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MODIFICATIONS FOR AN OVERNIGHT CAMP FOR CHILDREN WITH
CHRONIC ILLNESSES

A Capstone Project Presented in Partial Fulfillment
of the Requirements for the Degree Bachelor of Science
with Honors College Graduate Distinction at
Western Kentucky University

By

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November 2019

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MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

I dedicate this thesis to the strong, brave, and courageous kids who are fighting unimaginable battles and to their families. Their joy is contagious, and their love of life is inspiring. I hope this thesis is able to raise awareness for these diseases and allow others to feel as inspired as I do.

ACKNOWLEDGEMENTS

I would like to acknowledge my project advisor, Dr. Sturgeon, for her constant support and guidance throughout this process. I could not have successfully completed this thesis without her. I would also like to acknowledge Dr. Garrett-Wright, my second reader. Her connections with staff from the Center for Courageous Kids (CCK) made the research and partnership for this thesis possible. I would like to acknowledge the staff and volunteers at CCK. Without their hard work, CCK would not be possible. Finally, I would like to acknowledge the WKU School of Nursing faculty and staff. Their passion for nursing and encouragement to student nurses is unmatched.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

ABSTRACT

An overnight camp is something that almost every child looks forward to attending. Unfortunately, children with chronic illnesses are often not able to attend these types of camps. However, medical camps that institute modifications can make overnight camp stays a reality for children with chronic illnesses. The purpose of this study was to explore modifications made for children with chronic illnesses at a medical camp. The two research questions for this study were: 1) what modifications do overnight camps make for children with chronic illnesses to keep them safe and promote fun, and 2) how can these modifications be applied to nursing practice? To answer these questions, a phenomenological study was conducted, and data was collected by direct observation and semi-structured interviews of parents or guardians and CCK staff members. While physical modifications were very important, the ones that made the most impact on the family and the children were the emotional ones. Based on these findings, it is important for nursing staff to encourage independence and family interaction when treating and caring for this population. Also, although nurses should help children feel “normal,” they should also let them know that their differences make them strong. Finally, a nurse should try to implement modifications that empower the child or family.

Keywords: *children, chronic illnesses, camp*

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

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MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

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MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

CONTENTS

Acknowledgements.....	iv
Abstract.....	v
Vita.....	vi
Introduction.....	1
Literature Review.....	2
Methodology.....	3
Findings	8
Discussion.....	18
References.....	23
Appendix: Important Documents	25

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

Modifications for an Overnight Camp for Students with Chronic Illnesses

Introduction

One can clearly see that medicine is making major advancements in the care of children with life threatening illnesses. At first glance, this appears to be fantastic: children with illnesses that were once deemed incurable are able to either be cured or lead full lives while managing their illness. In a study on disease-specific summer camps, the authors note, “advances in medical care over the past 25 years have improved life-expectancy and quality of life for children with chronic and/or life- threatening illnesses” (Meltzer et al., 2018, p. 272). However, does this improvement in quality of life and improvement in life-expectancy allow for children to be able to participate in common childhood activities like an overnight camp?

Many children across the United States suffer from either a cognitive or physical chronic illness. Chronic illnesses are defined by the Center for Disease Control (CDC) as “conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both” (2018, para. 1). In an article about coping with chronic illness it was noted that “as many as 1 out of 4 children in the United States suffer from a chronic health problem.” (Compas, Jaser, Dunn, & Rodriguez, 2012, p. 457). According to the U.S. Census Bureau, in 2018, there were almost 61 million people aged 17 or younger. With this data in mind, this could translate to as many as 15.25 million children are dealing with chronic illnesses. This is a staggering number of children which supports the need for research on how children deal with chronic illness.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

Despite having a chronic illness, all children deserve the opportunity to feel normal, have fun, and be taken care of in a safe environment. One of the best ways for children to experience this is by having the opportunity to attend an overnight camp. However, “activities enjoyed by healthy children, such as overnight summer camp, may be limited due to required medical care and other potential accommodations (e.g., wheelchair accessible, modified diet for food allergy)” (Meltzer et al., 2018, p. 272). Because of the prevalence of children with chronic illnesses, awareness is heightened about camps designed specifically for them. Due to this fact, this research paper focuses on what modifications overnight camps, specifically family weekend camps, make for children with chronic illnesses. The results will be used to establish tangible practices nurses can implement to improve care for children with chronic illnesses.

Literature Review

The current literature on this topic is minimal, and no research studies regarding specific modifications made by medical camps were located. A few studies were found that addressed how camp impacted children with chronic illnesses either psychosocially or as a form of respite for families. A study by Faith, Mayes, Pratt and Carter (2018) evaluated “changes in hope, attitude toward illness, and perceptions of illness benefit and burden following participation in a summer camp designed for youth with a variety of chronic illnesses”. The researchers found that no changes were noted in perceptions.

Conversely, a systematic review conducted by Moola, Faulkner, White and Kirsh (2014) sought to determine how camp impacted children psychologically and socially. These authors found that there was a high level of satisfaction with medical camp

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

experiences. The authors also reported that there was little evidence in their data to indicate a sustained impact.

It was noted that many of these research studies focus on the families of children of chronic illnesses and how camps – whether summer, weekend, or overnight – provide respite care for the families. Respite care is the temporary relief from the usual demands of caregiving. Meltzer & Johnson (2004) found that summer camps did provide respite care for mothers. However, this relief, which was mostly psychological, did not last long after camp was over due to the fact that caregiving demands did not lessen once the child returned home. One topic of interest that all literature in this field of study struggles to determine is whether or not these perceptions, psychological impacts, or social impacts can last past the time period the child is actually attending camp. There is a gap in the literature regarding specific modifications overnight camps make to allow for a beneficial and successful camp experience for children with chronic illnesses.

Methodology

Research design

This research is a phenomenological study that seeks to understand how the lived experience of children and their families at camp are related to the modifications that CCK makes to accommodate them. This research was approved by the Western Kentucky University Institutional Review Board by full board review on March 27, 2019. Data was acquired by direct observation and semi-structured interviews of parents or guardians and staff.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

Information for the literature review was obtained by searching the following databases: CINAHL, PubMed, and Academic Search Complete. Only peer-reviewed studies were accepted with the majority of the studies being published after 2014.

Keywords used to search were *children, chronic illnesses, and camp*. The PICO question (Population, Intervention, Comparison, Outcome) for this study is as follows:

P - Children with chronic illnesses attending overnight camp

I – Specialized modifications

C – No specialized modifications

O – Increased safety and well-being of child and family

Participants

Interview participants were chosen by purposive sampling. They consisted of the parents, specifically the mothers, of the child(ren) with a chronic illness that I was assigned to work with during physical disabilities weekend or Angelman Syndrome weekend at CCK. Additional interviews were conducted with two staff members whose positions were applicable to this research, as well as whose experience working with chronically ill children made them reliable sources. Direct observation was conducted of a child who attended either Physical Disabilities or Angelman Syndrome weekend. These children were members of the family I was assigned to for the weekend camp.

All interview participants signed informed consent stating their understanding of the nature of this research, as well as any risks or benefits that may be associated with it. Children who were being observed signed an informed assent, either by signing themselves, circling a smiley or sad face (to represent a yes or no), or allowing a parent to

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

sign on their behalf and a witness signing after them. Sample consent documents are attached at the end of this document.

Setting

The Center for Courageous Kids was established in 2004 in Scottsville, KY as a not-for profit Medical Camping Facility by Ms. Betty Turner Campbell. It received its first family campers in February of 2008. Ms. Campbell lost her 17-year-old son to cancer which inspired her to establish “a place where children living with life threatening illnesses and their families could come free of charge and have fun, find respite, feel normal and forget about their everyday struggles” (Center for Courageous Kids, n.d.).

CCK has several family weekend camps throughout the fall and spring, as well as week-long camps just for the children with chronic illnesses during the summer. In addition some summer camp weeks also include the participation of siblings or entire families. For this study, I chose Physical Disabilities weekend (March 29-31, 2019) and Angelman Syndrome weekend (April 5-7, 2019) to observe children with both physical and cognitive disabilities.

On a Family Weekend, families arrive around 5:00 pm on Friday, attend orientation, and enjoy dinner. An evening carnival is available after dinner. Saturday is full of activities with families choosing from three activity rotations. Some of these activities include horseback riding, bowling, swimming, fishing, and arts and crafts. Campers can also choose a movie night or a swim night after dinner. Finally, on Sunday, families have one more opportunity to experience an activity before closing ceremony.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

Procedure

After being assigned a family for the weekend, I found the family during orientation on the Friday of their family weekend, introduced myself, explained the research study, and asked if it would be ok to observe their child during the weekend. I also asked the child if it would be alright to observe him or her, or the family asked the child on my behalf. After introducing the study, I had the parent or guardian sign an informed consent for an interview. The child then either signed an informed assent or the parent or guardian signed on their behalf and a witness provided his or her signature as well. During the weekend, I only observed the child I was assigned to and the specific modifications used in the child's situation.

I conducted recorded phone interviews with a parent or guardian of the child with a chronic illness with my thesis advisor present in the room at least one week after camp but no more than one month afterwards. The parent or guardian had previously initialed on the informed consent form that he or she was giving permission to be audio-recorded during this follow-up interview. Upon making formal greetings and introductions, I then asked a series of questions and allowed the parent or guardian to answer honestly. The questions are worded with student instead of child based on the recommendation of the IRB as follows:

1. How old is your student? What is your student's diagnosis? What is your student's gender? How many years has your student had this condition?
2. What are the most challenging aspects about caring for your student?

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

3. What were the benefits of the camp experience for your student and your family?
4. Was there any education about your student's condition provided by the camp? Was this information helpful?

After these questions were answered, I asked a clarifying question or another relevant question if I or my advisor deemed it necessary to gather additional information. This allowed the parent or guardian to make comments or ask questions. The total number of parents or guardians I interviewed were two (n=2) and the total number of children I observed were two (n=2).

In order to choose appropriate staff to interview, I examined various staff members' job titles and years of experience and selected two that I thought would provide the best information (n=2). I obtained informed consent for an interview and conducted one in-person and one phone interview which were audio recorded. Audio recording was used for transcription only. The questions asked were as follows:

1. How long have you been working at CCK? What are some of your job duties? Did you volunteer at CCK before you got a paid position here?
2. What are the most challenging aspects about caring for the students at camp?
3. What have you noticed about camp that benefits families most?
4. Do you provide any education about the students' conditions to the parents/guardians? Do you feel like this is helpful?

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

Data analysis

After interviews were completed and transcribed, information was categorized into relevant topics. For the staff interviews, information was divided into five overarching topics: a) information that supported the staff member's expertise, b) what the staff member found most challenging about caring for this population, c) what benefits he or she felt camp provided, d) whether or not education was provided, and e) any other comments or important information not covered by the other questions. In regard to the parent or guardian interviews, information was categorized into six topics: a) background on the child's condition, b) what are the most challenging aspects of caring for their child, c) benefits of camp for their family and child, d) whether or not education was provided and if they felt it would be or was beneficial, e) modifications they noticed CCK made throughout the weekend, and e) other comments or relevant information not contained to the above questions. Direct observations made were also added to the information provided by staff and parents or guardians.

Findings

Parent or Guardian Interviews

Physical Disabilities Weekend.

The child with a chronic illness assigned during Physical Disabilities weekend was a 10-year-old female with a genetic mutation of the KAT6A gene. She had only been officially diagnosed with this mutation for about one year. Before that time, according to her mother, she was diagnosed with "developmental delay, autism, and cerebral palsy,

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

and of course all those led into 30 or 40 different types of disorders.” This chronic illness caused the child to have both physical and cognitive disabilities.

According to the KAT6A Foundation, the KAT6A gene makes KAT6A proteins. These proteins are responsible for the creation of other proteins. This means that when there is a problem with this gene, various other genes will be affected, and problems can occur throughout the entire body. (n.d., para. 1) In addition, only about 200 people have been diagnosed throughout the entire world in 2019. (n.d., para. 2) Finally, “common traits are: developmental delay, intellectual disability, feeding difficulties, constipation, acid reflux, significant speech and language deficits, vision problems and hypotonia. Less common traits include: heart defects, seizure disorders, frequent infections, sleep disturbances, abnormal muscle tone, autism, sensory issues, skull abnormalities and distinct facial features.” (n.d., para. 3) The mother stated the most challenging aspects of caring for this child were related to her behaviors. The mother reported “she is severely self-harming, aggressive to others, screams constantly, pinching, bites, kicks, pulls hair.” This made it difficult for her parents to go into public because of the stress it would cause their child and themselves.

For this family in particular, the mother felt like there were really no benefits for their family attending camp other than the fact that the child’s sibling got to have a fun weekend. This child was so severely cognitively and physically impaired that “she doesn’t understand the simple tasks of what she’s participating in, nor does she care to participate.”

The mother discussed that she understands CCK provides modifications for various illness but that it was not beneficial in her personal situation for her child to

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

attend an overnight camp. She mentioned, “Don’t get me wrong, I think the program is absolutely phenomenal for children that can benefit from it – I mean it’s huge for them – [child] just cannot benefit...” The mother then commented that the assistive devices used to get children on the horses were great, but that her child has equilibrium issues, so she constantly feels like she’s falling. She did state that she thought her child enjoyed the pool because, “she likes the water.”

The mother reported that disease specific education was not provided but she did not feel it would have been beneficial anyway. She felt she was well educated on her child’s condition. She stated “there’s not any education. They don’t really even know what happens.” In addition, the mother reported this child is “the only one at this time that has the mutation in the gene where the gene is located at and has the severity that she has.”

The mother emphasized that at CCK “they do phenomenal things and I think most families and most kids truly – this is an experience for them that they... look forward to. But in our specific situation, we really have no benefit.”

Angelman Syndrome Weekend.

The participant for Angelman Syndrome weekend was an 8-year-old male that was diagnosed with Angelman Syndrome deletion positive of the 15th chromosome. He was diagnosed officially in June of 2012. Angelman Syndrome is a neurogenetic disorder that is similar in symptoms to cerebral palsy, autism, and Prader-Willi Syndrome. Due to this commonality, these children often suffer from misdiagnosis (Angelman Syndrome Foundation, n.d., para. 1-2). The common symptoms of Angelman are developmental delays, a happy demeanor, seizures, lack of speech, delayed motor skills, and little to no

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

fear (Angelman Syndrome Foundation, n.d., para. 1-2). The number of people affected by this disease is estimated to be 1 in 12,000 to 20,000 (Genetics Home Reference, 2019).

When discussing challenging aspects of caring for this child with his mother, she said “the biggest part is finding a communication system that he likes and is willing to work with to help him with all of his needs – the biggest thing is communication.” She mentioned that it would be extremely helpful if CCK provided communication boards for families that need them, along with pictures of their counselor so they could be looking for them and getting to know them. The mother talked about how having a child with Angelmans is also difficult for the parent emotionally. She said, “it is challenging to see other 8-year-olds be able to interact with their family members and peers, and also just being able to do little things like ride a bike... and having a child not be able to ride a bike is kind of hard too.”

For this family, one of the major benefits of camp was having a counselor or volunteer with them throughout the weekend. She went on to mention that having another person available to help care for her other children allowed her to not have to tell her children "no." She explained that many times, she has had to tell the child's siblings that they can not do something because the child with Angelman Syndrome is “having a meltdown” or something of that nature. Along with this, she said that some of her children were comfortable enough with her counselor to call her “big sister.” She said “they just don't normally get to connect with different people.” Her children being able to develop a close connection with someone outside their family “meant more than anything”.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

She also stated that “everything was accessible” for her child. While they were at the weekend camp, the child used the bathroom by himself for the first time. She did not know whether this was because he was “in a happy place” or because “he was getting all his needs met” to the point where he felt like he could be independent. Along with promoting independence, the mother said one of her favorite pictures from the weekend was her child doing archery because “he has the proudest little face! He’s like, ‘look what I’m doing!’ ... It was just great seeing him be him.”

When asked about what specifically she felt CCK did to benefit her and her family, she discussed how it was the “little things” that impacted her the most. For example, CCK provides wagons for families to use throughout the weekend to transport them across camp. This helped her “round everybody up” and keep the family together. She also discussed how having medical staff on property at all times was very helpful because she never had to worry about being able to get medical attention if something happened during camp.

This parent commented she was able to develop a sense of community with other parents, knowing that her children were in a safe environment with trained staff. She stated, “I knew they were going to be safe and I could actually interact with other adults and parents that are going through the same stuff we’re going through.”

This weekend was unique in the fact that it was sponsored by the Angelman Syndrome Foundation (ASF). While they did not provide any education during the weekend, there is information available for families who have children with Angelman Syndrome. This family had a hard time getting information from their physician after getting the diagnosis, but the ASF was able to provide them with information explaining

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

their child's situation. In addition to basic information for families, "now they tell you what kind of therapies you can do - what gene therapies and things are happening in the science community. So they do have a lot of resources." One suggestion this parent made in regard to education at CCK was that it would be useful to have a roundtable discussion or small seminar where parents could discuss their child's situation with other parents, as well as learn more about what's going on in the science community regarding Angelman Syndrome.

Finally, when asked if she had any comments, she stated, "...raising awareness is the biggest part about having a kid with special needs, because if nobody knows about it, they can't help out or learn or understand what you're going through."

Staff Interviews

Staff Member #1.

Staff member # 1 has volunteered at CCK since it opened and has been on full-time staff since 2017. She also believes in what camp does for a child. She said, "Everyone needs to come to camp. Period. That's it. Every child deserves a camp experience. I'm very passionate about that." All of her expertise combined with her passion for allowing children to have a camp experience makes her an excellent source for this research.

When discussing what is most challenging about caring for this population of children, the two aspects she mentioned were dealing with behavioral problems and unforeseen medical emergencies. The behavioral problems were difficult because it was difficult to determine the line between allowing parents to govern their child's behavior but also needing to maintain safety. While unforeseen medical emergencies are always

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

difficult, they could be especially challenging at camp. One type of specific event discussed was aspiration. She stated, “when you serve this population of campers, you just have to be ready to respond to any eventual thing like that.”

There were two aspects of camp this staff member found most beneficial to campers and their families. These benefits are making connections and networking. She says, “I think it’s a very special moment at camp when a camper with a rare diagnosis makes a friend who also has a similar challenge because that really normalizes the experience they’re having.” Along with that, “parents get to network and come up with plans to troubleshoot some of the challenges their kid is experiencing”.

Finally, the staff member discussed how CCK does not have many education sessions. However, this is something that she would love to build on and create more of in the future. She added there needs to be a balance between having fun and being medically helpful.

Staff Member #2

The second staff member (#2) interviewed began working for CCK in 2006. Because this was before family weekend and summers camps opened, his main role was related to programming. This staff member has helped start three different types of camps and is a reliable source for information related to this topic.

The aspects of caring for this population he finds the most difficult are twofold. First he says, “there’s a firm reality that we experience. And that’s that sometimes summer camps are the last fun things our kids do, and some of them pass away”. This is difficult because it puts pressure on the staff and volunteers involved in camp to make sure these children get the best experience possible. The other difficult aspect is making

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

sure that these children are cared for medically while at camp. He mentions how “we’re seeing them at their healthiest... it can turn at any second”. Because of the nature of this population, the parents or guardians generally are more protective of their child, so the fact that they trust the staff with their child is huge. In summary he said, “probably the hardest part of it is just making sure we are doing the right things all the time and making sure that we’re honoring the commitment that the parents gave to us because they truly gave us their prized possession.”

In regard to the benefits of camp for the children and their families, he discussed their two camp offerings: summer week-long programs just for the children and weekend family camps. Summer camps, he said, benefited children because “camp is a place where you become the person you’re supposed to when mom and dad are not around.” He further discussed how these children can practice safe socialization and safe risk-taking. As for weekend family camps, the biggest benefits he has seen have been that camp allows families to have fun and just be together, have inclusive activities that are free, and that caregivers get to network. On the subject of being able to be together, he mentioned that, “they sit together every single meal... they do activities together. They drive here... together.” Many times, these families are so focused on protecting their child that they never get to relax enough to simply be together.

On the topic of education, he discussed an educational session about self-care for children attending summer camps. The staff promotes independence as much as possible and encourages children to learn to take responsibility for their own medical care within their capability. During the family weekend, however, there is very little education. This seems to be due to the fact that weekend camps are designed to be more recreational

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

versus educational. Staff member #2 stated, “I kind of wish we did [more education], but I also say, if I made it optional and the parent was choosing between horseback riding with their kids or being in a workshop, they’re going to pick the horseback riding every time.”

When asked what final comments he had, he strongly emphasized that everyone should volunteer at camp because it benefits the volunteers just as much as it does the campers and their families.

He said, “camp teaches you how to kind of be the best of yourself and help other people do that along the way. I always advocate to anyone who would read this: volunteer for camp... you’ll see that the benefit for the people who serve are every bit as great as the ones the family receive, and I don’t think we communicate that enough.”

Direct Observations

When developing the layout and focus of this project, the initial focus was to look at what physical modifications camp made for children with chronic illnesses and then apply the knowledge gained in developing physical modifications for pediatric nursing practice. While CCK definitely makes physical modifications, the emotional and supportive modifications they encourage seem to make the biggest difference for families. For this section of the paper, physical modifications observed will be discussed first followed by the other emotional and/or supportive modifications.

CCK is a state-of-the-art camp facility with many recreational activities. Some of the most popular activities include horseback riding, swimming, and bowling. CCK makes modifications in these activities so all children can participate. In the horse barn,

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

there is a handicap accessible loading area that is almost even with the horses' backs. This allows for easier transfer of children to and from the horse. They also have a saddle with a seat back and arm rests for children who have less physical control of their bodies. The pool has a handicap lift to help get children into and out of their wheelchair as well as a 0 feet entry pool so children can sit or crawl into the water. CCK has a six-lane bowling alley with automatic pin reset machines and ball return. They also have a ramp that children can use to push the ball down the lane instead of rolling it, as well as bowling shoes that fasten with Velcro instead of lace-ups. These modifications promote the child's independence by allowing them to do these activities with little to no assistance.

In addition to these program area modifications, CCK also makes physical modifications for children in basic ways as well. For example, the chairs in the dining room do not have arm rests on them. This helps parents and volunteers transfer children easier. Also, there are few stairs in the camp, and where there are stairs one will always find a ramp that allows for wheelchair access. The bathrooms in the lodging area have fold-down shower chairs for families that can use this accommodation.

These physical modifications helped promote independence, but the modifications camp made that impacted families and children the most were emotional in nature. For example, CCK seeks to promote normalcy in spite of difficult situations. Ultimately, kids just want to be kids. They deserve to be able to have fun in a safe environment, meet other children, and feel like they are not that different from other children. CCK allows all of these psychosocial needs to be met. Staff and volunteers show empathy and understanding to these families and children. Understanding the strain that chronic and

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

life-threatening illness puts on these children and their families is something all volunteers and staff seek to keep in mind. This helps staff and volunteers develop empathy which in turn allows them to make connections with these families. Finally, the goal of having everyone at camp focused on making these children feel included is perhaps the most impactful modification CCK could make. Every human has the desire to feel like they belong to something. CCK allows these children to know that they belong and that they have worth and something to contribute to the world despite their illness or physical condition.

Discussion

Conclusions

The focus of this study was to learn about modifications an overnight camp made for children with chronic illnesses. Based on observation and interviews, the modifications this camp made were twofold: physical and emotional. The physical modifications were apparent throughout camp, but the most impactful ones appeared to be those present in the program areas. For many children, CCK provides the only camp experience they will ever get, making their experience there truly memorable. This is one reason why physical modifications are so important.

In addition to physical modifications, staff and volunteers also provided emotional modifications. These modifications include promoting normalcy, independence and fun. While these modifications are not physically observable, they make a huge impact in the lives of these children. Children have an innate desire to feel normal, so the fact that CCK allows children to feel that way is monumental. Parents or guardians of children seem to appreciate this particular modification as well. Parents are

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

often so concerned about meeting basic physical and medical needs, there is a lack of time to address emotional needs and growth. The opportunity to grow in independent recreational activities and friendship building is a benefit of camp experiences at CCK.

It is important to remember that one cannot take care of a child without also caring for his or her family. If caregivers are not taking care of themselves, they will not adequately be prepared to care for their child. Therefore, when discussing with caregivers what modifications CCK made, they were asked how it impacted their families as a whole. One of the biggest benefits CCK provided to families was community and respite care. Because parents or guardians were provided with an opportunity to not have to worry about their child as much, they were able to relax more, talk to other parents, and actually have fun with their children. This benefits the caregivers because they get to recharge, as well as their children; they get to enjoy a fun weekend with their family. The interviews of staff members as well as direct observations seem to emphasize these conclusions as well.

Limitations

While this study provided new information about what camps are doing to provide for this population of children, it has several limitations. One of these limitations is the limited number of weekend camps observed. Initially, the study design included participation and observation of four family camp weekends. The number of weekends was reduced due to time constraints related to gaining IRB approval for the study.

Another limitation of this study were the illness groups observed. Weekends were selected to provide a specific view of either a predominately physical or cognitive illness. However, throughout these weekends it was noted that diseases are rarely completely

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

physical or cognitive in nature. While this somewhat allows for categorization of information, it makes it difficult to differentiate which modifications make the most difference for each type of disability.

The fact that direct observation is subjective in nature is also a limitation. Due to the nature of this camp, although I was able to volunteer and spend extensive amounts of time with these families, I was limited to observing what they did. Also, many of the modifications CCK makes were “unobservable”. This means the modifications were not visible without speaking with the parents. Also, some of the physical modifications CCK made may have gone unnoticed due to the focus being on promoting the child’s fun versus observing them for this project.

While the weekend camps allowed connections with the families and gaining participants for the study, it was limited to only observing these weekends. CCK provides week-long, disease-specific, individual camps for many of these children. These weeks provide individualized modifications for the special needs associated with the disease. Not having the opportunity to observe this type of camp limits the data collected.

Finally, this study is limited by the location. The information gained is limited in its scope due to data collection occurring at only one camp. There are many other medical camps throughout the United States and each camp may use varying types of modifications.

Future studies could continue to expand on the subject of modifications overnight camps make for this population of children. More information could be gained by comparing a medical camp to a non-medical camp. Sometimes it is easier to determine differences by understanding the likenesses. Many of these differences may be the

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

modifications made for this population of children. Another way of gaining more insight into these modifications could be comparing two or more different medical overnight camps. Finally, observing different lengths of stay provided by overnight camps could yield information about what modifications are necessary for children with chronic illnesses based on the length of the camping experience.

Implications for Practice

Based on these findings, there are several ways one could apply these modifications to practice. First, nurses need to encourage independence and family interactions for chronically ill children. One of the modifications that made the biggest impact was that CCK promoted independence as much as possible. In the clinical setting, nurses can apply this by encouraging children to be in charge of their own health and activities of daily living. In addition, when families are so concerned with taking care of a child medically, they often do not fulfil the child's need for love and play. Therefore, a nurse caring for this population should reassure the parents or guardians that their child is being provided with the best care and encourage them to play and spend time with their child instead of focusing on their medical care.

Another way that these findings could be applied to practice is by promoting normalcy. Maintaining a schedule, encouraging school, and making the child feel normal should be encouraged. However, the nurse should also let these children know that their differences make them strong. One way this could be applied in a hospital setting is by creating a group time for children to interact with one another and perhaps do an activity that was appropriate to the unit. Allowing the children to meet at a certain time and do

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

activities promotes a school-type setting. It also permits children to meet others like them, showing them that they are not alone. Finally, the nurse or other employee that organized this group could emphasize to all of the children that, battling a chronic or life-threatening illness makes them unique and strong.

In conclusion, any modification that can be implemented by the nurse, whether that be physical or emotional, should be incorporated into the plan of care. Children with chronic illnesses are a population with unique needs. One of these needs is to be able to have fun in a way that “normal” children do. The need for fun, love, and belonging can be met by a medical overnight camp and by caring nurses. By observing and learning about the modifications an overnight camps makes for these children, the nurse can likewise implement measures in his or her practice to promote this population’s well-being.

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

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Appendix: Important Documents

Appendix A: Informed Consents and Assents



INFORMED CONSENT DOCUMENT-PARENTS/GUARDIAN

Project Title: Modifications Used in Overnight Camp for Students with Chronic Illnesses
Investigator: Victoria Walker, WKU School of Nursing, 270-871-5387

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have. If you then decide to participate in the project, please sign this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

- 1. Nature and Purpose of the Project:** The purpose of this project is to discover how modifications at a camp designed for chronically ill students promotes independence and improves the student's quality of life. Data collected during the camp will be used to determine if nursing practice should be changed as a result. This study will include observations made during the camper's weekend at the Center for Courageous Kids and a recorded phone interview with the parent/guardian at a later date.
- 2. Explanation of Procedures:** You will receive a call from the investigator within one month after your camp weekend has concluded. The phone interview will include four (4) questions and will take approximately 30-45 minutes of your time. The investigator's faculty sponsor will be present during the conversation and the interview will be audio recorded for transcription at a later date.
- 3. Discomfort and Risks:** This study will present minimal risks to you. The phone interview will take approximately 30-45 minutes of your time and may elicit sad or uncomfortable memories. Direct observation of modifications made during the camp weekend will produce no risks, as the observations would not impede upon the student's time at camp.
- 4. Benefits:** The benefits of this study include 1) learning about chronic illnesses that affect students and their families, 2) observing how a camp for medically fragile students can benefit the family as a whole and 2) discussing ways to improve future nursing practice in these students.
- 5. Confidentiality:** All data, forms, and interview transcriptions will be kept in a password protected file on the faculty sponsor's computer in a locked office. In addition, no identifying information will be linked to the forms, data, and interview transcriptions.

WKU IRB 19-300
Approved: 3/27/2019
End Date: 12/31/2019
Full Board
Original: 3/27/2019

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

6. **Refusal/Withdrawal:** Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

Signature of Participant

Date

Witness

Date

- I agree to the audio recording of the research. **(Initial here)** _____

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Robin Pyles, Human Protections Administrator
TELEPHONE: (270) 745-3360



WKU IRB 19-300
Approved: 3/27/2019
End Date: 12/31/2019
Full Board
Original: 3/27/2019

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES



INFORMED CONSENT DOCUMENT- STAFF

Project Title: Modifications Used in Overnight Camp for Students with Chronic Illnesses
Investigator: Victoria Walker, WKU School of Nursing, 270-871-5387

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have. If you then decide to participate in the project, please sign this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

- 1. Nature and Purpose of the Project:** The purpose of this project is to discover how modifications at a camp designed for chronically ill students promotes independence and improves the student's quality of life. Data collected during the camp will be used to determine if nursing practice should be changed as a result. This study will include observations of staff made during the weekend at the Center for Courageous Kids and a recorded phone interview with the staff at a later date providing time does not allow for the interview during the camp weekend.
- 2. Explanation of Procedures:** You will be asked for an interview if time allows during the camp weekend, otherwise you will receive a call from the investigator within one month after the camp weekend has concluded. The phone interview will include four (4) questions and will take approximately 30-45 minutes of your time. The interview will be audio recorded for transcription at a later date.
- 3. Discomfort and Risks:** This study will present minimal risks to you. The phone or in-person interview will take approximately 30-45 minutes of your time.
- 4. Benefits:** The benefits of this study include 1) learning about chronic illnesses that affect students and their families, 2) observing how a camp for medically fragile students can benefit the family as a whole and 2) discussing ways to improve future nursing practice in these students.
- 5. Confidentiality:** All data, forms, and interview transcriptions will be kept in a password protected file on the faculty sponsor's computer in a locked office. In addition, no identifying information will be linked to the forms, data, and interview transcriptions.

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Approved: 3/27/2019
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MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

6. **Refusal/Withdrawal:** Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

Signature of Participant

Date

Witness

Date

- I agree to the audio recording of the research. *(Initial here)* _____

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Robin Pyles, Human Protections Administrator
TELEPHONE: (270) 745-3360



WKU IRB 19-300
Approved: 3/27/2019
End Date: 12/31/2019
Full Board
Original: 3/27/2019

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES



**INFORMED ASSENT DOCUMENT
FOR RESEARCH INVOLVING MINORS**

I, _____, understand that my parents/guardians have given permission for me to participate in a study concerning modifications for an overnight camp for students with chronic, under the direction of WKU School of Nursing.

My participation in this project is voluntary, and I have been told that I may stop my participation in this study at any time. If I choose not to participate, it will not affect my grade (treatment/care, etc., as appropriate) in any way.

Signature _____ Date _____

If unable to physically sign this assent, this signature by my parent/guardian and witnessed by a Camp staff member constitutes my signature.

Signature of Parent/Guardian _____ Date _____

Signature of Camp Staff _____ Date _____

OR

Placing a mark on the "YES" face constitutes my assent to participate in this study.
(Ask participant to point: smile=yes, frown=no)



WKU IRB 19-300
Approved: 3/27/2019
End Date: 12/31/2019
Full Board
Original: 3/27/2019

MODIFICATIONS FOR CHILDREN WITH CHRONIC ILLNESSES

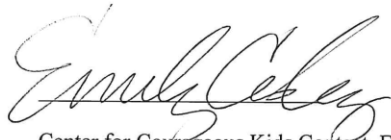
Appendix B: Verification of Partnership with the Center for Courageous Kids

2/27/18

To Whom it May Concern:

I am writing to verify that the Center for Courageous Kids and I, Victoria Walker, have met in person and discussed aspects of this project. They are willing to let me ask for parent's permission to use observational data from the weekends I will be volunteering and are willing for me to approach parents about my project as long as it does not interfere with the children's weekend.

By signing below, this organization acknowledges that they understand my project and are willing to partner with me. My signature constitutes understanding of this agreement.



Center for Courageous Kids Contact, Emily Cosby

2/28/19

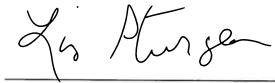
Date



Victoria Walker, Primary Researcher

2/28/19

Date



Liz Sturgeon, Project Advisor

Text

Date