ORIGINAL ARTICLE

Problems in Malaysian children with large angle infantile esotropia: Children and parents' perspectives

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ABSTRACT

Introduction: There is limited information regarding the problems faced by children with large angle infantile esotropia (LAIE). The aim of this study was to explore the problems that children with LAIE encounter from both their perspectives and those of their parents.

Methods: This study included children who had LAIE (with angle of 40 prism dioptres or greater), aged 5 and 17 years who had attended the Ophthalmology Clinic, Hospital Universiti Sains Malaysia from March to September 2016. The children and their parents or guardians were interviewed face-to-face using a validated semi-structured interview guide. Interviews were tape-recorded and transcribed verbatim. Content analysis was performed using the NVivo 12 software.

Results: A total of 30 children and 30 parents were interviewed. The most common problems identified by the children were social interactions (73.3%, 22 children), visual functions (60.0%, 18 children), emotions (60.0%, 18 children), physical issues (40.0%, 12 children) and difficulties regarding treatment options (26.7%, eight children). The parents reported that their children were more affected in terms of visual functions (100.0%, 30 parents), social interactions (56.7%, 17 parents), emotions (43.3%, 13 parents), physical issues (20.0%, six parents), and difficulties regarding treatment options (16.7%, five parents).

Conclusion: The major problems that the children with LAIE identified were social interactions, while the parents observed that problems with visual functions was the most common issue encountered by their children. This suggests that the children affected have different perspectives from their parents and require support.

KEYWORDS:
infantile esotropia, large angle, children, parent, perspective

INTRODUCTION

Both children and adults with childhood onset of strabismus have psychosocial problems such as embarrassment, trouble making eye contact, low self-esteem, poor self-confidence, and intelligence scores that are perceived to be low.[1-3] The functional problems from which these patients suffer include rubbing their eye, photophobia, tired eyes, problems with eye focussing, double vision, difficulty in reading, difficulty with depth perception, pain or burning sensations in the eyes and vision-related problems.[1-12]

Valuable information regarding children's psychosocial and functional problems can be obtained from the close observations by their parents.[13,14] Furthermore, the parents of affected children reported adverse outcomes of strabismus on their own daily lives and family relationships. The parents were distressed by remarks of other people, worried about their children, had unsupportive relationship with their children, and had not been advised about corrective surgery.[13,14]

Few authors have described the concerns regarding strabismus from the perspectives of the children and their parents.[4-7] Based on a PubMed search, data regarding actual problems faced by children with large angle esotropia of infantile onset are limited. Hence, it is necessary to measure the daily problems of both the affected children and their parents from their own perspectives. The aim of our study, then, was to identify relevant problems that affect the daily activities of Malaysian children with large angle infantile esotropia (LAIE) and of their parents.

MATERIALS AND METHODS

This qualitative study was conducted in the Ophthalmology Clinic at Hospital Universiti Sains Malaysia (USM), Kelantan, Malaysia. Clinical data collection and procedures were conducted in accordance with the Declaration of Helsinki. The study protocol was approved by the Human Research Ethics Committee of USM. Informed consent was obtained from the parents and informed assent was attained from the affected children. Only one of each parent of the children was recruited for the interview. Purposive sampling using the maximum variation sampling was applied for this study.

The number of participants was decided according to the saturation of information given by the participants. Saturation was achieved when all the participants had given

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almost the same information and the collection of new data did not shed any further light on the problems under investigation. In this study, the in-depth-interviews were conducted on 30 children who had infantile esotropia and 30 parents of these children, based on the minimum required sample size for qualitative study.[15,16]

All the children who were screened had been diagnosed with infantile esotropia greater than 40 prism diopters from 5 to 17 years of age. Children were excluded from the study if they had other types of strabismus (e.g. Duanne syndrome), secondary causes of esotropia (e.g. trauma and sensory deprivation due to congenital cataracts, corneal opacity, optic atrophy, and macular scars), organic eye diseases, neurological disorders, facial, ocular or cosmetic abnormalities, syndromic or chromosomal anomalies, known intellectual disability, abducens nerve palsy and had ocular surgery. Parents with known intellectual disability and psychological illness were also excluded.

Detailed demographic data were obtained, including birth history, onset of esotropia, visual performance, family history of esotropia, and history of prematurity. The children underwent complete clinical assessment, which involved visual acuity tests, assessment for stereopsis, cover tests, testing for extraocular motility, examinations of their pupils and convergence tests. The children were also examined carefully for signs of anomalies of the anterior and posterior segments. An identified paediatric ophthalmologist examined all the patients who had been recruited, and a trained senior optometrist performed cycloplegic refraction assessments in all patients.

Semi-structured interview guides were developed and validated separately for the versions for children and parents. Content validity was also performed for the semi-structured interview guides that had been drafted. A panel of experts was selected based on their knowledge and experience in questionnaire development and paediatric ophthalmology subspecialty. During this validity assessment, the panel of experts commented on the comprehensiveness, relevancy, and representativeness of all the items in the interview guides. The interview guides were then modified according to the experts' suggestions.

A second draft of the semi-structured interview guides was piloted with 28 new participants, that included 9 children and 19 parents for face validity. The children and parents who consented to do this were asked about the clarity and transparency of the interview guides. Based on comments and observations during the interviews, the wordings in the interview guides were then modified to simplify and shorten the sentences to produce a third semi-structured interview guides for both the children and the parents.

The third semi-structured interview guides were re-assessed in a second pilot study with new participants, including 6 children and 12 parents. This step was performed to assess the clarity and simplicity of the items. No further modifications were needed following these interviews, since the children and their parents stated that the interview guides were easy to understand and the sentences were clear. These third and final semi-structured interview guides for the children (18 items) and parents (17 items) was forward translated into English versions and back translated to Malay language.

The interviews were conducted in a quiet examination room by the primary investigator using the validated Malay versions of the final versions of the semi-structured interview guides (Appendix I) for the children and their parents. The children were encouraged to share their difficulties and describe in detail their problems they had with regard to infantile esotropia. There was no time limit set for the interviews. Both the children and parents were given adequate time to talk and express their views.

While the children were interviewed, the parents generally waited in another room, having agreed that their children might feel uncomfortable being interviewed in their presence. However, if the parents preferred to stay in the same room during the interview, they sat at the back of the room and were asked not to interrupt or interfere. With consent from their parents, the children waited in an adjacent room while the investigator interviewed the parents. The aim of this procedure was to allow freedom for both children and their parents to express their views spontaneously and avoid feeling concerned that their opinions may disturb or hurt either their parents or their children.

The interviewer used a natural tone of voice throughout the interview process. The questions were repeated slowly to ensure that the participants had a solid understanding of them and to avoid confusion or misinterpretation. The interviews were tape-recorded with the permission of both the children and their parents. All the interviews were conducted in Malay and transcribed verbatim.

Before starting the coding process, the primary investigator underwent formal training to establish a common understanding regarding the coding process. The primary investigator read the transcripts and listened to the recordings repeatedly to ensure the accuracy and relevancy of the data. The investigator read and checked the transcripts many times before the actual interview process. This was important in order to choose appropriate themes and subthemes and to ensure the relevancy and consistency of the coding.

Specific problems with regard to LAIE were identified and coded by using different words, phrases and labels to address the nature of the problems for the children and their parents. These codes were subsequently reviewed by the expert panels to verify the appropriateness of the coding.

The socio-demographic and clinical data were analysed using the Statistical Package for the Social Sciences for Windows version 24.0 (SPSS Inc, Chicago, IL, USA). The transcripts from the interviews were reviewed and coded using NVivo 12 software (QSR International, Doncaster, Australia), which allowed for the organisation and tracking of interview content and thematic analysis. The frequencies and percentages relating to the problems were calculated independently for the self-reported perceptions of the children and their parents, using SPSS version 24.0.

Table I: Demographic and clinical characteristics

Characteristics	Children n (%)	Parents n (%)
Gender		
Female	10 (33.3)	23 (76.7)
Male	20 (66.7)	7 (23.3)
Race		
Malays	27 (90.0)	29 (96.7)
Chinese	3 (10.0)	1 (3.3)
Children's age (years)		
5-8	10 (33.3)	
9-17	20 (66.7)	
Parent's age (years)		
20-30		7 (23.3)
31-40		11 (36.7)
41-50		10 (33.3)
51-60		2 (6.7)
Parent interviewed		
Father		6 (20.0)
Mother		24 (80.0)
Parent's level of education		
Primary school		2 (6.7)
Secondary school		18 (60.0)
College/University		10 (33.3)
Parent's monthly income		
Less than RM 580		2 (6.7)
RM 580 - RM 1500		11 (36.7)
RM 1500 - RM 3000		10 (33.3)
More than RM 3000		7 (23.3)
Best corrected visual acuity		
6/6-6/18	30 (100.0)	
6/24-6/60	0 (0.0)	
Worse than 6/60	0 (0.0)	
Stereopsis		
Present	3 (10.0)	
Absent	27 (90.0)	
Distant angle of deviation (Prism dioptre)		
Less than 40	0 (0.0)	
40-45	10 (33.3)	
More than 45	20 (66.7)	
Near angle of deviation (Prism dioptre)		
Less than 40	0 (0.0)	
40-45	5 (16.7)	
More than 45	25 (83.3)	
Spherical Equivalent (Dioptre)		
Less than +1.00	20 (66.7)	
+1.00 to +1.75	8 (26.7)	
+2.00 to +3.00	2 (6.6)	

RESULTS

A total of 30 children and 30 parents were interviewed. The majority of the children were aged from 9 to 17 years (66.7%, 20 children), were males (66.7%, 20 children), and were of Malays (90.0%, 27 children). The majority of the parents involved were mothers (80.0%, 24 parents), aged from 31 to 50 years (70.0%, 21 parents), with secondary school education (60.0%, 18 parents) and had a monthly income of less than RM 3,000 (76.7%, 23 parents). All children had corrected visual acuity from 6/6 to 6/18 (20/20 to 20/60). Only 10.0% of the children had binocular single vision. The majority had angles of deviation that were greater than 45 prism dioptres at distance (66.7%, 20 children) and near (83.3%, 25 children). Furthermore, 66.7% of the children presented with low hypermetropia. Table I shows the tabulation of these figures.

Five broad problems were identified among the children, aged from 5 to 17 years, who had infantile esotropia: social interactions (73.3%, 22 children), visual functions (60.0%, 18 children), emotions (60.0%, 18 children), physical issues (40.0%, 12 children) and difficulties with treatment options (26.7%, 8 children) (Table II). The children noted 32 specific problems. Being teased by friends (60.0%, 18 children) was the most frequently reported among these problems, followed by feeling anxious (40.0%, 12 children) and experiencing blurred vision for distance (33.3%, 10 children).

From the interviews with the parents regarding their children's problems, five broad issues were also identified. However, unlike their children, the parents perceived that the most frequent problem was with regard to visual functions

Table II: Problems of children with LAIE

Problems (Themes and subthemes)	Child n (%)	Parent n (%)
Visual Functions		
Blurred vision for distance	10 (33.3)	14 (46.7)
Whiteboard writings	5 (16.7)	1 (3.3)
Focusing	5 (16.7)	7 (23.3)
Bumping into objects	3 (10.0)	7 (23.3)
Gadget	3 (10.0)	7 (23.3)
Reading	3 (10.0)	5 (16.7)
Writing	3 (10.0)	3 (10.0)
Searching object	3 (10.0)	4 (13.3)
Turning back	3 (10.0)	1 (3.3)
Outdoor activities	3 (10.0)	1 (3.3)
Field of view	3 (10.0)	0 (0.0)
Closing one eye	3 (10.0)	0 (0.0)
Head tilt	0 (0.0)	12 (40.0)
Climbing stairs	0 (0.0)	5 (16.7)
Watch television	0 (0.0)	4 (13.3)
Walking	0 (0.0)	3 (10.0)
Eating	0 (0.0)	2 (6.7)
Photophobia	0 (0.0)	1 (3.3)
During school examination	0 (0.0)	1 (3.3)
Emotions		
Anxiety	12 (40.0)	5 (16.7)
Shy	8 (26.7)	1 (3.3)
Negative perception	5 (16.7)	5 (16.7)
Fear	5 (16.7)	3 (10.0)
Hope to be normal	5 (16.7)	0 (0.0)
Angry	3 (10.0)	5 (16.7)
Stress on appearance	3 (10.0)	1 (3.3)
Positive perception	3 (10.0)	1 (3.3)
Sad	3 (10.0)	0 (0.0)
Depressed	0 (0.0)	2 (6.7)
Refuse to talk	0 (0.0)	2 (6.7)
Physical Issues		
Eye strain	8 (26.7)	1 (3.3)
Ocular discomfort	3 (10.0)	0 (0.0)
Headache	3 (10.0)	1 (3.3)
Tearing	3 (10.0)	3 (10.0)
Moving eye	0 (0.0)	1 (3.3)
Double image	0 (0.0)	1 (3.3)
Social Interactions		
Teasing by friends	18 (60.0)	13 (43.3)
Public insecurity	5 (16.7)	1 (3.3)
Eye contact	3 (10.0)	1 (3.3)
Interaction	3 (10.0)	3 (10.0)
Teacher's bias	0 (0.0)	3 (10.0)
Treatment Options		
Patching	8 (26.7)	3 (10.0)
Surgery	8 (26.7)	3 (10.0)
Spectacle	3 (10.0)	3 (10.0)

(100%, 30 parents), followed by social interactions (56.7%, 17 parents), emotions (43.3%, 13 parents), physical issues (20%, 6 parents) and difficulties with treatment options (16.7%, 5 parents). The parents observed 39 specific problems (Table II). The most common reported among these problems were blurred vision for distance (46.7%, 14 parents), being teased by friends (43.3%, 13 parents), and head tilts (40.0%, 12 parents).

DISCUSSION

The available data is focussed on children with exotropia and combination esotropia/exotropia and their parents in India and the United States of America.[4-6] Only a limited amount of data is available regarding the concerns and perspectives of children with esotropia.[7] Therefore, we conducted a hospital-based study which acts as a referral centre for strabismus consultation in the states in the East Coast of Peninsular Malaysia. We recruited children with LAIE, and 66.7% of these children had esotropia greater than 45 prism dioptres for distance fixation. Table III summarises the above reports,[4-7] and also includes the outcome of our study.

The children in our study reported social interactions as their most common problem. They suffered from being teased by friends at schools and found it difficult to mix in society.

Table III: Published reports regarding children and parents' perspective

Author / Year	Country	Type of strabismus	Number of children/parents	Main concern by children (Percentage)	Main concern by parents (Percentage)
Hatt et al. (2008)[6]	United States of America	Intermittent Exotropia	24 children (aged 5-17 years old) 24 parents	Worry (42%) Troubled by blurriness (33%) Comments from others (33%)	Comments from others (63%) Appearance to others (38%) Troubled by need to correct exotropia (25%)
Kothari et al. (2009)[4]	India	Horizontal comitant strabismus	Guardians of 93 children (aged 4-16 years old)	Not reported	Extremely distressed due to people's remarks (55%) Severely ostracized (57%) Severe difficulty in communication (38%) Difficulty to cope (50%) Severe difficulty in communication (38%)
Liebermann et al. (2016)[7]	United States of America	Childhood esotropia	40 children (aged 5-17 years old) 40 parents	Visual Function (80%) Treatment (78%) Emotion (65%) Social (58%) Physical (58%) Worry (45%)	Visual Function (83%) Treatment (85%) Emotion (67%) Social (68%) Physical (32%) Worry (7%)
Hatt et al. (2016)[5]	United States of America	Intermittent exotropia	35 children (aged 5-13 years old) 35 parents	Rubbing the eye (83%) Problems with eyes in the sun (63%) The eyes feeling tired (63%)	Not reported
Current study (2021)	Malaysia	Infantile esotropia	30 children (aged 5-17 years old) 30 parents	Social interactions (73.3%) Visual functions (60.0%) Emotions (60.0%) Physical issues (40.0%) Treatment options (26.7%)	Visual functions (100.0%) Social interactions (56.7%) Emotions (43.3%) Physical issues (20.0%) Treatment options (16.7%)

Large angles of deviation in children with infantile esotropia are easily noticeable, and this is supported by reports that esotropia is perceived to be more disturbing than exotropia by non-strabismic adults and children.[8,17,18] Paysse et al. confirmed that a negative attitude toward strabismus appears to emerge at approximately 6 years of age.[19]

Our finding contradicted those of Liebermann et al. who reported that the majority (80%) of the children with esotropia experienced visual functions as their major problem.[7] This observation probably resulted from the study involving different types of esotropia with variable angle of deviations. Liebermann et al. recruited patients with small angles of deviation (less than 10 prism dioptres) in the majority (74%) of their cases along with cases involving accommodative or partial accommodative types of esotropia (47%).[7] A different observation was also reported by Hatt el al., who conducted a similar study on children with intermittent exotropia.[6] The majority of the children reported worrying as their major problem. This can be explained by the history of intermittent exotropia. Children with this type of exotropia become noticeable after two to three years of age or later in life and have good stereopsis at near and breaks into tropia only when they are tired, not focused or suffering from febrile illness. Their eye conditions may not be so obvious to their peers and friends until they break their fusion abilities.[9-11] This clearly suggest that type, severity and onset of strabismus contributes to the psychosocial effects with regard to the affected children.

In contrast to the reports by their children, the parents in our study described visual functions as the most common problem faced by their children. Other problems included blurred vision for distance (46.7%), head tilts (40.0%), bumping into objects (23.3%), watching television (13.3%) and searching for objects (13.3%). The parents also noted that their children had near vision problems including focusing on and difficulties using electronic gadget (23.3%), reading (16.7%), writing (10.0%), eating (6.7%) and school examinations (3.3%). This finding is slightly different from that of Liebermann et al., who reported that treatment options (85%) was their main concern.[7] One possible explanation for this is that our study was conducted in a government hospital that provides low-cost treatment and consultation. Hatt et al. reported that parents (63%) of children with intermittent exotropia were also concerned about comments made by others.[6]

In our study, we observed that there were a few concerns that were mentioned only by the parents. These included head tilts (40.0%), while climbing stairs (16.5%), watching television (13.3%) and walking (10.0%). Liebermann et al. also noted in their study that 2% of the parents mentioned anxiety in their children, although this was not noted by the children in their study. However, self-confidence and relationships (17% in each subtheme) were mentioned by parents only in the study by Hatt et al.[6] This is an interesting observation in relation to our study, in which visual functions were still the main concern noticed by the parents of children with large angle esotropia, even though visual functions were not mentioned by the children. This observation contradicts the outcome of other studies where the parents reported more concerns with regard to emotions.[6,7]

Both the children with infantile esotropia (60.0%) in our study and their parents (43.3%) agreed that teased by friends was an issue of great concern. A similar study on childhood esotropia reported that this issue was stated by 48% of the children and 38% of their parents.[7] In contrast, other studies reported fewer comments about being teased, with 33% in children with intermittent exotropia and 63% in their parents.[6] Kothari et al. reported that 55% of parents were extremely distressed by remarks that people made.[4] This issue merits attention, and we have been unable to find published reports on the long term consequences regarding this. However, we encountered a study by Olson et al., who reported that congenital esotropia increases the odds 2.6 times of developing mental illness by early adulthood in comparison to a control group.[20] The authors evaluated a cohort of patients who had been diagnosed with congenital esotropia at ages 10 to 30, and reported that the prevalence of major depression was 50% and 19% for anxiety.[20]

Our study found a vast difference in the major concerns between the children with LAIE and their parents. There are a few possible explanations for this. Firstly, age gap may contribute to the differences in perceptions between the children and their parents. Secondly, the children may be more concerned with their social relationships, while the parents focus more on health, family and safety. Thirdly, the parents' perceptions were based on observation of their children at home or during the time they spent together, and may not include times when the children run into difficulties with friends, at school or in public places. Therefore, it is advisable for the parents to improve their communication and understand the difficulties faced by their children who have infantile esotropia.

In addition, conducting interviews with very young age groups, especially those aged less than eight years, can be problematic. These young children took more time to understand the questions. They also became silent and refused to talk to strangers, and this attitude may have affected the results. To minimize these problems, a simpler and shorter semi-structured interview guide was developed in this study to help these young children to understand better and hence to cooperate more fully.

CONCLUSION

Children with LAIE who were treated in Hospital USM reported that social interaction was their major problem. However, their parents perceived that visual functions were the main issue encountered by these children. The parents need to improve communication with their children to gain a better understanding of the actual problem and help these children with LAIE to overcome the obstacles they face.

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Appendix I: Interview questions for children with infantile esotropia

A. For children

1. When do you notice about your squint eyes?
   Sejak bila anda sedar mata anda juling?

2. Tell me how your eyes feel?
   Apa yang anda rasa mengenai mata anda?

3. What things would you like to do, but can't do because of your eyes?
   Apa perkara yang anda mahu lakukan, tetapi tidak dapat dilakukan disebabkan mata anda?

4. Do you feel difficult to climb up the stairs?
   Adakah anda merasa sukar semasa menaiki tangga?

5. Do you feel difficult to jump over the drain?
   Adakah anda merasa sukar untuk melangkah longkang?

6. Do you feel difficult to estimate depth when you go swimming?
   Adakah anda merasa sukar untuk menganggar jarak kedalaman semasa berenang?

7. Do you have any problem at school because of your eyes?
   Adakah anda mengalami masalah di sekolah kerana mata anda?

8. What do other children say about your eyes?
   Apakah yang kawan-kawan anda perkatakan mengenai mata anda?

9. Do you have any problem during your conversation with others?
   Adakah anda mempunyai masalah semasa bercakap dengan orang lain?

10. Do your teachers give comment regarding your eyes?
    Adakah guru-guru memberi komen mengenai mata anda?

11. What do other grown-ups mention about your eyes?
    Apa yang orang-orang dewasa perkatakan mengenai mata anda?

12. What do your parents say to you about your eyes?
    Apa yang ibu bapa perkatakan mengenai mata anda?

13. How do you feel about your eyes?
    Apa perasaan anda mengenai mata anda?

14. How do your parents feel about your eyes?
    Apa perasaan ibu bapa terhadap mata anda?

15. Do you know about the treatment of your eyes?
    Adakah anda tahu mengenai rawatan tentang mata anda?

16. What do you think about the treatment of your eyes?
    Apa yang anda fikir mengenai rawatan mata anda?

17. Is there anything else that bothers you about your eyes?
    Adakah terdapat perkara lain yang mengganggu disebabkan mata anda?

18. What is your wish after your squint surgery?
    Apa harapan anda selepas menjalani pembedahan mata juling?

B. For Parent

1. When did you notice your child had squint eyes?
   Sejak bila anda menyedari mata anak anda juling?

2. How much do you notice your child's eye is wandering?
   Berapa kerapkah mata anak anda kelihatan juling?

3. What activities do you associate with your child's eye wandering in? What makes it worse or better?
   Apakah yang anak anda lakukan semasa mata anak anda kelihatan juling?Apa yang menyebabkan keadaan tersebut semakin buruk atau baik?

4. Did your child tell you how do his/her eyes feel?
   Pernahkah anak anda memberitahu perasaan tentang keadaan matanya?

5. What do you child do or not do because they have squint?
   Apa yang anak anda lakukan, atau tidak lakukan kerana mata juling?

6. In what ways does the squint affect your child?
   Apa yang mengganggu anak anda berkaitan matanya?

7. Does your child have difficulty to climb up the stairs?
   Adakah anak anda sukar menaiki tangga?

8. Does your child have difficulty to jump over the drain?
   Adakah anak anda sukar melangkah longkang?

9. Does your child feel difficult to estimate depth when you go swimming?
   Adakah anak anda berasa sukar untuk menganggar jarak kedalaman semasa berenang?

10. What bothers you most about your child's eyes?
    Apakah yang paling mengganggu anda mengenai mata anak anda?

11. In what ways does the squint affect your child's ability to interact with other children or adults?
    Bagaimanakah keadaan mata anak anda memberi kesan dalam pergaulannya dengan rakan-rakan atau orang dewasa?

12. How do other people react when they notice your child has squint?
    Apa reaksi orang lain mengenai mata anak anda?

13. How do you feel about your child having squint eyes?
    Apakah perasaan anda bila anak anda mengalami mata juling?

14. Do you know about the treatments of the squint eyes?
    Adakah anda tahu mengenai kaedah-kaedah rawatan mata juling?

15. What are the main issues or concerns for you regarding the treatment or management of your child's eyes?
    Apakah perasaan anda mengenai rawatan mata anak anda?

16. Is there anything regarding your child's eyes that makes you unhappy?
    Adakah terdapat perkara mengenai mata anak anda yang menyebabkan anda tidak gembira?

17. Can you describe any other ways that squint affects you or your child that we have not discuss?
    Adakah terdapat perkara yang mengganggu mengenai mata anak anda yang kita belum dibincangkan?