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University of North Dakota

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A Single Case Study: Occupational Therapy Home Program
For a Child With Congenital Cataracts

by

Melissa R. Edwards

Thomas J. Clifford, Ph. D., Advisor
Gail Bass MS OTR/L, Advisor

Scholarly Project

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of the

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CHAPTER I

INTRODUCTION

Infantile/congenital cataracts is a rare disorder, however it accounts for a substantial proportion of childhood blindness (SanGiovanni et al., 2002, p. 1559). Reuters Health (2003) indicates that, “nearly 40 percent of otherwise healthy babies who have infantile cataracts, a birth defect that requires surgery before the age of six weeks, are not diagnosed with the condition until they have passed that age”(p.1). “Vision provides a critical role in the overall development of children who are sighted, because vision allows infants and children to develop skills through imitation” (Baker-Nobles, 1997, p. 375). According to Baker-Nobles, “because of the importance of vision in the learning process, visual impairments can result in significant developmental delays, particularly in the absence of intervention services” (p. 376).

Occupational therapy literature does address the assessment and intervention of individuals diagnosed with visual deficits, but there remains little information specific to congenital cataracts. Occupational therapists that have knowledge in the area of visual deficits, including congenital cataracts, could provide holistic treatment to these children not only by looking at their visual deficit, but also by assessing the child’s ability to participate in age appropriate activities. Occupational Therapy services would provide children with opportunities and encouragement to interact socially, play, and complete self-care activities.

This scholarly project is based on a single case study of a child diagnosed with congenital cataracts. The child is the daughter of close friends and I have had the opportunity to be involved in her care since she was born on October 26, 2000. Tristan appeared healthy and upon examination her pediatrician noted no concerns. It was not

until Tristan was almost 3 months old that her older brother was playing with her and noticed she was not following his face. He commented that he thought Tristan was “blind” to his parents and they immediately took action. Tristan was taken to a pediatric ophthalmologist/surgeon at The Children’s Hospital in Denver where she was diagnosed with a dense congenital cataract of the right eye. Surgery was immediately scheduled for January 17 when Tristan was almost three months old and follow-up appointments were scheduled for contact lens fitting. Tristan began wearing the corrective contact lens on February 11, 2001, on a full time basis. Occlusion therapy was also initiated at four months of age, beginning with one hour of patch time a day and progressing to four hours of patch time each day. Tristan is now three years old and has good fixation in each eye, straight eyes, and 20/100 visual acuity in the right eye. The family is pleased that early treatment was implemented and they are very happy with Tristan’s visual and functional abilities.

Tristan passed through the normal developmental milestones of rolling, turning, sitting, crawling, standing, walking and dressing. Tristan enjoys gross motor activities; however, she is very cautious when trying new or unfamiliar activities. Fine motor activities appear to be slightly more challenging for Tristan, which may be due to difficulties with near vision. Therapeutic activities have been recommended to help Tristan in transitioning to preschool assignments and activities. The family has been compliant with all treatment; therefore a home program would benefit this child.

The product of this scholarly project is a home program designed specifically for the child in the above case study. Activities are designed to be carried out by the family and caregivers’ involved with this child. The home program emphasizes supportive intervention, compensatory intervention, and direct remediation strategies for following through with therapeutic activities in the home. It is based on a comprehensive literature review that provides background information on infantile/congenital cataracts, surgical and optical interventions and occupational vision therapy.

CHAPTER II REVIEW OF LITERATURE

Introduction

Congenital cataracts is an uncommon disorder, however it accounts for a significant amount of childhood blindness. With early detection, surgical and optical intervention, the outlook for children with infantile cataracts can be good. Further visual improvements are possible for children who receive early intervention services. Occupational therapists working in conjunction with optometrists/ophthalmologists can improve the visual and functional outcome for children with cataracts.

Congenital/Infantile Cataracts

Infantile cataract is “the condition defined as a lens opacity present at birth or detected within the first year of life” (SanGiovanni et al., 2002, p. 1559). “A congenital cataract is an opacity (cloudiness) in the lens of the eye that is present at, or develops shortly after, birth” (Congenital cataracts fact sheet, 2003, p. 1). Cataracts can affect one eye (unilateral) or both eyes (bilateral) depending on the cause of the cataracts. For the purposes of this paper infantile and congenital cataracts will be used interchangeably.

“Pathogenic factors implicated in infantile cataractogenesis are multiple and diverse; many are rare and remain uncharacterized. There are genetic, environmental and metabolic causes” (SanGiovanni et al., 2002, p. 1559). According to Rahi, Dezateux, and British Congenital Cataract Interest Group (2000), there are nine categories in which congenital and infantile cataracts can be placed. These categories include “isolated

cataract, associated ipsilateral ocular disorder, intrauterine infection/maternal infection embryopathy, intrauterine drug exposure, intrauterine ionizing radiation, prenatal/perinatal metabolic disorder, hereditary without associated systemic disorder, hereditary with associated systemic disorder or multisystem dimorphic syndrome, and idiopathic” (p. 2109). According to SanGiovanni et al., “approximately half of all bilateral and all of unilateral infantile cataract cases are idiopathic. Hereditary causes are attributed in approximately 40% of cases with known cause. Environmental or metabolic factors are attributed in approximately 30% of all cases” (p. 1559).

Understanding the structures of the eye and how they affect vision is important when discussing congenital cataracts. The lens of the eye is located behind the pupil and serves an important function in the visual processing system. “As the lens is able to change its shape, it can focus objects at different distances” (Congenital cataracts fact sheet, 2003, p. 1). The healthy human lens is arranged so that it is transparent, like glass. When the arrangement of the cells is disturbed in any way the transparency is lost and an opacity results. When this happens the retinal image is blurred or blocked depending on the location and density of the opacity (Congenital cataracts fact sheet, p. 1). In the case of an infant this not only blurs the retinal image, but also disrupts the development of visual pathways (Yamamoto et al., 1998, p. 411). This alters the quality of sensory information available to the child during sensitive periods of visual development (SanGiovanni et al., 2002, p. 1559). The cataract could deprive the child of stimulation needed for typical development.

Studies have found differing prevalence rates of congenital cataracts over the years. According to SanGiovanni et al., in economically developed nations, the

prevalence of congenital/infantile cataracts is approximately 6.0 per 10,000 infants surviving in early childhood (p. 1559). Population based studies have suggested a much lower prevalence rate of 2.1 per 10,000 live births; however, it is thought that these figures are incorrect secondary to unreported or missed cases (Taylor, 1998, p. 10).

Congenital/infantile cataract is a rare disorder however, it accounts for a substantial proportion of childhood blindness (SanGiovanni et al., 2002, p.1559). “The rate of blindness from congenital cataracts is much greater in developing countries, probably because better and earlier intervention is possible in industrialized economies” (Long & Chen, 2003, p. 2). “Prevention of visual impairment and blindness in childhood due to congenital and infantile cataract is an important international goal” (Rahi et al., 2000, p. 2108). Reuters Health (2003) indicates that, “nearly 40 percent of otherwise healthy babies who have infantile cataracts, a birth defect that requires surgery before the age of 6 weeks, are not diagnosed until after they have passed that age” (p. 1)

“The visual outcome for pediatric cataracts is dependent on many factors, including the age when the cataracts develop, the density of the cataracts, the age at which optical correction is initiated and the degree to which the fellow eye is occluded” (Yamamoto et al., 1998, p. 414). “Amblyopia (lazy eye) and strabismus (misaligned eyes) are commonly associated with congenital cataracts and these conditions must sometimes be treated both before and after cataract surgery in an infant or child” (EyeMDLink, 2001, p. 1). According to Congenital cataracts factsheet (2003), in cases of unilateral cataracts there is a strong tendency for the child to prefer the healthy eye; therefore the eye affected by the cataract may not achieve normal vision (p. 2). “In early childhood, visual development progresses rapidly, and congenital cataract may obstruct proper visual

stimulation and cause occlusion amblyopia” (Lee & Kim, 2000, p. 221). It is now known that a unilateral cataract must be treated in the first few months of life for the child to obtain useful vision in the affected eye (EyeMDLink, p.1). However, in cases of bilateral cataracts, vision may be near normal if complications are avoided. According to EyeMDLink, children with bilateral cataracts may undergo surgery at an older age without developing amblyopia. However, de Bradander, Kok, Nuijts, and Wenniger-Prick (2002) found, “surgical correction is essential at an early age to prevent amblyopia, strabismus, or poor fusion and should be followed by immediate and permanent optical correction of the resulting aphakia” (p. 31).

According to Hiatt (1998), successful management of cataracts in infants and children is one of the most difficult challenges in pediatric ophthalmology (p. 476). Due to the significance of this disorder, it is important that pediatricians are familiar with the diagnosis of congenital cataracts in order for early detection to occur. “The medical, paramedical, and lay communities should be educated to detect this ocular defect early by observation of abnormal visual behavior, strabismus, nystagmus, or leucokoria” (Hiatt, p. 476). In a study conducted by Rahi (1999), “congenital and infantile cataracts were not detected by a health professional before the first birthday in 29% of cases, despite recommendations to examine all newborn and young infants routinely for cataracts” (p. 5). Reuters Health (2003) emphasized the need for direct ophthalmoscopic examination of the red reflex in the newborn period to facilitate early detection and improved outcomes for children with this disorder (p. 2). Once detected surgical and optical interventions must be considered.

Surgical Intervention

There are a number of things to consider when deciding whether to operate on an infant or child with congenital cataracts. According to Hiatt (1998), “congenital cataracts may be associated with anomalies, disease, or syndrome, which limits adequate visual rehabilitation, even with early surgery, optimal optical correction, and excellent parental compliance with optics and occlusion therapy” (p. 475-476). Taylor (1998) reported, when the visual defect in a child with congenital cataracts is severe enough to interfere significantly with visual development, then surgery and post-operative treatment are necessary; however, if the vision of the infant is “good enough” then active management should be postponed until the child is older (p.16). Each child must be assessed on an individual basis to determine if surgery and the complex process of visual rehabilitation after surgery are appropriate. Hiatt also reported the importance of assessing the parents’/caregivers’ motivation and their understanding to participate and comply with the demanding postoperative care of the child. “The family should be emotionally and financially motivated to cope with the long duration of the aphakic optical correction and amblyopia therapy” (Hiatt, p. 476).

“The indications for cataract extraction in children remain highly controversial” (Hiatt, 1998, p. 477). However, it is generally accepted that the earlier surgery is carried out for congenital cataracts, the greater the likelihood of positive visual results (Long & Chen, 2003, p. 2). According to Lee and Kim (2000), studies have reported good visual results after performing surgery within two, four and six months of age (p.221).

The Congenital cataracts factsheet (2003) indicated that, “removal of the cataract via surgical extraction of the lens is the most effective means of treatment for most cataracts” (p. 2). The main objective of surgical extraction of the lens is to achieve a clear pupillary space in a single operation (Hiatt, 1998, p. 477). Long and Chen (2003), wrote the two most commonly considered surgical interventions for infantile cataracts were lensectomy and lens aspiration. “Lensectomy involves the removal of the entire contents of the lens, central capsule and anterior vitreous (the gel which fills the body of the eye) with a suction cutting device” (Long & Chen, p. 2). “Lens aspiration removes the cataract but leaves the posterior capsule intact. A posterior capsulotomy (making a hole in the capsule) is almost invariably necessary because it normally thickens and opacifies quickly” (Long & Chen, p. 3). Wright (2001) reported, with today’s modern pediatric anesthesia and microsurgical techniques, the risks of cataract surgery are low and there are several gains that can be made with aggressive rehabilitation (p. 1122).

Late complications may occur in congenital cataract extraction therefore the child needs to be monitored closely by the physician. The most prominent among these complications is glaucoma (increased in intraocular pressure) with subsequent optic nerve damage and visual loss due to retinal detachment (Congenital cataracts factsheet, 2003, p. 2). There are treatments for these complications; however, visual development will again be affected. Everyone involved in the child’s care should be aware of signs of complications in order to prevent further visual problems.

Optical Intervention

After surgically extracting the cataract there are choices to make regarding optical corrections. “Removing the cataract removes a major element of the refractive power of the eye. This refractive error must be corrected as soon as possible after the cataract is removed so that normal visual stimulus and the potential for normal visual development is restored” (Long & Chen, 2003, p. 3). “An optical correction is necessary to provide suitable vision for the aphakic eye. Without the use of a correcting lens, the aphakic image on the retina remains blurred, unintelligible, and inducing amblyopia” (Hiatt, 1998, p. 478). There are currently several options to choose from to correct the resultant aphakia. The treating physician and the child’s parents or caregivers must make the decision of which optical treatment is best suited for the child.

According to Hiatt (1998), “the optical treatment of aphakia fall into three categories fixed by the geometry of the system: precorneal (spectacle), corneal (contact lenses or modified corneal surface), and postcorneal (intraocular lenses)” (p. 478). Spectacles/glasses are the oldest known form of rehabilitation for children who have had a cataract extracted. Hiatt wrote the advantages of spectacles; these include no contact in the eye, no ocular discomfort, easy adjustment and low loss rate (p. 478). However, Taylor (1998) addressed some of the disadvantages of spectacles such as optical, cosmetic, and the fact that infant’s ears and nose are often too small to support the large/heavy aphakic glasses (p. 21). Other disadvantages include distorted peripheral images, constriction of the visual field and problems with low compliance (de Bradander, Kok, Nuijts, & Wenniger-Prick, 2002, p. 31).

“Contact lenses are considered optically superior to spectacles for both unilateral and bilateral aphakia in children” (Hiatt, 1998, p. 479). The same author addressed the advantages of contact lenses in children as a reduced incidence of nystagmus, increasing optical zones, decreasing glare, and marked cosmetic improvement (Hiatt, p. 479). The success of contact lenses does, however, depend on the child’s willingness to wear them and the parents’ patience and perseverance (Hiatt, p. 479). The parents must also understand the increased cost, care, follow up and swift replacement when lost (to reduce risk of amblyopia). The high turnover rate due to lost or broken lenses may be a source of failure for some children and their families (Taylor, 1998, p. 22). “Contraindications of contact lenses include chronic external eye diseases, abnormal tear film, and inadequate blinking” (Hiatt, p. 479). For children with these problems, intraocular lens may be considered.

“The implantation of intraocular lenses (IOL’s) in pediatric patients remains a controversial issue” (Hiatt, 1998, p. 480). However, according to Long and Chen (2003) they are now being used more commonly in pediatric cataract surgery and may be implanted at the time of the original surgery or planned for sometime in the future, once the eye has stopped developing so rapidly (p. 3). Hiatt reported, “the best candidates for intraocular lens implantation are children with traumatic cataracts and corneal scars that preclude successful contact lens wear” (p. 480). Some literature reports that there is a lack of long-term, sufficient data to predict all the advantages and disadvantages of IOL’s in pediatric patients. However, Sinskey, Stoppel, and Amin (1993) reported improvements in instrumentation and surgical techniques that allowed pediatric patients

to achieve good visual acuity without the psychological trauma caused by spectacles and contact lenses (p. 407).

Even with early surgical and optical intervention, derivational amblyopia may cause a poor outcome for children with congenital cataracts (Francis, Ionides, Berry, Bhattacharya, & Moore, 2001, p. 1104). “In unilateral cases, amblyopia is caused by abnormal interaction between both eyes and inadequate visual stimulus, whereas in bilateral cases, only inadequate visual stimulus causes amblyopia” (Lee & Kim, 2000, p.223). For this reason, occlusion therapy is an important determinant of visual outcome in children with cataracts; however the amount of occlusion is a controversial issue. “Patching the fellow eye in infancy is a well recognized therapy to encourage visual development in the lensectomised eye in cases of unilateral congenital cataract” (Thompson, Moller, Russell-Eggitt, & Kriss, 1996, p. 794). According to Wright (2001), “excessive early occlusion may be associated with an increase in nystagmus and effects on the phakic eye, the child starts with occlusion of the phakic eye for 1 hour per day for each month of age until the baby is 6 months old; from 6 months, the vision is monitored by preferential looking, and the amount of occlusion of the phakic eye is modulated depending on the interocular difference” (p. 1125). According to Jeffrey, Birch, Stager, Stager, and Weakley (2001) alternate day occlusion is also an option for occlusion therapy. This requires that the patch be worn for 8 to 24 hours one day followed by a day of no patching. “The rationale underlying alternate day occlusion is to provide a reduced number of hours of occlusion during the period of binocular development but in a protocol that can be easily understood by parents” (Jeffrey et al., p.210). In a study conducted by Thompson, et al. (1996), the children had an occlusion regimen of patching

the phakic eye for 50% of waking hours in the first year of life, irrespective of the interocular acuity difference (p. 795). In this study it was found that the phakic eye had a loss of recognition acuity. According to The Future of Visual Development/Performance Task Force (1988) there is evidence that occlusion therapy along with active vision therapy is more effective than occlusion alone. For this reason it is important for family members to research the results of various patching regimens and discuss with their physicians vision therapy for their child (p. 97).

Choosing the appropriate patch for occlusion therapy for the child is also important. “This is generally done by the optometrist in consultation with the rehabilitation team” (Scheiman, 1997, p. 320). The main goal is to find out what type of patching the child will tolerate and which type will prevent them from “peaking”. According to Scheiman, “there are many choices available, among them a pirate patch with strap, bootie patch and adhesive patches that can either be placed directly on the eye or on the glasses” (p. 320). The use of a contact lens occluder may also be used. This is a lens worn in the phakic eye and is either very high power to blur vision, or a lens with a blackened center that prevents light from reaching the eye (Scheiman, p.320).

Visual Prognosis

Wright (2001) stated, good visual outcomes in children who have congenital cataracts can be expected (p.1120). “With aggressive treatment the visual prognosis is good, and there is even the possibility of obtaining binocular vision with stereoscopic acuity” (Wright, p. 1120). Brown, Archer, and Del Monte (1999) found that with

compliant caregivers (limiting occlusion therapy), good central visual acuity could be achieved and the opportunity to develop binocularity could be enhanced (p. 113). Brown et al. also found that, “in addition to obtaining a degree of stereopsis that is useful to patients daily living, the development of better motor cooperation may decrease the incidence of strabismus” (p. 113). Taylor (1998) reported that, 50% of cataract cases operated on in the first year of life obtained 20/50 or better and that 50% of the children with early surgery and optical correction had some binocular function (p. 24). Other studies have found less promising results regarding the child’s visual acuity and binocular vision; however, all agree that early intervention is in the best interest of the child.

Although some areas of visual functioning are looking more and more promising for aphakic children it must be recognized that some visual abilities are not achievable. The lens and the ciliary muscles of the eye allow accommodation (focus). When the lens is extracted from a child with congenital cataracts they lose that ability to accommodate. For this reason, aphakic children are required to wear bifocals/reading glasses to enable them to view objects at an arms length or closer. Caretakers and the medical community must find appropriate ways to assist the child with accommodative difficulty to increase their success and decrease their frustration.

Each child and their family must be assessed to determine which treatment will best suit them. Every case may be slightly or significantly different and, therefore, different results can be expected for each individual child. Furthermore, treatments and inventions for congenital cataracts are progressing rapidly; therefore, the medical and lay communities must stay updated on current treatment options and their results. Different

types of therapy are also available to enhance visual skills and performance for children with congenital cataracts.

Vision Therapy Intervention

“Vision Therapy is a training process in which the patient is taught to use their visual skills more efficiently” (Pacific University College of Optometry, 2002, p. 1).

“The American Optometric Association considers vision therapy as an integral part of the practice of optometry (The Future of Visual Development/Performance Task Force, 1988, p. 95). Visual therapy is individually designed for the patient and his/her specific problems (Polsdorfer, 1999, p. 3). This process can last anywhere from several weeks to several months depending on the needs of the patient. Some risks associated with vision therapy for children and their families include the cost and the time involved in treatment. The costs can be substantial and are not typically covered by health insurance (American Academy of Ophthalmology, 2001, p. 1). Another potential struggle for those involved in the vision therapy process is the increased amount of time that needs to be spent at home completing therapy activities (American Academy of Ophthalmology, p. 1).

“While visual acuity refers to how clearly each eye can see, vision training addresses how well two eyes work together as a team” (Polsdorfer, 1999, p. 1). Visual defects, such as congenital cataracts, can cause problems in reading and other complex tasks that require the integrated function of the eyes and the body. According to American Academy of Ophthalmology (2001), “behavioral vision therapy is based on the premise that differences in children’s visual perceptual motor abilities exist and that these

perceptual motor abilities influence cognitive and adaptive skills such as reading, writing, and motor activities used in activities of daily living” (p. 1). Therefore, the goal of vision therapy is to improve these subtle interactions using carefully devised exercises and devices (Polsdorfer, p. 1). Vision therapy is appropriate for individuals who have undergone surgery for congenital cataracts and should be considered for these children.

Occupational Therapy Intervention

Other health professionals outside of optometry may also play a significant role in the rehabilitation of children with visual impairments. “There are some commonalities between the models of human performance used by optometry and occupational therapy. Both recognize the importance of the ongoing relationship between vision and movement in development and in human performance” (Hellerstein & Fishman, 1990, p. 122). Optometry focuses on the role of vision as primary and movement skills as foundational, whereas occupational therapy stresses the individual’s abilities holistically with vision being one of the most important sensory systems (Hellerstein & Fishman, p. 122). “The productive overlap and uniqueness of these two fields allow for the sharing of views and natural division of labor, which allows the most qualified professional to carry out the treatment. Thus, the combined treatment can be of greatest benefit to the patient” (Hellerstein & Fishman, p. 126).

“Occupational therapy focuses on several components of performance that an individual must possess in order to function optimally in his or her activities of daily living, occupational, and/or scholastic roles” (Hellerstein & Fishman, 1990, p. 122). One

of these performance components is sensory integration, which is the ability of the central nervous system to take in, sort and process information received from the environment to allow for purposeful responses (Hellerstein & Fishman, p. 122). The sensory integrative process includes, but is not limited to, stereognosis, kinesthesia, proprioceptive awareness, ocular control, body scheme, postural security, awareness of both sides of the body and motor planning.

These mechanisms lay the foundation for perceptual motor skills such as visual-motor integration, visual-spatial skills and auditory language skills.

These skills therefore provide a basis for academic learning, emotional and social adjustments and activities of daily living (Hellerstein & Fishman, 1990, p. 122-123).

For a sighted infant, vision is the sensory system that drives the infant to visually seek out light, movement, color, and pattern (Baker-Nobles, 1997, p. 377). In children with infantile/congenital cataracts, early visual experiences may be disrupted. “Infants with visual impairments do not have the same opportunity for these varied experiences and tend to engage in concrete, repetitive actions with objects” (Baker-Nobles, p. 380). Early occupational therapy intervention services can provide children with congenital cataracts additional opportunities to engage in age appropriate activities that can help alleviate this disruption.

Because of the nature of occupational therapy, the range of activities that an occupational therapist uses in evaluation and treatment settings is more extensive than those used in optometry. An occupational therapist can conceivably use any visual activity as a therapeutic medium, ranging from

self-care to mobility to recreation to work-related and academic activities
(Scheiman, 1997, p. 368).

This, however, does not mean that an occupational therapy evaluation can replace an optometric evaluation. It is important for the occupational therapist, when working with children with visual impairments to collaborate with the eye expert.

Occupational therapy literature does address the assessment and intervention of individuals diagnosed with visual impairments, but there remains little to no information specific to infantile/congenital cataracts. For occupational therapy intervention to be maximally effective the therapist must first and foremost understand infantile/congenital cataracts and its effects. Skilled occupational therapy services would provide holistic treatment not only looking at the child's visual deficits, but also looking at the child's ability to participate in appropriate activities for their age. Occupational therapy services would provide the child with opportunities and encouragement to interact socially, play, and complete self-care activities.

According to Scheiman (1997), "before discussing specific vision therapy procedures, it is important to understand that there are general principles and guidelines that apply to all vision therapy techniques" (p. 184). The occupational therapist must recognize these general principles when working with children with congenital cataracts to ensure successful intervention techniques. The therapist must first determine a level at which the child can perform easily which helps build confidence and motivation (Scheiman, p. 184). The therapist must also be attuned to the child's level of frustration during certain tasks. Positive reinforcement is crucial during the therapy process and needs to be utilized even if the task is not successfully completed. "Reinforcers can be

verbal praise, tokens that can be exchanged for prizes or participation in a task the patient enjoys” (Scheiman, p. 184). The therapist must also maintain an effective training level, starting with easy tasks and gradually increasing the level of difficulty. Scheiman reported, “vision therapy should be success oriented, that is, built on what the patient can do successfully as opposed to giving tasks that are too difficult” (p. 184). Another important aspect of occupational vision therapy is client-centered practice. The therapist must always make the patient/caregivers aware of the goals of therapy. The last general guideline for vision therapy is to “set realistic therapy objectives and maintain flexibility with these objectives or endpoints” (Scheiman, p. 185).

Occupational therapy intervention for children with congenital cataracts can take three different forms: supportive intervention, compensatory intervention and direct remediation. These interventions can be used by occupational therapists to supplement optometric treatment and therapy. “These procedures are not designed to be used by therapists in isolation of, or instead of, optometric intervention” (Scheiman, 1997, p. 176).

Children with congenital cataracts may be seen by an occupational therapist specifically for the visual deficit or there may be other conditions for which the therapist is treating the child. In either case, it is important that the therapist support the optometric treatment recommendations. The therapist may do this by helping to ensure that the child and the child’s caretakers follow recommendations at least during occupational therapy treatment sessions (Scheiman, 1997, p. 176). For the patient with congenital cataracts this may involve making sure the patch or contacts/glasses are worn in the appropriate manner (Scheiman, p. 176). The therapist may also use their

educational background to recommend or suggest creative ways to make patching or contact/glasses easier on both the parent and the child. According to Scheiman, suggesting different colors of eyeglass frames for patients who require different glasses for near and far may be helpful (p. 176).

The therapist may also be able to modify the task or the environment or help the patient to compensate for the vision disorder in question in some other way. “The goal should be to manipulate and organize the patient’s visual environment so that he/she receives the highest level of visual processing possible in spite of deficits” (Scheiman, 1997, p. 176). For the child with congenital cataracts, visual acuity may not always be 20/20; therefore environmental adaptations may be useful. Adaptations may include such things as “enlarging targets, controlling contrast and lighting” (Scheiman, p. 176). Examples of enhancing the environment can be found in Table 1. The use of larger print may also help children with accommodative disorders. Children may also benefit from magnification devices for enhancement of vision during nearpoint activities. They may respond well to a variety of stand magnifiers that are placed directly above pictures or letters (Scheiman, p. 311). “They especially enjoy dome stand magnifiers, as they can easily incorporate the magnifier into playtime activities as a crystal ball that magically makes things easier to see” (Scheiman, p. 311). For binocular vision disorders the therapist can encourage frequent breaks during tasks and reduced emphasis on tasks requiring intense visual attention (Scheiman, p. 179).

Table 1, (Scheiman, 1997, p. 326)

Enhancement of Contrast in the Environment

- High contrast stripes on stairs, curbs, and on other drop-offs.
- Bold primary colors or black on white figures for all visual targets.
- Use of contrasting backgrounds to offset the visual target (ie, use of a white plate on a black placemat at mealtime).
- Reduce glare as much as possible by using task lighting that is directed toward the visual target and not toward the individual's face.
- Explore the use of colored filters to enhance visual contrast (ie, evaluate the use of yellow filters for reading purple mimeograph printed materials).

A third option for occupational therapy intervention is direct remediation to actually eliminate the visual problem and restore normal visual function (Scheiman, 1997, p. 176). Vision exercises may also be implemented by the occupational therapist to improve the visual acuity and the poor visual functioning of the amblyopic eye. “Aside from patching, activities to improve other areas of visual functioning such as tracking and figure ground activities are equally beneficial in improving the visual skills of the amblyopic eye” (Scheiman, p. 321). A sample activity can be found in Table 2. Along with compensatory techniques, the therapist may also provide activities to enhance reduced contrast awareness (Scheiman, p. 326). An activity to enhance reduced contrast awareness can be referred to in Table 3.

Table 2, (Scheiman, 1997, p. 321)

Flashlight Tag

Objective: The objective of flashlight tag is to work on the development of accurate pursuit eye movements of the amblyopic eye.

Equipment Needed:

1. Two flashlights with color filter over one light.
2. Eye patch over better seeing eye.

One flashlight is held by the therapist, the other by the individual if possible. Room illumination is initially kept to a minimum, but sufficient so the therapist can watch the individual's eyes. If the child is unable to hold a flashlight, he is encouraged to simply follow the therapist's light with his eye. The therapist shines the light in various and random patterns on the wall, ceiling or floor. The child is to keep the beam on the assistant's beam as much as possible. Once this is easily achieved, a second method is to have the child keep the light about 2 feet behind the leading light as he "follows the leader."

Table 3, (Scheiman, 1997, p. 326)

Enhancing Reduced Contrast Awareness

Objective: The objective of this activity is to increase the individual's awareness of reduced contrast visual targets.

Equipment Needed:

1. High contrast visual symbols that are meaningful to the individual and are appropriate for the developmental age level.
2. Reduced contrast visual symbols identical in size and shape to the high contrast symbols that are within the contrast threshold of the individual.
3. High contrast border of identical size and shape to be placed around the lower contrast targets. This can be obtained by cutting out the symbol from contrasting construction paper. Target sizes should be appropriate for the individual's level of visual acuity based upon the results of the optometric evaluation.

High contrast targets are placed in front of the individual who is asked to point to the named targets. If successful, low contrast targets are then placed before the individual who is asked to point to the named targets. If they are unable to find the targets, the contrasting borders are placed on the lower contrast symbols and they are asked to point to the named symbols. The contrasting borders are then removed and the individual is again asked to point to the named symbols. The individual is then asked to participate in a scavenger hunt for specific poor contrast targets. They are scattered throughout the visual environment on backgrounds of varying contrast. The child is rewarded for bringing back the targets.

Another remedial vision therapy approach is anti-suppression therapy; this can be used for individuals who have the ability to develop normal binocular vision, but are unable to because they are suppressing the information from one eye. “Anti-suppression therapy is useful in certain cases of amblyopia or intermittent strabismus” (Scheiman, 1997, p. 317). A sample activity of this type of therapy can be found in Table 4. This should only be instituted by the occupational therapist if it has been recommended by the optometrist, due to the potential for negative results if binocular vision is truly not achievable (Scheiman, p. 317).

Table 4, (Scheiman, 1997, p. 319)

Bear Families: Anti-Suppression Therapy

Objective: The objective of the Bear Families activity is to increase awareness of when the two eyes are working together as a team through a playful sorting activity.

Equipment Needed:

1. Red, green, and black 1-inch bears
2. Red and green anaglyphic glasses.

This technique uses small, 1-inch bears that are red, green and black in color. The individual wears the red and green filter glasses. In this variation, if one eye is not being used, the bears of that color will darken and the individual will be unable to distinguish them from the black bears. The goal of this game is to sort the bears by color into piles of red, green and black.

When providing direct remediation therapy it is important for the occupational therapist to collaborate with the optometrist/ophthalmologist in order to ensure the appropriate interventions are being implemented. It is also important that the optometrist, occupational therapist and other members of the professional team regularly discuss the child's outcomes. Each member of the team possesses different skills and abilities, that combined, can be of the greatest benefit to the child. The occupational therapist brings to this team the knowledge and skills to holistically treat the child by providing age appropriate supportive, compensatory and remedial interventions.

Another benefit of occupational therapy services for children with visual impairments is the reduced amount of cost placed on the family. In 1990, The Health Care Financing Administration (HCFA), broadened its definition of physical impairment to include low vision as a condition that merited rehabilitation (Warren, 1995, p. 857). This means that occupational vision therapy, in many cases, may now be covered unlike behavioral vision therapy.

Occupational vision therapy does, however, still have limitations that must be addressed. If occupational therapists do intend to provide services to individuals with visual impairments, they must prepare themselves to work effectively with this population. "Although visual impairments are addressed along with other sensory impairments in undergraduate occupational therapy curriculums, few professional programs include specific, comprehensive instruction in ocular pathology, functional visual evaluation, or low vision techniques" (Warren, 1995, p. 858). The amount of research being published for occupational vision therapy is increasing; however, for now

we must also refer to resources outside the field of occupational therapy to provide information regarding visual deficits and the appropriate interventions.

Conclusion

Congenital cataracts, a uncommon disorder, can cause significant visual impairments if not treated early in the child's life. With early detection, extraction, and optical intervention the visual outcome for congenital cataracts is promising. Each child and their family must be assessed on an individual basis to determine what treatment option is most appropriate. Visual and occupational therapy may also be implemented to enhance visual skills and performance for children with infantile cataracts. Occupational therapists who have knowledge in the area of visual deficits, including congenital cataracts, could provide age appropriate supportive intervention, compensatory intervention, and/or direct remediation while providing the child with opportunities to interact socially, play, and complete self-care activities.

CHAPTER III

ACTIVITIES/METHODOLOGY

I was accepted into the University of North Dakota Occupational Therapy Program in 2001; the year that Tristan, the child of close family friends, was diagnosed with congenital cataracts. I was providing childcare for the family at this time and had learned a great deal about congenital cataracts and the possible interventions for children with this diagnosis. It was not until later in my OT education that I was told I would be completing a scholarly project for my Master's Degree; it was at that time I decided to pursue occupational vision therapy for congenital cataracts as a topic.

Before completing any formal research I discussed my topic idea with Tom Clifford, my Casper College advisor, and LaVonne Fox, an advisor at the University of North Dakota. Once I had approval of this topic from the advisors, I discussed the idea with the family of the child to ensure they were comfortable with me using Tristan as a case example. The family was very supportive and they have helped me throughout my research process.

While completing my Level II Fieldwork in Minneapolis/St. Paul, MN I utilized the medical library at the University of Minnesota. I found a number of journal articles about congenital cataracts and interventions. Due to the large amount of information I obtained regarding congenital cataracts I placed the information in a three ring binder and as I read the information, I marked the articles that would contribute to my project. During this time I discussed with my advisors the information I had found and how the

information would be applied to my scholarly project. While researching the topic I found that there was not a great deal information specific to vision therapy and occupational therapy for the condition. It was for this reason that I decided to contact professionals in the community.

Tristan's mother knew of someone in the Minneapolis area that had a child with an unrelated visual diagnosis. I was given the contact information for the family in Minneapolis and I contacted them to see if they could be of any assistance. They were more than willing to assist me and they gave me the contact number for Minnesota Vision Therapy Center, which provides developmental optometry services to individuals with functional and perceptual vision disorders. The center provided me with an information packet regarding their services and treatment outcomes. Although none of this information applied specifically to my project it was interesting to learn more about their services and the patient populations that they served. I proceeded to contact other vision centers in the area in an attempt to find information specific to therapy for congenital cataracts.

As a result, I contacted Yelena Merman an OTR at Phillips Eye Institute, who specializes in adult and pediatric low vision and neurological visual deficit, and scheduled an interview and tour of the facility. Yelena described their program to me and allowed me to ask questions, however she had not treated a child with congenital cataracts. We discussed the case and she said that she did feel vision therapy would be appropriate for this child, but without assessing the child she would not provide any treatment protocols.

At this point I began to wonder if I would be able to follow through on this project due to the lack of information specific to congenital cataracts and occupational vision therapy so I contacted Tristan's mother and she informed me that the mother of a child on the congenital cataracts support group was currently working with an OT. At this point, I knew I would be able to complete a home program for congenital cataracts.

While on my Level II Fieldwork in Phoenix, AZ I had the opportunity to spend time at the outpatient pediatric therapy facility on the hospital grounds. The occupational therapy assistant at the facility was also interested in vision therapy and had numerous books and resources that she was willing to loan me until my project was complete. These resources proved to be very helpful in completing my project. Although they did not have specific treatment ideas for congenital cataracts they had therapy suggestions for disorders that children with congenital cataracts may experience.

I kept in close contact with Tristan's mother at all times since she, as a parent, had researched information about the diagnosis and outcomes related to congenital cataracts. I made note of any concerns the family had regarding their daughter's visual and functional abilities. During my time with Tristan, I used my observation skills so that I could design a home program to specifically fit her needs. I also took the opportunity to travel to Denver for Tristan's appointment with the ophthalmologist so I could learn more about her current visual function.

When compiling the information for my literature review I felt it was very important to give my readers a complete background on congenital cataracts, surgical and optical interventions, and treatment options since it is a rare disorder. While formulating the home program I considered both the child and the families' needs and goals to ensure

it was manageable and appropriate for them. Although challenging, the project has been very educational and rewarding to me as a student and future therapist.

CHAPTER IV

PRODUCT: HOME PROGRAM

The following is a home program designed for Tristan, a three-year-old child born with congenital cataracts. Congenital cataracts, a rare disorder, can cause significant visual impairments if not treated early on in the child's life. With early detection, extraction, and optical intervention the visual outcome for congenital cataracts is promising. Each child and their family must be assessed on an individual basis to determine what treatment option is most appropriate.

Occupational therapy services may provide the child with age appropriate opportunities to interact socially, play, and complete self-care activities. The home program emphasizes supportive intervention, compensatory intervention, and direct remediation strategies for following through with therapeutic activities in the home. The program is based on a comprehensive literature review that provides background information on infantile/congenital cataracts, surgical and optical interventions, and occupational vision therapy.

Suggestions to Make the Home Program Successful

Consistent follow-through of therapeutic activities in the child's natural environment is extremely important to the child's success in a vision program. The home program is intended to be meaningful to both you and your child. The following information is adapted from Lewis, Bacon, Eskew, & Carr, 2002, p. 7.

- Set a consistent routine.
- Sometimes it is more effective to divide the daily therapy into two or more shorter sessions.
- Learning is easiest in a pleasant and supportive environment. Therefore, if you or your child are overtired or ill, skip the home program that day.
- Make activities fun. The more positive the experience the more likely your child will want to continue therapy.
- Utilize siblings' help to assist in activities. This decreases the child's feelings of being singled out.
- Report any concerns to your child's therapist and doctor/ophthalmologist. No concern is silly.

Home Therapy Report Sheet

The following information sheet should be quickly completed after each therapy session so that the therapist and doctor can benefit from your observations. When performing tasks at home you may notice different things at different times of day, etc. By quickly filling out an observation form, a pattern may be found and further modifications and adaptations may be made to the home program assist your child. The following information and sample form are adapted from Lewis, et al., 2002, p. 11.

The following are observations/comments are to be recorded, which will help you and your child's therapist determine performance on each home therapy activity.

1. Length of time spent on activity.
2. Time of day.
3. Amount of perceived difficulty for the child (difficult, easy, etc.).

Monitor and record any problems in:

1. Posture- relaxed, head turn to right or left, feet flat on the floor, etc.
2. Working distance- when reading does the child hold the book out in front of them at an arms length or bring it closer?
3. Behavior- Make note of any behavior problems.
4. Attention- Motivated or not?
5. Overall reaction to the task at hand- likes, hates, etc.
6. Stress symptoms- headaches, excessive blinking, rubbing eyes, tearing, etc.

Supportive Intervention

When working to improve your child's visual outcome it is crucial that everyone involved in your child's care follow through on doctors' orders. You may distribute this handout to your child's caregivers and teachers to remind them of the importance of your child's individual needs. The following is adapted from Lewis, et al., 2002, p. 3.

- A patching schedule is very important to ensure the child is being patched for the correct amount of time. Here is a sample patch schedule. This may need to be modified if the child's patch time is broken up throughout the day.

Day	Patch on at	Patch off at
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

- Glasses should be worn for all near point tasks.
- The child should sit upright with shoulders wide and back straight when reading and writing. Sit erect with feet flat on the floor.

- Provide for adequate general light as well as good central light at the near task.

The light on the task should be about 3 times that of the surrounding background.

- A one-minute break should be taken for every fifteen minutes of reading or close work.

Compensatory Intervention

“The goal should be to manipulate and organize the child’s visual environment so that he/she receives the highest level of visual processing possible in spite of deficits”(Scheiman, 1997, p. 176). This can help improve the child’s functional outcome and reduce the amount of frustration they experience during activities.

- Reduce glare as much as possible by using task lighting that is directed toward the visual target and not toward the individual’s face (Scheiman, p. 326).
- Explore the use of colored filters to enhance visual contrast (ie, evaluate the use of yellow filters for reading purple mimeograph printed materials) (Scheiman, p. 326).
- Enlarge print. This can be accomplished by simply enlarging the font on handouts printed from the computer to 18 or more if needed.
- Again encourage rest breaks between near point activities.
- Tilt the book up 20 degrees (this slopes up 4 in. in 12). A tilt top for the desk can be made by screwing two door stops to the back of a piece of ½” plywood or drawing board and two rubber knobs to the near end so it does not slip off the desk. This can be used for reading and writing and enables the child to work further away from the task than when it is flat on the desk or table (Lewis, Bacon, Eskew, & Carr, 2002, p. 3).

Remedial Intervention

Direct remediation to actually eliminate the visual problem and restore normal visual function may be utilized in a home program. Aside from supportive and compensatory strategies, activities to improve other areas of visual functioning such as tracking and figure ground activities are equally beneficial in improving the functional visual skills in children with congenital cataracts.

Glow

Objective: To increase the child's skill in making spatial judgments. This should be done binocularly with children with aphakia to help them judge depth.

Equipment Needed:

1. Glow Stick
2. Pointer (can use pencil)

The parent holds the glow stick in various positions while the child attempts to place the tip of the pointer on the end of the glow stick. The parent should hold the glow stick in horizontal, vertical, and diagonal planes at different distances and heights.

Flashlight Tag, modified from (Scheiman, 1997, p. 321)

Objective: The objective of flashlight tag is to work on the development of accurate pursuit eye movements of the amblyopic eye and develop eye hand coordination.

Equipment Needed:

1. Two flashlights with color filter over one light. Fun flashlights with cartoon characters, etc. are encouraging.
2. Eye patch over better seeing eye.

One flashlight is held by the parent, the other by the child. Room illumination is initially kept to a minimum, but sufficient so the parent can watch the child's eyes. The parent shines the light in various and random patterns on the wall, ceiling or floor. The child is to keep the beam on their parents beam as much as possible. Once this is easily achieved, a second method is to have the child keep the light about 2 feet behind the leading light as he/she "follows the leader." Other possible modifications may include the parent naming a familiar object in the room and the child must shine the light on it or the parent may place the light on an object while the child's eyes are closed and upon opening their eyes they find and name the lighted object.

Bear Families: Anti-Suppression Therapy (Scheiman, 1997, p. 319)

Objective: The objective of the Bear Families activity is to increase awareness of when the two eyes are working together as a team through a playful sorting activity.

Equipment Needed:

1. Red, green, and black 1-inch bears
2. Red and green anaglyphic glasses.

This technique uses small, 1-inch bears that are red, green and black in color. The child wears the red and green filter glasses. In this variation, if one eye is not being used, the bears of that color will darken and the individual will be unable to distinguish them from the black bears. The goal of this game is to sort the bears by color into piles of red, green and black.

Suggested Therapeutic Play Activities

Window Art:

Equipment Needed: Crayola has come out with markers that are specifically for windows and glass surfaces. These can be purchased at toy stores and other general stores that carry Crayola products.

Objective: This activity is a fun way to work on fine motor coordination and is perfect for children with visual difficulties. The natural light that shines through the window provides the child with his/her own personal horizontal lighted surface.

Dress Up:

Equipment Needed: Some of mom, dad, or older siblings clothes that have buttons, zippers, or snaps.

Objective: This is a fun activity for children who are becoming independent in dressing themselves. While playing *dress up* the child is able to work on the fine motor coordination required to fasten clothing. This activity can also help improve the child's eye hand coordination. Along with all these benefits the child can be using their imagination during this playtime activity.

Tile Art:

Equipment Needed: Picture Perfect can be purchased through Integrations catalog. The kit includes a see through grid that is placed over picture patterns and the tiles to make the picture (Integrations, 2003, p. 83).

Objective: This activity encourages eye-hand coordination, pattern recognition, and color learning and matching.

Magic Pipes:

Equipment Needed: There are a variety of different kinds of magical pipes or whistles that can be purchased at toy stores or from specialty rehabilitation catalogs at a very low cost. Integrations catalog features pipes that when blown through have a ball or a string that floats. Whistles are also available with various spinning objects for the child to visually focus on while blowing (Integrations, 2003, p.27).

Objective: Both the pipes and whistles encourage the child to focus on the object in front of them which in turn strengthens eye muscles.

HOME PROGRAM REFERENCES

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CHAPTER V

SUMMARY AND CONCLUSIONS

Congenital cataracts is an uncommon disorder, however it accounts for a significant amount of childhood blindness. For a sighted infant, vision is the sensory system that drives the infant to experience their environment. In children with infantile/congenital cataracts, early visual experiences may be disrupted. Early occupational therapy intervention services can provide children with congenital cataracts additional opportunities to engage in activities that can help alleviate this disruption.

Occupational therapy literature does address the assessment and intervention of individuals diagnosed with visual impairments, but there remains little information specific to infantile/congenital cataracts. Occupational therapists that have knowledge in the area of visual deficits, including congenital cataracts, could provide holistic treatment to these children not only by looking at their visual deficit, but also by looking at the child's ability to participate in age appropriate activities. Occupational therapy services would provide the child with opportunities and encouragement to interact socially, play, and complete self-care activities.

This scholarly paper provides the reader with information regarding congenital cataracts, surgical, optical, and vision/occupational therapy interventions. The home program is based on the comprehensive literature review and is designed to specifically fit the needs of the child and her caretakers'. This program emphasizes supportive

intervention, compensatory intervention, and direct remediation strategies for following through with therapeutic activities in the home.

Occupational therapy intervention does not replace optometric services, rather, the two disciplines work as a team to provide comprehensive services to the child. When providing occupational vision therapy it is important to individually assess the child and their caregivers' needs. What is appropriate for the specific case discussed in this paper may not necessarily be appropriate for another child with congenital cataracts.

Since there is currently not information specific to congenital cataracts and occupational therapy, further research should be completed on specific assessments to use with this population. The development of occupational therapy protocols specific to congenital cataracts would also be beneficial to the profession. Follow-up studies to measure the effectiveness of occupational vision therapy for children with congenital cataracts are recommended.

APPENDIX A
GLOSSARY OF TERMS

Accommodation: The ability to change the focus of the eye so that objects at different distances can be seen clearly.

Amblyopia: A condition in which the visual acuity is less than 20/20 and this loss of visual acuity cannot be attributed to refractive error or observable eye disease.

Aphakia: Result of the surgical removal of the cataract.

Binocular: Both eyes accurately pointing to the same object.

Blind: Individuals for whom the visual system does not provide a useful input channel.

Lens: A transparent, flexible structure that is held in position by zonular fibers. It is located posterior to the iris and anterior to the vitreous humor. Like the cornea, the lens is both transparent and avascular and is another key part in the refractive system of the eye.

Low Vision: Individual is able to use the visual system for reading, but standard size, contrast, and/or is inadequate.

Nystagmus: A condition in which there are involuntary, rhythmic oscillations of one or both eyes.

Red Reflex: A luminous red appearance seen upon the retina during retinoscopy.

Stereopsis: Binocular visual perception of three-dimensional space.

Strabismus: A condition in which the eyes are misaligned all or part of the time.

Suppression: A condition usually associated with strabismus and amblyopia in which the visual system ignores the input from one eye.

Visual Acuity: A measure of the resolving power of the eye. An individual with "20/20" acuity is considered to have normal ability to see small detail at the distance tested.

Visual Field: The extent of physical space visible to an eye in a given position. Its average extent is approximately 65° inward and 95° outward.

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