

Quality of Life in Pseudophakic Children Operated Both Eyes for Congenital and Developmental Cataract

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Abstract

Introduction: Pediatric cataracts contribute a very significant proportion of avoidable blindness in children. Despite the recent advances made in pediatric cataract management, many patients may not be satisfied with their quality of life (QOL). We conducted this study to evaluate the quality of life in pseudophakic children operated both eyes for congenital or development cataract. We also assessed the parameters which could determine the quality of life of patients operated for congenital and developmental cataract.

Objective: To evaluate the quality of life in pseudophakic children operated both eyes for congenital or development cataract. To assess the quality of life of the patients with the help of questionnaire.

Methods: In this prospective cross sectional hospital based study, we report quality of life in children operated both eyes for congenital and developmental cataract attending the outpatient department at Lumbini Eye Institute from 2009 April to 2010 October.

Results: Quality of life in children with bilateral congenital and development cataract who were operated earlier had better results than the children who were presented late at cataract surgery. Majority of our patient had good to fair quality of life after correcting with glasses. Some parents rated day to day activities of their children better than what the children actually felt. This shows that parents sometime over estimate their children's performance.

Conclusion: Improvement in visual functioning and the quality of life have been demonstrated following cataract surgery. These gains were sustained if both eyes were operated in early life. Assessment of the outcomes of cataract surgery by clinical indicators alone may underestimate the overall benefits of surgery, particularly in patients with poor visual outcome. Questionnaire helps in determining the quality of life.

Keywords: Visual Functioning; Quality of Life; Uncorrected Visual Acuity; Best Corrected Visual Acuity

Abbreviations

VF: Visual Functioning; QOL: Quality of Life; IOP: Intra Ocular Pressure; UCVA: Uncorrected Visual Acuity; BCVA: Best Corrected Visual Acuity

Introduction

Quality of life is general well-being of an individual, his relation with society, his hopes and ambitions, his evaluation of current life circumstances in the context of the culture in which he lives and the values it holds.

Quality of life is determined by the extent to which hopes and ambitions are matched by experience. Individuals' perceptions of their position in life taken in the context of the culture and value systems where they live and in relation to their goals, expectations, standards, and concerns. Appraisal of one's current state against some ideal. The things people regard as important in their lives. In this respect, quality of life measures capture patients perspectives of their disease and treatment, their perceived need for health care, and their challenge in measuring quality of life lies in its uniqueness to individuals [1].

Pediatric cataract takes an enormous toll on developing countries in the form of human morbidity, economic loss, and social burden [2]. Pediatric cataracts contribute a very significant proportion of avoidable blindness in children. Despite the recent advances made in pediatric cataract management, many barriers exist in the management of pediatric cataract. Misconceptions among parents, general public including some health care professionals about pediatric cataract results in delayed presentation to eye care providers.

This study shows how the quality of life is affected by pediatric cataract. It enables us to know their ability and the limitations imposed on them right from their day to day activities to education, sports, job, hobbies and social acceptance. Parental worries and their concern about their children's future also have been addressed in this study. It may throw light on issues, which could be told to parents of children with pediatric cataracts in the future so that it can make life more comfortable for them and their children. It would show the burden of blindness and visual impairment due to cataracts. Also the study would show the impact of management on the life style of patients operated for congenital and developmental cataract.

Methodology

After taking written consent from the patients and their parents, screening of cases was done for the patient operated for bilateral congenital and developmental cataract. All patients who visited Pediatric eye care department at Lumbini Eye Institute, who were operated for congenital and developmental cataract six months before were included in the study and also patient operated elsewhere for congenital and developmental cataract were included in our study. Patients within 6 months of cataract surgery were excluded as it provides very short time for patient and their parents to understand their quality of life. The collected was checked, verified and was transferred to SPSS (Statistical Package for Social Sciences).

A clinical evaluation was carried out in each case with questionnaire session, in which the patient and their parents answered question regarding the quality of life. Detail history was taken from the patient and/or patient's party emphasizing on the quality of life, like questions for day to day activities, hobbies- extracurricular activities, academics and career, personal – self-confidence, self-esteem, social factors and economic factors. Profile of patient including age, gender, ethnic group, and occupation, patient's location according to geographic zone and country were noted. Treatment history, past medical/surgical history, family history and personal history were also asked.

Patients who were operated one eye alone at the time of consultation were excluded. However, when they were operated for the second eye and after 6 months, they were included in the study. Patients who were on patching therapy and showed improvement in visual acuity were included in the study. Patients following YAG capsulotomy or surgical membranectomy due to posterior capsule opacification were included 6 months after the surgery in the study.

Children with traumatic cataract, unilateral cataract and cataract associated with other anterior and posterior segment anomalies were excluded from the study. Physically and mentally challenged children were excluded as they independently affect the quality of life. Pre term children were excluded from the study as Prematurity per se imposes its own limitations.

Children less than 5 years were excluded from the study as the study involves answering a Questionnaire by both parents and children independently. All patients above 5 years of age, 6 months post cataract surgery of the second eye were given a Questionnaire to be filled. Younger children were assisted by pediatric counselor in filling the questionnaire. The parents preferably mother was asked to fill a questionnaire.

The visual acuity unaided and best corrected visual acuity (BCVA) was documented. Refractive error was documented. Anterior segment examination was assessed with slit lamp. Posterior capsule opacification was assessed with direct ophthalmoscope and slit lamp. Intra ocular pressure (IOP) was assessed in co-operative patients using Keeler pulsair puff tonometer. Fundus examination was done with indirect and direct ophthalmoscope and patients who were found to have posterior segment anomalies were excluded from the study. Sensory examination, binocularity and stereopsis were assessed. Stereopsis was assessed with Randot stereo test. Color vision was assessed with Hardy Rand Ritter test, which can detect both congenital and acquired color deficiencies and also quantify the defect. Contrast sensitivity was assessed with Pelli Robson chart.

Children with best corrected visual acuity less than 6/24 in the better eye were subjected to a low vision assessment and were given optical aids in indicated patients. Visual acuity less than 6/60 was considered visually impaired and visual acuity less than 3/60 was considered blind.

A literature review was performed to construct a list of question for vision-related tasks, social as well as financial aspect of the patient and their family. Three questionnaires were designed, for the interview with patients and their parents. One for the patient less than 20 years age group, second for the patient more than 20 years and the third for the parents of the patient. There were 15 questions for the patients less than 20 years, to keep the questions simple and short. 20 questions for the patients more than 20 years and 20 questions for the parents of patients with more focus on age appropriate activities were included.

A scale of 20-25 marks was designed to assess the quality of life of the patient. A total number of 55 questions was made out of which 11 questions for day to day activities, 10 questions for hobbies- extracurricular activities, 8 questions for academics and career, 11 questions for personal – self-confidence, self-esteem, 12 question for Social factors and 3 question were for the economic factors.

Each question carried 1 mark except for few conditions which contained more value was rated 2 marks. Patient obtained 0, 1 and 2 marks depending on their answers. Below 5 was rated very poor, 5 - 10 was poor, 10 - 15 was fair and 15 - 20 was rated good.

Results

The total number of patients included in our study was 46 out of which there were 80.4% males and 19.6% females. Congenital cataract was found in 34 patient whereas 12 patient were of developmental cataract. The age of the patients included in the study ranged from 5 years to 24 years with mean age of 8.826 years and a standard deviation of 3.673 (Table 1). Maximum numbers of patients were in of 6 - 10 years age group

Total number of patients	Minimum age at presentation (years)	Maximum age at presentation (years)	Mean age at presentation (years)	Std. Deviation
46	5	24	8.86	3.673

Table 1: Age of the patients at the time of presentation. The age of the patients ranged from 5 to 24 years with mean age 8.826 years.

In this study we found most of the patient from Nepal and India were males in comparison to females. Most of the patients were diagnosed about their disease at early age, less than five years, but the age of surgery was five to ten years, showing late presentation at surgery. Male children were diagnosed and operated earlier than the female child.

In our study we found that congenital and developmental cataract were more among those patient whose parents had non-consanguinity relationship, however seven out of eight children of parents having consanguinity relationship developed congenital and developmental cataract, thus it shows that consanguinity does play a role in developing congenital and developmental cataract (Table 2). In this study we have found that intra ocular pressure was within the normal limits for most of our patients 44 out of 46. Nystagmus was present in 11% of the patient, four female child developed nystagmus out of six. Almost twenty three of forty six patients had strabismus. We found that decrease in stereopsis was present in almost 55% of the people operated for congenital and developmental cataract.

Consanguinity	Frequency	Percent
No	38	82.6
Yes	8	17.4
Total	46	100.0

Table 2: Consanguinity of the parents.

Colour vision was almost normal after cataract surgery just 4% of the patient had defective colour vision. In our study contrast sensitivity was good in 55% of patient. Binocular single vision was absent in almost 50% of the patient.

Majority of patient had uncorrected visual acuity (UCVA) in both eyes from 6/18 to 6/60. But there was improvement in visual acuity after correction, 4 - 6% were visually impaired.

The quality of life according to majority of patient was fair almost 49%, followed by good quality 39% and least of them had poor quality of life 13% (Table 3). However, according to parents, 84% of their children had good quality of life and rest had fair quality of life. This study shows that parents may over estimate the quality of life of their children (Table 4).

QOL	Frequency	Percent
Good (15 - 20)	18	39.1
Fair (10 - 15)	22	47.8
Poor (5 - 10)	6	13.0
Total	46	100.0

Table 3: Quality of patients.

The quality of life according to majority of patient was fair almost 49%, followed by good quality which was 39% and least of them had poor quality of life 13%.

QOL	Frequency	Percent
Good (15 - 25)	39	84.8
Fair (10 - 15)	7	15.2
Total	46	100.0

Table 4: Quality of patient according to the parents.

Quality of life according to parents, 84% had good quality of life and rest had fair quality of life.

Discussion

Our study measures the Quality of Life and Visual Function in children operated for congenital and developmental cataract. We included those patients who were operated six months or more, because less than six months, it will be little time to comment on the patient's quality of life.

A research done in England shows finding that indicate that the greatest impact of surgery on visual function and quality of life (health and vision related) is apparent by 4 months, with the mean gains achieved by this time being sustained at 1 year following surgery to the first eye [3].

We had male patients more as compared to female. Male children were operated at early age after the diagnosis made, whereas female child were delayed for cataract surgery after the diagnosis. As in South Asian country male child is responsible for taking care of their parents and family later in life so may be due to this reason the male child were operated earlier as the diagnosis was made. In this study the ratio between male and female was 4.11: 1.

Similarly a study done in Tanzania shows that among congenital cataract patients, there was significant variation in the length of delay, particularly among girls. Boys receiving surgery at hospital generally outnumber girls two to one and it is assumed that this preponderance of boys has more to do with societal expectations of gender roles than any biological reason [4].

We found that congenital and developmental cataract was more among those patients whose parents had non-consanguineous relationship. However seven out of eight children of parents having consanguineous relationship developed congenital and developmental cataract, thus it shows that consanguinity does play a role in developing congenital and developmental cataract.

Study in India done by Vanita and Dalgit Shingh shows nearly one third of congenital cataract patient have positive family history [5].

Nystagmus was observed in 13% of our patients with bilateral cataract in whom treatment was delayed or who showed poor compliance with postoperative visual rehabilitation. We think that early surgery associated with immediate optical correction can eliminate this problem.

The work of Robb and Petersen has shown poor visual results in children who had nystagmus before surgery [6].

The occurrence of strabismus after cataract surgery was higher in the patients who were operated late, or one eye was operated early and other eye late. In some cases the difference of time of surgery between two eyes was more than five years. Almost twenty three of forty six patients had strabismus. Esotropia was more common in bilateral cataracts. Loss of compliance with glass and patching may also have added to strabismus. There were 18 patients i.e. 39.1% of patients did not patch accordingly or refused wearing glasses.

We found that decrease in stereopsis was present in almost 55% of the people operated for congenital and developmental cataract and binocular single vision was absent in almost 50% of the patients.

A study done in Canada reveals stereopsis among children deprived from birth, short deprivation appears to have the least destructive influence on visual development. Among unilateral cases, short pattern deprivation and rigorous patching can promote good spatial vision and, perhaps as a consequence, preserve a degree of binocularity [7].

Five patients had posterior capsular opacifications at presentation at our hospital; they were treated with YAG laser posterior capsulotomy.

A study done by Ondraek O. and Lokaj M. shows posterior capsular opacification was frequent in the eyes of children younger than 5 years in whom the posterior capsule remained without capsulectomy and anterior vitrectomy. Nine eyes were treated by YAG laser posterior capsulotomy and 16 underwent secondary operative capsulectomy and the aspiration of proliferated epithelial cells [8].

Visual acuity is one of the main factors for determining the quality of life. Patients with poor vision are unable to perform their daily works so the quality of life gets poor for the patients.

There have been few studies regarding relation between visual function and quality of life and most of the studies show that patient having good vision have good quality of life [9].

Cataract operated patient amenable to solution is refractive error. The substantial improvement in vision among operated individuals possible with refractive error correction points to the need for such follow up services among both aphakics and pseudophakics [9].

The questionnaire was for the patients and their parents. And both were interviewed in hospital one by one. The patient who were small and had trouble in understanding the questionnaire were helped by pediatric counselor.

In a study done in India the patient were allowed to take the question paper home and answer the questionnaire [10]. By taking home the questionnaire, the patient may get help from other member of family, so the reliability of the questionnaire is not there. In our study the surgeon and his team did not participate in questionnaire interview to avoid bias amongst patients.

Most of our patients were advised not to swim and play for the rest of life after cataract surgery by their doctors. But three of our patients were swimming after cataract surgery and some of them were involved in sports too. However they were not allowed to swim in rivers by their parents. This shows that we do not need to restrict patient for swimming and playing after cataract surgery.

One of the drawbacks of our study was academic scale, as in our study we had few patients with good vision but were illiterate, so their quality of life decreased despite of good visual acuity. The other drawback was that for some patient we did not know the condition of eye before surgery, neither the patients had any past treatment records, as they were operated elsewhere. Similarly we did not reevaluate the patients again after few months or years, because as the patient grows his quality of life may change.

We found that most of the parents were more optimistic about the visual function and quality of life of their children, on the other hand most children had problem in their visual acuity, which disturbed them from doing their duties.

In a study done by Vijaya K Gothwal, *et al.* showed that children may under or overestimate their level of difficulty. One way of overcoming this problem could be to have subjects actually perform the required tasks in the presence of the clinical practitioner or investigator [10].

Several studies have shown that there is a disparity between patients', doctors', and relatives' ratings of the patient's quality of life [1].

Conclusion

Pediatric cataracts contribute a significant proportion of avoidable blindness in children. They take an enormous toll on developing countries in the form of human morbidity, economic loss, and social burden.

Blindness due to pediatric cataract can result from late presentation, social and economical factors as well as complications related to faulty surgical technique, inappropriate Intra ocular lens power, and failure to comply with glasses and patching. Poor follow up contributes to a significant cause of visual loss and visual impairment.

Gains in visual functioning and quality of life have been demonstrated following cataract surgery. These gains were sustained if the eyes were operated in early life.

Assessment of the outcomes of cataract surgery by clinical indicators alone may underestimate the overall benefits of surgery, particularly in patients with poor visual outcome therefore Questionnaire helps in determining day to day activities, social, academic, economical factors, as well as extracurricular activities of the patient thus determining the quality of life.

Declaration

No financial interest.

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