacy. Wilderness experience also necessitate an ongoing assessment of the potential risks presented by physical challenges, terrain, animals and weather and requires travelers to make decisions with immediate and serious consequences. The tangibility of their decisions helps to improve decision-making capacity.

In addition to improving decision-making capacity and self-confidence, the third focus area of the WE-AD program is the creation of an environment of peer support. Throughout the trip, participants will benefit from the encouragement of others as they struggle to complete the expedition. Participants can also provide support for one another in their efforts to self-manage their diabetes and achieve positive lifestyle changes.

Participants empowered with the decision-making capacity and confidence to travel in the wilderness with peers may return to their daily lives and transfer these skills to help them take control of their disease. Through improved nutrition, increased physical activity, medication adherence, and the avoidance of tobacco and alcohol, participants can reduce their risk of diabetic complications and improve the longevity and quality of their lives.

In the first section of this paper, I have conducted a systematic review of the literature to identify programs with similarities to the WE-AD program in order to inform the planning and evaluation of the program. Lessons learned from other programs have been applied in the development of

the WE-AD program plan and evaluation strategy. In the second section, I describe the WE-AD program plan including; the rationale for the program, relevant program theories, its goals and objectives, the plan for implementation, a detailed budget and a plan to provide for its sustainability. In the third section, I detail the WE-AD program evaluation plan in which I describe; the rationale for the evaluation, my approach to the evaluation, the study design and methods, and present a logic model. Detailed evaluation planning tables and a plan for dissemination of the findings are also included. I conclude with a discussion of potential challenges and outline the next steps to be undertaken.

SYSTEMATIC REVIEW

Introduction

I conducted this systematic review of the literature to find programs similar to the Wilderness Experience for Adolescents with Type 2 Diabetes (WE-AD) program. The core elements of the WE-AD program include:

- 1. Target population is adolescents, aged 13-18, with type 2 diabetes.
- 2. Program involves a wilderness experiential education intervention.
- 3. Development of decision-making capacity, self-confidence, positive body image, and peer support are program priorities.
- 4. Program addresses tobacco/alcohol/drug use, physical activity, diabetic diets and adherence to medical treatment.
- Program addresses principles of disease self-management and personal responsibility for health-related decision-making.

I searched the literature and was unable to find a single article or program evaluation that included adolescents with type 2 diabetes or overweight/obese adolescents in a wilderness experiential education program. Due to a lack of information on programs targeting this population, I expanded my search to include wilderness programs that involved adolescents with any chronic illness or disability or their healthy peers. I decided to exclude "rehabilitation" programs due to likely underlying baseline differences between my target population and those with alcohol, drug or behavioral problems. While I considered expanding my search to include the significant body of literature on summer camps for those with obesity or chronic illness, I

decided to strictly limit my review to programs that involved a wilderness component as I believe that this is a unique and important element of the WE-AD program. The underlying central concept is the ability for wilderness experiences to foster independence and personal responsibility leading to improved decision-making capacity and increased self-confidence, in an environment of peer support. The wilderness experience is unique and this review thus focuses only on those programs for which an extended wilderness experience is a core component.

The planning, implementation and evaluation processes of included programs are examined and critically appraised so that lessons learned can be applied to the development of the WE-AD program.

Methods

Research Question: My research posed the question: Have there been other programs similar in nature to the WE-AD program from which we can learn lessons to help in the development, implementation and/or evaluation of the WE-AD program?

Inclusion/Exclusion criteria: This literature review included programs that involved a wilderness experience and targeted adolescents. Programs limited to summer camp activities were excluded to emphasize the unique aspects of the wilderness experience. I also excluded programs that targeted adolescents with alcohol/drug or behavioral problems due to likely differences in baseline characteristics with the intended target population for this intervention.

Search strategy: My search strategy included a search of PubMed (Medline), Google Scholar, and ISI (Web of Science). Titles and available abstracts were reviewed for inclusion and exclusion criteria.

PubMed (Medline): I performed a PubMed (Medline) search using a combination MeSH and keyword search with the following terms: wilderness OR camping OR adventure OR mountaineering OR "outward bound" OR backpacking OR hiking OR "outdoor education".

Search results were limited to: adolescents age 13-18, articles available in English, published within the past 30 years. Three articles met inclusion/exclusion criteria. Search syntax included: ("wilderness"[MeSH Terms] OR "wilderness"[All Fields]) OR ("camping"[MeSH Terms] OR "camping"[All Fields]) OR adventure[All Fields] OR "outward bound"[All Fields] OR backpacking[All Fields] OR hiking[All Fields] OR "outdoor education"[All Fields] AND (English[lang] AND "adolescent"[MeSH Terms] AND ("1981"[PDAT]: "2011"[PDAT]))

Web of Science (ISI): I performed an ISI/Web of Science search using search terms: wilderness, camping, adventure, mountaineering, "outward bound", backpacking, hiking, "outdoor education". Search was refined by adolescent and separately by diabetes. One additional article met inclusion/exclusion criteria. Search syntax included: Topic=(wilderness) OR Topic=(camping) OR Topic=(adventure) OR Topic=(mountaineering) OR Topic=("outward bound") OR Topic=(backpacking) OR Topic=(hiking) OR Topic=("outdoor education"). Refined by: Topic=(adolescent). Refined by: Topic=(diabetes).

Google Scholar: I performed a Google Scholar search using key search terms including: adolescent, wilderness, camping, adventure, mountaineering, "outward bound", backpacking, hiking, "outdoor education". Two additional articles met inclusion/exclusion criteria.

Search syntax included: adolescent wilderness OR camping OR adventure OR mountaineering OR "outward bound" OR backpacking OR hiking OR "outdoor education".

Other sources: One article regarding an unpublished observational study of the Wilderness Leadership Program at Camp Joslin, Massachusetts was provided via personal communication with the author, Gary Maslow, MD, MPH.

Summary of Programs

No programs specifically targeting adolescents with type 2 diabetes or obesity were identified in this literature review. The following summary examines other wilderness programs that targeted adolescents with a chronic illness, disability and/or those without health problems. For the purpose of this literature review, I defined "wilderness" programs as those that remove participants from the built environment to spend a period of time traveling, living, sleeping, etc. in the mountains or other wilderness area. These programs could include a range of activities including camping/backpacking, mountaineering, rock climbing, canoeing, etc. See Appendix (Table 1) for summary table of included programs.

The curricular elements of the programs focused on improving wilderness skills, fostering self-confidence and independence, creating an environment of peer support, and helping participants to adapt to the social demands of group living in close quarters. The safety of participants was of primary importance and many programs included safety training prior to the trip for staff and/or participants and also staffed trips with a physician or other medical provider.

Many of the following programs offered insight that was utilized in the planning, implementation and evaluation of the WE-AD program.

Adventure, Etc.

Adventure, Etc. was a two year joint venture (1979-1981) between the University of Minnesota Adolescent Health program and the Minnesota Outward Bound School.¹² The goal of the program was to increase the independence, sense of skill mastery, social skills and positive body image of adolescents with a chronic illness or disability. The program objectives focused on locus of control (self-efficacy), positive body image, and family environment and dynamics.

The program involved a two week experience which included a 9 day wilderness expedition and a 5 day urban experience. The wilderness part of the program involved a range of activities including a safety skills session, whitewater canoeing, portaging (carrying canoes on land around areas of low water or dangerous sections of whitewater), camping, orienteering (map and compass navigation), rock climbing, and independent small group and solo experiences. The program activities were based on an experiential learning model, encouraged group problem solving and developing a sense of trust between participants. Group leaders facilitated discussions on personal independence and responsibility, leadership and conflict resolution.

There was no discussion of medical problems that arose during the expeditions, but given the nature of the participant population, it is likely that safety was a major concern. All participants took part in an initial safety skills session and all trips were staffed by a physician.

Over two years, there were 37 participants (6-10 participants per trip) that comprised four mixed groups including both chronically ill or disabled adolescents (23 participants) and healthy peers

(14 participants), a trip physician and an outward bound instructor. Participants with a wide range of chronic illnesses were able to participate including those with: diabetes mellitus, lymphoma, cystic fibrosis, chemical dependency, seizures, depression, leukemia, diabetes mellitus, congenital heart disease, polyarteritis, cerebral palsy, Ewing sarcoma, myotonic muscular dystrophy, seizure disorder, juvenile arthritis, myelodysplasia, hearing impairment, cerebral vascular accident, congenital scoliosis, and hearing loss.

Evaluation of the program was conducted using a pre-post test design. Researchers utilized the Offer Self-image questionnaire for adolescents, ¹³ the Nowicki-Strickland personal reaction survey which is a measure of locus of control/self-efficacy, ¹⁴ and the Moos family environment scale. ¹⁵ They also used semi-structured interviews with participants and parents within two weeks of completion of the program and at six months. Results of the evaluation found that chronically ill or disabled participants demonstrated an increased sense of self-efficacy following participation in the program. Both chronically ill or disabled and healthy participants experienced improvement in body image. There was a mixed picture with regard to the family environment with researchers noting a decrease in family conflict but no change in the amount of family recreational activity at 6 months.

Participants were volunteers and there is no description of where the participants were recruited from or their baseline characteristics apart from mean age and aggregate illness categories. There is no comparison of the baseline characteristics between the chronically ill/disabled group and the healthy peer group. It is, however, the only intervention that I found that included both chronically ill/disabled adolescents and healthy peers in the same experience thus providing some measure of an internal control. There was also a differential loss to follow-up with 5/23 of the chronically ill/disabled participants and 1/14 of the healthy participants with incomplete data. These factors raise the possibility of selection bias. In terms of measurement, all participants

used the same established questionnaires. It does not state whether telephone interviewers were blinded as to study group, although this would have been difficult to accomplish. We also do not know much about the baseline characteristics of the participants and there may be other confounding variables that are not accounted for in the analysis.

Overall, this is a useful study that can be applied to the program planning and evaluation of the WE-AD program. It provides some evidence that wilderness trips can be undertaken safely with a group of adolescents including those with a range of chronic illness or disability. This program also focused on similar objectives as the WE-AD program including personal independence, responsibility, and leadership which correlate well with the WE-AD objectives of increasing decision-making capacity and building self-confidence/self-efficacy. Furthermore, this study used several standardized questionnaires including the Offer Self-image questionnaire for adolescents and the Norwicki-Strickland locus of control instrument which could be utilized in the WE-AD intervention to assess changes in self-confidence/self-efficacy.

Outward Bound, diabetes and motivation

This 1990 article discusses a series of six wilderness Outward Bound courses conducted at the Hurricane Island Outward Bound School in Maine.¹⁶ The goal of the program was to improve self-reliance, self-care and effective interaction with support systems for a population of participants with type 1 diabetes.

The courses included sailing expeditions lasting 3-4 days. Curricular components focused on wilderness skills including sailing and navigation, camp living and cooking, and group living and decision-making. Participants were also given the education and responsibility to self-manage their diabetes throughout the trip by testing blood sugars and self-adjusting insulin levels. Trip

leaders and the staff physician supervised and assisted participants as needed. Throughout the experience, instructors helped participants to employ healthy coping strategies under challenging and stressful conditions.

Instructors also ensured the safety of all participants. Courses were staffed by instructors with emergency medical training and attended by the author who was a physician at the Joslin Diabetes Center in Boston. During the program trips, about one-half of the participants experienced mild hypoglycemia and three participants suffered severe hypoglycemia provoking one case of nocturnal seizure and two episodes in which participants were difficult to arouse. Under instructor supervision, other participants treated those in need by giving cake frosting in the cheek and were prepared to administer glucagon if needed.

The six trips included a total of 56 participants with type 1 diabetes. Several had co-morbid conditions and diabetic complications including retinopathy, hypertension, and proteinuria.

Participants ranged in age from 14-42 years.

Nine participants were asked to complete several psychosocial questionnaires including; the Achenbach Youth Self-Report Profile,¹⁷ the Nowicki-Strickland measure of locus of control,¹⁴ the Diabetes Adjustment Scale,¹⁸ the Coopersmith Self-Esteem Inventory,¹⁹ and the Patterson's 'Acope" scale.²⁰ Eight of those asked completed pre-experience questionnaires. Of these eight participants, six completed the same tests again 7-11 months after the course. There was a comparison group of randomly selected patients at the Joslin Diabetes Center but the article does not discuss how many patients were in the comparison group or give any characteristics of the group.

The researchers cite improvements in the Achenbach Youth Self-report profile, based on the 6

Comment [kaa1]: Pretty broad age range, any details on how many were truly adolescents (<25)?

I wondered this too, but unfortunately the article didn't say.

completed pre-post questionnaires, as compared to the comparison group. There were no statistically significant changes in the other psychosocial measures. Anecdotal reports from participants note; increases in self-confidence, learning new wilderness skills, improved self-esteem, improved diabetes control, increased determination to self-manage their diabetes and acquisition of the skills necessary to do so.

This article illustrates the potential for wilderness programs to help teach participants to better self-manage their insulin-dependent diabetes and improve their sense of self-efficacy and self-confidence. Whereas only six of the participants completed both pre- and post- test psychosocial measures, the evidence presented from the program evaluation must be considered anecdotal.

An important limitation of the program is that most of the participants were volunteers who took the initiative to sign up. It is noted that there were 5 participants that were actively recruited because they demonstrated poor self-care. This largely motivated group of participants may have been more likely to show improvements in psychosocial testing.

British Diabetic Association/Eskdale Outward Bound Mountain Course

In this 1984 article, Hillson describes the initial courses conducted through a joint British Diabetic Associatoin/Eskdale Outward Bound Mountain School in Cumbria, England in the early 1980s.²¹ The goal of the program was to teach participants with type 1 diabetes to self-manage their diabetes under conditions of wilderness travel.

Courses included 1-2 week long expeditions that involved rock climbing, orienteering, canoeing,

and mountaineering. Participants were recruited from throughout the United Kingdom and ranged in age from 14-20. The safety of participants was a primary concern and responsibility for this was shared between participants and staff. Each participant carried an emergency bag containing dextrose tablets, glucagon, insulin, insulin syringes, and snacks. Courses were staffed by a physician from the British Diabetic Association, a nurse, a dietician and Outward Bound instructors. Instructors also attended an educational session about handling diabetes during mountaineering expeditions before each course.

Incoming students were interviewed by British Diabetic Association staff and asked about their knowledge and attitudes regarding their diabetes. At the conclusion of the course, a facilitated discussion explored how diabetes had influenced and was influenced by each aspect of the course. Emphasis was placed on translating these lessons into everyday life and written summaries were given to students, diabetes clinicians and primary care doctors. No participant outcomes for the program were discussed.

An abstract presented at a 1986 Diabetologia meeting presented additional information regarding participant outcomes derived from subsequent courses.²² Questionnaires were mailed to 69 participants from 5 different courses and also to their physicians. Researchers received a response rate of 74% from participants and 44% from their physicians. Those physicians that did respond reported that their patients were more confident, self-reliant, careful and happy in managing their diabetes care. Participants and their physicians reported increased knowledge of diabetes and exercise, insulin dose adjustment and administration technique, risks of hypoglycemia and diet. There were no long term changes in glucose control identified although some participants either started or increased their frequency of home glucose monitoring. Statistical significance is not reported. The author also notes a decrease in aggregate diabetic hospital admissions among program participants following the course.

This meeting abstract provides only limited data on which to base a critical appraisal. It is not stated whether the questionnaires were mailed to all participants from the five selected courses or if not, how recipients were selected. Overall, the researchers received a good response rate (74% from participants, 44% from physicians), but the sample size may have made it difficult to assess for the statistical significance of the results. Potential differences between responders and non-responders may also present concern for selection bias. We also do not know anything about the validity of the questionnaires. There may also be a significant measurement bias on the part of both participants and their physicians who may have been more likely to report improvements due more to optimistic thinking or desire to please the researcher than actual change.

The article does support the use of qualitative measures in program evaluation to get a sense of changes in self-confidence and disease management knowledge. It remains important to continue with a mixed methods approach, however, combining qualitative and quantitative analyses of these programs to achieve a more thorough understanding of the intervention and potential changes.

<u>Wilderness Leadership Program</u> - Barton Center for Diabetes Education/Camp Joslin

Maslow describes an observational study conducted with participants in the Wilderness
Leadership Program at Camp Joslin in Massachusetts.²³ The program offers wilderness
expeditions for adolescents with type 1 diabetes that focus on teaching wilderness skills,
providing diabetes education and leadership development. Two 5-7 day trips involving a total of
11 participants, age 15-19 years, were run during the summer of 2007. Trips were led by two

wilderness guides certified in wilderness first aid and accompanied by a nurse. All leaders underwent wilderness diabetes safety management training prior to the course. During the trip, participants frequently checked their blood sugars and managed their insulin dose. No episodes of severe hypoglycemia occurred.

The study conducted an evaluation based on; demographic data, medical records from the trip, an evaluation questionnaire and exit focus groups. Participants reported feeling more confident and motivated to self-manage their diabetes, more independent in caring for themselves and also reported gaining wilderness travel skills.

This study emphasizes the importance of a program curriculum focused on wilderness leadership and independence and the inclusion of an expectation that students will self-manage their disease during the trip. A mixed quantitative and qualitative approach was used to determine the immediate outcomes of the experience including a quantitative assessment of blood sugar control during the trip and a qualitative assessment of changes in knowledge and attitudes. This type of mixed evaluation approach is able to garner a more thorough understanding of program outcomes than either quantitative or qualitative approaches alone.

Adventure Therapy for Adolescents with Cancer

Stevens et al describe an adventurous 10 day expedition to the Arctic Circle in the summer of 2000 undertaken as part of a documentary film production.²⁴ Throughout the experience, two interviewers with the film crew did multiple unstructured interviews with participants in which they asked them about their participation in the expedition and how the adventure impacted their lives. The team set out with a stated goal to climb a mountain in the Arctic but more

importantly, to provide adventure therapy for these adolescents and to help them to re-build their self-confidence, have a new experience, and develop friendships with those who share similar struggles.

Participants included 11 adolescents, age 15-18 years, with cancer. The group was accompanied by a pediatric oncologist, a pediatric surgeon, two pediatric oncology nurses and a child life educator.

The trip participants were studied as a convenience sample drawn from five Canadian provinces. To be eligible for the trip, participants must have been in remission of their cancer, not neutropenic, not taking IV chemotherapy drugs (oral chemotherapy was acceptable), and must have had approval from their oncologist.

Researchers conducted a secondary retrospective analysis of the raw footage from the documentary film to perform a qualitative analysis of the experience. Interviews were coded and displayed several central concepts including: developing connections, togetherness, rebuilding self-esteem, and creating memories.

Participants described the value that they placed on 'developing connections' with their peers during the trip. They felt more comfortable discussing their cancer treatments, side effects, and illness experiences with others who had the same thing and felt better knowing that they were not alone. Illness aside, they also bonded as a group travelling through the wilderness. They recognized their mutual dependence on one another and individually built their self-confidence as integral members of the team. This was closely linked to a feeling of 'togetherness' formed from their collective efforts to accomplish a goal. Participants described 're-building self-esteem' by accomplishing something in the face of physical and environmental challenges that

they did not think that they could overcome. Lastly, they described 'creating positive memories' that they could carry with them as they faced challenges in the future.

The authors acknowledge that the study had its limitations including the small sample size and secondary analysis of data collected in an uncontrolled format for another purpose. This qualitative analysis of the documentary film recordings does however offer some insight into the power of wilderness experiences. This experience brought this group into an environment where they had to be largely self-sufficient, make good decisions and ended up building up their self-confidence by achieving a challenging goal. While further research needs to be done, it is plausible that these types of experiences could help adolescents facing chronic illness to take on more responsibility for self-care and give them a perspective that could improve their quality of life.

Adolescent coping styles and outdoor education

This 1998 paper by Neill and Heubeck detailed a wilderness program during which researchers examined types of coping strategies for obstacles encountered.²⁵ In total, the program involved 251 students, ages 14-15, from 4 Australian high schools. Participants were divided into 13 groups for 9-10 day Outward Bound Australia expeditions.

Researchers administered a modified version of the Adolescent Coping Scale (ACS) questionnaire. The questionnaire includes 80 questions, 79 of which are structured and ask subjects questions about their coping strategies on a five point Likert scale. These scales refer to 18 categories of coping strategies. These 18 categories are then divided into three coping themes: Reference to Others, Solving the Problem, and non-productive. The strategies most commonly used by participants included: Work hard and achieve, focus on solving the problem,

focus on the positive, seek relaxing diversions, and seek social support. In conclusion, the authors claim that participants in outdoor education settings utilize more productive coping strategies than do adolescents in other settings based on normed data.

Participation in the experience was a mandatory part of their schooling for over 90% of the participants. This decreases the concern for selection bias and increases the internal and possibly external validity of the study. I remain concerned, however, with the use of such a long study questionnaire and wonder if subjects took the time to give thoughtful answers.

This study offers a unique perspective on the psychological aspects of a wilderness expedition. Coping strategies learned or developed during such an expedition could be transferred back to day to day life and may help adolescents to employ more productive coping strategies. It is important to note that this study was conducted with a group of adolescents without known health problems and the results may or may not be applicable to adolescents with type 2 diabetes.

Wilderness Therapy and Adolescent Depression

Norton examined the effect of wilderness experiences on the prevalence of depression and psychosocial development in a group of adolescents participating in the Outward Bound Intercept program for at-risk youth.²⁶ The program included a 28-day wilderness expedition involving canoeing and camping.

Evaluation was conducted using pre-post testing with the RADS-2 and MPD instruments.

Qualitative evaluation was also undertaken via interviews. The author cites a decrease in the

prevalence of depression and an increase in psychosocial development among program participants based on pre-post testing 1 week prior to and 1 week after the intervention.

This study again raises the potential benefits of wilderness experiences on psychological health and development. Many of the details of the study are, however, lacking and critical appraisal is difficult. The author does not tell us how the participants were selected and does not state how many participants were involved. Nonetheless, the findings are consistent with other research in the area suggesting positive psychological benefits from wilderness experiences.

Analysis

This systematic review examined seven wilderness programs for adolescents to determine which elements of the planning, implementation and evaluation processes could be applied to aid in the development of the WE-AD program. These programs had several common elements and various differences worth consideration.

Selection of Participants-

According to the inclusion criteria for the systematic review, all articles included programs that involved adolescents, however at least two programs did also include some older participants. Most of the programs included participants on a strictly voluntary basis but one program in Australia was a required part of a secondary school curriculum. Four of the programs included only participants with some type of chronic illness. Two programs included only participants without health problems. One interesting program in Minnesota included participants with a chronic illness or disability and participants without health problems.

Comment [kaa2]: If they say there is a decease in prevalence and incidence it is important to again describe the comparison group and over what time frame. Is this over several years or months? Decreasing depression incidence over a month is not meaningful, while if they are followed for a longer period of time that is interesting. If they just mean that the prevalence of depression is lower at the end of the program then the beginning, then say that explicitly. — YOU'RE RIGHT. THIS CONCLUSION WAS BASED ON RESULTS OF A PRE-POST TESTING 1 WEEK PRIOR AND 1 WEEK POST EXPERIENCE. I

Program Implementation-

According to the inclusion criteria, all programs included some type of wilderness experience although the range of activities varied to include: camping/backpacking, mountaineering, rock climbing and whitewater canoeing. Trip length also varied lasting anywhere between five and twenty-eight days. Programs were run in several parts of the world, from the Australian wilderness to the Arctic Circle. A key element in four of the programs was collaboration with Outward Bound, an organization with a long history of expertise in the area of wilderness experiential education. All programs that targeted adolescents with a chronic illness included medical professionals (MDs, RNs) as trip co-leaders to provide medical support and health education.

While an educational component may have been a strong part of many of these programs, the educational objectives and curriculum were not clearly outlined in the material available. Some of the educational and therapeutic themes that emerged included those tailored to improving skills in; leadership, social skills, technical wilderness skills, conflict resolution and problem solving. Some programs also specifically included objectives to teach about disease self-management, improve body image and increase self-confidence/self-efficacy/internal locus of control. Only one program specifically noted the inclusion of formal group discussions as a part of the wilderness education process.

Program Evaluation-

Each program was evaluated in some capacity using either questionnaires, interviews, or a combination of both. Some programs were also evaluated using quantitative data to assess changes in blood sugar control in type 1 diabetics.

Five of the studies utilized a pre-post test design with a variety of questionnaires administered to the participating adolescents. Questionnaires used included; the Offer Self-image questionnaire for adolescents, the Norwicki-Strickland personal reaction survey, the Moos family environment scale, the Achenbach Youth Self-report profile, the Adolescent Coping Scale (ACS) questionnaire, RAD-s and MPD instruments, and one unspecified questionnaire. One study also administered a mailed questionnaire to each participant's physician. None of these studies, however, used an appropriate comparison group.

Four of the studies conducted interviews with participants during and/or after the trip to assess changes in knowledge and attitudes. One study also conducted interviews with the parents of trip participants. One study used exit focus groups to gather information.

Two of the studies also collected some data on glucose control and frequency of glucose testing during and after the trip to provide an additional quantitative method of assessing the program outcomes.

The evaluative processes of the included studies almost exclusively focused on the trip participants. Across studies, researchers examined both shifts in knowledge and attitudes as well as some measures of disease control where applicable. Evaluation focused primarily on *outcome* measures with little attention to *process* evaluation regarding how the program was implemented.

Conclusion

This review of the literature has examined a wide variety of programs involving wilderness experiences for adolescents. These programs have encompassed those specifically designed for adolescents with a chronic illness or disability and those for healthy adolescents. Several common themes stand out in the planning, implementation and evaluation of these programs that are useful in the development of the WE-AD program. The themes expressed in this literature review that correspond to the central concepts of the WE-AD program include:

- · Decision-making capacity- leadership skills, wilderness skills
- Disease self-management education
- Self-confidence/self-efficacy- independence
- Body image
- Peer support- social skills, conflict resolution, shared experiences and friendship building

A strong and clear educational curriculum focused on these themes interwoven into the wilderness experience is integral to promoting positive outcomes for participants. Trip leaders must make these formal and informal educational elements an important priority throughout the trip by facilitating group discussions, encouraging group decision-making and responsibility, and setting an expectation that students will take responsibility for themselves while traveling in the wilderness. The knowledge gained, skills developed, and confidence inspired during these wilderness experiences can help adolescents to utilize more positive and productive coping strategies that empower them to successfully improve health-related behaviors.

The planning of any wilderness expedition requires careful consideration of the potential risks to

program participants and staff. A program targeted to adolescents with type 2 diabetes certainly needs to take into account the baseline physical abilities of program participants in the trip planning process. It will also be important for trip safety and participant/parent/trip leader peace of mind to have a medical professional experienced in acute and chronic care of diabetes to accompany all trips to provide medical support and education.

The most difficult barriers that the WE-AD program must overcome are participant recruitment and motivation. Extended trips are both physically and mentally taxing and perhaps more importantly, force many participants to reach well outside of their traditional comfort zones. While this barrier may be present with any target population, it is especially applicable to the target population for the WE-AD program. Adolescents with type 2 diabetes are likely to be overweight/obese and accustomed to a sedentary lifestyle. It may be useful to begin recruiting participants for the wilderness program from summer camps for overweight/obese adolescents or other social service programs that have recruited this population into other efforts to increase physical activity and/or control diet.

Evaluation of this program may be challenging as we will typically have a small sample size and don't have an easy comparison group against which to measure our success. It may be possible to develop a non-equivalent comparison group consisting of similar participants enrolled in a summer camp program or educational intervention. A true control group would have to be formed based on random assignment among adolescents eligible and motivated to participate in the WE-AD program to either the WE-AD program or other educational intervention.

As has been done in the included studies, a mixed qualitative and quantitative approach is

necessary. The evaluative strategy for the WE-AD program should include the use of questionnaires and other psychological measures before and after the program. Interviews before, during and after the program with participants is an important source of qualitative information on outcomes including changes in knowledge and attitudes. The inclusion of additional data derived from trip leaders, parents, teachers, and physicians may be useful in triangulating multiple sources to gain a better understanding of actual changes. It would also be useful to include some objective measures of behaviors change including body mass index (BMI), hemoglobin A1c measurements, pill counts for those on medication as well as dietary and exercise logs.

Finally, it should be noted that these programs represent relatively short periods of intervention. For adolescents with type 2 diabetes, a wilderness experience must be only one part of an ongoing effort. These participants may change their attitudes and intend to change their behaviors in part due to their experience on such a trip, but these changing attitudes must be reinforced over time. One idea would be an ongoing supplemental curriculum that involved trip alumni in an outing club or some other recreational pursuit that can build upon the peer relationships established during the trip and encourage continued lifestyle change.

PROGRAM PLAN

Program Overview and Rationale

The growing epidemic of type 2 diabetes mellitus (DM) presents a major public health concern with far-reaching medical, social and economic costs. It is estimated that 8.3% of all adults currently have the disease.² More disturbing is the fact that a disease that was once termed "adult-onset" diabetes has begun to affect a growing proportion of our nation's youth with an estimated 3,600 new cases diagnosed in the pediatric population each year.² Those with type 2 diabetes are at increased risk for infections and diseases of the heart, kidneys, nervous system and eyes. In order to avoid the complications of diabetes, patients must work to control their blood sugars with proper diet, physical activity, adherence to medication regimens, and avoidance of tobacco and alcohol.

The Wilderness Experience for Adolescents with Type 2 Diabetes (WE-AD) program seeks to utilize wilderness experiences to allow adolescents to increase their self-confidence/sense of self-efficacy and improve decision-making skills in an environment of peer support. The wilderness provides time and space for self-reflection, requires participants to push limits, fosters personal responsibility, and demands an ongoing assessment of the hazards presented by physical challenges, terrain, animals and weather. Participants empowered with the confidence to travel in the wilderness can transfer these skills to help them take control of their disease. Through improved nutrition, increased physical activity, medication adherence, and the avoidance of tobacco and alcohol, participants can reduce their risk of diabetic complications and improve their quality of life. While this type of program has the potential to bring benefits to all adolescents, it is especially important for those with type 2 diabetes as they

stand to face greater health consequences from unhealthy behaviors than do their otherwise healthy peers.

Program Context

In designing the WE-AD intervention, it is important to consider the context in which the program is being developed, implemented and evaluated. Considerations include; consistency with national /state/local priorities, the political environment, financial resources, technical feasibility and likely stakeholders.

Consistency with national and state/local priorities - The goal of the program is to help adolescents with type 2 diabetes mellitus develop greater self-confidence/sense of self-efficacy and improved decision-making skills. Increased ability to make thoughtful, mature decisions will help these patients to live healthier lives by affecting their choices with regard to nutrition, physical activity, medication adherence, smoking and alcohol use.

Increasing attention has been recently drawn to the rising rate of type 2 diabetes among children and adolescents. In his October 2010 Presidential Proclamation establishing a National Diabetes Month, President Obama cited growing concern for both diabetes prevention and improved management in this population. Prevention efforts from the White House are being led by First Lady Michelle Obama with her signature "Let's Move" campaign to promote physical activity and improved nutrition. Those already with diabetes can now no longer be denied health insurance coverage on the basis of a pre-existing condition under the Patient Protection and Affordable Care Act (PPACA).²⁷

Also at the national level, the Center for Disease Control and Prevention (CDC) has begun to focus resources on the growing problem of type 2 diabetes in children and adolescents.

Accurate numbers for those with diabetes are difficult to ascertain as the condition can progress for many years before becoming noticeable symptomatic. In a joint venture with the National Institutes of Health (NIH), the CDC launched the SEARCH for Diabetes in Youth study in 2000.²⁸ The study sought to calculate the prevalence and incidence rates of type 1 and type 2 diabetes, develop strategies for classification, to examine risk factors for end organ damage and other complications and impact quality of life.²⁹

The Healthy People 2020 guidelines, an initiative of the U.S. Department of Health and Human Services, set a goal to "reduce the disease and economic burden of diabetes mellitus (DM) and improve the quality of life for all persons who have, or are at risk for, DM." Early diagnosis and improved management of type 2 diabetes in children and adolescents has the potential to decrease the burden of disease. Also important to maintaining normalcy in adolescent life is the ability to participate in school. Included in the guidelines is an objective to "decrease school absenteeism among adolescents due to illness or injury." Good, self-directed management of diabetes is consistent with this stated objective.

The initiative also sets forth goals in adolescent health and substance abuse which become especially important for a population living with a chronic disease, like diabetes. Healthy people 2020 sets goals and objectives that seek to decrease the rates of tobacco, alcohol and illicit substance use among adolescents. The initiative also calls for efforts to improve nutrition, achieve healthy body weights and to increase physical activity. While important for the health of all adolescents, these goals are especially important for those with diabetes as substance abuse, poor nutrition and physical inactivity can have greater negative and long-term consequences in this population.

The Healthy North Carolina 2020 objectives reinforce the national Healthy People 2020 guidelines.³⁵ With regard to chronic disease, the Healthy NC 2020 objectives include an effort to reduce the cardiovascular disease mortality rate. As a major risk factor for cardiovascular disease, improved management of diabetes is consistent with this related goal. The guidelines also address substance abuse in adolescents, seeking to reduce tobacco, alcohol and illicit drug use in this population. The guidelines also promote efforts to decrease overweight and obesity among high school students in the state.

Improved decision-making capacity in adolescents with diabetes has the potential to encourage healthy lifestyle choices including reduced risk-taking behaviors, improved nutrition, increased physical activity and increased self-directed management of their diabetes and adherence to medical treatment. Long-term goals include reduced morbidity, reduced incidence of diabetic complications, reduced mortality and improved quality of life.

<u>Political environment</u>- The priority placed on promoting healthy lifestyles by national and local/state organizations lends itself well to creating a conducive political environment for this intervention.

The WE-AD program will seek to partner with local agencies throughout the state of North Carolina including the North Carolina Department of Health and Human Services (NC DHHS), the NC Division of Public Health (NCPH), local health departments and local school districts to identify eligible participants for the program. As the major intended outcome of the intervention is to help improve the health of adolescents with type 2 diabetes, the goal is in line with the objectives of these organizations. A successful program also has the potential to improve disease management and reduce health care utilization and costs which is also attractive given

the financial pressures facing government agencies.

Other relationships with community organizations including youth groups, churches and neighborhood associations may help to garner community support to encourage adolescents to participate in this program. These organizations have an interest in promoting the health and development of area youth.

Throughout program development, we will seek to partner and collaborate with NC Outward Bound and/or the National Outdoor Leadership School (NOLS) to utilize their extensive knowledge and experience in the design of wilderness programs for adolescents. These outdoor schools have a long history of educating adolescents in wilderness survival and helping participants to push personal limits. Important and applicable aspects of these programs are leadership development, increasing self-confidence, fostering independence and teaching risk assessment and decision-making skills. It is precisely these aspects of wilderness programs that promote the goals of the WE-AD program.

Acceptability to providers and recipients- The major foreseeable obstacle to the successful implementation of this program is acceptability to the proposed program participants.

Adolescents may feel uncomfortable pursuing these wilderness experiences as it is likely something that is outside the realm of experience for many. Adolescents with type 2 diabetes are typically overweight/obese, making the physical rigors of wilderness travel and life more challenging. Strategies to motivate participants will require thoughtful planning. To increase recruitment into the program, we will seek referrals of motivated teens from medical providers, school teachers and administrators and social service organizations across the state. We may also target those adolescents who have already demonstrated some desire to change by participation in summer camp programs for overweight or diabetic adolescents.

Acceptability to health care providers and parents may also be challenging if there are concerns over safety and appropriate diabetes management during the experience. These factors need to be addressed with well-planned medical management guidelines and emergency procedures. Organizations like NC Outward Bound and NOLS have extensive experience in this area and offer training in wilderness medicine and rescue. Review of literature demonstrates the feasibility of safely conducting wilderness programs for adolescents with a broad range of chronic disease given appropriate planning.

Possible financial resources- Eligible adolescents will be able to participate in the program for a minimal tuition charge and scholarships will be available for those with demonstrated financial need. We hope to minimize the financial cost of the intervention by partnering with existing wilderness education organizations like NC Outward Bound and NOLS. Sources of funding could include grant funding from public agencies including; the Department of Health and Human Services, the Centers for Disease Control and Prevention, and the National Institutes of Health, and private foundations including; the American Diabetes Association, the Kate B. Reynolds Charitable Trust, and the Duke Endowment, as well as private monetary and in-kind donations.

<u>Technical feasibility</u>- Standard wilderness travel preparation and precautions will need to be expanded to plan for the needs of a diabetic participant population. Instructors will need to be trained in disease management and the program will require direct supervision by a skilled nurse or other health care provider. In addition, we will need to collaborate with area Search & Rescue (SAR) organizations to plan for possible medical emergencies and required evacuation.

<u>Stakeholders</u>- Primary stakeholders include participants, parents, healthcare providers, and wilderness staff. Secondary stake holders include local area Search & Rescue organizations and government agencies responsible for potential Search & Rescue operations. Tertiary stakeholders include officials from government health agencies, school teachers and administrators and community leaders.

Relevant program theories

A program theory helps us to understand the underlying assumptions and the expected relationship between program activities and desired outcomes. It provides a "plausible and sensible model of how a program is supposed to work."³⁶ Program theory is useful in the planning of programs but also in evaluation. Using the theory as a framework, evaluators can analyze whether a failed program was due to design based on the wrong theory, failure to implement the intervention as planned, or due to problems with the design of the evaluation.³⁶

The WE-AD program is based on a model that proposes that wilderness education experiences will improve health outcomes in adolescents with type 2 diabetes by 1) building self-confidence and a sense of self-efficacy, 2) developing decision-making capacity, and 3) providing peer support and a social environment focused on healthy living. These aspects of the program will help to empower adolescents with diabetes to make healthier choices with regard to nutrition, physical activity, medication adherence, and the avoidance of tobacco and alcohol.

The theoretical basis of this program will be rooted in a conceptual framework that focuses on the individual participants. Applicable program theories include the Stages of Change Model, the Health Belief Model and the Social Learning Theory model.

The Stages of Change model framework- The three areas of focus noted above will target those in various stages of change. The Stages of Change Model describes a theory comprising five stages of change: Pre-contemplation, Contemplation, Decision-making, Action, and Maintenance.³⁷ Pre-contemplation is a stage in which adolescents with diabetes may be in a state of denial or are unwilling to consider that lifestyle changes need to be made. In the commentary "Emerging epidemic of type 2 diabetes in youth," Rosenbloom et al note that several studies found that denial is a main reason why adolescents with asymptomatic diabetes often fail to adhere to diabetic treatment guidelines.³⁸ Adolescents with diabetes in the contemplation stage acknowledge that they have a chronic disease and may think about the necessity of taking steps to better manage it. Those in the decision-making stage have accepted the need to make healthy choices in order to better control their diabetes but have not yet begun to change behaviors. As these adolescents move into the action stage, they are actively working to change their lifestyle and improve disease management by improving nutrition, increasing physical activity, adhering to medication regimens, and avoiding tobacco and alcohol, but have not yet achieved healthy lifestyle goals. In the maintenance phase, adolescents have taken ownership over their diabetes management and are consistently making healthy choices. This phase reinforces good behaviors and helps them to resist unhealthy temptations.

Decision-making capacity (contemplation → decision-making)

The focus on building decision-making capacity caters to those who are in the contemplation stage of change. Wilderness travel requires participants to think through their travel plans including an evaluation of the terrain, environmental risks, weather, sources of water, potential camping spots, equipment needs, food as a source of energy, etc. Participants must actively

consider potential threats and learn to balance the risks and benefits of actions. The development of decision-making capacity will be applied both in the realm of wilderness travel and in diabetes self-management throughout the trip. In addition, formal diabetes education sessions will help students to bring those skills to bear on their assessment of the threat of diabetic complications and the benefits and barriers of changing health related behaviors. It is this core aspect of decision-making skill development that can empower adolescents with diabetes to move from the contemplation to the decision-making stage of change.

Building confidence and a sense of self-efficacy (decision-making \rightarrow action)

The second important focus is on building confidence and a sense of self-efficacy. This element is targeted to those in the decision-making stage of change and can encourage them to move into the action phase by increasing confidence in their ability to make substantial changes in their lives. Wilderness education programs require students to gradually take responsibility for personal care, trip logistics, decision-making and route planning. As students begin to take over these duties, they are given increasing responsibility for trip leadership. Expeditions often culminate with an independent student-led trip lasting 2-4 days in which groups of students travel independently of the instructors. The sense of confidence instilled by these experiences can be transferred to other aspects of life including risk taking behavior modification and disease management.

This aspect of the program also corresponds well to the Health Belief model. This model is comprised of several elements including: perceived threat of disease (susceptibility and severity), perceived benefits of action, perceived barriers to action, cues to action, and self-efficacy.³⁹ Learning to travel and survive in the wilderness boosts the self-esteem of participants and nourishes confidence in their ability to accomplish their change goals.

Peer support and healthy social environment (action → maintenance)

The third important aspect of the WE-AD program is the social environment created during a wilderness expedition. In this program, participants will be surrounded by other adolescents who also have diabetes and immersed in a culture of healthy living. In addition to the traditional aspects of a wilderness program, instructors will include diabetes management as a regular part of trip logistics planning. They will facilitate discussions about the physiology of diabetes and what precautions must be taken in a wilderness environment including blood glucose measurement, dietary adjustments and medication administration. Creating a social environment in which all participants are dealing with the same health issues can provide positive social reinforcement. In addition, the rigors of wilderness travel can emphasize the impact of good diabetes management and the ability to maintain the energy and hydration status to travel safely. This positive social and physical feedback can provide encouragement to participants to continue making healthy choices and move them from the action to the maintenance stage of change.

This aspect of the WE-AD program can also be viewed through the Social Learning theory explanatory model. This model describes a theory of behaviors in which people influence and are influenced by their social environment. The creation of an environment of *peer support*, a core aspect of the program, works within this framework by providing positive reinforcement for health-related behavior change. With the potential benefit of peer reinforcement of positive health-related behaviors also comes the potential risk that participants will instead end up reinforcing one another's unhealthy habits. Trip leaders will carry a responsibility to facilitate the direction of this informal peer-to-peer support.

Sum greater than the parts

The three core aspects of the program (decision-making, self-confidence/self-efficacy, peer support) are intertwined throughout the experience. In this way, participants in different stages of change may participate together. Those who have progressed further along the cycle of change may adopt leadership positions within the group or take on responsibility for facilitating group discussions about disease management. The integrated nature of the program has the potential to bring in participants who are in the contemplation stage of change and encourage them to progress through several stages during the course of the expedition by improving decision-making capacity, building confidence and a sense of self-efficacy and providing positive social reinforcement.

Goals and Objectives

Goal: To improve the health of adolescents with type 2 diabetes in North Carolina.

Short-term objectives (1-3 years):

- By 2012, three medical professionals (RN/NP/PA/MD) skilled in diabetes management will be recruited to participate in the wilderness program
- By 2012, six WE-AD program trip leaders will complete basic training in routine and emergency treatment of diabetes.
- By 2012, 50% of adolescents participating in the WE-AD program will demonstrate increased self-confidence/sense of self-efficacy at the end of the program and at 1 year
- By 2014, 100 adolescents with type 2 diabetes will participate in the WE-AD program. (3 trips per summer x 12 participants/trip x 3 years = 108 participants)
- By 2014, 75% of adolescents participating in the WE-AD program will demonstrate increased knowledge of the health consequences of poor nutrition, sedentary lifestyle, non-adherence to medical treatment, tobacco and alcohol use.

- By 2014, 50% of adolescents participating in the WE-AD program will demonstrate increased control of their diabetes and adherence to recommended medical treatment

Long-term objectives (3-5 years):

- By 2015, smoking among program participants is decreased by 50%
- By 2015, binge drinking among program participants is decreased by 50%
- By 2016, 25% of overweight/obese participants in the WE-AD program will demonstrate at least a 5% reduction in BMI
- By 2016, 50% of the initial one hundred WE-AD program participants will demonstrate sustained improvement in diabetes control and adherence to recommended medical treatment

Implementation Plan

The initial implementation of the WE-AD program will include a series of three separate wilderness trips in the mountains of North Carolina during the summer of 2012. Three additional trips will run during the summers of 2013 and 2014. Each trip will include twelve adolescent participants with type 2 diabetes, two trip leaders and at least one medical professional. The implementation of the WE-AD program requires several areas of focus in the planning process, including: partnership development, recruitment of staff, recruitment of participants, trip logistics, curriculum development, and development of an evaluation protocol.

Partnership development

Leaders in wilderness experiential education

Several organizations including Outward Bound and the National Outdoor Leadership School

(NOLS) have long histories of running wilderness experiential education programs for adolescents involving a wide range of outdoor activities. There is an independently run North Carolina Outward Bound school based in Asheville, NC (www.ncobs.org). The WE-AD program will seek to partner with NC Outward Bound to take advantage of their extensive experience in conducting wilderness trips for adolescents.

Leaders in wilderness medicine

A medical professional will accompany all WE-AD wilderness trips, however, there can be great differences in the management of disease in the wilderness as compared to standard care in familiar settings. The WE-AD program will seek to partner with experts in the field of wilderness medicine such as the Wilderness Medicine Institute (http://www.nols.edu/wmi/) or wilderness medical associates (http://www.wildmed.com/) in order to supplement the medical training of volunteers with a wilderness perspective.

Local Search & rescue

While we have every expectation that all participants will be able to travel safely throughout their participation in the WE-AD program, given the potential for additional diabetes related complications, we will liaison with local search and rescue organizations that operate in the areas within which we will be travelling to detail safety protocols and plan for possible evacuations.

UNC Healthcare

We will seek to partner with UNC Healthcare and develop the WE-AD program with input from various professionals including clinicians experienced in the care of adolescents with type 2 diabetes, diabetes health educators, psychologists and social workers. The UNC outpatient clinics and UNC affiliates throughout the state may serve as an initial recruiting ground for participant selection. Program recruitment may then be extended to other hospitals and clinics throughout the state.

Wellspring Academy of the Carolinas

We will seek to partner with the Wellspring Academy of the Carolinas in Brevard, NC. This is an organization that conducts summer camp programs for adolescents that are overweight/obese. Their experience and insight into the characteristics of successful programs will be invaluable. They may also serve as a source of participant recruitment.

Recruitment of staff

Trip Leaders

The WE-AD program seeks to combine a wilderness experience with a purposeful educational curriculum. To this end, we will seek seasoned trip leaders that have experience working with wilderness experiential education programs. Through our partnerships with organizations like North Carolina Outward Bound, we may be able to involve trip leaders that work for our partner organizations. The medical member of the leadership team will work collaboratively with the

wilderness trip leaders to integrate disease self-management and health related decisionmaking into the wilderness curriculum.

Medical professionals

The program will seek to recruit medical professionals including medical doctors (MD, DO), nurse practitioners (NP) and/or registered nurses (RN) with experience in the management of adolescents with diabetes. At least one medical professional will accompany each trip to provide medical oversight and diabetes self-management education to program participants. Medical personnel will also be responsible for working collaboratively with our wilderness medicine partners to train trip leaders in diabetes care. Initial recruitment will target faculty and staff affiliated with UNC Healthcare but may be extended to others with interest from across the state.

Recruitment of participants

Participants will be drawn from throughout the state of North Carolina and will take part in <u>a</u>two week wilderness expeditions. It is important to consider that adolescents who have developed type 2 diabetes are typically overweight/obese, have poor nutrition habits and lead sedentary lifestyles. The characteristics of this target population make recruitment of participants a significant challenge. A wilderness expedition is physically challenging and requires personal motivation and determination. Participants will need to be recruited from a wide range of sources including referrals from physicians, dieticians, psychologists or other healthcare workers, school teachers and officials, social workers, parents and self-referrals.

We will also target participants who have enrolled at summer camp programs for overweight/obese adolescents like the Wellspring Academy of the Carolinas in Brevard, NC.⁴⁰ Students enrolled in the Wellspring camps program have already demonstrated the willingness and motivation to participate in a program that focuses on weight loss through proper nutrition, physical activity and psychological counseling and support. In order to encourage participation, the program will be offered to participants at minimal cost and scholarships will be provided according to financial need.

Trip Logistics

Route planning

Two week expeditions will be planned to take place throughout National Forest and/or wilderness areas in western North Carolina. Route planning will need to take into account the initial physical condition of the participants. It is anticipated that trips will begin with short 1-3 mile days and work up to longer days averaging 5-7 miles per day. Multiple alternative plans will be researched and documented prior to the trip to allow for modification of trip difficulty based on participant needs during the trip. We want to challenge participants to push the boundaries of their physical capabilities but also want to ensure that every participant will be able to successfully complete the program. Route planning will account for the travel distance, terrain difficulty, elevation change, sources of water and possible campsite locations.

Backpacking gear

Trips will be conducted during the summer months which will necessitate less backpacking gear due to the warm weather. Individual participants will need backpacks, sleeping bags, sleeping

pads, personal clothing, boots and rain gear, headlamp/flashlight, diabetes medications, glucometers and test strips. As a group, trips will also need tents, cooking stoves/fuel/gear, first aid supplies and emergency supplies including a satellite phone as cell phones may not have reception in wilderness areas. These supplies may be borrowed from partner organizations like Outward Bound. We will also solicit donations or discounted rentals of needed equipment from outdoor supply companies like Recreational Equipment Inc. (REI) and other local outfitters.

Meal and snack planning

Meal planning for the WE-AD program must take into account the energy demands of an extended wilderness trip and also the special considerations required for participants with type 2 diabetes. In order to appropriately balance these needs, we will consult with a diabetes educator or registered dietician to help in the planning of meals. Throughout the program, participants will check their blood sugar frequently to ensure that it is staying within an acceptable range. Participants will partake in several small meals throughout the day rather than large meals at traditional times in order to help maintain a steady blood glucose level.

Transportation

The twelve participants, two wilderness trip leaders and medical leader will be transported in a 15-passenger van either borrowed from a partner organization or leased from a car rental agency or local university.

Curriculum development

The WE-AD program places a strong emphasis on an educational curriculum that focuses on; building decision-making capacity and increasing self-confidence/self-efficacy in the context of both wilderness skills and diabetes self-management.

Decision-making capacity

The wilderness setting provides an extraordinary setting for fostering growth in decision-making capacity. Trip leaders will begin the expeditions as directors but will transition into the role of facilitators throughout the experience. Participants will learn to take charge of route planning, meal preparation, campsite selection, and the continual risk analysis presented by changing terrain, weather and physical conditions.

Throughout the trip, participants will also be responsible for self-management of their diabetes. They will carry glucometers and check and record blood sugars throughout the day. This will provide an opportunity for informal education and problem solving around diabetes management for each participant in an individualized way. The medical leader on the trip will also lead and facilitate discussions about the physiology and management of diabetes at home and under the physical stresses of wilderness travel. These formal sessions will also include participant-centered group discussions on the risks of poor nutrition, sedentary lifestyle, non-adherence to medication regimens, tobacco use, alcohol abuse and the short and long term complications of type 2 diabetes.

Increasing self-confidence/self-efficacy

For participants, increased knowledge about diabetes self-management and the consequences of poor nutrition, sedentary lifestyle, non-adherence to medication regimens, tobacco and alcohol abuse merely set a foundation of knowledge needed for behavior change that must be built upon. Wilderness programs are physically and mentally challenging, pushing participants beyond their comfort zones to accomplish more than they had thought possible. Trips will be designed to challenge participants but also to ensure success. Learning to live and travel self-sufficiently through the wilderness can increase the self-confidence of participants that can be transferred to overcoming the barriers to lifestyle change.

Evaluation protocol

The WE-AD program will include a rigorous evaluation protocol which is described in detail in the Program Evaluation section.

Logic model

See Appendix (Figure 1) WE-AD Program Logic Model.

Detailed Budget

Budget Year: Sept. 1-						
August 31						
Title	% full	Base	Fringe	2011-	2012-	2013-
	time	Salary		2012	2013	2014
D 10 1	effort					
Personnel Costs						
Trip Leader (6) - 4 weeks each	0.08	\$36,500	\$9,125	\$21,900	\$21,900	\$21,900
medical professional (3) - 3	0.06	voluntee	voluntee	\$0	\$0	\$0
weeks each		r	r			
project coordinator (1) -	0.2	\$42,000	\$10,500	\$10,500	\$10,500	\$10,500
part-time year round				*	000 100	# 00 100
Total				\$32,400	\$32,400	\$32,400
Consultant Costs						
Wilderness trip				\$5,000	\$5,000	\$5,000
development						
Wilderness medical training				\$5,000	\$5,000	\$5,000
Curriculum development				\$5,000	\$5,000	\$5,000
Total Consultant costs				\$15,000	\$15,000	\$15,000
Equipment						
maps, compass (4) -				\$100	\$25	\$25
\$25/each						
sleeping bags (15) -				\$2,250	\$563	\$563
\$150/each						
sleeping pads (15) -				\$450	\$113	\$113
\$30/each outdoor clothing (45) -				#0.07 5	#0.075	ФО 07F
\$75/each				\$3,375	\$3,375	\$3,375
hiking boots (45) - \$75/each				\$3,375	\$3,375	\$3,375
rain gear (25) - \$50/each				\$1,250	\$313	\$313
• ,				\$225	\$56	\$56
flashlights (15) - \$15/each					·	
tents (5) - \$300/each				\$1,500	\$375	\$375
cooking stoves/fuel/gear (4) - \$120/each				\$480	\$120	\$120
first aid supplies (4) - \$50/each				\$200	\$50	\$50
satellite phone (1)				\$1,000	\$0	\$0
food - \$7.50/person/day				\$1,575	\$1,575	\$1,575
Total Equipment				\$14,205	\$9,939	\$9,939
11.1	<u> </u>		1	. ,	,	/

Comment [g3]: Yearly salary???

Outward Bound Instructors get paid \$80-\$120/day. If you were to work every day for a year at avg. \$100/day then annual salary would be \$36,500.+ approx.. \$9,125 in fringe benefits = total \$45,625. Each leader would work for 4 weeks each which is 0.08 full time effort (4 weeks/52 weeks). So each gets paid about \$3650 including any benefits x 6 leaders = \$21,900 total salary for all 6/year.

Comment [g4]: Why wold you have these costs beyond the first year?

Thought maybe we would have ongoing program development throughout the years to make positive changes to the program based on what worked well and what didn't work well. Estimated costs for the following years are probably overstated....

Comment [g5]: Why would you have these costs beyond the first year?

Same as above

Title	% full	Salary	Fringe	2011-	2012-	2013-
	time effort			2012	2013	2014
Communications						
Promotional/recruitment materials				\$2,500	\$2,500	\$2,500
trip information and consent forms				\$500	\$500	\$500
Total Communications				\$3,000	\$3,000	\$3,000
Supplies						
Office supplies				\$500	\$500	\$500
computer (1)				\$1,000	\$0	\$0
Total Supplies				\$1,500	\$500	\$500
Travel						
15 passenger van rental (6 weeks)				\$3,000	\$3,000	\$3,000
gas				\$400	\$400	\$400
Total Travel				\$3,400	\$3,400	\$3,400
Evaluation Costs				\$3,000	\$3,000	\$3,000
Total Cost				\$72,505	\$67,239	\$67,239
Indirect Costs (2%)						

Plan for Sustainability

The WE-AD program is an innovative approach to improving disease management for young people. During the program planning process, it is important to look ahead and make a plan for how the program will be sustainable beyond the initial funding cycle. Our goal is to develop a program with high sustainability that will operate well into the future. Key to ensuring the sustainability of the program is; the development of a clear vision, a results orientation, strategic financing, and strong community support.

Comment [g6]: That is a pretty substantial cost for 100 participants. That would be over \$1,500 per participant. Just something to consider and something that if you do try to implement this as a real program you'd want to be able to explain to funders and/or justify. It might make sense to have a real budget with a high upfront planning/consultation costs (which would make sense) followed by a more tight budget for the actual program imiplementation.

Otherwise looks very good and seems well thought out.

Good point. I don't think that it's something I need to develop for this Masters paper but definitely an important issue to address in the future.

Vision- The WE-AD program takes on the ambitious goal of transforming the lives of adolescents with type 2 diabetes. The program utilizes the power of wilderness experiences to help participants improve their decision-making skills and increase their self-confidence/sense of self-efficacy in a setting of peer support. These new skills and confidence will help them to make better health decisions with regard to medication adherence, diet, physical activity, smoking and alcohol use. To be successful, we must work to get our partner organizations, referral base, program medical staff and participants to buy-in to the program.

Results orientation- The WE-AD program will set forth a rigorous evaluation protocol to obtain data that can be used for ongoing quality improvement and recruitment of a diverse donor base. Data will include both quantitative and qualitative assessments of the impact of the program and also anecdotal "success" stories that can appeal to the emotions of potential donors.

Strategic funding- While the WE-AD program will require limited funding to ensure its sustainability, we will still pursue a diverse portfolio of funders. We will apply for federal and state funding for healthcare prevention made available under the Affordable Care Act. The Centers for Disease Control and Prevention and the National Institute of Health also provide additional grant opportunities. Finally, we will appeal to non-governmental organizations including the American Diabetes Association, the Kate B. Reynolds Foundation and the Duke Endowment as well as private members of the community to provide cash donations.

Community support- Our greatest asset will be our strategic partnerships with existing outdoor education schools like NC Outward Bound that may be able to provide the wilderness expertise, equipment and staff needed for implementation of the program at reduced costs. We will also strive to develop our partnerships with the Diabetes branch of the NC Department of Health and

Human Services (NCDHHS) and local healthcare providers on whom we depend for recruitment of both participants and volunteer medical staff.

With a shared vision, data driven programming and fundraising, a broad funding portfolio, and strong community support, the WE-AD program will be sustainable long into the future.

EVALUATION PLAN

Introduction and Rationale for the Evaluation

The Wilderness Experience for Adolescents with type 2 Diabetes (WE-AD) program aims to improve the health of adolescents with type 2 diabetes in North Carolina. The program will utilize wilderness experiences to help participants improve decision-making capacity, increase self-confidence/sense of self-efficacy and provide positive reinforcement from a supportive group of peers. These program foci will empower participants to make better health-related decisions and change behaviors with regard to nutrition, physical activity, medication adherence, tobacco and alcohol use.

An important component of the planning process is the development of a rigorous evaluation protocol. The goals of the evaluation will be to:

- · Determine if the program is being implemented as intended
- Assess the effectiveness of the program in achieving the intended short and mediumterm outcomes
- Provide a measure of accountability to funders and other stakeholders
- Produce data for quality improvement and innovation

Approach to the Evaluation

The evaluation will include an assessment of both program implementation and outcomes. This program will utilize an internal primary evaluator with an external consultant to conduct the evaluation. The evaluation will include qualitative analysis including interviews and/or focus groups with participants, parents and program staff. The evaluation will also include a quantitative analysis including pre-post and follow-up questionnaires regarding health-related knowledge and behaviors. We will also include some biophysical markers to assess disease management and weight reduction. These tasks are best undertaken using a participatory evaluation model with an internal evaluator. This evaluator must have wilderness skills, a background in experiential education, excellent communication and listening skills. It will be helpful if this person also has had training in evaluation, interviewing, focus group facilitation, and questionnaire development.

In the development of the evaluation strategy, it is important to involve the important stakeholders including participants, trip staff, medical personnel, and funders. Participants could offer valuable insight into the emotional aspects of undertaking a wilderness trip with a chronic illness. They can also identify the obstacles to behavior change that they find most difficult. These considerations can help the evaluator structure interviews, focus groups, and questionnaires to capture changes in knowledge, attitudes and behaviors. It will also be important to address any concerns that participants may have regarding confidentiality and use of the information. Trip staff can offer their expertise in wilderness skills and experiential education in elucidating methods for capturing changes in participant's decision-making skills and self-confidence. Medical personnel can offer insights into the assessment of disease self-management skills. Finally, it is important to involve current and possibly potential funders in

the evaluation process to ensure that we produce information that is important to them. All of these stakeholders should be involved in the formation, execution, review and improvement of the evaluation strategy. Involvement could be in the form of individual meetings, group planning sessions or written exchanges.

The evaluation of the WE-AD program faces several challenges. Whereas the primary evaluator will be a participating member of the expedition, he/she may be vested in a positive outcome and thus be biased in his/her assessments. Much of the qualitative evaluation will also rely on data from interviews and focus groups and participants may also be inclined to report more positive outcomes due to optimistic thinking or a desire to please the evaluator rather than actual change. It may also be difficult to accurately assess the primary program outputs including improvements in decision-making capacity and self-confidence. Regardless of the direction of the findings, proving statistical significance may be difficult.

While there are distinct advantages and disadvantages to this approach, the use of an internal evaluator is the best fit for the WE-AD program. Whereas the greatest challenge will be bias in the assessment by an internal evaluator, it may beneficial to also utilize the services of an external consultant in the development of interview and focus group protocols and questionnaire designs to help make the evaluation as objective as possible. It would also strengthen the analysis if the external consultant could also independently analyze the data to identify themes and code the data.

Evaluation Study Design

The evaluation of the WE-AD program will utilize observational and quasi-experimental study designs. The methods of data collection will involve a mixed method approach including qualitative and quantitative assessments. We will consider the evaluation of program implementation and outcomes separately.⁴¹

Implementation evaluation

Evaluation of the implementation of the WE-AD program will utilize an observational study design. The goal of this part of the evaluation is to determine if the program was implemented in the way in which it was intended. Data will be obtained from the program coordinator, trip leaders, medical professional volunteers, wilderness medicine consultants, program participants, their parents, and primary care doctors. Input from these stakeholders will be solicited via interviews, focus groups, surveys, pre-post testing and document review. This data will allow us to determine if the program was able to effectively recruit staff and participants, train staff, and conduct the wilderness experiential education expeditions as intended. This part of the evaluation will include mostly qualitative elements regarding the recruitment and training processes and the logistics and curricular components of the wilderness trips. Quantitative elements will include the number of participants and staff recruited and an assessment of the staff training process via pre-post testing.

Outcomes evaluation

The outcomes evaluation of the WE-AD program will utilize a quasi-experimental design with

pre-post testing with the entire group of participants studied prospectively as a single cohort. It will focus most on obtaining data directly from program participants but will also gather information from trip leaders as well as the parents and primary care providers of participants. Data will be obtained through a combination of pre-post testing, surveys, interviews, and document review.

In choosing the evaluation strategies for this program, I considered the cost and logistical feasibility of conducting the evaluation as well as the time requirements that it will place on those involved. The use of an observational design for the implementation evaluation is low cost, allows us to obtain the needed information and places a minimal burden on those contributing to the evaluation. The use of a quasi-experimental design with a single cohort for the outcomes evaluation is also low cost and adequately feasible. We will not have a comparison group but will use pre-post testing, surveys and interviews to assess changes in knowledge, attitudes, and behaviors from baseline data after participation in the program.

The major strengths of the chosen study designs are their low cost and feasibility of implementation. Given the nature of the program and the recruitment process, an observational design for the implementation evaluation and a quasi-experimental design for the outcomes evaluation are the only feasible options. Limitations to the chosen study designs are potential threats to internal validity and limited generalizability. Threats to internal validity include confounding by factors in the lives of participants unrelated to the intervention. Generalizability of the results will be, at best, limited to adolescents with type 2 diabetes or overweight/obesity that choose to participate in programs requiring significant physical activity due to the voluntary basis for WE-AD program recruitment.

Evaluation Methods

The evaluation of WE-AD will include the use of surveys, interviews, focus groups, pre-post testing, and document review. In the following, I detail in what way each member will be involved in the evaluation process. Similar data will be solicited from various stakeholders so as to strengthen the reliability of the data collected through triangulation.⁴²

Program coordinator

Interview/survey - Data will be collected from the program coordinator regarding the recruitment of participants and medical professional volunteers, the quality of wilderness medical training provided and any problems encountered with participant completion of the program. These data will be collected via a written questionnaire and interview conducted at the conclusion of each wilderness trip.

Document review - A document review of coordinator records will provide supporting documentation related to the recruitment process (demographics of participants and medical volunteers, clinic recruited from, collaborating physicians), the response to the wilderness medical training (did all leaders successfully complete the training/earn certification?).

Medical professional volunteers

Interview/survey - Data regarding the recruitment process for medical volunteers will also be

obtained from these volunteers directly. In addition, these volunteers will be asked for their opinions about the quality of the wilderness medical training, their experience in general and ideas for improvement. These data will be collected at the end of each wilderness trip.

Program participants

The evaluation process will have a strong focus on obtaining data directly from program participants. Interviews, surveys, focus groups, pre-post testing, and document review will be utilized to obtain the information needed for evaluation.

Interview/survey — Participants will be interviewed and asked to complete surveys prior to the experience, immediately following and annually for 3 years following completion of the program. The pre-interview/survey will focus on the recruitment process, their goals, fears and expectations of the program and the collection of baseline health-related knowledge, attitudes and behaviors. The immediate post-interview/survey will focus on what they learned about themselves and wilderness experiences during the trip, how they viewed their experience, the challenges encountered and how they were overcome and changes in their knowledge and attitudes related to nutrition, physical activity, adherence to medical treatment, tobacco and alcohol use. They will also be asked to discuss perceptions about decision-making capacity, self-confidence/self-efficacy and the contribution of peer support. The follow-up interviews/surveys will revisit these questions and also address changes in health-related behaviors (nutrition, physical activity, tobacco and alcohol use), diabetes control and adherence to medical treatment, need for diabetic medications, and any diabetes-related complications. Participants will be asked about daily blood glucose measurements, level of and trends in hemoglobin A1c measurements, medications required and any diabetes related complications.

This information will be compared to that recorded in the home clinic medical chart.

Comment [g7]: Would you want this at the pre time as well?

No. This is a part of the interview/survey section. It is designed to get more at whether participants are aware of their last A1c level, not a measure of whether or not they are improving control of their diabetes since a reported A1c level on a questionnaire filled out by participants may not be reliable. That info will come from the home clinic medical chart

Focus groups – Focus groups conducted at the conclusion of each trip will focus on the recruitment process, goals/fears/expectations, and the overall experience of the trip.

Pre-post testing - Changes in knowledge with regard to nutrition, physical activity, adherence to medical treatment, tobacco and alcohol use will be assessed prior to the trip to establish a baseline and immediately following the trip.

Document review – Home blood glucose measurement records will be reviewed to assess diabetes control and adherence to medical treatment. This will be done in conjunction with the interview/survey schedule detailed above.

Parents of participants

Interviews (telephone) – Parents of participants will be asked about the recruitment process and their opinions on whether there have been any changes in decision-making capacity, sense of self-confidence/self-efficacy, efforts at diabetes control and adherence to medical treatment, and efforts to improve nutrition or increase physical activity. They will also be asked their opinion on the role that peer support or peer pressure has played in any observed behavioral change.

Surveys - Parents will also be asked about changes in diabetes medications needed, diabetesrelated complications, changes in weight, and trends in blood glucose measurements. **Comment [g8]:** Do you need to specify actual survey instruments? Not sure, would check with Diane about that. If not, then this works.

Diane didn't have any comments about identifying instruments on her review of the draft. I don't think that she expects that level of detail at this point. I also sent her a copy of my draft with your comments for her review.

Comment [g9]: How much is interview versus survey. Interviews with 100 parents takes a lot of work and would require more money in your budget, while surveys are less work and cost less. I think you should specify when you are actually doing interviews versus surveys. Are the interviews a one time thing or with every data collection?

This is also a great point. Ideally, I would really like to have both interviews and surveys to collect both qualitative and quantitative data. I have separated the areas of data collection between the interview and survey here in the text. I would envision that these data would need to be collected at baseline before the intervention and then annually post-intervention for 3 years to help evaluate short and long term outcomes. Maybe a telephone interview would be less resource intensive? This is my ideal and would need to be adjusted to fit within constraints

Primary care providers

Interviews/surveys- Primary care providers will be asked about the participant recruitment process and their opinions on whether participants have shown changes in; decision-making capacity, sense of self-confidence/self-efficacy, diabetes control and adherence to medical treatment.

Focus groups – Providers may be asked to participate in a focus group session to discuss the participant recruitment process, challenges encountered, and ideas for bolstering recruitment.

Document review – The medical record will be reviewed to obtain information including; hemoglobin A1C measurements, recorded weights, prescribed medications and any diabetes-related complications.

Wilderness medicine consultants

Interview/survey – The wilderness medicine consultants will be asked to give input on the capabilities of the medical professional volunteers to conduct instructor training, diabetes education in a wilderness setting and medical oversight in the backcountry.

Trip leaders

Interviews/surveys – Trip leaders will be asked about the quality and usefulness of the wilderness medical training, the quality of the diabetes education provided on the trip and asked for ideas for program improvement. They will also be asked to assess for any changes in the decision-making capacity and sense of self-confidence/self-efficacy of each participant on the trip.

Pre-post testing – Testing will assess changes in diabetes care knowledge immediately before the training, immediately after the training and after completion of the wilderness trip to check for retention using a standardized questionnaire.

Logic Model

See Appendix (Figure 1).

Evaluation Planning Tables

Short-term objectives

Short Term Objective 1: By 2012, three medical professionals (RN/NP/PA/MD) skilled in diabetes management will be recruited to participate in the wilderness program to provide trip instructor training, diabetes education to program participants and medical oversight during the trip.

Evaluation Question	Participant	Evaluation Method
Were three medical professionals skilled in diabetes management recruited to participate in the wilderness program?	Program Coordinator	Interview Document Review (coordinator records)
How did they find out about the program?	Program Coordinator Medical Professionals	Interviews Survey
Were there barriers to recruitment or participation that were encountered and how were they overcome?	Program Coordinator Medical Professionals	Interviews Survey
Were the medical	Medical Professionals	Interviews

professionals who participated in the program well equipped to conduct instructor training, diabetes education to participants, and medical oversight during the trip?	Wilderness Medicine Consultants Trip leaders	Surveys
Did the medical professionals who participated have a positive experience?	Medical Professionals	Interviews Surveys
Did the medical professionals who participated have ideas for improvement?	Medical Professionals	Interviews Surveys

Short Term Objective 2: By 2012, six WE-AD program trip leaders will complete basic training in routine and emergency treatment of diabetes.

Evaluation Question	Participant	Evaluation Method
Did six WE-AD program trip	Program Coordinator	Document Review
leaders successfully complete		
basic training in routine and		
emergency treatment of diabetes?		
	T	D 1D 1 1
Did the wilderness trip leaders	Trip leaders	Pre- and Post- testing
who participated in the		
training increase their		
knowledge of diabetes		
management?		
Did the trip leaders think that	Program Coordinator	Interviews
the training was useful and at	Trip leaders	Surveys
the appropriate level?		
What changes to the diabetes	Program Coordinator	Interviews
medical training would the trip	Trip leaders	Surveys
leaders suggest?		

Short Term Objective 3: - By 2012, 50% of adolescents participating in the WE-AD program will demonstrate increased self-confidence/sense of self-efficacy at the end of the program and at 1 year

Did 50% of participants demonstrate increased self- confidence/sense of self- efficacy at the end of the program and at 1 year?	Program participants	Interviews pre- and post- testing
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What factors do participants think contribute to their self-confidence/sense of self-efficacy?	Program participants	Interviews
Did participants feel supported by their parents and peers in efforts to increase their self- confidence?	Program participants	Interviews

Short Term Objective 4: By 2014, 100 adolescents with type 2 diabetes will participate in the WE-AD program. (3 trips per summer x 12 participants/trip x 3 years = 108 participants)

Evaluation Question	Participant	Evaluation Method
Did 100 adolescents with type	Program Coordinator	Interview
2 diabetes participate in the		Document Review (coordinator
program? What challenges to participant	Program Coordinator	records) Interviews
recruitment were encountered	Program participants	Surveys
and how were they	Parents of participants	Focus groups (participants and
overcome?	Primary care providers	providers)
How did participants describe	Program participants	Pre-post interviews
their goals, fears and		Pre-post surveys
expectations of the program		Post-Focus groups
prior to their participation?	D	(participants)
Did participants view the program as a positive	Program participants	Interviews Surveys
experience?		Focus groups (participants)
охранонов.		r odd groups (participartis)
What did participates learn	Program participants	Interviews
about themselves and about		Focus groups (participants)
wilderness experiences during their trip?		
Did all participants	Program coordinator	Interviews
successfully complete the	Trip leaders	Surveys
program? If not, why not?	Program participants	Document review (coordinator
-		records)

Short Term Objective 5: By 2014, 75% of adolescents participating in the WE-AD program will demonstrate increased knowledge of the health consequences of poor nutrition, sedentary lifestyle, non-adherence to medical treatment, tobacco and alcohol use.

Evaluation Question	Participant	Evaluation Method
Did 75% of participants demonstrate increased knowledge of the health consequences of poor nutrition, sedentary lifestyle, non-adherence to medical treatment, tobacco and alcohol use at the end of program?	Program participants	pre-post testing
Do participants demonstrate improved health-related decision-making and strive for behavioral change?	Program participants Trip leaders Parents of participants Primary care providers	Interviews Surveys
Did participants increase their level of confidence in their ability to make substantial behavioral changes in their lives?	Program participants Trip leaders Parents of participants Primary care providers	Interviews Surveys
Did participants feel supported by their participant peers and trip leaders in their efforts to make changes in their lifestyle?	Program participants	Interviews Surveys

Short Term Objective 6: By 2014, 50% of adolescents participating in the WE-AD program will demonstrate increased control of their diabetes and adherence to recommended medical treatment

Evaluation Question	Participant	Evaluation Method
Did 50% of participants	Program participants	Survey
increase control of their	Parents of participants	Document review (medical
diabetes and improve	Primary care providers	record)
adherence to medical		
treatment?		
Has there been a sustained	Program participants	Document review (medical
decrease in, or maintenance	Parents of participants	record)
of target hemoglobin A1c	Primary care providers	
levels?		
Have participants been able to	Program participants	Surveys
reduce the dose or eliminate	Parents of participants	Document review (medical
the need for diabetes	Primary care providers	record)
medications?		
Have participants developed	Program participants	Surveys
any diabetic complications,	Parents of participants	Document review (medical
been hospitalized or required	Primary care providers	record)
acute care visits for diabetes	·	

Comment [g10]: How measured?
Surveys
Standardized self-efficacy scales

Standardized self-efficacy scales
Locus of control scales
Should I specify which ones at this point? I don't
think I need that level of detail at this point

Comment [m11]: I deleted the row about changes in daily blood sugars since no one is really going to sit down and read through months of daily blood sugar readings. We'll rely on A1c measurements to demonstrate changes.

Long Term Objectives

Long Term Objective 1: By 2015, smoking among program participants is decreased by 50%

Evaluation Question	Participant	Evaluation Method
Has smoking among program	Program participants	Survey
participants decreased by		
50%?		
What % of participants	Program participants	Survey
smoked at baseline?		
What % of participants	Program participants	Survey
attempted to quit smoking?		
What % of participants who	Program participants	Interviews
attempted to quit smoking		Survey
were successful? What were		
the obstacles to quitting		
encountered and how were		
they overcome?		
For those who attempted to	Program participants	Interviews
quit smoking but were		Survey
unsuccessful, what obstacles		
to quitting were the most		
difficult?		
Do participants feel that the	Program participants	Interviews
WE-AD program influenced		Survey
their decision to use or avoid		
tobacco?		
What was the role of peer	Program participants	Interviews
support or pressure in their		Survey
tobacco use choices?		

Long Term Objective 2: By 2015, binge drinking among program participants is decreased by 50%

Evaluation Question	Participant	Evaluation Method
Was binge drinking among program participants decreased by 50%	Program participants	Survey
What % of participants participated in binge drinking in the previous 6 months at	Program participants	Survey

baseline?		
What % of participants participated in binge drinking in the previous 6 months at follow-up?	Program participants	Survey
Do participants feel that the WE-AD program influenced their decision whether or not to participate in binge drinking?	Program participants	Interviews Survey
What was the role of peer support or pressure in their binge drinking choices?	Program participants	Interviews Survey

Long Term Objective 3: By 2016, 25% of overweight/obese participants in the WE-AD program will demonstrate at least a 5% reduction in BMI

Evaluation Question	Participant	Evaluation Method
What % of overweight/obese participants demonstrated at least a 5% reduction in BMI?	Program participants Parents of participants Primary care providers	Survey Document review (medical record)
Have overweight/obese participants attempted to lose weight? If so, what have they done and what obstacles have they encountered?	Program participants Parents of participants	Interviews Survey
Have participants demonstrated improved nutritional habits that follow diabetic guidelines? What challenges did they face and how were they overcome?	Program participants Parents of participants	Interviews Survey
Have participants demonstrated sustained and increased levels of regular physical activity? What obstacles did they face and how were they overcome?	Program participants Parents of participants	Interviews Survey
What influence did the WE-AD program have on participants' efforts to lose weight?	Program participants Parents of participants	Interviews Survey
Did participants feel supported in their efforts to lose weight by peers? family? healthcare providers? teachers?	Program participants Parents of participants	Interviews Survey

Long Term Objective 4: By 2016, 50% of the initial one hundred WE-AD program participants will demonstrate sustained improvement in diabetes control and adherence to recommended medical treatment

Evaluation Question	Participant	Evaluation Method
What % of participants	Program participants	Surveys
demonstrated sustained	Parents of participants	Document review (medical
improvement in diabetes	Primary care providers	record)
control and adherence to		
medical treatment?		
If a log of daily blood glucose	Program participants	Document review (participant
is available, has there been	Parents of participants	records)
sustained improvement in		
blood sugar values?		
Has there been a sustained	Program participants	Surveys
decrease in, or maintenance	Parents of participants	Document review (medical
of target hemoglobin A1c	Primary care providers	record)
levels?		
Have participants been able to	Program participants	Surveys
reduce the dose or eliminate	Parents of participants	Document review (medical
diabetes medications?	Primary care providers	record)
Have participants developed	Program participants	Surveys
any diabetic complications,	Parents of participants	Document review (medical
been hospitalized or required	Primary care providers	record)
acute care visits for diabetes		
related problems?		

Dissemination Plan

The data derived from the implementation and outcomes evaluations will be analyzed and the results interpreted to give insights into the effectiveness of the program and its implementation. These results will need to be shared with multiple stakeholders who may have different expectations of the program, disparate ideas of what information is important and varying levels of literacy.⁴³ In developing a plan for dissemination of the findings, it is useful to identify different strategies with different purposes in mind.⁴⁴

The stakeholders involved include; participants and parents, program staff, healthcare volunteers, primary healthcare providers, wilderness medicine consultants, and local Search & Rescue agencies. The findings may also be presented through publication to the larger scientific and educational community.

One advantage to the WE-AD program is that it will be implemented longitudinally as sets of 3 wilderness expeditions per summer over 3 years for a total of 9 trips in all. This provides a unique opportunity for analysis of the preliminary data and the ability to make responsive changes from year to year. This data will be shared through a combination of formal reports, presentations and possibly journal publication.

Internal quality improvement

This analysis will include two parts; effectiveness of the implementation and effectiveness in achieving the program's intended outputs and short term outcomes. The evaluator will prepare a report detailing the implementation assessment and identify areas of strength, areas of weakness and make suggestions for improvement. The evaluator will then conduct a meeting with the program coordinator, wilderness staff, and healthcare volunteers to discuss these findings and collaborate on developing strategies for improvement.

A smaller separate report will be created that focuses on the medical and safety aspects of the trip with regard to diabetes control and any medical problems that arose during the trip. This report will be presented to the program coordinator, wilderness staff, healthcare volunteers, primary healthcare providers, wilderness medicine consultants and local Search & Rescue agencies. Stakeholder representatives from each of these groups will be asked to attend a

single annual meeting to address any medical issues that came up during the trips and to discuss ways in which these situations could be better handled or prevented in the future.

Participants and their families

The data will also be presented to participants and their families through a report detailing the activities of the program and its impact on the decision-making capacity, self-confidence/sense of self-efficacy, and changes in health-related knowledge, attitudes and behaviors of participants. Care will be taken to create a report free of jargon and at an appropriate level of literacy. Participants and their families will be invited to attend an optional presentation and discussion meeting with the program coordinator, wilderness staff, healthcare provider volunteers and the evaluation team.

Scientific and educational community

The data from the interviews, surveys, focus groups, and document review will be coded if necessary and analyzed with the pre-post testing data to produce a manuscript describing the program and its outcomes. This will be submitted to professional journals in order to share the findings with the larger academic community. The program and its findings may also be presented via oral or poster presentations at national conferences.

Promotional materials

Promotional materials about the program will also be created to help bolster future participant recruitment and to attract potential donors, staff and volunteers.

DISCUSSION

The emergence of type 2 diabetes mellitus in the adolescent population is cause for great concern. This disturbing trend is fueled by the growing prevalence of obesity within this population. Results from the NHANES study cite an increase in the prevalence of obesity among adolescents, age 12-19, from 6.1% in 1971-1974 to 18.1% 2007-2008. Given the upward trend in obesity, it is likely that the population of adolescents diagnosed with type 2 diabetes will continue to increase. Those affected by this disease are at risk for acute complications and the long-term development of micro- and macro- vascular complications leading to disease of the eyes, kidneys, nervous system, heart and brain. The burden of disease in the affected population is significant and includes increased morbidity, decreased quality of life and decreased life span.

On a societal level, type 2 diabetes in all ages has an enormous financial impact with an estimated cost of \$174 billion in 2007 including direct medical expenditures and indirect costs associated with loss of productivity. ⁴⁶ As adolescents are increasingly diagnosed with type 2 diabetes, we can expect an increase in disease-related healthcare expenditures, great loss of productive life from these young patients, and decreases in the longevity and quality of their lives.

The Wilderness Experience for Adolescents with type 2 diabetes (WE-AD) program seeks to provide affected adolescents with an experience that will improve their decision-making skills and increase their self-confidence/sense of self-efficacy, reinforced by an environment of peer support. These skills can be transferred to health-related aspects of their lives leading to improved health-related decision-making; improved adherence to medical treatment and diabetic diet guidelines, increased physical activity, and decreased substance abuse. Healthier

lifestyles will help adolescents with type 2 diabetes to improve control of their blood sugar and decrease the burden of acute and long-term complications in this population.

In the design of this program plan and evaluation, I utilized lessons learned from my review of the literature. There were no studies that specifically included adolescents with type 2 diabetes in wilderness programs, but guidance can be derived from wilderness programs that targeted adolescents with other types of chronic illness, disability, or their healthy peers.

Themes important to the planning process that emerged from the literature included participant safety and curriculum development. All programs included safety training for trip leaders and/or the inclusion of at least one medical provider as a trip co-leader. Curricular elements focused on leadership development, wilderness skills, fostering self-confidence and independence, disease self-management, facilitating an environment of peer support, improving body image and helping participants adapt to changing conditions. All of these elements contribute to an overall goal of helping participants learn to employ more successful coping mechanism when faced with new challenges.²⁵

Elements of the literature review were also useful in planning for the evaluation of the WE-AD program. Several studies utilized pre-post questionnaires, interviews and focus groups with participants. In some studies, the parents and physicians were also interviewed about perceived changes in the attitudes and behaviors of participants. These strategies were employed in the WE-AD program evaluation plan. The interventions cited in the literature review, however, only focused on outcomes evaluation. In planning the WE-AD program evaluation strategy, equal focus was placed on a process evaluation to enable us to determine if the intervention is implemented as intended.

Comment [m12]: Hmmm..... I agree with you, the previous ending citing the Neill and Heubeck study is repetitive and sounded a little out of place so I deleted it. I think the last line is an important idea though and I left the citation to the Neill and Heubeck study since it specifically addresses this point.

I anticipate that the program will face challenges, the most pressing of which will be in participant recruitment as the target population is characteristically obese and likely accustomed to a sedentary lifestyle. We will begin our recruitment efforts by targeting adolescents with type 2 diabetes that have enrolled in summer camp programs with a focus on weight loss. We will also need the help of medical providers, parents and community members to recruit and motivate potential participants.

I have thus far outlined a comprehensive general plan for the implementation and evaluation of the WE-AD program. The next steps to be undertaken include establishing collaborative working relationships with NC Outward Bound, local wilderness medicine experts, medical providers with expertise in adolescent diabetes, and selected adolescents with type 2 diabetes. This group will work to develop a detailed educational curriculum that addresses the core components of the WE-AD program; decision-making, self-confidence, peer support, body image, disease self-management, and substance abuse education. Once the curriculum is fully developed, promotional materials will be designed to aid in the recruitment of participants.

Adolescents with type 2 diabetes face many challenges in their efforts to make healthy lifestyle decisions and maintain self-control over their disease. The WE-AD program works to build a strong foundation for lifestyle change by helping participants to improve their decision-making skills, gain the self-confidence necessary to successfully act upon their decisions, and change the way they view themselves and their disease. The program is, however, only a beginning. Changes in knowledge, attitudes and behaviors engendered by the program must be reinforced throughout the lives of these adolescents. The WE-AD program could attempt to build upon the social relationships formed between participants during the experience by facilitating the formation of participant-led social, activity, or outdoors clubs that can continue to provide a forum for participants to receive peer support and encourages healthy lifestyle choices. The

WE-AD program could also host reunions for participants, involve alumni as future trip coleaders or sponsor alumni only trips. All of these efforts will help to strengthen the social relationships formed during this experience.

The development of this program draws from the existing literature on wilderness therapy experiences for adolescents with other chronic illnesses, disabilities or their healthy peers.

There are likely significant differences, however, between the populations included in other studies and the target population for the WE-AD program. Lessons learned from this program will fill an important gap in the literature and provide a basis for future study and can be applied to the development of similar programs throughout North Carolina and beyond.

Setting out to dramatically alter the trajectory of youth with type 2 diabetes is no small task. The program will undoubtedly face many unforeseen challenges in its implementation and evaluation. The potential rewards, however, are too great and the risk of failure too frightening to allow them to stand in the way. This program has the potential to change lives by encouraging disease self-management, good nutrition, physical activity and the avoidance of tobacco, alcohol and drugs. The WE-AD program can improve the ability of participants to make good decisions, act on those decisions, and maintain those healthy actions. In doing so, WE-AD helps participants learn to employ healthy, productive coping strategies that empower them to face challenges and overcome obstacles to healthy living. In doing so, the program has the potential to improve the health and wellbeing of youth with type 2 diabetes.

Comment [g13]: Cliché, restate without cliché or in a way that doesn't make it sound like this intervention alone will solve the natoin's obesity problem. It is a great idea and intervention, but the risk of failure is not too frightening for this particular program

You're absolutely right, it is a little cliché and overly dramatic. Diane commented that she specifically liked this sentence (a lot). If you're ok with it, I'd like to leave it. It's a little dramatic but I thought that the concluding paragraph needed a little pizazz.

ACKNOWLEDGMENTS

I would like to take this opportunity to thank the following people for their help in completing this Master's paper. I greatly appreciate it and couldn't have done it without you.

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APPENDIX

Appendix : Table 1 – Summary of programs with similarities to the WE-AD program

Program	Goals/Objective s	Shared Elements	Activities	Evaluation Methods	Outcomes
Adventur e, Etc. ¹²	To increase the independence, sense of skill mastery, social skills and positive body image of adolescents with a chronic illness or disability	1, 2, 3, 4, 5, 6, 7	9 day wilderness expedition (canoeing, camping, orienteering, rock climbing, small group and solo experiences) and a 5 day urban experience	pre-post test design, Offer Self-image questionnaire, Nowicki- Strickland personal reaction survey, Moos family environment scale, interviews with participants and parents	Improvement in self-efficacy, body image, family conflict
Outward Bound, diabetes, and motivatio n ¹⁶	To improve self-reliance, self-care and effective interaction with support systems for adolescents with type 1 diabetes	1, 2, 3, 4, 6, 7	Sailing expeditions lasting 3-4 days	Achenbach Youth Self- Report Profile, Nowicki- Strickland measure of locus of control, the Diabetes Adjustment Scale, the Coopersmith Self-Esteem Inventory, Patterson's 'A- cope" scale	Improvements in the Achenbach Youth Self-report profile. Anecdotal increases in self-confidence, wilderness skills, improved self-esteem, improved diabetes control, increasing determination and ability to self-manage
British Diabetic Associati on/Outwa rd Bound Mountain Course 21, 22	was to teach insulin-treated diabetic patients to self- manage their diabetes under conditions of wilderness travel	1, 2, 3, 4, 7	1-2 week long expeditions that involved rock climbing, orienteering, canoeing, and mountaineeri	Pre-interview about diabetes knowledge and attitudes. Post- questionnaire to participants (74% response) and physicians (44% response)	Increased self- confidence, self- reliance, improved self- management. Increased knowledge of diabetes and exercise, insulin dose adjustment and

					administration technique, risks of hypoglycemia and diet.
					No long term changes in glucose control
					Decrease in hospital admissions
Wilderne ss Leadershi p Program ⁴⁷	To teach wilderness skills, provide diabetes education and foster leadership development for adolescents with type 1 diabetes	1, 2, 3, 4, 7	5-7 day backpacking trips	Analysis of demographic data, medical records from the trip, an evaluation questionnaire and exit focus groups	Increased self- confidence, increased motivation to self- manage their diabetes, increased independence
Adventur e Therapy for Adolesce nts with Cancer ²⁴	Documentary film about adventure therapy expedition to the Arctic circle with adolescents with cancer. To build self-esteem and build supportive relationships	1, 2, 3, 4, 6	10 day expedition to the Arctic Circle	Secondary analysis of multiple unstructured interviews	Themes emerged that focused on developing connections, togetherness, rebuilding selfesteem, and creating memories
Adolesce nt coping styles and outdoor education 25	To examine differences in coping strategies under stressful conditions	1, 2	9-10 day Outward Bound Australia expeditions	Modified version of the Adolescent Coping Scale (ACS) questionnaire	Participants in outdoor education settings utilize more productive coping strategies than do adolescents in other settings
Wilderne ss Therapy and Adolesce nt	To assess the impact of wilderness experiences on the prevalence of depression	1, 2	28-day wilderness expedition involving canoeing and camping	Pre- and post- tests using the RADS-2 and MPD instruments	Decrease in the incidence and prevalence of depression and an increase in the rate and

Depressi on ²⁶	and psychosocial development in a group of at-		prevalence of psychosocial development
	risk adolescents		

- * Shared elements with the WE-AD program. Central elements of the WE-AD program include:
- 1) Target population includes adolescents, aged 13-18.
- 2) Program involves a wilderness experiential education experience3) A program focus is on decision-making capacity (including leadership skills and/or wilderness
- 4) A program focus is on building self-confidence (including self-efficacy and/or independence)
- 5) A program focus is on fostering a positive body image
- 6) A program focus is on providing an environment of peer support (including social skills, conflict resolution, shared experiences, friendship building)
- 7) Program includes chronic disease self-management education and/or personal responsibility
- 8) Program includes education on tobacco/alcohol/drug use, physical activity, and/or diabetic diets and adherence to medical treatment

Inputs	Activities	Outputs	Short-term Outcomes (1-3 years)	Long-term Outcomes (3-5 years)	Long-term Impact (7-10 years)
Partnerships with wilderness education organizations Partnerships with local Search & Rescue organizations Program staff and trip leaders Volunteer medical professionals Backcountry camping gear and supplies (backpacks, tents, stoves, etc.) Transportation Appropriate meal planning and food provisions Finances Data	Recruit medical professionals for program staff training, participant education and medical oversight Train trip leaders in basic and emergency diabetes care Recruit program participants Conduct two week backcountry expeditions with program participants Provide didactic education on diabetes physiology and combined lifestyle and medication management Provide didactic education on increased risks of tobacco, alcohol and drug use	Six volunteer medical professionals recruited for program All trip leaders trained in diabetes management At least 100 adolescents with type 2 diabetes complete the program over 3 years Program participants will increase decision making capacity, confidence and sense of self-efficacy Participants will receive positive reinforcement from trip leaders and peers	Program participants demonstrate increased knowledge of the consequences of tobacco and alcohol use Participants increase knowledge of lifestyle modifications for diabetes management Participants will increase diabetes control and medication adherence	Participants will demonstrate decreased rates of tobacco and alcohol use Overweight/obe se participants will decrease BMI by >10% Initial 100 participants will demonstrate sustained improvement in diabetes management and treatment adherence	Lower morbidity and mortality from diabetes Improved quality of life