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Development and initial validation of quality of life questionnaires for intermittent exotropia

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Abstract

Purpose—We report the development and initial validation of patient-derived, health related quality of life (HRQOL) questionnaires for intermittent exotropia (IXT).

Design—Cross-sectional study

Participants—In a development phase, 27 children (aged 2–17 years) with IXT and one of their parents. In an initial validation phase, 33 children with IXT and 49 control children (aged 5–17 years) along with one parent for each child. Children in the control group had no strabismus or amblyopia.

Methods—Individual patient interviews generated 35 items for Child and Proxy (parental assessment of child's HRQOL) questionnaires and 46 items for a Parent questionnaire. To reduce to a feasible number of items, questionnaires were administered to 5–17 year old children with IXT (n=15) and parents of 2–17 year old children with IXT (n=27). Responses were analyzed using standard item reduction methodology. Three final derived IXT questionnaires (IXTQ): Child, Proxy, and Parent (12, 12, and 17 items respectively) were administered to children with IXT and control children, and to parents of IXT and control children. Likert-type scales ranging from 'never' (score 100, best HRQOL) to 'almost always' (score 0, worst HRQOL) were used for responses.

Main outcome measures—Median scores for IXT and control groups, compared using Wilcoxon tests.

Results—Median Child scores were significantly lower (worse HRQOL) in the IXT group compared with the control group: 85 (quartiles 73–92) versus 92 (79–96); P=0.04. Median Proxy IXTQ scores were significantly lower for IXT children than controls: 83 (75–94) versus 98 (92–100); P<0.0001. Median Parent IXTQ scores were also significantly lower in the IXT group compared with the control group: 68 (quartiles 56–79) versus 93 (87–99); P<0.0001.

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Conclusions—We have developed and validated a new 3-part patient-derived HRQOL questionnaire for children with IXT and their parents, comprising Child, Proxy and Parent questionnaires. These questionnaires detect reduced HRQOL in children with IXT as reported by the child themselves and as perceived by their parents (proxy report). Childhood IXT also appears to affect the HRQOL of the parents. The IXTQ HRQOL questionnaires may prove useful in the clinical assessment of IXT and for clinical trials.

Evaluation of severity of childhood intermittent exotropia (IXT) relies principally on assessment of angle of exodeviation, ability to control, and stereoacuity. Nevertheless, recent studies have demonstrated a great deal of variability in measures of control and stereoacuity in IXT, even from moment to moment.^{1, 2} New approaches to assessing severity of IXT, such as measuring effects on health related quality of life (HRQOL) may therefore be helpful in determining indications for intervention. In a previous report³ we described the identification of specific HRQOL concerns for children with IXT and their parents. We now describe the use of these patient-derived concerns to develop condition-specific HRQOL questionnaires for children with IXT and their parents, and the initial validation of those questionnaires, by comparing scores in children with and without IXT.

Patients and Methods

Institutional Review Board approval was obtained. Each parent gave informed consent and children 8 years and older gave informed assent, before participating. All procedures and data collection were conducted in a manner compliant with the Health Insurance Portability and Accountability Act.

We report two phases comprising this present study: first the development of final IXT questionnaires and second the initial validation of the newly developed final IXT questionnaires. For both phases of the study, we enrolled children with IXT along with one of their parents. All children with IXT had either divergence excess or basic type IXT: no child had a near angle ≥ 10 prism diopters (pd) greater than distance (convergence insufficiency type exotropia). None of the children with IXT had amblyopia, defined as ≥ 0.2 LogMAR (Logarithm of the Minimum Angle of Resolution) inter-ocular difference and ≥ 0.3 LogMAR in one eye. In the second, testing phase of the study, three children in the control group had an interocular acuity difference of 0.2 LogMAR, attributable to refractive error. Patients with neurodevelopmental delay or coexisting ocular pathology were not included.

Phase 1: Development of final IXT questionnaires

Questionnaire items were identified from individual interviews of children with IXT and one of their parents, as reported previously.³ Unique statements or phrases regarding the effects of IXT on HRQOL were converted into questions. Statements or phrases considered likely to discriminate between patients based on socio-economic, cultural, or educational status or that did not explicitly address HRQOL (but were more descriptive of symptoms) were not included. Three types of questionnaires were derived: Child (35 items addressing child's own HRQOL), Proxy (35 items parallel to the Child questionnaire addressing parent's perception of their child's HRQOL) and Parent (46 items addressing the parent's own HRQOL). Child and Proxy questionnaires contained identical items pertaining to the child's HRQOL expressed in the first person for the Child and third person for the Proxy.⁴ These questionnaires were administered to a cohort of children with IXT and their parents to reduce the number of items in each questionnaire to a more feasible number addressing concerns.

Twenty-seven children with IXT (aged 2–17, median 5 years) were recruited with one of their parents. Two (7%) of 27 had undergone previous surgery but had recurrent IXT. Median angle of deviation at distance by prism and alternate cover test (PACT) was 20 pd (range 10 to 30

pd). Four (15%) children wore refractive correction. Fifty-two percent were female and for 93% race was self-reported as 'White.' Fifteen (56%) were aged 5 to 17 years (n = 6 aged 5 to 7 years and n = 9 aged 8 to 17 years) and completed the Child questionnaires, which were designed to be completed by 5- to 17-year-old children. Proxy questionnaires were completed by parents of the 5- to 17 year children (i.e. 15 of 27 parents). In 13 (87%) of 15 cases, the mother of the child completed the Proxy questionnaire. Parent questionnaires were completed by all 27 parents (i.e. parents of 2- to 17-year-old children). In 19 (70%) of 27 cases, the mother of the child completed the Parent questionnaire. For 2 (7%) of 27 children, both the father and mother of the child circled responses on the questionnaires: where there were differing responses, one parent was selected at random.

We developed the Child questionnaire in two formats, similar to the design of the generic PedsQL™ questionnaires.⁵ The format for 5- to 7-year-olds used simple language and a 3-point Likert type scale for responses ('Not at all', 'Sometimes', 'A lot') as well as the option to respond 'I don't know.' A matching card with face symbols representing the responses could also be used, depending on the child. Questionnaires were read, verbatim, by a trained observer, in a neutral tone of voice. If the child did not respond, the question was repeated verbatim without any explanation or elaboration. Inability to respond despite repeating the question was recorded as 'I don't know.' The format for 8- to 17-year-olds used a 5 point Likert type scale for responses ('Never', 'Almost never', 'Sometimes', 'Often', 'Almost always') as well as the option to respond 'I don't know.' Questionnaires were self-administered following simple verbal and written instructions, with supervision as necessary (depending on the child) by a trained observer. If the child did not understand a question, it was read verbatim by a trained observer, without any explanation or elaboration. Inability to respond despite repeating the question was recorded as 'I don't know.' Parents were instructed not to interfere with their child's responses and communication (verbal and non-verbal) between child and parent was limited by positioning the child with their back to their parent whenever possible. Any comments made by the child regarding the wording or clarity of a question were recorded.

For Proxy and Parent questionnaires a 5-point Likert type scale was used for responses ('Never', 'Almost never', 'Sometimes', 'Often', 'Almost always') as well as the option to rate the question 'Not applicable.' Questionnaires were self-administered, following simple verbal and written instructions including an explanation to use the 'Not applicable' option only if the item could not be understood or if it was considered to be not at all relevant. Any comments regarding the wording or clarity of a question were recorded.

Analysis of Child and Proxy questionnaires - development phase

Child and Proxy responses were analyzed together to enable retention of items that were pertinent from both child and parent perspectives and the development of a proxy questionnaire that paralleled the child self-report.⁶ For 8- to 17-year-old Child questionnaires, and for Proxy questionnaires, the 5-point scale used for responses was collapsed to the 3 categories used for the Child 5- to 7-year-old questionnaire: 'Never' and 'Almost never' were converted to 'Not at all'; 'Often' and 'Almost always' were converted to 'A lot.' Questionnaire items were excluded using the following four pre-defined criteria: 1) removed items where $\geq 20\%$ of either Child or Proxy responses were 'Not applicable'; 2) removed items where $\geq 80\%$ of either Child or Proxy responses were 'Not at all'; 3) removed items where there were any comments regarding the meaning of the item; and 4) removed items that were unlikely to be responsive to intervention or that would become irrelevant after treatment. To further reduce items in parallel for the child and proxy questionnaires, we plotted the correlation of the individual item scores with the total scores (item-total correlation using Cronbach's alpha) against number of items retained in item-total correlation rank order. To determine if there were any systematic differences between the scores of younger and older children and between children and parents,

two separate graphs were plotted showing 1) Child 5–7 and Child 8–17 data and 2) Child 5–17 and Proxy 5–17 data. The inflection point on the graph was used to determine the threshold for retaining items, i.e. points on the steep portion of the plot would indicate high item-total correlation, and items that should be retained. Common items with item-total correlation values greater than the inflection threshold on each graph were retained. Factor analysis was performed, replacing any remaining ‘Not applicable’ responses with a ‘Not at all’ value.

Analysis of Parent questionnaire - development phase

For Parent questionnaires, items were excluded using the same 4 pre-defined criteria described for Child and Proxy questionnaires described above. Once steps 1–4 were completed, any remaining ‘Not applicable’ responses were replaced with a ‘Never’ value for factor analysis. To further reduce the number of items, loading thresholds were analyzed (a measure of the correlation between an item and the underlying factor) and because we had a large number of items, we retained only items loading above a threshold of 0.70 on the strong factors.

Phase 2: Initial validation of final IXT questionnaires

As a first step in validating final IXT questionnaires (IXTQ), 5- to 17 year-old children were recruited to complete questionnaires, along with one parent for each child. Questionnaires were administered as described for the development phase with the 3-point Likert type scale used for 5-to 7-year olds (‘Not at all’ =score 100, ‘Sometimes’ =score 50, ‘A lot’ =score 0) and the 5-point Likert type scale for 8–17 year olds (‘Never’ =score 100, ‘Almost never’ =score 75, ‘Sometimes’ =score 50, ‘Often’ =score 25, ‘Almost always’ =score 0). Proxy and Parent questionnaires were self-administered and the 5-point Likert type scale used for responses (‘Never’ =score 100, ‘Almost never’ =score 75, ‘Sometimes’ =score 50, ‘Often’ =score 25, ‘Almost always’ =score 0).

Patients - IXT group

Thirty-three children (median age 8 years, range 5–15 years) with IXT were recruited with one of their parents for this phase of the study. Fifteen (45%) of 33 were aged 5- to 7 years and 18 (55%) were aged 8- to 15 years. One had undergone previous surgery nearly 10 years prior and had recurrent IXT. Median angle of deviation at distance by prism and alternate cover test (PACT) was 25 (range 10 to 40 pd). Eleven (33%) children wore a habitual refractive correction. Twenty-two (67%) were female and for 28 (85%) race was self-reported as ‘White.’ All 33 children completed the 12-item final Child questionnaire. Thirty-one of 33 parents completed the 12-item Proxy questionnaire (two overlooked) and all 33 parents completed the 17-item Parent questionnaire. The same parent completed both Proxy and Parent questionnaires: in 27 (82%) of 33 cases, this was the mother of the child.

Patients - Control group

Forty-nine control children (median age 8 years, range 5–13 years) were recruited with one of their parents for this phase of the study. 19 (39%) of 49 were aged 5- to 7 years and 30 (61%) were aged 8- to 13 years. All children were orthotropic with no more than 10 pd of horizontal and no vertical heterophoria by PACT. Seventeen (35%) of 49 children wore a habitual refractive correction. Thirty-three (67%) were female and for 46 (94%) race was self-reported as ‘White.’ All 49 children completed the 12-item Child final questionnaire. All 49 Parents completed the 12-item Proxy questionnaire and 17-item Parent questionnaire. The same parent completed both Proxy and Parent questionnaires: in 37 (76%) of 49 cases, this was the mother of the child. IXT and control groups were therefore comparable for age, gender, race and which parent completed the questionnaires.

Initial validation analysis

Median Child, Proxy and Parent questionnaire scores were calculated, ranging from 100 (best HRQOL) to 0 (worst HRQOL) and compared between IXT and control groups using Wilcoxon tests. Scores on individual questions and subscales were also compared between groups. For Parent questionnaires, subscale scores, also ranging from 100 to 0, were calculated and compared between IXT and control groups. Scores were calculated as an average of all answered questions. Where more than one answer was circled, the response indicating better HRQOL (higher score) was used. All statistical analyses were done using SAS statistical software version 9.1.3.

Results

Development of final Child and Proxy IXT questionnaires

Of the 35 original questionnaire items, 10 were removed because $\geq 20\%$ of either Child or Proxy responses were 'not applicable' and an additional 3 items were removed because $\geq 80\%$ of either Child or Proxy responses were 'Not at all.' There were no negative comments regarding the clarity or wording of questions and no items were considered potentially unresponsive to, or inappropriate after treatment, therefore no items were excluded for these reasons. In total, 13 (37%) of 35 items were removed, leaving 22 items. A 'Not at all' response was imputed for the 58 remaining 'Not applicable' responses (24 child responses and 34 proxy responses of a total 660 responses). Using Cronbach's alpha, the correlation of the item score to total score (item-total correlation) was plotted against the number of items retained in item-total correlation rank order. The item-total vs. correlation rank plot for the Child questionnaire in children ages 5 to 7 was compared to the plot in children ages 8 to 17 (Figure 1A available online only at <http://aaojournal.org>) to rule out any gross differences in item functioning between these two age ranges. No meaningful differences were found and children ages 5 to 17 were combined for comparison of the Child questionnaire to the Proxy questionnaire. The inflection point of the item-total vs. correlation rank plot for the Child (ages 5 to 17) and Proxy questionnaires was determined to be 0.3 (Figure 1B available online only at <http://aaojournal.org>), which was then used as a threshold to further reduce the number of questionnaire items. Items with item-total correlation > 0.3 were retained, yielding 16 items on Child questionnaires and 20 on Proxy questionnaires, with 12 items common to both Child (ages 5 to 7, 8 to 17, and 5 to 17) and Proxy questionnaires. Factor analysis was performed on these 12 remaining common items and review of the scree plots indicated 1 prominent factor, accounting for 4.8% of the variance for the Child questionnaire (Figure 2A available online only at <http://aaojournal.org>) and 8.8% of the variance for the Proxy questionnaire (Figure 2B available online only at <http://aaojournal.org>). These analyses therefore resulted in final Child and Proxy questionnaires containing 12 parallel items (Table 1; also available on line in administrable format with user instructions: <http://public.pedig.jaeb.org>, accessed 15th June 2009). Cronbach's alpha reliability coefficient was 0.93 for the final Child questionnaire and 0.97 for the final Proxy questionnaire.

Development of final Parent IXT questionnaire

Of the 46 original questionnaire items, 1 item was removed because $\geq 20\%$ of responses were 'Not applicable,' 1 was removed because $\geq 80\%$ of responses were 'Never,' 2 items were removed due to negative comments regarding wording or clarity and 1 item was removed as potentially irrelevant after treatment. In total, 5 (11%) of 46 items were removed, leaving 41 items for factor analysis. A 'Never' response was imputed for the 38 remaining 'Not applicable' responses, of a total 1107 responses. Factor analysis showed 3 strong factors on the scree plot (Figure 2C available on line only at <http://aaojournal.org>), accounting for 16%, 4% and 4% of the overall variance respectively. Principal component analysis also revealed three similar

principal components (data not shown). Three factors were forced for remaining analyses. Loading thresholds were reviewed and 0.70 was applied, reducing the total number of items to 17. Repeat factor analysis confirmed the 3-factor structure. Items within the 3 factors addressed parental worry for their child in 3 broad areas which we proposed as subscales: 1) psychosocial effects of IXT (n=7 items), 2) function (n=8 items) and 3) surgery for IXT (n=2 items). (Table 2; also available online in administrable format with user instructions: <http://public.pedig.jaeb.org>, accessed 15th June 2009). Cronbach's alpha reliability coefficient for the final Parent questionnaire was 0.92 overall, 0.94 for the psychosocial subscale, 0.94 for the function subscale and 0.91 for the surgery subscale.

Initial validation of final IXT questionnaires—Median Child IXTQ scores were significantly lower (worse HRQOL) in the IXT group compared with the control group: 85 (quartiles 73–92, range 54–100) versus 92 (quartiles 79–96, range 50–100); $P=0.04$ (Figure 3). At the individual question level the greatest difference between IXT and control groups was: 'Does it bother you that you have to shut one eye when it is sunny?' ($P=0.007$; question 7, Table 1).

Median Proxy IXTQ scores were significantly lower for IXT children than controls: 83 (quartiles 75–94, range 54–100) versus 98 (quartiles 92–100, range 65–100); $P<0.0001$ (Figure 3). At the individual question level most questions showed a significant difference between IXT and control groups, particularly: 'It bothers my child because he/she has to shut one eye when it is sunny' ($P<0.0001$; question 7, Table 1).

Median Parent IXTQ scores were also significantly lower in the IXT group compared with the control group: 68 (quartiles 56–79, range 24–100) versus 93 (quartiles 87–99, range 49–100); $P<0.0001$ (Figure 3). On each of the 3 subscales, median Parent scores were significantly lower in the IXT group compared with the control group: Psychosocial subscale 79 (quartiles 57–89, range 11–100) versus 100 (quartiles 93–100, range 50–100); $P<0.0001$, Function subscale 66 (quartiles 50–78, range 34–100) versus 88 (quartiles 78–97, range 41–100); $P<0.0001$, Surgery subscale 50 (quartiles 50–75, range 25–100) versus 100 (quartiles 100–100, range 38–100); $P<0.0001$.

Discussion

Using specific concerns identified directly from children with IXT and their parents, we have developed a 3-part questionnaire (Child, Proxy and Parent components) for assessing HRQOL in IXT. Children with IXT showed worse HRQOL (lower scores) than control children when measured using the Child IXTQ self report and when measured using the parental Proxy IXTQ report. Parents of children with IXT also showed lower scores when reporting their own HRQOL using the Parent IXTQ.

There are limited data on quality of life in children with IXT. McKeon et al,⁷ mailed two self-report questionnaires to children and adults (aged 8 to 46 years), and found both instruments differentiated between subjects with and without IXT. Nevertheless, the scales were not used in children less than 8 years of age, thereby excluding a large proportion of the population affected by IXT. The generic PedsQL instrument, allowing child self-report from 5 years of age and proxy reporting from 2 years of age, was administered by Powell et al to children with IXT and their parents (Quality of Life in Intermittent Exotropia. Powell CJ et al. Poster presentation, AAPOS 2007); they found mean scores were significantly lower (worse HRQOL) in their IXT cohort compared to published mean scores for normal populations. Nevertheless, generic instruments are typically less sensitive to change in a condition than condition specific instruments.^{8–10}

Using the Child self-report IXTQ, we found children with IXT scored lower, indicating worse HRQOL, compared to a control group of children without strabismus and with normal visual acuity. Certain questions appeared to discriminate particularly well between children with IXT and children in the control group. Children with IXT were bothered by having to close one eye in sunlight, a symptom reported in a previous study, to affect up to 76% of children with IXT.¹¹ Despite the well-recognized association between monocular eye closure and IXT,^{11–13} it is unclear whether troublesome monocular eye closure should be considered a criterion for intervention or whether it can be improved,¹³ although interestingly, some treatment studies stipulate resolution of monocular eye closure as necessary before defining IXT as ‘cured.’¹⁴ Prospective analysis of HRQOL using the IXTQ before and after treatment will allow evaluation of change in such effects of IXT.

We developed a 3rd IXT questionnaire to measure any effects of the child’s IXT on the HRQOL of the parents themselves. Previous studies have shown that mothers of chronically ill children are more likely to develop anxiety and depression¹⁵ and that strabismus in particular may affect the parent’s HRQOL.¹⁶ Akay et al found that mothers of children with strabismus demonstrated higher depression scores, were more nervous and distressed and had more problems with family functions than mothers in a control group.¹⁶ In our study, using a patient-derived, condition-specific questionnaire, parents of children with IXT also showed worse HRQOL than parents of children in a control group.

It is noteworthy that all items in the Parent IXTQ relate to different types of worry, with subscales assessing worry regarding the child’s everyday functioning, psychosocial interactions and possible surgery for IXT (Table 2). It is possible that improving parental education regarding the nature of IXT may reduce parental worry and the Parent IXTQ may be a useful tool for measuring the effectiveness of such interventions. We need further advances in our understanding of the natural history of IXT to better advise and reassure parents.

There are several limitations to this present study. Our study sample was racially homogeneous, despite recruiting consecutive patients, and this may have influenced the selection of final questionnaire items. We attempted to overcome this potential bias by excluding at the outset questions that may be discriminatory based on cultural, social, economic, or educational factors. We used what were considered to be the most appropriate methods for deriving final questionnaire items, but alternative item-reduction methods may have resulted in different final questionnaires. In addition, we did not have sufficient numbers to analyze data for any affect of age or severity of IXT on HRQOL during the validation phase and we have thus far only validated the questionnaires on children aged 5–17 years. Further validity testing of the IXTQ is planned.

We have developed and initially validated a new 3-part patient-derived HRQOL questionnaire for children with IXT and their parents. The IXTQ detects reduced HRQOL in children with IXT both as reported by the child themselves and as perceived by their parents. Childhood IXT also affects the HRQOL of the parents by causing worry about various aspects of the condition and its management. The IXTQ HRQOL questionnaires may prove useful in the clinical assessment of IXT and for clinical trials.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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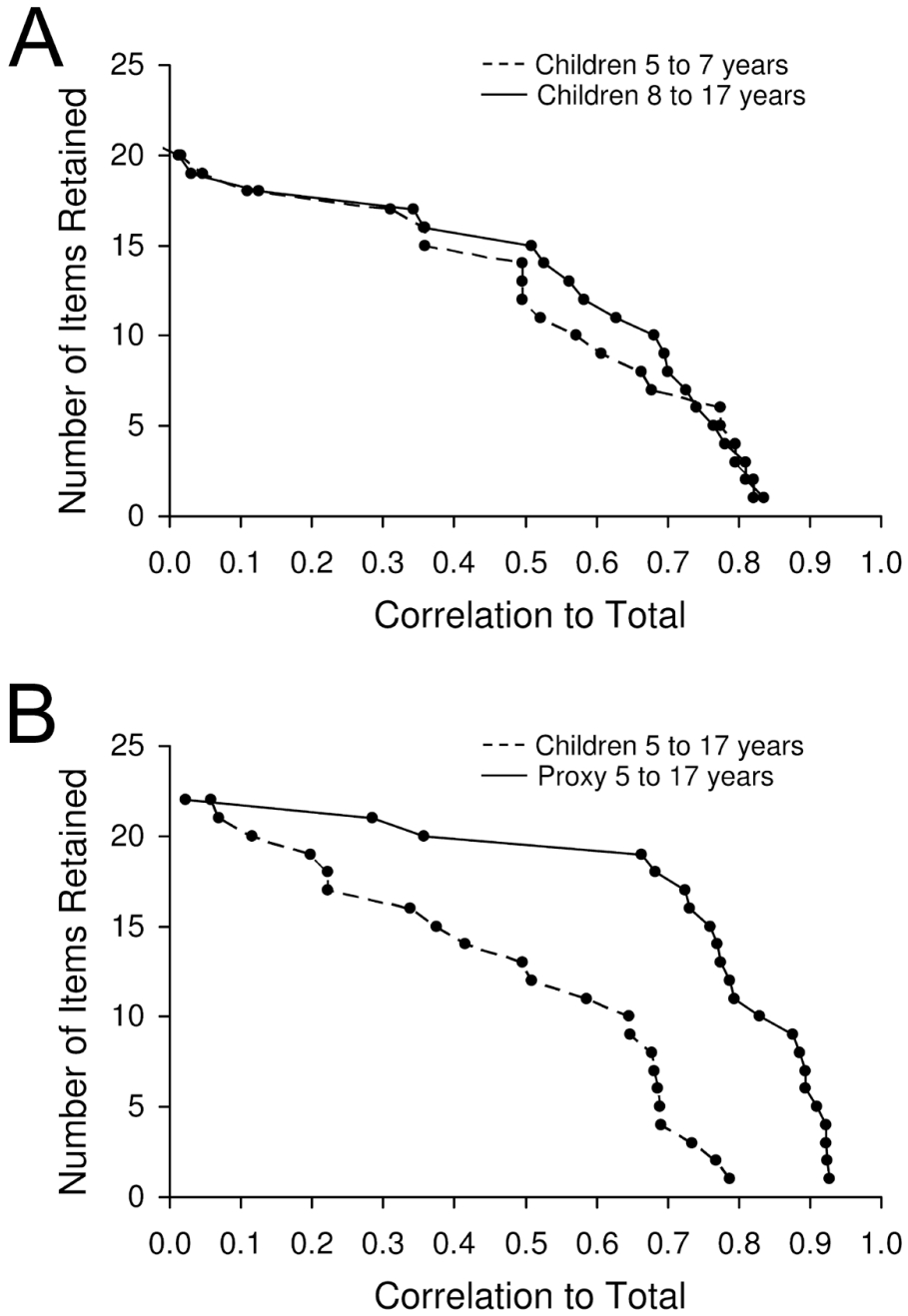


Figure 1. (online only) Plot using Cronbach's alpha to show the item-total correlation against the correlation rank of individual items in descending order. Plotting Child questionnaire scores for children aged 5–7 years and 8–17 years (A) showed no meaningful differences between these age groups. Plotting Child questionnaire scores for children aged 5–17 years and Proxy questionnaire scores for children aged 5–17 years (B) showed the inflection point to be 0.3. This threshold was then used to further reduce items; those with item-total correlation > 0.3 were retained.

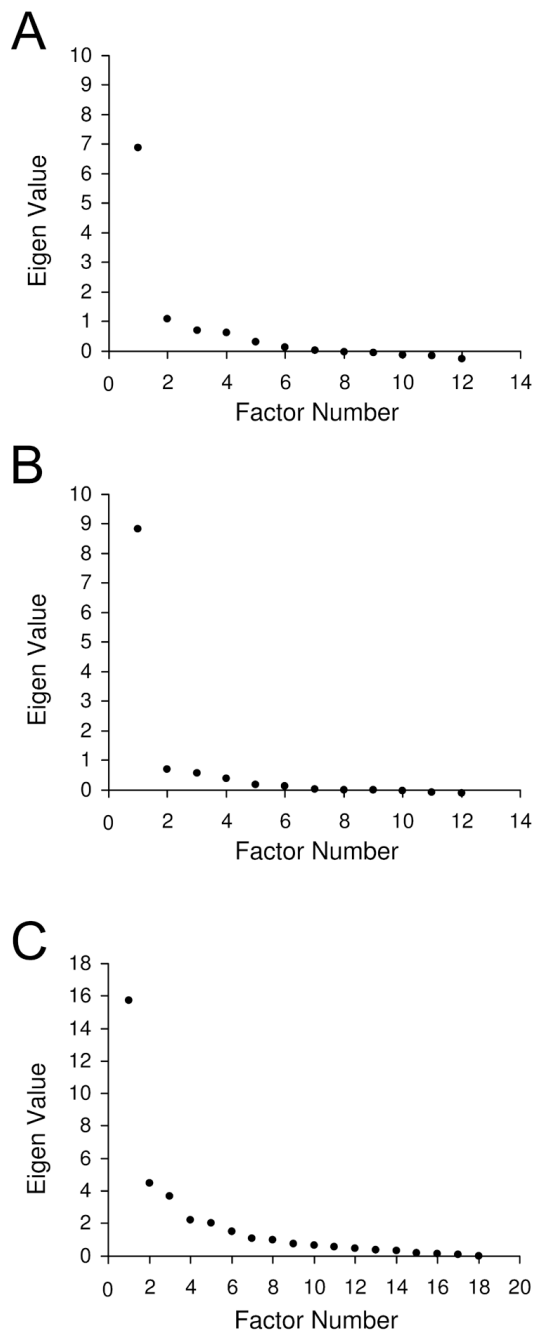


Figure 2. (online only) Scree plots for Child questionnaire scores of children aged 5 – 17 years, indicating 1 prominent factor (A), for Proxy questionnaire scores of children aged 5 – 17 years, indicating 1 prominent factor (B), and for Parent questionnaire scores of parents with children aged 2 – 17 years, indicating 3 possible factors (C).

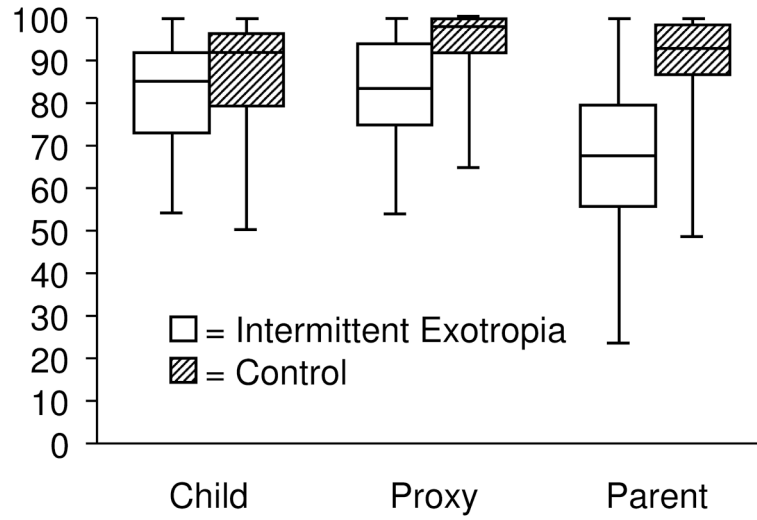


Figure 3. Child, Proxy, and Parent questionnaire scores in both the intermittent exotropia group and control group. Whiskers indicate the extremes and the boxes represent the 1st quartile, median, and 3rd quartile.

Questions for final Child and Proxy health-related quality of life questionnaires for intermittent exotropia. Formatted questionnaires available online at : <http://public.pedig.jaeb.org>, accessed 15th June 2009).

Table 1

Questions formatted for 5-7-year-old CHILD questionnaires	Questions formatted for 8-17-year-old CHILD questionnaires	Questions formatted for PROXY questionnaires
Are you worried about your eyes?	I worry about my eyes	My child worries about his/her eyes
Does it bother you that people ask what is wrong with your eyes?	It bothers me that people wonder what is wrong with my eyes	My child is bothered about people wondering what is wrong with his/her eyes
Does it bother you because you have to wait for your eyes to clear up?	It bothers me because I have to wait for my eyes to clear up	My child is bothered because they have to wait for his/her eyes to clear up
Do kids tease you because of your eyes?	Kids tease me because of my eyes	Kids tease my child because of his/her eyes
Does it bother you when grownups say things about your eyes?	I am bothered when grownups say things about my eyes	My child is bothered when adults say things about his/her eyes
Does it bother you when dad or mom say things about your eyes?	I am bothered when my parents say things about my eyes	My child is bothered when his/her parents say things about his/her eyes
Does it bother you that you have to shut one eye when it is sunny?	It bothers me that I have to shut one eye when it is sunny	It bothers my child because he/she has to shut one eye when it is sunny
Do you feel different from other kids because of your eyes?	I feel different from other kids because my eyes go in and out	My child feels different from other kids because of his/her eyes
Are you worried what other people think of you because of your eyes?	I worry about what other people think of me because of my eyes	My child worries about what other people think of him/her because of his/her eyes
Do you find it hard to look at people because of your eyes?	My eyes make it hard to look people in the eye	My child finds it hard to look people in the eye
Is it hard for you to concentrate because of your eyes?	It is hard to concentrate because of my eyes	My child finds it hard to concentrate because of his/her eyes
Do your eyes make it hard to make friends?	My eyes make it hard for me to make friends	My child's eyes make it hard for him/her to make friends

Table 2

Questions for final health-related quality of life questionnaire for Parents of children with intermittent exotropia. Formatted questionnaire available online at: <http://public.pedig.jaeb.org>, accessed 15th June 2009).

Questions addressing concerns of Parents of children with intermittent exotropia
Function subscale
I worry that my child will be less independent because of his/her eyes
I worry about my child's eyes
I worry that my child doesn't see well
I worry that my child will get hurt physically because of his/her eyes
I worry that my child will not be able to see the board at school
I worry about my child's eyesight long term
I worry about my child's depth perception
I worry that my child will have permanent damage to his/her eyes
Psychosocial subscale
I worry that my child's eye condition will affect his/her personality
I worry that my child's eyes will affect his/her social life if nothing is done
I worry about my child becoming self conscious because of his/her eyes
I worry about other kids teasing my child because of his/her eyes
It worries me what others will think about my child because of his/her eyes
I worry about how my child's eyes will affect him/her socially
I worry about my child's ability to make friends
Surgery subscale
I worry about whether or not my child should have surgery
I worry about the possibility of surgery

For administration of the questionnaire, these items are reordered and not grouped by subscale