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DOI:

[10.1038/eye.2016.323](https://doi.org/10.1038/eye.2016.323)

*Document Version*

Peer reviewed version

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*Citation for published version (APA):*

Taylor, V. K., Abou-Rayyah, Y., Brookes, J., Khaw, P. T., Papadopoulos, M., Adams, G. G. W., Bunce, C., & Dahlmann-Noor, A. (2017). Quality of life and functional vision in children treated for cataract-a cross-sectional study. *Eye (London, England)*. Advance online publication. <https://doi.org/10.1038/eye.2016.323>

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1 **Title: Quality of Life and Functional Vision in children treated for cataract - a cross-**  
2 **sectional study**

3

4 Authors:

5 Vijay Tailor<sup>1</sup> MSc

6 Yassir Abou-Rayyah<sup>1</sup>

7 John Brookes<sup>1</sup>

8 Sir Peng T. Khaw<sup>1</sup>

9 Maria Papadopoulos<sup>1</sup>

10 Gillian Adams<sup>1</sup>

11 Catey Bunce<sup>1, 2</sup>

12 Annegret Dahlmann-Noor<sup>1</sup> PhD FRCOphth

13

14 Authors' address:

15 1 NIHR Biomedical Research Centre at Moorfields Eye Hospital and UCL Institute of

16 Ophthalmology

17 162 City Road, London EC1V 2PD

18 2 London School of Hygiene & Tropical Medicine, Keppel Street, London

19

20 Corresponding author:

21 Annegret Dahlmann-Noor, NIHR Biomedical Research Centre at Moorfields Eye Hospital and

22 UCL Institute of Ophthalmology, 162 City Road, London EC1V 2PD, UK, e-mail

23 [annegret.dahlmann-noor@moorfields.nhs.uk](mailto:annegret.dahlmann-noor@moorfields.nhs.uk)

24 Contribution of authors: ADN and MP developed the study protocol. VT enrolled  
25 participants, collected data and entered data onto the electronic database which ADN had  
26 developed. ADN and CB conducted data analysis. All authors reviewed and discussed and  
27 interpreted the data acquired. ADN drafted the manuscript, which was then critically  
28 reviewed and modified by all authors.

29

30 Conflict of interest: None of the authors have conflicting interests to declare.

31

32 Keywords: Child, Adolescent, Congenital, Hereditary and Neonatal Diseases and  
33 Abnormalities, Quality of Life, Cataract

34

35

36 **Word count:**

37 **Abstract**

38

39 Aims: Children with cataract and their families face intensive medical and surgical  
40 management, with numerous hospital attendances, topical medications and surgical  
41 procedures, as well as uncertainty about the child's future visual ability, education and  
42 independence. Little is known about the impact on functional visual ability, vision- and  
43 health-related quality of life (VR-, HR-QoL).

44

45 Methods: 72 children age 2 to 16 years (mean 8.45, standard deviation SD 4.1) treated for  
46 developmental or secondary cataract and their parents/carers completed three validated  
47 instruments measuring functional visual ability, VR- and HR-QoL: the Cardiff Visual Ability

48 Questionnaire for Children (CVAQC), Impact of Vision Impairment for Children (IVI-C) and  
49 PedsQL™ V 4.0.

50 Results: All scores are markedly reduced: median (interquartile range IQR) CVAQC score -  
51 1.42 (-2.28 to -0.03), mean (SD) IVI-C score 65.67 (16.91), median (IQR) PedsQL™ family  
52 impact score 75 (56.94-88.19), parent report 71.74 (51.98-88.5), self-report 76.09 (61.96-  
53 89.13). Psychosocial PedsQL™ subscores are lower than physical subscores. Parent-  
54 completed tools (PedsQL™ family and parent report) state greater impact on HR-QoL than  
55 tools completed by children/young people, particularly in teenagers. Older children/young  
56 people have higher functional visual ability scores than younger children.

57

58 Conclusions: Cataract has a marked and long-term impact on functional visual ability and  
59 quality of life of children and young people, with HR-QoL affected to degrees reported in  
60 children with severe congenital cardiac defects or liver transplants.

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62

63

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65

66 **Main Text**

67 **Introduction**

68 With an incidence of 1-3 per 10,000 live births, congenital/infantile cataract is a rare, but  
69 sight-threatening condition <sup>1</sup>. Congenital/infantile cataract poses significant management  
70 challenges. The risk of developing glaucoma is high, with 31% of children either having  
71 glaucoma or being monitored as “glaucoma suspect” at five years after cataract surgery <sup>2</sup>,  
72 and an overall annual incidence of postoperative glaucoma of 5.25 per 100 cataract  
73 operations <sup>3 4</sup>. Visual outcomes are often disappointing. Younger age at surgery is associated  
74 with better visual outcomes <sup>5, 6</sup>. Unilateral cases have a worse visual prognosis in the  
75 affected eye than bilateral: at six years after surgery, a median visual acuity 0.48 in bilateral  
76 and 1.0 logMAR (affected eye) in unilateral cases has been reported <sup>3</sup>. Amblyopia and its  
77 management with hours of occlusion or blurring of the better seeing eye may affect the  
78 child’s motor co-ordination, functioning and emotional state <sup>7, 8</sup>.

79 Children with cataract require frequent hospital attendances, which means that children  
80 miss school and parents lose time from work. If glaucoma develops, additional treatment in  
81 the form of eye drops (95%)<sup>2</sup> or glaucoma surgery (up to 40% at 5 years of follow-up)<sup>2</sup> is  
82 required, carrying an additional burden of anxiety for the child and the family. Yet little is  
83 known about the impact of cataract and its management on children and their families.

84  
85 Studies using parental proxy VR-QoL-tools such as the Children’s Visual Function  
86 Questionnaire found that family impact and treatment difficulty scores are worse in families  
87 of children with unilateral compared with those with bilateral cataracts, and in those  
88 treated with an aphakic contact lens compared with those treated with an intraocular lens  
89 implant <sup>9</sup>. Bilateral congenital/infantile cataract is associated with reduced VR-QoL scores

90 compared to healthy controls <sup>10</sup>. A study in China using a specifically developed self-report  
91 tool showed a correlation of QoL scores with visual acuity, surgery and density of cataract <sup>11</sup>  
92 <sup>12</sup>.

93 Over recent years, self-report instruments have been developed to measure health-related  
94 quality of life (HR-QoL) in children with various conditions, and vision-related quality of life  
95 (VR-QoL) and functional visual ability (FVA) in children with sight impairment. For example,  
96 the Impact of Vision Impairment for Children (IVI-C) instrument <sup>13</sup> can be used to assess the  
97 impact of visual impairment on VR-QoL, and the Cardiff Visual Ability Questionnaire for  
98 Children (CVAQC) <sup>14</sup> and the Functional vision questionnaire for children and young people  
99 with visual impairment <sup>15</sup>, to assess the impact on activities of daily living (functional visual  
100 ability).

101

102 Whilst none of these has been used specifically in children with cataract, previous studies in  
103 this population have applied a generic HR-QoL tool for children and families, the PedsQL™  
104 Inventory ([www.pedsq.org](http://www.pedsq.org)) <sup>16 17</sup>. The PedsQL™ covers different domains (physical and  
105 psychosocial - emotional, social, school) and contains age-specific versions as well as  
106 separate questionnaires for parents/ carers, one as a report about their child, and another  
107 to evaluate the impact of the child's condition on the family. Using the PedsQL™, it has  
108 been reported that six years after treatment for congenital/infantile cataract, parents and  
109 children report lower HR-QoL scores than normative controls <sup>18</sup>.

110

111 However, none of the previous studies included children/young people with secondary  
112 cataract, and none offers data on long-term impact of cataract treatment in early  
113 childhood.

114

115 The main objective of the present work was to explore FVA, VR-QoL and HR-QoL in children  
116 treated or monitored for developmental and secondary cataract and their parents/carers,  
117 using CVAQC, IVI-C and PedsQL™. We included young people up to the age of 16 years to  
118 explore long-term impact of childhood cataract and its management.

119

## 120 **Materials and methods**

121 This work is part of a larger cross-sectional observational study, approved by the National  
122 Research Ethics Committee South Central – Oxford A (14/SC/1052). Between 25/6/2014 and  
123 03/06/2015 we enrolled children and young people age 2-16 years who attended clinics at  
124 Moorfields Eye Hospital, London, UK. In the present study, we included children with  
125 congenital/infantile and cataract secondary to uveitis. At enrolment, exclusion criteria were:  
126 visually not significant cataract, inability to communicate in English, surgical intervention  
127 (incisional or laser) within one month of date of completing questionnaires (before or after).  
128 We enrolled consecutive patients, noting reasons for not wanting to take part. We gave  
129 parents/carers and children age-appropriate information material about the study and  
130 addressed any questions. Parents/carers gave written consent, and children could sign an  
131 assent form.

132 We recorded age at study participation, gender and ethnic background. From the medical  
133 notes, we recorded ocular and systemic diagnoses, age at diagnosis of the eye condition and  
134 best corrected visual acuity (BCVA) with both eyes open in logMAR on the day of study  
135 participation. Where visual acuity was recorded as “counting fingers”, we noted a BCVA of  
136 1.3 logMAR, for “hand movements only” we noted 1.6 logMAR, for “perception of light” 2.7  
137 logMAR, and for “no perception of light” or “ocular prosthesis/artificial eye”, 3 logMAR<sup>19</sup>.

138 We also recorded details of previous and current treatment, such as number of previous  
139 surgical interventions (sum of interventions right and left eye, including incisional surgery,  
140 laser treatment, removal of sutures, injections, excluding examinations under anaesthesia),  
141 number of general anaesthetics including examinations under anaesthesia and number of  
142 current topical medications (sum of eyedrop applications per day right and left eye).

143

#### 144 **Main outcome measures**

145 Functional visual ability was assessed with the CVAQC<sup>14</sup>. The 25 questions with answers  
146 selected on a four-point scale were completed by children from the age of 5 and covered  
147 areas such as education, near and distance vision, getting around, social interaction,  
148 entertainment and sports. We transformed the raw CVAQC scores into logarithmic scores  
149 <sup>14</sup>. The resulting scores range from -3.00 (normal visual ability) to +2.80 (severe visual  
150 impairment).

151

152 To evaluate VR-QoL, children aged 8 years or older completed the IVI-C questionnaire  
153 regarding mobility, interaction, school and emotional state. Due to delays in agreements  
154 and permissions we started using the IVI-C<sup>13</sup> five weeks after the start of the study  
155 (01/08/2014). We scored responses as recommended by the developers, allocating values  
156 between 0 and 4 to the responses from “never” to “always”. We did not allocate a score  
157 when the response “no, for other reasons” was selected. As the tool comprises 24 items,  
158 the resulting raw scores range from 0 to 96, with 96 indicating normal VR-QoL.

159

160 To assess HR-QoL age specific versions of the PedsQL<sup>TM</sup> Inventory were completed by  
161 children between the ages of 5-16 years and their parents/carers. The questionnaire for



162 children age 8-12 years consists of 23 questions in the domains of “my health and  
163 activities”, “my feelings”, “how I get along with others” and “about school”; answers are  
164 given on a 5-point Likert scale from 0 (never a problem) to 4 (always a problem). The set for  
165 young children (5-7) and teenagers aged 13-18 years comprises of 23 questions about  
166 physical, emotional, social, and school functioning; answers are on a 5-point Likert scale. We  
167 asked parents to complete two questionnaires, the PedsQL™ Parental report about the  
168 child/young person, and the PedsQL™ Family report, which measures the impact of a child’s  
169 condition on the family. The parental report on: children aged 5 years and older; children  
170 aged 8-12 years and that for teenagers aged 13-18 years consisted of 23 questions with  
171 answers on a 5-point Likert scale The parental report on children age 2-4 years consisted of  
172 21 questions. The family impact questionnaire includes “physical”, “emotional”, “social”,  
173 “cognitive” functioning of the parent, “communication”, “worry”, “daily activities”, and  
174 “family relationships”. This questionnaire contains 36 questions with answers on a 5-point  
175 Likert scale. Parents and children from the age of 5 can self-administer the questionnaire  
176 (PedsQL™ administration guidelines). We calculated the PedsQL™ scores as detailed in the  
177 scoring instructions. If items were left blank, we adjusted the denominator, using the  
178 number of completed items instead of the number of total items. It is recommended to  
179 remove questionnaires from the analysis if 50% or more of the items have been left blank;  
180 this did not occur in our sample. In summary, self, parent and family overall total, physical  
181 and psychosocial HR-QoL scores are generated with PedsQL™ scores ranging from 0 to 100,  
182 100 indicating normal health-related quality of life.

183

184 All questionnaires were self-administered and completed on the same day, during a regular

185 clinic appointment. When children needed help completing the questionnaires, they were  
186 assisted by a member of the research team or play leaders, but not by family members.

187

## 188 **Statistics**

189 We aimed for an overall sample size of between 50-100 children with cataract, as  
190 recommended for Bland Altman limits of agreement analysis. Demographic and clinical data  
191 and the CVAQC, IVI-C and PedsQL™ scores were transferred to a dedicated database in  
192 Microsoft Office Excel by a member of the research team. Calculation of scores and data  
193 transfer were double-checked by a second member of the team.

194 Analysis was carried out in Microsoft Office Excel, SPSS v23 (IBM) and Stata (V14). Where  
195 data were missing, datasets were excluded from the relevant analyses. We applied  
196 descriptive statistics throughout, reporting means and standard deviations or median and  
197 interquartile range (IQR) as appropriate.

198 Where data were missing for individual items in the PedsQL™ and IVI-C, we adjusted the  
199 denominator accordingly. The conversion from raw to logarithmic CVAQC scores takes into  
200 account missing data <sup>14</sup>.

201 We assessed relationships between age and quality of life scores using Spearman rank  
202 correlation and assessed whether differences observed between age groups were  
203 statistically significant using the Rank Sum test or independent t-test. Agreement between  
204 adult and child PedsQL scores was assessed using Bland-Altman techniques.

205 Statistical significance was set at the 5 % level and all tests conducted were two-tailed.

206

207

208 **Results**

209

210 **Enrolment**

211 We screened approximately 3,800 sets of medical notes to identify children eligible to take  
212 part in the wider study. We approached 214 children and their families; 13 declined taking  
213 part, all because of a perceived lack of time to complete the questionnaires. We enrolled  
214 201 children and young people (Fig 1). As this report focuses on childhood cataract (ChC),  
215 we excluded 124 datasets of children who did not have cataract or a history of cataract  
216 surgery. We removed two datasets as children had undergone incisional surgery or laser  
217 treatment within four weeks of study participation and had been enrolled in error. In  
218 addition, we removed two datasets of children with traumatic cataract, which was not  
219 included in our inclusion criteria, and one dataset, as neither parents nor child completed  
220 the questionnaires after having given consent. The statistical analysis was carried out on the  
221 remaining 72 datasets (Fig 1).

222

223 **Missing data**

224 The proportion of missing data was low. No data were missing for age, gender, diagnoses,  
225 laterality, BCVA and number of daily eye drops. Ethnicity was unknown in 8 participants  
226 (11.11%). Age at diagnosis of the eye condition could not be determined exactly in 3  
227 children (4.17%). Two children had previous surgical interventions at other centres, and  
228 information about previous number of operations and general anaesthetics was incomplete  
229 (2.78%). For all questionnaires administered, response and completion rates were high. The  
230 response rate for the PedsQL™ family report was 95.83%, for the parent report 97.22%, for  
231 the self-report 90.74% (Supplementary Material). The proportions of fully completed

232 questionnaires were 88.41, 90.00 and 97.96%, respectively. CVAQC and IVI-C response rates  
233 were 90.74% and 77.78%, respectively. CVAQC and IVI-C scores both contain a “for other  
234 reasons” category; selection of this category is taken into account during calculation of the  
235 scores.

236

### 237 **Participants**

238 The mean (SD) age of participants was 8.45 (standard deviation SD 4.10) years. Eighteen  
239 children were 2-4 years old, 16 were 5-7 years old, 25 were 8-12 years old and 13 were 13-  
240 16 years old (Table 1). Thirty-eight participants (52.78%) were female. Sixty-eight percent of  
241 participants were White, 15.28% Asian or Asian British, 4.17% Black or Black British, 1.39%  
242 other; ethnicity was unknown in 11.11%.

243

### 244 **Clinical details**

245 Sixty-nine participants (95.83%) had congenital/infantile cataract, of these, 31 (43.06%) had  
246 developed glaucoma after cataract surgery. Eight also had microphthalmia; another had  
247 microphthalmia, cataract surgery and secondary glaucoma. Two had cataract associated  
248 with either aniridia or primary congenital glaucoma. In total, 37 children and young people  
249 (51.39%) had glaucoma.

250

### 251 **Lens status**

252 Over a third of participants were aphakic in both eyes (n=28, 38.89%) (Table 1). Sixteen  
253 (22.22%) had aphakia in one eye, whilst the other eye had not undergone surgery. In one  
254 case, one eye was aphakic, the other replaced by an ocular prosthesis. Seven participants  
255 (9.72%) had lens implants in both eyes, and another seven had not undergone surgery.

256 The condition was bilateral in 43 cases (59.72%), and the mean age (SD) at diagnosis was  
257 1.25 years (SD 2.84) (Table 1). Median best corrected visual acuity in the better seeing eye  
258 or with both eyes open was 0.18 logMAR (IQR 0.02-0.43). Children applied a median of 0 (0-  
259 2.25) eye drops each day, with a maximum of 16 daily drops. The median number of eye  
260 operations (incisional or laser) performed on both eyes combined was 3 (2-5, maximum 35),  
261 and the median number of general anaesthetics including examinations under anaesthesia  
262 the children/young people had undergone was 3 (2-5.75, maximum 26).

263

### 264 **Functional visual ability**

265 Forty-nine of 54 children and young people age 5-16 years completed the CVAQC (90.74%).  
266 The median score was -1.42 (IQR -2.28 to -0.03), indicating moderate impairment of FVA  
267 (Table 2). Scores were better in older children than in the younger age group: -1.91 (-2.30  
268 to-1.36) in 13-16 year olds, -1.42 (-2.37 to 0.06) in 8-12 year olds, and -0.36 (-1.94 to 0.37) in  
269 5-7 year olds (-3.00 indicating normal visual ability) (Figure 2a). There was evidence of an  
270 association between age and CVAQC score (Spearman's rho correlation coefficient SRCC -  
271 0.291, P = 0.04).

272

### 273 **Vision-related quality of life**

274 Twenty-one of 27 eligible children and young people age 8-16 years completed the IVI-C  
275 (77.78%). The mean score was 65.67 (SD 16.91). The mean score in the older age group  
276 (73.5, SD 9.26, in 13-16 year olds) was higher than that in the younger age group (63.82, SD  
277 17.96, in 8-12 year olds), with 96 indicating normal VR-QoL (Figure 2b). The observed  
278 difference was not statistically significant in these data however there were just four  
279 subjects in the older age group and thus power to detect such a difference was limited.

280

281 **Health-related quality of life**

282 The median of the overall self-report completed by children/young people (n=49/54,  
283 90.74%) was 76.09 (61.96-89.13) (Figure 2c), the median of the parent report about the  
284 child (n=70, 97.22%) was 71.74 (51.98-88.19) and the median score of the family report  
285 completed by 69/72 parents/carers (response rate 95.93%, supplementary material) was 75  
286 (56.94-88.19, Table 2 with 100 indicating normal HR QoL. Figure 2d shows a Bland-Altman  
287 plot assessing agreement between parent and child PedsQL™ scores. There is evidence of  
288 decreasing dispersion – for individuals with lower scores, there is larger disagreement  
289 between child and adult score than for individuals with higher scores. The average  
290 disagreement (ie estimated bias) between adult and child score was -4.06 (-7.94, -0.18),  
291 indicating significant evidence that parents scores are lower than their child's.

292

293 The overall self-report scores were slightly higher in the older age groups than the younger  
294 ones: median (IQR) 66.30 (57.07-73.91) in 5-7 year olds, 81.52 (65.76-96.2) in 8-12 year olds,  
295 and 80.98 (68.75-91.85) in 13-16 year olds (Table 2) and the Family impact PedsQL™ scores  
296 tended to be higher in parents of children age 5-12 years than in very young children and  
297 teenagers (Table 2).

298

299 The median “physical wellbeing” PedsQL™ subscores were 82.81 (64.84-94.53) in the self-  
300 report, 81.25 (50-93.75) in the parent report and 79.17 (58.33-100) in the family report. The  
301 median “psychosocial wellbeing” subscores were 73.33 (60-85.95) in the self-report, 68.33  
302 (53.33-85.71) in the parent report and 73.33 (54.79-85.63) in the family  
303 report. Psychosocial scores appeared more affected than physical scores. Figures 2e and 2f

304 are Bland-Altman plots for physical and psychosocial scores. There was no evidence of  
305 systematic bias for physical scores, but parents tended to give lower scores than their  
306 children on the psychosocial score with an estimated difference of -4.19 (-8.12, -0.26).

307

### 308 **Associations**

309 Our study was not powered to detect statistically significant associations. However, older  
310 age at study participation tended to be associated with better CVAQC and PedsQL™ self-  
311 report scores. Bilaterality of cataract tended to be associated with worse PedsQL™ self-  
312 report and parent scores and poorer BCVA tended to be associated with worse a lower  
313 CVAQC score, IVI-C score, PedsQL™ self-report, parent and family scores.

314

315

### 316 **Discussion**

#### 317 **Key results**

318 The principal aim of this study was to explore the effects of childhood cataract on functional  
319 visual ability (FVA), vision-related quality of life (VR-QoL) and general health-related quality  
320 of life (HR-QoL) as reported by children/young people and their parents/carers. Due to its  
321 inclusive design, involving children of a broad age range and their parents, this study  
322 delivers new insights into the impact of childhood cataract on families.

323

324 Childhood cataract is not only associated with sight impairment, but is often complicated by  
325 a need for multiple additional operations and anaesthetics and the need for daily eye drops,  
326 most commonly for secondary glaucoma. The effect on FVA, VR-QoL and HR-QoL is  
327 profound. Children themselves report reduced levels of FVA and VR-QoL; this is most

328 pronounced in younger children. Health-related quality of life (HR-QoL), reported by the  
329 young person themselves and by parents on behalf of their child, is significantly reduced, as  
330 is the HR-QoL experienced by the family. Children and young people of all age groups report  
331 a greater impact on psychosocial than physical well-being.

332

### 333 **Limitations**

334 Our study design carries a number of potential sources of bias. Firstly, enrolling children  
335 attending a single site may induce selection bias. We attempted to reduced further bias by  
336 approaching consecutive patients; only a small proportion (n=13/224, 5.8%) declined to take  
337 part. However, families may have stopped attending clinics due to dissatisfaction with the  
338 services, or unwillingness or inability to comply with intense treatment regimes. On the  
339 other hand, families of children with good visual outcome may equally stop attending and  
340 be lost to follow-up. We have no data to estimate the proportion of families who stop  
341 attending, but from clinical experience consider the overwhelming majority of parents to be  
342 eager to provide the best possible healthcare for their child. Lack of a control group of  
343 healthy children may be considered a limitation. However, CVAQC and IVI-C were  
344 specifically developed for children with sight impairment; this would lead to a ceiling effect  
345 if used in healthy children, and comparison with healthy children would be misleading. For  
346 the PedsQL™, normative data are available from large numbers of healthy children, and a  
347 control group is not required. We limited inclusion to families able to communicate in  
348 English, which may induce selection bias. However, during enrolment we did not encounter  
349 any family who could not communicate in English.

350 It would be interesting to explore a possible association between the number of surgical  
351 interventions and QoL. Previous studies have used the number of surgical procedures as a



352 proxy of painful episodes the child had encountered as part of their eye treatment <sup>20</sup>.  
353 Similarly, the number of general anaesthetics (including EUAs, as these are often arranged  
354 on the understanding that should findings indicate a need for additional surgery, this will be  
355 carried out under the same anaesthetic) has been used as a proxy for episodes of emotional  
356 upset and anxiety <sup>20</sup>. However, our study was not powered to explore associations between  
357 QoL and putative risks factors for a reduction in QoL. As we were mindful of the need to  
358 avoid multiple significance tests and the potential for misinterpretation of non-  
359 statistically significant findings, we focused our analysis on the main objectives of the study.

360

361 Whilst logMAR visual acuity is a well-established measure of visual function, it is not always  
362 possible to use logMAR methods in children with sight impairment, and “hand movements”  
363 or “counting fingers” at a specified testing distance are still occasionally used. Complete  
364 blindness, “no perception of light”, or “artificial eye/ocular prosthesis” can also not be  
365 expressed in logMAR. In order to allow a quantitative analysis, we followed the approach of  
366 using logMAR values of of 1.3 to 3 in these cases <sup>19</sup>. This may have led to an under- or  
367 overestimate of logMAR acuity in some cases.

368

369 The heterogeneity of our study population, including children with secondary cataract and  
370 secondary glaucoma, may be considered problematic, but it allowed us to gather the views  
371 of older children and young people, which no previous study had explored. Another  
372 strength of our study is that children/young people completed the questionnaires by  
373 themselves, or were supported by play specialists if necessary. This eliminated parental  
374 perceptions influencing the children’s answers, though it may not have fully eliminated an  
375 adult’s bias from children’s answers.

376 **Interpretation**

377 The reduction in HR-QoL in children with cataract we report here is comparable to levels  
378 reported by children with severe congenital heart defects or liver transplants<sup>21 22</sup>;  
379 psychosocial subscores are reduced to levels comparable with children undergoing  
380 treatment for acute lymphoblastic leukaemia<sup>23</sup>. A previous study exploring HR-QoL in  
381 children who had undergone surgery for congenital cataract and their parents also reported  
382 reduced levels<sup>18</sup>; the scores we observed in the equivalent age group are even lower. In  
383 addition, the present study extends the finding of reduced HR-QoL to children who have not  
384 undergone surgery and children with secondary cataract.

385

386 A novel finding is that family and parental HR-QoL scores are higher in children age 5-12  
387 compared with younger children and teenagers. The cause for this is unclear; possibly child  
388 and family initially adjust, but in teenagers expectations and frustrations about education  
389 and transition to independence may increase. Alternatively, as better QoL is associated with  
390 better BCVA, the observed improvement in vision over time may explain increased levels in  
391 HR-QoL.

392

393 Two of the tools we used, the CVAQC and the IVI-C, have not previously been used in  
394 children with cataract, so direct comparison with other studies is not possible.

395

396 **Generalisability**

397 Within the limits of the study design, i.e. selection bias which may have led to inclusion of a  
398 higher proportion of more treatment-adherent families and the limitation of enrolling

399 participants at a single site in one highly developed country, our findings can be generalised  
400 to other children with cataract who receive care in similar settings.

401

## 402 **Conclusions**

403 Whilst treatment for cataract in adults is a highly successful sight-restoring procedure,  
404 cataract in children can have a dramatic effect on the life of affected children/young people  
405 and their families. More research is needed to evaluate the impact of multiple interventions  
406 and lifelong hospital follow-up. Families and young people may benefit from support to  
407 address psychosocial problems and difficulties with children's activities of daily living.

408

## 409 **Acknowledgements**

410 We thank Miss Anneka Tailor for supporting data collection and entry and Miss Konstantina  
411 Prapa for facilitating enrolment of participants into the study. We thank all children, young  
412 people, parents and carers who took part in this study.

413 The study was not supported by specific funding. AHDN and VT are employed by the  
414 National Institute for Health Research (NIHR) Biomedical Research Centre at Moorfields Eye  
415 Hospital and UCL Institute of Ophthalmology, and as such the work was supported by the  
416 NIHR. The views expressed are those of the authors and not necessarily those of the NHS,  
417 the NIHR or the Department of Health.

418

## 419 **Conflicts of interests**

420 None of the authors has interests to declare with regards to this publication.

421

422

423 **What was known before:**

- 424 • Only five previous studies have investigated QoL in children with cataract, all  
425 including congenital cataract patients only. The applied tools varied between  
426 studies. In children with congenital/infantile cataract:
- 427 • Health related quality of life scores are reduced to levels similar to severe systemic  
428 chronic diseases.
- 429 • Parent- and children’s self-report scores on health-related quality of life differ.
- 430 • Low visual acuity is associated with lower QoL scores, and surgery improves visual  
431 acuity and QoL.

432

433 **What this study adds**

- 434 • Paediatric cataracts can have a profound impact on health- and vision-related quality  
435 of life, and on functional visual ability, even many years after primary surgery.

436 Amongst children who have undergone cataract surgery

- 437 • Functional visual ability and vision-related quality of life scores are higher in  
438 teenagers than in younger children.
- 439 • Children/young people report higher health-related quality of life scores than their  
440 parents.
- 441 • Self-reported physical and psychosocial PedsQL™ subscores are higher in older  
442 children.

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538 **Figure legends**

539

540 Fig. 1. Enrolment, intervention and analysis flowchart (modified from CONSORT,

541 [www.consort-statement.org](http://www.consort-statement.org) ).

542

543 Fig. 2. Top: Box plots of median and interquartile range (IQR) Cardiff Visual Ability for

544 Children (a), Impact of Vision Impairment for Children (b) and PedsQL™ self-report scores

545 (c) of children with cataract. There is a trend towards less impairment with increasing age

546 (decreasing scores on CVAQC, increasing scores on IVI-C and PedsQL™), but with large

547 overlap of the IQR.

548 Bottom: Bland Altman plots of agreement between parent and child PedsQL scores; x axis:

549 mean of parent and child scores; y axis: difference of parent and child scores. Parents report

550 lower overall scores than their children; the lower the scores, the larger the disagreement

551 (d). The plot for physical and psychosocial PedsQL subscores shows no systematic bias (e),

552 but parents tended to report lower scores than their children on the psychosocial scale (f).

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557 **Table legends**

558

559 Table 1. Demographic and clinical characteristics, associated conditions and lens status in  
560 study participants.

561

562 Table 2. Scores for functional visual ability (FVA), vision- and health-related quality of life  
563 (VR-QoL, HR-QoL) reported by parents/carers and children. Possible CVAQC scores (FVA)  
564 extend from -3.00 (normal visual ability) to +2.80 (severe visual impairment). Possible IVI-C  
565 scores are between 0 and 96 (96 = normal VR-QoL); participants in this study reported  
566 markedly reduced VR-QoL. Possible PedsQLTM scores range from 0 to 100 (100 = normal  
567 HR-QoL); in this study, scores were severely reduced in all versions and subscales of the  
568 instrument (parent report, family report, self-report, physical and psychosocial subscores).

569

570 Supplementary Material: Table “Response and Completion Rates”. Parents were asked to  
571 completed two questionnaires, and children from the age of 5 years were asked to  
572 complete two or three questionnaires. Response and completion rates were high.

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