

PATCHING FOR THE TREATMENT OF AMBLYOPIA

SUBJECTIVE RESPONSES OF PARENTS

■ Gopal Bhandari, B. Optom.¹

1. Bharatpur Teaching Hospital, Chitwan, Nepal

Abstract

Amblyopia is a serious health problem with the traditional treatment being to patch the non-amblyopic eye, encouraging the amblyopic eye to become more sensitive. Patching has been shown to be effective if the patient is compliant. Unfortunately many children do not comply with the prescribed patching regimen. This non compliance involves the whole family. To explore parental difficulties and experiences while undergoing occlusion therapy for their children, a survey was administered. The interview questions were developed following a review of the literature, pilot interviews and discussions with the study team. Fifty-two parents of amblyopic children, receiving a minimum of two months of occlusion therapy for all types of amblyopia were included in the study. Questions at the interview specifically explored the parents' perception regarding amblyopia and its treatment, their experiences regarding patching and self perceived views regarding compliance. Parents described dilemmas and tensions for themselves and their child when they patched for long periods. It is necessary to take into account the difficulties and tensions experienced by parents if compliance with occlusion therapy is to be improved.

Key Words

amblyopia, compliance, parental difficulties, patching

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INTRODUCTION

Amblyopia is the most common childhood vision disorder, with prevalence of 1% to 5%.¹ The lifetime risk of serious loss of vision for the individual with amblyopia is substantial.² Both series reports and case reports have shown that amblyopia can be treated effectively in patients who have passed 7 years of age but is easier earlier in life.³ The primary treatment for children with amblyopia is occlusion of the better eye, with a regimen ranging from a few hours per day to all waking hours.⁴

Treatment of amblyopia by occlusion dates back to at least the early eighteen century. Charles de Saint-Yves first described the occlusion of dominant eye to promote use of the squinting eye in 1722.⁵ The value of amblyopia therapy is widely recognized. There is a general clinical belief that occlusion can be successful, with thousands of children treated every year. There is, however, continuing uncertainties over occlusion therapy since many studies fail to address compliance.³⁻⁷ Occlusion therapy works only when the occluder is worn. Compliance in wearing the occluder as prescribed is essential if the therapy goals are to be achieved. Children wear an occluder because their parents require them to do so. Adequate support from both parents and family members is, therefore, required for amblyopic children undergoing occlusion therapy. Clinical experience attests to common parental difficulties and bitter experiences while accomplishing occlusion with the child. In spite of their child's strong dislike and hesitation in occlusion therapy parents demand the child wears the occluder. In the course of oc-

cluding their child, parents may then experience a wide range of difficulties and stresses. The purpose of the present study is to investigate factors that can interfere with occlusion therapy for amblyopia.

METHODS

A total of 52 parents of amblyopic children who underwent a minimum of two months of occlusion therapy for all types of amblyopia were included in the study. Informed consent was obtained from each family. Parents (one or both parents) of children were interviewed in the clinic at B.P Koirala Lions Centre for Ophthalmic studies. Only the parent(s), present at the time occlusion therapy was prescribed, were involved in the interview. The interview questions were developed following a review of the literature, pilot interviews and several discussions with the study team. Demographic details: age of the child, best corrected visual acuity at the time of prescription of occlusion therapy, types of amblyopia and the occlusion regimen were obtained from the child's record file. The age, gender, occupation and educational status of parents were also recorded. The experiences and difficulties expressed by parents during the interview were recorded in their own words and later translated into English.

RESULTS

Of 52 parents taking part in interview 37 (71.2%) were mothers and 15 (28.8%) were fathers. The mean age of parents was 32.76 sd 7.37 with age range 21 to 60 years. One of the parents in the study was from Somalia staying in Nepal at a refugee camp. Most of the mothers of amblyopic children taking part in interview were housewives. Among the participants only 11.5% were illiterate. The mean age

of children undergoing occlusion therapy was 6.79 years sd 2.5 and an age range 2 to 13 years. Out of 52 amblyopic children, 27(51.9%) were females and 25(48.1%) were males. Maximum number of children (N=28) in the study was in the age group of from 5 to 7 years. The presumed cause of the amblyopia was based on an optometric examination. When more than one condition was present, we categorized only the condition that the clinician considered the primary cause. The cause of amblyopia in this sample was: strabismus 28.8%; isoametropia 26.9%; anisometropia 25%; stimulus deprivation amblyopia 11.5%; 3.8% both anisometropia and strabismus and 3.8% nystagmus.

Five major areas of concern were identified as barriers to patching compliance by the interview. Table 1 contains these five areas with selected translated statements from the parents as to challenges they faced in complying with a patching regimen.

A second paper is being developed to statistically address, in detail, the demographic factors of this sample in an attempt to identify if family and social characteristics were factors in compliance to therapy.

DISCUSSION

Patching as a means of treating amblyopia has shown disappointingly modest improvements in visual acuity.⁶ One of the major reasons for the apparent failure with occlusion therapy is non compliance with the prescribed treatment. This report provides insight into the parents' difficulties and typical experiences while undergoing occlusion therapy for their child. Compliance with occlusion therapy has been shown in one study to be related to initial visual acuity, refractive error and amblyopia type. That study, however, failed to explore the parental difficulties in occluding the child as one of the reasons for poor compliance.⁶

The treatment of amblyopia is not easy to implement and is commonly associated with some degree of distress to both parents and children.⁷ Another study interviewed 20 families with children aged 2 to 7 years that were occluded two to seven hours per day. It found that many parents experienced distress related to patching.⁸ Our study also discovered a wide range of difficulties and experiences faced by the parents of amblyopic children while undergoing occlusion therapy for their child.

The strong dislike of amblyopic children to wear the patch is a major problem for many parents particularly parents of the very young. The child does not understand the need for patching. Patching the school age child is also very challenging for parents as children have strong objections to wearing a patch, mainly because of the increased risk of being teased by their friends at school. Our study likewise indicates that patching had social impact on parents. Some parents felt uncomfortable in public with their children. They felt they were continually being asked to explain the patch. Parents are also concerned about how others may perceive their child. It is necessary to educate parents, teachers and children about occlusion therapy. Attempts should be made by school teachers to support a patching regimen at school, as part of the overall therapeutic regimen.

The visual impact of patching was also a cause for parental difficulties as children reported they were restricted in the daily activities and school work while patching. In most cases, parents themselves did not allow their children to wear the patch during examination periods in school. Parents also sustain distress and stress in the course of occlusion therapy for their children.

Other studies have shown that parents find it difficult to comprehend and retain verbal explanations of various components regarding occlusion therapy for amblyopia.⁹ Also, studies have shown that providing written information about the sensitive period, importance of occlusion and potential negative consequences of not treating amblyopia is effective in improving parental understanding and subsequent compliance.¹⁰ In our study some parents expressed dissatisfaction with the verbal information given to them by different clinicians. Parents however were found to be highly sensitive to the credibility of the treatment and tried their best to make occlusion therapy successful.

A study performed by pediatric Eye Disease Investigation Group has also found that patching also created significant social stigma for parents.¹¹ Parental preference should be considered when occlusion therapy is planned.^{12,13} We agree that if parental distress and difficulties are addressed, compliance to patching will be improved.

CONCLUSIONS

It is evident that, when prescribing a patching regimen for the treatment of amblyopia that compliance is a major factor. To improve compliance, not only does the child have to be considered but emphasis should also be given to education of the parent(s) and educators of the child. Evaluation of the compliance of patching should also be better monitored. Education to counteract the negative aspects of patching identified here will have a better chance of improving compliance.

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TABLE 1
PARENTAL RESPONSES: BARRIERS TO PATCHING

1. Confusion on the part of parents as to need and the proper schedule of patching

I do not exactly know why I need to patch my child, and my child does not like it either so I quit patching him (Participant 20)

I am confused regarding occlusion therapy, how many actual years do I have to patch my child? I am being told different things by different doctors when I come in for different follow up (Participant 3)

2. Children absolutely refusing to wear the patch

When I try to put the patch on her eye she runs away and hides from me. (Participant 16)

We catch him and forcefully put the patch on but he takes it off within minutes and then runs away and hide from us, later he developed a fever so we stopped patching him from that day. (Participant 17)

He goes to sleep, when I come with the patch (Participant 27)

It was very difficult to make her wear the occluder the first few initial days, but later she cooperated well. (Participant 1)

She was cooperative initially but these last 2 to 3 months she cries when I attempt to patch her eye (Participant 5)

3. Children used the patching regimen as a means of fulfilling desires (black-mail)

He throws the patch from his eyes if he is angry with me for not fulfilling his desires. (Participant 31)

It is difficult to make him wear the patch; I have to buy things he wants, because he throws the patch if I do not buy them (Participant 52)

4. Patching interfering with quality of life issues

Since I started patching he had problems with his studies, he writes slowly and makes spelling mistakes (Participant 36)

I do not make him wear the patch during school examinations (Participants 41, Participants 32)

It is difficult for my child to play when wearing the patch so I take the patch off when he goes out to play with his friends. (Participant 42)

5. Patching seen as social stigma

I do not patch my child when I am attending special functions with him. (Participant 2)

I usually do not make my child wear the patch when I am attending a special function or party with her. I am required to constantly explain the reason my child is wearing the patch. (Participant 37, 38)

Because of the patch she developed marks in the skin and she frequently complains of itching (Participants 49)

Initially my child refused to go to school with the patch because he was laughed at by friends. I went to his school and told all the teachers to convince the students in his class not to tease. Now the child does not complain of being teased. (Participant 50)

Child is cooperative and always ready to patch if vision improves, but I do not patch him while sending school because I am afraid other children will take the patch away. (Participant 49)

She usually complains that her friends in class try to take patch from her eyes. (Participant 35)

She hesitates to put the patch on at school because she is always afraid of being teased by her friends. (Participant 19)

Participant = one parent
Participants = two parents

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Corresponding author:
Gopal Bhandari, B. Optom
Bharatpur Teaching Hospital
Chitwan, Nepal
uniteforsightgopal@gmail.com
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