Introduction

Over the past several decades, clinicians have begun to consider measures of health-related quality of life (HRQL) as an essential component to patient care and treatment evaluation\(^1\). It is increasingly considered to be a reliable method of gauging treatment effectiveness and quality of care for a variety of patient groups. It is currently being used by both the World Health Organization (WHO) and Healthy People 2020 to measure comprehensive health including its physical, emotional and social dimensions in a general population\(^2\)\(^3\). It is also used to measure quality of life in patients with specific disease states or long-term disabilities, focusing on areas of function related to chronic illnesses (for example, measuring gross and fine motor functioning in children with cerebral palsy\(^4\)). My proposed Clendening summer research project focuses on the standardized quantification of HRQL measures at Bay Cliff Health Camp, a seven week therapy camp that seeks to improve the quality of life of children with physical disabilities through therapy sessions, recreation and fellowship with peers.

Background

I became interested in this topic after working at Bay Cliff Health Camp’s Summer Therapy Camp for several summers. Bay Cliff is located in the Upper Peninsula of Michigan and functions as a therapy and wellness facility throughout the year. The camp was established by Dr. Goldie Cornelieuson and Elba Morse, a nurse supervisor, during the Depression for children who were poorly nourished due to the impoverished conditions of the time. The camp transitioned to a therapy camp during the 1940’s when polio left many children in the Upper Peninsula unable to walk and in need of physical rehabilitation. While polio became less common over time, Bay Cliff continued to provide therapy to children with a wide range of physical disabilities. Today, it provides children with a variety of therapies including physical therapy, occupational therapy, speech therapy, hearing therapy, and vision therapy depending on their goals toward independence. Recreational activities such as camping, hiking in the woods, and taking a walk or ride down the beach trail to Lake Superior continue to be an integral part of how Bay Cliff seeks to incorporate therapy into everyday activities.

I spent three full summers over the past five years working at Bay Cliff. The first summer I worked at Bay Cliff, I worked as a housekeeper and laundry aide. I was entering college in the fall and had not decided that I wanted to go into a health-related field after I graduated. Bay Cliff introduced me to a type of healthcare that was hands-on, personalized, and encompassed the needs of the whole person. During the second summer I worked at camp, I worked as a counselor for four girls, aged 6 to 10, each with a different diagnosis and each with different goals for what they wanted to learn at camp. One of my campers transitioned from her wheelchair to a walker after a spring surgery; another camper learned to tie her shoes; one worked on putting on her
ankle foot orthotics without assistance while another learned to brush her hair and pull it into a ponytail by herself. Each of them had goals focused on improving their independence, regardless of their diagnosis. I worked exclusively with the teen campers for my third full summer, where I learned that the social dimensions of a camper’s life are essential components to their quality of life. While an individual’s physical capabilities strongly influenced therapy goals and methods, they are not the only factors that affect a patient’s quality of life.

My decision to enter medical school was strongly influenced by my time working at camp. It continues to influence my interests in specialties, including my interests in pediatrics as well as physical medicine and rehabilitation. Designing my research project around the question of HRQL for campers at Bay Cliff serves two purposes. First, it would allow for a better understanding of the multidimensional aspects of camper’s quality of life; it could also provide early quantitative measurements of potential benefits and costs to the six week therapy program. Secondly, it would also help me to professionally develop my understanding and skills of the therapeutic approaches to working with individuals with physical disabilities.

**Description**

My research proposal will be carried out before, during and after Bay Cliff’s Summer Therapy Camp which runs from June 14 until August 2. My timeline is coordinated with this schedule, although some adaptations will be made to accommodate my academic schedule.

In order to evaluate health-related quality of life measures, my project will be using a group of surveys called the Child Health Questionnaire (CHQ)\(^5\). The surveys are designed and normalized to be administered to children ages 5-18. It measures physical and psychosocial areas of quality of life, which are broken down into 14 major categories. I will be administering two form types: parental and child self-report. The parental form, CHQ-P50, consists of 50 questions pertaining to their perception of their child’s HRQL and can be administered to parents of children age 5-18. The child self-report is for children age 10 and older; it is 87 questions and pertains directly to their HRQL.

There are several reasons for choosing to use this questionnaire. First, among similar surveys addressing research questions pertaining to pediatric HRQL, it is cited frequently in published articles and is used worldwide to measure HRQL in a various patient populations. Unlike many other measures of HRQL, it is also preferable because it is not disease-specific. Bay Cliff has a diverse group of campers every year and the survey needs to be able to accommodate the complexity of their health impairments, strengths and goals that they bring to camp. After reading through sample questions of the CHQ parental and self-report surveys, these questions cover a variety of topics that are pertinent to campers at Bay Cliff.

Along with the survey’s qualities, CHQ also allows for scoring, analysis, and comparison with standard values provided by the survey administrators. This will allow for straightforward and fruitful analysis of the data I will be collecting. I believe this will be advantageous for two reasons. First, it produces a greater opportunity for meaningful quantitative data to be collected and then potentially reported in publication. Second, it provides a unique opportunity for Bay Cliff to analyze and evaluate their strengths in providing therapy while also determining
potential areas of HRQL that they can addressed more fully in future summer therapy camp sessions.

Finally, both versions of the survey allow for a unique research opportunity for Bay Cliff. It allows for a larger age range of campers to be included in the process (the parental form included children age 5-18 while the child self-report version includes children age 10-18). It also sets a groundwork for future analysis if the survey is considered to be useful in analyzing and improving therapeutic methods and goals for subsequent years. Many campers return year after year, with approximately 70% of total campers each summer being returners, allowing both child and parent to see changes in themselves or their children. There is considerable anecdotal evidence that campers benefit from the therapy they receive while at Bay Cliff which is reported by campers, their parents, and their health care providers. In addition to anecdotal evidence, measurements of HRQL would allow for a greater understanding of what role a camp like Bay Cliff currently serves in providing therapy as well as what role it could serve for future campers.

Timeline:

March- Licensing approval has already been attained through HealthActCHQ. Fees would be paid to gain access to the surveys. I would spend this month becoming familiar with the surveys and Scoring and Interpretation manual.

April- Before camp begins, a packet of information is sent out to parent. I would like to draft and send a letter explaining the project and its goals to the parents. The parental survey will not be sent out until after camp has begun.

May- I will be driving up to camp so that I have access to a car for the summer. My schedule for arriving at camp depends upon camp needs and will be spent doing work for personal development (shadowing the camp physician Dr. Michael Nidiffer in his private practice, working at the Autism camp and Down Syndrome Camp hosted by Bay Cliff). The six weeks spent for the Clendening Summer Fellowship will take place during the Summer Therapy Camp during June.

June through July- All staff will be present for orientation starting June 8. Campers arrive June 14 and remain at camp until August 2. I will remain at camp until I need to return to Kansas City for leadership commitments for M1 orientation week (July 24).

Parental forms will be distributed by mail during the week of June 16-20. They will be sent with a stamped return envelope to encourage completion and return. Potential monetary incentive, such as having name entered into a gift card raffle, for returning the completed forms will be considered (pending IRB approval).

During camp, I will conduct interviews for child self-report questionnaire. Due to therapy and activities scheduling, I will coordinate camper interview with their therapists and counselor. I will be interviewing approximately 70-80 campers age 10 to 18. I will conduct my interviews within the first three weeks after campers arrive (June 16-July 5) and will begin analysis on data
collected from both parent and child surveys during my final three weeks (July 6-24). I will finish any remaining analysis when I return to Kansas City.

Methods

I will be working with the staff at Bay Cliff Health Camp while conducting my research. I have spent five summers at camp and am familiar with the camp’s rules, mission, and schedule. I have received permission from the Camp Director Mr. Tim Bennett to carry out this project under the direction of Miss Christy Osborn, PT, DPT, and Therapy Coordinator at Bay Cliff. Miss Christy and I have been in contact with one another concerning this project since December and she will continue to mentor me during the summer while I am carrying out my research.

I will be driving to camp with my personal vehicle, allowing me access to transportation throughout the course of the summer. My accommodations will be on camp, including housing and food. All staff including nurses, therapists, activity coordinators, auxiliary staff and counselors (except for a few members of auxiliary staff with families nearby) reside on camp grounds.

My daily schedule will be influenced by the camp’s schedule for the day. I will be conducting interview with campers throughout the first three weeks of camp and analyzing data throughout the last three weeks of my time at camp. Depending on the camper’s communicative ability, the interview should take between 30-60 minutes. Because some campers are unable to write, read or speak without the use of sign language or an assistive communication device, I will be interviewing all campers. Sign language instructors and speech instructors will be used when needed.

In addition to the data collection portion of my project, I will also be working with the therapists in their daily therapy sessions with campers. I have been offered the opportunity to work in a unique inter-professional team of health professionals.

I will also be using the time to spend time with three physicians associated with Bay Cliff. Dr. Carl Eiben, MD, is a Physical Medicine and Rehabilitation (PM&R) physician who practices nearby at Marquette General Hospital. He also participates within camp during Rehab Team Meetings where a camper is evaluated by the whole team of individuals responsible for the camper (including therapists, counselors, the camp orthotist, and the PM&R physician). Dr. Mike Coyne is a retired PM&R who has offered to help with the project if needed. Dr Mike Nidiffer is the camp pediatrician who visits camp twice a week in the health clinic on camp.

Budget

- **Gas**
  - 860 miles- KC to Bay Cliff, MI via Minneapolis (rest stop)
  - $0.52/mile X 860 miles = $447
  - Return trip = $447
- **CHQ Liscencing Fee** = $350
- **Supplies for camp (food, toiletry, camping equipment)** = $75
- **Parental survey completion/return incentive (gift card raffle)** = $150
Sources

Thank you for your request, you will be contacted within 3 - 5 business days!

Your request was sent as it appears below:

Name: Sarah Scrafford  
Position: Medical Student  
Organization: University of Kansas School of Medicine  
Address 1: 3580 Rainbow Blvd  
Address 2:  
City: Kansas City  
State: KS  
Province:  
Zip: 66103  
Country: USA  
Email: sscrefford@kumc.edu  
Phone: 3167374056  
Proposed Use: Academic Research - Funded  
Funding Source: Clendening Summer Fellowship- KUSOM  
Research Condition: HQOL in campers at Bay Cliff Health Camp  
What is the Clinical Trial and/or Project 1 Number(s)?  
Research Sites: 1  
Sample Size: 150 children and their parents  
Administrations / Subjects: 1  
Proposed Online Use: We want to administer the Survey(s) online: No  
Surveys will be presented on our internal servers: No  
Access will be for our study patients/respondents only by password-protected access: No
Comments:
I am applying for a Clendening Summer Fellowship at the University of Kansas School of Medicine as a first year student. I would like to do research at Bay Cliff Health Camp, a therapy camp for children with disabilities. If I do not receive the fellowship grant, I would still like to carry out the research with the camp administration, at which point it would be unfunded research.

Research State Date: 05/2014
Research End Date: 08/2014
Additional Languages(s):
Condition-Specific Survey(s):
Desired Survey(s): CHQ-PF50: English (US)
CHQ-CF87: English (US)
Dear Sarah Scrafford:

We appreciate your interest in licensing quality of life outcomes surveys from HealthActCHQ. The grant of your license is based upon the specific terms you provided for one project during the online registration process. Your limited-use license is for the following HealthActCHQ surveys and translations:

CHQ-PF50 English (US)
CHQ-CF87 English (US)

Your licensing fee for the term of your project is US $350.00.

The link below will connect you to the HealthActCHQ's secure, protected payment area. If you decide to purchase and license the surveys, please click on the link below, or copy and paste the link into the address bar of your browser to finalize payment.


Orders are shipped and licenses issued within three-to-five business days of the receipt of licensing fees. We thank you for the use of the HealthActCHQ surveys.

Your licensing fees have been lowered to the minimum as a professional courtesy. Thank you for your interest in the Child Health
Questionnaire.

Licensing Department
HealthActCHQ Inc.

800 Boylston Street, 16th Floor | Boston, MA 02199
P (857) 453-6665 | F (857) 453-6501
Email correspondence with Site Mentors

Screen shots of email correspondences were taken. Any personal information or camper names have been marked out.

Permission granted by the camp director was obtained via telephone. After receiving permission, my main contact at camp has been the therapy coordinator Christy Osborn.

Several other conversations have occurred over telephone to discuss the details of the project. The emails included archive the most pertinent emails exchanged concerning the project and permission to arrive at camp during May.

**archives@baycliff.org on behalf of Christ...**

Monday, December 30, 2013 8:16 AM

Hi Miss Sarah!

I look forward to working with you on this! Looking forward to talking soon!

~Miss Christy

Christy Osborn, PT, DPT
Therapy Coordinator

**Bay Cliff Health Camp**
Children's Therapy and Wellness Center
N4175 County Road KCA, P.O. Box 310
Big Bay MI, 49808
(906) 345-9314
Oh Yes! So Sorry! I have been thinking of you, but forgot about the contact info. I'll have it to you by tomorrow. Thank you for reminding me!

Every once in awhile, another thought of an opportunity for you pops into my head. :)

If you're able to be with us, we have 3 campers who will be having surgeries prior to camp, and will especially benefit from the intensive therapy. Wonderful learning experiences for you!
- CP (and you know how insightful she is...)
- Arthrogryposis (I have good case history info to share too...)
- I'm blanking on the third camper at the moment... (Different from...)

How did your meeting go last week?
~Miss Christy

Christy Osborn, PT, DPT
Therapy Coordinator
Hi Miss Sarah,

Both "Dr Mikes" look forward to talking with you. Here's there contact info.

Dr Mike Coyne (PM&R):
- email: JMCoynemd@chartermi.net
- cell: (908) 999-9999

Dr Mike Nidiffer (Pediatrician):
- email: g.michael.nidiffer@mghs.org
- cell: (908) 999-9999

I'll review the HQOL info you sent and get back to you soon. I'll check the info I've collected too, including a book I haven't read yet: "Life Quality Outcomes in Children and Young People with Neurological and Developmental Conditions". I picked it up at a conference I was at in October (American Academy of Cerebral Palsy & Developmental Medicine). (I highly recommend this conference for you in the future; remind me to tell you more sometime :)

Hi Miss Sarah,

I've been having difficulties emailing from the place I house sit at in the winter. I hope to email more tonight, but in case I'm unable to, I will email you tomorrow.

Here's some info for the meantime...
- Great proposal!
- In 2013, 73% of the campers were returners (107 returners, 39 new). (Average over last 5 summers is 70%, with average total number of campers is 157). We have other data too, let me know...)
- Yes! It's definitely okay to send info to the parents. The month of May is more realistic from our perspective, since parents aren't informed until May if we have a spot for their child. The month of April can still be when the info is developed so it's all ready to go.
- Let's talk more about May! You're welcome anytime!!
- Dr Coyne is now retired, but we can see if you can observe Dr Eiben (PM&R) in May. I'm sure Dr Nidiffer would welcome you...
- The meetings at camp are "Rehab Team Meetings"

Hi Sarah,  Ms Christie contacted me about your plans for the summer.  I would be most happy to talk with at your convinience before you come this summer.  Your time is no doubt more restricted than mine ,so when you have some free time  call me

Cell  
Home  