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Coping Styles of Parents with Visually Impaired Children Compared to Parents with Fully Sighted Children

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COPING STYLES OF PARENTS WITH VISUALLY IMPAIRED CHILDREN COMPARED TO PARENTS OF FULLY SIGHTED CHILDREN

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An Abstract Presented to the Faculty of the Graduate School of Lindenwood University in Partial Fulfillment of the Requirements for the Degree of Master of Arts
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ABSTRACT

The purpose of this research study was to determine if the coping styles of parents with visually impaired children are different from the coping styles of parents with fully sighted children. These results indicated that there is no difference on coping styles with the parents with the visually impaired children and the parents with the fully sighighted children.

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To the most wonderful husband who has given me the strength and support to get through this long journey.

TABLE OF CONTENTS

LIST OF TABLES

Chapter One

Introduction

Coping Styles of Parents with Visually Impaired Children Compared to Parents of Fully Sighted Children

Research on the various coping styles of parents who find out that they have a visually impaired child is limited. Various coping styles throughout time have been researched in different areas, but there continues to be a need for more research at this time. Visual impairment in children can be a devastating issue for many parents, but with many different coping techniques the transition may lesson the negative feelings experienced by the parents going through this crisis.

Purpose

The purpose of the present research study is to determine if the coping styles of parents with visually impaired children differ from the coping styles of parents with fully sighted children.

Hypothesis

The coping styles of parents with visually impaired children will differ from the coping styles of parents with fully sighted children.

Chapter Two

Review of Literature

Visual Impairment in Children

Visual impairment refers to any condition in which eyesight cannot be corrected to what may be considered "normal". Visual impairments are often due to a loss of visual acuity which makes it difficult or impossible to complete daily tasks without specialized adaptations (Kwan, 1995). Visual impairments may also be due to the loss of the visual field - which is the complete area that can be seen without moving the eyes or head. A child with this visual field loss may or may not be able to see objects clearly within his or her smaller field of vision (Kwan, 1995).

There are three underlying reasons for the impairment of vision. First, there can be damage to one or more parts of the eye that are essential to vision. This damage may interfere with the way that the eye receives and processes this visual information (Holbrook, 1996). Second, the eyeball may be incorrectly proportioned which can make it harder to focus on objects. Third, the section of the brain that processes the visual information may not function properly. The eye may be completely normal, but the brain is not able to analyze and interpret this visual information so that the child can see (Holbrook, 1996).

Diagnosis of Visual Impairment

Many times visual impairments are detected at birth, before the infant leaves the hospital. Other times, parents may be the first to notice that something is not quite right with their child's eyes (Holbrook, 1996). Many parents may notice that their child does not watch them as they walk across the room. The child's eyes may stagger or the child may cry when someone picks him or her up without talking to them first. No matter how strong a parent's suspicions are, however, the diagnosis of a visual impairment is not official until an eye care professional confirms that there is a significant loss of the visual acuity or field (Glasspool, 1984).

Professionals Qualified to Make a Diagnosis

Two separate professionals are qualified to measure vision and then to determine whether the child has infact a visual impairment. The first is an opthlamologist, a medical doctor who has specialized training in diagnosing and treating diseases and conditions of the eye (D'Alonzo, 1991). This doctor is qualified to prescribe medications, perform various surgeries on the eye, and address medical problems. This individual can also measure visual acuity, visual fields and prescribe glasses. The second individual who can measure vision is an optometrist. An optometrist is a doctor of optometry

who has spent four years in optometry school, but is not considered a medical doctor. This eyecare individual is also qualified to measure visual acuity, visual fields and prescribe glasses.

Either an opthlamologist or a optometrist can make an initial determination of whether the child has a visual impairment. They are both qualified to prescribe corrective lenses and will be able to discuss the childs visual impairment with the parent. If, however, the child needs medical attention due to his eye condition, it is advisable for him to be under the close care of an ophthalmologist (Holbrook, 1996).

How Vision is Measured

In understanding how visual impairments are diagnosed, it is important to understand how vision is measured. First it is important to know how acuity is measured. The phrase 20/20 vision is a measurement of how well an individual is able to read a chart that contains letters and/or numbers of different sizes. The most common chart that is used by the eye care professionals is the Snellen chart. Visual acuity is then determined by the size of the letters that can be read and the distance at which they can be read. The typical testing distance is twenty feet from the chart due to the fact that at twenty feet the eyes are relaxed

and the lens of the eye are in their natural position instead of trying to focus (Holbrook, 1996).

Children with normal visual acuity can clearly read 3/8" letters or numbers at a distance of twenty feet. These individuals are said to have 20/20 vision due to the fact that at twenty feet from the chart they can see what normally sighted children can see at twenty feet. When the child's visual acuity is worse than normal, the second number will be larger than twenty. A child with 20/80 vision, for instance sees at twenty feet what a normally sighted child sees at eighty feet.

Naturally, the Snellen chart is only used with children who are able to read letters and numbers. For young children, there are other ways that visual acuity is measured. One of the most common is through a special test known as the Lighthouse Flash Card Test For Children (Holbrook, 1996). This individual test works the same as the Snellen chart except that there are bold line drawings of a circle, an apple, a house and a square instead of letters and numbers. Even very young preschoolers can identify these shapes, so then acuity can be measured at this young age. Approximate visual acuities can also be gathered by using toys and household objects to determine the child's ability to see objects at various distances.

It is extremely difficult and sometimes even

impossible to determine an accurate acuity for infants or for children with communication difficulties. One way to try to determine appropriate visual acuity is through Preferential Looking. A doctor may sometimes use this technique by administering two cards to the child at the same time. One card has black and white stripes, and the other has a large grey area. The doctor then watches the child to determine whether the child focuses on the striped card which is usually said to be more interesting to look at. The doctor then continues to present the cards with the stripes that are smaller and closer until the child no longer focuses on them (D'Alonzo, 1991). This gives the doctor a general idea of visual acuity until a more accurate measure can be made.

The doctor may then measure the acuity in each eye and in both eyes working together. It may also be possible to have a visual acuity of 20/20 in one eye, and 20/40 in the other and still see with an acuity of 20/20 with both eyes together.

Measuring Visual Field

A doctor may conduct additional assessments on the child to test their visual field. This procedure will help to determine how much of the space around the child can be seen without moving their eyes or head (Glasspool, 1984). Visual fields are obstructed by the facial

features such as the nose and eyebrows, but are approximately 160 to 170 degrees horizontally.

It may be difficult to test the visual field of the child because in order to get accurate results, the child must keep their head straight while continuing to focus their eyes for an extended period of time on a focus point directly in front of them. If the child is unable to perform this task, the doctor may ask the parent to sit on the floor with their child on their lap while the doctor sits directly in front of them. While the doctor watches the childs eyes, he will be able to see when the childs gaze shifts to something new coming into their visual field. This procedure will be repeated several times, while bringing objects into the child's visual field at several locations, sometimes from above, below or even on the sides of them (Glasspool, 1984).

When the child gets older and is able to sit still for longer periods of time, the doctor will then conduct a more sophisticated assessment of the childs visual field (Glasspool, 1984; Holbrook, 1996).

Degrees of Vision Loss

When a child's visual acuity and visual field have been measured, the ophthalmologist or optometrist will be able to conclude whether the child has a visual impairment, and if so, how significant that impairment

is. If the child does indeed have a visual impairment, the parents may find that additional labels are frequently used to describe the amount of vision the child has.

In fact, many debates have been made over labels and terminology to be used when referring to the child with the visual impairment (Rosenthal, 1997). In part this debate continues due to the need or desire to use terminology which accurately reflects the child's visual ability, but also because of an unfortunate sensitiveness over the use of the words "blind" and "blindness" (Rosenthal, 1997).

Historically, the word "blind" has not been used positively in the society. For example, a child who is said to blindly follow his peers is pegged as a person with little independence and poor judgement (Rosenthal, 1997). Truly the word blind is accurate when describing significant loss of vision and does not carry judgement of a persons worth of their ability.

Still, in order to accurately describe children with various degrees of vision loss, additional terms may be used. For example, children who read either regular or large print may be referred to as being partially sighted or having low vision. It is possible that parents may also be told of the term "legal blindness". This term does not imply that the child is completely blind, but it

does mean that the visual acuity is 20/200 or less in the better eye after correction and/or a visual field of no greater than twenty degrees (Rosenthal, 1997).

There are children whose vision is so limited that it can not be expressed in 20/20 terms. These visually impaired children can not see any of the letters on the eye chart as they sit or stand twenty feet away (Rosenthal, 1997). The first thing an eye doctor may do is test the child closer than twenty feet away from the chart. If this is the case, the top number of the acuity measurement will show the distance at which the testing is done (Rosenthal, 1997). The lower number continues to indicate what the child is able to see at that specific distance.

Some children's acuity can never be used using the eye chart. In these specific cases, the doctor may try to use alternative methods for testing the child's vision. Some terms that may be used are CF at_____feet, HM at_____feet, light projection or light perception. CF which stands for "Counts Fingers" means that the doctor holds up his fingers and then asks the child to count them, while taking notes of the of the distance at which the child can do this. HM which stands for "Hand Movement" is a measurement which shows the distance at which the child can recognize the movement of the hand in front of their eyes (Holbrook, 1996; Rosenthal, 1997).

Light projection refers to the ability to communicate to the doctor where the light is actually coming from and this can also be tested by asking the child to point to the light coming from the window (Rosenthal, 1997). Lastly, light perception refers to the ability to see the presence or absence of light without being able to tell where it is coming from (Rosenthal, 1997).

Many terms may be used to describe various visual abilities. Rarely, is it assumed that the child has absolutely no vision, unless the eyes have been removed for some reason (Recchia, 1997). If the child has some level of visual ability, it may be used for tasks such as orientation, mobility and daily living skills.

Functional Vision

Often two children who seem to have the same visual acuity have very different abilities to use in their every day activities. One two year old with 20/400 vision may be able to walk independently, while another child with the same visual acuity may not. It is very important for the child to be given a functional vision assessment (Recchia, 1997). This assessment will usually be conducted by a teacher who has special training in the area of visual impairment (Recchia, 1997).

There are several types of visual assessments. In

general, information about how the child uses his or her vision will be collected by observing in a variety of settings. The teacher conducting this assessment should observe the child during inside and outside activities during structured activities along with unstructured activities as well. This assessment should be able to find out a lot about the childs visual assessment, such as how well the child uses their eyes to scan across places to locate someone, or what lighting is best for this child. It will also be able to determine if the child gets tired easily when trying to accomplish tasks such as reading or writing (Recchia, 1997).

When gathering this information by using this assessment, the vision specialist can help to create a safe environment for the child that is stimulating and visually interesting to him (Recchia, 1997). Even if the child has very little vision, they can be taught to move around safely throughout their world.

Before the child has a functional vision assessment, parents may be able to see situations in which the child can use vision to gather information, and situations in which they will find their other senses most useful. It is important for parents to communicate how the child functions visually with individuals who work with them. The more time that parents spend loving, playing with and observing their child, the more they will understand how

their child will use their vision throughout the daily activities (Reccia, 1997).

Causes of Visual Impairment

There are many ways that vision can be impaired because so many parts and brain work closely together. With children, there are numerous reasons that one or more sections of the visual system may be damaged or malfunction. In general, Berne (1994) feels that visual impairments are due to one of three causes.

First, structural impairment, which is some sort of damage to one or more parts of the eye (Berne, 1994). Second, a refractive error, which is the inability of the eye to focus sharply on the images on the back of the retina. Third, cortical visual impairments, which are due to damage to the section of the brain that interrupts visual information (Berne, 1994).

Structural Impairments

Structural impairments can occur before or after birth (Berne, 1994). When it occurs before birth, it may be due to an inherited condition that causes the structural impairment or because something happened to disrupt the normal development of the visual system. After birth, this damage may be caused by injury to the

eye , disease, inherited conditions or many other causes. Regardless of when exactly the damage occurred, it is very important to identify the vision problem as soon as possible and take steps to minimize the impact of the child's growth and learning.

Cataracts

A cataract is considered a cloudiness of the crystalline lens of the eye. Light can not pass through the cataract normally, so it obscures vision. The effect on vision may be considerably different from no detectable visual impairment to an extreme loss of vision. In many extreme cases, a child may only be able to detect light from dark. Many types of cataracts progressively worsen, while others remain the same throughout life. Cataracts many also be located in one eye or in both depending upon the circumstance (D'Alonzo, 1991; Holbrook, 1996).

There are many different causes of cataracts in children. They can be inherited, or may even be a result of an infection to the mother during her pregnancy. The cataracts may also occur as a part of a disease or syndrome that affects several parts of the childs body. Examples of conditions associated with cataracts are: Marfan Syndrome, Crorezone Syndrome, Down Syndrome and many more (D'Alonzo, 1991; Holbrook, 1996).

Cataracts come in different sizes and severities. Since the early months and years in childhood are extremely important in learning, prompt assessment and diagnosis is critical.

The definitive treatment involves surgically taking the cataract from the actual eyes. Cataracts that are sufficiently cloudy to obscure vision may require immediate attention. Many times surgery is important within the first three months of life so that the vision can develop properly and effectively. Cataract surgery is performed under general anesthesia for children, and is done either on an outpatient or inpatient basis, depending on the childs needs. Young infants often are kept in the hospital overnight and rarely is it important to keep them for a longer stay, and the operation is not usually a painful one (D'Alonzo, 1991; Glasspool, 1984).

Removing the crystalline lens results in an eye with no lens called aphakia (D'Alonzo, 1991). Without a lens, the eye can no longer focus by itself, so the child will then have to get contact lenses or glasses to give them a clearer image of the retina. Cataract surgery is generally successful for all ages. If the childs eyes are healthy, in many cases they will see normally after the surgery.

Many times children tend to become far sighted after the surgery and need to have their sight corrected with

strong corrective lenses. The farsightedness can be corrected with one contact lens or glasses if both eyes had the surgery. The amount of the farsightedness frequently decreases over many years as the childs eyes grow, normally reaching adult size near puberty. As the childs eyes grow, it will be noticeable that there will be a need for several prescriptions changes, and once the eyes have stopped growing, there many be a need for an artificial lens to be permanently implanted (D'Alonzo, 1991; Glasspool, 1984).

Many times children who have cataracts have trouble learning to use their vision in one or both eyes (D'Alonzo, 1991; Glasspool, 1984). If this is the case, the eye care specialists may prescribe the use of an eye patch to strengthen the weaker eye.

Nystagmus

Nystagmus is considered a rhythmic oscillation or jiggling of the eyes that the child can not control (Berne, 1994). Very often the eyes move back and forth, but can also move up and down in a rotary fashion, or in a combination of these two movements. Nystagmus may also occur alone, or may accompany another visual problem.

In children who have nystagmus, their distance vision is usually limited to 20/40 to 20/400 (Berne, 1994). Often, however, children with nystagmus find a specific head or eye position in which they can increase

their vision and now have a strong focus point. This position is referred to as a null position, and the child prefers this position because it gives them the best possible visual acuity. Sometimes this position that the child has created for themselves is so extreme that surgery to alter this alighnment of the eyes and then move the null point over may be helpful. This kind of operation usually suceeds in moving the null point, but does not remove the nystagmus. Many times, the nystagmus is dampened when the child focuses on an object near by. Therefore, the childs vision when they are reading may be much better than the vision for distant objects. Some parents have reported that the nystagmus gets worse as the child tends to get tired (Berne, 1994).

At this time, there is no accepted treatment for nystagmus. Special prescription prism lenses may improve the visual effeciency and comfort of the child. If they are able to reduce the nystagmus by turning their head. The prisms would not usually be prescribed for daily full time wear, but only work during special activities (Berne, 1994). At this time, the eye care specialist will determine whether the child has nearsigntedness or farsightedness that could be somewhat improved with eye glasses.

After finding out that the child is indeed visualy impaired many thoughts and worries go through the heads

of these parents and being able to adjust can be a big concern (Berne, 1994).

Family Adjustments

As soon as a women becomes pregnant, both parents begin to fantasize about the child that they have created. The child will be perfect. The child might have her color hair, his smile and may be very successful. The name will be thought of, the room decorated, and special items of clothing will be purchased. At this time, thinking of having a child with a visual impairment probably never entered the mind (Glasspool, 1984).

When the diagnosis was made whether at birth or maybe sometime later, parents may undoubtly experience a variety of emotions. Researchers have stated that some parents refer to being "devastated", and some to being "confused"(Albrecht, 1995). Many parents have even said that they did not believe the diagnosis at first or maybe did not want to believe it. All of these emotions are very normal. A wide variety of parents have found to have had these same feelings when trying to adjust to their child's visual impairment, but that does not mean that coping with these emotions is easy or that parents will be able to adjust to this news overnight (Albrecht, 1995). Coming to terms with the childs visual impairment

will be a many stage process that could take months or years to complete (Albrecht, 1995).

Being told that your child has a disability is stated by Segal (1988) to be one of the most emotional experiences that anyone can experience. This experience can not be planned for, and certainly these parents can not plan on what the reaction will be. There are no correct or incorrect emotions. It is also normal for husband and wife to experience different emotions, of different intensities, at different stages than one another. The acknowledgment of emotions that parents do feel, is often the first step to being able to cope effectively. At this time, denying the emotions that are being felt is said to only prolong the adjustment process.

Grief

After the initial shock of the childs diagnosis, many parents have said that they tend to feel extremely sad (Bright,1997). Due to the fact that parents are human and caring, grief is unavoidable. Everyone grieves at some time in life and it is an inevitable part of the life cycle which is natural and a healthy response to the pain that is being experienced. Grieving is said to be an extremely powerful process that has its own stages. It also has the power to heal and move individuals to a

new view (Finston,1990).

The grief that is experienced when finding out about the childs visual impairment diagnosis must be honored and allowed to surface. Grief that is not acknowledged will be pushed deeper down inside, and eventually eat away at the individual whether it is acknowledged or not.

Not allowing an outlet for these feelings can lead to problems such as tension headaches, nightmares, inability to sleep, anxiety reactions, generalized stress reactions later on (Bright, 1997). This can be a double tragedy for the child. The parents who seem to close themselves off from the pain of grieving often say that they do not go on to have a close relationship with their child (Finston, 1990).

Each individual has their own way to cope with grief. It can certainly be an enormously hard task due to the fact that many parents do not have previous experience to guide them.

Thompson (1986) suggests some methods of coping with grief. First, parents should try to set aside a time which will allow the feelings of grief to be explored fully. Second, it is important that these parents share this grief with another individual. Third, it is also important for these parents to let things go for awhile- to be less organized, less productive and so on. Fourth, it is important for these parents to find a quiet area to

actively feel the grief which can be called a private place to them. Fifth, these parents should try to avoid as much noise and excitement as possible during this time, so the true emotions can be expressed. Sixth, it is important for these parents to find some relaxation tapes so unwinding can be essential. Parents may also find other comforts or coping styles in which would best to suitable for them.

Parents who have a special church find comfort through their religion. Other parents may find that mediation or reflection along with long walks helps them to survive this hard first period. Many parents also grieve so endlessly about having an imperfect child that they are never able to enjoy the child they now do have (Finston, 1990).

There is a delicate balance between grieving and making grief into a life style. In the beginning, it is important to grieve , but eventually there must be ways to let the grief and pain lesson so that parents can start to live again (Finston, 1990).

A measure of maturity is the ability to face the problem issues of daily living , even the terrible ones, head on. Real issues require energy, attention and intelligence to find solutions.

Guilt

It is very normal for parents to experience quilt when they find out that their child is visually impaired. It is also natural to feel desolate, at fault or to feel that the impairment is in someway a sign of their own failure (Weiss, 1989).

Guilt is a feeling that can many times promote more pain. Older parents have experienced feelings such as regret and guilt, and even some intensely painful feelings as well. However, if parents choose to enmesh themselves in guilt and shut everything else out, precious opportunities are lost. Parents who have enmeshed themselves in guilt can cause themselves unnecessary pain, harm their children and hurt their visually impaired child even more (Simons, 1987).

Anger

Undoubtedly the most common, most unsettling, and strongest response expressed by parents when hearing that their child has a visual impairment diagnosis is profound anger. This reaction is said to be a normal and a healthy response to the pain and hurtful feelings that parents may be feeling when they find out about their child's impairment and yet this anger can be the most difficult of all emotions to handle. Anger usually frightens most people. Individuals feel that they will be extremely overwhelmed, loose control and are afraid of

what they may do.

The anger that a parent feels when hearing of their childs impairment commonly takes the form of questions such as "Why me?, What did I do to deserve this? or What does this mean?". Working through the anger to acceptance is one way to help the child grow emotionally and have a satisfying life. By helping the child to uncover strengths that were felt prior to the visual impairment diagnosis (Bowman, 1995).

Denial

Denial is another emotion that can be experienced by parents when finding out that their child has a visual impairment (Bloom, 1990). Denial is a very common emotion that can take on many forms. Many times denial is destructive. When parents refuse to believe the visual impairment diagnosis, they end up causing their child more harm than good. Some parents might deny that there is a diagnosis of visual impairment or ignore the explaination to about how this disability will affect their childs development (Bloom, 1990). Parents often feel that others do not know their child and how can they possibly understand what they are going through, so as a consequence they may not participate in any early intervention programs that would benefit their child (Bloom, 1990).

It is extremely important to remember that the more information that parents have about their children and the more interaction with the eye care professionals, the more realistic parents can be able to be about their child.

In summary, there are several emotions that parents may feel when they first receive the diagnosis of their child's visual impairment; grief, anger and denial. All of these feelings are normal and are more or less intense depending on unique circumstances.

Coping Strategies

The concept of coping and the examination of specific coping styles which families use to manage stressful situations has been of great interest to researchers (McCubbin, 1996). Coping is considered an active process involving both the utilization of existing family resources, which may help strengthen the family unit and help to reduce the impact of stressful events and facilitate their recovery (Bennett, 1996; McCubbin, 1996). Coping may also be defined as a specific effort by which individual family members as a whole attempt to manage a demand on the family system and bring resources to try to manage the situation (Margalit, 1991; McCubbin, 1996)

Although many researchers have found that coping has

often been conceptualized at the individual level, it has also been investigated at the family level (Lu, 1996; McCubbin, 1996). Family coping can be viewed as a coordinated problem solving behavior of the whole system, but it could also involve complementary efforts of individual family members, which usually fit together as a synergistic whole. This seems to create a balance between demands and resources and at the same time takes away stressors and hardships. In addition, coping can involve direct action to eliminate or reduce the number and intensity of particular demands that may be created when a parents finds that they have a visually impaired child. Coping may also involve direct action to acquire additional resources that are not available within the family itself. Coping may also involve managing the tension associated with having a impaired child or it may involve the family to work together as a whole to work out the stressful times. In summary, coping and problem solving may be directed at the reduction of stresses and hardships, the use of additional resources, the ongoing management of the family system tension, and shaping the individuals within the stressful situation.

McCubbin (1996) feels that there are two levels of coping which consist of high coping and low coping. The parents and families that are considered to have low coping have indicated that they cope with family

difficulties by getting upset, indicating less respect for each other, blaming other individuals or other family members, as well as showing less caring and understanding, less pride and less acceptance for family togetherness.

The parents and families who show high coping scores indicate that they cope with their family problems by achieving trust and respect while maintaining an emotional calm and stability. These parents also seem to cope through having faith, accepting stressful life expectancies and difficulties while working together to solve problems. Furthermore, the high coping families are secure in their sense of purpose, in being able to plan ahead, and in being valued for their efforts and in feeling that life is meaningful (McCubbin, 1996).

Parents of children with a visual impairment are usually in close contact with professional helpers regardless of the child's age (Hanline, 1992; McCubbin, 1996). Professionals have been seen as sources of formal support, providing information or counseling when needed. Professional support is usually distinguished from the more informal sources of emotional support often received from family and friends. However, it has been noticed that professionals are now being viewed as potential partners who can offer informal as well as formal support to help parents and families with their difficult issues

in life. Professionals can also provide support to parents by providing resources such as a supportive network and expertise. They can also help to create and maintain an open, honest and collaborative relationship with the parents so they will be able to cope more effectively.

Developing a Support System

When parents have questions about their child, advice and support are easy to come by. Parents often ask advice from friends, family or neighbors when raising a child with a visual impairment. They may ask for time off from the care giving duties and see if a loved one will take a night to watch their child. The parents may at times need a shoulder to cry on or just need a helping hand. Parents usually can find an understanding ear most of the time when they want to talk about the stresses of parenting a child (Holbrook, 1996).

When a parent has a child with a visual impairment, the usual avenues of support are not always there. Although family and friends may want to be supportive, they may not know how to give the help that is needed. Fortunately, there are many great sources of support for families of children who have visual impairments. These include: other parents with visually impaired children and support groups for visual impairments (Holbrook, 1996).

Other Parents Who Have a Visually Impaired Child

As difficult as it may seem, there are other parents who understand what it means to have a visually impaired child. These parents may not be close personal friends or long lost relatives ,but there are other parents who are in the same situation who may be able to give many different types of support. Other parents can also be found through the child's early intervention or in the preschool program. The early intervention programs can be extremely supportive and beneficial and while the parents of these visually impaired children are there they may also find notices of various support groups that they may be offering that would also expand the supportive network that they have created for themselves (Holbrook, 1996).

Support Groups

Many times, the easiest way to meet other parents is through support groups for parents of visual impaired children. These support groups consist of loosely structured groups who meet together to talk and share experiences with each other about their children's visual impairments (Knussen, 1992).

There are several national organizations that have local or state chapters in various communities. The

National Association for Parents of the Visually Impaired (NAPVI) is also an organization which has been developed by parents for parents of visually impaired children. This organization offers information through workshops and publications to help parents meet the unique needs of their visually impaired children. Another organization offered to parents is the National Organization of Parents of Blind Children. According to Knussen (1992), this organization is also founded by parents for parents and also publishes a newsletter called Future Reflections which includes many informative articles by parents and their children.

It may also be helpful for parents to join groups for parents with various disabilities or visual impairments. Within these groups, parents often express same situations, emotions, social lives, education and much more which can be extremely beneficial.

In conclusion, once a parent has found out that they have a visually impaired child, it is important to find qualified professionals to care for the child, and to understand the visual impairment in detail. It is also important to learn how to adjust emotionally and find coping strategies that will help to alleviate the unresolved emotions and attitudes so living life will be fun and less stressful with the visuallly impaired child.

Chapter Three

Methods

Subjects

Sixty parents whose children's ages ranged from one month to three years old were located in the St. Louis area. A total of thirty parents of visually impaired children and thirty parents of fully sighted children were chosen to participate in the study.

The parents of the visually impaired children were found at a The Delta Gamma Center for Children with Visual Impairments located in St. Louis. This center gave approval to the researcher to come into their facility and ask the parents of the program if they would like to participate in a study. This facility also agreed that on three separate days, the researcher would come into the groups and ask them if they would like to participate. These parents participated in support groups and preschool programs at the center where their child attends on a regular basis. All of the parents were told about the study and agreed to participate as long as they would remain anonymous.

The parents of the fully sighted children were found in various locations throughout St. Charles County. Each of these parents were also told about the study and also felt as though they also would like to contribute as long as they also remained anonymous.

Procedure

The parents of the visually impaired children were informed in advance that they would have the opportunity to be involved in a study involving coping styles conducted by the researcher, a student from Lindenwood University. The parents were also told that participation was voluntary and anonymous and no one was obligated to be involved.

On three separate days, three various parent groups were held at The Delta Gamma Center for Children with Visual Impairments. The parents in these groups were informed prior to the researcher coming in about the study by their group facilitator. The researcher then came into the groups and again told them about the study being conducted and the participants were asked if they would like to participate. They were also informed that they would then have to answer a few demographic questions (Appendix B) along with a thirty item survey. All of the parents who in attendance returned the surveys as requested.

The parents who had the fully sighted children were asked to participate at various times and locations throughout St. Charles County. All thirty parents who were approached agreed to be involved in this research as long as they could also remain anonymous. As these parents were approached they were asked if they could

complete a ten minute parent survey along with a few demographic questions (Appendix C) about themselves. When all of the surveys were completed there were a total of thirty visually impaired packets and thirty fully sighted packets for this study.

Materials

All sixty parents were given a parent survey packet which included five demographic questions implied along with the Family Crisis Oriented Personal Evaluation Scale "F-COPE" (McCubbin, 1996). Permission to use this scale was obtained from Dr. McCubbin at the University of Wisconsin by completing an abstract which which is included in Appendix A which informed Dr. McCubbin how his test would be used. The F-COPE Scale (Appendix D) is designed to record problem solving attitudes and behaviors that families seem to develop to respond to problems of difficulties.

This scale has thirty coping style questions which looks at how the family internally handles the problem between its members, along with five subscales which looks at: Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family to Acquire and Accept Help and Passive Appraisal (McCubbin, 1996). The instrument was rated on a five point Likert scale indicating the extent to which agreed or disagreed.

The reliability of the instrument was then examined. Cronbachs alpha was also computed showing good reliability for the total sample and the overall alpha reliability is .87. The results were replicated with reliability and validity checks. Husbands, wives and adolescents were pooled and the total sample was randomly split into two halves, giving sample one and sample two (McCubbin, 1996).

Test Retest was also used with these participants. This test was given during the months of November and December of 1981. It was administered to undergraduates, graduates and high school students who were enrolled in psychology and family studies classes. During the months of January and February of 1982, the test was given again to the same 116 subjects which consisted of two thirds female and one third male. The mean age of these subjects was thirty.

The findings suggested that the more concrete behavioral questions provided more response consistency over time than the factors which related to more cognitive adjustment. In determining the norms, data was obtained from adolescents who were in a residential treatment for deviancy and social adjustment problems.

Design

A quazi-experimental, descriptive analysis was

done by using the F-COPES assessment. The design used a comparison of coping techniques of parents who have visually impaired children by parents who had fully sighted children.

Chapter Four

Results

Table 1, shows that when conducting this study some demographic questions were asked about the relationship to the child. Table 1 shows that 49 mothers, nine fathers and two grandparents completed the survey which totalled 60 individuals.

Table 1

Demographic of Relationship to Child

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
MOTHER	1.00	49	81.7	81.7	81.7
FATHER	2.00	9	15.0	15.0	96.0
GRANDPARENT	3.0	2	3.3	3.3	100.0
TOTAL		60	100	100	100

VALID CASE 60 MISSING CASES 0

Table 2 and table 3 also show a demographic chart that indicates if the individual who completed the survey works outside the home on a full/part time basis or does not work at all. In table 2, it shows that 33 of the individuals who completed the survey did indeed work

outside of the home and 27 did not. Table 3 also shows that 26 individuals stayed at home and did not work at all, 37 individuals worked full time and seven worked part time.

Table 2

Demographic of Parents Who Work Outside The Home

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
YES	1.00	33	55.0	55.0	55.0
NO	2.00	27	45.0	45.0	100.0
		60	100.0	100.0	
VALID CASE	60	MISSING CASES			0

Table 3

Demographic of Parents Who Work Full or Part Time

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
STAY HOME	0	26	43.3	43.3	43.3
FULL TIME	1	27	45.0	45.0	88.3
PART TIME	2	7	11.7	11.7	100.0
		60	100.0	100.0	
VALID CASE	60	MISSING CASES			0

Table 4 and Table 5 continues with the demographics of the sample and shows whether the individual completing the survey shares the caregiving responsibility with someone else during the week other than themselves and if the care giving roles are shared who are they shared, with. Table 4 shows that 50 individuals did share this responsibility with another individual and ten did not. Table 5 shows that the care giving role was shared with someone else.

Ten individuals share that role with a paid care giver, six with a grandparent, six with a spouse, 21 with another relative and 3 with a combination of care givers.

Table 4

Demographic On The Shared Roles of The Caregiver

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
YES	1.00	50	83.3	83.3	83.3
NO	2.00	10	16.7	16.7	100.0
PART TIME	TOTAL	60	100.0	100.0	

VALID CASE 60 MISSING CASES 0

Table 5

Demographic On Who The Shared Responsibility is With

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
PAID CAREGIVER	-1.00	10	16.7	16.7	16.7
GRANDPARENT	1.00	6	10.0	10.0	26.7
SPOUSE	2.00	6	10.0	10.0	36.7
OTHER RELATIVE	3.00	21	35.0	35.0	71.7
COMBINATION	4.00	3	5.0	5.0	76.7
	5.00	14	23.3	23.3	100.0
TOTAL		60	100.0	100.0	
VALID CASE	60		MISSING CASES		0

Table 6 shows the education demographics of the sample. This table shows the highest level of education that was completed by the participants completing the survey. The table shows one grade school graduate, 22 high school graduates, 35 college graduates, one business school graduate and one tech school graduate out of a total of 60 cases.

Table 6

Demographic of The Caregiver's Education

VALUE LABEL	VALUE	FREQUENCY	PERCENT	VALID%	CUM%
GRADE SCHOOL	1.00	1	1.7	1.7	1.7
HIGH SCHOOL	2.00	22	36.7	36.7	38.3
COLLEGE	3.00	35	58.3	58.3	96.7
BUISNESS	4.00	1	1.7	1.7	98.3
TECH	5.00	1	1.7	1.7	100.0
TOTAL		60	100.0	100.0	

VALID CASES 60 MISSING CASES 0

Table 7 shows the total coping score of the individuals who completed the parent survey. The mean was calculated to be 101.2330 and the median 103.0000 with 60 cases in all.

Table 7

Total Coping Score

VALUE CASES: 60.0 MISSING CASES 0.0 % MISSING: 0

MEAN 101.2330 STD ERR 1.5860 MIN 75.0000 SKEWNESS -0.2694

MEDIAN 103.0000 VARIANCE MAX 125.0000 S E SKEW 0.3087

5%TRIM 101.3619 STD DEV 12.2853 RANGE 50.0000

KURTOSIS 0.5237

IQR 15.5000 SE KURT 0.6085

Table 8 concludes the tables and shows the coping scores by group. Group one shows the mean of 101.800 and the standard deviation of 11.5889 for parents of the visually impaired children, while group two shows the mean of 100.667 and the standard deviation of 13.1184 for parents of the fully sighted children.

Table 8

TOTAL COPING SCORES BY TOTAL GROUP

	MEAN	STD DEV	SKEW	KURTOSIS	LEVENES	T
GROUP 1	101.800	11.5889	0.4269	-0.2672		
					P=.517	0.35
GROUP 2	100.667	13.1184	0.4269	-0.6288		
			.724>	0.05		FAILED
			TO REJECT	0		(2-TAILED)

GROUP 1= VISUALLY IMPAIRED GROUP 2= FULLY SIGHTED

Research has been conducted to determine if parents with visually impaired children have better coping strategies than parents with fully sighted children. The present study has shown that there is no difference between the two variables on the total coping score.

Chapter Five

Discussion

The present research has shown no difference when comparing coping styles of parents with visually impaired children to parents with fully sighted children on a total coping scale. Segal (1988) has also shown that a wide range of emotions can be experienced from parents when dealing with a crises in the family, and denying any crises will only prolong the adjustment process. Thompson (1986) has also agreed with the research and feels that any parent who is in a crises may experience many emotions such as grief, guilt, anger or denial whether they are parents of a visually impaired child or not. Prinz (1996) continues to agree with the research and goes on to say that any parent who may be going through a crises may also find a supportive network of their own such as other parents with the same crises, support groups or national organizations.

McCubbin (1996) has found that every parent has their own coping styles which may be different from others, but they do cope in a way that is most beneficial to them. It has also been found that whether the parent has a visually impaired child or not it does not show a significance in coping styles.

Although the research has shown no significant difference between the two groups, there are many

limitations that are important to be discussed. First, this study looked at a sample of sixty parents of visually impaired children and parents of fully sighted children from various locations throughout the St. Louis area, but there was no random sample gathered which would make this a more thorough study.

This was a study with one variable, so to make this study more thorough it would be helpful to look at more variables. This study looked at a sample of parents on one occasion and based the results on that one time without looking at other variables involved such as if the parents were going through a family crises or a very positive time in their lives. This study looked at parents with children whose ages ranged from 1 month-3. With these ages there is no way in telling when exactly the parents had to experience this crises or whether it was a crises at all for them. If the study was done longitudinally there might of been different results.

Due to the fact that the sample of parents were only given this survey once may also be a limitation instead of applying the Test Retest method. Another limitation may be how the survey was administered. This particular survey was a sample of convenience which was given out to mothers, fathers, grandmothers and grandfathers in no particular order to whomever came in contact with this researcher. While the survey was administered, the

researcher also told all of the participants that this study was a coping technique survey which may have biased the research. If the survey was administered in another way and there was minimal information disclosed about the research it may also have had different results. Another limitation may have been the fact that some parents have had numerous supportive avenues along the way during their crises where others may not have had. There are a number of ways in which this study could have been more efficient if there was more time, more avenues or a larger sample.

Suggestions for further research may be to look at parents right after their child was diagnosed with an impairment or while they are still going through a crises. This would give a more accurate sample of how the sample copes. Another suggestion may be to include more variables in the study and get a bigger sample if possible. It may also be helpful to look at various ethnicities and ages of the sample of parents that are going to be researched. A longitudinal study may also be helpful and may show how these parents cope with various crises in their life.

Appendix A

ABSTRACT FOR PERMISSION OF PROPOSED STUDY
Family Stress, Coping and Health Project

Name: Lisa Tackett
Adress: 715 Tobermory Ct.
City: Wentzville
State: MO Zip: 63385
Phone: (314) 332-5666

Doctoral Dissertation Project:
( ) Yes (X) No

Master's Thesis Project:
(X) Yes ( ) No

University/Institution Affiliated with Project or Awarding Degree:
Lindenwood University

Title of Project, Publication, or Dissertation:
Comparing coping techniques of parents who have visually impaired children to parents with fully sighted children.

Projected Year of Completion, Publication, or Graduation:
Graduation May 1998

Brief Description:
Comparing coping techniques/styles of parents with visually impaired children employ. The sample is from the Delta Gamma Center for Children with Visual Impairments in St. Louis along with parents of like age children who do not have any visual impairments.

Research Variables:
Sample:

Type of Group: Parents who have young visually impaired children.

Sample Sizes: 30 - 40 parents with visually impaired children and 30 - 40 parents with fully sighted children.

Design & Methods:
Quassi-experimental, descriptive

CONTINUED ABSTRACT FOR PERMISSION OF PROPOSED STUDY

A. Research Instruments Developed by the Family Stress, Coping and Health Project (Check all the you are requesting permission for)

1. Stress and Strain Scales
( ) A-FILE: Adolescent - Family Inventory of Life Events and Changes
( ) FILE: Family Inventory of Life Events and Changes
( ) FPRES-E: Family Pressures Scale-Ethnic
( ) YA-FILE: Young Adult family Inventory of Life Events

2. Coping Scales
( ) A-COPE: Adolescent - Coping Orientation for Problem Experiences
( ) CHIP: Coping Health Inventory for Parents
( ) DECS: Dual Employed COping Scales
( ) Family Resiliency
( ) FAMCI: Family Coping Index
( ) FCCI: Family Cping Coherence Index
(X) F-COPES: Family - Crisis Oriented Personal Evaluation Scales
( ) YA -COPES: Young Adult- Coping Orientation for Problem Experiences
( ) YCI: Youth Coping Index

3. Family Resources and Social Support Scales
( ) FCAELAEBI: Family Celebrations Index
( ) FHI: Family Hardiness Index
( ) FIRM: Family Inventory of Resources for Management
( ) FTRI: Family Time and Rountine Index
( ) FTS: Family traditions Scale
( ) Social Support Index
( ) Social Support Inventory
( ) YA-SSI: Young Adult Social Support Inventory

4. Appraisal Scales
( ) FAM - AIDS: Family Adaptation Index of Developmental Support
( ) FIC: Family Index of Coherence
( ) FSCH-E: Family Schema-Ethnic

5. Family Problem Solving Scales
( ) FPSC: Family Problem Solving and Communication

6. Work and Family Scales
( ) FIB: Family Index of Balance (Educational Tool)
( ) OCS: Organizational Climate Scale

7. Family Functioning Scales
( ) FACI8: Family Attachment and Changeability Index

8. Family Resiliency Scales
( ) FIRA-G: Family Index of Regerativity and Adaptation - General
( ) FIRA-M: Family Index of Regerativity and Adaptation - Military

9. Family Adjustment and Adaptaion Scales
( ) FDI: Family Distress Index
( ) FMWB: Family Member Well- being Index

B. Other family Measures Used in Your Study

( ) APGAR
( ) FACES I, II, III
( ) FAD: Family Assessment Device
( ) FAM: Family Assessment Measure
( ) FES: Family ENvironment Scales
( ) Others: Describe briefly

C: Other Physiological Measures Used in Your Study
( )
( )

D: Child Measures Used in Your Study
( )
( )

Do you wish to be kept on the mailing list?
(X) Yes
( ) No

* This abstract should be completed and returned when requesting permission to use any of the instruments. Thank you for completing this form.

Send To: Dr. Hamilton I. McCubbin, Director
Dr. Anne I. Thompson, Associate Director
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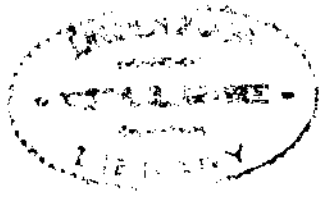

Appendix B

COVER LETTER FOR PARENTS WITH VISUALLY IMPAIRED CHILDREN

Parents,

Hi, my name is Lisa Tackett. I am currently enrolled in the Masters program at Lindenwood University and am interested in doing some research on the various coping techniques that parents with visually impaired children use.

At this time, I am asking parents with visually impaired children to please complete a few questions about themselves followed by a thirty question survey which will help me with my research. Also when answering these questions and survey, it is important that you know that these answers will be anonymous, so please do not include your name on the packet.

Thank you in advance for your cooperation!

Age of child_____

Relationship to child:

Mother_____
Father_____
Grandmother_____
Other (please explain)_____

Do you work outside the home?

Yes_____ No_____
Full Time _____ Part Time_____

On a weekly basis do you share the primary caregivers responsibilities with someone else other than yourself?

Yes_____ No_____

Paid Caregiver_____
Spouse_____
Grandparents_____
Neighbors_____
Other (please explain)_____

Highest level of education completed:

Grade School_____
High School_____
College_____ Other (please explain)_____

Appendix C

COVER LETTER FOR PARENTS WITH CHILDREN

Parents,

Hi, my name is Lisa Tackett. I am currently enrolled in the Masters program at Lindenwood University and am interested in doing some research on the various coping techniques that parents with children use.

At this time, I am asking parents with children to please complete a few questions about themselves followed by a thirty question survey which will help me with my research. Also when answering these questions and survey, it is important that you know that these answers will be anonymous, so please do not include your name on the packet.

Thank you in advance for your cooperation!

Age of child_____

Relationship to child:

Mother_____
Father_____
Grandmother_____
Other (please explain)_____

Do you work outside the home?

Yes_____ No_____
Full Time _____ Part Time_____

On a weekly basis do you share the primary caregivers responsibilities with someone else other than yourself?

Yes_____ No_____

Paid Caregiver_____
Spouse_____
Grandparents_____
Neighbors_____
Other (please explain)_____

Highest level of education completed:

Grade School_____
High School_____
College_____ Other (please explain)_____

Appendix D

Parent Survey

Directions:

First, read the list of response choices one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you **STRONGLY AGREE**; if the statement does not describe your response at all, then circle the number 1 indicating that you **STRONGLY DISAGREE**; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other family who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head -on" and trying to get solutions right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in god	1	2	3	4	5

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