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Comparison of quality of life instruments in childhood intermittent exotropia

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Abstract

Purpose—To compare 2 health-related quality of life (HRQOL) instruments: the condition-specific intermittent exotropia questionnaire (IXTQ) and the generic Pediatric Quality of Life Inventory (PedsQL) questionnaire in children with intermittent exotropia.

Methods—Fifty-one children with intermittent exotropia (median, 7; range, 5–16 years) were recruited from outpatient clinics with one of their parents. All children completed age-appropriate Child IXTQ (12 items) and Child PedsQL (23 items). Parents completed parallel Proxy IXTQ and Proxy PedsQL questionnaires (parent assessment of child's HRQOL). Possible scores ranged from 0 to 100 (worst to best HRQOL). Normal thresholds were defined using the 5th percentile in a control group of 47 normal non-strabismic children. Proportions scoring below normal on each questionnaire were compared. Median scores in intermittent exotropia and control groups were also compared.

Results—More scores were subnormal using Proxy IXTQ than Proxy PedsQL (55% vs 18%, $p = 0.0004$). Using Child questionnaires, similar proportions scored below normal (IXTQ 8% vs PedsQL 14%, $p = 0.3$). Median scores were lower for intermittent exotropia children compared to controls using Child IXTQ (83 vs 92; $p = 0.04$), Proxy IXTQ (81 vs 98; $p < 0.0001$), and Proxy PedsQL ($p = 0.04$), but not using Child PedsQL ($p = 0.3$).

Conclusions—The Proxy IXTQ detects reduced HRQOL related to intermittent exotropia more often than the Proxy PedsQL. There were few subnormal scores on Child IXTQ and Child PedsQL. Children with intermittent exotropia scored, on average, lower than controls using the IXTQ, but most individual scores fell within the normal range. The IXTQ may prove useful for clinical assessment of intermittent exotropia.

Introduction

Quantitative assessment of health-related quality of life (HRQOL) may be helpful in establishing the overall impact of childhood intermittent exotropia. Standard methods of assessing severity in intermittent exotropia—principally angle of deviation, stereoacuity and ability to control the deviation—rely on objective assessment over the short duration of an office examination. Variability in control and stereoacuity over short periods of time, even within the course of an office examination,^{1,2} suggests these isolated measures in a clinical

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setting may not truly represent overall severity. Assessing HRQOL may be helpful in the management of intermittent exotropia since a questionnaire score provides a standardized measure of severity as perceived by the patient and parent and since it draws from experience over a period of weeks and thus may better represent the patient's everyday life. Nevertheless, few studies have examined the effects of intermittent exotropia on HRQOL or compared methods for measuring HRQOL in intermittent exotropia. The aim of this study was to assess HRQOL in children with intermittent exotropia using two instruments, the Pediatric Quality of Life Inventory (PedsQL),³ a well-established, commonly used generic HRQOL instrument, and the Intermittent Exotropia Questionnaire (IXTQ), a recently developed patient-derived, condition-specific questionnaire.⁴ The PedsQL instrument assesses general HRQOL concerns and was designed to be used in various different pediatric diseases, whereas the IXTQ was designed purely to address concerns specific to children with intermittent exotropia. Nevertheless, it is possible that despite being generic, the PedsQL may be as sensitive as the IXTQ when detecting HRQOL concerns in children with intermittent exotropia. In the initial validation of the IXTQ, we found lower average scores (indicating worse HRQOL) in children with intermittent exotropia compared to controls on both the Child and Proxy questionnaires.⁴ In the present study, we compared quality of life scores using the PedsQL and IXTQ to determine which instrument best detected subnormal HRQOL related to strabismus in children with intermittent exotropia.

Patients and Methods

Institutional review board approval was obtained and each parent gave informed consent before participating. Informed assent was obtained from children aged 8 years and older. All procedures and data collection were conducted in a manner compliant with the Health Insurance Portability and Accountability Act.

All children included in this study were prospectively recruited from outpatient clinics, along with one of their parents, and completed the IXTQ and the PedsQL during their office examinations. To standardize testing order, both children and parents completed the IXTQ before they completed the PedsQL. Whenever possible, verbal and nonverbal communication between parent and child was limited by positioning children with their back toward their parent. Parents were asked not to interfere with their child's responses. Children and parents were given simple verbal and written instructions and asked to base their responses on their experiences over the previous month.

The IXTQ comprises a Proxy report (parent report of *their child's* HRQOL), a Child self-report, and a Parent report (parent report of *their own* HRQOL)⁴ (available online in administrable format with user instructions: <http://public.pedig.jaeb.org/>, accessed January 14, 2010). Child and Proxy reports contain 12 parallel items (e-Supplement 1, available at jaapos.org). In the Child report items are phrased in the first person (eg, I worry about my eyes) and in the Proxy report the same question is phrased in the third person (eg, My child worries about his/her eyes).⁴ The Parent component of the IXTQ, containing 17 items, is not further reported in this present study, because our aim was to compare Child and Proxy reporting using the IXTQ and PedsQL. The PedsQL Child and Proxy reports consist of 23 parallel questions in 4 subscales: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items)³ (see: <http://www.pedsq.org/index.html>, accessed January 14, 2010—full PedsQL questionnaires available by purchase only).

Proxy-Report Questionnaires

For each child, Proxy questionnaires were completed by one parent (or legal guardian), with a 5-point Likert-type scale for responses: never (score 100), almost never (score 75),

sometimes (score 50), often (score 25), almost always (score 0). The same parent completed both IXTQ and PedsQL Proxy questionnaires. The Proxy IXTQ has one format suitable for all age groups. The Proxy PedsQL has different formats for ages 5–7, 8–12, and 13–18 with minor changes in wording such as referring to ‘teens’ in the 13- to 18-year-old format and “kids” in 8- to 12-year-old format.

Child Self-Report Questionnaires

IXTQ and PedsQL Child self-reports can be completed by children from 5–17 years of age. Both Child IXTQ and Child PedsQL use a simplified format for 5- to 7-year-olds with a 3-point Likert type scale for responses: not at all (score 100), sometimes (score 50), a lot (score 0) with accompanying face symbols and a matching card. Questionnaires for 5- to 7-year olds were administered by trained personnel who read the questions to the child and recorded their responses. For 8- to 17-year-old children, questionnaires were self-administered and a 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).

Scoring

For each patient, on each questionnaire, mean composite scores were calculated, ranging from 0 to 100 (worst to best HRQOL). Composite scores, as well as PedsQL physical and psychosocial summary scores, were calculated as a mean of all answered items. The PedsQL physical health summary score is derived from the 8 items in the physical functioning subscale, and the psychosocial health summary score is derived from the 15 remaining items.

Normal Thresholds

For the purposes of this study, we defined subnormal responses on IXTQ and PedsQL questionnaires as scores below the 5th percentile for children with normal visual acuity and no strabismus or amblyopia, and no history of strabismus or amblyopia. We chose to use the 5th percentile rather than 1.96 standard deviations below the mean because HRQOL data are not normally distributed.⁵ Forty-seven children with normal visual acuity (median, 8; range, 5 to 13 years) were recruited to complete IXTQ and PedsQL questionnaires, along with one of their parents. Questionnaires were completed after it had been established that visual status was within the normal parameters defined below. Children in this control group were typically attending either because parents had initiated an exam or the child had failed school screening. All control children had best corrected visual acuity of 20/40 or better (median, 20/20) in each eye and were orthotropic at distance and near fixation, with no more than 10^Δ of horizontal heterophoria and no vertical heterophoria by prism and alternate cover test. Of the 47 controls, 18 (38%) wore habitual refractive correction, 29 (62%) were female, and 44 (94%) reported race as white; 20 (42.5%) aged 5–7 years and 27 (57.5%) were aged 8–13 years. In 37 (79%) cases the mother of the child completed Proxy questionnaires. Of the 47 controls, data on 42 have been reported previously as controls for the initial validation of the IXTQ.⁴

The 5th percentile of scores in control children using the Child IXTQ was 62.5 and using the Child PedsQL was 62 (composite scores). The 5th percentile for the Child PedsQL physical health score was 62.5 and for the Child PedsQL psychosocial health score was 50. For Proxy questionnaires the 5th percentile for control children was 85 using the IXTQ and 74 using the PedsQL. The 5th percentile for the Proxy PedsQL physical health score was 81 and for the Proxy PedsQL psychosocial health score was 72. These 5th percentile values were applied as normal thresholds for the analysis of subnormal scores in children with intermittent exotropia.

Children with Intermittent Exotropia

Fifty-one developmentally normal children with intermittent exotropia completed IXTQ and PedsQL questionnaires, along with one of their parents (median, 7; range, 5–16 years, not significantly different from controls; $p = 0.07$). Questionnaires were generally completed after the orthoptic evaluation and before the patient met with the physician. For inclusion in this intermittent exotropia cohort, the minimum distance angle of exodeviation was 10^Δ and presenting visual acuity was 20/40 or better in each eye. Median angle of deviation at distance by prism and alternate cover test was 25^Δ (range, 10^Δ – 40^Δ) and median near stereoacuity was 40 (range, 40 to nil) arcsec using the Preschool Randot. Median best-corrected visual acuity was 20/20 (range, 20/15–20/40) for the right eye and 20/20 (range, 20/15–20/40) in the left eye. Overall, 17 (33%) children were wearing habitual refractive correction at the time of questionnaire administration, 32 (63%) were female, and for 44 (86%) reported race as white; 28 (55%) of 51 were aged 5–7 years and 23 (45%) were aged 8–16 years. One (2%) had undergone strabismus surgery historically (more than one year prior to assessment) but had residual intermittent exotropia at the time of assessment. Of the 51 children with intermittent exotropia, data on 32 were reported in our previous study on initial validation of the IXTQ.⁴ In 43 (84%) the mother of the child completed Proxy questionnaires. Two of 51 Proxy IXTQ reports were not completed (overlooked), preventing calculation of a Proxy score for these parents. Proxy IXTQ data is therefore based on responses from 49 parents.

Analyses

The proportion of intermittent exotropia patients with subnormal composite IXTQ scores was compared to the proportion of intermittent exotropia patients with subnormal composite PedsQL scores using McNemar's tests. Proportions were compared between IXTQ and PedsQL Child questionnaires and between IXTQ and PedsQL Proxy questionnaires. In a secondary analysis we compared median IXTQ and PedsQL questionnaire scores in intermittent exotropia patients and controls using Wilcoxon tests. We previously reported comparison of median IXTQ values in a smaller cohort of intermittent exotropia patients and controls.⁴ We now include analysis of PedsQL in addition to IXTQ in larger cohorts of intermittent exotropia patients and controls.

Results

Subnormal Scores on IXTQ and PedsQL in Children with Intermittent Exotropia

Proxy Questionnaires—Overall, the proportion of subnormal scores was greater with the Proxy IXTQ than with the Proxy PedsQL (55% vs 18%, $p = 0.0004$, McNemar's; Figure 1A): 12% were subnormal on the PedsQL physical health summary score and 27% on the PedsQL psychosocial health summary score.

Child Questionnaires—Overall, similar proportions were subnormal on Child IXTQ and Child PedsQL (8% vs 14%; $p = 0.3$, Figure 1B): 2% were subnormal on the PedsQL physical health summary score and 8% on the PedsQL psychosocial health summary score.

Median Scores of Children with Intermittent Exotropia versus Controls

Proxy Questionnaires—Median Proxy IXTQ scores were significantly lower for the intermittent exotropia group (81.3) compared to the control group (97.9, $p < 0.0001$; Figure 2A and Table 1). Using the Proxy PedsQL questionnaire, median scores were significantly lower for intermittent exotropia patients compared to controls for the composite score (90.2 vs 94.6, $p = 0.04$; Figure 2A and Table 1) and for the psychosocial health scale (86.7 vs 93.3, $p = 0.03$; Table 1), but differences were of much lower magnitude than with the IXTQ.

Child Questionnaires—Median Child IXTQ scores were significantly lower for the intermittent exotropia group (83.3) when compared to the control group (91.7; $p = 0.04$, Figure 2B and Table 1). Median scores on the Child PedsQL were not significantly different for the intermittent exotropia group (80.4) and the control group (84.2; $p = 0.3$, Figure 2B and Table 1).

Discussion

Comparing the intermittent exotropia-specific IXTQ and the generic PedsQL HRQOL instruments, we found more subnormal HRQOL scores using the Proxy IXTQ questionnaire than using the Proxy PedsQL questionnaire. There were few subnormal scores on both Child IXTQ and Child PedsQL questionnaires. Comparing median scores in intermittent exotropia patients and controls, intermittent exotropia patients scored lower (worse HRQOL) on Proxy IXTQ, Child IXTQ, and Proxy PedsQL, whereas there was no difference between intermittent exotropia patients and controls on the Child PedsQL.

Few previous studies have reported HRQOL assessment in children with intermittent exotropia or compared instruments for measuring HRQOL in this population. In a study by Powell and colleagues (Powell CJ, Buck D, Clarke MP, Hatt SR. Quality of life in intermittent exotropia. *J AAPOS* 2007;11:100 [abstract]) scores on the PedsQL instrument were compared between children with intermittent exotropia ($n = 94$) and previously published controls.^{6,7} Mean composite scores were found to be significantly lower (worse HRQOL) in children with intermittent exotropia compared to controls using the Child PedsQL, but no differences were found between intermittent exotropia and control groups using the Proxy PedsQL. Unlike Powell and colleagues, we found a difference in averages between intermittent exotropia patients and controls using the Proxy PedsQL, but found no difference between intermittent exotropia children and controls using the Child PedsQL. One difference between studies that may explain this apparent contradiction in findings is that in our present study we used a local population of visually normal children for a control group, whereas Powell and colleagues used control population data from two studies by Varni and colleagues.^{6,7} Our control children scored lower on the Child PedsQL than the children reported by Varni and colleagues,⁶ but we believe that controls drawn from a local population provided a more relevant reference group.

In a study by McKeon and colleagues,⁸ a general quality of life instrument (SF-20) and a vision-specific instrument (Vision Function Scale or VFS) were mailed to patients (children and adults) with intermittent exotropia and a control group with no eye problems except corrective lenses. The authors found that both SF-20 and VFS questionnaires differentiated between intermittent exotropia and non-strabismic patients.⁸ Nevertheless, the number of children in their study is not reported (none were less than 8 years old), and data for children and adults were not analyzed separately, so it is not possible to determine how their questionnaires performed just in children with and without intermittent exotropia. By using questionnaires designed for younger children, with parallel proxy reports, we found the Proxy IXTQ scores differed between children with intermittent exotropia and controls; whereas, using child self-reporting, lower HRQOL in intermittent exotropia was only found when scores were averaged and when using the Child IXTQ.

In this present study, our primary analysis for comparing the performance of HRQOL questionnaires in children with intermittent exotropia was analyzing proportions scoring below the 5th percentile (defined in controls). This approach to comparing instruments was used previously in a study comparing HRQOL questionnaires in adults with strabismus⁵ and provides a rigorous estimate of how well questionnaires detect *subnormal* HRQOL. In our present study, far more children with intermittent exotropia scored subnormal using Proxy

IXTQ than using Proxy PedsQL (55% vs 15%, $p = 0.0004$), indicating that by parental assessment the Proxy IXTQ was more sensitive in detecting reduced HRQOL.

In contrast, for Child questionnaires, only 8% and 14% of children had subnormal scores by Child IXTQ and Child PedsQL, respectively. One possible explanation for this finding is that children with intermittent exotropia have few concerns that differ from controls. Further studies are needed to determine whether or not such a finding is age or gender dependent. It is possible that younger children are not bothered by intermittent exotropia whereas older children are, or that males and females are bothered by differing concerns. Our sample size was not sufficient to address the issue of age or gender in the present study. An alternative explanation for the few subnormal scores on Child IXTQ and Child PedsQL may have been that the instruments used in this study were insensitive to the HRQOL concerns of children with intermittent exotropia. Nevertheless, items in the IXTQ were acquired from multiple interviews of children with intermittent exotropia,^{4,9} which should have maximized our ability to detect HRQOL issues relevant to this population. It is noteworthy that while children with intermittent exotropia had significantly lower average values than controls, most values were still within the range of scores for a normal population. Using a normal threshold such as the 5th percentile as a benchmark for assessing scores in an affected population provides important information when interpreting average scores and when comparing performance on different instruments.

There are few reports comparing child self-reporting and proxy-reporting of HRQOL in intermittent exotropia or even in other eye diseases. Nevertheless, child and proxy rating has been studied in other medical conditions. When comparing parents of healthy children with parents of children with cancer, Russell and colleagues¹⁰ found parents of healthy children tended to overestimate their child's HRQOL, whereas parents of children with cancer tended to underestimate their child's HRQOL. In our present study, we found more subnormal proxy scores in children with intermittent exotropia than in controls, but at present it is unclear whether or not subnormal proxy scores in intermittent exotropia reflect a possible overestimation of subnormal HRQOL. We have previously reported different types of worry in parents of children with intermittent exotropia^{4,9} and worse HRQOL in parents of children with intermittent exotropia than in parents of controls. Therefore, it is possible that proxy rating of HRQOL may be driven by parental worry about the condition, leading to lower scores. Comparing subnormal scores on the Parent IXTQ (measuring the effect on the parent themselves) to the Proxy IXTQ may be helpful in the future to determine whether there is a relationship between the effect of intermittent exotropia on the parent themselves and the perceived effect of intermittent exotropia on the child (proxy rating).

We found more concerns were reported using proxy rating of HRQOL than using child rating of HRQOL, and this finding may have implications for the management of intermittent exotropia. It has been noted in previous studies that, typically, it is parental perception of their child's HRQOL that directs healthcare utilization^{11,12} and therefore clinicians should be cognizant of potential differences between parental and child reporting of concerns when evaluating for treatment.

Formal evaluation of HRQOL in intermittent exotropia may be helpful in assessing perceived severity of the condition, providing a measure of concerns from the child's perspective and also from the parent's perspective. Assessment using generic instruments such as the PedsQL allows for comparison of the effects of intermittent exotropia to the effects of other conditions. Nevertheless, it is recognized that generic instruments are less sensitive to specific concerns, and therefore condition-specific instruments can be more useful for measuring differences between patients and change over time.^{13,14} We now aim

to evaluate children with intermittent exotropia longitudinally to assess change over time and following treatment using the IXTQ.

One of the potential weaknesses of this study is that we used a small, local population of visually normal children as a control group and scores may have been different in a larger, more diverse population. In addition, assessing HRQOL in the physical environment of an eye clinic may have increased awareness of vision-related concerns (lowering HRQOL scores) more than if assessment had been carried out in a more neutral environment. Nevertheless, we chose to recruit control patients who had undergone a complete eye exam to be sure that they were visually normal. It is also possible that children's responses reflected what they thought the doctor or orthoptist or even their parent wanted to hear, rather than what they truly felt. We tried to encourage honest answers by stipulating in written and verbal instructions that there are "no right or wrong answers."

Based on the proxy assessment, parents perceive intermittent exotropia to affect their child's HRQOL. Using child self-reports, there were few subnormal responses on both Child IXTQ and Child PedsQL. On average, scores were lower for children with intermittent exotropia than controls using the Child IXTQ, but most individual scores fell within the normal range. The IXTQ questionnaires may prove useful as one component of the clinical evaluation of intermittent exotropia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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FIG 1. Individual IXTQ and PedsQL questionnaire scores in patients with intermittent exotropia. Significantly more subnormal scores using Proxy IXTQ compared to Proxy PedsQL (A, $p = 0.0004$). No difference in proportions of subnormal scores using Child IXTQ and Child PedsQL (B, $p = 0.3$).

FIG 2.

A, Median Proxy IXTQ and PedsQL scores were significantly lower for children with intermittent exotropia than controls, although differences were more pronounced using the Proxy IXTQ. B, Median Child IXTQ scores were worse for children with intermittent exotropia than controls whereas Child PedsQL scores were not. Whiskers indicate extremes; boxes, 1st quartile, median, and 3rd quartile.

Table 1

Median and mean values on the IXTQ and PedsQL health related quality of life questionnaires for control group and children with intermittent exotropia. There was a significant difference (bold) between median scores for intermittent exotropia and control groups using the Proxy IXTQ ($p < 0.0001$) and using the Child IXTQ ($p = 0.04$). There was a significant difference between intermittent exotropia and control groups using the Proxy PedsQL ($p = 0.04$) but not using the Child PedsQL ($p = 0.3$). Mean and standard deviations are also given for reference, but because the data are not normally distributed, nonparametric tests were used.

	Median (1 st quartile, 3 rd quartile)		Mean $\pm$ standard deviation	
	Control group (n = 47)	IXT group (n = 51)	Control group (n = 47)	IXT group (n = 51)
IXTQ				
Child composite	91.7 (75.0, 95.8)	83.3 (72.9, 91.7)	86.5 $\pm$ 13.2	81.8 $\pm$ 13.3
Proxy composite	97.9 (91.7, 100.0)	81.3 (75.0, 91.7)	95.6 $\pm$ 6.8	82.1 $\pm$ 12.5
PedsQL				
Child composite	84.2 (69.6, 95.7)	80.4 (69.6, 89.1)	82.4 $\pm$ 14.5	78.9 $\pm$ 14.5
Child physical health	90.6 (81.3, 96.9)	87.5 (78.1, 93.8)	86.9 $\pm$ 13.1	85.6 $\pm$ 11.5
Child psychosocial health	80.8 (66.7, 95.0)	76.7 (63.3, 90.0)	79.9 $\pm$ 17.0	75.3 $\pm$ 17.5
Proxy composite	94.6 (89.1, 98.9)	90.2 (77.2, 97.8)	92.3 $\pm$ 8.8	86.3 $\pm$ 13.3
Proxy physical health	100.0 (93.8, 100.0)	96.9 (90.6, 100.0)	95.5 $\pm$ 8.5	92.2 $\pm$ 12.2
Proxy psychosocial health	93.3 (83.3, 98.3)	86.7 (71.7, 96.7)	90.6 $\pm$ 10.3	83.2 $\pm$ 15.2