What Do You Tell Parents Who Ask Why Their Preschooler Can’t See Out of One Eye?

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**ABSTRACT**

The diagnosis has been made and confirmed: amblyopia. But what exactly does it mean to the parent and child who are most likely hearing it for the first time? Essentially nothing until the time is taken by us, ophthalmic medical personnel, to adequately explain the condition, the treatment options available, the goals for treatment, and the prognosis. How does one educate parents and children alike about amblyopia? How does one communicate in such a way as to facilitate and promote a favorable response to treatment?

One hundred families of children with amblyopia, as well as a large consortium of orthoptists, were surveyed regarding the diagnosis and methods employed to communicate more efficiently and effectively. The diagnosis, it turns out, is only the beginning. Our responsibility to the parents and child does not simply end there: with good interpersonal skills and open communication, a team is established, and the task at hand of obtaining equal acuities should prove to be less daunting.

**INTRODUCTION**

Amblyopia is a unilateral or bilateral reduction in best-corrected visual acuity that cannot be attributed to any structural anomalies of the eye, nor to any abnormalities in the posterior visual pathway. Clinically speaking, amblyopia is defined as a two-line disparity of interocular...
lar acuities. Amblyopia is a defect of central vision, and is not only an eye problem but is also a brain problem, a result of abnormal visual stimulation during the sensitive period of visual development. Children are susceptible to amblyopia between birth and eight years of age. Amblyopia is said to be responsible for more unilaterally reduced vision of childhood onset than any other known pediatric ocular condition. Amblyopia affects 2–4% of the general population, rivaling that of glaucomatous visual deficiencies. Amblyopic vision loss, however, is completely preventable, treatable, and reversible with appropriate and timely intervention. 1,3,4,5.

CLASSIFICATION

Amblyopia can be classified as strabismic, anisometropic, ametropic, deprivation, or organic. Strabismic amblyopia is the most common form of amblyopia. Strabismic amblyopia develops in the deviating eye and is a direct result of the competitive and inhibitory interaction between the eyes. Second in frequency of occurrence is anisometropic amblyopia. Anisometropic amblyopia is caused by an inequality of refractive errors between the two eyes, causing one image to be chronically defocused. Children with anisometropic amblyopia often go undiagnosed until the school-age years because of the general lack of associated strabismus, which would have prompted the parents to seek a professional opinion. Precious treatment time is often lost in these cases, as diagnosis is many times delayed. Ametropic amblyopia occurs when there are large, bilateral uncorrected refractive errors. Deprivation amblyopia is, fortunately, the least common form. Deprivation amblyopia arises from either a unilateral or bilateral lack of form vision. It is the most damaging to the immature visual system and is the most difficult to treat. 1,3,5.

METHODS OF TREATMENT

When treating amblyopia, the first step is to eliminate any obstacle to vision, correct the refractive error when necessary, and, in unilateral or asymmetric cases, force and promote use of the poorer eye by limiting use of the better eye. There are many alternative methods to treating amblyopia, but the “gold standard” remains patching. Penalization (optical or pharmacologic), foils, and opaque occluder lenses all remain viable alternatives, but should be considered on a case by case basis. 2

In amblyopia, the prognosis depends on the age of the patient at diagnosis, the severity and depth of the amblyopia, and the type of amblyopia. The earlier the amblyopia occurs, and the longer it remains untreated, the worse the prognosis. To be successful in treating amblyopia, one must be diligent. Detection and diagnosis of the amblyopia is key, and the portrayal of the urgency of appropriate, aggressive, and timely treatment is paramount. Not only is a knowledge of ophthalmology fundamental in the success of treating children and their families with amblyopia but also an understanding of communication, psychology, and child development. 3,4,5.

TALKING TO PARENTS

Before one can master the language of “Parentese,” one must appreciate the gamut of emotions that a parent faces at the time of their child’s diagnosis. When we, as health care professionals, can truly understand and respect this innate response, then and only then will we be able to communicate effectively and facilitate the necessary treatment for their child. In addition to being conscious of the ever-changing dynamics during the exam, the examiner must also ask themselves: “What do parents need from us as health care professionals?” and “What do they want?” In
my pursuit to foster better communication at the clinical level, I did just that: I asked. I questioned parents of children who have undergone or are currently undergoing amblyopia therapy. After surveying 100 parents of children with amblyopia about their needs, their feelings at the time of diagnosis and throughout treatment, and their suggestions for improved care, I think I may finally have an answer. (Table 1)

PARENTS’ REQUESTS

Parents have asked for better communication between caregiver and health care provider. They ask for clear and precise explanations free from any extraneous medical jargon. They ask that goals, treatment and treatment options, as well as prognosis, be clarified prior to the onset of any given treatment. Some even request that those goals be written out, in black and white, so that the children may have something tangible. Parents request that as much information regarding the condition that is affecting their child be given; be it supplemental literature or video education. Lastly, parents desire and deserve our support and recognition during this long, arduous road to equal acuities.

Parents have suggested that physicians take an interest in the siblings of the amblyopic child once diagnosis is confirmed, reiterating to the parents the importance of vision screening. We have been asked by parents to be positive when handling and delivering the diagnosis, and to take the necessary time to address the child’s concerns at their level. It is suggested that we strive to include the child, when at all possible, in the treatment planning, for children live day to day, minute to minute. We should listen to and get to know the child, taking the time to explain progress to both the parent and the child after each and every appointment. We need to be encouraging, even in the bleakest of situations, and we ought to be sensitive to both the emotional and social factors that may influence a child’s compliance with the prescribed treatment regimen. It is only when we are responsive to these issues that we will begin to make progress.

Offer alternatives, suggestions, and viable resolutions in an effort to promote compliance while continuing to be firm in treatment of the initial diagnosis. The impact that treatment, which can be taxing, has on the family also needs to be appreciated and considered. Offering a support system or outside resources to families who are just beginning treatment can prove to be beneficial in ensuring compliance. Lastly, parents ask that we make each and every visit as fun and comfortable as we can for the child, thus promoting a positive experience each time.

In addition to surveying the parents of amblyopic children, I also questioned a large group of orthoptists about their explanation of amblyopia, its diagnosis, and treatment. Recommendations were pro-
vided to foster improved communication and interaction with both the parent and the child.

ORTHOPTISTS’ SUGGESTIONS

Orthoptists suggested, when initially discussing amblyopia, that explanations be tailored to individual dynamics and perceived education level of the parents. Descriptions should be modified according to the parent’s comfort level. It is best to keep the explanation simple, but emphasize the seriousness of the diagnosis, and the almost emergent nature of prompt and timely treatment. The importance of appropriate treatment in this small window of time needs to be stressed. Attention should be paid to the whole child and family, family issues and behavior issues should be broached, and the potential frustrations expected during treatment ought to be validated, stressing that consistency and compliance is ultimately the key to a successful outcome. A partnership must be established with the child, and every effort made to ensure that the child understands the benefits of treatment and, conversely, the consequences of non-compliance, because, ultimately, it is the child who is doing the work.

Lastly, small, attainable, easily achieved goals should be set when initiating treatment, since children can be discouraged when they feel they are not “improving” quickly enough. By having attainable goals in place, children will more often have a sense of accomplishment at achieving the goals that were set for them. When goals are met, small rewards should be given, whether it is stickers, a kind word, a lollipop—in the eyes of a child, a little goes a long way.

OTHER SUGGESTIONS

The explanation of amblyopia often forces us, the medical health care profession, to employ the use of analogies to paint a clear picture for both the parent and the child. Orthoptists and ophthalmologists alike employ the use of analogies when discussing amblyopia. The amblyopic eye can be equated to one that is sick, and the patch is synonymous to the medicine that is vital to health. We have been known to state that amblyopia is similar to the atrophy of a casted arm or leg, with the idea that if you don’t use it, you lose it. We have likened amblyopia therapy to immunizations, where there is definitive short-term discomfort with no immediately recognizable benefits, but the long-term outcome is significant and the payout is priceless. Amblyopia therapy can also be compared to recharging a weak battery, or opening the blinds of a window in a room that had been previously closed.

When the diagnosis of amblyopia has been confirmed, and the time has come to educate the parents, amblyopia can be explained as a result of the eyes being unable to work together. Eyes work together, much like the reigns of a horse, but for some reason, as is the case in amblyopia, they are unable to. In anisometropic amblyopia, the brain has a choice to make, and most often it is to focus with the eye that requires the least amount of effort. Being that the eyes can only focus equally, the eye that is more hypermetropic goes unfocused and is chronically blurred and effectively “shut off” by the brain, resulting in amblyopia. In the case of strabismic amblyopia, the brain again has a choice to make. This time, however, it is a choice between single and double vision. The brain will suppress the deviating eye that is responsible for the second image. Suppression of the strabismic eye, in time, leads to amblyopia. In treating amblyopia, whether it be a result of suppression or a chronically blurred image, our goal is to turn the eye back on, for it has been in the off position for a period of time. In chil-
Children with anisometropia, glasses are required to artificially make the eyes the same power to facilitate simultaneous and equal focusing. At times, glasses alone are enough for children with anisometropia, and spontaneous resolution of the amblyopia occurs. In instances where spontaneous recovery does not occur, or when a plateau in vision has been met, the brain often needs a kick-start, whether from patching, foils, or penalization.

Children with strabismus may or may not benefit from glasses: in either case, spontaneous improvement is rare and requires patching, foils, or penalization to force the brain to re-recognize images originating from the deviating eye, and to re-wire previously failed connections. When speaking with parents and children about treatment, we must stress that timing is critical. The visual system is mature or hard-wired at 8–10 years of age, so for treatment to be successful it must be done as early as possible. The reward is a lifetime of useful vision. Goals and prognosis in treatment depends on the type of amblyopia, with deprivation amblyopia being the hardest to treat. Goals and the prognosis for successful restoration of vision are also dependent on the age of the child at diagnosis. The earlier the diagnosis and the earlier the treatment, the better the prognosis for successful visual outcome.

One must, however, never say “never”: a trial of patch is always warranted, regardless of age, and the outcome may be a pleasant surprise for everyone involved.

CONCLUSION

When educating parents, it is of utmost important to present the information at their level, and to insure that they understand and are comfortable with what you are telling them. The use of written literature and/or educational videos after verbal instruction may be of benefit to the parent and child (Table 2). We, as ophthalmic medical personnel, must be diligent in detection and diagnosis, be aggressive and firm in therapy, but be kind, considerate, and compassionate in treatment. A child is just that, a child, and should be handled accordingly. Keeping in mind the analogies, parental needs, and suggestions, fluency is easily attainable. In time, and with some effort, we will all be masters in the intricate second language of “parentese.”

REFERENCES


Key words: amblyopia, therapy.