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Assessing the impact of a program for late surgical intervention in early-blind children

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ABSTRACT

Objective: Many blind children in the developing world are unable to obtain timely treatment due to lack of financial and medical resources. Can public health programs that identify and treat such children several years after the onset of blindness enhance their quality of life? The notion that visual development is subject to an early 'critical period' argues against this possibility. However, there are inadequate empirical data from humans on this issue. To address this need, we examined the quality of life of children living in India and who were treated for early-onset blindness (before one year of age), due to cataracts or corneal opacities.

Study design: Survey study.

Methods: As part of an ongoing scientific effort named Project Prakash, we screened over 40,000 children in rural northern India to identify those suffering from early-onset blindness. They were provided eye surgeries in a tertiary care ophthalmic center in New Delhi. We subsequently surveyed 64 Prakash children, ranging in age from 5 to 22 years and obtained their responses on a multi-dimensional quality of life questionnaire.

Results: Nearly all of the subjects indicated that their quality of life had improved after treatment. Children reported marked enhancement in their mobility, independence, and safety, and also in social integration. Surprisingly, we found no significant correlations between quality of life metrics and factors such as age at treatment, gender, time since treatment, and pre-surgery and post-surgery acuity.

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Conclusions: A key question for public health policy makers is whether a program of surgical intervention for older blind children is likely to be beneficial, or if the resources are better spent on rehabilitation via vocational training and assistive devices. The marked improvements in quality of life we find in our data strongly argue for the provision of surgical care regardless of a child's age.

Introduction

The WHO estimates that there are nearly 39 million blind people worldwide.[1] One and a half million are children below the age of 15 years, and nearly 90% of them live in the developing world.[1] Most of these children live in poverty, which contributes significantly to their poor prospects for receiving treatment.[2] Furthermore, the consequences of living with visual impairment in developing countries are much more severe compared with developed countries. Over 50% of blind children die before they reach the age of 5 years.[3] Given these dire statistics, there is an urgent need to provide appropriate interventions to blind children. From a public health policy perspective, it is crucial to define what form the intervention should take.

For children with conditions like micro-ophthalmos or optic nerve hypoplasia, for which no satisfactory medical procedures currently exist, interventions are constrained to be rehabilitative, with the goal of helping those children best adapt to their blindness. However, for causes like congenital cataracts and corneal opacities, the issue is more complex. Surgical procedures for treating these conditions do exist, but their usefulness for children who have suffered several years of blindness since birth is not certain. Whether they will have a beneficial impact on the lives of the treated children is dependent on the answer to an important, and hitherto open, scientific question: Can the human brain learn to interpret visual information from the eyes even several years after birth?

Past research in visual neuroscience with non-human animal subjects suggests that visual deprivation early in life results in permanent deficits in visual functioning and supporting brain mechanisms, leading to the notion that the visual system has a 'critical period' for acquiring visual proficiencies.[4–8] The implication of this idea for human development is that children who have been blind since early in life due to cataracts or other conditions will not be able to gain functional vision if treated late in childhood. Hence, there is the belief that such treatments will not result in improvements in their quality of life.

Despite the results of previous animal studies, recent work has demonstrated that children treated late in life for blindness can, in fact, develop significant visual proficiencies. Project Prakash is a joint humanitarian and scientific effort to alleviate treatable blindness in the developing world while also studying key questions regarding human brain plasticity and the development of visual functions.[9] Its operations are currently focused on India, which has an estimated 200,000–700,000 blind children, nearly 40% of whom have preventable or treatable conditions.[10–12] Results from Project Prakash show that after treatment for congenital cataracts, patients are able to acquire proficiency on an array of visual dimensions, ranging from basic functions such as acuity and contrast sensitivity[13,14] to more complex abilities such as face localization and classification, spatial imagery, and mapping between visual and haptic senses.[15–17] Although the children do not reach normal levels for basic visual functions, such as acuity and contrast sensitivity, these findings suggest that the visual system and its underlying neural mechanisms do retain enough plasticity to allow for significant improvements, even late in childhood.

This article focuses on the issue of whether the visual improvement exhibited post-treatment in the laboratory translates into an improved quality of life for these children. The Prakash children and their families typically live in impoverished conditions, harsh rural environments with limited access to basic necessities such as electricity, and many of the children do not have access to education. These challenges are compounded by the handicap of blindness. How does the ability to see, even if vision is not perfect, alter the lives of these children? The goal of this study was to address this question by surveying the children and their families after treatment on multiple dimensions related to the quality of life. The results have bearing on the potential effectiveness of large-scale public health programs designed to proactively identify and treat early-blind children.

Methods

Participants

Patients who were surgically treated through Project Prakash for cataracts were eligible for the study. Most patients were treated in both eyes, but a few were only treated in one eye because they had previously received unsuccessful treatment in the other eye, resulting in pseudoaphakia or, in one case, pupillary capture. Patients had been blind since one year of age or earlier as reported by the child's guardian

at the time of treatment. A cohort of 110 patients was identified based on the availability of their contact information in the medical record files. Of these, we were able to reach and interview 64 patients and their families over the period of a year (the remainder could not be contacted typically because the mobile phone numbers we had for them were no longer functional). The participants ranged in age from 5 to 22 years at the time of surgery and were interviewed between 7 months and 8 years after the treatment. The pre-surgical visual acuity of the participants ranged from light perception to finger counting at a distance of 3 m. The participants were residents of states in northern India (Delhi, Rajasthan, Haryana, Uttar Pradesh, and Madhya Pradesh). Most came from rural areas; those who resided in Delhi at the time of the study either lived in slum areas or in resident blind schools. Details of the patient demographics are described in Table 1.

Survey and method

In pilot testing with some of the extant quality of life surveys, such as the National Eye Institute Visual Function Questionnaire,[18] we found that several of the questions posed were not appropriate for our unique patient population. For instance, queries regarding how difficult it is to read newspaper print or street signs assume basic literacy, which is generally lacking in our participant pool. In fact, even the concepts of newspapers and street signs are alien in the remote hinterlands of rural India. Similarly, questions regarding the ability to pick out matching clothes or to see movies/plays/sporting events implicitly assume a basic financial capability and access to resources that are almost entirely missing in the rural context of a developing nation. Along the same lines, queries related to driving prowess are meaningless for the Prakash children. These reasons made it imperative for us to develop a Quality of Life questionnaire that was better suited to the cultural/financial/medical/educational milieu from which our patient population had been drawn. Accordingly, we created the Prakash Quality of Life Survey (see Appendix). The survey comprised four sections: 'basic vision and mobility', 'social integration', 'attitudes', and 'general' with five items per section. For each item, participants were asked to give one of three answers: whether there was an improvement (+1), no change (0), or worsening (−1) of the described item. We intentionally asked broad questions and simplified the responses to make the survey comprehensible for children while still being able to assess the impact of restored vision on their quality of life. The questionnaire was translated into Hindi by native speakers who worked at the hospital.

Surveys were conducted during the summer of 2013 by social workers and outreach coordinators. Interviews were conducted in the local language (Hindi) at a hospital in Delhi or at the patients' homes, or over the phone. The patient was interviewed in the presence of a parent or guardian; older patients (older than age 10 years) answered for themselves, whereas the parent or guardian would answer for younger patients. The aggregate survey results were analyzed by totaling the number of points across survey items and across subjects. To reduce the possibility of the children or their families giving biased responses because of a sense of obligation, none of the surveys were conducted by members of the medical, nursing, or research teams who had worked with the children during their visits to the hospital. In addition, it was made clear to the families that participation in this survey was entirely voluntary and not a precondition for any further medical care the child might need.

We also examined the relationship between survey scores and several subject characteristics (age, time since treatment, pre-surgery and post-surgery acuity, and gender). Acuity measurements were obtained by pediatric optometrists at the hospital. Pre-surgery acuity was measured as perception of light, hand motion, or finger counting. Post-surgery acuity was either measured the same way or using a chart-based test, which produced a logMAR measurement, depending on subjects' visual ability.

Table 1 – Demographics of survey participants.

Subject characteristics	Number of subjects ($N = 64$)
Age in years	
5–9	16
10–14	36
15–19	10
20–24	2
Gender	
Male	46
Female	18
Treatment	
Binocular	58
Monocular	6
Pre-surgery acuity	
Light perception	33
Hand motion	7
Finger counting ≤ 50 cm	9
Finger counting > 50 cm	15
Geographic location	
Delhi	10
Bihar	4
Haryana	8
Madhya Pradesh	7
Rajasthan	6
Uttar Pradesh	25
Not available	4

Results

Fig. 1 shows data from the survey per item aggregated across participants. The maximum score possible for each question is 64 (assuming that every survey participant indicates a post-surgical improvement on that question). Similarly, the lowest possible score is −64, and 0 corresponds to no overall change (or as many instances of improvement as worsening). As is evident from the figure, a majority of the subjects experienced an increase in their quality of life following treatment for blindness. A multinomial goodness of fit test was conducted for each question to test whether the measured score was attainable by chance, assuming a null hypothesis that each response category (improvement [+1], no change [0], or

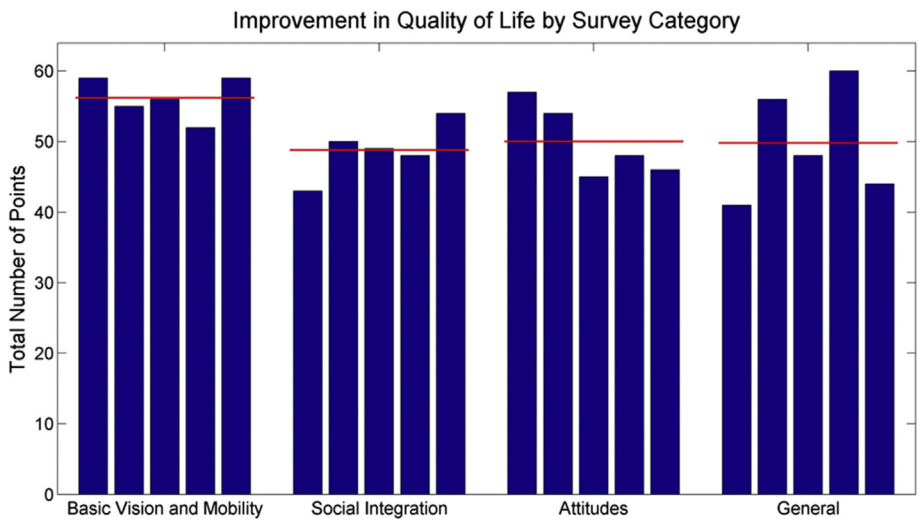

Fig. 1 – Number of points totaled across subjects for each item in the four categories. The horizontal lines indicate the average score in that category. The specific questions included in each of the four categories are presented in the Appendix.

worsening [−1]) was equally likely. The score for each question was significantly higher than chance at a level of $P < 0.01$ after Bonferroni correction for multiple tests. The area of most improvement was in the category of 'basic vision and mobility.' The five questions that received the lowest scores (41–46 out of 64) were:

- Your ability to watch TV, movies, or do other things for enjoyment;
- The number of friends you have;
- Change in overall health after gaining sight;
- Your sense of what you can accomplish when you grow up; and
- Your prospects for financial security.

Fig. 2 shows the scores summed across the entire survey plotted for each subject. The highest score here is 20, corresponding to an improvement on all questions asked. Of the 64 patients surveyed, only three experienced no change or a worsening of their quality of life. Two of these subjects had poor acuity after surgery, due to untreatable posterior segment ocular pathologies that could not be detected before the cataract surgery. It is likely that this is also the case for the third subject, but it could not be assessed since he had not returned to the hospital for post-surgery follow-up.

We examined variability in the responses to the quality of life survey with respect to: the age at treatment, time since surgery, pre-treatment acuity, post-surgery acuity ($n = 57$ because seven of the patients had not returned to the hospital for post-surgery follow-up), and gender of the patients (Fig. 3). Spearman rank correlations (age, time since surgery, post-surgery acuity [measured in logMAR shown on the right side of Fig. 3D]) and Kruskal Wallis one-way analyses of variance (pre-surgery acuity, post-surgery acuity [measured as perception of hand motion or finger counting shown on the left side of Fig. 3D] and gender) revealed no significant relationships between these variables and the quality of life scores. There was a trend that better post-surgery acuity was correlated with higher quality of life scores, but this relationship did not reach statistical significance (rho = −0.254, $P = 0.061$).

Discussion

The overarching goal of our study was to examine whether a public health program that provides ophthalmic surgeries to early-blind children can positively impact their quality of life. Our results revealed two important findings. First, even though these children had suffered profound visual deprivation for several years beginning at or soon after birth, treatment in late childhood or even early adulthood had a positive impact on their quality of life. The greatest change reported was in the participants' abilities to use their vision and to travel on their own. Positive improvements were also seen in other domains, including social interactions and societal attitudes toward the children and their families. Therefore, treatment for blindness, even at a late age, can result in significant improvements in a child's quality of life. This conclusion is reinforced by data in Fig. 3. The observed improvements are not confined to a specific gender, limited by age or even precise pre-acuity/post-acuity status. Instead, they indicate that surgery benefits almost all participants, despite their marked diversity.

Second, although all four dimensions probed by the survey registered improvements, the magnitude of improvement was least for questions related to future

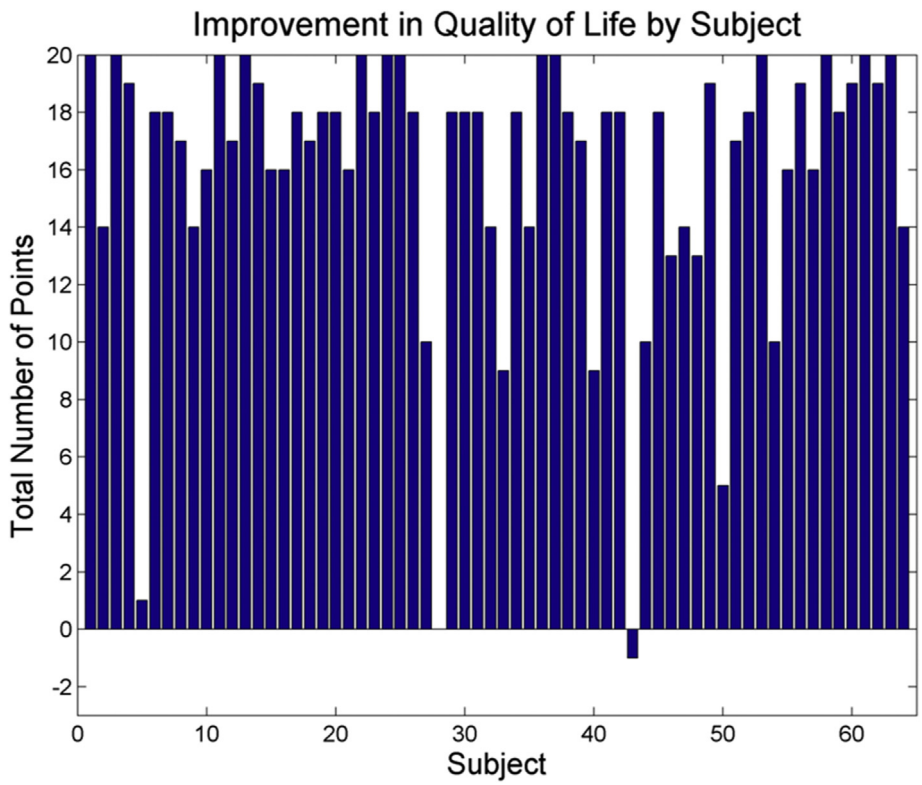

Fig. 2 – Number of points totaled across the entire survey for each of the 64 subjects. The maximum score for each subject is 20, corresponding to an improvement across all questions posed in the survey.

prospects for the child. Although their vision has improved, some children and their families do not feel that the child's ability to find employment or be financially secure improved as a result of treatment. Through further interactions with these families, we have learned that several children either remain in blind schools after treatment or do not go to school at all. Many children return to their villages where their families work as day-laborers and where there are few other options for employment. Therefore, the survey results reveal that providing treatment to curably blind children is just a first step to helping them live fulfilling, productive lives. The next step toward this goal may be to develop a program that helps bridge the educational gap and gives children access to other resources, such as optical devices, to help them gain the training and skills needed to function independently.

In interpreting the results, it is important to note that a potential limitation of the study is the lack of pre-treatment and post-treatment survey measures. Because these patients had been treated before, we developed the questionnaire, we asked patients and their families to judge how much improvement they noticed after surgery compared with before surgery. Given the simplicity of the questions and response options, we believe the results are still a reasonable reflection of quality of life outcomes. However, in the future, we will conduct the survey before and after the treatment to validate the results presented here. Second, even though the visual abilities of most patients improve markedly, they are still considered to be visually-impaired because of their below-par acuity and many would still be considered blind according to WHO criteria.[14] This may be why patients and their families perceived the least improvement in social situations and future prospects. However, despite having impaired vision, it is encouraging to find that patients still experienced an overall improvement in quality of life.

On the methodological front, we also wish to point out that the Prakash Quality of Life Questionnaire that we developed and deployed for this study can prove a useful tool for other researchers working with similar populations in the developing world. The survey is not country specific, does not assume literacy or significant socio-economic status on the part of the respondents, and includes only those questions that can be responded to by individuals across a wide age range, spanning young children as well as adults. We are making the survey publicly available for use by all researchers.

In conclusion, the results of our survey revealed that treatment of blindness, even late in childhood, results in an overall improvement in quality of life. However, there are still some domains, such as education and employment, in which extra support is required. These results are especially notable considering previous notions that treatment after an early 'critical' period would not lead to improvement in the visual abilities of blind children. Our data argue instead for public health programs that can provide medical care to all blind

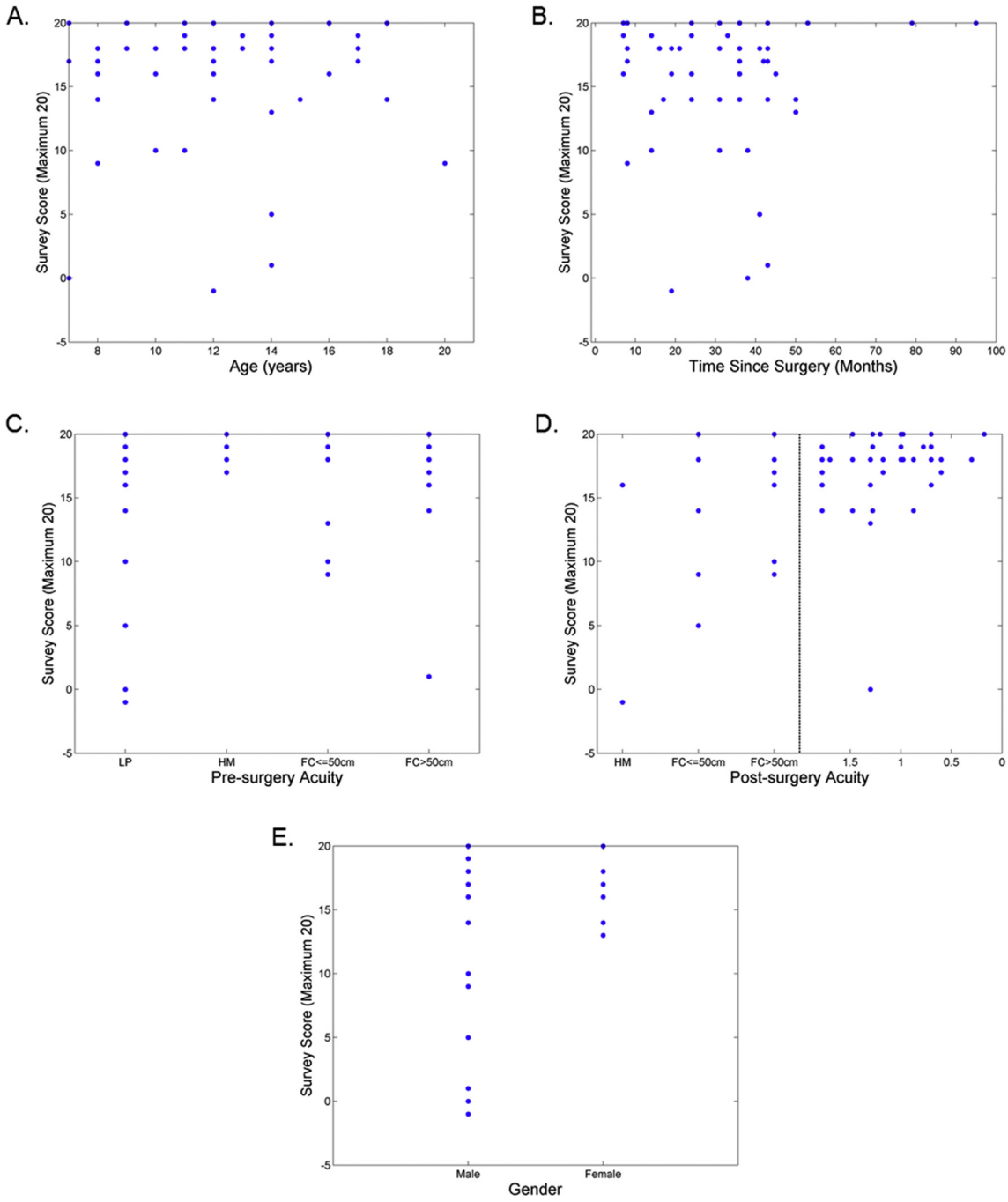

Fig. 3 – Scores, totaled across all items in the survey for each subject, plotted against (A) the age of the subject at treatment, (B) time since surgery, (C) pre-surgery acuity (LP = light perception, HM = hand movement, FC ≤ 50 cm = finger counting at a distance of 50 cm or less, FC > 50 cm = finger counting at a distance more than 50 cm), (D) post-surgery acuity (on the left side of the dotted line: HM, FC ≤ 50 cm and FC > 50 cm as in (C); on the right side of the dotted line: units are in logMAR), and (E) gender. Each blue dot may represent more than one subject. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

children with treatable ocular conditions, irrespective of the age at which they are identified.

Author statements

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Ethical approval

This work was approved by the Committee on the Use of Humans as Experimental Subjects at the Massachusetts Institute of Technology.

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Competing interests

None declared.

Contributorship statement

All authors were involved in study design. AK, TG, GC, and P Sinha designed the survey, analyzed the data and wrote the manuscript. P Swami, HD, and SB contacted the patients and conducted the interviews. NC and SDG coordinated outreach efforts and logistics associated with conducting the study. P Swami and SS helped with data recording and conducted initial data analyses. P Sharma assessed acuity outcomes and compiled data. SG conducted surgeries and follow-up medical assessments. UM provided additional medical expertise and advice regarding study objectives.

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Appendix

Quality of Life Questionnaire
जीवन प्रश्नावली की गुणवत्ता
Project Prakash
प्रोजेक्ट प्रकाश

Pre-Screen:
प्रथम-जाँच:

Since the time of the surgery, have there been any other major changes in your life unrelated to the surgery? Examples include moving to a new place, starting to go to school, a new job for the father, major illnesses in the family.

शल्यचिकित्सा के बाद, क्या आपके जीवन में शल्यचिकित्सा से असंबंधित कोई अन्य बड़ा बदलाव आया हैं? जैसे की – किसी नई जगह पे जाना, स्कूल जाने की शुरूवात करना, पिता की नई नौकरी लगना, परिवार में कोई प्रमुख बीमारी ।

If yes, then mention detail here:
यदि हाँ, तो यहाँ विस्तार से उल्लेख करे:

****

For each of the following items, please say whether things have improved, worsened or stayed the same from before to after your sight surgery.

निम्नलिखित वस्तुओं में से प्रत्येक के लिए, बताइये कि क्या चीजों में सुधार हुआ है, बिगाड़ हुआ है या आपकी दृष्टि शल्यचिकित्सा के बाद भी पहले की तरह ही हैं ।

(The scoring is: -1 for worsening, 0 for no change and +1 for improvement.)

अंक इस प्रकार करे: **-1** बिगड़ने के लिए, **0** कोई परिवर्तन नहीं होने के लिए और **+1** सुधार होने के लिए ।

Basic vision and mobility

आधारभूत दृष्टि और गतिशीलता

- The clarity of your vision during daytime
- Your ability to move around in the evening and night-time
- Your ability to go to places on your own
- Your feeling of safety when outside your house
- Your ability to do things on your own inside the house

- दिन के दौरान आपकी दृष्टि की स्पष्टता
- आपकी शाम और रात के समय में चारों ओर जाने की क्षमता
- आपकी अपने आप स्थानों पर जाने की क्षमता
- आपकी अपने घर के बाहर सुरक्षित महसूस करने की भावना
- आपकी घर के अंदर अपने आप काम करने की क्षमता

Social integration

सामाजिक समन्वय

- The number of friends you have
- Your ability to recognize people at a distance
- Your ability to participate in games
- Your ability to understand whether people are looking angry or happy or sad
- Your ability to help your friends and family

- आपके मित्रों की संख्या
- आपकी लोगों को पहचाने की क्षमता
- आपकी खेलों में भाग लेने की क्षमता
- आपकी लोगों को देख कर उनके नाराज या खुश या उदास होने का अनूमान लगाने की क्षमता
- आपकी अपने दोस्तों और परिवार की मदद करने की क्षमता

Attitudes

मनोभाव

- People's behavior towards you
- People's behavior towards your family
- Your sense of what you can accomplish when you grow up
- Your prospects for marriage and having a family of your own
- Your prospects for financial security when you grow up

- आपके प्रति लोगों का व्यवहार
- आपके परिवार के प्रति लोगों का व्यवहार
- आप बड़े होकर क्या हासिल कर सकते यह समझने की भावना
- आपकी शादी और अपना खुद का परिवार होने की संभावना
- आपकी बड़े होकर वित्तीय सुरक्षा होने की संभावना

(continued).

General

सामान्य चित्रण

- Your ability to watch TV, movies or do other things for enjoyment
- Your and your family's overall satisfaction with your new sight
- Your prospects for getting more education
- Your willingness to recommend such surgery to other children who are blind
- Has your overall health changed after you gained sight

- आपकी टीवी, फिल्में देखने या मनोरंजन के लिए अन्य काम करने की क्षमता
- आपकी नई दृष्टि के साथ आपकी और आपके परिवार का समग्र संतोष
- आपकी अधिक शिक्षा प्राप्त करने के लिए संभावना
- आपकी अन्य नेत्रहीन बच्चों के लिए इस तरह की शल्यचिकित्सा किये जाने के सूझाव पर राय
- क्या दृष्टि अर्जित करने के बाद आपके समग्र स्वास्थ्य में कोई बदलाव आया है