Original Article

Vision-related quality of life in children with treated retinopathy of prematurity

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Purpose: To evaluate vision-related quality of life in children treated for retinopathy of prematurity. **Methods:** Cross sectional observational study of 54 treated ROP babies 2–7 years of age. The study excluded babies with chronic pediatric conditions and babies of parents suffering from mental illness. Detailed examination including visual acuity was done for all. Two versions of CVFQ questionnaire for children under 3 and above 3 years of age were posed to parents in this study. CVFQ contains six subscales: General health, vision health, competence, personality, family impact, and treatment difficulty. The scores ranged from 0 (worst score) to 1 (best score). **Results:** The study included 54 children with mean birth weight was 1194 grams, mean gestation age 30 weeks. The age, gender, birth weight, and gestational age didn't affect the overall quality of life ($P > 0.05$). The severity of ROP (stage 4 and 5) had poorer CVFQ scores (personality and family impact subscales). Competence and personality scores were significantly lower in zone I disease. The quality of life especially general vision, competence, personality, and treatment difficulty subscales had significantly lower values in ROP with higher clock hour involvement ($P < 0.05$). With myopia after ROP treatment, only personality subscale was significantly affected (P 0.02). Mean CVFQ score including the family impact and treatment difficulty subscale score was also significantly lower in amblyopic and anisometropic children (P value < 0.05). Family impact subscale and overall quality of life was significantly lower in children with strabismus than children without strabismus (P 0.001). **Conclusion:** ROP has negative effect on the vision-related quality of life of children and their parents. The overall quality of life worsened with the increase in the severity of disease and the occurrence of ocular sequelae of ROP. The vision of the baby may not be the only cause of low scores in the quality of life questionnaire in ROP.

Access this article online

Website: www.ijo.in

DOI: 10.4103/ijo.IJO_323_19

Quick Response Code:

Key words: Quality of life, retinopathy of prematurity, visual outcome

Retinopathy of prematurity (ROP) is a potentially blinding disease of prematurely born low birth weight babies. The incidence of ROP in India is on the rise and and according to various studies it varies between 38% and 51.9%.[1,2] As the neonatology services are improving in developing countries, there is increased survival of preterm babies and the rise in the number of babies with ROP. At present developing countries like India are facing the third epidemic of ROP.[3]

Most cases of ROP regress and over 90% of stage 1 and 2 do not require any treatment. The treatment options for ROP include cryotherapy, laser photocoagulation, and intravitreal anti vasculoendothelial growth factor (anti-VEGF) agents.[4] Surgical treatment is required for advanced disease. Babies with treated ROP are at higher risk of developing long-term sequelae including anisometropia, amblyopia, squint, cataract, glaucoma, and retinal detachment. The disease is relatively newer to our country and parents are having difficulty in comprehending the nature of the disease and the need for urgent treatment of the disease and its comorbidities. The onset of eye-related problems during the childhood may have grave consequences on the physical, mental, and social well-being of children and their parents. Hence, regular follow-up is required to detect and manage the sequelae of ROP which may require repeated hospital visits. The knowledge of quality of life in these children and their families is desirable as these children may require prolonged and expensive care in neonatal period and beyond.

Till date the quality of life in ROP babies and the social impact of the disease on life of the child and their families have been an ignored aspect of the management and literature on the topic is scant.[5,6] The Western population data may also not be valid for developing countries due to gross social, cultural, and economic differences. In this study, we evaluated the impact of treated ROP on quality of life of affected children and their families.

Methods

In this prospective observational cross-sectional study, consecutive children with treated ROP were enrolled from the retina clinic of a tertiary care hospital from January 2014

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Manuscript received: 16.02.19; Revision accepted: 27.04.19

Cite this article as: Kesarwani P, Narang S, Chawla D, Jain S, Chandel M, Sood S. Vision-related quality of life in children with treated retinopathy of prematurity. Indian J Ophthalmol 2019;67:932-5.

to July 2016. All these babies were under pediatric care of our institute and were inborn babies. Children with chronic medical disorders or severe neurodevelopmental disability effecting the quality of life were excluded. The parents of the children were informed about the aims and procedure of the study and they agreed to participate after signing the informed consent form. The study was approved by the Research and Ethics committees of the institute.

Detailed history was obtained about gestation and weight at birth, antenatal, or intrapartum complications in mother and significant postnatal problems and therapeutic interventions like respiratory distress, respiratory support, apnoeic spells, systemic infection, blood transfusion, and intraventricular haemorrhage. Information was supplemented and cross-checked by screening the neonatology clinical records. The exact zone and worst stage of ROP, treatment given for ROP, refractive error and its correction, amblyopia treatment (patching) and any other intervention were also recorded.[7] The best corrected visual acuity was recorded using Lea symbolic chart in children younger than 3 years and using ETDRS-modified Snellen's chart in children 3 years and older.[8]

Outcome measurement

Age-specific Children's Visual Function Questionnaire (CVFQ) for babies <3 years of age and CVFQ designed for babies ≥3 years of age were used to measure vision-related quality of life in children.[9] The CVFQ is a questionnaire about child's everyday activities completed by parents/caregivers and is designed to measure vision-related quality of life in children up to 7 years of age. For babies less than 3 years another questionnaire is available. It contains 35 questions and is divided into 6 subscales: General Health (questions about the general health conditions of the child); Vision Health (or General Vision, questions about the child's visual health); Competence (questions about the child's ability to perform daily activities); Personality (questions about the effect of visual impairment on the child's social behavior and personality); Family Impact (questions about the effect of visual problems on the parents and family and their concerns); and Treatment (questions about the effect of treatment for visual impairment on the child and family). The subscale scores ranged from 0 (worst score) to 1 (best score). The score for each subscale is determined from the mean score of the responses to the subscale questions. The score for the Total Index was determined from the mean scores of the subscales. Responses classified as "not applicable" and unanswered items were omitted from the mean scores.

General health (questions about general health conditions of the child); vision health (or general vision, questions about child's visual health); competence (questions about child's ability to perform daily activities); personality (questions about child's visual impairment on child's social behaviour and personality); family impact (questions about the effect of visual problems on parents and family and their concerns); and treatment difficulty. The subscale scores ranged from 0 (worst score) to 1 (best score). The score for each subscale was determined from the mean score of responses to the subscale questions. The score for the total index was determined from the mean scores of the subscales. Responses classified as "not applicable" and unanswered items were omitted from the mean scores. The questionnaires were completed by both the parents during a 20–30 minutes personal interview conduced by the principal investigator (PK).

Data was analyzed using the SPSS 16.0 software. Student t-test and Chi square test were used appropriately to assess the statistical significance of the associations. The significance level was set at 5% ($P < 0.05$).

Results

Fifty-eight children (mean age 28 months ± 3.6 months years, range 2–7 years, 30 boys) with treated ROP were enrolled from the retina clinic of the hospital. Of these 4 children with chronic disorders including patent ductus arteriosus ($n = 2$), cerebral palsy ($n = 1$) and bronchopulmonary dysplasia ($n = 1$) were excluded. Mean birth weight was 1193 ± 284 g and mean gestation at birth was 29.8 ± 2.1 weeks. ROP extent, severity, treatment received and anatomical and functional outcomes are presented in Table 1. The mean CVFQ score was 0.94 ± 0.11 and 0.95 ± 0.07 in babies aged ≤ 3 years and > 3 years, respectively. The mean general health subscale score was 1 and all other subscale sores were lower than 1. The maximally impacted domains were treatment difficulty and family impact [Table 2]. None of the baseline demographic variables like birth weight,

Table 1: Demographic variables and anatomical and functional outcome after treatment of ROP

Variable	*n*=54
Birth Weight (g)	1193±290
Period of gestation (weeks)	29.8±2.1
Sex (male:female)	30:24
Multiple births	6 (10.3%)
ZoneI:II:III	4:50:0
Stage 1:2:3:4:5	1:28:22:1:2
Severest Treatment given	
Laser ablation	46 (85.2%)
Anti VEGF and laser	4 (7.4)
Cryotherapy	1 (1.9%)
Surgery with LSV/sclera buckling	2 (3.7%)
Surgery with lensectomy	2 (3.7%)
Successful Anatomical outcome	51 (94.4%)
Successful Functional outcome (BCVA LogMAR <1)	51 (94.4%)
BCVA of 20/40 (logMAR ≥0.3)	48 (88.9%)
Unsuccessful Functional outcome (BCVA LogMAR ≥1)	3 (5.7%)
Myopia ≥3 Dioptre	6 (11.1%)

Table 2: Children's Visual Function Questionnaire (CVFQ) subscale scores in two different age groups

	CVFQ score Babies <3 years age	CVFQ score Babies ≥3 years age
General health	1.00±0.00	1.00±0.00
General vision	0.97±0.16	0.97±0.089
Competence	0.98±0.10	0.97±0.099
Personality	0.99±0.05	0.99±0.08
Family impact	0.90±0.15	0.91±0.12
Treatment difficulty	0.77±0.22	0.86±0.16
CVFQ Mean Score	0.94±0.11	0.95±0.07
Total CVFQ Score	5.62±0.61	5.7±0.39

gestational age, sex, or multiplicity of birth had any significant impact on CVFQ scores of the babies ($P > 0.05$).

The mean total index score was lower in zone 1 of ROP than zone II. However, this did not reach statistical significance. The competence and personality subscale scores of CVFQ were significantly lower in zone I than zone II of ROP [Table 3].

The mean CVFQ score in myopic babies was 0.89 ± 0.09 compared to 0.95 ± 0.08 in non-myopic babies (*P* value 0.27). The babies with myopic eyes had significantly lower personality subscale score (0.93 ± 0.17) than babies without myopia (0.99 ± 0.03) (*P* value < 0.02). The general vision and family impact scores were also affected with myopia but difference was statistically insignificant [Table 4].

Amblyopia was present in 23 babies. The quality of life (total CVFQ Score, 5.48 ± 0.19) in amblyopic babies undergoing occlusion therapy was significantly lower than babies without amblyopia (5.78 ± 0.62, *P* value 0.01). Family impact (0.84 ± 0.09, *P* value 0.002) and treatment difficulty (0.67 ± 0.16, *P* value 0.00) subscale score 3.6 amblyopic babies were also significantly lower than babies without amblyopia [Table 4].

The difference in refractive errors in two eyes (anisometropia) was present in 9 babies. The vision related CVFQ scores in anisometropic babies was significantly lower than non-anismetropic babies (5.14±0.83 versus 5.76±0.34; *P* value 0.00). The family impact (0.70 ± 0.19, *P* value 0.00) and treatment difficulty (0.62 ± 0.17, *P* value 0.002) subscale scores were also significantly lower in anisometropic babies. Strabismus was present in 4 babies. The vision related quality of life (total CVFQ score) in squint babies was statistically lower (*P* value 0.03) than babies without squint. The family impact subscale scores of these babies were also significantly lower than babies without squint (*P* value 0.001).

Table 3: Children's Visual Function Questionnaire (CVFQ) subscale score of babies according to zones of ROP

CVFQ Subscale	Zone-I (*n*=4)	Zone -II (*n*=50)	*P*
General health	1.00±0.00	1.00±0.00	1.00
General vision	0.90±0.20	0.98±0.12	0.50
Competence	0.81±0.23	0.99±0.07	<0.01
Personality	0.89±0.21	0.99±0.04	0.003
Family impact	0.85±0.15	0.91±0.14	0.48
Treatment difficulty	0.80±0.16	0.82±0.22	0.83
CVFQ Mean Score	0.88±0.13	0.95±0.07	0.33
Total CVFQ Score	5.27±0.71	5.69±0.48	0.32

Discussion

The present study is the first quantitative study about quality of life in ROP babies in developing countries. ROP was seen to have negative impact on the vision-related quality of life of affected babies on age-matched CVFQ scale. Messa *et al*. also showed that all CVFQ subscale scores were significantly lower in ROP babies compared to control groups and the total CVFQ score, vision, health, and competence scores were more impacted in children with severe ROP.[5] Interview of both the parents was conducted in the present study as opposed to interview of the mother alone in majority of the babies in the study by Messa *et al*. Higher number of babies were undergoing treatment for associated conditions of amblyopia and strabismus as compared to only 5 babies undergoing treatment in the study by Messa *et al*.

In the present study, the subscale scores analysis revealed that the maximum impacted domains were the "family impact" and "treatment difficulty". Family impact highlights the effect of visual problem of child on the family and their concerns. The family impact was the most affected domain in a study by Birch *et al*.[8] also. A recent qualitative study about the family impact of children blind from ROP showed that majority of the parents are very distressed by their child's blindness and anxious about the future. The study was undertaken in a hospital where there are fees for every service and non affordability was one of the issue addressed by the parents. However in the present study the economic concerns were bare minimum and still family impact was noted.

The "treatment difficulty" subscale score tells about the effect of treatment for visual impairment on the child and the family. The use of spectacles is still considered a taboo in our country and with the added problem of the use of glasses in the pediatric age group, treatment difficulty was the most impacted domain in the present study.

Myopia and amblyopia after ROP had negative impact on the CVFQ scores in the present study. Myopic babies had significantly lower personality subscale scores. This could be due to the use of glasses. The subscales affected in amblyopia were family impact and treatment difficulty. Treatment of amblyopia in the form of occlusion or glasses have significant family impact. Birch *et al*. also found that the refractive errors, amblyopia, anisometropia, and strabismus, had significant

Table 4: Children Visual Function Questionnaire subscale score of babies with myopia and babies with amblyopia

CVFQ Subscale	Babies with myopia using glasses (*n*=6)	Babies without myopia (*n*=48)	*P*	Babies with amblyopia undergoing occlusion treatment (*n*=23)	Babies without amblyopia (*n*=31)	*P*
General health	1.00±0.00	1.00±0.000	1	1.00±0.00	1.00±0.00	1
General vision	0.90±0.17	0 0.98±0.118	0.14	0.96±0.16	0.99±0.04	0.29
Competence	0.95±0.12	0.98±0.096	0.58	0.98±0.09	0.97±0.10	0.81
Personality	0.93 ± . 17	0.99±0.036	0.02	0.98 ± . 09	1.00±0.00	0.17
Family Impact	0.79±0.14	0.92±0.130	0.09	0.84±0.09	0.95±0.15	0.002
Treatment difficulty	0.76±0.15	0.83±0.218	0.36	0.67±0.16	0.93±0.17	0.000
Mean CVFQ score	0.89±0.09	0 0.95±0.081	0.27	0.91±0.03	0.96±0.10	0.000
Total CVFQ score	5.34±0.587	5.7±0.487	0.20	5.48±0.19	5.78±0.62	0.01

negative family impact (*P* value < 0.05). The, negative impact on treatment difficulty score has been associated in earlier studies with the start of amblyopia treatment, which was maximum after occlusion therapy followed by occlusion to atropine, start of glasses, and the least when shifted from contact lens in IOL.[10]

The severity of ROP reflected by posterior zone 1 ROP had negative impact on the quality of life in the present study. The severity of ROP had significant impact on the child's personality and competence. Felius *et al*. also showed that the general vision CVFQ and all other subscales were affected by severity of ROP and the refractive error and anisometropia.

In our study, the general health of these babies was not impacted by the CVFQ score. In a study by Felius *et al*. general health subscale score was the impacted domain and was associated with developmental delay or other non-visual diagnosis. The babies with any other chronic health problems or mental retardation were excluded from our study. Thus ROP as a disease did not impair general health of the child which has also been demonsrrated in another study by Messa *et al*.[5]

None of the demographic variables had any significant impact on any subscale of CVFQ. The structural and visual outcome of ROP in the present study was comparable to the previous studies.[11,12] It has been seen that the vision impairment in childhood has further effects on overall health in adulthood, self-perception, educational attainment, job choices, and a number of other social factors.[13,14] We did not have long-term follow-up till adulthood in the present study. The major impact of the disease in the present study is on treatment difficulty and "family impact" which can be taken care of by a coordinator. The use of glasses and ocular patching can be facilitated by coordinator with counseling.

The major limitation of the present study was absence of the control group, younger age group and small sample size. Since all the babies in the present study were inborn babies, and ours is a relatively newer institute, the younger age group is due to the shorter available follow-up in the present study. Longer follow-up is required to accurately ascertain the vision related QOL in adulthood.

Conclusion

ROP has negative impact on vision related quality of life. Treatment difficulty and family impact are the most affected domains. These can be taken care of by coordinators and counsellors which may improve the vision-related quality of life.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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