

Parental Understanding and Psychosocial Impact of Occlusion Therapy on Amblyopic Children and Their Parents

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Abstract

Background: It is reported that 0.2 to 5.3% of children suffer from amblyopia. The traditional treatment for amblyopia has been to correct the refractive error and occlude the non-amblyopic eye. Compliance, however, with patching is a significant problem. The aim of this study was to investigate the parental knowledge of amblyopia and its treatment. We also wanted to explore the demographic and psychosocial impact of occlusion therapy on children with amblyopia and their parents.

Methods: Fifty-two parents and their children ages 2 to 13, undergoing occlusion therapy for amblyopia, participated in this study. Visual acuity at the initiation of occlusion therapy and the prescribed occlusion regimen were obtained from patient files. The compliance with occlusion therapy was based on self report of the parents. The emotional impact of occlusion therapy was determined by an emotional impact questionnaire. The experiences and the difficulties expressed by parents and children were noted in their own words.

Results: Strabismic amblyopia was the most prevalent type of amblyopia, followed by isoametropic amblyopia. Only 42% of the parents had an understanding of amblyopia and its treatment. However, the compliance with occlusion therapy was 78%. The occlusion therapy was a difficult experience for a majority of parents and their children. Many parents reported undue distress, difficulty, and a psychosocial impact secondary to occlusion therapy. Behavioral changes induced by occlusion therapy were also detected in 25% of children.

Conclusions: Parental understanding regarding amblyopia and occlusion therapy was lacking, but the compliance was good despite the psychosocial impact on both child and parent.

Key Words

amblyopia, occlusion, parental understanding, psychosocial impact

INTRODUCTION

Amblyopia is a form of visual impairment characterized by abnormal neuronal numbers and connections in the visual pathway and cortex caused by the disturbance of vision during the sensitive period.¹ It predominantly arises from interference of binocular or refractive development. Amblyopia is the most common cause of monocular visual impairment in children, young adults, and middle-aged adults. The prevalence of amblyopia has been reported to range between 0.2% and 5.3% depending on the criteria of visual acuity used and the population studied. Amblyopia is a frequent cause of lifelong visual impairment.² Amblyopia can bar one from certain occupations, affects binocular vision and stereopsis, and causes significant disability if the normal eye suffers trauma or disability.^{3,4} The rationale for the treatment is to optimize visual function and binocular vision.

The most common treatment options are lenses, occlusion, and vision training. Filters, prisms, and penalization with medications such as atropine and other cycloplegic drops have been considered alternatives to occlusion. In a randomized

clinical trial study, it was found that substantial improvement in visual acuity of the amblyopic eye occurred with either daily patching or daily atropine treatment regimen. The difference between the patching and daily atropine regimen was clinically insignificant after six months. It was found that the weekend atropine treatment was as effective as the daily treatment for moderate amblyopia.⁵ Atropine therapy is not cosmetically obtrusive and compliance is not an issue once the drop or ointment is instilled. Side effects like flushing, hyperactivity, and tachycardia may occur, particularly in children with Down syndrome.⁶

The mainstay treatment of amblyopia for more than 250 years has been occlusion of the better seeing eye with an opaque patch to promote visual function in the amblyopic eye. The value of occlusion in the treatment of amblyopia is widely recognized. Lack or limited understanding on the part of parents regarding amblyopia and its treatment is consistently reported as a major factor contributing to the failure of occlusion therapy. Occlusion therapy compliance is difficult to implement.

Occlusion may be prescribed in one of three time plans: continual (day and night patching), full time (occlusion for all waking hours), and part time (any time less than full time). Compliance is essential if therapy goals are to be achieved.

A recent study randomly grouped parents of children aged one to seven years into a "leaflet" group and a control group. The leaflet group was provided with written educational material while the control group was not. The concordance was monitored by a parental diary. The parent's knowledge and the reason(s) for non-concordance were assessed by a questionnaire. The result showed that parental knowledge was significantly greater in the leaflet group (88%) compared to the control group (49%) $p < 0.001$. Concordance was significantly greater in the leaflet group compared to the control group.⁷

Another study was conducted with parents of children with unilateral visual impairment referred from preschool vision screening. The children were randomly assigned, receiving spectacles with or without patches, spectacles alone, or treatment that was deferred for one year. A self-completed questionnaire, including a psychometric behavioral scale, was sent to the parents of all children. The results showed that most parents reported difficulties with patching their child regardless of age (77% at age 4 years and 73% at age 5 years). Fewer reported difficulty with spectacles alone (42% at age 4 and 53% at age 5 years). Children were significantly more upset by patching than glasses only ($p = 0.01$). Most parents thought their children were happy, cooperative, and good tempered. The behavioral score did not differ among treatment groups.⁸

The aim of another study was to assess the psychosocial impact on the child and family for patching and atropine treatment of moderate amblyopia in children younger than seven years. In the randomized clinical trial, 419 amblyopic children with visual acuity range of 20/40 to 20/100 were assigned to receive treatment consisting of either patching or atropine. After five weeks of treatment, a parental quality of life questionnaire was completed for 364 (87%) patients. The results showed the overall amblyopia treatment index scores, and the three subscale scores were consistently worse in the patching group compared with the atropine treatment group (overall mean: 2.52 vs 2.02, $p < 0.001$: adverse effect of treatment; mean 2.35 vs 2.11, $p = 0.02$, difficulty with compliance; mean 2.46 vs 1.99, $p < 0.001$: social stigma: mean 3.09 vs 1.84, $p < 0.001$, respectively). It was concluded that the occlusion therapy had a greater psychosocial impact on the child and family in comparison to the atropine treatment.⁹

Although the value of occlusion therapy is well recognized, our study goal was to explore the impact of the therapy on both children and their parents. The study also aimed to find out if parents of children prescribed occlusion therapy had an adequate understanding of amblyopia and occlusion therapy.

METHODS

Children who were undergoing occlusion therapy for one calendar year and their parents at the Department of Ophthalmology at Tribhuvan University in Kathmandu, Nepal from 1 September 2008 to 30 August 2009 participated in this study.

Inclusion criteria:

- Children who had undergone occlusion therapy for more than two months.
- Parents of the amblyopic children who were present at the time occlusion therapy was prescribed.

Exclusion criteria:

- Presence of ocular pathology causing the reduction in vision

This study included 52 children (27 females and 25 males) and their parents. Informed consent was obtained and an explanation about the research was provided. The parental educational status, based on the self-report of parents at the time of interview, was categorized as illiterate, below intermediate level, intermediate level, and above intermediate level. A family history of amblyopia was queried to ascertain any previous experience of the parents with occlusion therapy.

The types of amblyopia recorded from the patient record file at the initiation of occlusion therapy were:

- Strabismic amblyopia
- Anisometropic amblyopia
- Aniso-Strabismic amblyopia
- Isoametropic amblyopia
- Stimulus deprivation amblyopia (SDA)
- Amblyopia associated with nystagmus (AN)

The data gathered was:

- Age of the child when first patched was noted in years
- The visual acuity at the time of prescription of occlusion therapy was noted as per notation on the child's examination file
- Visual acuity at the time of interview was taken with appropriate methods depending on the age and development level of the child
- Prescribed hours of patching in terms of hours/day was recorded as mentioned at the time of prescription of occlusion therapy
- The number of hours patched was determined from the self report of the parents at the time of interview and questionnaire

The compliance with occlusion therapy was calculated by dividing the total hours patched (based on self report of parent) by the total hour prescribed (based on record on the file). This was expressed as a percentage.

Parental compliance was classified into four groups.¹⁰

- Poor - (<25%),
- Moderate - (25-50%),
- Adequate - (51-75%)
- Good - (>75%)

The parental understanding regarding amblyopia and its treatment was assessed through the parental questionnaire based on the standard questionnaire from a previous, similar study.¹¹ (Appendix A) Psychosocial impact of occlusion therapy on the child and parent was assessed by means of emotional impact questionnaire items.⁸ (Appendix B) Parental and child

Table 1. Educational status of parents

Educational level	Frequency	Percent
Illiterate	6	11.5
Below intermediate	14	26.9
Intermediate	20	38.5
Above intermediate	12	23.1
Total	52	100.0

Table 2. Types of amblyopia

Amblyopia type	Number(percentage)
Strabismic	15(28.8%)
Isoametropic	14(27%)
Anisometropic	13(25%)
Stimulus deprivation	6(11.6%)
Aniso-strabismic	2(3.8%)
Nystagmus associated	2(3.8%)
Total	52(100%)

Table 3. Change in visual acuity after occlusion therapy

Visual Acuity Status	Right eye		Left eye		Total
	Number of lines	No of eyes	Number of lines	No of eyes	
Improvement	1 line	11	1 line	14	25(33.75%)
	2 lines	3	2 lines	11	14(19%)
	3 lines	4	3 lines	2	6(8.1%)
	4 lines	3	4 lines	2	5(6.73%)
No Improvement		12		7	19(25.67%)
Deterioration		3		2	5(6.75%)
Total		36		38	74

perception of experiences and difficulties with occlusion therapy were noted at the time of the semi-structured interview.

RESULTS

The 52 amblyopic children ranged in age from 2 to 13 years. (Females, n=27, 51.9%; Males, n=25, 48.1%) The mean age was 6.79 (±2.54). Most children (n=28, 53.8%) were from 5 to 7 years of age and only 5 (9.6%) were in the age range of 11 to 13 years. All the children included in the study lived at home with their parents and the majority were attending school (n=48, 92.3%). Only two subjects (female twins) had a family history of amblyopia. The age of the parents ranged from 21 to 60 years with the mean age of 32.79 (±7.37) years. Regarding the educational status of the parents, six (11.5%) were totally illiterate and the rest were at an academic level ranging from below intermediate to Masters Level. (Table 1)

Types of amblyopia

Table 2 contains the types of amblyopia, with strabismus and isometropia being the most prominent. In those that had strabismic amblyopia, all but one was categorized as constant esotropia. SDA was due to congenital cataract in all cases.

Occlusion history

The age children were first prescribed occlusion therapy ranged from 1 year to 10 years, with mean age of 5.06 (±2.36). Among the different types of amblyopia, strabismic amblyopia and SDA were detected and patched earlier than other types. There is a significant association between the patching age and the type of amblyopia. ($\chi^2=3.867$, $p=0.049$, $d.f=1$) In a majority of patients with strabismic amblyopia (n=14, 93.3%) and SDA (n=6, 100%), patching was initiated before seven years of age.

Compliance with occlusion therapy

The mean total hours of occlusion prescribed was 7.04 hours (±1.64) and ranged from 2 hrs to 10 hours per day. The total mean hours of actual occlusion as reported by the parents at the

time of interview and questionnaire was 5.46 hours (±1.798) and ranged from 1 hrs to 8 hrs per day. The compliance with occlusion therapy was found to be 77.6%. It was calculated by dividing the total hours patched by the prescribed hours of patching. Compliance was found best in the age group 3 and 4 years and least in age group between 5 and 7 years.

Compliance with occlusion therapy was similar between educated and illiterate parents. There was 71% compliance in the educated group and 69% in the illiterate group. Two sets of the parents (3.8%) occluded the wrong eye (educated group). The status of visual acuity after occlusion therapy of each eye was analyzed separately. (Table 3) Thirty-four percent showed one line improvement while 26% showed no improvement.

Our interviews revealed that 23 (44.2%) of the parents were told the treatment of amblyopia was patching. Nine (17.3%) reported glasses and patching, and 7 (13.5%) indicated only glasses as the treatment. Thirteen (25.0%) did not have any knowledge of the treatment for amblyopia. In addition, 4 (7.7%) of the parents were unaware of the reduced visual acuity of their child. The relation between the parental educational status and knowledge regarding treatment of amblyopia was not statistically significant ($\chi^2=0.70$, $d.f=1$, $p>0.1$), although parental knowledge was found to increase with the increase in education level.

Parental knowledge of treatment

The majority of the parents (36, 69.2%) felt it was easy to patch the child when the child was more than 6 years of age. Fourteen (26.9%) stated that it was easier when the child was younger than 2 years and only 2 (3.8%) thought the age of the child did not matter in the easiness of patching. Nine of the parents of children with strabismus thought that the patching was prescribed to correct the strabismus, not the amblyopia. Fourteen (26.9 %) parents believed that surgery was an alternative to occlusion therapy. Eighteen (34.6%) parents reported some knowledge of the need for near vision stimulation activities and engaged their child in these activities while occluded.

Figure 1. Coping with patching therapy

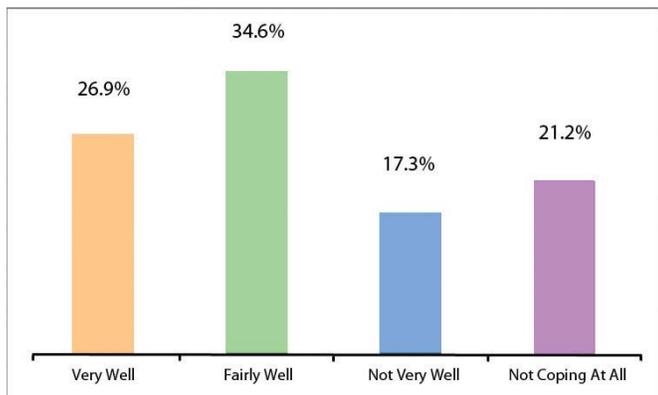
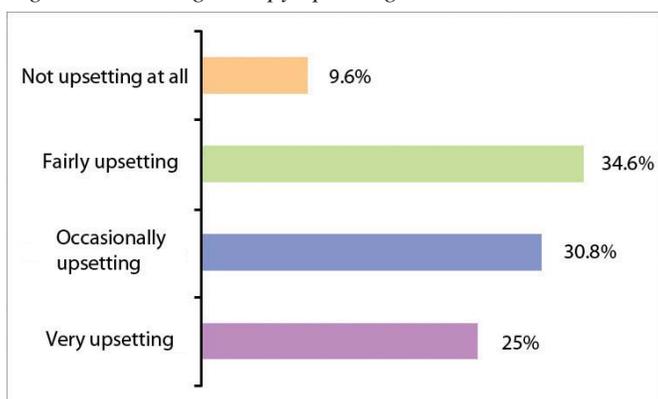


Figure 2. Patching therapy upsetting children



Psychosocial impact of occlusion therapy

According to the parents, the coping abilities of the children with patching therapy were varied. (Figure 1) Five to 7 year olds coped best with occlusion, while children below 5 years and above 7 years did not cope well. Parents reported that 25% of the children were very upset with patching while 9.6% were not upset at all. (Figure 2) The most common age of children upset by patching was in the age range of 2 to 4 years. The “easy group” was mostly children ages 5 to 10. It was most difficult for parents to comply with their children being occluded when the children were either very young or older.

Parents worried about the children undergoing patching therapy. (Figure 3) The age of the parents and level of concern with patching therapy was found to be statistically significant ($\chi^2=17.562$, $p=0.041$, d.f. =9). Patching was more upsetting for parents of younger aged children.

Child’s psychosocial development

Twenty-three (44.2%) children reported being teased by friends or siblings. Of these, 14 (26.9%) complained of being teased occasionally, 7 (13.5%) slightly, and 2 (3.8%) complained about being teased a lot. The teasing was statistically significant ($\chi^2=4.245$, $p=0.039$, d. f. =1) in children above 7 years of age. The majority (36, 69.2%) of parents reported that occlusion had no effect on their child’s academic performance while 15 (28.8%) reported that the child was behind classmates since occlusion started. One child’s academic performance was reported as totally hampered when patched. Seven (13.5%) children became uncooperative and 6 (11.5%) developed bad tempers. Behavioral changes due to occlusion were found in 14 (73.6%) children; none under the age of 5. (Table 4) Twenty children (38%) had restrictions in their daily

Figure 3. Parental worry with patching therapy

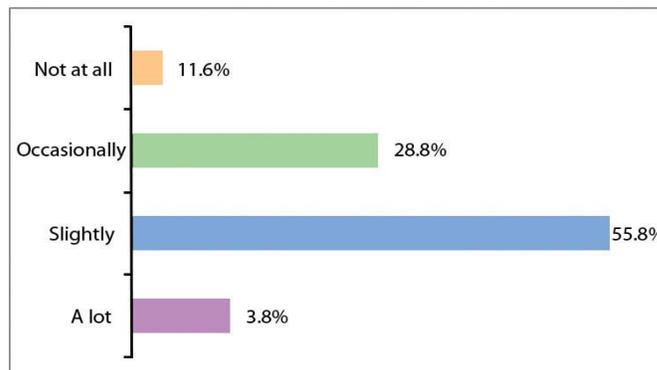


Table 4. Age range vs. behavioral change due to patching

Age range of children	Behavioral change due to patching			Total
	No change	Uncooperative	Bad tempered	
2-4	7	0	0	7
5-7	23	3	2	28
8-10	7	2	3	12
11-13	2	2	1	5
Total	39	7	6	52

activities of varying magnitudes. Children with anisometric, aniso-strabismic, and isoametric amblyopia were the majority that complained of restriction in activity.

Itching secondary to the patch was also reported. Fourteen (26.9%) complained of itching occasionally while 15 (28.8%) complained of itching very often and two (3.8%) children complained the patch always itched. These children also were found to have patched less than the prescribed hours, although it was not significantly correlated ($p>0.05$). Only five (9.6%) complained of trouble keeping the patch in place, especially during summer because of perspiring.

DISCUSSION

The patient compliance with occlusion therapy was found to be good (77.6%). This is comparable to previous studies. Brian et al. showed patient compliance to be 67.3% for boys and 66.3% for girls. The aggregate compliance scores did not reveal significant differences between classes of amblyopia.¹⁰

The method used to determine compliance in the present study was based on the self report of each parent. Since it is a subjective response, we cannot state if bias existed.¹² In a previous study using an objective measure of compliance, the Occlusion Dose Monitor (ODM), compliance was found to be 80% for those who had a satisfactory visual acuity increase and 34% in those who had an unsatisfactory visual acuity increase.¹² This indicates that efficacy of patching therapy is directly related to compliance with the patching regimen. Exact compliance is difficult to determine without the use of an ODM. In the present study, compliance appeared better among younger and older children, but there was no significant relationship between age and compliance. Likewise, there was no significant difference in compliance between the educated and

illiterate parents: 71% compliance in the educated group and 69% compliance in the illiterate group.

Compliance was good in our study but only 38.4% occluded the eye as recommended. This is less than the study by Searle et al. where 53% achieved the practitioner recommendation.¹³ We also cannot be certain as to the extent that parental self-report of compliance is accurate.¹⁴

Visual acuity was improved in only 67.6% of the total amblyopic eyes with a range of one to six lines improvement. Visual acuity was not improved in 25.7% of amblyopic eyes. In 6.8% of the amblyopic eyes, the visual acuity had deteriorated as compared to initial the visual acuity.

The parental understanding of amblyopia and its treatment and knowledge on the effectiveness of near vision stimulation activities at the time of patching was poor. This indicates that parents were often unaware of their child's vulnerability to amblyopia or the efficacy of treatment. Some parents even felt occlusion therapy did not work. Only 42% of the parents whose children were undergoing occlusion therapy had adequate knowledge of amblyopia and its treatment. This is comparable to a study by Newsham where 49% of the parents had a thorough knowledge.⁷ Sixty percent of the parents of children who had strabismic amblyopia thought that occluding the eye would also correct the strabismus.

Parents of any education level can have knowledge regarding amblyopia and its treatment if given proper education and counseling. Failure to appreciate this information may be a compounding factor in the lack of compliance. Since most parents responded that it was easy to patch the older (6 years) than the younger child (2 years), parents may wait to initiate treatment, consciously or unconsciously. Of the total cases, 2 (3.8%) occluded the incorrect eye. This is similar to a previous study.⁷ The parents, when educated as to proper patching protocol, might have been confused by the clinician's explanation. Research by Newsham has compared the effect of parental understanding on concordance. When parental understanding increased, the parental concordance increased from a mean concordance index of 0.71 to 0.85. Therefore, knowledge/understanding of issues surrounding the prognosis and treatment regimen of amblyopia needs to be improved to increase compliance and ensure that the treatment is correctly implemented.⁷

Findings from the present study indicate that occlusion therapy can have adverse consequences for both the child and family. Difficulties with therapy by the parents and children were noted both during the interview and questionnaire. Many of the children did not cope well with therapy (age range 5-7 years). Those who coped better were either below 5 years or above 7 years. Only 9.6% of the children were not bothered at all by occlusion.

Making the child wear a patch was not an easy task for the parents. Approximately a quarter of the parents reported that it was very difficult, particularly for the children who were too young or old. This agrees with previous studies, where patching with older children was more difficult for parents.^{15,16} The majority of the parents were worried about their child's reduced vision and occlusion therapy. Parents who worried were mainly below the age of 40. Occlusion therapy was upsetting for the family. Many participants reported that their child refused to wear a patch during school hours. Few parents

reported that their children had academic problems after initiation of occlusion therapy. Some parents complained that when the sound eye was occluded, the child had problems seeing the blackboard and could not write in a straight line. One of the parents reported that the adverse effect of patching on the child's academic background was so great that they discontinued therapy. Removal of the patch by the child during examinations was also a reported difficulty.

There were adverse psychological changes in the children induced by occlusion therapy. A number of children had some form of psychological change. This behavioral change may stem from forcing the child to wear a patch in spite of his/her unwillingness. Moreover, some children hesitated to wear a patch in front of relatives, claiming they were weary of telling people and relatives why they were wearing a patch. Some studies indicate that amblyopia¹⁷ and its treatment¹⁸ have adverse psychosocial consequences, while other studies suggest that amblyopia management does not cause significant psychosocial problems¹⁸

The main limitation of this study was the method of determining compliance. In addition, since the initial visual acuity recorded was extracted from the examination file, the room conditions and type of visual acuity chart used may have differed. This could lead to non-uniformity in visual acuity testing. Another limitation was that there was no objective measure of the psychosocial status of the parent and child.

CONCLUSION

While the overall compliance with occlusion therapy was good, the same could not be said concerning parental understanding in the key areas of amblyopia and occlusion therapy. The educational status of the parents, however, had no significant effect on the level of understanding regarding amblyopia and its treatment. Occlusion therapy was found to be a difficult experience for the child and parents, but the parents were found to be more serious, sensitive, and dedicated to treatment. The undue distress created by treating amblyopia appeared disabling and had a psychosocial impact on the children. Although treatment should be aimed at reducing amblyopia and restoring visual acuity, efforts to minimize the parent's and child's difficulties, distress, and negative psychosocial consequences of occlusion therapy should also be considered.

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Appendix A Questionnaire to explore parental understanding of amblyopia and patching therapy

1. Does your child have reduced vision?
2. What is the treatment of reduced vision (amblyopia)?
3. Does the treatment have to be carried out by a certain age?
4. Would it be easier to correct weak vision in one eye at 2 years or 6 years of age?
5. Which eye are you putting the patch on?
6. How many hours were you told to put the patch for?
7. Do you think patching will correct strabismus?
8. Do you think amblyopia can be treated if patching does not work?

Appendix B Emotional impact questionnaire Section A (child's experience)

1. How well has your child been coping with his/her treatment?
 - a. very well
 - b. fairly well
 - c. not very well
 - d. not coping at all
2. Has the treatment been at all upsetting for your child?
 - a. not at all
 - b. fairly upsetting
 - c. occasionally upsetting
 - d. very upsetting

3. Have you had any difficulties getting your child to wear his/her patch?
 - a. very easy
 - b. fairly easy
 - c. fairly difficult
 - d. very difficult

Section B (family experience)

1. Do you worry about your child's vision?
 - a. a lot
 - b. slightly
 - c. occasionally
 - d. not at all
2. Do you worry about your child's treatment?
 - a. a lot
 - b. slightly
 - c. occasionally
 - d. not at all
3. Has the treatment caused any argument in your family?
 - a. a lot
 - b. a few
 - c. occasionally
 - d. not at all
4. Has the treatment been at all upsetting for you?
 - a. very upsetting
 - b. fairly upsetting
 - c. occasionally upsetting
 - d. not at all

Section C (child's well being)

1. Over the last three months has your child been teased by a sibling or friends?
 - a. not at all
 - b. occasionally
 - c. slightly
 - d. a lot
2. How is your child been getting on at the nursery/school?
 - a. no problem
 - b. a bit behind classmates
 - c. very behind
 - d. does not attend
3. Over the last three months has your child been:
 - a. unhappy/happy
 - b. cooperative/uncooperative
 - c. good/bad tempered
4. Has the patching caused restriction in his/her daily activities?
 - a. not at all
 - b. occasionally
 - c. often
 - d. most of the time
5. How often does your child complain of itching around the patch?
 - a. not at all
 - b. occasionally
 - c. very often
 - d. always

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