Information Sources and Their Use by Parents of Children with Ophthalmic Disorders

Jugnoo S. Rahi, Irene Manaras, and Katharine Barr

PURPOSE. Parents’ input is critical to clinical management in pediatric ophthalmology. The importance of providing parents with appropriate information to enable them to participate effectively is recognized. However, little is known about the range of sources parents use to learn about their child’s ophthalmic condition, which sources they find most useful, and how this relates to their understanding.

METHODS. Cross-sectional survey of the parents or usual caregivers of children with diverse ophthalmic disorders, diagnosed at least 1 year earlier, who attended pediatric ophthalmology clinics at Great Ormond Street Hospital, London, during 1 week in August 2001.

RESULTS. Eighty-nine percent (n = 58) of parents with eligible children participated. Most parents received information from more than one source, with ophthalmologists (79%) and family practitioners (42%) being the two most frequently reported. Family support groups and voluntary organizations (29%) and the Internet (23%) were less commonly cited than anticipated. Parents reported receiving verbal information much more frequently than written information from professionals working with their children. Although 72% (n = 42) of parents could correctly name their child’s diagnosis, only 46% (n = 27) were able to describe correctly the nature and impact of the disorder(s). Ophthalmologists were ranked as the most important source overall.

CONCLUSIONS. The findings emphasize the key role of ophthalmic professionals in improving parental education directly, as well as their responsibilities and opportunities to do so through supporting and shaping information provision through other sources, especially colleagues in primary care and the Internet.

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RESULTS

During the week of the survey, 65 of 86 eligible children attended their scheduled appointments. The parents of 89% (58/65) of these completed the questionnaires, although incompletely in some cases. Thus, denominators are reported separately for each item. The nonresponding parents and their
children (n = 7) were similar in sociodemographic and clinical characteristics to those who participated.

The responding parents of 22% (n = 13) of the children were in professional occupations, 21% (n = 12) in intermediate occupations (for example, clerical workers), and 14% (n = 8) in working occupations (for example, manual laborers), using the UK Standard Occupational Classification,1 with 34% (n = 20) being full-time housewives and 9% (n = 5) unemployed. Most (71%; n = 41) were white, 12% (n = 7) were Asian, and 2% (n = 1) black; ethnicity was unspecified in 15% (n = 9).2 In 27% (n = 14) there was a family history of pediatric eye disease and in 47% (n = 25) the children had additional systemic disorders or other impairments. The mean Townsend deprivation index score3 was 0.398, with 62% (n = 35) of the children having economically deprived half of the total distribution. Thus, participating parents were similar to the overall UK population (range, 1.5–18 years). They had a range of ophthalmic disorders, as shown in Table 1.

The mean age of the children in the study was 8 years (range, 1.5–18 years). They had a range of ophthalmic disorders, as shown in Table 1.

Figure 1 shows the range of professionals working formally with children with ophthalmic disorders from whom parents had obtained verbal or, less commonly, written information. Although ophthalmologists were by far the most frequently cited source (79% verbal, 27% written), 15% (n = 9) of respondents did not report receiving either verbal or written information from them. Family doctors were the second most common professional source. Informal sources were much less frequency cited (Fig. 2), with information received from family support groups and/or voluntary organizations and through the Internet, reported by 29% and 23%, respectively.

Of the responding parents, 60% (n = 35) cited the two sources they found most useful. Ophthalmologists were cited most frequently by both parents (52%; n = 18) and clinical staff in the ophthalmology department (67%; n = 20) to be the most important source, followed by other professionals, family support groups and voluntary organizations, and the media. There was less agreement about the second most important source (Table 2).

Most respondents could correctly name their child’s eye condition (88%; n = 49) with 12% (n = 7) being unable to name it at all. However, only 46% (n = 27) gave completely correct and 31% (n = 18) partially correct explanations or descriptions of the disorder, the rest giving incorrect (2%; n = 1) explanations or not providing one. (21%; n = 12) We found no association between parental understanding (ability to describe disorders correctly) and professional occupation (odds ratio, 95% confidence interval [CI]: 2.4, 0.72–8.58), reduced socioeconomic deprivation (3.71, 0.87–16.68), or ophthalmologist as the most important source (0.90, 0.19–4.19). However, the size of the study may have limited the power to detect such differences, as it did the ability to examine use of different sources according to socioeconomic characteristics. The diversity of disorders affecting children in the study was too great to allow meaningful analysis of the relationship between the nature or severity of the disorder and parental understanding. Because nonattending parents were not contacted, we were unable to examine the question of whether regular attendance was related to either parental understanding or the sources of information used.

### Table 1. Ophthalmic Disorders Affecting the Children

<table>
<thead>
<tr>
<th>Disorders Grouped by Anatomical Site</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual pathways and cortex (5 cortical visual impairment, 1 tumor)</td>
<td>7 (4)</td>
</tr>
<tr>
<td>Whole globe and anterior segment of the eye (glaucoma 2, microphthalmos 1, persistent hyperplastic primary vitreous 1)</td>
<td>7 (4)</td>
</tr>
<tr>
<td>Cornea (microcornea 1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Lens (cataract 18, subluxed 1)</td>
<td>33 (19)</td>
</tr>
<tr>
<td>Retina (albinism 6, retinopathy of prematurity 1)</td>
<td>15 (9)</td>
</tr>
<tr>
<td>Uvea (uveitis 1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Optic nerve (hypoplasia 2, neuropathy 3)</td>
<td>9 (5)</td>
</tr>
<tr>
<td>Other (squint/amblyopia 8, lid hemangioma 3, ptosis 2, idiopathic nystagmus 2)</td>
<td>26 (15)</td>
</tr>
</tbody>
</table>

*Great Ormond Street Hospital*
DISCUSSION

Pediatric ophthalmology encompasses the long-term medical and surgical management of disorders and requires specialized and complex explanation to parents. The parents participating in this study were experienced users of health services and information, having attended a specialized ophthalmic unit for more than 1 year after their children’s initial diagnoses and, in the main, having children with complex and/or multiple disorders. As would be expected, they had received some information from a diverse range of sources. The findings are likely to have been different had parents been surveyed at an earlier time point—for example, soon after diagnosis, or if parents of children with less complex disorders attending a less specialized unit been included. It is possible that the pattern of sources used may have differed for parents who did not participate (nonresponders and nonattenders), although they did not differ significantly according to sociodemographic and clinical characteristics.

The findings emphasize the value of appropriate information provided directly by ophthalmologists and that ophthalmic professionals recognize this responsibility. They also identify that ophthalmic professionals have an opportunity to support and shape information provision through other sources—in particular, colleagues in primary care and education, to whom parents are likely to turn. The low reported frequency of written information provided by all professionals working with children with eye disorders is of concern, given its influence on parental knowledge and concordance with treatment. It may be that some of the discrepancy between parents’ ability to name, as opposed to their ability to describe, their children’s conditions reflects the lack of written information.

Information was less frequently obtained from family support groups and voluntary organizations and through the Internet than had been anticipated from surveys in other clinical specialties. This may partly reflect the relative rarity of visually impairing disorders in childhood and thus of relevant disorder-specific groups and Internet resources. It is also likely to reflect some lack of awareness of existing sources and inadequate coordination between them: ophthalmic professionals can influence both. The findings of this survey show that professionals working with children with ophthalmic disorders currently have an opportunity to influence the quality of information available through the Internet, reliance on which can be expected to increase with time. This may help to avoid the concerns about accuracy and consistency that prevail in other areas of child health. Implementation of existing guidance by statutory and voluntary sector organizations working in the area may be helpful in achieving this.

<table>
<thead>
<tr>
<th>Source</th>
<th>Ranked First by Parents</th>
<th>Ranked First by Ophthalmic Health Professionals</th>
<th>Ranked Second by Parents</th>
<th>Ranked Second by Ophthalmic Health Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologist</td>
<td>52 (18)</td>
<td>67 (6)</td>
<td>36 (8)</td>
<td>—</td>
</tr>
<tr>
<td>Other professionals</td>
<td>17 (6)</td>
<td>11 (1)</td>
<td>36 (8)</td>
<td>22 (2)</td>
</tr>
<tr>
<td>Family support groups/voluntary organizations, family, and friends</td>
<td>11 (4)</td>
<td>11 (1)</td>
<td>—</td>
<td>45 (4)</td>
</tr>
<tr>
<td>Media</td>
<td>14 (5)</td>
<td>11 (1)</td>
<td>28 (6)</td>
<td>33 (5)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (2)</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

Data are percentages with the number of children in parentheses.
Acknowledgments

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References


APPENDIX

Study Questionnaire for Parents/Caregivers

I You and Your Family

1. What is your relationship to the child attending clinic?
2. Do you usually attend the Eye Department with this child? Yes ☐ No ☐
3. What is your occupation? (for example, housewife, teacher, nurse, unemployed) __________________________
4. If applicable, what is your spouse/partner's occupation? __________________________

II Your Child Attending Clinic Today

1. How old is your child (in years)? ___
2. What is the name of your child's eye problem or condition? __________________________
3. How do you think this condition affects your child's sight? __________________________
4. Does your child have any other medical conditions? Yes ☐ No ☐
5. If Yes, please list: __________________________

III Sources of Information about Your Child's Condition

1. Information from people who work with your child:
   Have you received information from any of the following people?
   Please tick all that apply.
   Written ☐ Spoken ☐
   ☐ Family Doctor (GP)
   ☐ Health Visitor
   ☐ Eye Doctor
   ☐ Other Hospital Doctor/Specialist
   ☐ Hospital Nurse
   ☐ Community Nurse
   ☐ Optician (Hospital or Community)
   ☐ Orthoptist (Hospital or Community)
   ☐ Social Worker
   ☐ Teacher for Visually Impaired
   ☐ School Teacher
   ☐ GOS Eye Department Community Link Team
   ☐ Other (please specify): __________________________

2. Information from other sources:
   Have you received information from any of the following?
   Please tick all that apply.
   ☐ Family Support Groups/Voluntary Organizations (please tell us which ones): e.g., RNIB, RLSB, SightSavers, Contact a Family, Look, Sense:
   ☐ Newspaper/Magazine (please list):
   ☐ Books (please list):
   ☐ Television/Radio Programs (please list):
   ☐ Internet (please tell us which Web sites):
   ☐ Family and Friends (please tell us your relationship with them): __________________________
   ☐ Other (please specify): __________________________

3. Of all the sources of information, which two were the most useful?
   1. __________________________ 2. __________________________

Please use this box for any extra comments you may have