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Bilateral childhood visual impairment: child and parent concerns

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Patient-reported outcomes measure the impact of eye conditions on children and their families and are helpful for documenting the efficacy of treatments and for guiding treatment decision making. The aim of the present study was to elicit specific health-related quality of life and visual function concerns in children (0–17 years old) with visual impairment, during the patient-parent input stage of a larger project to develop new patient-reported outcome measures for pediatric eye conditions.

Subjects and Methods

We enrolled 37 children with visual impairment, defined¹ as worse than 20/70 in the better-seeing eye by optotype testing ($n = 16$), or below the lower limit of published normal values² by Teller Acuity testing ($n = 21$). We also enrolled one parent or legal guardian for each child. Additional information was collected on specific clinical diagnoses, refractive error, and whether there was any global developmental delay. Basic demographic data were also collected.

Semistructured, audio-recorded individual interviews were conducted using 12 open-ended questions (Tables 1 and 2), following recommended guidelines for developing patient-reported outcome measures.^{3–7} One parent was interviewed for every child enrolled (for children <5 years of age only the parent was interviewed). All interviews were transcribed verbatim, reviewed and coded using NVivo 10 software (QSR International, Doncaster, Australia). For each interview, specific concerns were identified and then coded by assigning phrases to “nodes” (a category of concern). All interview and coding procedures are described in additional detail in previous reports.^{8,9}

The specific nodes were reviewed and similar nodes grouped together so that groups of nodes represented broader themes. The frequency of both specific nodes and broader themes

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was then calculated separately for child concerns (derived from child interviews of children age 5 years and older), proxy concerns (child concerns derived from parent interviews of all children), and parent concerns (derived from all parent interviews).

Results

Diagnoses in these children with visual impairment were retinal or optic nerve disease, cortical visual impairment, nystagmus, high myopia, and anterior segment disease (Table 3). Demographics and clinical characteristics are listed in Tables 4 and 5. Mean child age was 6 years (range, 7 months to 15 years).

Of the 37 children, 16 of 23 (70%) aged 5–15 years were interviewed (7 children had developmental delay and were unable to be interviewed). From these interviews, a total of 20 specific categories of concern (nodes) were created; these were subsequently grouped into 6 broad themes: visual function (expressed by 81% of the children), treatment (63%), emotions (50%), physical discomfort (50%), social (50%), and worry (38%) (Table 6). Within the visual function theme, the most frequently mentioned concerns were regarding the quality of their vision (11/16 [69%]).

Thirty-seven parents were interviewed: 14 of 37 (38%) were parents of children aged 0–4 years (child too young to be interviewed); 16 (43%), of children 5–15 years who were interviewed; and 7 (19%), of children 5–15 years who were not interviewed due to developmental delay. From these interviews, a total of 22 specific categories of concern (nodes) were created. The 6 broad themes identified for proxy concerns were the same as those identified for child concerns, but with somewhat different frequencies: visual function (expressed by 89% of the parents), treatment (54%), emotions (68%), physical discomfort (22%), social (70%), and worry (8%). The most commonly mentioned specific concerns within the visual function theme were: the quality of the child's vision (31/37 [84%]), effects on activities-sports-hobbies (73%), and the need to compensate-adjust for the condition (65%) (Table 6).

From the 37 parent interviews, 28 specific categories of concern were coded as relating to the parent's own experience, and 5 broad themes were identified: worry (100%), compensation for condition (89%), treatment (84%), emotions (81%), and affects family (46%). All parents reported some form of worry, with worry about the future being most frequently mentioned (30 of 37, 81%) (Table 7).

Discussion

This first stage of developing new patient-reported outcome measures for children with eye disorders identified a range of concerns in interviews with children with moderate and severe visual impairment and their parents. For the parents, the most frequently occurring theme was worry. For children and proxy, the most frequently occurring theme was regarding visual function. Children with visual impairment experience a variety of health-related quality of life and visual function concerns. Specific concerns will be used to generate questions to populate patient-reported outcome questionnaires for visually impaired

children that capture information critical for evaluation of comparative effectiveness of treatments.

References

1. World Health Organization. [Accessed May 12, 2017] International Statistical Classification of Diseases and Related Health Problems 10th Revision. 2015. <http://apps.who.int/classifications/icd10/browse/2015/en#/H54>
2. Leone JF, Mitchell P, Kifley A, Rose KA. Sydney Childhood Eye Studies. Normative visual acuity in infants and preschool-aged children in Sydney. *Acta Ophthalmol*. 2014; 92:e521–9. [PubMed: 24606232]
3. Lasch KE, Marquis P, Vigneux M, et al. PRO development: rigorous qualitative research as the crucial foundation. *Qual Life Res*. 2010; 19:1087–96. [PubMed: 20512662]
4. Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing best practices based on science and experience. *Qual Life Res*. 2009; 18:1263–78. [PubMed: 19784865]
5. Rothman M, Burke L, Erickson P, Leidy NK, Patrick DL, Petrie CD. Use of existing patient-reported outcome (PRO) instruments and their modification: the ISPOR good research practices for evaluating and documenting content validity for the use of existing instruments and their modification PRO Task Force report. *Value Health*. 2009; 12:1075–83. [PubMed: 19804437]
6. Patrick DL, Burke LB, Gwaltney CJ, et al. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 1—eliciting concepts for a new PRO instrument. *Value Health*. 2011; 14:967–77. [PubMed: 22152165]
7. Patrick DL, Burke LB, Gwaltney CJ, et al. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 2—assessing respondent understanding. *Value Health*. 2011; 14:978–88. [PubMed: 22152166]
8. Castañeda YS, Cheng-Patel CS, Leske DA, et al. Quality of life and functional vision concerns of children with cataracts and their parents. *Eye (Lond)*. 2016; 30:1251–9. [PubMed: 27391939]
9. Liebermann L, Leske DA, Castaneda YS, et al. Concerns of children with esotropia and their parent's concerns. *J AAPOS*. 2016; 20:295–300. [PubMed: 27381528]

Table 1

Interview questions for children

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

Table 2

Interview questions for parents of children

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

Table 3

Primary diagnoses and additional diagnoses and their frequency

Primary diagnosis	No. (%)
Retinal / optic nerve disease	17 (46)
Stargardt	5
Albinism	3
Sequelae of ROP	2
Congenital stationary night blindness	1
Leber congenital amaurosis	1
Achromatopsia	1
Optic atrophy	1
Pigmentary retinopathy	1
Optic nerve hypoplasia	1
Isolated foveal hypoplasia	1
CNS	11 (30)
Nystagmus	4 (11)
Idiopathic infantile nystagmus	3
Unknown etiology	1
Anterior segment disease	4 (11)
Glaucoma	2
Cataract/aphakia	2
High myopia	1 (3)
Additional diagnoses	
Refractive error	26 (70)
Strabismus	16 (43)
Nystagmus	13 (35)
Other retinal / optic nerve disease	18 (49)
Anterior segment disease	4 (11)
Amblyopia	3 (8)
Orbital condition	1 (3)

Table 4

Child and parent demographics

Demographic parameter	No. (%)
Sex of child	
Female	15 (41)
Male	22 (59)
Age	
0–4	14 (38)
5–11	16 (43)
12–17	7 (19)
Race	
White (including Hispanic / Latino)	24 (65)
Asian	4 (11)
More than 1 race	1 (3)
Black/African American	4 (11)
American Indian / Alaskan Native	1 (3)
Other	1 (3)
Unknown / not reported	2 (5)
Ethnicity	
Not Hispanic / Latino and not Middle Eastern/North African and not Indian subcontinent	24 (65)
Hispanic / Latino	11 (30)
Indian subcontinent	2 (5)
Parent / legal guardian interviewed	
Mother	30 (81)
Father	7 (19)
Parent age	
21–30	8 (22)
31–40	21 (57)
41–50	7 (19)
51–60	1 (3)
Parent highest level of education	
Attended high school	4 (11)
High school graduate	8 (22)
Attended college	8 (22)
College graduate	14 (38)
Postgraduate / professional degree	3 (8)
Housing	
Own	21 (57)
Rent	16 (43)
Number of parents in home	
1	7 (19)
2	30 (81)

Demographic parameter	No. (%)
Care of child	
Parents only	17 (46)
Day care	2 (5)
Other relative	5 (14)
Other	9 (24)
Babysitter	1 (3)
More than 1 source of assistance	3 (8)

Table 5

Child clinical characteristics

Clinical parameter	N (%)
Test used to assess vision	
Snellen	3 (8)
HOTV	6 (16)
ETDRS	7 (19)
Teller acuity cards	21 (57)
Best-eye visual acuity	
Worse than 20/70 to 20/200	26 (70)
Worse than 20/200 to 20/400	7 (19)
Worse than 20/400 to 20/1200	2 (5)
Worse than 20/1200 to LP	2 (5)
Global delay	25 (68)
Refractive error (spherical equivalent, by eye) (N = 74) Range	-12.00 D to 22.125 D
<-4.00 D	11 (15)
-4.00 to < -3.00 D	3 (4)
-3.00 to < -2.00 D	1 (1)
-2.00 to < -1.00 D	5 (7)
-1.00 to <0.00 D	6 (8)
0.00 to <1.00 D	9 (12)
1.00 to <2.00 D	10 (14)
2.00 to <3.00 D	9 (12)
3.00 to <4.00 D	4 (5)
4.00 to <5.00 D	7 (9)
5.00 to <6.00 D	2 (3)
6.00 D	7 (9)
Current treatment	
Glasses	23 (62)
IOL	2 (5)
Atropine	3 (8)
Patching	2 (5)
Other (cyclogyl, cane, drops for glaucoma, sunglasses)	4 (11)

Table 6

Concerns of children with visual impairment expressed by the child themselves and by their parent (proxy reporter), grouped into overall themes, and showing the frequency of specific concerns within those themes

Theme Specific concern	Frequency child (n = 16) no. (%)	Frequency proxy (n = 16)^a no. (%)	Frequency proxy (N = 37)^a no. (%)
Visual function	13 (81 [CI 54–96])	15 (94 [CI 70–100])	33 (89 [CI, 75–97])
Vision	11 (69)	14 (88)	31 (84)
Compensate / adjust for condition	10 (63)	14 (88)	24 (65)
Limitations	7 (44)	8 (50)	20 (54)
Academic-reading	6 (38)	12 (75)	19 (51)
Activities / sports / hobbies	5 (31)	13 (81)	27 (73)
Coordination	2 (13)	4 (25)	10 (27)
Injury	0 (0)	4 (25)	10 (27)
Treatment	10 (63 [CI, 35–85])	11 (69 [CI, 41–89])	20 (54 [CI, 37–71])
Glasses	6 (38)	8 (50)	13 (35)
Patching	3 (19)	3 (19)	6 (16)
Surgery	2 (13)	2 (13)	5 (14)
Drops	1 (6)	0 (0)	0 (0)
General treatment	1 (6)	0 (0)	1 (3)
Other treatment	0 (0)	1 (6)	3 (8)
Emotions	8 (50 [CI, 25–75])	11 (69 [CI, 41–89])	25 (68 [CI, 50–82])
Negative emotions	8 (50)	11 (69)	24 (65)
Appearance / self-conscious	1 (6)	2 (13)	3 (8)
Self-confidence	1 (6)	2 (13)	2 (5)
Social	8 (50 [CI, 25–75])	11 (69 [CI, 41–89])	26 (70 [CI, 53–84])
Being different from others	8 (50)	6 (38)	12 (32)
Comments	4 (25)	7 (44)	9 (24)
Social interactions	2 (13)	8 (50)	21 (57)
Teasing	1 (6)	4 (25)	5 (14)
Looking-staring	0 (0)	1 (6)	2 (5)
Physical discomfort	8 (50 [CI, 25–75])	3 (19 [CI, 4–46])	8 (22 [CI, CI 10–38])
Ocular discomfort / sensations	8 (50)	3 (19)	8 (22)
Worry	6 (38 [CI, 15–65])	2 (13 [CI, 2–38])	3 (8 [CI, 2–22])
Worry	6 (38)	2 (13)	3 (8)

CI, 95% confidence interval.

^aProxy frequencies were calculated both for all children (N = 37) and for children who were interviewed (n = 16)

Table 7

Concerns of parents of children with visual impairment (affecting themselves), grouped into overall themes and showing the frequency of specific concerns within those themes

Theme	Frequency (N = 37)
Specific concern	no. (%)
Worry	37 (100 [CI 91–100])
Future	30 (81)
Vision	23 (62)
Limitations	23 (62)
Treatment	22 (59)
Coordination/injury	18 (49)
General	15 (41)
Social	14 (38)
Deterioration	13 (35)
Teasing / comments	10 (27)
Activities/sports/hobbies	10 (27)
Different (aware)	10 (27)
Academics/reading	10 (27)
Appearance/self-conscious	5 (14)
Self-confidence	2 (5)
Heredity/genetics	2 (5)
Compensate for condition	33 (89 [CI 75–97])
Treatment	31 (84 [CI 68–94])
Inconvenience	22 (59)
Glasses	17 (46)
Limitations	14 (38)
Cost	8 (22)
Surgery	7 (19)
Patching	5 (14)
General treatment	4 (11)
Drops	3 (8)
Other Treatment	3 (8)
Emotions	30 (81 [CI 65–92])
Negative emotions	30 (81)
Anxiety	1 (3)
Affects family	17 (46 [CI 29–63])

CI, 95% confidence interval.