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Childhood esotropia: child and parent concerns

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Abstract

Purpose—To identify specific health-related quality of life (HRQOL) concerns affecting children with esotropia as expressed by children or one of their parents (proxy) and concerns affecting the parents themselves.

Methods—Sixty children with esotropia (0–17 years of age) and 1 parent for each child were prospectively enrolled. Individual semistructured interviews were conducted with children aged 5–17 years (n = 40) and 1 parent each for child ages 0–17 years. Transcripts of recorded interviews were evaluated using NVivo software. Specific concerns were identified from both child and parent interviews and coded. From these specific codes, broad themes were identified. Frequency of each theme was calculated, along with the frequency of specific codes within each theme.

Results—Regarding the child's experience 6 broad themes were identified: visual function (mentioned by 32 of 40 children (80%) and by 50 of 60 parents (proxy assessment of child, 83%), treatment (78% and 85%), emotions (65% and 67%), social (58% and 68%), physical (58% and 32%), and worry (45% and 7%). Regarding the parents' own experience, 5 broad themes were identified: treatment (59 of 60 parents, 98%), worry (97%), emotions (82%), compensation for condition (80%), and affects family (23%).

Conclusions—A wide range of concerns were identified from interviews of children with esotropia and their parents. Concerns reflect the impact of esotropia in physical, emotional, and social domains, and specific concerns will be used for the development of questionnaires to quantify the effects of esotropia on children's and parents' quality of life.

Esotropia is one of the most prevalent forms of childhood strabismus in Western populations.¹ Nevertheless, few studies to date have evaluated how esotropia affects children in their everyday lives. Patient-reported outcomes are becoming increasingly recognized as

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important in management decisions and, for a pediatric population, the perception of both the child and the parent should be considered. There are few validated instruments to assess strabismus-specific health-related quality of life (HRQOL), symptoms and effects of treatment, and existing instruments are targeted at conditions other than esotropia or at older children.^{2–9} The purpose of this study was to identify specific HRQOL concerns of children with esotropia as expressed by children or a parent (proxy) and concerns affecting the parents themselves. This was the first stage in developing new patient-reported outcome measures for pediatric eye conditions.

Subjects and Methods

Institutional Review Board approval was obtained from the institutional review boards at the Mayo Clinic, Rochester, Minnesota, and the University of Texas Southwestern Medical Center, Dallas, Texas. All procedures and data collection were conducted in a manner compliant with the US Health Insurance Portability and Accountability Act of 1996. Informed consent was obtained from the parents of participating children; informed assent was obtained from children 7 years of age at the Mayo Clinic and 10 years at the Retina Foundation of the Southwest. Both the child and 1 parent were enrolled.

Participants were enrolled at one of two sites, Mayo Clinic, where both the child and one parent were required to be conversant in English, and Retina Foundation of the Southwest, where both English- and Spanish-speaking subjects were eligible because Spanish-language consent forms and a Spanish-speaking interviewer were available.

Children 0–17 years of age in 10 diagnostic categories (esotropia, exotropia, hypertropia, nystagmus, amblyopia, refractive error, orbital condition, anterior segment, retina, and central nervous system) were eligible for enrollment in the parent study of patient-reported outcomes in pediatric eye disease. Clinical diagnoses were made by a pediatric ophthalmologist (Mayo Clinic and Retina Foundation of the Southwest sites) or pediatric optometrist (Mayo Clinic). The study's initial goal was to enroll 30 children in each diagnostic category, increasing enrollment if necessary to achieve coverage of a range of clinical severities, ages, and racial/ethnic diversity.

In the present study we report concerns of children with esotropia and their parents. Because the distinction between esotropia as a primary diagnosis and esotropia secondary to other conditions can be somewhat artificial, we included all patients with esotropia to represent the full spectrum of concerns associated with esotropia and its comorbidities. Nevertheless, we excluded all patients with coexisting organic eye disease (retina, anterior segment, orbital, or visual loss directly due to CNS lesions) because we expected that concerns regarding the organic disease would dominate and we wanted to reflect concerns related to the esotropia itself. Regarding nystagmus, 2 patients had a primary diagnosis of nystagmus of unknown etiology, 1 had a primary diagnosis of idiopathic infantile nystagmus, and 1 had a secondary diagnosis of latent nystagmus. Children were not eligible if they had undergone strabismus surgery within the past 6 weeks.

Interview Procedure

Following recommended guidelines for developing patient-reported outcome measures,^{10–14} one of 3 examiners conducted individual, semistructured, audio-recorded interviews in a quiet examination room. The interview was structured around 12 open-ended questions for the child (Appendix A [e-only]) and 12 open-ended questions for the parent (Appendix B [e-only]). In order to elicit additional concerns not covered in the initial response to the question, probes such as, “How does that make you feel?” or, “Tell me more about that,” were used throughout the interview. In addition, the interviewer allowed any avenue of discussion regarding concerns. There was no time limit set for the interviews.

We attempted to interview all enrolled children 5–17 years of age. If the child was comfortable being interviewed by themselves (with verbal approval from the parent), the parent was asked to wait in a different room. If the parent stayed in the room, they were positioned out of the child’s line of sight and asked not to interrupt.

One parent was interviewed for every enrolled child (for children <5 years of age, only the parent was interviewed). To allow the parent freedom to express concerns without having to worry about upsetting their listening child, the child either wore earphones and watched a movie on a portable DVD player inside the room during the parent interview or waited outside the room on their own (with verbal approval from the parent) or with other family members.

Coding of Interviews

All interviews were transcribed verbatim. Interviews conducted in Spanish were transcribed in English by a translator working independently of the interview process. Interview transcripts were reviewed and coded using NVivo 10 software (QSR International, Doncaster, Australia), which allows organization and tracking of interview content. For each transcribed interview, specific concerns were identified and labeled by assigning words or phrases to nodes, that is, labels that described the nature of the concern. New nodes were added as new areas of concern were identified. Separate nodes were created according to whether comments related to the child’s experience reported by the parent as proxy or to the parent’s own experience and the reviewer determined which node assignment to make for each concern.

A total of 3 reviewers coded the interviews, with one pair of reviewers independently coding each interview. At the start of the coding process, reviewers underwent training to establish a common understanding of how concerns could be coded. Six interview transcripts were reviewed together, with the reviewers discussing which codes should be assigned. For all subsequent interviews, all assigned nodes from both reviewers were retained.

Clinical and Demographic Data

For each patient, additional information was collected, including specific diagnoses, visual acuity, angle of deviation (largest of distance or near, by simultaneous prism and cover test when available, or if not available, by prism and alternate cover test, or Krimsky) grouped into one of 3 bins as either orthotropic, microtropic (<10°), or moderate (≥10°), refractive

error, type of optical correction, current treatment, previous surgery, and whether or not there was any global developmental delay. Basic demographic data were also collected, including age, sex, race, and ethnicity of the child, parental age, parental highest level of education, type of housing, and childcare arrangements.

Analysis

Specific nodes were grouped into broader, overarching themes. The frequency of nodes and themes was calculated separately for child concerns (derived from interviews of children 5 years), proxy concerns (child concerns from parent interviews), and parent concerns (from all parent interviews).

Results

A total of 60 children with a current primary or additional diagnosis of esotropia were enrolled (mean age, 7 years; range, 0–17 years), along with 1 parent or legal guardian for each child. Of the 60 children, 44 (73%) had a current primary diagnosis of esotropia at the time of the interview; the remaining 16 (27%) had a diagnosis of esotropia in addition to their current primary diagnosis (Table 1). Of the 44 with a primary diagnosis of esotropia, 31 had additional diagnoses commonly associated with esotropia, including amblyopia, hypertropia, nystagmus, and/or consecutive exotropia. In the 16 children with a primary diagnosis other than esotropia, esotropia was documented as a secondary diagnosis. Demographics of enrolled children and their parents are listed in Table 2.

Six (10%) of 60 parent interviews and 1 (3%) of 40 child interviews were conducted in Spanish. The enrolled cohort of children represented a range of clinical characteristics in terms of esotropia type, magnitude of the esodeviation, visual acuity, global developmental delay, refractive error, and treatments (Tables 3 and 4). While all patients had a history of esotropia, some were not frankly esotropic at the time of the interview (Table 3), either because of improvement with refractive correction or because they had undergone surgical correction. In these cases interview questions were directed toward the child's (or parent's) experience when the esotropia was present.

Thirty-five (58%) had a current or previous diagnosis of amblyopia, of which 26 (74%) had been patched or were currently patching and 12 (34%) had received or were currently receiving atropine treatment.

Child Concerns

Forty of 41 (98%) children aged 5–17 were interviewed, and a total of 25 specific areas of concern (nodes) were created as the interviews were coded. These were subsequently grouped into 6 broad themes on review of the individual nodes: visual function (80%), treatment (78%), emotions (65%), physical (58%), social (58%), and worry (45%). See Table 5. Within visual function, concerns regarding vision were the most frequently mentioned specific concerns (28 of 40 [70%]), including references to poor vision such as “my eyes are moving in ... and making me not see good.” The most commonly mentioned specific concerns within the treatment theme were glasses (19 of 40 [48%]) and patching (18

[46%]). For example, one child said, referring to the patch, “I hate it. I keep on wanting to take it off because I can’t see. I keep running into a wall.”

Proxy-reported Child Concerns

Of the 60 interviewed parents, 19 (32%) were parents of children aged 0–4 years (child too young to be interviewed) and 41 were parents of children 5–17 years (1 parent was interviewed where the child was unable). The overall, frequency of themes was similar to that of the children themselves: treatment (85%), visual function (83%), social (68%), emotions (67%), physical (32%), and worry (7%). See Table 5. The most commonly mentioned specific concerns within the treatment theme were: glasses (62%), patching (47%), and surgery (25%). For example, one parent said “It hurt him, he would come home and [say] I hate glasses, he would take them off and he would whip them across the room.” The second most commonly occurring theme was visual function (50 [83%]), with the most common specific concern being activities/sports/hobbies (52%), for example: “She can’t see the ball approaching her. When she goes to kick it, she kicks in the wrong place.”

Parent’s Own Concerns

A total of 27 specific areas of concern were coded relating to the parent’s own experience and 5 broad themes were identified: treatment (98%), worry (97%), emotions (82%), compensation for condition (80%), and affects family (23%). See Table 6. The most commonly mentioned specific concerns within the theme of treatment were inconvenience (75%) and concerns related to glasses (58%) (Table 6). For example, one parent said, “I would have more time, I wouldn’t be here, I would be at work.” Treatment-related worry was the type of worry most frequently mentioned by the parents (82%), for example: “My only real concern is if he is going to need surgery; surgery is scary.”

Discussion

During this patient/parent input stage of developing a new patient-related outcome measure for childhood eye conditions, a wide range of concerns were identified in semistructured interviews of children with esotropia and their parents. Child concerns were grouped into 6 broad themes and parent concerns were grouped into 5 broad themes. The two most frequent themes for child concerns (mentioned by both the children and parents as proxy) were visual function and treatment. For parents, the most frequently identified themes were treatment and worry.

Most children with esotropia in our clinics had already been treated or were undergoing treatment and often had other comorbidities such as amblyopia. It appears that the clinical condition of esotropia is often associated with prior or current treatment and the presence of associated conditions. We felt it would be most useful to include children who had experienced treatment for esotropia and associated conditions along with the effects of other comorbidities to collate the spectrum of concerns related to esotropia that would be used in future questionnaires.

Few previous studies have reported interviews of children with esotropia. In a study by Menon and colleagues,¹⁵ 40 participants aged 15–25 years were interviewed (35 with large-

angle esotropia), and the majority (87.5%) reported social concerns. In the present study, social concerns were not among the top concerns, but the participants in the study of Menon and colleagues¹⁵ were older than ours and had large-angle strabismus, whereas 77% of our patients were orthotropic or microtropic at the time of interview (wearing refractive correction). Either of these factors may have contributed to the lower proportion reporting social concerns. Parents, as proxies for their children, also mentioned social concerns less frequently than other types of concerns, but it is important to note that social concerns were still expressed by more than half of the children and two-thirds of parents. Social concerns have been highlighted in previous studies, including social bias against children with esotropia by teachers¹⁶ and negative interactions of children playing with strabismic versus nonstrabismic dolls.¹⁷ Many studies have also reported the negative psychological impact of strabismus in older children and adults.^{18–20}

The high proportion of children and parents who reported vision function-related concerns may be explained by the presence of vision-reducing comorbidities that commonly accompany childhood esotropia (eg, refractive error and amblyopia). These conditions, as well as some treatments (eg, patching, atropine) compromise visual function and may therefore affect a child's everyday life. Nevertheless, there were also vision function-related problems expressed in relation to depth perception or double vision, which may be more directly attributable to the esotropia itself. Of note, children most often reported vision itself as a specific concern, whereas parents seemed more likely to report the effects of their child's vision on, for example, activities/sports/hobbies.

Nearly every parent (98%) expressed concerns regarding the impact of their child's treatment on their own (the parent's) experience, especially the inconvenience (75%) of attending appointments, having to take time off work, rescheduling, and so forth. In addition, most parents expressed worry about treatment and a number of other worries and negative emotions. There are few data on the effects of a child's strabismus on the parents themselves, but Akay and colleagues²¹ reported that mothers of strabismic children were more likely to be depressed than mothers in a control group, which may be consistent with our finding of a high proportion of parents expressing worry and negative emotions.

The FDA has emphasized the critical value of patient input in supporting content validity in the development of patient-reported outcome measures.^{10–14} Individual interviews and focus groups are acknowledged as the standard methodology for deriving the items for new instruments to ensure content validity. Child, proxy, and parent concerns identified in the interview stage of this current study will be used to create questionnaires as part of a larger research effort to develop patient-reported outcome measures for pediatric eye conditions.

The present study is limited by the small number of children/parents within each age bin and for each specific esotropia subdiagnosis. Nevertheless, the aim of the study was to identify concerns from a diverse population of children with esotropia. We did not insist on the parent leaving the room during the child interview, and this may have affected the child's freedom to express their concerns. Also, the concerns identified in this study may be influenced by coexisting diagnoses of amblyopia, refractive error, or other strabismus; nevertheless, these other eye conditions are commonly associated conditions of childhood

esotropia, so identified concerns are likely representative of children with esotropia. The distinction between primary and secondary diagnoses of esotropia was somewhat arbitrary, so our analysis combined these patients to have an overall assessment of esotropia and associated conditions. Another limitation is that the majority of parents interviewed were mothers. Fathers' views may have differed. Finally, the majority of children with current esotropia were either orthotropic or microtropic (with refractive correction) and may have undergone surgery some time previously, potentially making it difficult to recall every aspect of their experience of living with a larger-angle esotropia.

A strength of our study is that we included both English- and Spanish-speaking children and parents from two geographically, socioeconomically, and socially disparate centers. While our patients were diverse in terms of diagnosis and age range, our sample does not represent all children with esotropia. Future studies using the initial and subsequent instruments will formally explore differences among diverse populations.

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Appendix A. Interview questions for children with esotropia

1. Is there anything you'd like to tell me about your eyes?
2. What things are difficult to do because of your eyes?
3. What things would you like to do, but can't do because of your eyes?
4. What bothers you about your eyes?
5. How are your eyes different from other children's eyes?
6. Tell me how your eyes feel?
7. What do other people say about your eyes?
8. How much do you worry about your eyes?
9. How do you feel about the treatment that you have had/are having for your eyes?
10. Is there anything about your eyes that makes you unhappy?
11. Is there anything else that bothers you about your eyes?
12. Is there anything else you want to tell me?

Appendix B. Interview questions for parents of children with esotropia

1. What things bother or concern you about your child's eyes?
2. In what ways does your child's eye condition affect them in everyday life? Physically, emotionally, socially?
3. In what ways does your child's eye condition affect you? Your family?
4. Is there anything that you do because of your child's eye condition, which you wouldn't normally do (for example safety precautions, extra supervision)?
5. Is there anything that you would like to be able to do, but do NOT do, because of your child's eye condition?
6. Do other people treat your child differently because of their eye condition? In what ways?
7. What concerns for the future do you have regarding your child's eye condition? For your child/for you?
8. How would life change for your child if their eye condition was corrected? For you?
9. In what ways does your child's eye condition affect their ability to interact with other children? With adults?
10. How does the treatment for your child's eye condition affect your child? How does it affect you?
11. What are the main issues or concerns for you regarding the treatment or management of your child's eye condition?
12. Can you describe any other ways your child's eye condition affects you or your child that we haven't covered?

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Table 1

Current primary diagnoses and additional diagnoses and their frequency

Diagnosis	Current primary diagnosis, ^b no. (%)	Additional diagnosis, no. (%)
Esotropia ^a	44 (73)	16 (27)
Exotropia	4 (7) ^c	5 (8) ^d
Hypertropia	6 (10)	7 (12)
Amblyopia	3 (5)	32 (53)
Nystagmus	3 (5)	1 (2)
Refractive error	0 (0)	44 (75)

^aFor 13 children with a current diagnosis of esotropia, no other ocular condition besides refractive error was present.

^bChildren with organic eye disease excluded (e.g. retina or anterior segment).

^cChildren who initially had esotropia but currently had a consecutive exotropia.

^dChildren who initially had exotropia but current had a consecutive esotropia.

Table 2

Child and parent demographics

Characteristic	No. (%)
Sex of child	
Female	31 (52)
Male	29 (48)
Age	
0–4	19 (32)
5–11	25 (42)
12–17	16 (27)
Race	
White (including Hispanic/Latino)	45 (75)
Asian	5 (8)
More than 1 race	5 (8)
Black/African American	3 (5)
American Indian/Alaskan Native	1 (2)
Other	1 (2)
Ethnicity	
Not Hispanic/Latino and not Middle Eastern/North African and not Indian Subcontinent	44 (73)
Hispanic/Latino	12 (20)
Indian Subcontinental	2 (3)
Middle Eastern/North African	1 (2)
Unknown/Not Reported	1 (2)
Parent/legal guardian interviewed	
Mother	45 (75)
Father	14 (23)
Grandmother	1 (2)
Parent Age	
Under 21	3 (5)
21–30	8 (13)
31–40	26 (43)
41–50	20 (33)
51–60	2 (3)
Not reported	1 (2)
Parent highest level of education	
Attended high school	7 (12)
High school graduate	5 (8)
Attended college	11 (18)
College graduate	27 (45)
Post-graduate/professional degree	10 (17)
Housing	
Own	45 (75)

Characteristic	No. (%)
Rent	14 (23)
Other	1 (2)
Number of parents in home	
1	7 (12)
2	53 (88)
Care of child	
Parents only	34 (57)
Day care	7 (12)
Other relative	4 (7)
Other	4 (7)
After school program	3 (5)
More than 1 source of assistance	8 (13)

Table 3

Child clinical characteristics

Characteristic	No. (%)
Esotropia type ^a	
Accommodative or partially accommodative	28 (47)
Congenital/infantile	9 (15)
Nonaccommodative	7 (12)
Paralytic	5 (8)
Consecutive	4 (7)
Mechanical	3 (5)
Sensory (due to amblyopia)	3 (5)
Unknown	1 (2)
Current deviation magnitude, PD ^b	
Orthotropic	30 (50)
<10	17 (28)
10	13 (22)
Best eye visual acuity	
20/25 or better	41 (68)
2/30 to 20/40	6 (10)
Worse than 20/40	12 (20)
Not reported	1 (2)
Worst eye visual acuity	
20/25 or better	18 (30)
2/30 to 20/40	16 (27)
Worse than 20/40	25 (42)
Not reported	1 (2)
Global Delay	12 (20)
Refractive error (spherical equivalent, by eye; n = 120), D	
Range	-12.25 to 8.75
<-4.00	6 (5)
-4.00 to < -3.00	1 (1)
-3.00 to < -2.00	1 (1)
-2.00 to < -1.00	0 (0)
-1.00 to <0.00	6 (5)
0.00 to <1.00	13 (11)
1.00 to <2.00	23 (19)
2.00 to <3.00	17 (14)
3.00 to <4.00	15 (13)
4.00 to <5.00	11 (9)
5.00 to <6.00	9 (8)
6.00	14 (12)
Not recorded	4 (3)

D, diopter; *PD*, prism diopter.

^aCurrent esotropia type if currently esotropia or original esotropia type is not currently esotropic.

^bLargest of distance or near.

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Table 4

Child treatment history

Treatment	No. (%)
Previous extraocular muscle surgery	36 (60)
Nonsurgical treatment at time of interview	
Spectacles	45 (75)
Patching	12 (20)
Atropine/cyclogyl	6 (10)
iPad binocular treatment	4 (7)
Other (other binocular, nail polish on lens)	2 (3)
Prism	1 (2)
Historical nonsurgical treatment prior to interview	
Patching	30 (50)
Spectacles	20 (33)
Atropine/cyclogyl	10 (17)
iPad binocular treatment	7 (12)
Prism	2 (3)
Convergence/fusion exercises	1 (2)

Table 5

Frequency of concerns of children with esotropia expressed by the child themselves and by their parent (as proxy reporter), grouped into overall themes, and of specific concerns within those themes

Theme and specific concerns	Frequency, N (%)	
	Child (N = 40)	Proxy (N = 60)
Visual function	32 (80 [CI, 64–91])	50 (83 [CI, 71–92])
Vision	28 (70)	28 (47)
Activities/sports/hobbies	12 (30)	31 (52)
Compensate/adjust for condition	12 (30)	25 (42)
School/reading	10 (25)	14 (23)
Limitations	4 (10)	16 (27)
Coordination	4 (10)	14 (23)
Injury	4 (10)	1 (2)
Treatment	31 (78 [CI, 62–89])	51 (85 [CI, 73–93])
Glasses	19 (48)	37 (62)
Patching	18 (45)	28 (47)
Surgery	11 (28)	15 (25)
Drops	3 (8)	7 (12)
Other treatment	3 (8)	3 (5)
Inconvenience	2 (5)	7 (12)
Emotions	26 (65 [CI, 48–79])	40 (67 [CI, 53–78])
Negative emotions	25 (63)	35 (58)
Appearance/self-conscious	11 (28)	14 (23)
Self-confidence	1 (3)	10 (17)
Anxiety	0 (0)	1 (2)
Social	23 (58 [CI, 41–73])	41 (68 [CI, 55–80])
Being different from others	19 (48)	14 (23)
Comments	13 (33)	23 (38)
Social interactions	4 (10)	25 (42)
Teasing	4 (10)	16 (27)
Looking-staring	2 (5)	6 (10)
Physical	23 (58 [CI, 41–73])	19 (32 [CI, 20–45])
Ocular discomfort/sensations	23 (58)	19 (32)
Worry	18 (45 [CI, 29–62])	4 (7 [CI, 2–16])
Worry	18 (45)	4 (7)
Deterioration	3 (8)	0 (0)

CI, 95% confidence interval.

Table 6

Frequency of concerns of parents of children with esotropia (affecting themselves), grouped into overall themes, and showing specific concerns within those themes

Theme and specific concern	Frequency, No. (%) (N = 60)
Treatment	59 (98 [CI, 91–100])
Inconvenience	45 (75)
Glasses	35 (58)
Surgery	28 (47)
Patching	27 (45)
Cost	18 (30)
Drops	9 (15)
Other treatment	5 (8)
Limitations	4 (7)
Worry	58 (97 [CI, 88–100])
Treatment	49 (82)
Future	40 (67)
Vision	40 (67)
Appearance/self-conscious	32 (53)
Deterioration	26 (43)
Teasing/comments	21 (35)
Social	20 (33)
Limitations	19 (32)
Unspecified eye-related	19 (32)
Coordination/injury	17 (28)
Activities/sports/hobbies	16 (27)
Different from others	14 (23)
Academics/reading	13 (22)
Self-confidence	10 (17)
Heredity/genetics	1 (2)
Emotions	49 (82 [CI, 70–90])
Negative emotions	49 (82)
Anxiety	2 (3)
Compensate for condition	48 (80 [CI, 68–89])
Affects family	14 (23 [CI 13–36])

CI, 95% confidence interval.