

THE RELATIONSHIP BETWEEN ATTENDANCE AT  
MUSCULAR DYSTROPHY ASSOCIATION SUMMER  
CAMP, ATTITUDE TOWARDS ILLNESS  
AND LEVEL OF ANXIETY

By

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## CHAPTER I

### INTRODUCTION

Medical advances in the past century have led to an increased number of people surviving for a longer period of time with chronic illnesses, including those manifested in childhood or adolescence. Even with this increase in numbers of those living with chronic illnesses, research related to their psychological adjustment has been limited. In fact, studies that examine the behavioral and psychological effects of chronic illnesses or disabilities on children and adolescents are in their budding stages.

There are more people now who live with a long-term chronic illness than ever before. Prior to the 20<sup>th</sup> century, such illnesses were often acute and frequently fatal. However, in contemporary society, over 110 million people have one or more chronic health conditions (Royer, 1998). Mattson developed a widely accepted definition of chronic illness: a prolonged illness that could be progressive and fatal, or that could instead compromise physical or mental functioning without necessarily shortening lifespan (Mattson, 1972).

While there are limited studies of the psychological effects of chronic illness, generally these studies indicate that people with chronic illnesses may be more at risk for negative psychological effects than people without chronic illness. Both the negative psychological effects and regular coping with the disability impact the family as well as the individual. The type of chronic illness is important to facilitate the development of both reliable and valid studies. Neuromuscular diseases, one category of



chronic illness that affects 1 in every 1,000 people (Ringel, 1987), can dramatically impact affected children and adolescents and their families, as coping with the illness moves them away from societal norms. However, the psychological effects a neuromuscular disease may have on individuals and their families have not been thoroughly investigated.

Historical as well as current societal norms provide the anchor point in developing culturally appropriate research designs for looking at the impact of chronic health issues on children and adolescents. Researchers can gain breadth of knowledge in understanding disabilities and the challenges those who have them face in everyday life more clearly when societal norms are considered.

The family's influence on the child or adolescent with chronic illness must be examined. Family systems theory suggests that every person with whom a child interacts will have some impact on the child (Seligman & Darling, 1997). Because of the extensive extra care a child with a disability needs, and because much of that extra care is provided by the family, the home environment influences the child's ability to adapt to his or her illness. Insight into the family and its perceptions of the child's disability fosters better understanding of the impact the disability has on the child.

Children with a chronic illness may benefit from help with the psychological effects of their illness, so that they can learn to function appropriately with the illness as they transition to adulthood. Children are still developing appropriate coping mechanisms to handle environmental changes, and it is important to help them to learn to cope with their disease. One way this has been done is through programs specifically designed to help individuals learn more about themselves and their disability. Summer

camp programs have been started that focus on personal growth and development for children and adolescents with chronic illness. Here the psychological and behavioral responses of those children with neuromuscular disabilities who attend such a camp will be explored.

### Statement of the Problem

The empirical literature is scant concerning the impact of summer camp programs for children with chronic illnesses and disabilities (Briery & Rabian, 1999; Silvers et al, 1992; Thomas & Gaslin, 2001). Some recent literature has indicated that children with various chronic illnesses who attend summer camps are able to adjust and cope with their disabilities at higher levels than before attending camp (Briery & Rabian, 1999; Preston, 2000; Singh, Kable, Guerrero, Sullivan, & Elsas, 2000), but no study has been conducted examining the influence of summer camp on children with a neuromuscular disease. Nor has the literature examined factors associated with the camp that may be related to coping skills and attitude toward illness. This study is designed to examine the relationship that attendance at a weeklong summer camp has with attitude toward the illness and level of anxiety in children and adolescents with neuromuscular diseases. Specifically, the study will look at the impact that camp attendance has on a child's attitude toward illness, and the level of anxiety the child reports.

### Significance of the Study

Children and adolescents with chronic illness have physical needs above and beyond those of children without a chronic illness, and they may also have increased emotional needs caused by the illness. It is important for these children and adolescents to learn adaptive coping skills and strategies. By providing an environment, such as a

summer camp, methods for coping can be taught and practiced. These children can then return to their routine environment and use the skills and confidence gained at camp to help them in school, home, and work. The experience of summer camp can help these children and adolescents recognize what they are able to accomplish in spite of their illness. They can also gain a deeper understanding of what their illness means for them, and more importantly, they learn that they are not alone and that they can accomplish any task they set their minds to complete within the realistic parameters they come to understand.

This study will examine the relationships among camp attendance, attitudes toward the illness, and anxiety in children and adolescents. Summer camps are a cost-effective means of training children to learn about and gain a healthy attitude towards their illness. This study will specifically examine the relationship of attending a summer camp with attitude toward illness and level of anxiety.

### Hypotheses

1. Attendance at a muscular dystrophy camp will be positively related to the child's attitude towards his or her illness.
2. Attendance of a child at a muscular dystrophy camp will be negatively related to anxiety.
3. There will be a positive correlation between the number of goals that a child completes while at camp, and his or her attitude toward their disability.
4. There will be a negative correlation between the number of goals that a child completes while at camp, and his or her level of anxiety.

5. There will be a positive correlation between the amount of positive social behavior towards others given at camp, and his or her attitude toward their disability.
6. There will be a negative correlation between the amount of positive social behavior towards others given at camp, and his or her level of anxiety.
7. The more severe the level of disability the higher the impact the illness will have on the family.

## CHAPTER II

### REVIEW OF LITERATURE

In 1972, Mattsson developed a still widely accepted definition of chronic illness: “A disorder with a [prolonged] course that can be progressive and fatal, or associated with a relatively normal life span despite impaired physical or mental functioning” (p. 801).

Medical advances over the past century have led to prolonged life span and improved quality of life in children with chronic illness. This has led to an increased prevalence of chronic illness within the general population. When the more than 40 types of neuromuscular diseases incidence rates are calculated, the total rates comes out to approximately 1 case per 1,000 individuals (Ringel, 1987). As a result of the increase in survival rate of these diseases, the attention of researchers has begun to shift from prolonging life expectancy toward helping the child and the family to adapt chronic illness over an extended time (Thompson, 1996). Societal acceptance of a disability can also influence a child’s ability to adapt to a chronic illness.

#### *Society and Disabilities*

Societal norms influence the adjustment of an individual who has a disability. Some have called for a shift to return to “communal norms” (Parmentre, 1999). This is a societal belief that all people should receive equal resources from the society regardless of the person’s disabilities or handicap.

According to Taber's Cyclopedic Medical Dictionary a *disability* is any restriction or lack of ability to perform an activity in the manner considered normal for a human being (Thomas, 1993). A *handicap* is considered a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, and social and cultural factors for that individual (Thomas, 1993). Some could argue that these definitions are so similar that they should be considered interchangeable, but there is a distinct difference between the two definitions that is often overlooked. A person has a disability, but societal barriers result in a handicap for the person with a disability. For example, a student can be labeled to have a disability such as Duchenne Muscular Dystrophy. Another student uses a wheelchair and cannot get into school because no ramp has been built to give him access to the school. This reflects a handicap because society has not allowed the student to engage in the "normal" role of a student entering the building.

An important question then becomes, what is normal? It is generally agreed upon that normality is shaped by the society composed of location and era (Thurman & Fiorelli, 1979). What is a normal custom of drinking fresh blood of a cow with milk for some tribes of Africa would not be considered normal in America. On the other hand, it may not be normal for a tribe member to get up and get ready for work by dressing in a suit and tie. Historical time period must also be taken into account because what was not accepted 100 or even 10 years ago may now be considered acceptable. The 1950's *I love Lucy* television show pictured the bedroom with two twin beds, and the *I Dream of Jeannie* show would not show the actresses' belly button in fear of upsetting the viewing audience. Now many television shows and commercials portray sexually themed

messages. The concept of normality thus guides us to further examine how those that fit into the normal society attain rules to guide the community.

The concept of the social norm is somewhat difficult to define. Some researchers argue that norms have been created to offer “protection and enhancement of self-esteem” (Gibbins & Walker, 1996, p. 626), while others define norms as having two components that include prescription and parameters (Vaughn, 2000). The prescription of a given norm gives the actor involved a description of what the person should do or not do. For example, a common norm is to tell the truth. The parameters of a norm may vary based on situational application. Alternations from the norm may occur. For example, society may say that a person should be truthful unless his or her life or others lives would be in danger from telling the truth. Other theorists believe that a norm should be defined as simply “informal rules that structure behavior in a ways that allow individuals to gain the benefits of collective action” (Ensminger & Knight, 1997, p. 3). It is generally agreed upon that norms can inclusively be defined as “collective expectations for the proper behavior of actors within a given identity” (Corsaro & Eder, 1995, p. 428).

### *Social Norms and Law*

Blending of social norms and the legal law has not been an easy task for theorists, legislators, or even the common individual performer. Some suggest that social norms include sanctioned rules provided by the government (Kandori, 1992). Others feel that depending on the situation, legal rules and norms may be completely independent of each other (Coffee, 2001). A leader of a community may have privileges afforded to him or her that the common member of the community does not have. There may not be any law that governs the leader getting extra privileges, but these benefits are socially

accepted. Many argue that legal rules and social norms have no clear distinction between where one ends and the other begins. Still others may assert that the norms and legal laws are intertwined and cannot be separated from each other (Coffee, 2001). McAdams (1997) noted that norms and law together sometimes influence behavior, at times norms control behavior to the point of excluding the law, and on occasion social norms and laws have the ability to influence each other. Though no definite integration of social norms with legal law has been established, it is generally accepted in the literature that social norms and laws interact with each other at different levels depending upon the situation, and that both social norms and laws serve to form social order (Etzioni, 2000).

Sometimes choices are made by members of society to break laws and follow the social norm. In these cases the government may have to look at the social norm and shared beliefs of the members of the community to make a decision on whether the breaking of the law was justified by the situation (Verkuyten, 1994). Research has suggested that there are times when it is considered socially acceptable to break set laws (Corsaro & Eder, 1995). For instance, killing someone is considered murder, but if there is evidence of self-defense society may change the punishment of the person. Therefore the circumstances of the individual are taken into account by society.

Some may follow laws, but not always follow social norms. Those who do not adhere to societal norms typically have one of two reasons for lack of compliance. First, they may have a lack of knowledge or awareness of the norm. Secondly, the norm may not match the personal beliefs of the individual and therefore the person rejects them. Either reason for not following a societal norm could lead the individual to be viewed by other members of society as abnormal. A person who deviates from given norms of a



society may be labeled deviant (Thurman & Fiorelli, 1979). Deviance within a society may include those who purposely break the norm, but it may also contain those unable to follow the norm. The latter form of deviance could include an individual with a disability.

To better understand the relationships between disabilities, handicaps, and norms imagine a reversed society in an isolated community. Suppose that in this community all people are blind. The community therefore has been built to accommodate for blindness. All writing is in Braille. Sound signals are given for regulation of transportation, and lighting is not needed and therefore not used in any of the homes, offices, or schools. If individuals who are sighted were introduced into this society they might have a difficult time adjusting to the new culture. They may not know how to read Braille, know the right sounds to listen for when traveling from one location to the next, or they may not even be able to function without proper lighting. Therefore the people with sight now have a handicap as a result of contextual variables. They are deviant from the norm. By better understanding what norms are and how they relate to disabilities and handicaps it is easier to understand the friction that can occur within a society trying to follow set norms while dealing appropriately with variations from those norms

It may be that those who are not able to adhere to and fit into the established norms of society have a crisis in which they must change or the society to which they belong must change. What appears at face value to be the easiest solution would be to have them conform to the norms of the society. If a person became part of a society who had cultural beliefs that shoes should be removed from the feet before entering the house it would be easy to show the person how to conform to the society's norm. However, not

all deviances within a society can be fixed by having the deviant members conform. Sometimes the society must change current norms to fit the deviant members into the society. Just as a newborn baby would not be expected to sit quietly at the table and wait for dinner to be served, a student who is deaf should not be expected to be taught a lecture in the same manner as other students. It is therefore important for a society to understand those who deviate from societal norms due to disabilities and handicaps (Goggin & Newell, 2000).

Government policies sometimes form through past norms in society, but these policies are often changed to relate to current norms within the society. Parmenter (1999) actively discusses Australian policies toward people with disabilities. The policies dealing with individuals with disabilities originated after the individuals within the society gained awareness of those with disabilities not fitting into the norms of society. It has been commonplace in most Western societies to have the controlling parties try to categorize and group people into categories (Parmenter, 1999). This group tends to leave out the needs of the individual and focus on the needs of the majority groups. Take, for instance, the concept of the civil society's layers of income. The division of income indicates that 30% are wealthy, the middle class comprises 40% of the population, and the bottom of the social class takes up the remaining 30% of the population. Lathem (1998) argued that the lower 30% included those who are chronically ill or disabled. Lathem also argued that this portion of society does not have the ability to advance to a higher income based on limitations set by the norms of the majority.

Nirje (1969) was among the first to indicate a need for social reform to provide services to help those with disabilities. By providing the services a person with

disabilities may be able to better integrate himself or herself within the society. Nirje also suggested that those with disabilities should be able to show their differences and be embraced by the society, that societal norms need modification to include those differences exhibited by those with disabilities. Another main contributor to this reform movement was Wolfensberger (1980). He differed from Nirje's belief in that he felt it was more important for services to be provided for the individuals with disabilities to be able to conform to the societal norms than for the community's norms to enlarge to include the disability of the individual. Thus Wolfensberger (1980) felt that society should group individuals who cannot learn to fit into the norms of society together, although he did warn that too much deviance from any group could be harmful to the social make-up and therefore sub-groups must be formed within the groups to bring cohesion to each disorder's group. In sum, Wolfensberger wanted society to try to provide services for those with disabilities to learn how to fit into the norms set by the society involved, and if they could not conform they should not be placed in that society. On the other hand, Nirje felt that the society involved should provide services for both the person with the disability and the society so that the society could adapt to the needs of the individual with the disability (Storey & Horner, 1991).

With reformation, pressure was placed on governments to deinstitutionalize the mental facilities. Thousands of people who were excluded from mainstream society entered and became active members (Parmenter, 1999). These new members brought unique differences in behavioral, physical, and emotional needs that had to be integrated into the society. Even though each individual should have individual rights and choices, many lacked the knowledge and skills to act in society. Unfortunately many of these

individuals released from institutions were never able to adapt to society. Those who did not fit into the social role expected of them were often shunned, and many ended up homeless, in prison, or back in a mental hospital because they could not conform to the social policies expected of them.

The “independent living” movement began at the University of California. This movement was started by educated members of society who had overcome their disabilities and wanted to help themselves and those like them to overcome the barriers they felt were placed on them by society. The individuals involved were able to use strong social influence as power to lobby to not just change but establish rules and regulations that led to the enactment of the Americans with Disabilities Act (ADA) in 1990. This bill has since been revised, and continues to play an active role in helping to shape the new “rules” on social policies as well as set standards for more concrete changes with building codes, handicapped parking, and the inability for employers to discriminate against hiring those with a disability.

The United States was one of many nations involved in a wide spread change in social policies to reflect the acceptance of those with disabilities to become members of society. The United Nations continued to make policies under human rights that dealt specifically with those having disabilities. Australia and England also joined in the social change with new policies such as the Disability Service Act (1986) and the Handicapped Programs Review in 1985 (Parmenter, 1999).

Parmenter (1999) strongly believes that though these social changes were beneficial to all societies involved, there were central concerns that needed to be addressed. Due to the speed of some of the integration actions taken some clarification of

procedures and desired outcomes were overlooked. With the deinstitutionalization of mental facilities many new people entered society, but were not able to belong as members of the society. The society accepting these new groups were not provided information to help understand them. The Americans with Disabilities Act of 1990 gave strict codes and policies for the society to follow without educating the society on why it was important to follow the policy. This has brought about and still brings about some resistance to conforming for other members of society. By placing community service education meetings and discussion times it would be easier for all members of society to see the importance and benefits of adhering to the new policy.

### *Social Norms and Education*

Of concern for children with disabilities are norms within the schools. Two key federal laws were enacted to help deal with the children that have disabilities. The Rehabilitation Act of 1973 had enclosed in it the powerful Section 504 that no individual should “be excluded from the participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance” due solely to the fact that they have a disability (29 U.S.C. section 794 (a), 1998). All public education schools receive federal funding specifically earmarked to provide assistance for those with disabilities. In 1990 the Individuals with Disabilities Education Act stated that all children ages 3-21 are entitled to a free and appropriate public education (FAPE) that must be made available to them in the Least Restrictive Environment (LRE) (Thomas, 1999). Now public schools could no longer segregate those with disabilities from the rest of the school population. Children receiving special education could be placed in the same classrooms, and integrated into the general education setting. Many societal norms

had to be taught to these children, and the children, teachers, and administrators already in the regular education programs now had to learn about interacting and accepting those with moderate to severe disabilities in the classroom.

Though both laws are important within the school system it is important to understand how these laws relate to each other. All children who are determined eligible for special education services under IDEA are also automatically placed under the protection of section 504, but the reverse is not true. This small but important distinction has profound effects on not only the student with a disability but also on the school system they attend. A student who meets the criteria for an IDEA classification and who is entitled to receive special education services allows the school to receive federal funding for the provision of educational services, but a child that does not qualify for IDEA but is covered under Section 504 may not receive funding. Even though Section 504 enables a school system to receive funding, it remains an unfunded federal mandate. Therefore it is obvious why schools would want a child to be classified under both IDEA and Section 504 (Thomas, 1999).

Under IDEA a child must be diagnosed with a disability pertaining to one of the following categories: visual impairment, deaf-blindness, blindness, mental retardation, speech and language disorders, traumatic brain injury, emotional disturbance, autism, specific learning disabilities, orthopedic impairment, and other health impairments. Once categorized under IDEA a child with a disability will carry that label throughout their school years, and it would be difficult for a child to have the label removed (Jacobs-Timm & Hartshorne, 1998). Labeling children oftentimes brings about a stigma and signifies the child as different. As long as all members of the school community are

made aware of what differences the child may have and why, there may not be any problems with the child adjusting into the social circle. Sometimes other children and even teachers are not informed or told why a student may act in a way that deviates from the accepted norms.

A child with a disability then must not only deal with their unique circumstances, but they also must deal with the handicap the society has placed on them. Some of these handicaps may include an inability to socialize with other members of his or her age, not being given the same opportunity to learn due to pity or fear of their disability, and they may not ever be shown the accepted way to do something because others may not know that they could enable them to fit into the community (Corsaro & Eder, 1995). Members of the community have tried to follow Nirje's beliefs (1969) by expanding the norms, social structures and policies of the community rather than emphasizing the need to change an individual in their lifestyle, actions, or personality (Goggin & Newell, 2000), but more time is needed to see the results of this effort.

Societal norms influence all aspects of a child's life. The child's environment could be impacted by societal norms at school, in the home, and in other areas of the community. It is important for researchers to acknowledge the influence that societal norms have when studying those with disabilities. It would be difficult to control for societal influences with any study. It is therefore important to raise awareness as to the potential influence societal norms can have on any research conducted concerning those with disabilities.

The type of disability can also influence the ability of the child or adolescent to adapt to their illness. The epidemiology of childhood chronic illness varies significantly

from that of adulthood chronic illness. Adults have been found to have relatively fewer types of chronic illnesses than those of children (Thompson, & Gustafson, 1996). One of the effects of this is that health service providers are unfamiliar with knowing how to deal with many of the conditions children experience. Researchers who work with particular populations benefit from having at least a rudimentary understanding of their participant's chronic illness.

### *Neuromuscular Disease*

#### *History*

Muscular dystrophy has been around since ancient civilization, but the first written description of this disorder did not occur until the 19<sup>th</sup> century. Charles Bell, best known for his description of facial nerve paralysis (Bell's palsy), may have described the first case of this disorder in 1830 (Jay & Vajsar, 2001). Others credit Giola and Costa of Naples with the first mention of this disorder concerning the progressive muscle weakness and muscle enlargement of two brothers in 1838 (Jay & Vajar, 2001). Partridge presented the case of a young boy with progressive muscle weakness in 1847, and that same year Little reported on the case of a young boy with a strange gait whose muscle was being replaced by fatty tissue (Jay & Vajsar, 2001)

Edward Meryon is given the credit for originally providing an accurate description of Duchenne muscular dystrophy in 1851 at the Royal Medical and Chirurgical Society. He described this condition as a progressive muscle wasting that begins in early childhood and causes death by late adolescence (Emery, 2002). However, it was not until Guillaume-Benjamin-Amand Duchenne later detailed the clinical and muscle histology in *Paraplegie Hypertrophique de L'enfance de Cause Cerebale*, that the Duchenne muscular dystrophy finally had a name (Emery, 2002). The term dystrophy



comes from the Greek words dys- (abnormal or faulty) and trophe (food or nourishment) (Thomas, 1993).

Muscular dystrophy literally means an abnormal or faulty food or nourishment of the muscle. Since the days of Meyron and Duchenne several more types of muscular dystrophy have been identified and categorized. All of the types of muscular dystrophy can be traced to a core problem, which is a flaw in the muscle protein genes. To date nine types of muscular dystrophy are recognized. The muscular dystrophies all belong to a larger category of myopathies, which literally means pertaining to diseases of the muscle (Thomas, 1993). Other neuromuscular myopathies are often categorized with the muscular dystrophies (Ringel, 1987). In fact, over 40 different types of neuromuscular diseases are recognized under the Muscular Dystrophy Association (Emery, 2002).

#### *Genetics and Neuromuscular Disease*

A genetic disorder is caused by a change in a gene due to a mutation. The genes are contained on chromosomes that are located in every cell in the human body. When there is a mutation in the gene, the chemical that makes up the gene, DNA (deoxyribonucleic acid), is affected. The DNA brings information to the RNA (ribonucleic acid), which in turn processes that information into a protein.

When the gene has a mutation it leads to a defect in the proteins made by that gene. The severity of the effect this mutation has on production of the gene can vary from little change in the protein, to abnormal proteins, or even the absence of the protein being formed at all (Emery, 1994). Proteins are imperative for producing energy for cellular activity which result in a person's ability to perform muscle contractions, digest

food, regulate blood pressure, and perform such rudimentary functions as seeing, hearing, and thinking (Bonsett, 1969).

Genetic disorders can be inherited or spontaneous. Inherited genetic traits are defined as autosomal dominant, autosomal recessive, X-linked recessive, and X-linked dominant. Autosomal dominant conditions require only one mutation to display its trait. In autosomal dominant disorders, the chance of having a child with the disorder is 50 percent. Autosomal recessive conditions require two mutations to present themselves. In autosomal recessive disorders, the chance of having an affected child is 25 percent. However, there is a 50 percent chance that the child will be a carrier of the disorder. This means that the child will carry the genetic mutation, but because they have only one recessive gene mutation they will not usually display the symptoms of the disorder as they have a healthy corresponding gene (Emery, 1987).

X-linked disorders affect females and males differently. Because a male has only one x-chromosome, if they receive a mutated one, then they will have the disorder. If a female receives a mutated x-chromosome then they still have a normal x-chromosome that can usually compensate for the mutated gene. There is a possibility of the female carriers to display symptoms of the disorders, but rarely with the severity which is noted in males. Some geneticists refer to as X-linked dominant disorders as those in which a female is probable to show symptoms, while they refer to the disorders in which there is a low probability of symptomology X-linked recessive. Males have a 50 percent chance of having the disorder if their mother is the carrier, and no chance if the father is the carrier of an X-link disorder. Females have a 50 percent chance of receiving the disorder if their

mother is the carrier, and a 100 percent of receiving the disorder if the father is the carrier of an X-linked disorder (Ringel, 1987).

### *Myotonic Muscular Dystrophy*

Myotonic muscular dystrophy, also known as Steinert's disease, is the most common adult form of muscular dystrophy. The age of onset of this disease can vary from early childhood to adulthood. Myotonic muscular dystrophy results from a genetic flaw on chromosome 19. This disease is characterized by myotonia, which is a condition in which the muscles stiffen or spasm after use. This disease causes muscle weakness, although many people with this condition are not hampered by the physical muscle weakness until several years after the symptoms of the condition first appear. Myotonic muscular dystrophy has also been found to affect the central nervous system, the heart, gastrointestinal tract, cataracts in the eyes, and endocrine gland functioning. A unique characteristic of this condition is that the people with this disease may need a larger amount of sleep than others. Mild mental retardation has been found in some patients with myotonic muscular dystrophy (Emery, 1994). Some researchers have also found emotional and behavioral deficits can accompany this condition (Garstein, Noll, R. B., & Vannatta, 2000).

### *Limb-Girdle Muscular Dystrophy*

Limb-Girdle muscular dystrophy symptomology and diagnosis most often develops in adolescence and early-adulthood, but it can begin in childhood. The weakness and wasting of the voluntary muscles usually begins in the hip or pelvic area and then moves on to include the shoulders. The muscle disease then progresses into the arms and legs. A person with this condition usually progresses from diagnosis to finding

difficulty walking within twenty years. Researchers have found that autosomal limb-girdle muscular dystrophy can be seen as a result of defects on the 2<sup>nd</sup>, 13<sup>th</sup>, 15<sup>th</sup>, and 17<sup>th</sup> genes. An autosomal dominant form of the disease can be seen on the 5<sup>th</sup> gene. To date, 15 genetically different types of Limb-girdle muscular dystrophy have been identified (Emery, 2002). Several of these types show a higher risk of cardiac disease and respiratory functions. Studies have found no correlation between this disease and a decrease in intellectual or academic abilities.

#### *Facioscapulohumeral Muscular Dystrophy*

Facioscapulohumeral muscular dystrophy onset starts in the teenage to early adulthood years. The muscles affected include the facial, scapular, and humeral areas. Common early warning signs of Facioscapulohumeral MD include forward sloping of the shoulders, difficulty raising arms over head, and closing eyes. As the disease progresses, impairment may extend to the foot and limb-girdle areas. Progression of this condition is slow and is different than most of the other dystrophies in that the disease will progress in sporadic spurts and will vary greatly in rate of deterioration of the muscles. No clinical findings indicate mental impairment (Emery, 1994).

#### *Congenital Muscular Dystrophy*

Congenital muscular dystrophy encompasses a group of diseases whose symptoms can be detected from birth. These autosomal recessive inherited disorders present low muscle tone and an overall weakness. Brain abnormalities, and subsequent mental retardation, are associated within this condition, but not always present. Most of these children will eventually learn to stand, but a smaller percentage will actually be able to walk. Cardiac problems usually do not occur, however, the patients have a high

rate of respiratory and feeding difficulties. Usually the progression of any of the congenital muscular dystrophies is slow, but persistent. One type of congenital muscular dystrophy, Fukuyama, occurs in Japan at a rate second only to Duchenne. This same disease is considered rare elsewhere (Korenyi-Both, 1983).

#### *Emery-Dreifuss Muscular Dystrophy*

This disorder is characterized by early contractures of the Achilles tendon, elbows, and posterior cervical muscle. The disease then progresses to include muscle weakness and wasting in the upper limbs and lower limbs. As the disease progresses the limb-girdle muscle will be affected. In the final stage of the disease's development cardiac problems arise around the age of thirty. Emery-Dreifuss is a rare form of muscular dystrophy that occurs almost exclusively in males and the age of onset usually begins in childhood or early teenage years. The genetic defect can occur on the X-chromosome just as Duchenne and Becker MD, but on the X-chromosome that codes for the protein emerin. The autosomal dominant type of this disorder and the autosomal-recessive form of this disorder both are caused by mutations on the LMNA gene (Emery, 2002). In certain types of Emery-Dreifuss muscular dystrophy, serious cardiac manifestations can occur without muscle weakness. Some experts feel that this may actually be the cause of sudden death in some apparently healthy young adults (Emery, 2002).

#### *Distal Muscular Dystrophy*

Distal MD has muscle weakness occur in mainly distal parts of the body that may include muscles of the forearm, hand, lower legs and feet (Korenyi-Both, 1983). This disease can be divided into two groups, late (over the age of forty) and early (under the

age of twenty) onset. Some of the types of distal muscular dystrophy include Welander, Markesbery-Griggs, Nonaka, and Miyoshi. In general the distal muscular dystrophies are considered less severe, and usually progress more slowly than the other dystrophies.

#### *Oculopharyngeal Muscular Dystrophy*

This muscular dystrophy first affects the muscles of the eyelids and throat. This disorder has mainly been studied in Canada, where the disease has been traced back to immigrants from France in 1634 (Emery, 2002). Even though this disease occurs most frequently in Canada, the disorder is still seen in parts of North America and Europe. The age of onset of this disorder usually occurs around the third decade of life, and progresses slowly. The symptom usually seen first is the drooping of the eyelids, and is followed by other eye muscles weakening and then other facial muscles. In later stages of the condition weakness in the pelvic and shoulder muscles may occur. The disease will lead to difficulty with swallowing that can cause problems with choking and frequent occurrences of pneumonia (Emery, 1994).

#### *Duchenne Muscular Dystrophy*

Duchenne muscular dystrophy (DMD) is the most common childhood form of muscular dystrophy. The rate of males born with this condition is 1 in every 3500 births (MDA, 1998). In 1986, MDA-supported researchers identified the gene that caused the disorder. A year later they identified the protein, dystrophin, associated with the gene. Duchenne is generated by a genetic failure to make the protein called dystrophin. In the voluntary muscles, dystrophin is located just under the cell membrane (Emery, 1987). Research suggests that the role of dystrophin is to prevent damage when contraction of muscle fibers occurs. Some researchers have also indicated that dystrophin plays a role

in carrying signals from one area of the fiber to another. Recent findings suggest that dystrophin can be found in voluntary muscles that include the heart, brain, and retina (Muscular Dystrophy Association, 1998).

As an x-linked recessive disorder, the disease occurs almost exclusively in males. In approximately 5-10 % of the time, female carriers have similar symptoms that include muscle weakness, and enlarged-calves (Emery, 2002). These females are called manifested carriers. It is important for female carriers to receive medical assistance because cardiac problems can arise without previous signs of muscle weakness (Muscular Dystrophy Association, 1998). In rare circumstances a female can be born with no working dystrophin on either X chromosome. These females are considered to have full-blown Duchenne (Muscular Dystrophy Association, 1998).

Warning signs that a child might have Duchenne muscular dystrophy may begin to appear between the ages of 2 and 6 years. Children with Duchenne follow a fairly predictable developmental path of learning to walk late, appearing clumsy, and frequent falls. Observers may also notice that these children develop enlarged calves. It appears that these children are abnormally muscular, but in reality the muscles are being turned into fat and connective tissue, called pseudohypertrophy (Bosnett, 1969). Another signature characteristic of boys with Duchenne will be for the child to use the Gowers' maneuver. This technique entails that the child rise from a sitting position by first positioning arms in front of his body. He will then proceed to raise posterior and then walk his hands up his legs to a standing position. By school age, the child may begin to walk on his toes or the balls of his feet. This produces a waddling gait that makes

balancing more difficult. The children will compensate for the gait by sticking out their stomach and putting shoulders back (Emery, 1987).

Diagnosis of any muscular dystrophy usually begins by taking a patient and family history and giving a physical examination. Occasionally electromyography or nerve conduction studies are done to differentiate between problems in the nerves or muscles. A blood sample is often taken in the early stages of diagnosis to see if there is a high level of creatine kinase (CK), an enzyme that leaks out of damaged muscles. A muscle biopsy will also be conducted to specify the disorder. The biopsy will be analyzed to gain information about the presence, abnormality, or absence of certain proteins in the muscle. Sometimes a magnetic resonance scan will be ordered so the physicians can get a visual representation of what is happening inside the weakening muscle (Korenyi-Both, 1983). A DNA diagnostic test may also be conducted to obtain precise genetic information. Today, DNA analysis may be done to detect carriers of the disorder, for family counseling, and for prenatal diagnosis (Bushby, Hill, & Steele, 1999; Jay & Vajsar, 2001).

As the disease progresses it may become necessary to release the contractures that form in the ankle. The tendon release procedure, often referred to as heel cord surgery, is performed when the patient is still ambulatory (around 8 to 10). After this procedure the children will normally need to wear braces such as ankle-foot orthoses (AFO's) or even braces that extend over the knee (KAFO), also known as long leg braces (Muscular Dystrophy Association, 1998). All children with Duchenne will eventually need a wheelchair. Nearly all children with Duchenne lose the ability to walk between the ages of seven and twelve (Emery, 2002).



Those with Duchenne may also have difficulties with spinal curvature. The children may develop curvature of the spine that moves from side to side (scoliosis), the spine might also form a hunchback shape (kyphosis), or the children may develop a curvature that sways outward (lordosis). Eventually, spine-straightening surgery may need to be performed (Emery, 1994). The surgery procedure occurs by inserting metal rods with hooks into the spine. This surgery usually occurs in those with Duchenne around the age of 11 to 13.

Cardiomyopathy usually develops in patients with Dystrophy due to the lack of dystrophin in the heart muscles. The damage done to the heart of those with Duchenne can often become life threatening. Duchenne muscular dystrophy also causes respiratory problems due to the weakening of the diaphragm muscle and other muscles that help to regulate breathing. Children and young adults with this condition often develop pneumonia. This disease does lead to premature death often as a complication of cardiac and/or pulmonary distress. Management of this disorder has improved, but children with Duchenne muscular dystrophy rarely live past the early twenties (Bushby, Hill, & Steele, 1999).

#### *Becker Muscular Dystrophy*

The German doctor, Peter Emil Becker, first described this disorder in the 1950's. Becker muscular dystrophy is similar to that of Duchenne, but the disease usually does not appear until the age of 12 (can occur at the age 2 up to 25 years) and almost always progresses at a slower pace. The symptoms of Becker are similar to that of Duchenne, and in fact it is the same gene affected as well as the same dystrophin protein. It is a male dominated disease with female carriers sometimes showing some of the

genetic symptoms, but rarely actually possessing Becker muscular dystrophy (Ringel, 1987). The main difference between Becker and Duchenne muscular dystrophy, is that with Becker some dystrophin is usually made. The dystrophin that is made is made in smaller amounts than normal or the dystrophin is abnormal. Those found to have Becker muscular dystrophy often live into the forties and fifties. Cardiac problems are similar to those found in Duchenne.

### *Spinal Muscular Atrophy*

Spinal muscular atrophies (SMA) are inherited disorders covered under the Muscular Dystrophy Association that are not classified as a muscular dystrophy. Instead they are classified as a neuromuscular disease. The muscles are affected due to the destruction of the motor nerve cell bodies in the brain stem and spinal chord (Ringel, 1987). Muscles may become partially or completely paralyzed owing to this disease. Ninety percent of the cases within this disease are classified as autosomal recessive, but 10% of the cases can have either X-linked recessive or dominant occurrence (Ringel, 1987). The disease covers a spectrum of severity, and has three levels of severity used for classification.

Infantile SMA, which is also known as Type 1 SMA or Werdnig-Hoffman disease occurs in approximately 1 out of every 20,000 live births. Type 2, Intermediate SMA usually has an onset in early childhood, between the ages of 2-6. Type 3, Juvenile SMA's onset occurs between early childhood and adolescence, usually between the ages of 5-15. Type 1, Infantile SMA, is the most severe form of SMA, followed by Type 2, Intermediate SMA, and Type 3, Juvenile SMA. It is often difficult for physicians to classify the children who have SMA into the appropriate category, and the placement of a

child's disability is most often set by the age of onset of the disease. In Infantile SMA the children rarely are able to survive beyond the ages of one or two, whereas in Type 2 and 3 SMA the person having this disorder has the potential to live well into adulthood (Ringel, 1987). Although rare, there is also potential of developing spinal muscular atrophy in adulthood, known as Type 4 SMA. Some cases of SMA have shown up in adults in their 40's and 50's.

#### *Charot-Marie-Tooth Disease*

Charot-Marie-Tooth (CMT) disease is classified under the Muscular Dystrophy Association as a neuromuscular disease. Two Frenchmen and an Englishman first identified the most common form of this disease in 1886. Jean Martin Charot, Pierre Marie, and Howard Henry Tooth reported almost simultaneously on this disease of the peripheral nerve (MDA, 1998). The disease affects the myelin sheath surrounding the nerves in the body. More recent studies have found that the axon itself can also be defective in this disease (Ringel, 1987). Overall, about one in every 2,500 people has some form of CMT. Key signs of this disorder can be seen by weakness in the lower legs, feet, and hands.

The disorder can be classified as Type 1 CMT or Type 2 CMT. Type 1 CMT affects the myelin sheath surrounding the nerve, and Type 2 CMT affects the axon itself. Approximately two-thirds of the patients with CMT have Type 1 (MDA, 1998). CMT can vary greatly in the severity, even among members of the same family. Some people do not have any symptoms of this disease, while other patients with this condition can have great difficulty performing daily living activities without assistance. Life expectancy is not shortened by CMT (MDA, 1998).

### *Friedreich's Ataxia*

In the 1860's a German neurologist by the name of Nicholas Friedreich published the first description of what is today known as Friedreich's Ataxia (FRDA). This disease is marked by a gradual loss of muscle coordination and progressive muscle deterioration (MDA, 1998). Approximately 5,000 people in the United States currently have the diagnosis of FRDA. It is estimated that 2 out of every 100,000 people are affected by this condition (MDA, 1998). FRDA also has a high comorbidity of almost 10% with diabetes mellitus. People who develop FRDA usually live three to four decades after diagnosis.

### *Neuromuscular Diseases*

All of the diseases mentioned above can be described as some form of a neuromuscular disease under the Muscular Dystrophy Association. Classifying the neuromuscular diseases together helps researchers and other medical professionals see the similarities of each of the diseases.

These neuromuscular diseases can also be classified as a chronic illness. As mentioned previously, it is often difficult to find literature and research discussing specific types of childhood illnesses. Therefore, it is important when reviewing the literature to address what research has been done in all aspects of chronic illness (Thompson & Gustafson, 1996). The remainder of the literature review will focus on what influences children and adolescents ability to adapt to a chronic illness, acknowledging how the family system plays an important role in the child's ability to adapt to their chronic illness.

## Family

The discussion of a family system is not new in the field of sociology, but the field of psychology has only been starting to see this concept develop and gain acceptance in the field in the past few years (Marshak, Seligman, & Prezant, 1999; Seligman & Darling, 1997). Family systems theory lays an important foundation for professionals who work with families who have a member with a chronic disability. Seligman and Darling (1997) believe that the professional movement to include the family systems perspective in the psychological field has occurred for several important reasons. When a professional only looks at the individual with the disability, the other members of the family may be neglected. The other family members may be having a difficult time adjusting to having a disability in the family. By only looking within the child with a disability the professional ignores the dynamic nature of a family. If one member of the family has a problem, this problem may impact all members of the family, including the person with a disability.

Early resistance to adapting the family system theory in the field of psychology can in part be seen as a consequence to the psychoanalytic area (Seligman & Darling, 1997). In psychoanalytic psychology, the focus is on the process of the individual and intrapersonal being. Also, in the psychoanalytic perspective there is a tendency to focus on the mother and her relationship to the child. During the original development of psychoanalytic thought the mother was considered to be the primary caretaker, the father and other members of the family were often overlooked as an influence on the developing child (Seligman & Darling, 1997). Current society has changed the perspective of psychology because of the influence all family members have on a child.

The family system is an integral part of any child's environment. When a child has a disability the amount of time spent surrounded with family members may be even larger than a child without a disability. Chronic illness has considerable consequences to the family system (Kolk, Schipper, Hanewald, Casari, & Fantino 2000). The impact of a disability on the family must be looked at from a multi-faceted point of view. According to Turnbull and Turnbull (1990) the parts that make up the family system include the family, the disability, the individuals within the family, and the relationships between the individuals within the family (as cited in Marshak, Seligman, & Prezant, 1999). Change that affects one family member, will affect all family members. It is important to realize that the onset of a disability for one individual does not happen only to the individual, but also to the other members of the family (Padrone, 1994).

Within the family there are four primary subsystems. The first subsystem is the marital subsystem that includes the husband and wife. The second subsystem, parental, involves the relationship of the parent and child. The third subsystem includes the interaction of child with another child, or the sibling subsystem. The fourth and final subsystem is the extrafamilial, and it includes the extended family, friends, professionals that come into a relationship with the family group (Marshak, Seligman, & Prezant, 1999). Substages are influenced by the structure of the subsystem as well as the current life cycle stage. For example, the marital subsystem may be changed structurally if there is separation, divorce, or death. The current life cycle stage is dependent on whether certain members of the subsystems are school age, still under parental control, or independent. Single parents raising a child with a disability may have fewer supports

available to them than middle-age parents who are part of a nuclear family and have extended family members available to help (Marshak, Seligman, and Prezant, 1999).

Professionals who interact with family members must be careful when suggesting and implementing interventions on particular subsystems (Seligman & Darling, 1997). The professional needs to be mindful of the context of other subsystems in relation to the focus subsystem. By fixing one problem the professional must try not to cause other problems or difficulties to emerge in other subsystems. For example, an intervention that is designed to help relations between the father and child with a disability could create unintentional problems in the relationship of the father with the mother or sibling of the child getting extra attention from the father. A professional working with the family to improve one subsystem would be wise to look at the interaction of the subsystem they are working with in relation to the other subsystems. The professional can also look at the inclusion of other family members in the intervention plan. Professionals may also avoid potential pitfalls in this area by having open communication with all members of the family.

Another part of the family system theory involves the cohesion factor of the family (Seligman & Darling, 1997). Cohesion is described by using the concepts of enmeshment and disengagement (Marshak, Seligman, and Prezant, 1999). Enmeshment, in relation to family system theory, means that the boundaries between the subsystems are weak, and there is a tendency for certain family members to be overprotective and over involved. Families that are over involved between the subsystems have a toxic effect on any family member who wishes to gain a greater degree of independence. Overprotective parents may have a difficult time letting their child with a disability try to

accomplish tasks on his or her own, and this can have ill effects on a child's involvement in growth promoting activities (Seligman & Darling, 1997). The parents may also have a difficult time letting other people outside of the immediate family care for their child for fear that they lose control over the situation.

The disengaged family members, have a tendency to have rigid boundaries set-up between the subsystems (Marshak, Seligman, and Prezant, 1999). The boundaries may be set-up to help the family avoid anxiety. In this family, a child with a disability may feel they are allowed to try to perform independent activities, but they do not necessarily feel that they are supported when trying to accomplish the task. Families that live with certain members showing avoidant behavior will often times avoid the anxieties that stem from involvement until a crisis occurs, and then their anxieties must be addressed, and often times at a higher level than if they had been dealing with the smaller anxieties caused from the personal interactions with family members. Well-functioning families are those families that are able to find a balance between enmeshment and disengagement (Seligman & Darling, 1997). In well functioning families boundaries of subsystems are clearly designed, but the members of the family are able to communicate in a manner that allows all members of the family to have a close bond and still attain an appropriate level of autonomy.

Adaptability is the third component of family system theory (Marshak, Seligman, & Prezant, 1999). Adaptability refers to the family's ability to change in response to a stressful event or situation according to Olson, Sprenkle, & Russell (as cited in Marshak, Seligman, & Prezant, 1999, and Seligman, & Darling, 1997). The family can fall into two categories that can cause difficulties with family functioning. The first type of



family is the rigid family. Rigid families have set roles and do not make changes in response to stressful events. This could lead to difficulty within several subsystems if the family has a child diagnosed with a disability. The father may have the rigid role of breadwinner, and is unable and unwilling to help the mother out with her role of caretaker. When special care needs of a child enter into the family, the mother may become overwhelmed with her additional responsibilities if she is not helped by other members of the family. On the other side of the spectrum is the chaotic family (Seligman & Darling, 1997). In the chaotic family there are continuous changes occurring and instability marks the norm. The chaotic family usually has few rules, and the rules that the family sets are changed frequently. A member of this type of family can move quickly from enmeshment to disengagement, and this can create uncertainty and resentment on members of the family who can set no expectations.

Communication marks the final component of the family system model (Marshak, Seligman, & Prezant, 1999). Communication breakdowns are indications that there is a problem in the family system, and not that there is a problem individual. Since the focus of the family system theory is that of interactions, then the problems of a family stem from the interaction of two people, rather than within an individual person (Seligman & Darling, 1997). Often times it is the lack of communication within and between the subsystems that leads to a dysfunctional family. If the family members can find where the dysfunctional communication is occurring, and address this communication issue, then responsibility for addressing and correcting the problem is shared among all the family members (Seligman & Darling, 1997).

Family functions are the results that come from family interaction (Marshak, Seligman, & Prezant, 1999). Typical family functions include, economic, domestic, recreation, socialization, self-identity, affection, and education (Seligman & Darling, 1997). A child with a disability can place higher demands on the family system to produce increased family functions. For example, a child who is diagnosed with Duchenne muscular dystrophy, may require a family to produce a higher income to cope with increased medical expenses. The mother may need to spend more time helping the child with his hygiene care and daily functioning, and this time may be taken out of time that normally would have been spent with her spouse. The child may not be able to go out on overnight camping trips with the family due to the use of a ventilator, and this may take away from a sibling's growth and development with the family. Each of the areas of family functioning can and will be influenced in some manner by the disability. The ability of the family to interact within and between the subsystems, cohesiveness, adaptability, and communication skills will play into the family's ability to successfully function when a child is diagnosed with a disability.

Understanding the influence the family has on the child or adolescent will help in determining the individuals overall ability to adapt to their disability. The impact the disability has on the family is therefore important to examine. It is also important to look at the individual factors of the child or adolescent with the chronic illness.

### Psychological Issues

Children with a chronic illness can be considered at-risk for developing behavioral and psychological problems (Bradford, 1997; Kazak, Segal-Andrews, and Johnson, 1995). Padrone (1994) indicates that feelings of depression, desperation,

anxiety, confusion, conflict, guilt, and a sense of being overwhelmed are common feelings following the diagnosis, initial treatment, or ongoing progression of a disability. In fact, Padrone indicates a similarity of responses between those that are diagnosed with a disability, and those who have knowledge of impending death as observed by Kubler-Ross (1994). The stages include denial, anger, depression, and adjustment (Kubler-Ross, 1970). Padrone believes that the stages discussed by Kubler-Ross could be the common reaction of individuals to almost any major loss (1994). However, ongoing psychological issues must be addressed and dealt with in a timely manner and over an extended period of time when dealing with chronic and/or escalating symptomology within a disability.

The initial diagnosis of a chronic illness will not only involve a change in lifestyle, but emotional changes must occur as well (Taylor & Aspinwall, 1990). If emotional distress is left untreated, the patients of chronic illness could form barriers that prevent them from engaging in fulfilling life activities. If the quality of life of an individual is affected due to psychological problems dealing with the chronic illness then the individual needs to have treatment available to them to address these problems.

Upon further investigation of the literature it appears that children and adolescents with chronic illness adjust dependent on their unique circumstances (Blumberg, Lewis, & Susman, 1984; Drotar, Crawford, & Bush, 1984). Each person has individual methods of coping and adapting to their current experiences. Adapting and coping must occur when fears and anxieties are produced. Fears are considered the complex reaction to a perceived threat. This differs from anxiety. Anxiety can be defined as less intense, patterns of reactions to stimulus of a more ambiguous nature (Barrios & O'Dell, 1998). Anxieties are often produced with a child who has a chronic illness such as a

neuromuscular disease. The anxieties are developed and maintained through the thought patterns of what might happen. Behaviorally the children's anxieties are reinforced when the child is not able to accomplish a given task with the behavior they are displaying.

Even though each person adapts to change in their environment differently, an increased level of anxiety in children with chronic illness has been documented (Davis & Orto, 1991; Taylor & Aspenwall, 1990; Thompson & Gustafson, 1996). Heightened anxiety has been noted to exacerbate the physical disabilities and reinforce the psychosocial problems (Taylor & Aspenwall, 1990). Anxiety in children with chronic illness can be understood when it is looked at from a behavioral perspective. If the child is given a task to complete, but they are unable to complete this task due to their illness then the child will not receive positive reinforcement for completing the task. The next time they are asked to attempt the same task, anxiety may build based on their previous experience of not completing the task.

A person with a chronic illness will soon learn to avoid performing tasks that produce anxiety. If the same person was placed in an environment where the behaviors executed toward a given task would provide reinforcement the person's level of anxiety should, in theory, decrease. Once the person has mastered the given task in a supportive environment then the person should be able to generalize the behavior to other environments. The level of anxiety should continue to decrease as the person is able to master the tasks in different environments. While there are few empirical studies concerning anxiety levels and chronic illness, the overall picture of coping and adjustment has begun to be addressed.

### Coping and Adjustment

When looking at the challenges children with chronic illness face, it is not surprising that researchers have become more and more interested in looking at the psychological impact of the illness on the child and their family. Pertaining to chronic illness, psychology has tended to focus on the pathological model of psychology (Bradford, 1997). In this model the psychologist wants to find out what is wrong with the person. Once the discovery is made about what is wrong with the person the psychologist can then use different methods to create a solution to the problem. One of the major benefits to this method is the ability to discover the extent of the problem. Once the problem has been successfully mapped out the psychologist can then focus on services to help the subject. One major criticism of this approach is its tendency to focus on the negative aspects of the person, or the deviations from the “normal” population (Bradford, 1997).

By taking a systematic approach to the child’s illness a complex framework can be developed. This framework helps the psychologist to see the impact of the chronic illness on the child, their family, and the other factors that influence the adjustment of the child to their illness (Bradford, 1997). Many models of coping and adjustment have been developed. Lipowski (1970) developed one of the first models of adjustment. In this model coping is used as a mechanism to relieve perceived stressors. This relief of perceived stressors due to environment, disease, or personal conditions leads to adjustment. Pless and Pinkerton (1975) expanded on the model developed in 1970 by Lipowski. Pless and Pinkerton believed that adjustment is a dynamic model that

continues from childhood through adulthood. Pless and Pinkerton stressed the principle of feedback looping.

In this model the children bring with them certain attributes that are formed through genetics, social and family factors. This combines with the characteristics of the disease, and the reactions and attitudes of significant others such as parents, siblings, peers, and teachers. These factors all work together to form the child's self-concept and coping skills (Bradford, 1997). Over time Pless and Pinkerton believe that feedback loops are set up. These loops lead the child to react to current life situations based on past experiences.

The most recent model to emerge in the field of adjustment was produced by Wallander in 1989. Wallander and his colleagues attempt to add a cognitive factor and coping mechanism to the adjustment model. Wallander's model does not automatically assume that the presence of a chronic illness necessarily represents an adverse event for the family. Rather the focus is on the role of stressors and the individual's ability to cope to these stressors (Bradford, 1997).

Wallander's model works well with the family system perspective, and shows how every event in a child or adolescent's life can influence their ability to adjust and cope to future situations. This framework can also be used in the context of summer camps. At the summer camps the child is learning to adjust and cope based on past circumstances and influences, their current environment, and their personal ability to cope.

## Camp

The usage of short-term summer camps as a therapeutic tool has been around since the 1940's (Holden, Friend, Gault, Kager, Foltz, & White, 1991). These camps were originally started to serve as recreational, educational, and therapeutic tools for diabetic youth. Over the years, other camps were started for children with different types of chronic illnesses such as asthma, hemophilia, spina bifida, and muscular dystrophy (Briery, & Rabian, 1999; Thomas, & Gaslin, 2001; Silvers, et al, 1992). Summer camps are considered a relatively inexpensive setting for helping children with chronic illness (Holden et al., 1991).

A study by Holden et al. (1991) was the first to examine the impact a summer camp for children with diabetes had on the child and the family. Families were recruited from over 120 children and adolescents who had insulin-dependent diabetes that attended a two-week long summer camp in the state of Alabama. The parents completed the third version of the Family Adaptability and Cohesion Evaluation Scales (Faces-III) that was developed by Olsen in 1986. Faces-II is a twenty item self-report measure of family functioning that factors on two scales, adaptability and cohesion. The Who Does What? Questionnaire that was developed by Varni and Babini in 1987 was given along with the child manipulation scale that was taken from Johnson, Silverstein, Cunningham, and Carter's 1985s development of the Parent Diabetes Opinion Survey. The two aforementioned scales were given to look at who had responsibility for the treatment regimen, and to see if the parents perceived manipulative behaviors displayed from the child that related to diabetes. The campers were given the Diabetes Adjustment Scale produced by Sullivan in 1979 to look at illness adjustment. The Self Perception Profile

for Children (SPPC) developed by Harter in 1985 was given to look at overall self-competence. Two observation measures were also used to look at regimen adherence. The first was developed by Johnson, Lewis, and Alexander in 1981, and is called the Blood Glucose Monitoring Test. The second measure was the Insulin Injection Test, which was originally developed in 1979 by Pollack and Johnson.

The families that had children eligible to attend camp were contacted one month before camp to ask for participation in the study. A letter was sent describing the study, along with an informed consent form, a demographic information sheet, and the parent measures were sent to the families through mail. The mothers were asked to complete the measures and to forward the materials to the experimenter in a preaddressed and stamped envelope. The families were contacted by phone one week after the initial mail out had occurred to see if they had any questions.

Once the children arrived at camp, the researchers gained assent from the children, and then the measures were given to the children the first day of camp, and the measures were administered again the last day of camp. Three weeks after camp the Who Does What? Questionnaire and the child manipulation scale from the Parent Diabetic Opinion Survey were mailed out to the families. Instructions for filling out the measures asked the raters to rate the children on their behavior since camp. Six months after camp the same measures were given to the families with instructions to fill out the measures according to the child's current behavior. The researcher indicated a 60% response rate.

The results of the study found that children who came from a dysfunctional family, as measured by the FACES-III scale, reported more positive changes as a



function of camp than campers from a functional family. However, the researchers discovered that children from functional families maintained the changes from camp for a longer period of time than the children who belonged to a dysfunctional family. The dysfunctional family also reported a decrease in the manipulation of the child after the camp experience. This may indicate that children from dysfunctional families and the dysfunctional family itself may benefit from the camp experience the most.

The generalizability is somewhat compromised by the fact that the measures used were self-report, and there was a high correlation between variables discussed. Obviously a goal of this type of research is to be able to eventually generalize the benefits of the camp experience into the family context. A clearer understanding of the benefits of therapeutic summer camps on the family system may lead to an increased use in overall outpatient care. If a movement was made to shift inpatient care of children with chronic illnesses to outpatient care, the cost of current health care delivery could be substantially decreased. The quality of life of the individual and the family could also have significant beneficial impact.

Spevak et al. (1991) conducted a study to look at the effects of diabetes summer camp on adherence behaviors and glycemic control. Similar to Holden et al. (1991) the study also looked at the maintenance of camp related changes post-camp. The study looked at families who had children with insulin-dependent diabetes between the age of 7 and 12. In the study conducted by Spevak and her colleagues, two weeks prior to attending the summer camp subjects (the child with diabetes and one parent from each family) were interviewed on three separate occasions. The study used a 24-hour recall system developed by Johnson, Silverstein, Rosenbloom, Carter, and Cunningham in

1986. From these data thirteen adherence measures were found that could be quantifiable. The researchers took blood samples at the beginning of camp for use of as diabetic control index. During the camp the children were interviewed three times over the two-week period to record diabetes management behaviors from the previous day. The blood sample was again taken the last day of camp. Two, six, and twelve weeks after camp the campers and their parents were interviewed by phone using the 24-hour recall technique. At 12 weeks the campers also gave another blood sample to the researchers.

The results of the study show that though there was an increase in adherence to regimen at camp, the children did not maintain the strict regimen adherence after camp.

Thomas and Gaslin (2001) studied children who had hemophilia, and their summer camp experience. The researchers looked at the impact summer camp had on self-esteem. They defined self-esteem as the “degree to which one feels lovable and capable just for existing or being” (Thomas, & Gaslin, 2001, p. 256). The researchers evaluated whether the self-esteem increased in the campers through qualitative means. The researchers did determine that the campers had an increase in self-esteem. This study did an excellent job reviewing the literature, defining the variables of interest, and discussing what needs still to be found in the literature. This study did not use any quantitative measures to systematically measure changes in self-esteem. The researchers did report improvement in self-esteem based on qualitative measures.

Michalski, Mishna, Worthington, and Cummings (2003) used a multi-method design to evaluate the impact of a therapeutic summer camp program. The participants of the study came from families who had children and young adults between the ages of 8

and 18 attending one of two three-week summer camps in Ontario. The children and young adults were able to attend the camp if they were diagnosed with a learning disability, and also had a social, emotional, or behavioral problem. The first three-week session of camp was for children under the age of fourteen, and the second session of camp was for adolescents between the age of 14 and 18. The participants of the study included 48 children and 48 adolescents. The camp counselors were trained to use a variety of therapeutic and outdoor recreational activities to enhance social skills, self-confidence, and self-esteem in campers. The camp offered programs such as swimming, canoeing, camping, arts and crafts, and recreational sports. The camp also had a low counselor to camper ratio, and offered campers counseling dependent on their individual needs. Michalski, Mishna, Worthington, and Cumming (2003) looked at the ability of the summer camp to increase the campers' self confidence and self-esteem, decrease the campers' sense of isolation in a safe environment, and enhance self-competence. The multi-method evaluation included standardized measurements such as rating scales, feedback questionnaires, and interviews with the parents through telephone communication. The researchers used a pre-test, post-test, and follow-up design to evaluate the ability of the camp program to achieve the goals listed above.

The three standardized measurements used were the Self-Esteem Index, Children's Loneliness Questionnaire, and the Social Skills Rating System (Michalski et al., 2003). The campers were given the instruments within 48 hours of arriving at the camp. The campers were presented with the same measurements the last day of camp, and were also given a camp evaluation form. Six to eight months following the camp the campers were presented with the instruments again. The parents filled out the Social

Skills Rating System at the same times as the children. The parents also completed a camp evaluation questionnaire. Finally, random samplings of parents were called for telephone interviews during the 6-8 month follow-up period.

The study used paired sample t-tests to look at the differences between the pre-test, post-test, and 6-8 month follow-up phases. In terms of self-esteem, the campers exhibited levels similar to the general population before camp. However, the campers' self-esteem was reported to have increased by several points during the post-test phase, and this level stayed above average for the follow-up phase. The loneliness scales indicate a positive experience when comparing their camp experiences to their school experience. Also, the results of the study lead the researchers to conclude that the campers experienced lower levels of loneliness and social inadequacy at school the year after camp as compared to the year previous to camp. The social skills rating system did not indicate any significant changes over the three time periods.

The campers also filled out a camp satisfaction questionnaire with a five-point scale that ranged from 1 (not at all) to 5 (very much). Overall, the campers rated the camp experience favorably. The campers also noted favorable personal development. In the camp evaluation, the parents reported favorable changes in self-esteem level, increased independence, better expression of emotion, and improved self-awareness of self and others. In the Social Skills Rating System, the parents reported positive changes in the four areas measured: co-operation, assertiveness, responsibility, and self-control. The only area in which the parents did not report a significant change was in the level of assertiveness. Some parents were contacted for telephone interviews during the follow-up phase. The parents biggest concern was that the lack of opportunities the

“real-world” provided for reinforcing camp behavior. Many parents reported that they would like to have contact with the agency throughout the year, and not only at camp time.

Overall this study provides valuable information into the effects of a short-term summer camp on special interest population children and their parents. The effects of the camp show positive experiences that help the children and adolescents when returning to their normal routine.

Briery and Rabian (1999) researched the psychosocial changes that can be associated with participation in a pediatric summer camp. Specifically, the researchers wanted to look at changes in attitudes of children towards their disability and the level of trait anxiety experienced for children attending a one-week pediatric summer camp. The participants of the study attended one of three week-long camps offered at Camp Alderstate in Little Rock, Arkansas. Data from the asthma camp, diabetes camp, and spina bifida camp were collected. Ninety campers between the ages of 6 and 16 participated in the study.

The children were given the Child Attitude Toward Illness Scale (CATIS; Austin & Huberty, 1993). This is a 13-item scale that looks at the child’s attitude toward their specific illness or disability. Respondents answer each question on a 5 point Likert-type scale, and the average score is taken from the 13 responses to reflect the child’s attitude toward their illness or disability. The State-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1973) was another instrument the researchers used in the study. The STAIC, form A-trait is a 20-item measurement that uses a 3-point scale.

The participants of the study were recruited the first day of camp registration. Written consent was obtained from the parents, and assent was obtained from the children attending the camp. Parents completed a demographic questionnaire, and the children were given the CATIS and STAIC after checking in. At the end of the week, the campers filled out the CATIS and STAIC measures again. Overall, the study reported that the camp experience improved attitude toward illness in children with pediatric conditions. Self-reported anxiety also was reported to significantly decrease over the course of the camp. Another interesting finding of the study was that the three groups did not differ significantly on the baseline scores obtained from the CATIS or the STAIC. This helps to show that even though three different chronic illnesses were evaluated, the children all came into the camp experience with similar attitudes toward their illness and levels of anxiety.

Limitations reported by the researchers included the fact that they did not have a follow-up assessment phase. The study also failed to include a control group. The specific components of the camp that might have lead to decreased anxiety and a more positive attitude toward illness was also not looked at in this particular study.

Silvers, Holbreich, Go, Morrison, Dennis, Marostica, and Buckley (1992) looked at the ability of a summer camp for children with asthma to encourage the campers to enjoy outdoor activities without physical or psychosocial impairment. Camps were originally established, and further developed to help children and young adults with asthma have positive attitudes toward their health, realize their physical potential, and to help them to learn their physical limitations (Silvers et al., 1992). Statistics from parent satisfaction surveys were analyzed to help the staff better address the needs of the

children, and to improve the camp experience. The camp called “Champ Camp” was started in 1980 as a project to develop a model camp for children with asthma. The researchers combined all data, and developed a model for camps throughout the nation. The researchers provide valuable information that is backed by satisfaction measures obtained from the parents, and observations of the campers’ progress as observed by the staff.

Through eight years of experience, Champ Camp, has developed goals and objectives that are important to a successful camp. One of the goals of the camp is to improve the psychosocial outlook of a child with asthma and to also improve the children’s’ attitude toward their illness. The Muscular Dystrophy Association also has a camp that focuses on trying to improve the psychosocial outlook of the children and adolescents they assist.

#### *MDA Camp*

The Muscular Dystrophy Association has provided a camp for children with over 40 types of neuromuscular disease since 1955 (Muscular Dystrophy Association, 1998). This weeklong camp provides children and young adults between the ages of 6 and 21 an opportunity only available to those that have a disease served under the Muscular Dystrophy Association. The regional MDA camp is located outside Guthrie, Oklahoma. This camp provides services for the MDA population in the entire state of Oklahoma and Northern Texas. The three regional areas included are based out of Oklahoma City, Oklahoma, Tulsa, Oklahoma, and Wichita Falls, Texas.

The camp leadership, counselors, and campers are all asked to focus on meeting the primary camp goal. The camp goal:

*To provide the campers with a total camping experience, meaningful activities, and the opportunity of learning, growing, and developing friendships. An opportunity for the campers to experience and feel total inclusion. To provide the campers with a total feeling of safeness.*

The camp staff is comprised of two camp directors, senior counselors, cabin leaders, an arts and craft director, annual editor, nursing staff, a physician, a physical therapist, and a counselor for every child or adolescent who attends the camp. The camp has a chain of command that is always followed except in cases of physical, sexual, or verbal abuse. In the case of alleged child-abuse the person with the concern is to report directly to the camp directors. In all other cases the counselors report directly to the cabin leader. The cabin leaders, arts and crafts director, annual editor, and other camp staff report to the senior counselors. The senior counselors and medical staff report directly to the camp directors.

The campers are paired one-on-one with a counselor who is specially matched through the application process to best help the camper achieve the camp goal as well as personal goals set by the camper. The cabin leaders are chosen through a combination of past evaluations and cabin needs. The senior counselors are chosen based on previous camp evaluations, and the strengths that they can bring to camp leadership. All decisions on volunteer placement are made through the camp directors. Camp leadership arrives for training each Friday afternoon before camp. The leadership undergoes a two-hour training time the Saturday before the remaining counselors arrive. The leadership evaluates the management role and discusses where the individual strengths and weaknesses of all lie. Risk



management and safety concerns are also addressed and discussed in detail at this meeting.

Training for veteran and rookie counselors is the same, beginning Saturday afternoon and ending Sunday afternoon, based on the premise that all counselors can benefit from the material presented, even if they have been at the camp for numerous years. The leadership presents the material as a team. Each member of the team participates in discussing important aspects of training. The camp goal is discussed, leadership is introduced, and the chain of command is addressed.

Training includes discussion of the proper physical care of the camper, as well as emotional and psychological care. Behavioral techniques are discussed as tools for discipline. The counselors receive handouts to expand on each of the aforementioned topics. The counselors are also given a brief introduction to the different types of diseases they might be exposed to at camp. General medical care as well as disability specific discussion occurs. Risk management and safety issued are addressed at this meeting as well. A handout discussing the use of rewarding the campers for positive social behavior towards others is given; within the camp, the topic is also known as “random acts of kindness.” The importance of goal completion is also discussed. Discussion of the camp goal of the campers achieving personal growth is also discussed in detail.

The campers arrive at camp on Sunday afternoon. The parents check the campers in and help the counselors and cabin leaders to understand any special care or equipment handling that might be necessary. During the check-in

procedure the campers are given a detailed handout and told about the rewards the camper will receive for giving positive social behavior towards others. At camp this is called “random acts of kindness.” The campers are also encouraged to begin thinking of the goals they want to accomplish for the week. The campers and counselors then meet as a group at the conference center to discuss the rules of camp, state the goal of camp, and the leadership is introduced. Later in the evening the campers, counselors, and cabin leaders have a cabin meeting. The campers set their goals for the week that evening. The campers must set a minimum of three goals. One of the goals must focus on personal development.

Throughout the week the campers are given physically, socially, and emotionally challenging tasks to perform. Campers are given the opportunity to ride horses, ride in canoes or paddleboats, swim, dive off the diving board, and participate in the talent show. The campers also have the opportunity to help others, learn how to help themselves, and learn how to work with others to accomplish goals. Each camper comes with his or her own personal experience, and so every goal set at camp is formed to the individual camper’s needs. The camp staff will work to make sure every camper achieves the goals that they have set for themselves.

The camp lasts until Friday afternoon. Nightly activities are provided for the campers that they might not normally be able to experience. For example, the campers might take part in a dance, a talent show, a casino night, a carnival, or even a campout. Throughout the experience of MDA camp the children are learning more about what they are able to achieve. The campers are able to feel

that they are not alone, and that people love them unconditionally. This may be the one place where the campers feel they belong.

### Statement of the Problem

There is little empirical literature concerning the impact of attending a camp for children who have a chronic illness or disability (Briery & Rabian, 1999; Silvers et al, 1992; Thomas & Gaslin, 2001). Recent literature has indicated that children with a chronic illness who attend a summer camp are able to adjust and cope with their disability at a higher level than when they started at camp (Briery & Rabian, 1999; Preston, 2000; Singh, Kable, Guerrero, Sullivan, & Elsas, 2000). No empirical research has been conducted that looks at the influence summer camp has on children with a neuromuscular disease. The literature has also failed to address possible reasons as to why the children and adolescents who attend camp have improved coping skills and attitude toward illness. This study is designed to examine the impact a weeklong summer camp has on children with a neuromuscular disease. Specifically the study will look at the impact the camp has on the camper's attitude toward illness, the level of anxiety the camper reports, and the impact the illness has on the family. This study will also examine two possible quantifiable explanations for an increase in positive attitude toward illness and a decrease in the level of anxiety the children experience.

### Significance of the study

Children and adolescents with chronic illness have physical and emotional needs above and beyond that of a child without a chronic illness. These children need to have a means by which to learn positive coping skills and strategies. By providing an environment, such as a summer camp, skills for coping can be taught. These children can

then return back to their normal environment and use the skills and confidence gained at camp to help them in their environment at home. The experience of summer camp can help these children to recognize what they are able to accomplish even with having an illness. These children can gain a deeper understanding of what their disability entails. Children and adolescents learn that they are not alone, and they can accomplish many tasks they set they previously thought impossible.

This study will inspect the therapeutic benefits of a child or adolescent attending a weeklong summer camp. Summer camps are a cost-effective means of training children to learn about and gain a healthy attitude towards their illness. This study will examine perceptions of children and adolescents with a chronic illness who attend a summer camp toward level of anxiety and attitude toward illness.

The family as a whole will also be taken into context using a systems perspective. Caretakers need to be able to have a break from their daily regimen. The camp offers a positive space for the caretakers as well by providing a weeklong break from a child or adolescent who needs constant care. It is believed that this study will show that the families who have a child attend the summer camp will report a lower level of impact of the illness than those who do not have a family member attend the camp.

Finally, this study will try to demonstrate the benefits of two specific parts of the summer camp. Not only does camp improve the camper's and families' well being, but explore two possible explanations for the positive impact the summer camp has on the children, adolescents, and their families.

### Substantive Questions

The following Substantive Questions have been chosen for examination in this study.

1. Is there a relationship between attendance of a child at a muscular dystrophy camp and the child's attitude toward illness?
2. Is there a relationship between attendance of a child at a muscular dystrophy camp and level of anxiety?
3. Is there a relationship between the number of goals that a child completed while at camp and his or her attitude toward their disability?
4. Is there a relationship between the number of goals that a child completes while at camp and his or her level of anxiety?
5. Is there a relationship between the amount of positive social behavior towards others given at camp and his or her attitude toward the illness?
6. Is there a relationship between the amount of positive social behavior towards others given at camp and their level of anxiety?
7. Is there a relationship between the severity of the illness and the impact the illness has on the family?

### Hypotheses

1. Attendance of a child at a muscular dystrophy camp will be positively related to the child's attitude towards his or her illness.
2. Attendance of a child at a muscular dystrophy camp will be negatively related to anxiety.
3. There will be a positive correlation between the number of goals that a child completes while at camp and his or her attitude toward their disability.

4. There will be a negative correlation between the number of goals that a child completes while at camp, and his or her level of anxiety.
5. There will be a positive correlation between the amount of positive social behavior towards others given at camp, and his or her attitude toward their disability.
6. There will be a negative correlation between the amount of positive social behavior towards others given at camp, and their level of anxiety.
7. The more severe the level of disability the child has the higher the negative impact the illness will have on the family.

## CHAPTER III

### METHOD

The purpose of this study was to examine the relationship of children and adolescents attending a one-week Muscular Dystrophy Association summer camp with attitude toward illness and level of anxiety. The study also investigated how the number of goals completed and the number of positive social behaviors performed by the child or adolescent was related to the attitude toward illness and their level of anxiety. Finally, this study correlates the impact on the family with the severity of the illness.

Prior to the camps a letter was mailed out to all parents on the Muscular Dystrophy Association's mail list that had a child or adolescent between the ages of 6 and 21. Parents were notified in the letter that a study was taking place at the summer camp, and were given the opportunity to participate even if their child was not attending camp. Parents who chose to have their children participate in the study completed a general information questionnaire and a measure looking at the impact the illness had on the family. All children and adolescents that participated in the study were given self-report measures to fill out regarding level of anxiety and attitude toward their illness both on the first and last day of camp. The children and adolescents also recorded the number of goals that they completed throughout the week of camp as well as the number of positive social behaviors they completed.

## Participants

The participants (N=53) for this study were children and adolescents from the states of Oklahoma and Texas who attend the regional Muscular Dystrophy Association camp located near Guthrie, Oklahoma. Participants were between the ages of 6 years 0 months through 21 years 11 months. This age criteria was developed by the national muscular dystrophy association summer camps, limiting children and adolescents who participate in their camp to be no younger than six and no older than twenty-one. Each participant also agreed to fill out questionnaires and keep record of the goals and positive social behaviors that he or she completed throughout the week.

The demographic characteristics of the participants and their families are shown in Table 1. Seventy-seven percent of the guardian participants were mothers, 9% were fathers, 6% were legal guardians, and four participants were legal adults who filled out the family questionnaires themselves. Yearly incomes were reported in the range of below \$20,000 (21%), \$20-\$50,000 (56%), \$50-\$100,000 (21%), and over \$100,000 (2%) annually.

Sixty percent of the campers who participated in the study were male, and 40% were female. Ethnicities of the campers are as follows: 79% of the campers are Caucasian, 6% are African American, 9% are Asian, and 6% are Latino. The ages of the campers were: 6 years old (n=3), 8 years old (n=1), 9 years old (n=1), 10 years old (n=3), 11 years old (n=9), 12 years old (n=8), 13 years old (n=5), 14 years old (n=3), 15 years old (n=1), 15 years old (n=3), 17 years old (n=3), 18 years old (n=3), 19 years old (n=4), 20 years old (n=2), 21 years old (n=4).



Specific information regarding type of disease, and level of physical limitation, number of years since diagnosis, and the number of years the campers had each attended camp was also collected. Percentage of individuals with various types of neuromuscular disease were as follows: Duchene Muscular Dystrophy (49%), Becker Muscular Dystrophy (2%), Myotonic Muscular Dystrophy (9%), Limb Girdle Muscular Dystrophy (2%), Spinal Muscular Atrophy (23%), Myathenia Gravis (2%), Charcot Marie Tooth Disease (2%), Friedrich's Ataxia (8%), Other myopathies (2%), Pending or unknown diagnosis (2%). Eleven percent of the campers were able to walk independently, 8% need some assistance with some physical mobility, 9% wear leg or foot braces, 15% use manual or power wheelchairs or scooters part-time, 8% of the campers use a manual wheelchair full-time, and 49% of campers use a power wheelchair full-time.

Campers had been diagnosed with their respective disabilities at various ages. Five campers had been diagnosed with a neuromuscular disease within the past year; two years ago two campers received their diagnosis; two campers three years ago and four additional campers four years ago. Eight campers have been diagnosed for six years; three for seven years; three for 8 years; three for 9 years; and eight for 10 years. One camper had a diagnosis for 12 years; four for 13 years and one camper had his or her diagnosis for 14 years. Four campers had a diagnosis for 15 years; two for 18 years; one for 19 years; and two for twenty one years.

Fourteen of the 53 camper were attending camp for the first time; 4 campers were attending for their 2<sup>nd</sup> year; 5 campers attended for their 3<sup>rd</sup> year; five for their 4<sup>th</sup> year; 2 campers had been attending camp for 5 years, 1 camper had attended the camp for 7

years; two for 8 years, 6 campers have attended camp for 10 years; one for 11 years; five for their 12<sup>th</sup> year at camp; two for 13 years; and one for 15 years.

Table 1  
Demographic Characteristics of Participants

Characteristic	n	Percent of Total
Gender of Guardian		
Male	8	15%
Female	45	85%
Relationship of the Guardian		
Father	5	9%
Mother	41	77%
Guardian	3	6%
Self	4	8%
Income of the Family		
Under \$20,000	11	21%
\$20,000 to \$50,000	30	57%
\$50,000 to 100,000	11	21%
Over \$100,000	1	2%
Ethnicity		
Caucasian	42	79%
African American	3	6%
Asian	5	9%
Latino	3	6%
Gender of the Camper Participants		
Male	32	60%
Female	21	40%
Age of Campers		
Six	3	6%
Eight	1	2%
Nine	1	2%
Ten	3	6%
Eleven	9	17%
Twelve	8	15%
Thirteen	5	9%
Fourteen	3	6%
Fifteen	1	2%
Sixteen	3	6%
Seventeen	3	6%
Eighteen	3	6%
Nineteen	4	7%
Twenty	2	4%
Twenty-one	4	7%

Type of Neuromuscular Disease		
Duchenne Muscular Dystrophy	26	49%
Becker Muscular Dystrophy	1	2%
Myotonic Muscular Dystrophy	5	9%
Limb Girdle Muscular Dystrophy	1	2%
Spinal Muscular Atrophy	12	23%
Myasthenia Gravis	1	2%
Charot Marie Tooth Disease	1	2%
Freidrich's Ataxia	4	8%
Other Myopathy	1	2%
Pending of Unknown Diagnosis	1	2%
Physical Limitations		
Ability to Walk Independently	6	11%
Needs assistance with mobility	4	8%
Wears leg or foot braces	5	9%
Uses wheelchair part-time	8	15%
Uses manual wheelchair full-time	4	8%
Uses power wheelchair full-time	26	49%
Years Since Diagnosis		
One	5	9%
Two	2	4%
Three	2	4%
Four	4	8%
Six	8	11%
Seven	3	6%
Eight	3	6%
Nine	3	6%
Ten	8	15%
Twelve	1	2%
Thirteen	4	8%
Fourteen	1	2%
Fifteen	4	8%
Eighteen	2	4%
Nineteen	1	2%
Twenty-one	2	2%
Number of Years Attending MDA Camp		
One	14	26%
Two	4	8%
Three	5	9%
Four	5	9%
Five	2	4%
Six	5	11%
Seven	1	2%
Eight	2	4%
Ten	6	11%
Eleven	1	2%
Twelve	5	9%
Thirteen	2	4%
Fifteen	1	2%

## Instrumentation

The *Parent Information Sheet* (Appendix C) was an examiner-made data collection page designed to gather basic demographic information concerning the child and the family. Questions on the parent information sheet included questions about race, gender, and age of the child. Information was also gathered about the camper's neuromuscular diagnosis including: the type of diagnosis and the time since diagnosis.

*The Child Attitude Toward Illness Scale (CATIS)* (Austin & Huberty, 1993) is a 13-item scale designed to assess children's attitudes toward their specific illnesses or disabilities. The general form leaves space on several of the questions so that the informant can fill in the specific illness or disability that the child is facing (Briery & Rabian, 1999). The scale includes questions such as, "How fair is it that you have a \_\_\_\_\_?", and "How often do you feel different from others because of your \_\_\_\_\_?" Respondents answers each question on a 5-point Likert-type scale. The attitude toward illness is estimated as an average score across all 13 questions (Briery & Rabian, 1999). The higher the score, the better the child's attitude toward illness. The CATIS is located in Appendix D.

The CATIS standardization sample consisted of 269 children. Good internal consistency (.80) and test-retest (.80) reliability were found (Austin & Huberty, 1993). Construct validity was found through factor analysis with predicted relationships with scores on the Child Behavior Checklist and the Piers-Harris Children's Self-Concept Scale (Austin & Hubery, 1993). Heimlich et al. (2000) performed further validation measures for the CATIS using an adolescent sample with epilepsy. The psychometric analyses showed good internal consistency reliability and good test-retest reliability. The

CATIS was found to be moderately correlated with self-esteem and mastery. The results provided some evidence of construct validity (Heimlich et al., 2000).

The State-Trait Anxiety Inventory for Children (STAIC) is an adaptation of the State Trait Anxiety Inventory (Spielberger et al., 1973). The measures include two 20 item self-report scales. The items must be answered using a 3-point scale. The range of the scale is from “hardly ever” to “often.” The responses are totaled and the range of scores is between 20 and 60. A 20 indicates low trait anxiety and the higher scores indicate a higher level of anxiety (Spielberger et al., 1973). The psychometric properties of the STAIC are well documented (Briery & Rabian, 1999; Murriss, Merckelbach, Ollendick, King, & Bogie, 2002). Not only is the STAIC well documented, but the measure from which it is delivered is considered one of the most popular measures of anxiety (Bieling, Antony, & Swinson, 1998).

The Impact on Family Scale (IFS) was originally developed by Ruth Stein and Catherine Riessman to look at the effect a child’s illness has on the family (1980). The IFS consists of 24-items. The measurement looks at the negative impact the disability has on the family. The scale was found to have high internal consistency. The researchers also performed a factor analysis and found that four dimensions defined the measure. The ITS Factors are: Financial, Social/Familial, Personal Strain, and Mastery. This is the earliest scale in the literature that examines the impact of a child’s chronic illness on the family (Stein & Riessman, 1980). Kolk, Schipper, Hanewald, Casari, and Fantino developed an Italian version of the IFS to investigate whether the four dimension structure of the scale could be replicated (2000). The first three factors clearly replicated.

In addition the scales had high internal consistency and homogeneity. Overall the scale should be useful in determining the effects of a chronic illness on the family system.

Participants were also given a sheet to record goal completion and positive social behavior towards others. The participants and his or her counselor recorded each evening the number of goals completed for the day as well as the number of positive social behavior towards others each day. The total numbers of goals and positive social behaviors towards others were acquired for each participant.

### Procedure

Potential participants were mailed a letter of solicitation three weeks before the first session of the muscular dystrophy summer camp. All families who were known to have a child or adolescent between the ages of 6 and 21 registered with the regional MDA office received notification of the study. Those attending the camp who wanted to participate in the study were able to consent for the study at registration for the 1<sup>st</sup> day of camp. Those families who did not have a member of their family attending in the summer camp but who wanted to participate in the research program could call the number listed to have the material mailed to them. All who participated were entered in a drawing for a \$25 gift certificate to the store of their choice.

Three families called to gain more information about the study. One had a child attending camp, and two others had children that were not yet old enough to attend camp. No other inquiries were made. A control group for the study could not be obtained. The families ( $N=53$ ) who participated in the study completed all information on site the same afternoon that the child or adolescent was registered at the summer camp. The parents or guardians signed a consent form for the study and completed the *Parent Information*

*Sheet* and the *Impact on Family Scale*. The child or adolescent filled out the *Child Attitude Toward Illness Scale* and the *State-Trait Anxiety Inventory for Children* at the same time. Each day during the week the camper and his or her counselor filled out the goal/positive social behavior toward others research form. The primary investigator went to each cabin every night to see if there were any questions about filling out the forms and assisted where needed. The participants completed the CATIS and STAIC the second time on the last morning of summer camp.

## CHAPTER IV

### RESULTS

The effects of attending a Muscular Dystrophy Association summer camp on the participant's level of anxiety and attitude toward illness were investigated. Although the design of this study originally involved the use of a control group of children and adolescents with neuromuscular diseases, solicitation through letters did not result in enough participants to have a control group. Fifty-three participants were obtained through the summer camp: twenty-three from camp session one (older session) and 30 from camp session two (younger session).

The Child Attitude Toward Illness Scale (CATIS) was completed by the participants who attended the camp to assess their attitude toward illness at the start of camp and again on the last day of camp. The State-Trait Anxiety Inventory for Children (STAIC) was completed by participants as a pre-test and post-test measure to look at the change in the level of anxiety while at camp. The Child Attitude Toward Illness Scale and the State-Trait Anxiety Inventory for Children were used as the dependent variables in the pre and post test design. The total number of positive behaviors towards others and number of goals completed while at camp were also calculated for each participant. Finally, the level of physical impairment was noted to see how closely it correlated with the level of impact on the family. The Statistical Package for the Social Sciences version 12.0 (SPSS, 2003) was used to conduct statistical analyses of the data.



The following research questions were then addressed:

1. Is there a relationship between attendance of a child at a muscular dystrophy camp and the child's attitude toward illness?
2. Is there a relationship between attendance of a child at a muscular dystrophy camp and level of anxiety?
3. Is there a relationship between the number of goals that a child completed while at camp and his or her attitude toward their disability?
4. Is there a relationship between the number of goals that a child completes while at camp and his or her level of anxiety?
5. Is there a relationship between the amount of positive social behavior towards others given at camp and his or her attitude toward the illness?
6. Is there a relationship between the amount of positive social behavior towards others given at camp and their level of anxiety?
7. Is there a relationship between the severity of the illness and the impact the illness has on the family?

#### Research Questions

Question One: Is there a relationship between attendance of a child at a muscular dystrophy camp and the child's attitude toward illness?

The means and standard deviations of the pretest and posttest scores for all campers were analyzed. The means for each camp session were also measured. The means were noted to increase for the overall camp population as well as for both camp session one and camp session two participants.

Table 2  
Pretest and Posttest Scores for Campers on Attitude Toward Illness

	n	M	SD
Group (N=53)			
Combined Camp Sessions			
Pretest	53	3.50	.53
Posttest	53	3.56	.60
Camp Session One			
Pretest	23	3.43	.43
Posttest	23	3.43	.48
Camp Session Two			
Pretest	30	3.56	.60
Posttest	30	3.66	.68

A Pearson's r correlation was conducted between pre-test and post-test CATIS scores. Significant correlation was noted ( $p < .01$ ) with regard to the both the combined camp sessions as well as with each camp session.

Table 3  
Pearson r Correlation Between CATIS Pre-test and CATIS Post-test Scores

Subscale	n	CATIS post-test	Significance (2-tailed)
Combined Camp			
CATIS pre-test	53	.72**	.000
Camp Session One			
CATIS pre-test	23	.68**	.000
Camp Session 2			
CATIS pre-test	30	.73**	.000

\*\*Correlation is significant at the .01 level (2-tailed)

A correlation was also conducted to see if there was a relationship seen between CATIS post-test scores based on disability type. Only two groups, Duchenne and Spinal Muscular Atrophy had an n larger than 10 and could therefore be correlated. A significant correlation was noted for both disability types.

Table 4  
Pearson r Correlation of CATIS Scores by Disability Type

Subscale	n	CATIS post-test	Significance (2-tailed)
Duchenne	26	.61**	.001
CATIS pre-test			
Spinal Muscular Atrophy	12	.62*	.032
CATIS pre-test			

\* Correlation is significant at the .05 level (2-tailed) \*\*Correlation is significant at the .01 level (2-tailed)

A paired samples t-test was then conducted to look to see if there was a significant difference between the means of the pretest and posttest for the CATIS. No statistical significance was noted between pre-test and post-test CATIS scores.

Table 5  
Paired Samples t-test on the Attitude Toward Illness

	n	Ave. diff in M	t	sig. (2-tailed)
Group (N=53)				
Camp Session One				
Posttest- Pretest	23	.003	.046	.964
Camp Session Two				
Posttest- Pretest	30	.116	1.38	.178
Combined Camp Sessions				
Posttest- Pretest	53	.068	1.161	.251

\* significant at the 0.05 level.

A paired samples t-test was also conducted to look to see if there was a significant difference between the means of the pretest and posttest for the CATIS dependent on disability type. Duchenne Muscular Dystrophy and Spinal Muscular Atrophy were the only two subgroups with a large enough n to be included. Statistical significance (at the .05 level) was noted for participants who identified as having Duchenne Muscular Dystrophy.

Table 6  
Paired Samples t-test by disability type on the Attitude Toward Illness

	n	Ave. diff in M	t	sig. (2-tailed)
Duchenne Pretest- Posttest	26	.20	2.41	.024*
SMA Pretest- Posttest	12	.07	.55	.597

\* significant at the 0.05 level.

Question Two: Is there a relationship between attendance of a child at a muscular dystrophy camp and level of anxiety?

The means and standard deviations of the pretest and posttest STAIC scores for all campers were analyzed. The means for each camp session were also measured. A decrease between pre-test and post-test scores was noted for the combined camp sessions as well as camp session one and two.

Table 7  
Pretest and Posttest Scores for State Anxiety

	n	M	SD
Combined Camp Sessions			
STAIC-State Pretest	53	27.64	4.09
Posttest	53	26.77	4.79
Camp Session One			
STAIC-State Pretest	23	29.13	3.01
Posttest	23	29.09	5.01
Camp Session Two			
STAIC-State Pretest	30	26.50	4.48
Posttest	30	25.00	3.82

A Pearson's r correlation was conducted between pre-test and post-test STAIC-state scores. Significance was noted ( $p < .01$ ) with regard to the both the combined camp sessions as well as with each camp session.

Table 8  
Pearson r Correlation Between STAIC Scores

Subscale	n	STAIC post-test	Significance (2-tailed)
Combined Camp Sessions			
STAIC pre-test	53	.57**	.000
Camp Session One			
STAIC pre-test	23	.53**	.009
Camp Session 2			
STIAC pre-test	30	.53**	.002

\*\*Correlation is significant at the .01 level (2-tailed)

A correlation was also conducted to see if there was a relationship seen between STAIC post-test scores based on disability type. Only two groups, Duchenne and Spinal

Muscular Atrophy had an n larger than 10 and could therefore be correlated. No significance was noted for the Duchenne disability type, but a significant correlation was reported for those with Spinal Muscular Atrophy.

Table 9

Pearson r Correlation of STAIC Scores by Disability Type

Subscale	n	STAIC post-test	Significance (2-tailed)
Duchenne			
STAIC pre-test	26	.24	.242
Spinal Muscular Atrophy			
STAIC pre-test	12	.74**	.006

\*\*Correlation is significant at the .01 level (2-tailed)

A paired samples t-test was then conducted to look to see if there was significance between the means of the pretest and posttest for the STAIC State scales. Statistically significant differences were noted for the camp session two population.

Table 10

Paired Samples t-test on State Anxiety

	n	Ave. diff in M	t	sig. (2-tailed)
Group (N=53)				
Combined Camp Sessions				
STAIC-State Posttest-Pretest	53	-.87	-1.5	.134
Camp Session One				
STAIC-State Posttest-Pretest	23	-.04	-.05	.961
Camp Session Two				
STAIC-State Posttest-Pretest	30	-1.50	-2.03	.052*

\* significant at the 0.05 level.

A paired samples t-test was conducted to determine if there was a significant difference between the means of the pretest and posttest for the STAIC dependent on disability type. Duchenne Muscular Dystrophy and Spinal Muscular Atrophy were the only two subgroups with a large enough n to be included. No significance was noted for any of the disability types.

Table 11  
Paired Samples t-test by Disability Type on State Anxiety

	n	Ave. diff in M	t	sig. (2-tailed)
Duchenne	26	-1.577	-1.827	.080
Pretest- Posttest				
SMA	12	.667	.528	.608
Pretest- Posttest				

\*significant at the 0.05 level.

Question Three: Is there a relationship between the number of goals that a child completed while at camp and his or her attitude toward their disability?

A Pearson's r correlation was conducted between post-test CATIS scores and the number of goals completed at camp. The relationship was not significant.

Table 12  
Pearson r Correlation Between Goals Completed with final CATIS

Subscale	n	Change in Attitude	Significance (2-tailed)
Combined Camp Sessions			
Goals	53	-.04	.799
Camp Session One			
Goals	23	-.28	.192
Camp Session Two			
Goals	30	.10	.593

\* Correlation is significant at the 0.05 level (2-tailed).

Question Four: Is there a relationship between the number of goals that a child completes while at camp and his or her level of anxiety?

A Pearson's r correlation was conducted between post-test STAIC-state scores and the number of goals completed at camp. The relationship was not significant.

Table 13  
Pearson r Correlation Between Goals Completed and Post-Camp State Anxiety Level

Subscale	n	Anxiety (Post-test)	Significance (2-tailed)
Combined Camp Sessions			
Goals	53	-.02	.909
Camp Session One			
Goals	23	.04	.841
Camp Session Two			
Goals	30	-.06	.743

\* Correlation is significant at the 0.05 level (2-tailed).

Question Five: Is there a relationship between the amount of positive social behavior towards others given at camp and his or her attitude toward the illness?

The total number of positive social behaviors towards others was correlated with the post-test scores on the CATIS. Significance was noted ( $p < .05$ ) with regard to the camp session one's attitude toward their illness and the number of positive behaviors toward others. Significance was not reported on the camp session two nor total camp participants.

Table 14  
Pearson r Correlation Between Positive Behavior and final Attitude Toward Illness

<u>Subscale</u>	<u>n</u>	<u>Post-Camp Attitude</u>	<u>Significance (2-tailed)</u>
Combined Camp Sessions			
Positive Behavior	53	.24	.085
Camp Session One			
Positive Behavior	23	.44*	.035
Camp Session Two			
Positive Behavior	30	.63	.092

\* Correlation is significant at the 0.05 level (2-tailed).

Question Six: Is there a relationship between the amount of positive social behavior towards others given at camp and their level of anxiety?

This question was first addressed by looking at the total number of positive social behaviors towards others with the STAIC- State final post-test score. The Pearson's r correlation was then used for this analysis. Significance was noted ( $p < .001$ ) with regard to the total participants' attitude toward illness and the number of positive behaviors toward others. Significance was seen on the camp session two ( $p < .05$ ), but not on camp session one participants.

Table 15

Pearson r Correlation Between Positive Behavior and Post-Camp State Anxiety

Subscale	n	Anxiety (Post-test)	Significance (2-tailed)
Combined Camp Sessions			
Positive Behavior	53	-.43**	.001
Camp Session One			
Positive Behavior	23	-.36	.089
Camp Session Two			
Positive Behavior	30	-.45*	.012

\*Correlation is significant at the 0.05 level (2-tailed). \*\*Correlation is significant at the 0.01 level (2-tailed)

Question Seven: Is there a relationship between the severity of the illness and the impact the illness has on the family?

This question was addressed by looking at the total score on the Impact on Family Scale and was correlated with the degree of severity of the disability. The Spearman's rho correlation was used for this analysis. Significance was reported ( $p < .01$ ) for the total participant number in the study. Significance was noted for both camp session one ( $p < .05$ ) and camp session two ( $p < .001$ ).

Table 16

Spearman's rho Correlation Family Impact and Physical Limitation

Subscale	n	Impact on Family	Significance (1-tailed)
Combined Camp Sessions			
Physical Limitation	53	.50**	.000
Camp Session One			
Physical Limitation	23	.39	.066
Camp Session Two			
Physical Limitation	30	.73**	.000

\* Correlation is significant at the 0.05 level (1-tailed). \*\*Correlation is significant at the 0.01 level (1-tailed).

A Spearman's rho correlation was then conducted for both Duchenne Muscular Dystrophy and Spinal Muscular Atrophy with regard to the Impact on Family Scale and



level of physical impairment. A significant correlation was seen for those with Duchenne Muscular Dystrophy, but not those with Spinal Muscular Atrophy.

Table 17

Spearman's rho Correlation Between Impact on Family and Level of Physical Impairment

Subscale	n	Impact on Family	Significance (2-tailed)
Duchenne			
Physical Limitation	26	.49*	.012
Spinal Muscular Atrophy			
Physical Limitation	12	.40	.204

\*\*Correlation is significant at the .05 level (2-tailed)

## CHAPTER V

### DISCUSSION

Living with a long-term chronic illness is a relatively new occurrence in the history of civilization. Before the 20<sup>th</sup> century, illness of any type was acute and often fatal. With the recent advances in technology, chronic illness has become a part of today's world. In fact, over 110 million people have one or more chronic health conditions (Royer, 1998). Mattson developed a widely accepted definition of chronic illness in 1972: A prolonged illness that is progressive and fatal, or one that affects physical or mental functioning without affecting life span (Mattson, 1972).

Neuromuscular diseases fall into the category of a chronic illness, and 1 in every 1,000 people within the world have some form of a neuromuscular disease (Ringel, 1987).

There are some studies on the psychological effects of a disease on a person. These studies indicate that a person with chronic illness may be more at risk of showing negative psychological effects than individuals without chronic illness. However, the psychological effects of a neuromuscular disease on an individual and their family have not been empirically studied in depth.

When children are affected with a chronic illness it is beneficial for society to help them adjust to their illness so that they can function well as adults. Children are

still developing appropriate coping mechanisms to handle environmental changes, and it is important that society helps these children learn to cope with their disease. One of the ways this has been done is through programs specifically designed to help individuals learn more about themselves and their diseases. Summer camps that focus on personal growth and development for children and adolescents with chronic illness are one type.

There is little empirical literature concerning the impact of summer camp programs for children who have a chronic illness or disability (Briery & Rabian, 1999; Silvers et al, 1992; Thomas & Gaslin, 2001). Some recent literature has indicated that children with various chronic illnesses who attend a summer camp are able to adjust and cope with their disability at a higher level than when they start at camp (Briery & Rabian, 1999; Preston, 2000; Singh, Kable, Guerrero, Sullivan, & Elsas, 2000). No empirical study has been conducted examining the influence of summer camp on children with a neuromuscular disease. The literature has also failed to address factors associated with camp related to coping skills and attitude toward illness.

This study explored the impact of weeklong summer camp on children and adolescents with neuromuscular diseases. Specifically, this study addressed the relationship summer camp had on the camper's attitude toward his/her illness and their level of anxiety. The number of goals completed and the number of positive social behaviors toward others the participants completed at camp were studied with regard to their relationship with positive attitude toward illness and level of anxiety. Attention was also given to the relationship the level of physical impairment the child or adolescent had on the family as a system.

### *Research Question Number One*

Is there a relationship between attendance of a child at a muscular dystrophy camp and the child's attitude toward illness?

The scores on the Child Attitude Toward Illness Scale (CATIS) did show a positive difference between the pre-test and post-test. Results indicated that average attitude toward illness for all the campers did become more positive between when the first measure was taken and when the post-test was completed on the last day of camp. The CATIS post-test scores correlated significantly and positively with the pre-test measures taken, indicating that the test-retest reliability was significant. Significant positive correlations were also noted with regard to attitude toward illness in both the Duchenne Muscular Dystrophy and the Spinal Muscular Atrophy participant pool.

A paired sample t-test on the Child Attitude Toward Illness Scale failed to show significant differences between the pre-test and post-test measures on the combined camp session as well as camp session one and two participants. Significance was found with regard to a positive change in attitude toward illness with the Duchenne Muscular Dystrophy population. The implications of this finding indicate that individuals with Duchenne Muscular Dystrophy had a significant positive change in their attitude toward their disability while at camp. Duchenne Muscular Dystrophy is the most populous disability recognized in this study with twenty-six participants. This correlates with studies that have found this disability to be the most common childhood form of muscular dystrophy (MDA, 1998). Individuals with Duchenne usually have more significant physical impairments at a younger age than other neuromuscular diseases (Bushby, Hill, & Steele, 1999).

MDA camp allows individuals with physical impairment the ability to complete more activities than they may have an opportunity of completing in their other life environments. By completing these activities successfully, individuals with Duchenne Muscular Dystrophy may feel better about their accomplishments than those individuals that do not have the same type or level of physical impairment. Future studies should explore this question with a larger sample size, and also look at doing a follow-up measure once the campers return to their homes to see if positive attitude toward illness continues.

*Research Question Number Two*

Is there a relationship between attendance of a child at a muscular dystrophy camp and level of anxiety?

The post-test scores on the State-Trait Anxiety Inventory for Children (STAIC) did show a decrease between the pre-test and post-test scores. Results indicate that the average level of anxiety for all the campers did decrease between when the first measure was taken and when the post-test was completed on the last day of camp. The STAIC post-test scores correlated significantly and positively with the pre-test measures taken. The results of this correlation indicate that the test-retest reliability is significant. Significant positive correlations were also noted with regard to anxiety in the Spinal Muscular Atrophy participant pool, though positive, a significant correlation was not seen with the Duchenne Muscular Dystrophy participants.

The paired sample t-test on the STAIC failed to show significant differences between the pre-test and post-test measures on the combined camp session as well as camp session one participants. However, camp session two participants were noted to

have a significant decrease in levels of anxiety. Camp session two campers included the younger participants. There were fourteen campers that attended camp for the first time in this group. The novelty of attending camp for the first time may have impacted the change in the level of anxiety from pre-test to post-test measures more than the older camp session participants in session one. Future studies looking at variances in levels of anxiety between first time campers and return campers would be beneficial.

Significance was not found on paired sample t-tests with regard to anxiety levels in either the Duchenne Muscular Dystrophy or Spinal Muscular Atrophy populations. The Duchenne population is noted to be approaching significance with regard to the decrease in their level of anxiety. Future studies should explore this question with a larger sample size, and also look at doing a follow-up measure once the campers return home.

### *Research Question Number Three*

Is there a relationship between the number of goals that a child completed while at camp and his or her attitude toward their disability?

The post-test results on the Child Attitude Toward Illness Scale failed to significantly correlate with the number of goals the child/adolescent completed at camp. This variable was difficult to control because the camper was able to choose a wide variety of goals. A more controlled study with limited goals might produce statistical significance. No statistically significant findings may have been due in part to the small sample size as well as length of time between measures. Future research may need to be conducted to look at what types of goals may produce a more positive change in attitude towards others.

#### *Research Question Number Four*

Is there a relationship between the number of goals that a child completes while at camp and his or her level of anxiety?

The post-test results on the State-Trait Anxiety Inventory for Children-State form failed to significantly correlate with the number of goals the child/adolescent completed at camp. This variable was difficult to control because the camper was able to choose a wide variety of goals. A more controlled study with limited goals might produce statistical significance. The small sample size as well as the short length of time between measures may have also contributed to these results. Future research may need to be conducted to look at what types of goals may correlate with a decreased change in level of anxiety.

Goals were a difficult variable to control as the camper was able to choose from a wide variety of goals. If this research were being conducted in a controlled setting it might be easier to limit the types of goals completed. As with question number three, the inability to formalize the types of goals completed while at camp could have led to some of the results. Future research should look at a way to address the wide variance in goals attempted, and find a way to systematically measure the goals.

#### *Research Question Number 5*

Is there a relationship between the amount of positive social behavior towards others given at camp and his or her attitude toward the illness?

The results of this study indicate that positive social behaviors towards others significantly correlated with the children or adolescent's final measure of his/her attitude toward illness (using the CATIS). The significance occurred on the first session of camp

participants. In this study those that spent more time focused on helping others had a more positive attitude toward their disability. Though a causative statement cannot be made it is clear that one factor does highly correlate with the other for campers from the first session. The results of this part of the study may show that those individuals who are able to effect a positive impact on society may in turn see their disability as less of a handicap than those who are not connecting with society.

Significance was not found for the younger session of camp participants (second session). The results did show an overall positive correlation even though the results did not reach significance. The primary difference between the first and second sessions would appear on paper to only be indicated by the age difference. However, severity in disability is noted to increase with age and time since diagnosis. It is therefore possible that the more severe the level of disability the greater the correlation between positive behavior towards others and attitude toward illness. This would explain the difference in significance found between the older camp session one participants and the younger camp session two participants. For future studies it would be beneficial to have an increased number of participants, and also have an increased camp time to be able to take multiple measures.

#### *Research Question Number 6*

Is there a relationship between the amount of positive social behavior towards others given at camp and their level of anxiety?

The results of this part of the study confirmed that there is a significant relationship between decreased anxiety levels and increased positive behaviors towards others. The results were supported on both the total camp participants as well as with the



second session campers. Though not significant, camp session one participant's results were noted to be approaching significance. Camp session two campers were the younger participants. There were fourteen campers that attended camp for the first time in this group. The novelty of attending camp for the first time may have impacted the change in the level of anxiety from pre-test to post-test measures more than camp session two participants. Future studies looking at variances in levels of anxiety between first time campers and return campers would be beneficial. It would also be beneficial to have an increased number of participants and also have an increased camp time to be able to take multiple measures.

#### *Research Question Number 7*

Is there a relationship between the severity of the illness and the impact the illness has on the family?

The level of physical impairment was significantly correlated with higher impact on the family using the Impact on Family Scale. Significance was found for the total camp participants as well as for each of the camp sessions. This finding also held true when individuals with Duchenne Muscular Dystrophy cases only were analyzed, though no significant correlation was seen with the Spinal Muscular Atrophy population. The implications of this part of the research are varied. It verifies literature surrounding the family systems theory that indicates that chronic illness has considerable effects on the family system (Kolk, Schnipper, Hanewald, Casari, & Fantino, 2000; Padrone, 1994; Turnbull and Turnbull, 1990). For future studies it would be interesting to gain enough participants of each of the types of disabilities and see if there is a significant difference on the impact of the family with each type of disability.

### Summary of Results

The results of this study indicate that camp participation did have a positive impact on individuals with neuromuscular diseases. This study has shown that children and adolescents with a chronic illness who attended summer camp demonstrated lowered levels of anxiety and a more positive attitudes toward illness. This study demonstrated a significant correlation with the number of positive acts towards others completed with increased positive attitude toward illness and a decreased level of anxiety. Finally, it was noted that the more significant the physical impairment the more negatively it impacted the family system

### Limitations of Study

There were several limitations in this study. There were limits with regard to the sample size and the lack of a control group. A sampling bias and therefore lack of ability to generalize to the population are also possible concerns. The inability to scientifically measure the goals completed is limitation of this study.

The limitation of sample size was noted to be a possible concern before the study began. The sample size for research of children with chronic illness are typically small, and studies often report sample sizes with no more than 20 participants. Reasons for a small sample size included the child's illness preventing participation, the families' reluctance to have their child participate in research as they do not see benefits for their child, and the number of children and adolescents with a neuromuscular disease in any given area may be small.

Collecting data at the start of the camp session led to a high rate of participants among those attending camp. In fact, over 85% of the available participants and their

families chose to participate in the research while at the summer camp. Unfortunately, the population of eligible individuals with neuromuscular disease who were not attending camp also chose not to participate in the study. This led to the primary limitation of this study which was a lack of the control group.

The extent that this data can be generalized to the overall population of interest may be limited because the data was collected only at one summer camp location. The sample for this study was from one geographical region, the state of Oklahoma and northern Texas. It is difficult to state that the same emphasis of goals and encouragement of positive behaviors towards others would be used at all other MDA summer camps. It is, however, expected that the attitude toward illness and anxiety levels of children with a neuromuscular disease are universal.

A selection bias may have been present based on the characteristics of the participants and the families who agreed to participate. The lack of contact from families who did not have their child attend summer camp was surprising. This may be because they are not actively involved in working with the Muscular Dystrophy Association, not interested in participating in research, not able to see benefits participation would have for their child, not being able to participate due to a conflict in scheduling (such as a family vacation), or the child's severe physical limitations.

The instruments used to predict attitude toward illness and anxiety levels in children and adolescents were gathered after a careful review of the literature. However, there may be other variables that would provide additional information.

The collection of information on the number of goals completed was more difficult than originally thought. When this study began the plan was to find out what

types of goals the children and adolescents were planning on completing at camp, and then create a generalized form for each of the types of goals. It was found that this would not be possible after the first day of the first session of camp. There were too many different types of goals, and the children had too many different needs to be able to come up with a systematic way of measuring the goals. Overall 175 goals were successfully completed at camp, and there were 67 different types of goals listed. It was determined that the best way to measure the goals was solely on the number of goals completed while at camp.

#### *Implications for Future Research*

The results of this study provide for a myriad of other opportunities for future research. Options that may be used to repeat this study could include using a control group, increasing sample size, increasing the number of campgrounds conducting the study, and increasing the number of sampling times. A researcher may wish to improve on this study by locating a reasonably sized control group to use as a comparison sample. This would lead to a wider range of statistical tests that can be conducted on the data. Increasing sample size would lead to an increased ability to generalize to the population of interest. Finally, by increasing the number of campground locations researchers would be able to make their case even more robust for generalizability to the population of interest.

Researchers could also look at extending the study to include additional sampling times once the participant of the summer camp returns to his or her home. This may help researchers to understand how long the positive effects of summer camp last for each individual that participates in the study.

### Implications for Practitioners

Implications for practitioners are far-reaching. For individuals who work or volunteer at summer camps for children with disabilities, the results are promising. The results indicate that children with disabilities receive benefits from attending a week long summer camp. By providing an environment, such as a summer camp, methods for coping can be taught and practiced. Participants can then return to their regular environment and use the skills and confidence gained at camp to help them in other environments including school, home, and work. They are able to gain a deeper understanding of what their disability means for them and more importantly they learn that they are not alone, and they can accomplish any appropriate and realistic task they set their minds to complete.

Summer camps are a cost-effective means of training children to learn about and gain a healthy attitude towards their illness. This study has demonstrated that camps appear to be therapeutically beneficial to their participants.

### Conclusion

Children and adolescents with chronic illness have physical and emotional needs above and beyond that of a child without a chronic illness. These children need to have a means by which to learn positive coping skills and strategies. By providing an environment, such as a summer camp, skills for coping can be taught. This study has shown that some of the children and adolescents with a chronic illness who attended a summer camp demonstrated a significant relationship to lowered levels of anxiety and more positive attitudes toward illness.

This study demonstrated a significant correlation with the number of positive acts towards others completed with increased positive attitude toward illness and a decreased level of anxiety. Finally, the more significant the physical impairment the more negatively it impacted the family system.

The results of this study add to the limited research available regarding the study of summer camps used as a therapeutic tool. This study has led to further support for studying the effects patients with physical needs have on their families. It has also looked at a few of the possible benefits of encouraging positive behaviors toward others. This study shows strong evidence for continuing to study the benefits of summer camp and helps practitioners in this field begin to understand ways of helping campers gain understanding of their disability and decrease levels of anxiety.

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## APPENDICES

## APPENDIX A

### Solicitation Letter

June 2, 2005

Dear Parents:

Greetings! I am excited to be able to inform you of a study that will be conducted this summer. I am a doctoral student in the area of school psychology. I have also spent the past decade as a volunteer with the Muscular Dystrophy Association. Throughout this time I have learned something very important that all of you already know- children, adolescents, and young adults with a neuromuscular disease are some of the most amazing individuals on earth. One of the ways that I have been able to interact and learn from these individuals is through the summer camp provided every year by the Muscular Dystrophy Association. I have seen the benefits that this camp offers to individuals between the ages of 7 and 21, and would like to share the benefits that individuals who attend the camp may gain with individuals outside of the Muscular Dystrophy Association.

If your son or daughter is participating in the camp and you would like your family to be involved in this study you will need to do nothing now. The day of camp registration a detailed explanation of the study will be given and necessary forms can be completed at that time. If your son or daughter is not attending camp this year you can still participate in the study! All you need to do is call the number at listed at the bottom of the letter. Documents concerning the study will be mailed out to you during June.

All families who choose to participate in the study will be entered into a drawing to win a \$25 dollar gift certificate to the store of their choice. There will be one gift certificate awarded to a parent/guardian who participates in the study, and one gift certificate to a child, adolescent, or young adult who participates in the study. This means that each family that participates has two chances to win a \$25 dollar gift certificate.

This research is expected to benefit the knowledge of researchers, help the Muscular Dystrophy Association, and most importantly provide much needed information concerning the therapeutic benefits of attending a camp for children with a neuromuscular disease. I strongly feel that the camp staff and leadership have made the Tulsa, Oklahoma City, and Wichita Falls camp one of the most organized and positive camp experiences available. Now it is time to make others aware of this camp.

Sincerely,

Jamie C. Gant, M.S.  
School Psychology Graduate Student

226 Willard Hall • Stillwater, OK • 74078

Phone: 405-744-9505

APPENDIX B

Consent Form

I, \_\_\_\_\_, hereby authorize or direct Jamie Gant, or associates or assistants of her choosing, to perform the following procedure.

**Title of Proposed Research Study:** The Relationship of Attending Muscular Dystrophy Association Summer Camp and Attitudes Toward Physical Disabilities and Levels of Anxiety

This study will collect data for research purposes through Muscular Dystrophy Association.

**Purpose:** This study is designed to look at the impact a weeklong summer camp has on children with a neuromuscular disease. Specifically the study will look at the impact the camp has on the camper’s attitude toward illness, the level of anxiety the camper reports, and the impact the illness has on the family as a system. This study will also examine two possible quantifiable explanations for an increase in positive attitude toward illness and a decrease in the level of anxiety the children experience. The information will be gathered over the course of two weeklong summer camp sessions.

**Procedure:**

Camp Participants:

1. Parents will fill out two forms
2. Child, Adolescent, or young adult will fill out two forms
3. Forms should take approximately ten minutes to fill out total.
4. Throughout the week the child, adolescent, or young adult will be asked about goals completed while at camp and the number of acts of kindness completed.
5. On the final day of camp the child, adolescent, or young adult will fill out two additional forms.

Non-camp participants:

1. An envelope containing an information sheet and all necessary forms will be mailed out to participants.
2. Material will be completed and returned in the pre-addressed stamped envelope provided.

**Confidentiality:** Data collected will be kept in a secure location. The consent form has an identification number located in the upper right-hand corner. The remaining forms that are completed will have this exact identification number, but neither yours nor your minors name will be included on the remaining forms. Once all the data has been collected the consent forms will be separated from the remaining data and kept in a secure location. This will help to ensure protection of all information gained.

I understand that participation is voluntary and that I will not be penalized if I choose not to participate. I also understand that I am free to withdraw my consent and end my participation in this project at any time without penalty after I notify the project director. I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

---

Name (printed) Parent/Legal Guardian	Signature	Date
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I certify that I have personally explained all elements of this form to the subject or his/her representative before requesting the subject or his/her representative to sign it.

Signed: \_\_\_\_\_  
Project director or authorized representative

APPENDIX C

**Parent Information Sheet**

Please circle the answer or fill in the blank for the answer that most closely describes information about you and/or your child.

- 1. Your Sex:** Male Female
- 2. Relationship to the child:** Father Mother Guardian
- 3. Estimated annual income:** a. under \$20,000  
b. \$20,000-50,000  
c. \$50,000-100,000  
d. over \$100,000
- 4. Ethnicity:** Caucasian African American Asian  
Hispanic Other: \_\_\_\_\_
- 5. Your Child's Sex:** Male Female
- 6. Age of your child:** \_\_\_\_\_
- 7. Type of Neuromuscular Disease:**
- a. Duchenne Muscular Dystrophy
  - b. Becker Muscular Dystrophy
  - c. Myotonic Muscular Dystrophy
  - d. Limb-Girdle Muscular Dystrophy
  - e. Facioscapulohumeral Muscular Dystrophy
  - f. Congenital Muscular Dystrophy
  - g. Spinal Muscular Atrophy
  - h. Dermatomyositis
  - i. Myasthenia Gravis
  - j. Charcot-Marie-Tooth
  - k. Friedreich's Ataxia
  - l. Mitochondrial Myopathy
  - m. Other Myopathies
  - n. Pending diagnosis or Unknown at this time
- 8. Level of Physical Limitation:**
- a. Ability to walk independently
  - b. Needs assistance with some physical mobility (i.e. stairs, personal care, etc.)
  - c. Wears leg or foot braces
  - d. Uses manual or power wheelchair/ scooter part-time
  - e. Uses manual wheelchair full-time
  - f. Uses power wheelchair full-time
- 9. Number of years since diagnosis:** \_\_\_\_\_
- 10. Number of years attending MDA camp:** \_\_\_\_\_



## APPENDIX D

### CATIS

#### Questions

(1) How good or bad do you feel it is that you have a neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(2) How fair is it that you have a neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(3) How happy or sad is it for you to have a neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(4) How bad or good do you feel it is to have neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(5) How often do you feel that your neuromuscular disease is your fault?

• responses: very good    a little good    not sure    a little bad    very bad

(6) How often do you feel that your neuromuscular keeps you from doing things you like to do?

• responses: very good    a little good    not sure    a little bad    very bad

(7) How often do you feel that you will always be sick?

• responses: very good    a little good    not sure    a little bad    very bad

(8) How often do you feel that your neuromuscular disease keeps you from starting new things?

• responses: very good    a little good    not sure    a little bad    very bad

(9) How often do you feel different from others because of your neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(10) How often do you feel bad because you have a neuromuscular disease?

• responses: very good    a little good    not sure    a little bad    very bad

(11) How often do you feel sad about being sick?

• responses: very good a little good not sure a little bad very bad

(12) How often do you feel happy even though you have a neuromuscular disease?

• responses: very good a little good not sure a little bad very bad

(13) How often do you feel just as good as other kids your age even though you have neuromuscular disease?

• responses: very good a little good not sure a little bad very bad

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Scoring:

- questions are scored on a 5 point scale with 1 negative and 5 positive
- questions with reverse scoring: 1 2 4 5 7 9 11 13
- scores are summed then divided by 13 to give an average score

References

Austin, J.K. & Huberty, T.J.. Development of the Child Attitude Toward Illness Scale. *J Pediatric Psychology*. 1993; 18: 467-480.

APPENDIX E

**IMPACT ON FAMILY SCALE** by Stein & Reissman (1980)

1. Additional income is needed in order to cover medical expenses	Strongly Agree	Agree	Disagree	Strongly Disagree
2. The illness is causing financial problems for the family	Strongly Agree	Agree	Disagree	Strongly Disagree
8. Time is lost from work because of hospital appointments	Strongly Agree	Agree	Disagree	Strongly Disagree
4. I am cutting down the number of hours I work to care for my child	Strongly Agree	Agree	Disagree	Strongly Disagree
5. Our family gives up things because of our child's illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
6. People in the neighborhood treat us specially because of my child's illness	Strongly Agree	Agree	Disagree	Strongly Disagree
7. We see family and friends less because of my child's illness	Strongly Agree	Agree	Disagree	Strongly Disagree
8. I don't have much time left over for other family members after caring for my child	Strongly Agree	Agree	Disagree	Strongly Disagree
9. We have little desire to go out because of my child's illness	Strongly Agree	Agree	Disagree	Strongly Disagree
10. Because of the illness, we are not able to travel out of the city.	Strongly Agree	Agree	Disagree	Strongly Disagree
11. Sometimes we have to change plans about going out at the last minute because of my child's state	Strongly Agree	Agree	Disagree	Strongly Disagree
12. Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	Strongly Agree	Agree	Disagree	Strongly Disagree
13. I think about not having more children because of the illness	Strongly Agree	Agree	Disagree	Strongly Disagree
14. Nobody understands the burdens I carry	Strongly Agree	Agree	Disagree	Strongly Disagree
15. Traveling to the hospital is a strain on me	Strongly Agree	Agree	Disagree	Strongly Disagree
16. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	Strongly Agree	Agree	Disagree	Strongly Disagree
17. It is hard to find a reliable person to take care of my child.	Strongly Agree	Agree	Disagree	Strongly Disagree
18. I live from day to day and don't plan for the future.	Strongly Agree	Agree	Disagree	Strongly Disagree
19. Fatigue is a problem for me because of my child's illness.	Strongly Agree	Agree	Disagree	Strongly Disagree
20. Learning to manage my child's illness has made me feel better about myself.	Strongly Agree	Agree	Disagree	Strongly Disagree
21. Because of what we have shared, we are a closer family.	Strongly Agree	Agree	Disagree	Strongly Disagree
22. My partner and I discuss my child's problems together.	Strongly Agree	Agree	Disagree	Strongly Disagree
23. We try to treat my child as if he/she were a normal child.	Strongly Agree	Agree	Disagree	Strongly Disagree
24. My relatives have been helpful and understanding with my child.	Strongly Agree	Agree	Disagree	Strongly Disagree

APPENDIX F

**Daily Check Sheet**

Day and Date of Check Sheet Completion: \_\_\_\_\_

(Ex: Monday, July 9, 2004)

Name of Camper: \_\_\_\_\_

Goals

Total Number of Goals Completed for Week: \_\_\_\_\_

List Goals Completed since last check sheet:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Random Acts of Kindness (Positive Social Behavior Towards Others)

Total Number of Random Acts of Kindness Completed for Week: \_\_\_\_\_

List Random Acts of Kindness Completed since last check sheet:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_

Any Additional Comments Concerning Goal Completion or Random Acts of Kindness:

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APPENDIX G

STATE TRAIT ANXIETY FOR CHILDREN- *SAMPLE NOT FOR REPRINT*

HOW-I-FEEL QUESTIONNAIRE

Developed by C.D. Spielberger, C.D. Edwards, J. Montuori, and R. Lushene

STAIC From C-1

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide how you feel *right now*. Then put an X in the box in front of the word or phrase which best describes how you feel. There are no right or wrong answers. Don't spend too much time on any one statement. Remember, find the word or phrase which best describes how you feel right now, *at this very moment*.

- |                 |                 |            |                |
|-----------------|-----------------|------------|----------------|
| 1. I feel.....  | very calm       | calm       | not calm       |
| 2. I feel.....  | very upset      | upset      | not upset      |
| 3. I feel.....  | very pleasant   | pleasant   | not pleasant   |
| 4. I feel.....  | very nervous    | nervous    | not nervous    |
| 5. I feel.....  | very jittery    | jittery    | not jittery    |
| 6. I feel.....  | very rested     | rested     | not rested     |
| 7. I feel.....  | very scared     | scared     | not scared     |
| 8. I feel.....  | very relaxed    | relaxed    | not relaxed    |
| 9. I feel.....  | very worried    | worried    | not worried    |
| 10. I feel..... | very satisfied  | satisfied  | not satisfied  |
| 11. I feel..... | very frightened | frightened | not frightened |
| 12. I feel..... | very happy      | happy      | not happy      |
| 13. I feel..... | very sure       | sure       | not sure       |
| 14. I feel..... | very good       | good       | not good       |
| 15. I feel..... | very troubled   | troubled   | not troubled   |
| 16. I feel..... | very bothered   | bothered   | not bothered   |
| 17. I feel..... | very nice       | nice       | not nice       |
| 18. I feel..... | very terrified  | terrified  | not terrified  |
| 19. I feel..... | very mixed-up   | mixed-up   | not mixed-up   |
| 20. I feel..... | very cheerful   | cheerful   | not cheerful   |

STATE TRAIT ANXIETY FOR CHILDREN- *SAMPLE NOT FOR REPRINT*

HOW-I-FEEL QUESTIONNAIRE

Developed by C.D. Spielberger, C.D. Edwards, J. Montuori, and R. Lushene

STAIC From C-2

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

**DIRECTIONS:** A number of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide if it is *hardly-ever*, or *sometimes*, or *often* true for you. Then for each statement put an X in the box in front of the word that seems to describe you best. There are no right or wrong answers. Don't spend too much time on any one statement. Remember, find the word or phrase which best describes how you usually feel.

- |  |             |           |       |
|--|-------------|-----------|-------|
| 1. I worry about making mistakes.....                              | hardly ever | sometimes | often |
| 2. I fell like crying.....   | hardly ever | sometimes | often |
| 3. I fell unhappy.....   | hardly ever | sometimes | often |
| 4. I have trouble making up my mind.....                           | hardly ever | sometimes | often |
| 5. It is difficult for me to face my problems.....                 | hardly ever | sometimes | often |
| 6. I worry too much.....   | hardly ever | sometimes | often |
| 7. I get upset at home.....  | hardly ever | sometimes | often |
| 8. I am shy.....   | hardly ever | sometimes | often |
| 9. I feel troubled.....  | hardly ever | sometimes | often |
| 10. Unimportant thoughts run through my mind<br>And bother me..... | hardly ever | sometimes | often |
| 11. I worry about school.....                                      | hardly ever | sometimes | often |
| 12. I have trouble deciding what to do.....                        | hardly ever | sometimes | often |
| 13. I notice my heart beats fast.....                              | hardly ever | sometimes | often |
| 14. I am secretly afraid.....                                      | hardly ever | sometimes | often |
| 15. I worry about my parents.....                                  | hardly ever | sometimes | often |
| 16. My hands get sweaty.....                                       | hardly ever | sometimes | often |
| 17. I worry about things that may happen.....                      | hardly ever | sometimes | often |
| 18. It is hard for me to fall asleep at night.....                 | hardly ever | sometimes | often |
| 19. I get a funny feeling in my stomach.....                       | hardly ever | sometimes | often |
| 20. I worry about what others think of me.....                     | hardly ever | sometimes | often |

VITA

Jamie Colleen Gant

Candidate for the Degree of

Doctor of Philosophy

Dissertation: THE RELATIONSHIP BETWEEN ATTENDANCE AT MUSCULAR DYSTROPHY ASSOCIATION SUMMER CAMP, ATTITUDE TOWARDS ILLNESS AND LEVELS OF ANXIETY

Major Field: Educational Psychology

Biographical:

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Completed the requirements for the Doctor of Philosophy in Educational Psychology at Oklahoma State University, Stillwater, Oklahoma in December, 2009.

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Experience:

Academic Counselor at Oklahoma School of Science and Mathematics from 2008 until present.

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Name: Jamie C Gant

Date of Degree: December, 2009

Institution: Oklahoma State University

Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP BETWEEN ATTENDANCE AT MUSCULAR DYSTROPHY ASSOCIATION SUMMER CAMP, ATTITUDES TOWARD ILLNESS AND LEVEL OF ANXIETY

Pages in Study: 111

Candidate for Doctor of Philosophy

Major Field: Educational Psychology

Scope and Method of Study: The purpose of this study was to examine the relationship of children and adolescents attending a one-week Muscular Dystrophy Association summer camp to their attitude toward illness and their level of anxiety. The study also investigated how the number of goals completed and the number of positive social behaviors performed by the child or adolescent impacted the attitude toward illness and their level of anxiety. Finally, this study correlated the impact on the family with the severity of the illness.

Findings and Conclusions: Results from this study demonstrated that summer camp participants had lowered levels of anxiety and more positive attitudes toward illness after attendance at the camp. A significant relationship with number of goals completed at camp with attitude toward illness and level of anxiety was not seen, but there was a relationship seen between the number of positive acts towards others completed with increased positive attitude toward illness and a decreased level of anxiety. The more significant the physical impairment the more negatively the family system was impacted. Implications for practice and future research are discussed.

ADVISER'S APPROVAL: Dr. Terry Stinnett

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